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Aging and Trans
Part 4
Cancer

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Preface

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Acknowledgements

Thanks to all the people, too many to list individually, who contributed to my research for this book, and its parts. Any errors or omissions are nobodies fault except my own, but I would also refer you back to the disclaimer.

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About the author

My name is Sharon Kimble, and I am a former Registered General Nurse and a State Enrolled Nurse, living and working in the United Kingdom.

Sharon Kimble Email - sharon@tgmeds.org.uk Thursday 18th August 2016

The subject of this part of ”Aging and Trans” is very familiar to me having spent six and a half years working on a cancer ward.

I have used many different sources in an attempt to give information without scaring people, in a manner that is simple and easy to understand. Where I have used medical terminology I've tried to explain what it means, both in the text and in the glossary.

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Chapter 2

Introduction

Contents

This is written to be read online, or offline with your favourite PDF reader. If you were to print it out you would lose access to all the cross-references, and other stuff too.

I have placed the various sections in what I consider to be a logical order, but also in alphabetical order within the chapters.

Some terms need defining from the beginning as they will appear in all four parts.

Health

I am using the definition of health as provided by the World Health Organisation in 1948 (WHO, 1948).

> “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”

Quality of life

Quality of life refers to many things (MEDICINENET, 2016), and I am using the following definition as a simple guideline. A more comprehensive definition can be found at Quality of life.

> The individuals's ability to enjoy normal life activities. Quality of life is an important consideration in medical care. Some medical treatments can seriously impair quality of life without providing appreciable benefit, whereas others greatly enhance quality of life.

Onwards!

This book "Aging and Trans" is written in four parts -

Aging and Trans - Part 1 - General Health
Aging and Trans - Part 2 - General Conditions
Aging and Trans - Part 3 - Mental Health
Aging and Trans - Part 4 - Cancer

This is called "Aging and Trans" because now that I've reached the age of 60+ I'm more aware of being aged and what some of the problems are. And I believe that 'Trans' is a particular subset of the aged, with many of the same problems but also some others that relate only to transfolk.

Very little information seems to be available for the aged transperson, so I'm hoping to slightly fill that gap. Whether I succeed remains to be seen.

What is 'aged' and what does it mean?

The dictionary definition of 'aged' is - "Being of advanced age, or old". But my working definition that I'm using here is **aged** is *anyone over the age of 60.*

I have known some people who were in their early-sixties and had physically aged far older than their birth-age yet their mental age remained youthful.

So where are we going?

This book "Aging and Trans" is written in four parts -

Aging and Trans - Part 1 - General Health
Aging and Trans - Part 2 - General Conditions
Aging and Trans - Part 3 - Mental Health
Aging and Trans - Part 4 - Cancer

Chapter 3

Understanding cancer

Understanding cancer

What is 'cancer'?

Cancer is not a single disease with a single type of treatment. There are more than 200 different types of cancer, each with its own name and treatment (MACMILLAN, 2014aa).

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (otherwise known as a tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy [1]. The doctors examine the sample under a microscope to look for cancer cells.

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[1] a medical procedure that involves taking a small sample of body tissue so it can be examined under a microscope

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A lump that is not cancerous (benign) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system. When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis (MACMILLAN, 2014aa).

The lymphatic system

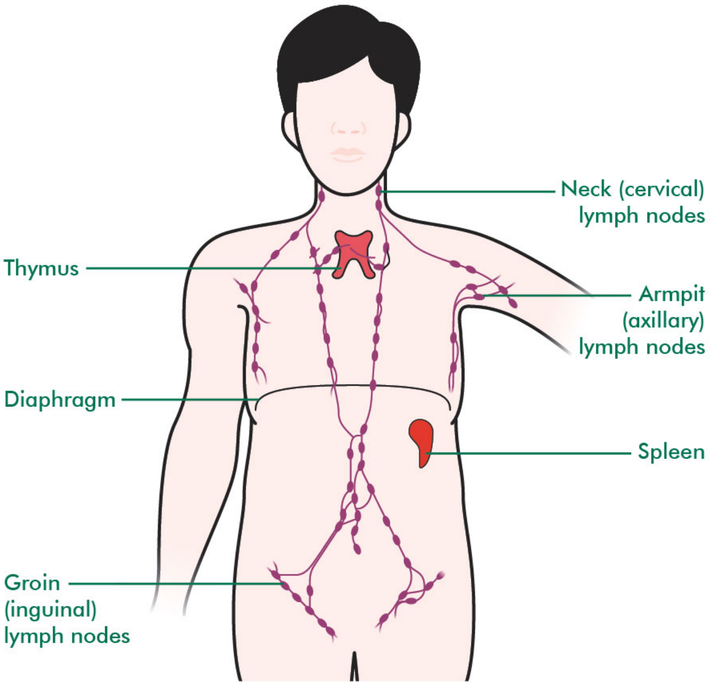

Figure 3.1: The lymphatic system

The lymphatic system helps to protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood. The lymphatic system is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

Lymph nodes (sometimes called lymph glands) are small and bean shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection lymph nodes often swell as they fight the infection (MACMILLAN, 2014aa).

Who gets cancer?

Each year over 330,000 people are diagnosed with cancer in the UK. In this section are some facts about how cancer affects different age groups of people and the most common types of cancer people get (MACMILLAN, 2014aa).

Age

It has been estimated that more than one in three people (33%) will develop cancer at some point in their lifetime.

Cancers can occur at any age, but the risk of developing cancer increases with age. Cancer isn't common in children or young people.

- More than a third (36%) of all cancers are diagnosed in people aged 75 or over.
- Over half (53%) of all cancers occur in people aged 50–74.
- About 1 in 10 (10%) of cancers are diagnosed in people aged 25–49.
- Less than 1 in 100 (1%) of cancers are diagnosed in teenagers and young adults aged 15–24.
- Less than 1 in 100 (1%) of cancers are diagnosed in children, aged 14 years or under (MACMILLAN, 2014aa).

Common cancers

Some cancers are very common and others are very rare. The most recent statistics for the UK (from 2011) show that for men the most common cancer is prostate cancer (25% of all cancers in men), followed by lung cancer (14%), colon and rectal cancer (14%) and bladder cancer (4%).

For women, the statistics show that the most common cancers are breast cancer (30%), lung cancer (12%), colon and rectal cancer (11%) and womb cancer (5%).

Nearly a third (30%) of all cancers diagnosed in children are leukaemia.

Teenagers and young people (aged 15–24) are more likely to be diagnosed with a lymphoma (21%) or a germ cell tumour (15%) like testicular cancer.

The most common types of cancer diagnosed in adults aged 25–49 are breast cancer, melanoma, colon and rectal cancer, testicular and cervical cancer (MACMILLAN, 2014aa).

Lifestyle and cancer

There are over 200 different types of cancer. We don't know the cause of most of these, but we know about some of the risk factors that can increase or influence a person's risk. Increasing age is a risk factor that we can't do anything about. But we can make lifestyle choices about some of the other risk factors, such as -

- stopping smoking,
- eating a balanced diet,
- avoid becoming overweight, or if you are overweight, try to reduce your weight,
- cutting down our alcohol intake,
- getting regular exercise (MACMILLAN, 2014aa).

We're getting better at recognising and treating cancer, so today many people with cancer can be cured. Even if a cancer can't be cured, it can often be controlled with treatment for months or years (MACMILLAN, 2014aa).

Types of cancer

It's important for doctors to know what type of cancer you have because different types of cancer can behave very differently and respond to different treatments (MACMILLAN, 2014a).

Cancers are grouped (classified) in two ways, according to -

- **site** - the part of the body where the cancer first developed (the primary site),
- **cell type** - the type of cell the cancer started from (MACMILLAN, 2014a).

Cancer types by site

Most people are aware of cancer types when they are described according to where the cancer first started in the body (the primary site). For example, lung cancer or breast cancer. The most common sites for cancer to develop include the -

- skin,
- lungs,
- breasts,
- prostate,
- colon and rectum (large bowel) (MACMILLAN, 2014a).

Cancer and cell types

Cancer can also be described according to the type of cell it started in. This can be just as important in how a cancer behaves and responds to treatment as the site where it started (MACMILLAN, 2014a).

Cells Our body is made up of millions of cells. The cells, organised together, make up all of our tissues and organs. There are different types of cells to carry out different functions in the body. Some types are very common and are found in almost all the organs in our body. Other types, such as the brain cells, are very specialised and only found in one part of our body (MACMILLAN, 2014a).

The main types of cells in our body are -

- **Epithelial cells** - These cover the outside of our body (as skin) and make up tissues that line the inside of our bodies and cover our organs,
- **Cells of the blood and lymphatic system** - These are found in our blood, in the bone marrow (where blood cells are made) and in the lymphatic system (which fights infection),
- **Connective tissue cells** - These cells are found in supportive and connective tissues in our body such as the muscles, bones and fatty tissue (MACMILLAN, 2014a).

Cancers that start in each of these types of cells have different names (MACMILLAN, 2014a).

Carcinomas Cancers that start in epithelial cells are called carcinomas. They are the most common type of cancer in adults and make up 80−90 out of every 100 (80−90%) cancers. Most lung, breast, prostate and bowel cancers are carcinomas (MACMILLAN, 2014a).

There are different types of epithelial cells -

- **Squamous cells** are found in the skin and cover the surface of many parts of the body including the mouth, oesophagus and the airways,
- **Adeno cells** form the lining of all the glands in the body including those in the breast, bowel, stomach, ovaries and prostate,
- **Urothelial (transitional) cells** line the bladder and parts of the urinary system,
- **Basal cells** are found in the skin (MACMILLAN, 2014a).

Carcinomas may start in any of these types of cells.

- **Squamous cell carcinomas** start in squamous cells,

- **Adeno carcinomas** start in the adeno cells,
- **Transitional cell carcinomas** start in the urothelial cells,
- **Basal cell carcinomas** start in the basal cells (MACMILLAN, 2014a).

Leukaemias and lymphomas Cancers that start in the blood or bone marrow (the tissues where white blood cells are formed to fight infection in the body) are called leukaemias.

Cancers that start in the lymphatic system (which helps the body fight infection) are called lymphomas.

Leukaemias and lymphomas are quite rare, making up fewer than 7 in 100 (7%) of cancers (MACMILLAN, 2014a).

Sarcomas Cancers that start in connective tissue cells are called sarcomas.

Sarcomas are rare. They make up fewer than 1 in 100 (1%) of cancers (MACMILLAN, 2014a).

Sarcomas are split into two main types -

- **bone sarcomas**, which are found in the bones,
- **soft tissue sarcomas**, which develop in the other supportive tissues of the body (MACMILLAN, 2014a).

Cancers that start in other types of cells Cancer can develop in other types of cells but these cancers are rare. Brain tumours are the most common cancers in this group (MACMILLAN, 2014a).

How is cancer treated?

Some cancer treatments treat a particular area of the body. These are called localised treatments (MACMILLAN, 2014o).

- **Surgery** - An operation to remove the tumour is the main treatment for many types of cancer. It is usually used for cancers that are in one area of the body.
- **Radiotherapy** - High energy X-rays are used to destroy the cancer cells. By targeting the area affected by cancer, there is as little harm as possible to the normal cells (MACMILLAN, 2014o)

Other treatments treat the whole body. These are called systemic treatments.

- **Chemotherapy** - This uses anti-cancer (cytotoxic) drugs to destroy cancer cells. There are many different chemotherapy [2] drugs. Which you are given depends on the type of cancer you have,
- **Hormonal therapy** - These therapies reduce the level of hormones in the body or block the hormones from reaching cancer cells. This can stop the cancer growing,
- **Targeted therapies** - These destroy cancer cells, usually by interfering with the cancer's ability to grow or survive (MACMILLAN, 2014o).

It's quite common for a combination of these treatments to be used. Many of these can cause side-effects (MACMILLAN, 2014o).

Cancer symptoms

Knowing how your body normally looks and feels can help you be aware of any changes that could be caused by cancer. If you have any symptoms that are ongoing, unexplained or unusual for you it's important to see your doctor.

There are certain symptoms you should always have checked. Don't be scared about getting symptoms checked by your doctor. The earlier cancer is found, the more likely it is to be cured. You won't be wasting their time (MACMILLAN, 2014b).

Common symptoms of cancer include -

- Unexplained bleeding,
- Unexplained weight loss,
- A lump or swelling,
- Unexplained pain (MACMILLAN, 2014b).

These symptoms can be caused by something other than cancer. However, it's always best to have them checked by your General Practitioner, a community-based doctor (GP) [3], as soon as possible. You are not wasting your doctor's time by getting your symptoms checked.

If you've already been to your doctor with symptoms but they haven't gone away, it is important to see your doctor again (MACMILLAN, 2014b).

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[2] a type of cancer treatment, with medicine used to kill cancer cells. It kills the cancer cells by damaging them, so they can't reproduce and spread

[3] General Practitioner, a community-based doctor

Symptoms to look out for

Knowing how your body normally looks and feels can help you notice any early changes that could be caused by cancer.

Always see your doctor if you have symptoms that are ongoing, unexplained or unusual for you (MACMILLAN, 2014b).

Ongoing symptoms If you have a symptom that lasts for more than three weeks, see your doctor. This might be a cough that doesn't go away, a change in bowel habits, a mouth ulcer that doesn't heal, or feeling bloated most days (MACMILLAN, 2014b).

Unexplained symptoms This means a symptom that doesn't have an obvious cause, for example having a lump or bleeding without any injury (MACMILLAN, 2014b).

Symptoms that are unusual for you This means a change in your body that is not normal for you. It could be a change in a cough you've had for a long time, a change to a mole, or a change in the skin on your breast (MACMILLAN, 2014b).

Recognise the symptoms of cancer

If you have any of the symptoms listed below, see your doctor (MACMILLAN, 2014b).

Unexplained bleeding Any unexplained bleeding is a sign that something might be wrong. You should always get this checked by your doctor.

This may be blood in your urine, bowel motions, spit or vomit. For women it also includes vaginal bleeding in between periods [4], after sex or after the menopause (MACMILLAN, 2014b).

Weight loss If you have lost weight without trying to and it can't be explained by changes in your diet or exercise, tell your doctor (MACMILLAN, 2014b).

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[4] the part of the menstrual cycle when a woman bleeds from her vagina for a few days. In most women this happens every 28 days or so

Lumps If you notice an unexplained lump or swelling anywhere on your body, see your doctor. It can be useful to tell them how long it has been there and if it is getting bigger or causes discomfort (MACMILLAN, 2014b).

Pain If you have a new, unexplained pain anywhere that lasts for three weeks or more, see your doctor to get it checked. Having any of these symptoms does not usually mean you have cancer, but it is sensible to get them checked. The cause of the symptoms is probably nothing to worry about. But they could be a sign of something that needs treatment.

If it is cancer, the sooner it is found, the more likely it is to be cured. And if it's nothing serious, your doctor can put your mind at rest.

If you've already been to your doctor with symptoms but they haven't gone away, it is important to see your doctor again.

You are not wasting your doctor's time by getting your symptoms checked (MACMILLAN, 2014b).

Getting diagnosed

If any symptoms or changes continue for a couple of weeks or more, speak to your doctor. This includes -

- A lump anywhere on your body.
- A cough or hoarseness that lasts for more than three weeks.
- A change in bowel habit that lasts for more than three weeks.
- Any abnormal bleeding from your vagina or back passage, in your urine or when being sick (vomiting) (MACMILLAN, 2015d).

At the appointment, your GP will discuss any symptoms and may want to examine you. They won't be able to tell you if you have cancer at this stage. But they may refer you for further tests.

There are guidelines to help GPs know when to refer people to a specialist if their symptoms might be due to a cancer (MACMILLAN, 2015d).

Know your body If you know your body and what's normal for you, it will help you to be aware of any changes. People sometimes think a change in their body isn't worth bothering their doctor about. Or they may feel embarrassed talking about it (MACMILLAN, 2015d).

But if you notice a change in how you feel or how your body works, it's better to be safe and get it checked. You should go to see your doctor if you have -

- a lump anywhere on your body,
- sore or ulcer that doesn't heal within three weeks,
- a mole that changes shape, size or colour, crusts over or bleeds,
- a cough or hoarse voice that lasts for more than three weeks,
- shortness of breath,
- loss of appetite, ongoing indigestion or difficulty swallowing,
- a change in bowel habit that lasts for more than three weeks,
- blood in your urine, bowel motions, semen, spit or vomit, or abnormal bleeding from your vagina,
- a need to pass urine more often or urgently, or pain when passing urine,
- unexplained weight loss or tiredness,
- an unexplained ache or pain that lasts for more than three weeks (MACMILLAN, 2015d).

Most of the time, these changes aren't due to cancer. But finding a cancer early can make a big difference to how successful treatment is (MACMILLAN, 2015d).

If you're an older person As you get older, you are more likely to experience one or more health conditions. It can be easy to assume that new problems are just part of ageing or existing conditions. But if you are experiencing any new, persistent symptoms, there is a chance they could be a sign of cancer, so it's important that you tell a GP or another healthcare professional (MACMILLAN, 2015d).

Visiting your GP Before visiting your GP it's a good idea to plan what you'd like to say and any questions you'd like to ask.

When you see your GP, you'll need to describe your symptoms. This helps them decide what the problem may be. Your GP may want to examine you. Sometimes, and depending on your symptoms, they may need to examine inside you. The GP will explain how they will examine you and answer any questions you may have.

Depending on the kind of symptoms you have your GP may arrange for you to have some routine tests and investigations. The results of these will help your GP to find out what the problem might be and decide what kind of specialist doctor you should see.

Sometimes the symptoms of cancer can be the same as other, much more common health problems, which are far easier to treat. This means that it can sometimes be hard for your GP to know whether your symptoms are a sign of cancer or something much less serious.

To help GPs, the National Institute for Health and Care Excellence (NICE) has produced referral guidelines. These are a list of risk factors, and signs and symptoms that could suggest cancer. They help your GP decide what sort of tests you should have and how quickly you should see a specialist, i.e. whether you should be referred within a few hours, called an immediate referral, within two weeks, which is an urgent referral, or longer, which is a non-urgent referral.

Your GP will give you information so that you know what's going on. They can also give you support if you need it (MACMILLAN, 2015d).

Symptoms and common cancers

Knowing the symptoms of common cancers could make a real difference. Usually, the earlier cancer is found, the more likely it is to be cured. Below are some of the most common cancers in the UK (MACMILLAN, 2014w).

- **Lung** cancer is common in both men and women. Smoking is the main cause of lung cancer, but non-smokers get it too.
- **Bowel** cancer can affect both men and women. Most people who get bowel cancer are over 50.
- **Prostate** cancer is the most common cancer in men. More than 41,700 men in the UK are diagnosed with it each year.
- **Kidney** and bladder cancers are more common in men and people over 50.
- **Breast** cancer is the most common cancer in women in the UK. Men can also get breast cancer, but this is rare.
- **Ovarian** cancer is more common in women over 50.
- **Melanoma** cancer is one of the most common cancers in people aged 15–34.
- **Mouth** cancer is more common in men and people over 50 (MACMILLAN, 2014w).

You're not wasting your doctor's time by getting symptoms checked. If you need support or just want someone to talk to, call Macmillan free on 0808 808 00 00 (MACMILLAN, 2014w).

Know what changes to look for More than 330,000 people are diagnosed with cancer in the UK each year. People of any age can get cancer, but it's most common over the age of 50.

You are not wasting your doctor's time by getting your symptoms checked. The earlier cancer is found, the more likely it is to be cured.

Knowing what changes to look for and when to see your GP could make a real difference. Don't be scared - if you have symptoms, get them checked (MACMILLAN, 2014w).

Why do cancers come back?

When you are first diagnosed with cancer, treatment is usually given to try to get rid of the cancer. Your doctor will decide which type of treatment you need. They will use a treatment or combination of treatments to help reduce the chances of any cancer cells remaining (MACMILLAN, 2014ac).

Unfortunately, cancer cells are sometimes left behind after treatment. If this happens, the cancer may come back. This can happen years after your initial treatment. Cancer can come back in the same area of the body or somewhere else in the body. Cancer that returns -

- in the same area of the body is known as a local recurrence,
- in a different part of the body is called a metastasis or secondary cancer (MACMILLAN, 2014ac).

Usually, treatment is used to control the cancer when it comes back. It is sometimes possible to use treatment to try and get rid of the cancer.

Sometimes cancer can come back. This can happen because tiny cancer cells, known as 'seed cells', which can't be seen with the naked eye or on scans, can sometimes be left behind after cancer treatment.

Over time these cancer cells can begin to divide again and form a tumour.

Treatment is often given to try to get rid of all the cancer so that it doesn't come back. Many people have an operation to remove a tumour. Some healthy tissue around the tumour will also be removed to try to make sure all the cancer cells are taken away during the operation. To help reduce the risk of any cancer cells being left behind after surgery, other treatments such as chemotherapy, radiotherapy [5] and targeted (biological) therapy may also be used. This is known as adjuvant treatment. Treatment can also be given before an operation - this is called neo-adjuvant treatment.

For some types of cancer, such as leukaemia and lymphoma, an operation isn't appropriate. In this case chemotherapy, radiotherapy or targeted therapy may be used. These treatments aim to destroy as many of the cancer cells as possible. Often a combination of treatments is given, which can be more effective.

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[5] a treatment involving the use of high-energy radiation. It's commonly used to treat cancer

Unfortunately, no treatment is guaranteed to be 100% effective. Sometimes cancer cells can remain and in some people the cancer might come back - sometimes many years later.

If cancer comes back in the same area of the body it's known as a local recurrence. If cancer develops in a different part of the body, it's called a secondary cancer or metastasis. A secondary cancer can develop if cancer cells break away from the original (primary) cancer and spread to other organs in the body through the bloodstream or lymphatic system. When these cells reach a new area of the body they grow to form a new tumour. Recurrent and secondary cancers are sometimes called advanced cancer.

If cancer does come back it can often be treated again. Usually in this situation, treatment is given to control the cancer, sometimes for many months or years. In some situations it may be possible to give treatment that aims to get rid of the cancer again (MACMILLAN, 2014ac).

Coping with a cancer diagnosis

Every two minutes someone in the UK is diagnosed with cancer. About half of people born after 1960 will develop some form of cancer during their lifetime. But how do you cope if it happens to you? (LIVEWELL, 2015)

Getting a cancer diagnosis

The C-word fills most people with dread. In one survey, most people said that getting cancer was their number one fear. So it's understandable that receiving a diagnosis of cancer can be very daunting.

"*When people hear they have cancer, they think the worst really,*" says Jane Fide, head of Maggie's cancer support centre in Cheltenham. Fide has supported lots of people in the centre after their diagnosis. "*It's shock, horror. Cancer has such scary connotations. But most people want to say 'OK, I've got cancer' and get out of the hospital so that they can take in what's happening.*"

When you're home, it's time to digest the information you've received. "*Once the initial shock has subsided, there is sometimes a flood of emotions that can be hard to deal with. But that's normal. It takes a while for you to absorb the information and come to terms with the situation,*" explains Fide (LIVEWELL, 2015).

Your emotions after a cancer diagnosis

A cancer diagnosis affects everyone differently, so there are no set rules about how you're likely to feel, or how you should deal with your emotions (LIVEWELL, 2015).

But, it is common to experience -

- sadness,
- fear about the future,
- anger,
- guilt,
- denial,
- confusion,
- stress,
- anxiety,
- depression (LIVEWELL, 2015).

"*Some people get very angry, some are very tearful, most are extremely anxious and worried*," says Fide.

If you think you may be depressed, it's important to speak to your doctor (LIVEWELL, 2015).

Symptoms of depression include -

- lasting feelings of sadness,
- losing interest in the things you used to enjoy,
- feeling constantly tired,
- having difficulty getting to sleep,
- loss of appetite, and
- feeling that life is not worth living (LIVEWELL, 2015).

See also Depression.

When you receive your cancer diagnosis, you may be given a number of options about your treatment. This can mean having to make some complex decisions at an already stressful time. If you're finding these decisions difficult or confusing, talk to a health professional from the hospital or your local cancer support centre. They should be able to guide you through all the information and help you make decisions about your treatment (LIVEWELL, 2015).

Your cancer support network

Lots of people find that having a network of friends, family and support services helps them to cope with the impact of a cancer diagnosis (LIVEWELL, 2015).

Family and friends Talking to your friends and family can be difficult because you don't want to upset them, but remember that they'll want to support you. Sometimes the people close to you don't know how to react. It may help to tell them whether you just need someone to listen, or to give you a hug, or to take some pressure off you by helping around the house.

Some people find that it helps them and their loved ones to go to doctors appointments or treatment sessions together. Your family may need some support of their own, so remind them that there are services to help them too if they need them (LIVEWELL, 2015).

Hospital staff The doctors and nurses in your cancer unit have been trained to deal with all aspects of cancer. As well as giving you medical care, they can answer your questions and give you advice and support. They'll be able to give you information about local support centres and support groups. Some hospitals also offer complementary therapies for people having cancer treatments (LIVEWELL, 2015). See also Complementary therapies.

Cancer support centres Your doctor or specialist nurse will let you know if you have a cancer support centre, such as Maggie's, in your local area. Cancer support centres often provide someone to talk to, and can offer practical and financial advice.

"*At Maggie's we provide a warm friendly environment that allows people to have space to think, talk if they want to, ask questions, cry on someone's shoulder - whatever they need,*" says Fide. "*All our centres have a psychologist to talk through the more difficult aspects of having cancer. All centres have a benefits advisor to give financial and welfare advice. Our services are available to everyone affected by cancer, including friends and family, and are completely free of charge.*"

You can find your nearest Maggie's centre. Maggie's has an online centre where you can post your experiences and read other people's stories. You can also ask questions and get expert advice (LIVEWELL, 2015).

Helplines and support groups Many people find it easier to talk to someone over the phone. There are a number of helplines, mostly run by charities, including -

- Macmillan Cancer Support - 0808 808 0000,
- Cancer Research UK - 0808 800 4040,
- Marie Curie Cancer Care - 0800 090 2309 (LIVEWELL, 2015).

A support group may suit you if you'd like to discuss your experience with other people who've been diagnosed with cancer. Your GP or specialist doctor or nurse will be able to put you in touch with suitable local groups. You can also search for your local cancer support services (LIVEWELL, 2015).

Self-help and cancer

Feel more in control When you're first diagnosed with cancer, you can have so many questions that it can be overwhelming. How will it affect my family? How will I cope with the treatment? How will I cope with losing a body part? Am I going to die?

There are many unknowns, and it's natural to feel that you've lost some control over your life. Being able to answer these questions will help you cope and regain that sense of control. If this has happened to you, try writing down your questions, then ask someone, such as your specialist nurse, when you're ready (LIVEWELL, 2015).

Look after yourself Taking care of yourself will help you to deal with the emotional side of your diagnosis. You might like to -

- get some rest and relaxation time,
- get some gentle exercise,
- try to eat a healthy balanced diet, see also Diet - Aging and Trans - Part 1,
- get a good night's sleep, see also Sleep - Aging and Trans - Part 1,
- avoid drinking too much alcohol (LIVEWELL, 2015). See also Drinking and alcohol - Aging and Trans - Part 1

Some of these can be difficult if you are feeling unwell or having side-effects of cancer treatments. See more about possible cancer treatment side-effects at Side-effects (LIVEWELL, 2015)

Stay positive It can be hard in such a difficult situation, but trying to be positive can really help you to cope. Try focusing on the positive things that you do know, and avoid negative thoughts that may not be true. Discuss your worries with your doctor, nurse or supporter - they can often reassure you.

Try to encourage yourself whenever possible, and be proud of your strength and courage. Remember to enjoy the times that you're feeling well, and have fun with your family and friends.

Fide says: "*Often, people who have had a cancer experience stand back and reflect on their lives, perhaps make new friends, change their lifestyle, and embrace life more*" (LIVEWELL, 2015).

Side-effects

What side-effects are

All drugs used to treat cancer cause side-effects. Side-effects are unwanted things that can happen to you as a direct result of medical treatment - in this case, taking a cancer treatment drug. It can sometimes be easy to confuse drug side-effects with symptoms of the cancer. Symptoms are the things that happen to you as a direct result of the cancer and are not due to your treatment. Treatment may shrink your cancer and make your symptoms better.

Different drugs have different side- effects - for example, they don't all cause hair loss or sickness. Ask your doctor or nurse to write down the names of your drugs so that you can look each one up (CANCERRESEARCHUK, 2016b).

The side-effects of each drug vary for different people though. Some people find that they get only very mild side-effects. You may get 1, 2 or a few side-effects of a particular drug. It is not possible to say beforehand whether you will have a particular side-effect, when the effect will start or stop, or how bad it will be for you. These issues depend on many factors including -

- Which drugs you are having,
- How long you have been taking the drug,
- Your general health,
- The dose (amount of drug),
- The way you have the drug (for example, as a tablet or injection),
- Other drugs or cancer treatments that you are having (CANCERRESEARCHUK, 2016b).

Important things about side-effects

- Some side-effects are serious medical conditions that need to be treated,
- Many side-effects are inconvenient or upsetting but are not harmful to your health,
- Discuss your side-effects with your doctor, nurse or pharmacist - often they can be reduced,

- Phone your cancer hospital and speak to a cancer specialist doctor or nurse urgently if you are worried about a side-effect,
- Most side-effects don't do any lasting harm and will gradually go away after your treatment finishes,
- If you don't get side-effects, it does not mean that your treatment isn't working (CANCERRESEARCHUK, 2016b).

Living with cancer

There is a commonality about some aspects of living with cancer, hence this section.

Relationships with others

It is not always easy to talk about cancer, either for you or your family and friends. You may sense that some people feel awkward around you or avoid you. Being open about how you feel and what your family and friends can do to help may put them at ease. Do not feel shy about telling them that you need some time to yourself, if that is what you need (NHS, 2014d).

Money and financial support

If you have to stop work or go part-time because of your cancer, you may find it hard to cope financially. If you have cancer or you are caring for someone with cancer, you may be entitled to one of the following areas of financial support -

- If you have a job, but cannot work because of your illness, you are entitled to Statutory Sick Pay from your employer.
- If you don't have a job and cannot work because of your illness, you may be entitled to Employment and Support Allowance.
- If you are caring for someone with cancer, you may be entitled to Carer's Allowance.
- You may be eligible for other benefits if you have children living at home or if you have a low household income.

Find out as early as possible what help is available to you. Speak to the social worker at your hospital who can give you the information you need (NHS, 2014d).

Free prescriptions

People being treated for cancer are entitled to apply for an exemption certificate, giving them free prescriptions for all medication, including medicine for unrelated conditions.

The certificate is valid for five years and you can apply for it through your GP or cancer specialist (NHS, 2014d).

Talk to others

If you have questions, your GP or nurse may be able to reassure you. You may find it helpful to talk to a trained counsellor or psychologist, or to someone at a specialist helpline. Your GP surgery will have information on these (NHS, 2014d).

Chapter 4

Living with cancer

Contents

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Cancer can affect your daily life in different ways, depending on what stage it is at and what treatment you are having.

How people cope with their diagnosis and treatment varies from person to person. There are several forms of support available if you need it (NHS, 2014a).

Not all of these will work for everyone, but one or more should help -

- talk to your friends and family - they can be a powerful support system,
- communicate with other people in the same situation - for example, through bowel cancer support groups,
- find out as much as possible about your condition,
- do not try to do too much or overexert yourself,
- make time for yourself (NHS, 2014a).

Talk to others

Your GP or nurse may be able to reassure you if you have questions, or you may find it helpful to talk to a trained counsellor, psychologist or specialist telephone helpline operator. Your GP surgery will have information on these.

Some people find it helpful to talk to others with bowel cancer at a local support group or through an internet chat room.

Beating Bowel Cancer offers support services to people with bowel cancer. They run a nurse advisory line on 08450 719 301 or 020 8973 0011 available 9am to 5.30pm Monday to Thursday, and 9am to 4pm on Fridays. You can also email a nurse at nurse@beatingbowelcancer.org.

The organisation also runs a national patient-to-patient network called Bowel Cancer Voices for people affected by bowel cancer and their relatives (NHS, 2014a).

Your emotions

Having cancer can cause a range of emotions. These may include shock, anxiety, relief, sadness and depression.

Different people deal with serious problems in different ways. It is hard to predict how knowing you have cancer will affect you.

However, you and your loved ones may find it helpful to know about the feelings that people diagnosed with cancer have reported (NHS, 2014a).

Cancer and your feelings

It's natural to have many different thoughts and feelings after a cancer diagnosis. Some people feel upset, shocked or anxious, while others feel angry, guilty or alone. There is no right way for you to feel.

Emotions can be difficult for you, and people close to you, to deal with. You may find that some feelings pass with time, while others last longer. Try to find a way of coping that suits you (MACMILLAN, 2014g).

It's impossible to know how you will react to a diagnosis of cancer. Common feelings include -

- shock and disbelief,
- anger,
- avoidance,
- guilt and blame,
- a loss of control, independence and confidence,
- sorrow and sadness,
- withdrawal,
- loneliness and isolation,
- fear and anxiety (MACMILLAN, 2014g).

There are many ways to manage your emotions. Sharing your thoughts and feelings is often a good place to start. Try talking with someone close. Remember, help is always available if you need it. Speak to your doctor, family or friend if you are struggling to cope (MACMILLAN, 2014g).

Common thoughts and feelings

A diagnosis of cancer means you will have to deal with issues and situations that may be very frightening and challenging.

Common fears and thoughts about cancer include -

- 'I don't want to lose my independence and freedom',
- 'I don't want my family or friends to treat me differently',
- 'I don't know how I'll cope financially',
- 'I might miss out on a promotion or lose important work contacts',
- 'I may have to make big changes to my lifestyle',
- 'I may die' (MACMILLAN, 2014g)

These are likely to be very real concerns for you and those close to you. When life feels uncertain, it can help to talk about your hopes and fears. It's fine to worry about and be upset by them. And it's fine to cry and say how you feel when things get tough.

There are many benefits of talking about your feelings and organisations are available to offer support.

Most people feel overwhelmed when they are told they have cancer. There is no right or wrong way to feel - reactions vary and people have different emotions at different times.

You will probably have a variety of emotions, which may cause confusion and frequent mood swings. These changing emotions are part of the process many people go through when dealing with their illness (MACMILLAN, 2014g).

Shock and disbelief

When your doctor tells you that you have cancer, you may find it hard to believe. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again.

At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you.

You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through (MACMILLAN, 2014g).

Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Sometimes, avoidance is the other way around. Family and friends may be reluctant to talk to you and may even avoid you. They may seem like they don't want to talk about your cancer, or they might change the subject when you try to. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you. If they still cannot give you the support you need, there are organisations that can help both you and them (MACMILLAN, 2014g).

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Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know you are angry at your illness and not at them (MACMILLAN, 2014g).

Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead of trying to find reasons, try to focus on looking after yourself and getting the help and support you need (MACMILLAN, 2014g).

Feeling alone

Some people feel alone or that they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. See What you can do if you feel lonely and isolated (MACMILLAN, 2014g).

Loss of control and independence

One of the hardest things to cope with can be the feeling that the cancer and its treatment have taken over your life, and that you've lost control.

Cancer may take over certain aspects of your life, but there are often things What you can do to help (MACMILLAN, 2014g).

Loss of confidence

Cancer and its treatments can change a person's role in their family or at work. You may not have the physical energy to do the normal, everyday tasks that you did before, such as going to work or doing jobs around the house. Things you used to find easy may now be much more difficult. These things plus the sense of no longer having control over your life may cause you to lose some confidence (MACMILLAN, 2014g).

Sorrow and sadness

It's natural to feel sad after cancer has been diagnosed. This feeling may be there a lot of the time, or it may come and go.

Cancer can often mean making changes that affect different areas of your life. As a result, you may feel sad that your future may not be as you had planned. You might need to grieve for this (MACMILLAN, 2014g).

Withdrawal

There may be times when you want to be left alone to sort out your thoughts and emotions. This is a very normal reaction for some people.

However, if you find that you would rather be on your own for long periods of time and avoid talking to other people, this could be a sign that you're depressed.

There may be times when you feel too tired and helpless to think about what could help. You will have good days and bad days, and it's important for you and your family to realise this. Over time, people usually find things they can do to help them feel better (MACMILLAN, 2014g).

Feelings about advanced cancer

If you have been told your cancer is advanced, you may feel shocked and find it hard to take in. You may feel frightened about the future, or angry with other people or yourself. With time, these feelings can become more manageable as you start making decisions and plans.

Although it is rare for advanced cancer to be cured, people may live with it for a long time - sometimes for years. During this time, many people carry on with their day-to-day lives and doing things that are important to them (MACMILLAN, 2014g).

Loneliness and isolation

It's common for anyone affected by cancer to feel lonely or isolated. These feelings can happen at any stage of the illness: at the time of diagnosis, or during or after treatment.

There are many reasons why you might feel alone. It may be because you feel like no-one understands what you're going through, or that other people are trying to be so positive that you can't say what you genuinely feel. Or it may be that your appearance has changed as a result of the cancer or its treatment. For example, some cancer treatments can cause hair loss or weight loss. These changes can add to your sense of being isolated and different from those around you. You can feel lonely even if you're surrounded by people close to you.

The sense of isolation can be made worse if you find it difficult to talk about your situation. It can be hard to tell your family and friends how you really feel, as you may want to protect them from a distressing conversation. You may tell them you're fine even when you're not. You might find yourself giving people other reasons for not being yourself, such as, 'I'm just feeling tired'.

You may find that the less you talk about it, the more the cancer becomes all you think about, and the more alone you feel. Finding the courage to talk to just one person can be the first step towards helping you feel better (MACMILLAN, 2014g).

If you live alone

If you live by yourself, you can feel even more alone and unsure of who to turn to. You may also have practical things to sort out. For example, you may need to work out who will look after your pet when you're in hospital, or how you will do everyday tasks like shopping when you're back at home.

Some people have family and friends who live nearby. But if you don't have anyone near you, it may be hard to know where to get help. You may find it helpful to join a local cancer support group, where you can meet people in a similar situation.

The internet has become a common way of socialising and keeping in touch with people. There are a number of online groups for people affected by cancer.

Some people find they feel less alone after seeing someone in a similar position with tips and advice on how to cope. Cancer Stories is a free online collection of real life stories showing how people coped with their cancer. Visit cancer-stories.info to watch videos of people affected by cancer. We also have lots of videos of people talking about their cancer experience. You can watch them all on Macmillan's Youtube channel (MACMILLAN, 2014g).

What may help

There are things you can do to help you feel less isolated and also help you manage your emotions. These may include -

- talking to family and friends,
- joining a self-help and support group,
- finding online support,
- speaking to healthcare professionals (MACMILLAN, 2014g).

Different things work for different people, so you may need to try a few to see what you find the most helpful.

You can use our online community to talk to people in our chat rooms, blog your journey, make friends and join support groups (MACMILLAN, 2014g).

Fear and anxiety

Feeling frightened and anxious is a natural reaction to an uncertain situation. Cancer is a serious illness, so it's normal to worry about what will happen in the months or years ahead. You may feel overwhelmed with information about treatment options, possible side-effects, and changes to your family and work life. You may be struggling to take all the information in and feel worried about making important decisions.

You may also be scared about the body changes that cancer treatment can cause. Whether these changes are temporary or permanent, they can affect your self-image and confidence. You may feel vulnerable if you can no longer do everything you used to do.

Our content on Cancer and body image concerns explains how cancer treatment can affect the way you see your body. It suggests ways of dealing with these thoughts and feelings.

Talking about your fears or concerns can often help. Discussing them with someone can help you understand them better and put them into perspective. It can also help you make important decisions. This can leave you feeling more in control of your situation and less fearful (MACMILLAN, 2014g).

Uncertainty

Feeling that we have some control over our lives gives us a sense of security and allows us to enjoy the things we do. It's natural to want to know what is likely to happen to us next, so that we can make plans for the future. But being diagnosed with cancer can take away that sense of security, and leave you feeling uncertain about what's ahead.

Uncertainty can be one of the hardest feelings to deal with, and it may make you feel irritable, angry and frightened.

Some people find it helps to find out as much as possible about their illness and what is likely to happen. This can help reduce feelings of stress, although not everyone feels this way. However, by talking through your fears, you may find the situation is better than you first thought. It's best to discuss this with your doctors and nurses, as they know your situation and are involved in your treatment.

Try to be clear with your doctor or nurse about how much you want to know about your illness. You could write down a list of the questions you want to ask before you see them.

You may find that doctors can't answer your questions fully, or that their answers sound vague. For example, it's often impossible for them to say for certain how effective a treatment will be. Doctors know approximately how many people will benefit from a treatment, but can't predict the future for a particular person with certainty.

Many people find this uncertainty hard to live with. We discuss things you can do to help you manage your feelings (MACMILLAN, 2014g).

Anxiety

It is natural to feel anxious when you have been diagnosed with cancer. But some people may have strong feelings of anxiety that are more difficult to manage. You may find that you can't concentrate, are irritable and easily distracted, sleep badly and get tired easily. These feelings may be there all the time, or they may come and go.

You may also experience some uncomfortable physical changes if you have anxiety. These can include tense muscles, breathlessness, dizziness, sweating or a dry mouth.

Reassurance from family and friends that 'everything will be alright' can sometimes make the anxiety worse. You may feel they do not take your concerns seriously. Or they may be struggling to accept your illness. Talking to someone who can listen to your fears objectively can be a great help. This may be your doctor, your nurse, a family member, a friend or a professional counsellor. Finding the right support and information may greatly reduce your anxiety.

If you feel that your anxiety is getting worse, speak to your GP or specialist nurse, or to a counsellor or psychologist. They can help you look at the reasons for the fear and find ways of coping with it. You may also find it helpful to contact Anxiety UK.

Many people who have anxiety may also have depression (MACMILLAN, 2014g).

Panic attacks

If you're very anxious then you may have a panic attack. This is a sudden and intense feeling of fear, along with physical symptoms of anxiety such as sweaty palms and a fast heartbeat. Panic attacks can feel overwhelming, but there are ways to help control them.

Techniques to help you manage panic attacks include breathing exercises and visualisation (MACMILLAN, 2014g).

SeeComplementary therapies for more information.

Hopes and fears

You may like to write down your hopes and fears. Even if you don't want to share these with other people, it might help you talk to other people about them.

You may find it helpful to use the 'Hopes and Fears' person-centred thinking tool, a table taken from thinkaboutyourlife.org, which was developed by cancer survivors. The website has examples, stories and support to help you use the tool. There's also space for you to think about the next steps you could take that may help you manage your concerns (MACMILLAN, 2014g).

How your feelings can affect you physically

You may have noticed physical changes such as difficulty sleeping, a lack of energy or loss of interest in sex. Try not to worry. Although physical changes can be due to the cancer or treatment, many are also caused by your emotions. Physical symptoms are normal and can affect anyone - not only the person diagnosed with cancer.

You may find it difficult to recognise the cause of any physical symptoms. Emotions affect people very differently, so any physical effects you have, may be different from what other people experience.

Sometimes, changes to your diet or routine may help manage your symptoms. You may also try Complementary therapies. Therapists can help you to manage individual emotions, which may improve any physical effects.

Try speaking with a counsellor, specialist or doctor if you are finding it difficult to cope (MACMILLAN, 2014p).

Physical effects of emotions

The stress of cancer and its treatment can affect your emotions in many ways. Our feelings can affect our energy levels, sexual desire, ability to sleep or appetite. How long these effects last will vary from person to person (MACMILLAN, 2014p).

Fatigue (extreme tiredness)

Fatigue [6] is an overwhelming feeling of tiredness or exhaustion. It is very common in people who are anxious or depressed. But it is also a very common side-effect of many cancer treatments. This can make it difficult to know what is causing your fatigue, and it is often a bit of both. If you think your tiredness is due to anxiety or depression, you may find that self-help techniques may help (MACMILLAN, 2014p), see also What you can do.

Doctors are still trying to find out exactly why cancer treatments cause fatigue. It's thought that fatigue may occur after having cancer treatment because -

- the body needs extra energy to repair and heal,
- there is a build-up of chemicals as the cancer cells are destroyed,
- the body's immune system is affected (MACMILLAN, 2013l).

Loss of appetite

Anxiety or depression can cause you to lose your appetite. In turn, this may make you lose weight.

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[6] extreme tiredness

Some people just don't feel hungry, or they feel full soon after starting a meal. Others find that food makes them feel sick, or they notice a change in the taste of some foods.

If your loss of appetite is due to anxiety or depression, you may find Coping with depression helpful (MACMILLAN, 2014p).

We also have information about Maintaining a healthy lifestyle. This gives helpful advice on -

- following a healthy diet,
- how to cope with eating problems caused by cancer or its treatment,
- how to boost your energy and protein intake when your appetite is poor (MACMILLAN, 2014p).

Loss of interest in sex

You may notice that your interest in sex decreases when you are anxious. You may also lose interest in sex if you're depressed. People are often reluctant to talk about this very intimate area of their lives, but if you have a partner, it can help to talk to them about how you feel. It may help you both feel more secure if you explain that your lack of interest doesn't mean a lack of affection.

You may need to focus more on sensuality than sexuality at this time. Using touch can be an important way of telling someone how you feel. It can help you communicate emotions that are not easily expressed in words.

Whether you're in a relationship or not, cancer and its treatments can affect your sexual identity. Treatments such as surgery or chemotherapy may lead to physical changes that affect your body image. Other aspects of treatment may leave you feeling unattractive or uninterested in sex.

These are very natural and understandable feelings. If you have trouble coping, you may find it helpful to discuss your feelings with a trained counsellor. In England, Wales and Northern Ireland, the charity Relate provides relationship counselling and offers support by phone and online. In Scotland, you can contact Relationships Scotland. If you feel comfortable, you can also discuss problems with your GP, cancer specialist or clinical nurse specialist. Or if you would prefer to speak to someone over the phone, you may want to call our cancer support specialists on 0808 808 00 00.

You may find the information on Sexuality and relationships helpful in coping with the effects of cancer and its treatment (MACMILLAN, 2014p).

Pain

Anxiety and depression can change how you feel and react to pain. This means that pain can be harder to bear.

Dealing with your emotions or treating the depression can help reduce your pain, as well as improve your mood. Your doctor or nurse can help you manage both physical and emotional pain. If your pain is due to your cancer or its treatment, you may find the information on controlling cancer pain in Pain useful (MACMILLAN, 2014p).

Sleep problems

Many people have trouble sleeping at some point in their life. If you have cancer, you may find it difficult to sleep because of general anxiety, worry about treatment or fears about the future. Some of the following suggestions may help you sleep better. These are examples and other things may work for you (MACMILLAN, 2014p).

- Have a regular routine at bedtime and get up and go to bed at the same time each day.
- If you can, avoid sleeping during the day.
- Doing gentle exercise before you go to bed may help you sleep.
- Avoid caffeinated tea, coffee or cocoa for a few hours before you go to bed. Try a warm, milky, decaffeinated drink instead.
- Have a warm bath using a relaxing bath soak or a few drops of lavender oil. You could also sprinkle a couple of drops of lavender oil on your pillow.
- If you can't sleep or if you wake up early, don't try so hard to sleep. Instead, try to relax and rest your body.
- If you find yourself lying awake and feeling anxious, it may help to go to another room for a while and do something else. You could read a book or listen to music or the radio.
- Keep your bedroom as a relaxing environment and your bed as a place to sleep. It's fine to spend some time reading before you fall asleep, but avoid watching TV or using a laptop in the bedroom.
- Switch off bright screens such as TVs, smart phones or computers one hour before going to bed.
- Make sure your bed is comfortable and cool.
- If it's very noisy, try using ear plugs.
- If streetlights or early morning sunlight affect your sleep, make sure you have thick curtains or blinds, or use an eye mask (MACMILLAN, 2014p).

Relaxation CDs, tapes or podcasts can also be very useful for helping you get to sleep. You can also access meditation and relaxation audio files and videos on our Learn Zone website.

We have more information about Difficulty sleeping which might be useful (MACMILLAN, 2014p).

What you can do

It can be hard to know what to do when you feel low. Knowing where to start can be especially daunting.

One of the best things to do is to talk about how you feel with someone close. Family and friends often know you best and will usually understand your feelings.

It's really important to take care of yourself. Try to eat well and exercise regularly. You may not feel like it at the time, but getting up and dressed each day can really help.

It's normal for your feelings to build up. If you feel like they are getting too much, there are ways to release your tension. Complementary therapies may help you to relax, while support groups allow you to share your experiences. Some organisations provide counselling and emotional support, if you feel this would help.

It may take a while for you to know what works and what doesn't. Advice and support is always available if you are finding it difficult to cope (MACMILLAN, 2014ab).

Managing day-to-day life

There are many sources of support that can help you. But there are also things you can do yourself to feel better.

It's important to look after yourself. If you're finding it difficult to manage your feelings, it can help to take things one day at a time and not look too far ahead. You may find that life gets easier to cope with as time passes (MACMILLAN, 2014ab).

Doing even the smallest tasks may help you feel better -

- Try to eat well every day. (If you have eating problems or a poor appetite, talk to your doctor or nurse.)

- If you can, get up and dressed every day.
- If you feel unwell, get some extra rest and don't delay seeing your doctor.
- Accept offers of help, or turn to other people for help.
- Keep to a regular sleeping pattern if you can.
- Try to exercise regularly - it can help you relax, boost your energy and help you sleep.
- Try to share your feelings.
- Try to keep your social life active by staying in contact with your family and friends.
- Recognise when you're feeling run down and stressed.
- For example, you may have headaches, trouble sleeping, tummy problems, or colds that don't go away. If you feel like this, see your doctor for advice.
- Try to find some time just for yourself every day when you can fully relax. But try not to sit still in one place for long periods of time. It can help to make your environment as comfortable as possible, perhaps with a comfy chair and plenty of light and fresh air. Listening to music or radio programmes may also help.
- If you can, try to make plans to do things you enjoy. You could book things a few weeks ahead, as this will give you something to look forward to.
- Some people find they lose motivation and begin to limit the amount of things they do. This can add to the feeling of being alone, so try to give yourself goals to achieve (MACMILLAN, 2014ab).

Taking control of your situation

Learning about the cancer and its treatment can give you back some feeling of control. This can help you feel more confident about the future. But it's up to you to decide how much information you would like at any time.

The information can help you during talks with your doctor, your family and your friends. It will also help you feel more involved in your care, and more in control generally.

It will also help if you tell people what you really think and feel. This will help them understand the issues that are important to you (MACMILLAN, 2014ab).

Reliable sources of information

Your doctors and nurses are in the best position to help you and answer your questions, because they know about your situation. They may not always have the information you're looking for though, and when they don't, there are lots of other reliable sources you can use.

A lot of misleading information is available, and many people still believe myths about cancer. It is important to get information that's up to date and comes from a reliable source.

You can get information from Macmillan. We have information in a range of formats about cancer, cancer treatments and all aspects of living with cancer. You can order any of our information by visiting be.macmillan.org.uk or by calling our cancer support specialists on 0808 808 00 00 (MACMILLAN, 2014ab).

Releasing tension

Tension can often be released by talking to other people. As well as talking to family or friends, you can call our cancer support specialists on 0808 808 00 00, or speak to your hospital staff or GP.

Some people find it helps to write down how they feel.

Keeping a diary or journal may be a way of expressing your fears and worries, without having to talk them through with other people.

You could also express yourself through drawing, painting, playing music or another creative hobby.

Sometimes you may feel like it's all getting too much for you.

If you feel this way, try thumping a cushion or pillow, turning the radio or CD player up very loud, or screaming. Having a good cry can also help release emotions. These things won't do anyone any harm and they may leave you feeling much better (MACMILLAN, 2014ab).

Physical activity

Doing physical activity can help us manage stress, anxiety and depression. It helps our bodies release chemicals (endorphins) that lift our mood and lower stress hormones. It can help with some side-effects of treatment, such as tiredness, and also help you sleep better. It can give you more energy, which can help you feel more able to deal with problems.

It can really help to be active with other people, for example by joining an exercise group or going with family or friends. It can also be helpful to be active outdoors in a green environment, like a park. You could try gardening or joining a walking group. There are free, guided health walks across the UK.

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Macmillan has teamed up with the Ramblers to offer Walking for Health - a network of organised walks across England. To learn more or find your nearest walk just visit Walking for Health.

We also have information on walking organisations in Scotland, Wales and Northern Ireland (MACMILLAN, 2014ab).

Complementary therapies

There are many types of complementary therapy [7] that may help you feel better, including acupuncture, aromatherapy, meditation, visualisation, homeopathy, art therapy and reflexology.

Complementary therapists usually work with the person as a whole. This is called a holistic approach. A complementary therapist who listens and cares may help you cope with some of your difficult feelings, which can help you get back some control.

Some hospitals and hospices provide complementary therapies alongside conventional cancer treatments, such as chemotherapy or radiotherapy. We have more information on hospices. Some support groups also offer complementary therapies (MACMILLAN, 2014ab).

Complementary therapies may help you -

- feel better and improve your quality of life,
- feel less stressed, tense and anxious,
- sleep better,
- feel more in control with some of your cancer symptoms,
- with some of the side-effects of your cancer treatment (MACMILLAN, 2014ab).

You might be advised not to have complementary therapies.

This is because it is not safe to have them if you have certain types of cancer or if you are having certain treatments. Your doctor will be able to give you more information about this. It is very important to tell your cancer doctor if you are thinking about having any complementary or alternative therapy.

If you have a complementary therapy, you should always use a registered therapist. And always let your complementary therapist know you have cancer. The British Complementary Medicine Association can give you the names of regis-

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[7] When a non-mainstream practice is used together with conventional, western-style, medicine

tered therapists and advice on what to look for. Remember to check the cost of treatment beforehand to make sure you're fairly charged (MACMILLAN, 2014ab).

See also Complementary therapies.

Self-help and support groups

Joining a self-help or support group can have many benefits. These groups offer a chance to talk to other people who may be in a similar situation to you, and who may be facing the same challenges. Not everyone finds talking in a group easy.

It may help to go along to see what the group is like and then make a decision.

You can search for groups in your area online by visiting macmillan.org.uk/in-your-area. Alternatively, you can call our cancer support specialists on 0808 808 00 00 and they can help you find local groups (MACMILLAN, 2014ab).

Changing priorities

Cancer often causes people to think about their lives and their priorities. Some people make significant changes to their lives, such as changing their job. Or it may be a good time to think about joining a local hobby group so you can meet people. Doing something new may also help you feel better (MACMILLAN, 2014ab).

Alcohol and recreational drugs

It may feel good at first to have a few drinks or take recreational drugs to help you forget how you're feeling. However, this is only a short-term solution. Alcohol and drugs can cause problems and damage relationships with family and friends. In the long-term, alcohol and recreational drugs may seriously damage your health.

Taking recreational drugs can also change the effect of some painkillers, so your doctor or nurse may ask you about this.

It is important to be open with them about using these drugs (MACMILLAN, 2014ab).

Do my feelings affect the cancer?

Your feelings and attitudes can affect the way you cope with cancer and its treatment, but there is no evidence that your thoughts, feelings or attitudes can influence the cancer itself. There is also no evidence that feeling negative or sad can delay your recovery from cancer or its treatment.

It is important to remember that cancer is influenced by many things, including our environment, our diet, and our genetic and physical make-up.

Whatever you're feeling is okay. It's important that you're able to talk honestly, and cry if you need to. This can help release tension and stress. It can even bring you closer to the person you're talking to. It's important to remember that all feelings and thoughts pass, and that you'll feel better at some point in the future (MACMILLAN, 2014ab).

Recording feelings

You may like to write about your good and bad days. This may help you decide on steps you can take to have more good days.

You may find it helpful to use the person-centred thinking tool. A table taken from thinkaboutyourlife.org, which was developed by cancer survivors. The website has examples, stories and support to help you use the tool (MACMILLAN, 2014ab).

Your feelings after cancer treatment

Cancer can affect a person's life in many different ways. So how you feel after cancer treatment may be very different to other people. There can be many reasons why you feel the way you do.

As you have fewer hospital visits and start to recover from the side-effects of treatment, you may begin to feel relieved and hopeful. You may need to take it slowly at first, but doing some of the activities you did before cancer treatment may help you to feel more positive.

It's understandable that having cancer can make you feel uncertain about the future. And it's natural for this to continue after cancer treatment has ended. Taking control of the things you can do something about can help feelings of uncertainty.

Other feelings you may have include isolation or loneliness, a loss of confidence, or anger. You may find these feelings come and go at different times. And some days they may feel stronger than others.

Talking about how you feel with someone close can make it easier to cope (MACMILLAN, 2014ad).

Your feelings after treatment

Everyone's experience of cancer and how it affects their life can be different. Cancer can be life-changing, and many people feel that things will never be the same again when treatment is over.

You may not always stop feeling the physical or emotional effects of cancer just because you have finished treatment. You may be feeling a mixture of emotions including relief, fear, loneliness and anger. If your body has changed because of treatment, the way you feel about yourself may also be affected.

You may find these feelings come and go at different times. And some days they may feel stronger than others.

Many people find ways of coping with their emotions. You may find it easy to talk about how you feel and have people you can speak to. Some people often find that over time their feelings become easier to cope with. But it won't be like this for everyone. It can take time for everything to go back to normal, and this may not happen as quickly as you expect.

In some cases, things won't ever be the same as they were before. And if you had low moods or depression before you had cancer, you may find these problems are worse after treatment.

You may have more time to think and reflect on your illness and what you've been through. You may find feelings you weren't aware of suddenly come to the surface. Some people find they're still struggling to cope with their feelings weeks, months or even longer after their initial treatment has ended.

Talking about your feelings can help you understand and manage them. This isn't always easy. We have some advice on putting your feelings into words (MACMILLAN, 2014ad).

Feeling relieved and hopeful

Once the main part of your treatment is over, you may feel relieved. You don't have to visit the hospital as much and you can start to recover from the side-effects of treatment.

You may start to think about having a holiday, going back to work, or doing some of the regular things you used to do.

These might be hobbies or just seeing friends. You may need to take it slowly at first but doing these activities again may help you feel better about yourself and your life.

You may have been encouraged to 'think positively' during your treatment. This may be something you hear even more after your treatment is over. But it's not always that easy. A lot of people have times where they feel low and this is natural. Being positive doesn't mean you have to feel happy all the time. It's a positive thing to acknowledge and talk about your feelings.

Some people feel a positive thing to come out of the cancer is a new outlook on life. You may feel like you can become a different person, stop or take on new work, change your lifestyle or do things you've always dreamed of. It can give you a greater appreciation of family, friends and life itself (MACMILLAN, 2014ad).

Uncertainty

Feeling that we have some control over our lives gives us a sense of security and allows us to enjoy the things we do. Having had cancer can take away your sense of security and control. This can be very frightening.

It's natural to want to know what is likely to happen to you, so that you can plan for the future. But at the end of treatment there can still be uncertainty, even when you've been told that everything has gone well (MACMILLAN, 2014ad).

You may find yourself asking some of these questions -

- What happens now?
- Will I ever get back to how I was before?
- Will I be able to go back to work?
- Will I be able to have children?
- Will the cancer come back and, if so, when? (MACMILLAN, 2014ad)

For some people, their treatment may have been aimed at curing the cancer, so they hope that they can put it all behind them. Others may have been told that the cancer is likely to come back, but no one can say for sure if and when this will happen. Feeling Worrying about cancer coming back.

Uncertainty can cause a lot of tension. You may feel irritable, angry and frightened. It's difficult to make plans when you can't be sure about the future. And even if you ask your doctors what's likely to happen, you may find that their answers are vague because they can't say for certain.

If you're finding this uncertainty hard to live with, try taking control of the things you can do something about. Getting back into a routine will help. As you get your strength back, you'll be able to do more of your usual activities.

Making some changes to your diet Lifestyle and diet may help or to your work-life balance can help. You may also want to think about using Complementary therapies for relaxation and to reduce stress.

You may find it helpful to know other people have the same kinds of feelings as you (MACMILLAN, 2014ad).

Isolation and feeling alone

It's very common for people with cancer to feel lonely and isolated. This isolation can affect people at different times during their illness. Sometimes this feeling stays after treatment ends.

There can be many reasons why you might feel alone. You may be coping with Changes to appearance and body image which make you feel different from those around you. This could be because of weight loss or losing your hair. This can be hard to cope with, especially if the differences aren't obvious to everyone.

You may still feel lonely even if you're surrounded by family or friends, because it can seem like no one understands what you've been through. Many people feel they have to be brave and don't want to upset their family and friends.

You may spend a lot more time on your own now. Your family and friends might not realise that you're feeling lonely, or they may assume that you're enjoying having time to yourself.

Some people may even feel a sense of grief or loss after treatment. This may be for the things you used to do but now can't keep doing. You may miss the routine of appointments, or the relationships you had with hospital staff. But some people find doing new things to fill the gaps can help, such as work or hobbies.

If you're back at work, you may feel isolated from your colleagues. This might be because you don't feel comfortable talking about your experiences, or because people avoid talking to you about it. If you don't normally work at home but you are at the moment, you may feel like you're missing out.

Feelings of isolation may be worse if you find it difficult to talk about yourself and your emotions. It can be hard to talk to others about how you really feel, especially if you sense that they think you should be able to get on with life now and 'feel fine'.

You may tell them you're okay when you're not. You may find yourself giving people other reasons for not being yourself, such as 'I'm just feeling tired'.

Talking about it can help you feel less alone. You may think that your family and friends are too busy to chat, or worry that you might be a burden to them. But you may find their responses surprising and reassuring. We have more information about How to talk to others about your cancer (MACMILLAN, 2014ad).

Loss of confidence

Having cancer can make you feel vulnerable. Your life may have worked around hospital visits and getting support from hospital staff, friends or family members. After treatment ends, it can seem as though you've become dependent on others.

This may make you feel like you have no control over your life.

Cancer and its treatments can change a person's role in their family or at work. Many people feel that these roles are an important part of their identity and if they change, it can affect their confidence.

Your social life often has to change after treatment. This can affect your confidence as you may not have the contact you once had with friends or colleagues. You can still feel tired and stressed after all you've been through, and the social things you used to do may be much more difficult.

It can take time for your strength to return. Some people have a loss of concentration too. This is sometimes called 'chemo brain'. Things you used to find easy may now be much more difficult, like reading a book or making small decisions. This can make you lose confidence in your abilities.

Getting back into these activities will take time. You'll probably build up your strength and confidence gradually. Setting yourself manageable goals can help. As you achieve these, your confidence will grow. Doing little things to reward yourself can help. This could be a trip to the cinema or doing something you enjoyed before you had cancer (MACMILLAN, 2014ad).

Anger

It's natural to feel angry when you've had cancer. You may feel angry about going through treatment and having to cope with the side-effects. You may be angry about the impact the cancer has had on your life. It may have affected your ability to work, your relationships and family life. Anger can also hide other feelings, such as fear or sadness.

We all express our anger in different ways. Some people might be impatient, or raise their voice. Others may get very upset and tearful. You may often direct your anger at the people closest to you. Letting others know that your anger is not about them, but about your situation, can be helpful. It means you can express your feelings and not bottle them up.

Try not to feel guilty about your angry thoughts or irritable moods. Anger can be a very powerful emotion, and you may find you can use it in a more positive way. It may give you the determination to start something new. This could be something like starting a new hobby or signing up to a sports challenge. Or these feelings may help you clarify what's important in your life.

If you're finding your feelings of anger are starting to affect your life in a negative way, you may find it helpful to talk to a counsellor or psychologist, see Help from your healthcare team (MACMILLAN, 2014ad).

Your spirituality

Not everyone is religious or spiritual. But some people affected by cancer may discover this side of themselves during or after their treatment. Having cancer and finishing treatment can strengthen some people's beliefs. Other people may have reconsidered them. They may have changed what they believe or have discovered new beliefs.

If you're having some of these feelings, you may want to talk to someone about them. This could be a partner, close friend, spiritual or religious leader, or a hospital chaplain (MACMILLAN, 2014ad).

Worrying about cancer coming back

After treatment has finished, it's normal to feel worried and uncertain. For some people, it can take years before they are confident the cancer is cured. Feeling worried or uncertain doesn't mean you're not coping with life after cancer. But if you feel like you're not coping, talk to your GP and ask for help.

There are ways to cope with feelings of worry and uncertainty so that you can continue with your life. Even if these feelings don't completely go away, you can learn to manage them.

Start by focusing on what you can do now rather than what is out of your control. You might want to try talking about your feelings, getting support or focusing on your well-being. You may find that some situations can trigger worry. If this happens, it's a good idea to talk to someone about your concerns. This can help you avoid getting into a habit of always worrying and make you feel you have some control (MACMILLAN, 2013o).

Worry and uncertainty

You will probably feel relieved when you have finally completed treatment to get rid of the cancer. But you may find yourself worrying about whether it has worked and what might happen in the future. It's natural to feel like this.

For many people, treatment will cure the cancer and it will never come back. Some people may want to know if they need to wait a number of years to be confident the cancer is cured. Or they may ask if there is a time when the cancer is more likely to come back and what can be done if it does.

Even when your doctor is reassuring, it's normal to still worry. Most people who have been through cancer treatment live with some worry and uncertainty. This doesn't mean they are not coping with life after treatment.

However, some people find it harder to cope with feelings of uncertainty. They may feel as if they have very little control over their lives. How uncertain or worried you are can depend on things such as your age, whether you have ongoing treatment side effects, and how you deal with life in general (MACMILLAN, 2013o).

Coping with these feelings

There are ways to help you manage worry and uncertainty. Realising that you will always have some of these feelings can be a good place to start. This may be hard and can take time, but there are people who can help you with this (MACMILLAN, 2013o).

Focusing on what you can control right now is one way of managing your worries. It can help you to stop dwelling on future 'what ifs'. Rather than worrying about things that may never happen, concentrate on what you can influence and do now. This can include -

- talking about your feelings,
- getting support,
- becoming more involved in your own care,
- following advice from your cancer team,
- focusing on your well-being,
- knowing when you need help with overwhelming feelings and where to get it (MACMILLAN, 2013o).

When we talk about your cancer team we mean the main people that have been involved in your cancer care. This usually includes your cancer doctor (oncologist), surgeon, specialist nurse, or other health professionals such as your physiotherapist [8], pharmacist, or dietitian.

Some of the suggestions we make may not fit in with your way of coping. There are no right and wrong ways to cope. You can adapt the suggestions in the ways that you find most helpful (MACMILLAN, 2013o).

Situations that may trigger worry

You'll probably find there are certain situations that trigger your feelings of worry and uncertainty. These can differ from person to person. Sometimes worry might feel more like a vague sense of dread. Recognising situations when you feel like this can help.

For example, you may worry that the doctor will give you some bad news when you're due for a follow-up visit or test. Or it may bring back memories of being diagnosed or of having treatment.

Another example could be hearing of a person you know whose cancer has come back or who has died. This could be someone you went through treatment with or perhaps a celebrity with the same type of cancer as you.

Any of these situations may trigger worries about your cancer coming back. But no two cancers are alike, even if they are the same type. So comparing yourself with others is not usually helpful.

Another situation that can trigger worry is having a new pain or symptom. You will still get everyday aches and pains after cancer treatment. A new symptom could be nothing to do with the cancer. Or it could be a late side-effect of treatment or a side-effect of a drug you're taking.

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[8] a person who helps to restore movement and function when someone is affected by injury, illness or disability. It can also help to reduce your risk of injury or illness in the future

It's important to get any new pain or symptom checked by a member of your cancer team if it continues. If you do nothing, you are likely to carry on feeling anxious.

Worrying that the cancer may come back is a natural reaction. However, some people get caught up in a cycle of worry. For example, a person with an ache or pain that's already been checked may still worry the cancer has come back. They may keep checking themselves for new symptoms. This can make them feel very anxious in the long run (MACMILLAN, 2013o).

Talking and getting support

Some people feel that they need to look as if they are coping well. They feel they must put on a brave face or protect other people's feelings. But people close to you usually want to know how you really feel so that they can support you. Sometimes they may find it hard to talk to you about their own feelings if you do not talk to them about yours. It can be lonely for everyone involved if you are all protecting each other.

Talk to someone you trust and feel comfortable with. If you find it hard to talk to people close to you, tell your cancer team or GP. They can refer you to a psychologist or counsellor (MACMILLAN, 2013o).

Talking about your worries or uncertainties helps you to -

- get them out in the open and stop you from going over things repeatedly,
- understand your feelings and put them into perspective,
- work out if you need to act on them, for example by contacting your cancer team to stop worries from growing bigger in your mind,
- feel closer to the people you talk to (MACMILLAN, 2013o).

Join a support group or online community

You may find it useful to talk to someone in a similar situation. Sometimes just realising that other people have similar thoughts and feelings can help you feel more able to cope.

You can get involved in a support group and attend their meetings. Some organisations or support groups offer buddy systems. Some offer counselling or complementary therapies.

You can also ask questions and get support from others through the internet. You can visit Macmillan's online community to talk about your experiences with other people.

Remember that other people's experiences may not be relevant to your situation. If you find sharing your own experience or reading other people's makes you more anxious, it's probably better to get support in another way (MACMILLAN, 2013o).

Write it down

Writing about what is happening to you can help you express your deepest feelings privately. You might find that it helps give you a sense of control. Sometimes keeping a diary or journal can help you work through various problems.

Reading it back can help you become more aware of your thoughts and feelings. It can also help you identify what the real issues are for you, what triggers them and what has helped you to cope.

Try to include the good or positive things that have been helpful as well as the things you find difficult (MACMILLAN, 2013o).

Knowing if you need more help

The worry of cancer coming back can sometimes be overwhelming. Some people find they repeatedly have the same worries and thoughts that their cancer will come back. This can make them feel constantly anxious or even depressed.

Feeling anxious all the time can be very hard. You may start to avoid social situations and this can lead to you feeling isolated. You may also have feelings of sadness and a low mood. If these feelings do not improve or get worse, it may mean that you are depressed.

Sometimes, it's difficult to know if you're depressed. It can also be hard to admit that you're depressed and to talk about it. Other people may notice and suggest that you might need help.

If you or someone close to you thinks you may need help with anxiety or depression, speak to your GP, specialist doctor or nurse at the hospital. They will listen and offer advice or refer you to a counsellor or psychologist. Your doctor may prescribe medication to help. This may only be needed for a short time.

Read more about Coping with depression. There are also organisations that can help you (MACMILLAN, 2013o).

Looking ahead

Having a sense of purpose in your life can help you shift your focus away from worrying and onto a positive outlook about life. Everyone does this differently. Some people like getting involved in a new activity. Others focus more on their everyday life such as family and friends.

The worry that your cancer may come back is something that may never go away completely. But while it may be tough at times, it is possible to live life to the full with the right help and support (MACMILLAN, 2013o).

When to contact your healthcare team after treatment

After finishing cancer treatment, it may take time to find out what feels normal for you. You may worry that every ache and pain is linked to the cancer. Try not to be anxious. Your healthcare team will tell you which signs and symptoms to look out for.

After treatment finishes, it can feel strange not seeing your healthcare team as often. You may feel you have less chance to talk about concerns. And you might put off asking questions you think aren't serious enough.

Your cancer doctors or nurses are usually still available for questions. You can get in touch if there's something worrying you between appointments. It's really important, even after treatment, to follow the advice of your healthcare team. Make sure any information you get is from a reliable source.

You may feel nervous going for follow-up appointments or tests but you may feel better afterwards. And if the cancer does come back, regular follow-up visits and tests can help to find it early (MACMILLAN, 2013n).

What to look out for

After treatment, it's common to worry that every ache and pain is linked to the cancer. You'll also still be getting used to what now feels normal. This makes it harder to know what to pay attention to and what to ignore.

Always let your doctor or nurse know if you have -

- any new or unusual symptoms that don't go away,
- symptoms or side-effects that don't improve over time,

- symptoms similar to ones you had when you were first diagnosed,
- general symptoms, for example losing weight, going off your food or feeling more tired than usual, for no obvious reasons (MACMILLAN, 2013n).

Remember that you can get in touch with your cancer doctor or nurse in between appointments. They can reassure you or explain if your symptoms are likely to be linked to your treatment. They can also do some tests if needed.

You may not always be able to speak to your cancer team when you need to. It may help to contact the Macmillan Support Line on 0808 808 00 00 and talk to one of our cancer support specialists

You may feel you don't want to be a nuisance by mentioning symptoms you think seem minor. But by not mentioning them you'll continue to worry, so it's always better to get them checked. Knowing the side-effects of any ongoing treatment and any possible late treatment effects can help.

There may be certain symptoms linked with your type of cancer coming back. You can ask your doctor or nurse about these. This may help you to know what to look out for and stop you worrying unnecessarily.

Checking yourself for symptoms can be a good way of noticing a cancer that comes back. However, for some people, checking themselves can become their main focus and take up most of their time. This is unhelpful and can cause them to worry more and feel very anxious. Focusing on other aspects of well-being may be more helpful (MACMILLAN, 2013n).

Follow the advice from your medical staff

Your cancer team may give you advice on what you can do and what to look out for after your treatment finishes. You may have ongoing side-effects that you need to manage. Or your nurse may have shown you how to do some simple checks and explained how to recognise anything unusual.

This might seem like too much to deal with after going through your treatment and you might just want to have a break from it all. But it's important to follow the advice from your cancer team and make it part of your routine. Getting to know what is normal for you now can help you feel more in control.

If your doctor has prescribed drugs - for example, hormonal therapy - to help reduce the risk of the cancer coming back, it's very important to keep taking them. Not taking your treatment can increase the risk of the cancer coming back.

If you have troublesome side-effects always let your cancer nurse or doctor know. They can often help with these or if necessary change you to a different drug (MACMILLAN, 2013n).

Follow-up visits and tests

You may find going back to the hospital for follow-up visits or tests difficult. It's normal to want to avoid situations that make you feel anxious or bring back difficult feelings. But many people feel reassured after follow-up visits.

Going for your visits and tests is an important part of looking after yourself. Your doctors can check whether there are any signs that the cancer has come back (recurrence) or has spread. Your cancer team also need to know if you have any side-effects or symptoms, and how you're coping emotionally.

If cancer comes back, finding it early can make it easier to treat and treatment may work better. In some cancers, treatment may cure a recurrence (MACMILLAN, 2013n).

You might find going to appointments or tests easier if you -

- have someone with you and let them know how you're feeling,
- have something to distract you while you're waiting, such as music or a book,
- write a list beforehand of what you want to talk about with your cancer team,
- plan something enjoyable to do afterwards (MACMILLAN, 2013n).

Having fewer hospital visits may make some people less anxious and help them move on after treatment. Instead of routine appointments, some people are asked to contact their nurse specialist or cancer doctor if they have any symptoms or concerns. If necessary, they will be seen urgently. This is sometimes called supported self-management or patient-triggered follow-up. It means you are more in control of your care.

Before your treatment finishes, your nurse will explain what will happen after treatment ends. They may tell you about symptoms to look out for, and what you can do to help your recovery. You will still have any regular tests or scans that you need (MACMILLAN, 2013n).

Getting the most from your visit

When you feel anxious, it can be difficult to take in what your doctor or nurse is saying. As well as having your list of questions, you can write notes on what happened and what was said during your visit. If someone goes with you, they can help you by going over what was said later. You can also ask your doctor if you can record your conversation so you can listen to it afterwards.

If you're unsure of anything, ask your doctor to explain it in simple, clear language. Otherwise you may worry afterwards about what they said.

Tell your doctor or nurse as much as you can about your health and don't play anything down. Try to be open with them about how you have been feeling emotionally. This way they are in a better position to support you (MACMILLAN, 2013n).

Make sense of statistics

Statistics about cancer can be difficult to understand.

Your cancer doctor is the best person to talk to if you want to know more about the chances of the cancer coming back. Doctors may know from trials how many people benefit from a treatment but they can't predict exactly what will happen to you. They may be able to give you some general guidance based on the stage of the cancer, how it tends to behave and the treatments you've had.

Some people try to find this information for themselves. Cancer survival statistics are based on large numbers of people. They help doctors decide which treatments are the most effective overall. But everyone is different so statistics can't be used to predict what will happen to an individual. There may also be factors that make your situation different from the usual.

Ask your doctor if any statistics you've seen seem unclear. It may be best to ask them in the first place so they can give you statistics based on your situation (MACMILLAN, 2013n).

Get reliable information

There is a lot of information available on the internet and in print. It is important to make sure any information you read is from a reliable source. A lot of information now has the Information Standard logo on it. This means that the information is based on evidence and is produced according to strict quality control guidelines.

If you're not sure whether something you've read is reliable, check with your doctor or nurse or contact the Macmillan Support Line free on 0808 808 00 00 (MACMILLAN, 2013n).

Changes to appearance and body image

Cancer and body image concerns

Body image is important to us. It's how we think and feel about our body and how we think others value us (MACMILLAN, 2016).

Concerns about body image are common in people affected by cancer. This is because cancer and its treatments can cause changes to how your body looks, works, and feels. These changes can include -

- hair loss,
- losing a part of your body,
- scarring,
- swelling of a body part,
- having a colostomy [9],
- weight gain or weight loss,
- changes to your speech (MACMILLAN, 2016).

Body changes that can't be seen also cause body image concerns. This includes no longer being able to have children (infertility [10]). Or, it could be late effects of treatment that interfere with how your bowel or bladder works.

It's important to remember that body image concerns are common after cancer. There are different ways you can get support and ways to improve your body image (MACMILLAN, 2016).

What is body image?

Body image is the picture in our mind of how our body looks and works. It's how we think and feel about our bodies and how we believe others see us.

Our body image is important. It's linked to our feelings of self-worth and how we think others value us.

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[9] a surgical procedure to divert one end of the large intestine (colon) through an opening in the abdominal wall (tummy)

[10] when a couple cannot get pregnant (conceive), despite having regular unprotected sex

Cancer and its treatments can change your body and how you feel about it. Because of this, body image concerns are common in people affected by cancer. Women and men at any age can have body image concerns.

Changes to your body may be temporary or permanent. They include changes that can be seen by you or others, such as hair loss or weight gain. They also include changes that are more private.

Body image concerns are different for everyone. Some people may feel uncomfortable or unhappy about their bodies. Others may feel so anxious they avoid going out or socialising. Sometimes body image concerns can make you feel less feminine or less masculine.

There are things you can do to improve your body image. There are also different ways to get help and support (MACMILLAN, 2016).

Cancer and body changes

Cancer and its treatments can cause changes to your body. These can affect how you see or feel about your body (body image). Body changes can affect -

- how your body looks,
- how it works,
- how it feels (MACMILLAN, 2016).

They can happen quickly or gradually and may be temporary or permanent.

Some changes can be seen by others (they are visible). Others may be hidden, except from you. There are also changes that can't be seen but can still affect your body image, for example infertility. These can make you feel vulnerable and self-conscious about your body.

You may be coping with more than one body change. Remember that body image concerns are common and there are different ways to get help and support (MACMILLAN, 2016).

Possible body changes We don't list all the possible body changes here. There are too many to mention, but below are some common visible changes -

- Hair loss. This means losing hair from your head. It can also include eyebrows, eyelashes and body hair. This is usually a side-effect of chemotherapy. Radiotherapy to the head also causes hair loss.
- Scarring from surgery, or losing a part of your body, such as a breast or a limb. You may decide to wear a prosthesis (false part) to replace a part of your body that's been removed.

- Changes in how your body works after certain types of surgery. For example, you may have changes after surgery to remove part of the bowel, or to remove the bladder or voicebox (larynx). This can include having a colostomy, an ileostomy [11], a urostomy or a tracheostomy.
- Losing weight or putting on weight. Putting on weight is often caused by steroids.
- Skin changes. Rashes, dry skin, spots or redness may be side- effects of chemotherapy, targeted therapies, hormonal therapies or steroids. Radiotherapy can affect the skin colour in the treated area or cause broken veins to appear later.
- Swelling of an arm or leg, or other parts of the body (called lymphoedema [12]).
- Changes in the way you speak, eat or breathe, or changes in your movement, balance or co-ordination (MACMILLAN, 2016).

Body changes that are not visible include the following -

- Infertility or early menopause [13].
- Reduced sex drive, or being unable to have sex.
- Feeling tired and weak or unable to do activities, such as sports or activities you did before treatment.
- Late treatment effects that change the way your bladder or bowel work.
- Changes in sensation. For example, you may have numbness in part of your body after surgery, or in your hands and feet after chemotherapy (peripheral neuropathy) (MACMILLAN, 2016).

How body image concerns may affect you

Changes to your body caused by cancer treatment can lead you to worry about your body image. This may make you feel anxious, less confident, angry or sad. Some people feel they are no longer the person they used to be, or worry about relationships, or going out.

There are ways to get support. This includes talking about your feelings with people you trust. You can also talk to your doctor, nurse or other people going through a similar experience.

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[11] where the small bowel (small intestine) is diverted through an opening in the tummy (abdomen)

[12] excess fluid build-up in your arm caused by blockage of the lymph nodes under your arm

[13] is when a woman stops having periods and is no longer able to get pregnant naturally

Before treatment, your doctor or nurse will explain what to expect afterwards. You'll need time to adjust to body changes. Be kind to yourself and if you have a visible change try not to delay looking at it. This can make it harder to accept and prevents you finding out if your fear is as bad as you think.

Anxiety can cause physical symptoms and be difficult to cope with. Coping with body changes may make you feel very low at times. Tell your doctor if these feelings don't improve so they can arrange for you to get the right support (MACMILLAN, 2016).

Body image concerns

Body changes may cause you to have concerns about your body image. This may start before or during your treatment, or you may not think about it until later.

Everyone's reaction is different. Some people may feel more self-conscious about their body but find it manageable. Or you may find your concerns are on your mind a lot of the time and find this upsetting (MACMILLAN, 2016).

Body image concerns may make you feel -

- less confident,
- anxious about people's reactions to you,
- worried about going out and meeting people,
- as if you've lost a part of yourself or aren't the person you used to be,
- worried about your relationship or about starting a new relationship,
- less feminine or less masculine (MACMILLAN, 2016).

You may also feel angry, anxious or sad. These are normal feelings when you're coping with cancer and body changes. You may feel as if you are grieving for what you have lost.

Talking openly with people you trust can be the best way forward. This could be your family or close friends, or your cancer doctor or nurse. Talking to another person who has been through something similar can also help. There are different types of support to help you cope with your feelings.

But you may also find you come to value how your body has coped. Some people see their body changes as signs of their survivorship. It can also be good to know that people appreciate you for who you are, not for your appearance (MACMILLAN, 2016).

Getting used to the changes

Try to allow yourself time to get used to your body changes and be kind to yourself.

Before treatment, your doctor and specialist nurse will explain what to expect. This can help you feel more prepared and less anxious. Finding out about the cancer and its treatment helps you understand it better. It also helps you learn about managing the side-effects of treatment.

If you have a body change you need to manage, for example a stoma, your specialist nurse will show you how to do this. Different support organisations can usually put you in touch with someone who has been through a similar experience. Or you could look for support online.

If you have a visible body change, such as a scar or stoma, try not to put off looking at it or dealing with it. You can do this with someone close to you, your nurse, or your doctor, or on your own. Delaying it often makes it more difficult to accept the change.

At first, you may feel shocked and upset, but these feelings usually lessen as you begin to get used to the change. You could look at the area covered up, then uncovered, and gradually build up to touching the area. Some people find it helpful to use a mirror when they start to look at the change in their body.

If you find it isn't getting easier, always ask your nurse or doctor for help (MACMILLAN, 2016).

Anxiety

It's common to feel anxious when you're concerned about your body image. For example, you may worry about people's reaction to how you look, or the effect it has on your relationships. Although everyone feels anxious sometimes, it becomes a problem when it interferes with your day-to-day life (MACMILLAN, 2016).

When we're feeling threatened, our bodies release the hormone adrenaline. This causes the physical symptoms we get with acute anxiety -

- feeling breathless or overbreathing (hyperventilating),
- feeling your heart is beating too fast,
- tight, aching muscles,
- feeling dizzy or sick,
- a dry mouth or sweating,
- needing to go to the toilet more often (MACMILLAN, 2016).

Avoidance

It's common to try to avoid situations or things that make us anxious. This may be a relief in the short term, but it can make things more difficult in the long term. It doesn't give you the chance to find out if facing your fear is as bad as you think. It also keeps anxiety and fears going (MACMILLAN, 2016).

Avoidance may result in -

- avoiding looking at or dealing with a body change,
- not going out, looking in a mirror or shopping for clothes,
- delaying or not making a decision about treatment because it involves a body change (MACMILLAN, 2016).

There are different ways to help you to cope with anxiety. You can do some of these for yourself, with the support of family or friends. Or you may feel you need further help from a doctor or nurse.

Getting help to understand your fears and working towards taking back control can help reduce them. You may also realise that other people see you in a different and more positive way than you'd imagined (MACMILLAN, 2016).

Depression

It's natural to feel sad and low at times when you're coping with body changes. If this continues or gets worse, you may be depressed. Sometimes other people may notice it first and talk to you about getting help (MACMILLAN, 2016).

Some symptoms of depression include -

- having a low mood most of the time,
- crying a lot or feeling unable to cry,
- getting little pleasure out of life,
- feeling very tired,
- being unusually irritable,
- having difficulty concentrating or making decisions,
- finding it difficult to sleep, waking up early, or sleeping more than usual,
- poor appetite or weight loss (MACMILLAN, 2016).

If you think you might be depressed, talk to your GP, specialist doctor, nurse or other healthcare professional at the hospital. They can listen and refer you for professional support from a counsellor. They may talk to you about taking prescribed drugs to help treat depression.

Occasionally, people may feel very low and need to talk to someone when they can't contact their doctor, nurse or counsellor. Samaritans have a 24-hour confidential helpline that provides support to anyone in emotional crisis (MACMILLAN, 2016).

See also Depression - Aging and Trans - Part 3 - Mental Health.

Managing anxiety and other feelings

Coping with body changes can make you anxious but there are ways to manage this. Talking to family and close friends may help you to put things into perspective and feel less anxious. Information from health professionals may also help to reassure you.

You might find sharing your feelings with people going through a similar experience helpful. This could be through a support group or organisation, or an online forum. Writing down your feelings or setting goals to manage challenges can also be useful (MACMILLAN, 2016).

Other things that may help you to unwind include -

- exercises to relax your breathing or your body,
- cutting down caffeine and alcohol,
- getting enough sleep,
- taking regular physical activity,
- using imagery (visualisation) meditation or mindfulness,
- complementary therapies such as massage or aromatherapy (MACMILLAN, 2016).

If your body image concerns become overwhelming, it's important to get help. Your doctor can refer you to a counsellor or psychological therapist. They can help you to understand your feelings better and find ways of coping with them (MACMILLAN, 2016).

Talking to other people

Anxiety is common when you are dealing with body changes. Try to talk to people you trust and who will listen to you sharing how you feel. This may be family or friends, or your doctor, nurse or other health professional.

Putting your concerns into words can help you make more sense of your situation and put things in perspective. You may feel less anxious and more in control.

If people don't allow you to talk but try to over-reassure you, or tell you not to worry, it can be unhelpful or make you more anxious. Try to explain to them that what you need is someone who will just listen.

Health professionals can give you information and practical advice. They can help you look at ways to reduce your anxiety. Tell them if your anxiety is difficult to manage or gets worse. They can refer you to a counsellor or psychologist, and prescribe medicines to help.

You could also talk to someone from a support group, an online forum or a support organisation. These give you a chance to talk to other people facing similar challenges (MACMILLAN, 2016).

Problem solving

It can be useful to think ahead of ways to solve a problem or to handle difficult situations. For example, preparing an answer for awkward questions such as, "*What happened to you?*" can help.

Setting yourself step-by-step goals can help you achieve simple things, such as meeting up with a friend. This means you're taking control of your situation (MACMILLAN, 2016). Setting goals can help you start.

Writing things down

It can also help to write about how you feel in a journal or diary. For example, you may find it helpful to use the hopes and fears tool below. There's space for you to think about the next steps you could take to help you manage your concerns (MACMILLAN, 2016).

Support organisations

There are different resources that give advice on managing anxiety. The NHS has content on stress and anxiety, and there is information on Anxiety UK's website. They also have DVD's, CD's and podcasts to help guide you at home (MACMILLAN, 2016).

What you can do

Some of the following suggestions may help you feel less anxious -

- Practise exercises that involve learning to relax your breathing or your body. Ask your GP about these - they may be able to refer you to a healthcare professional who can show you these techniques.
- Cut down on the amount of caffeine and alcohol you drink.

- Do regular physical activity to reduce stress and anxiety. Activities like yoga can reduce stress.
- Get enough sleep. Get advice from your GP if you have difficulty sleeping.
- Using imagery (visualisation) to have a picture in your mind of a place and time you felt relaxed and happy. Concentrating on how you felt at that time may help you feel less anxious.
- Some people use meditation or mindfulness to help calm their mind and help them focus.
- Some people use Complementary therapies to help them relax, such as massage, aromatherapy, reflexology or acupuncture (MACMILLAN, 2016).

Relaxed breathing exercises

You can do these lying down, sitting in a chair or standing up. To begin with, try to practise them regularly when you aren't anxious.

Your breathing should be slow and gentle but not deep, as this can make you light-headed (MACMILLAN, 2016).

- **Step 1** - Your shoulders, head and neck should be relaxed, and supported if you're sitting or lying down.
- **Step 2** - Place one hand on your chest and the other just below your ribcage.
- **Step 3** - Slowly and gently breathe in through your nose and feel your stomach move out.
- **Step 4** - After a full breath, pause for a moment then slowly and gently breathe out through your mouth (MACMILLAN, 2016).

Try doing this for five minutes, three times a day for a few weeks (MACMILLAN, 2016).

When you may need help

If your body image concerns are difficult to cope with, talk to your doctor or nurse. Let them know if you feel anxious or upset a lot of the time, or think you may be depressed. These are all normal reactions, but if they don't improve or are overwhelming, it's important to get help (MACMILLAN, 2016).

You may need help if you -

- find it hard to look at yourself after treatment,
- avoid socialising because of body changes,

- feel very unhappy with your appearance or spend a lot of time on 'fixing' your appearance,
- have difficulties in your relationship with your partner (MACMILLAN, 2016).

Your doctor can refer you to a counsellor or psychological therapist. They usually refer you for a type of 'talking therapy' that can help you understand your feelings better and learn new ways of managing your problems. They may also prescribe medicines to help (MACMILLAN, 2016).

Cognitive behavioural therapy (CBT)

CBT is a talking therapy that is helpful for people with body image concerns. The aim is to help you change your thinking so you can cope more positively when you feel anxious, helpless or depressed. A psychologist will talk to you about the number of sessions you need and set goals with you. CBT and other forms of therapy are available on the NHS.

There are also online CBT services approved by the NHS that you can do yourself.

Check the online NHS information service in your local area to see what services are available (MACMILLAN, 2016).

What can help - practical advice

There are ways to manage body changes to help you feel better about your appearance. Your doctor or nurse can also give you information and practical advice. They'll tell you about any possible options, such as reconstructive surgery. They can explain how to manage certain side-effects of treatment.

Reconstructive surgery, such as breast reconstruction, can be done immediately or years later. It may be possible to have surgery to improve the appearance of a scar. A prosthesis that doesn't fit well or isn't the right colour can be changed. Treatment late effects, such as lymphoedema, can also usually be improved.

There are lots of ways to cover up hair loss. You could wear wigs, hats or scarves. You can draw on your eyebrows or use false eyelashes if needed. Boots Macmillan Beauty Advisors can help with this and give you advice about looking after your skin, nails and hair.

Camouflage make-up can help cover up skin grafts or scars. You can use different clothing to help you cover up or draw attention away from changes (MACMILLAN, 2016).

Getting information

Before treatment, your cancer doctor and nurse will give you information to prepare you for your treatment and how it is likely to affect you. They'll talk about any options, such as reconstructive surgery, and help you make decisions. They can also -

- tell you about possible side-effects and what may help, such as cold cap treatment that may help reduce hair loss,
- refer you to other members of the team, for example occupational therapists [14], physiotherapists or speech and language therapists,
- refer you for services such as counselling if you think that would be helpful,
- arrange for a second opinion about your treatment if you feel this would be useful (MACMILLAN, 2016).

It's important to let your cancer doctor or nurse know if you have concerns about your body image at any point during or after your treatment. There are different ways they can help and support you (MACMILLAN, 2016).

Reconstructive surgery

If you feel less confident and attractive because of an operation that has changed your appearance, it may be possible to have further surgery to improve it.

For example, women who have had a mastectomy can have breast reconstruction. This can be done straight away or years after the first operation. It can help women feel more confident, feminine and sexually attractive. Women who had surgery to remove only part of the breast can also have surgery to improve the shape of their breast. Your specialist or breast care nurse will talk to you about this. They can refer you to a specialist surgeon (MACMILLAN, 2016).

Improving the appearance of a scar

Scars usually improve in appearance in the months after your operation. If a scar doesn't look better, ask your surgeon if there is anything that can be done to help. It may be possible to have surgery to make it less noticeable. Doctors call this scar revision. A surgeon can do this under a general anaesthetic [15]. They can

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[14] a person who provides support to people whose health prevents them doing the activities that matter to them

[15] a state of controlled unconsciousness caused by medications sending you to sleep in a controlled way

also sometimes do it under a local anaesthetic [16], where you have an injection to make the area numb.

You usually have to wait at least six months after your first operation to have scar revision (MACMILLAN, 2016).

Prosthesis

If you wear any type of prosthesis (false body part) and don't feel confident, talk to your nurse or doctor. The prosthesis may not be the right fit, type or colour match for you. They can arrange for you to be reassessed, even if your prosthesis is still in good condition. If you have had the prosthesis for a while, there may be new, improved types available.

For women who had breast cancer, Breast Cancer Care has information about prostheses. For people with facial prostheses, Changing Faces has some information (MACMILLAN, 2016).

Weight gain or weight loss

Some cancer treatments may cause you to gain or lose weight. This can be upsetting and cause body image concerns.

Steroids are often given with chemotherapy or hormonal therapy. They can cause weight gain. Some people lose weight if they can't eat enough because of symptoms, treatments, or their side-effects.

Ask your specialist nurse or dietitian for advice. It's not recommended that you try to lose weight on purpose during cancer treatment. After treatment, when you feel ready, you can look at ways of managing your weight by eating healthily and being more physically active.

If you have lost weight, it's important to get advice from a dietitian. There are different ways to add calories to food and nutritional drinks and powders to help build up your weight (MACMILLAN, 2016).

Late treatment effects

Late treatment effects, such as lymphoedema or bladder or bowel changes, often affect body image. There are usually things that can be done to improve and to manage them so you feel more confident.

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[16] involves numbing an area of the body using a type of medication called a local anaesthetic

If you are having problems with lymphoedema, contact your lymphoedema specialist nurse. If you don't have one, ask your doctor to refer you. Some people may need their support sleeve or stocking re-fitted. Or they might need new advice on managing lymphoedema.

If you have bladder or bowel late treatment effects, it's important to talk to your doctor or nurse. They can refer you to other healthcare professionals for advice and possible treatments (MACMILLAN, 2016).

Covering up changes

There are different ways to cover up changes and to help you feel better about yourself (MACMILLAN, 2016).

Different people can help you with this. This includes your healthcare team, who can -

- advise you about clothing and accessories, for example using a scarf to cover up hair loss,
- make sure you have the most suitable and least obvious product, for example a speaking valve after surgery to remove the voicebox (larynx),
- refer you to Changing Faces for advice about camouflage make-up, or to the British Association of Skin Camouflage,
- refer you for a replacement part (prosthesis), for example a breast prosthesis (MACMILLAN, 2016).

Hair loss If you choose to cover your head, there are lots of ways you can do it, for example using wigs, hats, turbans, scarves and bandanas. Some chemotherapy drugs make you lose all your body hair, eyelashes and eyebrows. Boots Macmillan Beauty Advisors can help you draw on eyebrows or use false eyelashes.

Your hair will usually grow back over a few months once you've finished treatment. It will be very fine at first and may be a slightly different colour or texture than before. You'll probably have a full head of hair after 3–6 months (MACMILLAN, 2016).

Make-up and beauty treatments Make-up and beauty treatments can help you make the most of your appearance so you feel better. You can use them to cover up some changes and to take attention away from others (MACMILLAN, 2016).

Boots Macmillan Beauty Advisors These advisors are specially trained by Macmillan and Boots. They give you face-to-face advice about caring for your skin, nails and hair during treatment. They'll show you how to use products to -

- disguise skin changes,
- draw on eyebrows,
- emphasise certain features (MACMILLAN, 2016).

Visit Boots Store Locator to find your nearest Boots Macmillan Beauty Advisor.

Look Good Feel Better (LGFB) This charity has trained volunteer beauty professionals who run free workshops for women and teenagers coping with cancer treatment. Workshops are available in over 80 hospitals and specialist cancer centres across the UK. Ask your nurse or doctor for a referral or visit the LGFB website to find one in your area.

LGFB USA has a cancer care website specifically for men. It gives advice about shaving, skin care and how to unwind and relax (MACMILLAN, 2016).

Camouflage make-up If you have had skin grafts (skin replaced with skin from another part of the body), the colour may not match your surrounding skin. Or you may have visible scars you'd like to cover up. Using camouflage make-up can help.

Changing Faces has trained skin camouflage practitioners. They find the best colour match for your skin tone and teach you how to apply the specialist waterproof cover creams and powders. You can get these on prescription. Changing Faces runs clinics across the UK.

If you wear a prosthetic and it doesn't match your camouflage make-up, go back and see the person who supplied it. They can match the colour to your camouflage make-up (MACMILLAN, 2016).

Clothing You can use clothes and accessories to feel comfortable and good about yourself and to cover up certain body changes. What you wear is also a way of expressing yourself. You can look at the clothes you already have to see what's suitable. Ask a family member or friend to help you.

Depending on the body change you have, you can get advice on clothing from support organisations, for example Breast Cancer Care, Changing Faces, the Colostomy Association, the Ileostomy & Internal Pouch Support Group or the National Association of Laryngectomee Clubs. Online community forums are also a good place to get advice (MACMILLAN, 2016).

Here are some tips that might help -

- If you have had surgery to the tummy area, have swollen legs or have put on weight, trousers with drawstring or elasticated waists or flat-front trousers are good.
- Long skirts, with or without slits, or wrap skirts can be a good alternative to trousers.
- If you have had a mastectomy and were used to wearing lower-cut dresses before it, try wearing them with a camisole top underneath.
- High V-neck shirts help if you want to cover a scar or central line in the chest area.
- High, mandarin-type collars or polo necks help cover up your neck area.
- Patterned shirts draw attention to the pattern and away from other areas.
- Bell-shaped sleeves are good if you have a swollen arm.
- Accessories help give different looks to one outfit. They also draw attention to certain areas and away from others.
- Be careful not to draw more attention to a change by hiding it. For example, instead of wearing a high-necked jumper in summer, try a lightweight scarf. It does the same thing and is less obvious (MACMILLAN, 2016).

If you need to buy new clothes because of body changes and can't afford it, ask about a Macmillan grant (MACMILLAN, 2016).

Relationships, intimacy and sex

Physical and emotional changes after cancer and its treatment may affect your sexual confidence or ability to have sex. This could cause difficulties with a partner, delay you getting back to having sex, or affect any new relationships.

Concerns about your sex life and intimate relationships are normal. If you are in a relationship, you may worry your partner will compare things to how they were before or no longer find you attractive. But your attractiveness to your partner will be linked to lots of different things. It's not about how a part of your body looks.

If you're not in a relationship, you may worry about how a new partner might react to any body changes. People who have cancer do go on to have close and intimate relationships in the future.

You'll probably need time to recover and adapt to body changes before you feel comfortable about having sex. How long this takes depends on what feels right for you and your partner.

Partners may also have concerns. Talking openly with each other can have a positive effect on your relationship and make you feel more comfortable with each other.

Even if you don't feel like having sex, you may still want to be close to your partner. Focusing on being intimate can take the pressure off. This could be spending more time together, holding hands, hugging, kissing or giving each other a massage. This intimacy can help you slowly get back to having sex again.

If difficulties with your sex life don't improve, talk to your doctor or specialist nurse. Try not to feel embarrassed - they're used to giving advice on intimate problems. They can give information on how to improve sexual difficulties and they can give advice on different ways of looking at problems. They can also refer you to a sex therapist if needed (MACMILLAN, 2016).

Helping you take control

If you have body image concerns, you may avoid going out and doing things because you're anxious. When you're ready, setting realistic goals can help you overcome anxiety and do things that are important to you. Think about what can help you to achieve your goal and break it into short-, mid- and long-term goals.

For example, if your long-term goal is to attend a family reunion, a short-term goal could be going for a coffee and your mid-term going for a meal with friends.

Working with problems in a structured way can make them more manageable. Identify the problem, write it down with solutions, advantages and disadvantages. Try it out and review how it worked.

There are NHS online resources that give advice on replacing unhelpful thoughts with more realistic and balanced ones. This approach is called cognitive behavioural therapy [7] (CBT). It teaches you how to react more positively to situations that would usually make you anxious. Mindfulness is another helpful technique that encourages you to focus on the present moment (MACMILLAN, 2016).

Ways of taking control

When you feel ready to start taking control of some situations, there are different approaches that may help (MACMILLAN, 2016).

These include -

- setting goals,
- problem solving,
- being aware of your thoughts,
- challenging unhelpful thinking (MACMILLAN, 2016).

Setting goals

If you have body image concerns, you may avoid social activities or doing things you enjoy because of anxiety. Setting goals can help you overcome anxiety and help you do things that are important to you. Here are some ways to help you decide which goals to set yourself and ways to help you achieve them (MACMILLAN, 2016).

Each goal should be -

- **personal** - it is important to you,
- **realistic** - you feel ready or able to deal with it,
- **achievable** - it is realistically possible,
- **measurable** - you will know you have achieved it,
- **specific** - you have thought about the details that will help you achieve it (MACMILLAN, 2016).

You can also break your goal into short-, mid- and long-term goals.

You may want to write down a goal and the steps that can help you achieve it (MACMILLAN, 2016).

Goal:

Steps:

Problem solving

Struggling and worrying about problems can make you feel anxious and stressed. Dealing with them in a structured way can help make them more manageable (MACMILLAN, 2016).

You can do this through a series of steps -

- **Step 1** - Identify the problem. Be as specific as possible and write down the problem.
- **Step 2** - Think of possible solutions. Write down any solutions that may help. Think about how you have solved problems in the past or what your family or friends would advise.

- **Step 3** - Decide on a solution. Think about the advantages and disadvantages of each possible solution. This will help you choose the best one. Choose one to begin with - you can always go back and try others later.
- **Step 4** - Break the solution down. Breaking it into smaller steps can make it easier and more manageable to do it.
- **Step 5** - Try it out and review how it worked. Follow the steps to carry out the solution at your own pace. If you solve the problem, use this approach for other problems. If it hasn't worked, go back and try it with another of your solutions (MACMILLAN, 2016).

Dealing with one problem successfully can help you overcome bigger problems.

You may want to identify a problem and think of the solutions that can help you overcome it (MACMILLAN, 2016).

Problem:

Possible solutions:

Best solution:

Steps:

Review:

Cognitive behavioural therapy (CBT)

There are many self-help books and online resources to help you understand your ways of thinking. Look at online information sources such as NHS Choices and NHS Inform in Scotland for advice on replacing unhelpful thoughts with more realistic and balanced ones. This approach is called CBT. CBT teaches you new skills and helps you understand how to react more positively to situations that would usually cause you anxiety.

But if you are struggling with difficult feelings about your body image, it's best to talk to your doctor or nurse for advice. They can refer you to a psychologist or counsellor trained in CBT (MACMILLAN, 2016).

Mindfulness Mindfulness helps you become aware of your thoughts and feelings without judging them or becoming overwhelmed by them. It uses techniques like meditation, breathing exercises and yoga to help you focus on the present moment.

Mindfulness-based cognitive therapy (MBCT) uses the techniques of mindfulness with some CBT to help you change thought patterns. A few centres in the UK offer MBCT classes on the NHS (MACMILLAN, 2016).

Changing the way you think

When you're coping with cancer and body changes, it's natural to have some negative thoughts. But if this becomes a usual way of thinking, it can make you less confident and more anxious. You may ignore positive things about yourself and believe all your negative thoughts are true (MACMILLAN, 2016).

Becoming more aware of your thoughts may help you to see unhelpful thinking patterns. This can help you challenge unhelpful thoughts and to think in a more positive, balanced way. For example, you could try asking yourself -

- Is what I'm thinking definitely right - what's the evidence for and against my thinking?
- How could someone else see this situation? (MACMILLAN, 2016)

One type of unhelpful thinking is over-generalising. When something goes wrong in our lives, we may see it as a sign that now everything will go wrong. You may think, for example, that if you go out everyone will stare at you. A more balanced way of thinking could be that some people will stare out of curiosity but you'll have your friends with you for support.

Remember that you can learn to change unhelpful thoughts into more positive thoughts (MACMILLAN, 2016).

Being aware of your thoughts

Thoughts go through our minds all the time. We're often not aware of them. They may be influenced by past experiences, or based on wrong assumptions or inaccurate facts.

It's not unusual to have some unhelpful or negative thoughts when you're coping with cancer and body changes. But if this becomes a usual way of thinking, it can affect your mood and make you less confident and more anxious. You may ignore positive things about yourself and believe your negative thoughts are true.

Becoming more aware of your thinking can help you see unhelpful patterns and the effect they have on your mood and behaviour. Some people find it helpful to write down their thoughts to see if there is a pattern (MACMILLAN, 2016).

Challenging unhelpful thinking

Recognising unhelpful thoughts can help you challenge them and think in a more positive, balanced way. Try asking yourself the following questions -

- Is what I'm thinking definitely right - what's the evidence for and against my thinking?
- How could someone else see this situation?
- What would I say to a friend who had this thought in a similar situation?
- Are my thoughts helpful to me, or do they stop me from doing and getting what I want?
- Am I jumping to conclusions, seeing the negative, forgetting the positive or getting things out of proportion?
- What would be the effect of thinking about things less negatively?
- What can I do to change my situation - am I overlooking possible solutions to problems? (MACMILLAN, 2016)

There are different unhelpful thinking patterns. In this section, we list a few of these and give some examples. We also show how you can change unhelpful thoughts into more balanced, positive thoughts (MACMILLAN, 2016).

Over-generalising When something has gone wrong in our lives, we may see it as a sign that now everything will go wrong (MACMILLAN, 2016).

- **Negative thought**

'Everyone will stare at me if I go to the pub.'

- **Balanced, positive thinking**

'Some people will stare, but it will probably be out of curiosity. I'll have my friends with me for support.'

Taking things personally When you're feeling anxious or low, it's easy to jump to conclusions or make assumptions. For example, you may think everything is related to your appearance or body change (MACMILLAN, 2016).

- **Negative thought**

'I didn't get the job because of my appearance.'

- **Balanced, positive thinking**

'I didn't get the job because there was someone who was better suited to it.'

Mental filtering When we focus on the negative and ignore the positive (MACMILLAN, 2016).

- **Negative thought**

'The woman in the shop didn't understand me as my speech is so poor now.'

- **Balanced, positive thinking**

'Although the woman didn't understand me the first time, she did when I repeated it - so I can make myself understood.'

Jumping to conclusions or mind-reading When we think we know what someone else is thinking without checking that we are right (MACMILLAN, 2016).

- **Negative thought**

'My partner will think I'm unattractive because of the changes in my body.'

- **Balanced, positive thinking**

'I'm aware of my body changes, but my partner may not notice it so much. Anyway, I have other attractive qualities that they love.'

Black and white thinking When we think in extremes of all or nothing, with no grey area in between (MACMILLAN, 2016).

- **Negative thought**

'If I can't eat a full meal then I can't go to the restaurant with my family.'

- **Balanced, positive thinking**

'It would be nice to go out with my family. I can ask for a small portion of food.'

Developing a positive body image

After treatment, you will need time to recover and adjust to any changes. Do things that make you feel good about yourself and let your body know you appreciate it. This could be having a relaxing bath or spending time somewhere peaceful. Other ideas to help improve your confidence include -

- being kind to yourself and spending time with people who support you,
- writing down things you like about yourself and your appearance,
- seeing yourself as a whole person and not focusing on parts of your body you don't like,
- replacing negative thoughts about your body with positive thoughts,
- making the most of yourself with make-up, clothes or a good hairstyle (MACMILLAN, 2016).

Making healthy lifestyle choices is a positive way of caring for your body. Being more physically active, healthy eating, not smoking and getting enough sleep all contribute to a healthy lifestyle. They bring different benefits, are good for your general health and can help you to feel more in control (MACMILLAN, 2016).

Developing confidence

You need time to recover from treatment and adapt to body changes, especially if they are permanent. Taking care of yourself and your body is important. It may help you develop a more positive body image.

Even if your body looks or feels different, you can feel good about it getting you through treatment. You may find you appreciate what it does for you every day.

Feeling good about yourself makes you more confident and self-accepting. It gives you an attractiveness that's about more than how you look. You may discover qualities you didn't know you had or find certain relationships are now closer.

Take time out regularly to do nice things for yourself so your body knows you appreciate it. This could just be having a relaxing bath, going for a massage, or spending time somewhere you find peaceful (MACMILLAN, 2016).

The suggestions below may help your confidence -

- Be kind to yourself.
- Spend time with people who support and encourage you.
- Write down the things you like about yourself and your appearance.
- When you see yourself in your mind, or in a mirror, look at yourself as a whole person. Don't focus on parts of your body you don't like.
- Try to replace negative thoughts about your body with positive thoughts.
- Make the most of your best features by using make-up or clothes to draw attention to them. Have your hair styled or keep it groomed (MACMILLAN, 2016).

Making healthy choices

Eating healthily, getting enough sleep and being more physically active are ways of taking care of your body. Not smoking or drinking more than recommended levels are also important. These are positive ways of looking after your body. They may help you feel more in control and improve your body image (MACMILLAN, 2016).

Being more active Doing regular physical activity can help you feel better about your body, its strength and what it's capable of doing. It makes you feel

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less tired and helps release chemicals (endorphins) that lift your mood and lower stress hormones.

It can be an opportunity to take up a new type of activity you wouldn't have thought of before. There are lots of different activities you can get involved with. Short walks that you build up gradually can often be a good start.

Some areas run physical activity programmes for people with cancer. Ask your healthcare team or look online for advice and to find out what's available in your area. Regular physical activity also helps keep your heart and bones healthy. It may help reduce the risk of certain cancers coming back (MACMILLAN, 2016).

Eat healthily A healthy, balanced diet gives you more energy. It also makes you look and feel better. Drink plenty of water, which helps look after your kidneys and keeps your skin clear (MACMILLAN, 2016).

Try to eat -

- plenty of fruit and vegetables,
- less red and processed meat,
- less saturated fat and sugar (cakes, biscuits, fried fatty foods) (MACMILLAN, 2016).

A healthy diet helps keep your weight healthy. It also reduces the risk of other diseases, such as diabetes and heart disease (MACMILLAN, 2016).

Sleep well We all feel and look better after a good night's sleep. Cancer treatment can make you tired for weeks or sometimes even months after it's over. Feeling anxious can also stop you sleeping. If you're having problems sleeping, ask your doctor or nurse for advice (MACMILLAN, 2016).

Don't smoke and stick to sensible drinking Stopping smoking is the best decision you can make for your health. Smoking is a major risk factor for smoking-related cancers and heart disease. It also causes premature skin ageing. Within a few weeks of stopping, your skin will look clearer and brighter. Straight away, your breath, hair and clothes will smell better.

Stick within the recommended guidelines for alcohol. Drinking too much can make you more anxious or depressed. It affects your health and how you look. It also stops you sleeping well.

Men and women are advised not to regularly drink more than 14 units of alcohol a week. Try to have several alcohol-free days a week. If your doctor has advised you to stop drinking, it's important to follow this advice.

It can be hard to stop smoking or cut down on alcohol when you're feeling anxious and stressed. Ask your doctor or nurse for advice. There's lots of different support to help you (MACMILLAN, 2016).

Managing other people's reactions to your body

Learning to cope with social situations and other people's reactions will help build your confidence. You'll often find people take much less notice of your appearance than you expected.

Being assertive can also help you face worrying situations. It means being able to ask for help and knowing you have the right to be treated with respect.

Social skills can help you to appear more confident and to take control of your situation. You can try to make eye contact, smile, and stand with your shoulders back and head up.

Preparing answers to difficult questions in advance is often helpful. You could give a brief reply and change the subject, or say you don't want to talk about it. You might prefer to bring up the subject of your body change yourself. It's up to you how much you want to tell.

If someone is staring or making remarks you can let them know you want it to stop using an assertive look, nod, or asking them to stop. Young children sometimes ask blunt questions but are usually satisfied with a simple explanation (MACMILLAN, 2016).

Coping with other people's reactions

As you and the people close to you get used to your body changes, you may begin to think about seeing other people. If you have visible changes to your appearance, you may worry about other people's reactions.

Occasionally, some people may make insensitive remarks or unwelcome suggestions. But you'll probably find most people take far less notice of you than you expected. Other people will soon respond to you as a person and not to your appearance.

Learning how to cope with social situations helps build up your confidence. This will help you slowly get back to your usual day-to-day activities. This can include returning to work or doing any hobbies or sports you did before (MACMILLAN, 2016).

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Being assertive

Learning how to be assertive can help you communicate better with other people (MACMILLAN, 2016).

Assertiveness means facing situations that worry you instead of avoiding them. It means giving your point of view but not getting angry with people when you can't do something. Being assertive is being able to ask for help and knowing you have the right to -

- say what you need,
- be treated with respect,
- make a request,
- be honest (MACMILLAN, 2016).

Dealing with awkward questions

People may want to talk to you to see how you are, or to understand what has happened. It may help to think in advance about the questions you may be asked and some possible answers (MACMILLAN, 2016).

What you tell other people depends on -

- how much you want to say and how you feel about your body change,
- your relationship with the other person,
- where you are and whether other people are around (MACMILLAN, 2016).

You can think of different responses, to prepare you for different situations. You could say you don't want to talk about it and smile, even if you don't feel like it, and reassure them that you're fine. Most people ask because they're concerned, and this is a good way of stopping the conversation without causing tension. Or you could give a short response and distract the person by asking them a question or changing the subject. Some people find it helps them feel more in control if they bring up the subject of their body change themselves (MACMILLAN, 2016).

Here are some examples of things you could say -

- *'Thank you for asking, but I'd rather not talk about it at the moment. Don't worry, I'm doing fine.'*
- *'I had an operation to remove a cancer a few weeks ago and I'm recovering well. How are you - what have you been doing lately?'*
- *'I've lost my hair because I'm having chemotherapy. But it will grow back when the treatment's finished. I really like the way your hair is styled - where do you get it done?'*

- '*You've probably noticed I've put on weight. It's a side-effect of some drugs I'm taking for my cancer treatment. But I'm not worrying about it too much right now.*'
- '*I had my operation to remove the cancer and I'm getting used to the changes, but it will take a while*' (MACMILLAN, 2016).

Using your social skills

Social skills help you take control of difficult social situations and manage other people's reactions to your change in appearance. But if you're feeling anxious or low, it can be hard to appear confident and sociable. Try these approaches and see what works for you -

- **Engaging with people** - Making eye contact, smiling and nodding tells people you're approachable.
- **Posture** - Standing with your shoulders back and head up makes you look confident and assertive, even if you don't feel that way.
- **Presentation** - The way you present yourself shows other people how you feel about yourself. For example, you could wear clothes and accessories that make you feel more confident.
- **Taking the initiative** - To help you feel more in control, you might want to bring up the subject of your body changes at the right time in a conversation (MACMILLAN, 2016).

These skills aren't difficult to learn, but you may need to practise them. They can gradually help you become more confident in managing social situations (MACMILLAN, 2016).

Staring or negative comments

You don't have to put up with staring or negative remarks. It's fine to let the person know you're aware of it and want it to stop. Sometimes people don't know they are staring. It only takes a frown or an assertive look from you to help them realise. You can also use other non-verbal signals, such as nodding, smiling or raising your eyebrows. Or you can say something, for example, '*Please don't stare at me. It's only a scar.*'

If you are in a situation where you can't walk away and don't want to draw attention, distract yourself by reading a book or newspaper. Holding it up in front of you can help stop the staring.

Young children sometimes ask blunt questions. They're curious and don't mean any harm, but without a response, they may carry on asking. You could try giving them a simple explanation they can understand. This might be all it takes (MACMILLAN, 2016).

Coping with family life and work

Everyday responsibilities like family life or work can be hard work when you are coping with cancer. Try to be realistic about what you can manage early on. Ask your partner, family or friends for support at home. Sharing your responsibilities may make it easier to concentrate on coping with the cancer and its effects.

It can also help to speak to your employer about the best way to manage your work. Taking time off or reducing your hours may help if you're finding it hard to cope. Support is available for people affected by cancer at work, including carers.

Cancer not only affects you as an individual, but those closest to you. It can also put a strain on relationships. But for some couples, overcoming a shared challenge like cancer can bring them closer together.

If you need more support than is available at home, you may decide to visit a hospice for day therapy. This can also give you the chance to meet people going through similar things to you (MACMILLAN, 2014f).

Getting help from others

Working or looking after a family can be hard work, even when you're well. It may seem impossible to try to juggle work life and/or family life at the same time as coping with cancer and all the emotions it can cause. It can also feel difficult to support other people when you feel in need of support yourself.

It is important to be realistic about what you can manage.

Try to get help from a partner, your family or your friends before things become too much for you to cope with. You may need to give up some or all of your responsibilities for a short time. This may help you concentrate on coping with the cancer and its effects.

If you're a parent, you may not be able to do all the things you usually do for your children. This doesn't mean you have failed in any way. It just means you need to plan your time and save your energy for the most important tasks.

Your family members may also be finding it difficult to cope with changes to family life. They also will have fears about the future. Try to talk openly about concerns and how you can help support each other.

Work is an important part of life for some people. It can help to have a discussion with your employer about the best way to manage your work. If you're finding things very difficult to cope with, you may need to take time off until you feel better. It can feel very different going back to work. Your priorities can change, and you may want to consider working part-time or returning to work gradually.

You may find our information about work and cancer helpful. If you're self-employed, you may also like to read our information about self-employment and cancer. We also have information for carers about working while caring for someone with cancer, see If you're supporting a loved one.

You may try to hide what you really feel so that you don't upset other people. But it can be reassuring to get your concerns out in the open and find that others feel the same. Talking about your worries may be all you need to do to help you manage your family and work life. You may find our information on talking to family and friends in How to talk to others about your cancer about your cancer helpful.

It may also be helpful to talk to someone outside the family, such as a good friend or trained counsellor (MACMILLAN, 2014f).

If you have a partner

Being diagnosed with a serious illness can be difficult for you as an individual, but if you have a partner, it can also affect them. Coping with cancer can put a strain on relationships. But some couples come to a new understanding and love for each another as a result of overcoming a shared challenge like cancer.

Communication plays a big part in any relationship. Talking about the illness and the impact it's having can be an important way of helping you both cope with it. You and your partner may have different feelings, and you may feel different things at different times.

You or your partner may not always want, or feel able, to talk. In these situations, you or your partner can get emotional support from your nurse specialist, other members of the hospital team as well as other organisations.

If you have become less interested in sex as a result of cancer or its treatment, help is available.

We have more information about the impact cancer can have on relationships, and what may help (MACMILLAN, 2014f).

Hospices

Hospices can help anyone with cancer and other chronic illnesses, not just people who are seriously ill.

They can offer symptom control, physiotherapy, psychological support and a range of Complementary therapies, such as massage and reflexology. The care is free and it may help you relax and reduce stress.

Visiting a hospice for day therapy can also give you the chance to meet people going through similar things to you. It can also give your family or carers some time for themselves.

Your GP or hospital doctor can organise a referral for hospice support (MACMILLAN, 2014f).

Tip - asking for help

It's easy to feel alone, when you need extra help. Many people also feel guilty about asking for help, and unsure of who to ask.

Try not to let these feelings stop you from getting the help and support you need. You may be surprised at the amount of help available. Friends and family are often happy and eager to help. Community-based schemes and services can also offer many different types of support.

Financial support can make the cost of travelling to hospital, or eating a special diet, more affordable. If you need extra support at work, or time off, your employer should be able to help. It's easy to feel overwhelmed trying to balance living with cancer with everyday tasks. But, practical help at home, with your children, pets or other responsibilities you may have is widely available.

If you're unsure where to get help, speak to Macmillan's cancer support specialists. Other local services and charities, such as Citizens Advice Bureau and your social services department, should also be able to help (MACMILLAN, 2014y).

Asking for help

Doing things for yourself is very important, but try not to feel guilty if you have to ask other people to help. Often friends and relatives want to help and are pleased to be asked. Many people are available to help you and your family. Different people can offer support in the community.

Your healthcare team and people who are close to you are likely to be some of the most important sources of support. Your healthcare team can help you to cope with any feelings or physical effects. They will also know what support services are available in your local area. District nurses work closely with GPs and can make regular visits to patients and their families at home.

Some areas have a 'good neighbour scheme'. The schemes can organise help from someone living locally every so often; for example, shopping, providing company, or offering transport. These schemes are usually run by the social services or local community organisations. Some are only available to people living alone. Look for 'Council for Voluntary Service' or 'Volunteer Bureau' in the phone book or online (MACMILLAN, 2014y).

If you live alone

If you live by yourself, you can feel even more alone and unsure of who to turn to. You may also have practical things to sort out. For example, you may need to work out who will look after your pet when you're in hospital, or how you'll do everyday tasks like shopping when you're back at home.

Some people have family and friends who live nearby. But if you don't have anyone near to you, it may be hard to know where to get help. You may find it helpful to join a local cancer support group, where you can meet people in a similar situation (MACMILLAN, 2014y).

Getting practical help

Help with costs

You may have to travel to hospital, which could mean paying for fares, petrol or parking. You may need a special diet. Your heating bills could go up because you're at home more during the day. Cancer may also mean a loss of income if you can't work because you're ill or caring for someone.

Financial problems can feel overwhelming. Talking through your worries with someone who understands can really help. Call the Macmillan Support Line and one of our cancer support specialists will tell you about the benefits and other financial help you may be entitled to (MACMILLAN, 2014y).

Advice about work

If you are very worried or distressed, you may have problems concentrating and may feel that work is the least important part of your life at the moment. If you are depressed you may find it difficult to work. In either case, you may decide that you need some time off work.

Most employers will be sympathetic and helpful. It can help to have a discussion with your manager or personnel officer so they know what is going on. If you need advice about your rights as an employee, you can contact your local Citizens Advice Bureau or call the Macmillan Support Line. We have information about Work and Cancer and Working While Caring for Someone with Cancer (MACMILLAN, 2014y).

Help at home

You can get help in the home to support you and the person you are caring for. This can give you a break and help you feel less tired.

Care attendants/carers come into the home to help in various ways. This may be with either jobs around the house, such as cleaning, washing and cooking, or just to sit with your relative or friend. They can also give some physical care with tasks such as washing and dressing. Some care attendant schemes provide someone to be there at night. Your local social services department or the Carers Trust will be able to tell you about schemes in your area (MACMILLAN, 2014y).

Help with childcare

It's important to try not to feel guilty if you're struggling to care for your children. It can be difficult to ask for help, but with the right support some of the stress can be eased. The time you then spend with your children is likely to be more enjoyable and relaxed.

It's important to ask for help when you need it. Social workers can be a useful contact and support in this situation. They can advise you about the childcare that's available in your local area (MACMILLAN, 2014y).

Help with pet care

Many people with cancer live alone but have the companionship of a pet. Looking after a pet can become a problem if you have to go into hospital for treatment, or into a nursing or residential home if you are less able to cope because of the cancer or its treatment. This can be a very distressing time and many pet owners worry about who will look after their pet when they can't.

There are arrangements you can make for your pets while you are in hospital, or if you become unable to care for them (MACMILLAN, 2014y).

You are not alone

Whatever your situation, you don't have to face it alone. Our cancer support specialists can answer any questions you have, offer support, or simply listen if you need a chat. Call us free on 0808 808 00 00 (MACMILLAN, 2014y).

Lifestyle and diet

Getting enough fruit and vegetables each day is very beneficial. Your diet can have a big impact on your risk of developing cancer and other health conditions. Eating a balanced diet can be difficult, especially if this isn't something you've ever thought about before. Try to take each day at a time.

Getting active is one of the best ways to lose weight. Being overweight can make you more at risk of developing cancer. You don't need to do strenuous exercise straight away. Building up your activity levels each day, moving even a small amount, can make a big difference to your health.

Positive lifestyle choices make a big difference in the long-term. Alcohol and drugs can lift your mood and improve how you feel. But this approach only works in the short-term and can have long-term consequences.

Eating well and exercising can be difficult. You may feel low and lose interest at times, particularly if it takes a while for you to see any improvements in your health or weight. Speak to your GP for advice if you need it (MACMILLAN, 2014q).

Diet and cancer

Experts think that up to 1 in 10 cancers (10%) in the UK may be linked to diet. There's a lot of research being done into which types of food may affect our risk of developing cancer.

Research suggests that a lack of fruit and vegetables in the diet may contribute to about 6 in 100 cancers (6%) in men. And being overweight may contribute to about 7 in 100 cancers (7%) in women. There are many reasons why people are overweight, but an unhealthy diet and lack of physical activity are often factors.

Our diets are made up of many types of foods, which in turn are made up of thousands of different substances. Some of these may increase our risk of cancer, but others may protect us. How diet affects our risk of developing cancer is complicated, and we still don't completely understand it.

Despite this, we do know that a balanced diet and regular exercise help us keep to a healthy weight, which can help reduce the risk of developing some cancers (MACMILLAN, 2014q).

Why be more active?

When you are living with or after cancer becoming more active can help you make a positive change to your life. We can all benefit from being physically active. It helps reduce the risk of health problems, such as heart disease, stroke and diabetes, and is recommended as a treatment for these conditions. There's also evidence that physical activity can benefit people affected by cancer.

Physical activity is any movement using your muscles that helps improve your fitness, health and wellbeing.

At first you might feel nervous about building up your activity levels, especially if you haven't been active for a while. You may be worried that you're too tired or you may not know where to begin.

Even a little physical activity is better than none. It can help you feel less stressed and generally healthier. It can also help you to feel more in control because you are doing something for yourself.

During treatment, doctors and nurses usually advise you to try to limit the time you spend sitting or lying down. They may encourage you to take some gentle activity such as going for short walks. Not being active can make you feel more tired and lose cardiorespiratory fitness and muscle strength. Cardiorespiratory fitness is how well your heart and lungs work to deliver oxygen to muscles over longer periods of time.

After treatment, being physically active can help you to cope with and recover from some side-effects.

Being active can range from simple daily activities such as, housework, gardening and walking to the shops to more energetic activities such as running, cycling, dancing or a gym-based exercise programme.

How much and what you choose to do will depend on where you are with your treatment, your preferences and level of fitness (MACMILLAN, 2014q).

Alcohol and recreational drugs

It may feel good at first to have a few drinks or take recreational drugs to help you forget how you're feeling. However, this is only a short-term solution. Alcohol and drugs can cause problems and damage relationships with family and friends. In the long-term, alcohol and recreational drugs may seriously damage your health.

Taking recreational drugs can also change the effect of some painkillers, so your doctor or nurse may ask you about this.

It is important to be open with them about using these drugs (MACMILLAN, 2014q).

Your sex life and sexuality

How cancer may affect your sexuality

Sexuality is the feelings and characteristics that make up your sexual identity. It's about who you are and how you feel as a person. Sexuality is a very personal matter and means different things to different people.

Sexual attitudes and behaviour vary a lot from person to person. They're influenced by our experiences, our upbringing, our genetic make-up, our cultural and religious beliefs, and our hormones. Sexual attitudes and behaviour can change due to different circumstances, and they can vary at different times during our lives.

You are a unique individual and your sexuality is part of who you are. There are many different sexual preferences. Your sexuality isn't fixed - you can change your mind, find new things pleasurable and communicate in new ways. Following a cancer diagnosis and treatment, you can still feel good about who you are, and how you express your sexuality with others (MACMILLAN, 2014af).

Effects of cancer on sexuality

It's very difficult to predict how cancer and its treatment will affect you. For many people, any changes in their sexuality will be temporary. However, you may need to get used to permanent changes and find new ways of giving and receiving sexual pleasure. With support and clear communication, you will still be able to enjoy a fulfilling sex life (MACMILLAN, 2014af).

There are four main ways that cancer or its treatment can affect your sexuality. It can affect your -

- physical ability to give and receive sexual pleasure,
- thoughts and feelings about your body (body image),
- emotions, such as fear, sadness, anger and joy,
- roles and relationships (MACMILLAN, 2014af).

These areas are linked - if there's a problem in one of them, it may have an impact on another.

Having cancer can affect how you feel about yourself sexually, or it can affect your physical ability to enjoy sex. Many people with cancer say they feel 'washed out' and have almost no energy for many months or even years. This may be because of the cancer itself or the treatment. This tiredness can make you lose interest in sex both during and after treatment (MACMILLAN, 2014af).

Sexuality and your feelings

Feelings, sexuality and cancer

Your feelings can have a very powerful influence on your sexuality and sexual behaviour. If you are feeling depressed or anxious, you're less likely to be aroused by thoughts of sex. This is also true if you're feeling afraid about your cancer, its treatment or your relationship.

Being diagnosed with cancer usually causes many strong emotions, which may make you less interested in sex. Fear, anxiety, pain, anger, envy and jealousy are common blocks to arousal.

If you have had a change in their body due to cancer or its treatment often have a fear of rejection. Normal, everyday feelings are intensified, which can be exhausting and may lead to a loss of interest in sex.

Some people feel an increase in sexual arousal. Others say they feel guilty for worrying about their sex life when they should just be grateful for being alive.

Feelings can sometimes be overwhelming and may be intensified by the worry that your emotions will also affect the people around you (MACMILLAN, 2014af).

Ways of releasing feelings

Sexual self-esteem is often directly related to overall feelings of well-being. If you feel unsure about yourself and lack confidence as a result of the cancer, you may also lack confidence sexually. It can help to talk about and express these difficult feelings.

You could share your feelings with someone who will listen and not judge you or tell you what to do - perhaps a family member or close friend. If you'd prefer to talk to someone anonymously, you could talk to our cancer information specialists on 0808 808 00 00.

If you have a partner, talking openly with them about sex and cancer can help you overcome communication problems. Your healthcare team might think you'd benefit from seeing a sexual health specialist. These are experts in dealing with issues about intimacy and relationships, and they can give you confidential advice and practical help. They can help you express your anger and other feelings. Many couples use these appointments to start being more honest with one another, sometimes after many years of avoiding sensitive issues. Keeping old feelings hidden won't help you or your relationship heal. By talking openly, you may find you can overcome the common problems in communication about sex and cancer.

Sexual contact can be a good outlet. After having sex, you may find that any anger subsides. Sex can also distract people from feelings that are upsetting them (MACMILLAN, 2014af).

Sexuality and relationships

Cancer or its treatment can affect the relationships you have now and any you may make in the future. These changes may impact on your sexuality.

Your role in the family may change. Treatment may mean you have less energy than you used to. For a while you may not be the main breadwinner and these changes can affect your sexual self-esteem.

Your relationship with your partner may change too. You both may worry about having sex again if you've had a break from it for a while. Your sex drive may have changed since treatment. It can help to be open with each other about how you feel and what you want.

It can be difficult to build new relationships. You may be unsure about what and when to tell a new partner. It can help to talk your worries over with family and friends.

Sex is a normal part of most people's lives. If you want help for sexual problems, talk to your GP or specialist nurse. They may be able to put you in contact with a relationship therapist (MACMILLAN, 2014af).

Changes in your roles and relationships

Cancer or its treatment can temporarily change your roles in your relationship or family.

You may find your relationships with friends change. Some friends may not be able to deal with your cancer, and you may find you lose touch with them. Sometimes this can feel like a rejection, which can lower your self-esteem. It's important to focus on the friends who are able to support and listen to you.

During treatment or after surgery, you may not have the physical energy to do all the things around the house that you did before. Relatives and neighbours may get involved in lending a hand, and sometimes this can leave you with a sense of not being needed, or not having control over your life. You may feel that you've lost your place. Fulfilling your role as a mum, dad or the breadwinner makes up part of your sexual self-esteem, so a change in that role is difficult to deal with.

Your future plans may change as a result of cancer and its treatment. Whether you are single or part of a couple, you may have made all kinds of plans, spoken or unspoken, for your relationships or sex life. Some people look forward to their children leaving home so they have more time, money and privacy for a relationship. They may feel that having cancer at this stage of life takes this opportunity away. It's very normal to grieve for this kind of loss.

When you've been through an experience of cancer, you may never be the same again. Your view of your life, your relationships, your job and your family may all change. Managing all this change can be difficult to deal with, but you can use this challenge to build your relationships (MACMILLAN, 2014af).

Many people say they -

- become more honest with their partner,
- stop putting off things they want to do - sexually or otherwise,
- start to be more realistic about life in general,
- take up new interests that they've been putting off for years (MACMILLAN, 2014af).

Being open to change encourages healthy sexuality. You may need to develop a whole new style of openness and flexibility. For example, you might have always taken the lead in sex, and this may have to change now. Your favourite sexual positions may not be comfortable any more, temporarily or permanently. You may have seen sex as being entirely about intercourse. But if penetrative sex is impossible, you may want to start exploring other ways to have and give sexual pleasure.

You may worry that you will lose your current or potential partner if you can't fulfil their sexual needs. Talking to a partner about sex can be difficult. But discussing your fears and worries about sex can help you both feel more comfortable with each other (MACMILLAN, 2014af).

If you're single

If you want to start a new relationship, it can be difficult to decide what to tell a new partner about your cancer, and also when to tell them. We often make assumptions about what other people think or feel about us and fear rejection.

There's no simple answer that will work well for everyone. You may find it helpful to think about how safe you feel in the new relationship, and whether you feel you can trust your new partner with very personal information. This is particularly important if you have a body change that you keep hidden and are anxious about revealing. With time, you'll probably feel stronger and more able to discuss your cancer.

Before making a strong commitment to a new partner, you should make time to discuss your cancer, especially if it could affect the length of your life or has affected your fertility. Lasting relationships are based on honesty, and keeping your cancer from your new partner may affect your future together. A loving partner should accept you as you are, and if they don't then they're probably not the right partner for you.

If you need help, you can usually find support from family and friends (MACMILLAN, 2014af).

If you're in a relationship

Whenever someone has an illness that's affecting their romantic or sexual life, it's helpful to think about what their relationship was like before. A relationship that was difficult before cancer was diagnosed probably won't be any better afterwards. However, some couples come to a new understanding and love for each other as a result of coping with a shared challenge like cancer.

You can use this information to help prepare yourself for any changes in your sexuality. You and your partner can consider how to manage this aspect of your life. You might want to get more information or resources to help you feel in control of maintaining good sexual self-esteem while having treatment.

It may be your partner who is concerned about sex. Some people find it more upsetting to watch someone they care for go through surgery or other treatments than to go through it themselves.

After your treatment, both you and your partner may be aware of the transition you both have to make from being ill or a care-giver, to becoming sexual partners again. Your partner may feel afraid to touch you in case they hurt you. Some people incorrectly believe they might catch the cancer through sexual contact. Your partner may lose desire because of the changes you've gone through. They may also feel rejected if they don't realise that your reduced sexual desire is due to the cancer or its emotional effects. Communication is important when you're trying to maintain a happy relationship (MACMILLAN, 2014af).

Changed sex drive

It's also important to acknowledge that your partner's sex drive may not be reduced. Sometimes it can even increase, if touch or being intimate helps reassure them in times of stress. It may be important to talk to your partner about other ways they can meet their sexual needs, such as masturbation. This can help reduce any frustration they're feeling because they're having less sexual contact. This may not be what you would ideally want, but it can be a useful way for both of you to meet your needs.

Even when sex is not possible, you may become more emotionally intimate through greater communication (MACMILLAN, 2014af).

Starting again

Being open with each other can often have a positive effect on an intimate relationship. If having sex is a worry, it may help if you agree to avoid it for a while. This can take the pressure off and let you concentrate on rebuilding intimacy. You can focus on spending time together and going out, holding hands or kissing and cuddling. Learning to massage each other can be supportive.

If you have had a break in sexual contact, it may be important to start again and re-learn about sexual contact. When you're rebuilding intimacy, you may need to start very slowly and gently.

Try caressing each other without a goal of penetration or orgasm. Remember that there are lots of loving and erotic activities other than intercourse.

Having cancer doesn't mean you have to give up sexual contact completely. However, you may find you don't miss sexual contact and that not having sex isn't a problem for you (MACMILLAN, 2014af).

Getting help

If you find you're having difficulties with your sex life, ask for help sooner rather than later. It's very common for people to delay asking for help with sexual issues. This may be because they're embarrassed or because they've been focused on their recovery. Remember that sex therapists and counsellors are used to helping couples who have had problems for a while, which might mean their relationship has serious issues by the time they get help.

A good place to start is your GP surgery. There might be a counsellor or psychologist in the practice. If not, they will know how you can contact one. You could also talk to your hospital team or specialist nurse about which sexual health services are available locally. The College of Sexual and Relationship Therapists has a list of nationwide counsellors and therapists who can offer advice and support.

You can buy books and DVD's about sexual issues from shops or online. Often they aren't on display in shops, so you may need to ask for them. Your local library may also have some useful books you can borrow (MACMILLAN, 2014af).

Sex and relationship therapy

You may be concerned about seeking help for a sexual problem from a counsellor or psychological therapist. You may worry you might be labelled in some way. Remember that sex is a normal part of most people's lives and that asking for help with a sexual problem is no different to asking for help with any other health concern.

You may think that all sexual problems are physical and that talking about how you feel won't help. Sex therapy (psychosexual counselling) can help you think about and adjust to any physical changes and help you explore different ways of getting sexual satisfaction. It can be very reassuring to discuss any sexual problems you have. You may be able to talk to someone in your healthcare team who has expertise in working through sexual issues.

Sex therapists are trained to help you work through the different physical, emotional and relationship issues that may be having a negative impact on your sexual function or well-being. Even if your sexual issues have mainly been caused by your treatment, such as changes to your breast(s), the sex therapist will pay attention to each aspect of your sexual concerns.

The therapist will ask you a lot of questions to assess what's worrying you and how they might help. You don't have to answer any questions you feel uncomfortable about. It can sometimes take a couple of sessions of therapy before you feel happy enough to openly talk about your feelings and concerns.

A sex therapist can't fix all your problems, but they'll help you, and your partner if you have one, explore the issues and work out ways for you to get what you want. The therapist may suggest some exercises to help you overcome the problem, but you don't have to follow their advice if you don't want to or if you feel uncomfortable.

Some sex and relationship therapists also have medical or nursing qualifications. If you have a physical problem that's affecting your sex life, they'll be able to give you advice about it.

If not, they'll refer you to your GP or specialist.

Sex and relationship therapy is confidential. The therapist won't discuss your sessions with anyone else unless they're concerned there's a risk you might harm yourself or someone else.

Your cancer doctor, specialist nurse or GP can refer you to a sex and relationship therapist. You can also find a therapist privately (MACMILLAN, 2014af).

Common questions about sexuality and cancer

Can sexual activity cause cancer?

Not in the strictest sense of the word. The development of some types of cancer may be influenced by a virus that's commonly passed from one person to another during sex through skin contact.

Anal cancer, cervical cancer, vulval cancer, penis cancer and some mouth cancers are more likely to occur in people who have the human papilloma virus (HPV). This is transmitted through sexual contact. Some types of HPV are known to increase the risk of developing particular cancers. These are known as high-risk HPVs. The types most often associated with cancer are types 16 and 18.

However, HPV is very common and most people who have it don't develop cancer because of it.

There are many factors other than the virus that can increase the risk of developing cancer, such as -

- whether or not you smoke,
- your age,
- your diet,
- the genes you inherit from your parents,
- your general health (MACMILLAN, 2014af).

These factors can influence whether or not infection with a virus will affect the development of a cancer (MACMILLAN, 2014af).

Can I catch cancer from my partner?

No. If your partner has cancer, you can't catch it from any sexual activity. You can't catch cancer by having sex (MACMILLAN, 2014af).

Could having sex make my cancer worse?

No. In fact, sex and all the love and caring that goes with it can be helpful for people with cancer. Many people feel depressed, unlovable, guilty or afraid when they have cancer or are having treatment. Affection and acceptance from a partner can make a big difference. Sex doesn't make the cancer more likely to come back or spread (MACMILLAN, 2014af).

How can I overcome tiredness?

Be flexible about the time of day you have sex. Try having sex in the morning when you feel refreshed after a night's sleep rather than last thing at night. Experiment with less demanding sexual positions. You and your partner can agree that sex doesn't always need to be a long session (MACMILLAN, 2014af).

How soon can I have sex after having surgery?

This will vary greatly depending on the sort of operation you had and how quickly you are healing. Your surgeon or specialist nurse can give you more information (MACMILLAN, 2014af).

Can chemotherapy drugs be present in sexual fluids?

If you have sex within the first couple of days of having chemotherapy, you need to use a condom. This is to protect your partner in case there is any chemotherapy in sexual fluids. Using barrier contraception removes any potential risks (MACMILLAN, 2014af).

When can I start trying for a baby?

It's essential to avoid trying for a child while you are having chemotherapy. This reduces the risk that the chemicals could be absorbed and harm the developing baby. Many doctors recommend not trying for up to a year after treatment, as this is the time when the cancer is most likely to come back (MACMILLAN, 2014af).

Which sexual positions should I use after having cancer?

This will depend a lot on which part of the body is affected. If it's the pelvic area, it will take some gentle and patient experimenting to discover which sexual positions now suit you and your partner. If you've had a mastectomy, you may not want your partner's weight resting on you. It may be better to have sex side by side, or swap who's on top. Most couples find that with loving communication they can find out what suits them best. The things you find most enjoyable will change with time, so be prepared to change what you do (MACMILLAN, 2014af).

What can I do if I'm embarrassed about my scars but still want to have sex?

Try to talk to your partner about your worries. Most people find their partner is much less concerned by their scars than they imagine, and that they love them as a person and not just because of the way they look. Once the subject has been discussed openly, most people feel more relaxed about the changes in their body.

Try having sex in semi-darkness, for example by candlelight, to avoid being seen so clearly. You may find it helpful to wear clothing during sex if you are worried about your scars (MACMILLAN, 2014af).

Difficulty sleeping

Many people affected by cancer have insomnia, which is difficulty sleeping. Long periods of not sleeping well can lead to other problems. There are some things you can do to try and improve your sleep. These include: -

- having a regular bedtime routine,
- being more physically active during the day,
- making sure your bedroom is not too hot, cold, light, or noisy,
- having a snack before bed, but avoiding caffeine, sugar and alcohol (MACMILLAN, 2013a).

If worry and anxiety are keeping you awake, talking to someone or writing down your worries can help clear your mind. Breathing and relaxation exercises may also help.

Some medicines used in the treatment of cancer can affect your sleep. Your doctor or nurse can give you advice on coping with this.

You may be able to take sleeping tablets to help. These can have side-effects, so they are only usually prescribed for 1–2 weeks. There are also some behavioural therapies that can help. Your GP can tell you if these are suitable for you (MACMILLAN, 2013a).

What is insomnia?

Insomnia means having difficulty falling or staying asleep. Many people affected by cancer have trouble sleeping for lots of different reasons.

Insomnia is described as having some or all of the following symptoms -

- difficulty getting to and staying asleep, or waking up too early,
- difficulty sleeping despite good conditions for sleep, such as a comfortable bed in a quiet, darkened room,
- daytime activities being affected by lack of sleep, for example problems concentrating at work, falling asleep during the day or starting to feel depressed (MACMILLAN, 2013a).

Other types of sleep problems You may be worried that you have insomnia if you only sleep for a few hours every night. However, having short periods of sleep can be perfectly normal and some people may only need 3–5 hours a night. Other people, such as night shift workers or parents with small children, might be sleep deprived. This generally means that they would be able to sleep quite well given the right conditions.

Some people find they wake up several times in the night. They may also feel as though the quality of the sleep they had was poor, for example, if they didn't experience a deep sleep or do not feel refreshed by the sleep. This could be because of a change in sleep pattern, possibly due to aging or a changed environment.

For most of us, losing one night's sleep will not have any overall effect other than feeling tired the next day. However, long periods of sleeplessness can lead to confusion, anxiety and depression. If you are worried about sleep problems, talk to your doctor or specialist nurse as they may be able to give you some advice (MACMILLAN, 2013a).

Barriers to sleep

Many different factors can influence sleep. Some are everyday things that anyone can experience and some are more common in people affected by cancer. Here are some possible causes for not being able to sleep well -

- a bedroom that's too hot, too cold or too noisy,
- an uncomfortable bed,
- a poor sleep routine,
- a partner who has a different sleep routine from your own,
- stimulants such as cigarettes, alcohol or caffeine,
- lack of physical activity,
- medicines that make you feel alert, such as steroids,
- anxiety, worry and emotional distress,
- physical problems such as pain, discomfort or feeling unwell,
- sleeping for too long during the day (MACMILLAN, 2013a).

Things you can do

Having a good sleep pattern and a regular bedtime routine (sometimes known as sleep hygiene) can help improve sleeping (MACMILLAN, 2013a).

Small cues such as a hot drink, brushing your teeth or reading in bed for a while can let your brain know that it's time to sleep. Here we give some suggestions of things that could help you sleep better -

Sleep for the right amount of time Spending too much time in bed is likely to affect the quality of your sleep. Try to sleep for just long enough to feel refreshed the next day, without oversleeping (MACMILLAN, 2013a).

Increase your physical activity if you can This could help you sleep better in the long term, although it may feel difficult if you've recently had treatment and are struggling with energy levels or side-effects. However, even regular short walks or a bit of gentle gardening can help to build stamina and improve the quality of your sleep. We have more information about the benefits of physical activity before and after cancer treatment (MACMILLAN, 2013a).

Wake up and go to bed at the same time each day This will help you get into a good sleep routine (MACMILLAN, 2013a).

Get out of bed if you can't sleep Rather than lying in bed tossing and turning, get up. You could try reading or listening to some soothing music. Wait until you feel tired again and then go back to bed (MACMILLAN, 2013a).

Keep your bedroom for sleeping If you wake during the night and find it difficult to return to sleep, go to another room in the house. If you need to sleep during the day, go to your bed and sleep (MACMILLAN, 2013a).

Reduce light and noise at night time Light makes it hard to fall asleep and affects the body's internal clock. Noise can also keep you awake - even occasional loud noises, such as an aircraft flying overhead, can affect sleep. If your bedroom is noisy, you could use ear plugs (MACMILLAN, 2013a).

Keep a steady temperature in your bedroom If your room is either very warm or very cold, your sleep may be affected. The room temperature should be comfortably warm (MACMILLAN, 2013a).

Have a bedtime snack but avoid stimulants Hunger can disturb sleep. Try having a light bedtime snack, warm milk or a hot drink before going to bed. But avoid food and drinks that contain stimulants such as caffeine or lots of sugar (for example, coffee, tea, cola or chocolate drinks) for a few hours before bedtime (MACMILLAN, 2013a).

Limit how much alcohol you drink at bedtime While alcohol can help people to fall asleep more quickly, the sleep tends to be broken. It may also give you a dry mouth and an unpleasant taste that can wake you, so it's best to limit how much alcohol you have near bedtime (MACMILLAN, 2013a).

Know how naps affect you Some people find that daytime naps help them sleep better at night, while others sleep less well after them. Find out what suits you best (MACMILLAN, 2013a).

Try mental exercises These could also help you sleep, as they focus your brain away from worries. Here are a few mental exercises that you might like to try, which usually take about 10 minutes -

- Try to remember the lines of a song or poem.
- Make alphabetical lists, for example of names or countries.
- Relive, in detail, a favourite experience (MACMILLAN, 2013a).

Worry and anxiety

Being diagnosed with cancer can naturally cause feelings of worry and anxiety, which can stop you being able to sleep. Many people find they stay awake, going over and over the same thing in their mind (MACMILLAN, 2013a). It may help to do some of the following -

Write down your concerns If you wake at night and are worrying about things, write them down. There's probably nothing you can do about them immediately, but if you note them down, you can then work through them during the day with support from relatives, friends, or your doctor or specialist nurse (MACMILLAN, 2013a).

Talk to someone Many people find that their fears and worries are reduced simply by telling someone else about them.

This type of 'offloading' can be a real relief and you may find that you sleep better afterwards. Try talking to a close friend or family member. You might prefer to talk to someone outside the family circle such as a counsellor. Your GP may be able to refer you to a local counsellor or you could talk to the Samaritans, a 24-hour confidential helpline, by calling 08457 90 90 90 (MACMILLAN, 2013a).

Try relaxation techniques Simple breathing and relaxation exercises may be very useful in reducing anxiety and stress. They can also reduce muscle tension. Many people with cancer and their relatives find that these simple methods relax them and give them a sense of calmness.

Almost anyone can learn relaxation techniques. You can learn them at home using a CD, tapes or podcasts, or you may be able to join a group. Self-help exercises need motivation and regular practice to provide proper benefits. It may be easier to stay motivated by attending group classes.

Lying flat can be uncomfortable for people who are breathless or in pain, but many relaxation exercises can be done sitting up or using pillows for support. The organisations Talking Life, Penny Brohn Cancer Care and The Pain Relief Foundation produce relaxation tapes and CD's, which are available to buy.

Some hospitals and support groups offer relaxation sessions. You can ask if they are provided at your hospital (MACMILLAN, 2013a).

Medicines that prevent sleeping

Many medicines for cancer and some other illnesses can prevent you from sleeping. Drugs used to treat cancer that can cause sleeplessness include prednisolone, dexamethasone, imatinib (Glivec®) and pamidronate (Aredia®).

Not everyone who takes these will have problems sleeping, as medicines affect people in different ways. You can discuss the possibility of your medicines affecting your sleep with your doctor or specialist nurse, as they may be able to give you suggestions. For example, it can help to take medicines that make you very alert (such as steroids) in the morning.

Or if some of your medicines cause drowsiness, it may be more helpful to take these at bedtime. However, it's important to check with a member of your healthcare team before making any changes to your medicine timings.

Some other medications don't cause sleeplessness directly but prevent you from sleeping due to other side-effects. Many of the hormonal therapies for breast and prostate cancer can cause hot flushes [17] and sweats, which can keep you awake at night. Your doctor or specialist nurse may be able to offer some help and advice with these side-effects so that you're able to sleep (MACMILLAN, 2013a).

Treating insomnia with sleeping tablets

If sleep becomes very difficult and is affecting your daily life, then it can sometimes help to take a short course of sleeping tablets. Doctors are normally keen for this to be a short-term solution, as sleeping tablets can have side-effects.

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[17] a sudden feeling of heat which seems to come from nowhere and spreads through your body

Generally, sleeping tablets are only prescribed for 1–2 weeks. If you think this may help, talk it over with your doctor, as they can advise whether tablets are suitable in your situation (MACMILLAN, 2013a).

There are different types of sleeping tablet that work in different ways -

- Benzodiazepines work by increasing the effect of a substance in the brain called gamma-aminobutyric acid (GABA). GABA is a chemical messenger that gives a feeling of calm and drowsiness. Some benzodiazepines are short-acting and can help you to get to sleep; others are long-acting and can help you to stay asleep. Temazepam, diazepam and lorazepam are all examples of benzodiazepines.
- Non-benzodiazepines work in a different way from benzodiazepines and have a different chemical structure, but similarly help you to sleep by increasing GABA in the brain. Zolpidem, zaleplon and zopiclone are all examples of non-benzodiazepines (MACMILLAN, 2013a).

Side-effects of sleeping tablets Most people experience the side-effects of sleeping tablets the next day, once they wake up. These are often described as being a bit like a 'hangover'. They usually go away quite quickly. Some of the most common side-effects of sleeping tablets are -

- clumsiness or poor coordination,
- feeling lightheaded, dizzy or still sleepy,
- difficulty concentrating and thinking clearly, or feeling 'foggy' (MACMILLAN, 2013a).

Tolerance and dependence Doctors may sometimes seem cautious when it comes to prescribing sleeping tablets. This is because sleeping tablets can cause problems with tolerance and dependence. It's helpful to understand the difference between these two terms.

Tolerance to a drug means that as you continue to take it, it begins to feel as though it's no longer helping and a higher dose is needed to get the same effect.

In time, the higher dose will also begin to feel as though it has no effect, while side-effects may worsen.

Dependence on a drug means that you may get withdrawal symptoms if the tablets are suddenly stopped. Withdrawal symptoms can include feeling anxious or restless and difficulty sleeping. For some people, this can feel much like the insomnia for which the tablets were prescribed.

Tolerance and dependence may sound frightening, but most people don't have these problems if they're only taking sleeping tablets for a short period. Your doctor will also check how you're getting on while you're taking sleeping tablets to prevent this from happening (MACMILLAN, 2013a).

Melatonin Melatonin is a naturally occurring hormone that is available as a tablet. It's used to treat insomnia as well as some other conditions. In the UK, melatonin is only licensed to be given as a short-term treatment of insomnia for people over the age of 55. This is because it's not very effective for people younger than 55. So far, research has shown that melatonin causes fewer problems with tolerance and dependence. However, for most people it only reduces the time it takes to get to sleep by 10–15 minutes (MACMILLAN, 2013a).

Over-the-counter medicines Sleeping tablets don't always need to be prescribed by a doctor. Over-the-counter sleeping tablets can be useful in the short term. However, many people find they develop a tolerance to these drugs if they take them for long periods.

Over-the-counter sleeping tablets often contain anti-allergy medication (antihistamine) and aren't suitable for everyone. They may also not be recommended if you're taking some other types of medicine. If you are thinking of trying an over-the-counter remedy, speak to your doctor, specialist nurse or pharmacist first (MACMILLAN, 2013a).

Treating insomnia with behavioural therapies

Behavioural therapies help to change the way you think, feel and behave when it comes to sleeping, bedtime or worrying at night. There are three main types of behavioural therapy that can be used for improving sleep -

Sleep restriction For some people, spending too much time in bed means they wake up too early. Sleep restriction aims to help you go to bed at certain times, usually later than you normally would, so that you get regular amounts of quality sleep (MACMILLAN, 2013a).

Stimulus control People who regularly have difficulty sleeping can have a strong link between their bed and not sleeping. This therapy aims to break that link by only using the bed for sleeping. Other activities such as watching TV, using a laptop, organising things or eating should be done elsewhere in the house.

If lying in bed worrying is the problem, this therapy recommends you go to another room and try to distract yourself until you feel tired. This aims to break the link between your bed and worrying (MACMILLAN, 2013a).

Cognitive behavioural therapy (CBT) This is carried out by a trained therapist and aims to change negative ways of thinking that may increase worries and anxiety. Reduced anxiety may help you get more sleep.

Some of these therapies can be carried out by a GP with specialist training or you may be referred to a clinical psychologist. You could speak to your GP about whether some of these therapies might be right for you (MACMILLAN, 2013a).

Your feelings when someone close to you has cancer

If someone close to you is diagnosed with cancer, you will probably be feeling lots of different emotions. Whether you're their partner, family member or friend, it's natural to feel overwhelmed by the news and be anxious about what might happen. You may need support to help you cope with the emotions you're feeling.

If your partner is diagnosed with cancer, you may feel angry about the situation you're both in. This can put a strain on your relationship. Talking about how you're both feeling can help you understand each other and feel closer.

If someone in your family has cancer, everyone in the family may react differently. Responsibilities at home can change and this can cause tension. It's important to talk openly with each other.

If your friend has cancer, you may be worried about knowing when and how to help. Try asking your friend what they might need (MACMILLAN, 2013p).

If someone close to you has cancer

Hearing that someone close to you has cancer can be one of the most emotional times of your life. For many people, it's a devastating and overwhelming experience. Whatever your relationship with that person, it's natural to feel a range of emotions (MACMILLAN, 2013p).

If your partner has cancer

When your partner has cancer, it can feel like your world has been turned upside down.

You may be concerned about how the diagnosis has affected your partner emotionally as well as physically. They might seem different, perhaps because they are under a lot of stress or in pain, or simply tired. This can put strain on you and your relationship.

There isn't one single way to cope with cancer. How you and your partner deal with it will depend on your personalities, your relationship, how long you've been together, your life experiences (for example, having children together), and how you both cope with challenging situations. It may also depend on how long the person has been diagnosed, any side-effects the treatment is causing, and how the condition affects your partner's day-to-day life (MACMILLAN, 2013p).

How you might feel

When one of you is diagnosed with cancer, you and your partner may experience a range of feelings. These can change at different times.

You may be anxious about the future and how you're going to cope. A cancer diagnosis can take away your sense of security and control. Uncertainty can be one of the most difficult things to deal with. It can cause tension between you and your partner. We have more information about coping with feelings of Anxiety when someone close to you has cancer.

You may find that you feel irritable or angry. Anger can sometimes hide other feelings, such as fear or sadness. We have more information about Anger and frustration and dealing with it.

Your partner may feel guilty about the changes their illness has made to you and your family. You may feel guilty about not being able to manage. You might sometimes feel resentful and angry, even when you know it's not anyone's fault. You may then feel guilty for having these thoughts. You may also feel stressed because you're having to cope with different responsibilities. We have more information to help you if you're feeling Guilt.

Some people cope with serious illness by continuing as if nothing has happened. You may be trying to avoid thinking about what is happening, and just want to carry on as normal. You may be in denial. Your partner may have noticed you are playing down their anxieties or changing the subject. Even though you are just trying to keep things normal, this can make your partner feel more isolated.

At times, you or your partner may want to be left alone. It's okay to have some time to yourselves to focus your thoughts.

You will both probably find your own ways of dealing with your emotions. Even if you and your partner have very different ways of dealing with the illness, try to be understanding of each other's reactions. Try to work together to understand and support each other. It's important to remember that negative feelings eventually pass, so you're likely to feel better at some time in the future.

Often partners try to protect each other by not being completely honest about their fears and concerns. However, talking about these things can help you understand each other and feel closer (MACMILLAN, 2013p).

If you and your partner are lesbian, gay, bisexual or transgender

If you are in a same-sex relationship, or if you or your partner is transgender, you may face additional emotional issues when your partner is diagnosed with cancer. It may be that your private or hidden sexuality becomes public for the first time when you're in hospital or dealing with healthcare professionals. Or, you may both feel that the people you meet during treatment don't recognise you as a couple. If there are already difficult family relationships, there may be conflict with your partner's relatives over who is the main support or carer for the person with cancer.

Sometimes, talking about these issues can help you to cope or resolve them. The Lesbian & Gay Foundation has a helpline and email advice service that may be helpful.

You can also call us on 0808 808 00 00. Our specialists are experts in supporting anyone who is affected by cancer. Or you could join our online community at macmillan.org.uk/community to talk to others.

Cancer can lead to changes in your relationship, home life and sex life. We have more information to help you and your partner if cancer has affected your relationship (MACMILLAN, 2013p).

If your family member has cancer

When someone has cancer, it can affect the whole family. All families are different. They vary in size, how they are structured, their relationships with each other, their beliefs and how supportive they are. They also vary in how they communicate with each other and how they handle stressful events. So, each family will respond differently when someone is diagnosed with cancer.

Each person in the family will also experience their own reactions and emotions. For example, young children will cope differently with cancer than older children or adults will. We have more information to help you if you need to talk to children about cancer.

All families have experienced stress or tension before, but something like cancer can test the family in a new way. Everyone in the family may be feeling anxious, sad and tired. This can make any existing relationship problems worse.

People sometimes become withdrawn and won't talk about their emotions. They may be afraid to show their feelings, or they may feel they have to protect themselves or other people from further distress. However, cancer can also bring families closer together as they deal with the challenge together.

It's important to talk to each other honestly about how you feel. Not talking can cause tension. Family can be a strong source of emotional support at this time. Talking to each other about what's going on will help increase the support you can all get.

Everyday responsibilities like family life and work can be hard when you are coping with cancer. You might find it helpful to read our information about managing day-to-day life when you're affected by cancer (MACMILLAN, 2013p).

If your friend has cancer

It's not only partners and families who are affected emotionally when someone has cancer. You can feel a range of emotions when your friend is diagnosed and as they go through treatment.

If your friend has a really supportive family, it might be hard to know where you fit in or what you should do. Talk to your friend or their family and find out how you can help. Maybe they need someone to talk to, or perhaps you can do practical things, such as find information, run errands or go to the clinic with them. The most valuable thing might be simply visiting and spending time with your friend (MACMILLAN, 2013p).

If you want to help

If you're not the main carer but want to help in some way, these tips might be a good place to start -

- Find out if your help is needed by asking the person with cancer. Rather than say, 'Let me know if I can help', say, 'What can I do to help? I'd really like to'.
- Ask yourself what help might be needed. You could offer to sit with the person with cancer while the main carer is resting. You could pay a social visit, do some laundry, make some meals (check which foods are best), pick up children from school or do the food shopping.
- Think about which jobs you can do best. If you're not very good at cooking, don't offer to help with this. There will be lots of other things you are good at.
- Offer to do things that you can easily do. Sometimes the smallest things, like weeding the garden, mean the most. If you offer to do everything, you could make the person feel awkward and embarrassed.
- Check how often you should visit and when it's convenient. Although you mean well, some people can be overrun with visitors. Spending regular time with your friend, and being reliable about your visits, could be the best way to show how much you care (MACMILLAN, 2013p).

If your friend is on their own without family to rely on, your company could be especially helpful in making them feel less lonely and isolated.

In some cases, someone may not have a family supporting them, but they may have a group of very supportive friends. This can cause similar issues as when family members are involved in care. Friends may not agree on what needs to be done, and by who. It might be best if you all sit down with the person with cancer to talk about it and ask them what they want.

If your friend has no-one else to look after them, you may feel responsible for their care. It's not only partners or family members who become carers, so if you provide substantial support to someone with cancer, you may also be classed as a carer.

If your friend begins to need more help, you might feel pressured into doing more for them. You don't have to do anything you don't feel comfortable with. Local authorities and health and social care trusts have responsibilities to arrange services that people need. We have more information about the support available to carers.

If you're a friend of someone with cancer, we are here for you. Talk to us for more support (MACMILLAN, 2013p).

Your feelings when looking after someone with cancer

If you're looking after someone with cancer, you may be going through lots of different feelings and emotions.

It's natural to feel frustrated, depressed, angry or resentful at times. Many people feel frightened about the future or feel guilty that they're not doing enough for the person they're caring for. You may be very tired and have no time to enjoy your hobbies or see friends. If the person you're caring for is in pain, they may be irritable. Or perhaps they don't seem to appreciate everything that you're doing for them.

Some people find that coping with things together brings them closer. Others find it more difficult to cope with the worries, uncertainties and responsibilities involved when they become a carer.

It's important to look after yourself too. It can help to talk to someone else about your situation. Ask your GP or healthcare team about the support available in your area. Macmillan also has an online community where you can connect with others in a similar situation (MACMILLAN, 2014ae).

Your moods and emotions

It's important to realise that your moods and emotions matter too.

You are likely to be very aware of how the person you care for is feeling. Family and friends will be thinking about this too. But it isn't only the person you care for who has feelings. People may forget to ask how you are feeling, but your feelings are important and you should try not to put them to one side. However you feel is okay and natural.

There's no need to apologise or feel guilty for having strong emotions or moods yourself. It's important that you find ways to express them, and to find the support and space that you need for yourself.

It's normal to ask for help. This may be from your family and friends, a counsellor, or a health or social care professional. We have more information about getting emotional support (MACMILLAN, 2014ae).

Anxiety

When someone close to you has been diagnosed with cancer, it's normal to worry about what will happen in the months or years ahead. Fear and anxiety are natural reactions to this situation (MACMILLAN, 2014ae).

Depression

Looking after someone with cancer is difficult and it is natural that you may feel very low sometimes. For some people, their low mood may get worse and this may mean they have depression.

Depression is a common condition that affects around 1 in 10 people. It can be triggered by difficult events, such as someone close to you being diagnosed with cancer. But it can also happen by chance or be related to other events that have nothing to do with cancer. If you're having these kinds of feelings, there are things you can do to help yourself (MACMILLAN, 2014ae).

Practical tips to help you cope with anxiety and depression

- Ask for support whenever you need it and don't be afraid of your own emotions. This is a very difficult time, so strong and confusing feelings are natural.
- Take some time out from caring. There may be help available so the person you care for isn't left alone while you have a break. Some carer organisations, such as the Carers Trust, offer free respite care. Or you can contact your local social services to arrange a carer's assessment. This is a meeting where you can find out what help is available.
- Chat with a good friend about your worries. And talk to the person you're caring for about how you are feeling. They may be able to offer you support and may be glad you asked.
- Gentle exercise, like a 10-minute walk, can help.
- Avoid drinking too much alcohol.
- Spend some time alone relaxing. You could have a candle-lit bath, listen to music or treat yourself to some of your favourite foods (MACMILLAN, 2014ae).

You could also speak to your GP or a counsellor. They can help you manage depression or anxiety. Or if you prefer talking on the phone, you can call us on **0808 808 00 00**, or the Samaritans on **08457 90 90 90** (MACMILLAN, 2014ae).

If the person you care for is anxious or depressed

If the person you care for is very unwell, they may become preoccupied and have low moods. You may also notice that they have less empathy if they are taking strong painkillers.

There are things that can help to lift their spirits. They could try relaxation techniques, mood music, books or audiobooks, or having a television in their bedroom. Or they could try downloading relaxing MP3's (audio files) and podcasts from the internet. The website learnzone.org.uk has a section called Relaxation Corner where you can download these.

Many people find complementary therapies such as reflexology, massage or aromatherapy can also help with relaxation.

Visitors can also help. Or you could encourage them to talk to other people in a similar situation. Support groups and online support can help.

Take time to sit together with family or friends and talk about your favourite memories.

If the person you care for has panic attacks, it can be helpful to keep paper bags nearby. Breathing into a paper bag can slow down their breathing and help them feel better.

If you think that the person you care for is depressed, talk to a health or social care professional. You can read more about depression and watch a video about it by visiting macmillan.org.uk/depression (MACMILLAN, 2014ae).

Being positive

As a carer you may feel like you should 'be positive' for the sake of the person you look after. Your family or friends may say you should keep being positive to help you through this difficult time. But it's not always easy - a lot of people have periods of feeling low at some time in their lives, and this is quite natural. Sometimes being told to be positive when you feel low can be frustrating. It can feel as though the person isn't accepting how you really feel, even if they are just trying to help.

Being positive can mean different things to different people. It's generally about dealing with whatever situation you're in, being optimistic and finding ways of coping. People do this in different ways. What works for one person may not work for another.

No one can be positive all the time. It's important that you don't feel you must always stay on top of things. Being positive doesn't mean having to feel happy and cheerful all the time. It's a positive thing to acknowledge and talk about it if you're feeling tired, worried, depressed or angry (MACMILLAN, 2014ae).

Practical tips about keeping positive

- Don't forget that you are only human and that your best is good enough. Trying to get the most out of your day personally can help you stay positive. If you have any spare time to yourself, think about what will give you a boost. This may just be reading a newspaper or having a cup of tea.
- Try some activities that distract you from the situation. Keep doing your hobbies and interests where possible.
- If you can keep working, it may be a good distraction and give you routine in your life. We have more information about working whilst caring.
- Talking about good times with the person you care for and not worrying about your current situation can help to lift your spirits, and theirs.
- Feel good about the fact that you have made a difference to the person you are caring for. Remember that you're doing something positive by helping with their stress and pain.
- At the end of each day, try to remember something good you both did that day, or something that made you both laugh (MACMILLAN, 2014ae).

Be Good to Yourself is a workshop that may help you manage negative thinking and plan ways to live a healthier life. To find out more call 0808 808 00 00 or email learning@macmillan.org.uk (MACMILLAN, 2014ae).

Guilt

You may sometimes feel guilty. This could be because you feel like you should be doing more for the person you care for. You may feel guilty about an argument you had with them or because you sometimes resent the support you have to give them. Feelings like these are common. It's important to accept that having negative thoughts does not make you a bad person. Talking about guilt will also help. If you can, try to share your feelings with your family and friends.

Remember, whatever you feel able to do is enough. Try not to feel guilty about having time to yourself - it's very important and can help you be a better carer (MACMILLAN, 2014ae).

Feeling isolated

You may feel isolated by your role as a carer. It may feel as though you are struggling alone. Remember that support is available.

Try to share your worries with the person you are caring for. Touch and cuddle them - a loving touch can make a big difference. They may feel isolated by the cancer too.

Some carers have trouble communicating with the person they care for, but talking to a professional can help (MACMILLAN, 2014ae).

Anger and frustration

When someone close to you is diagnosed with cancer, it's natural to feel angry. You might question why this has happened to them, and to you.

You may find you feel worried, anxious or hopeless, but you express it through anger or being irritable.

You might be looking for someone to blame, and get angry with the doctors and nurses. Or you might aim your anger at the people closest to you, even the person who has cancer. Not everyone feels this way but it's okay if you do.

It's really important to express your feelings as they happen, because they may become stronger if you try to hold them in. A hobby or sport where you can release your anger and frustrations may help. It may also help to write things down.

Even with members of your family and close friends, it can be difficult to say how you feel. You may find it helpful to talk about your anger with a counsellor or someone in a support group.

People being cared for can sometimes take their anger out on the people closest to them. Try not to feel responsible for their emotions. Some cancers can affect a person's behaviour, for example they might have sudden fits of anger. Speak to a healthcare professional about whether the person you are caring for may be affected in this way (MACMILLAN, 2014ae).

Fear

Try to understand what you are afraid of. It's natural to fear the unknown more than anything else, so the more you can learn about what frightens you, the easier it will be to deal with your situation.

Don't be afraid to ask questions. Knowing the facts will often help alleviate fear. If you are religious or have spiritual beliefs, religious and spiritual leaders may be a good source of support and comfort to you (MACMILLAN, 2014ae).

Tiredness and exhaustion

You will probably feel tired and even exhausted sometimes. Spending time looking after someone can be physically and emotionally draining. It's important to take care of yourself and make sure you don't become overwhelmed (MACMILLAN, 2014ae).

Practical tips to help with tiredness

- Rest whenever you can - short naps can help to revive you. Try a relaxation CD or MP3 (audio file). An hour or so in a state of deep relaxation can make you feel as if you've had a long sleep.
- Try to eat healthily and be active. You may feel too busy to exercise, but even walking can help. A short walk to the shops gets you outdoors and can refresh you.
- Think about having a flu jab - carers are automatically entitled to one for free, so ask your GP. It's important to take care of your health too. If you get ill, see your doctor as soon as you can (MACMILLAN, 2014ae).

Denial

Denying that someone close to you has cancer after their diagnosis is a normal reaction. If you feel in denial, don't blame yourself or feel that you must hurry to overcome it.

Denial can be a useful way of coping with the news, both for you and the person with cancer. But if it lasts for weeks or months, it can become a problem.

If the person you care for is diagnosed with advanced cancer, denial may be a way of coping for you both (MACMILLAN, 2014ae).

Resentment

Most carers have times when they feel resentful. It's natural to feel like this. You may not have much time to enjoy hobbies or go out and see your friends. The person you're caring for may sometimes be moody, self-centred and withdrawn. They may have become more irritable since they became ill, especially if they're in pain. They may not always seem to appreciate what you're doing for them. Many people take out their fear, anxiety or frustration on the person closest to them. If this is happening to you, you may sometimes feel unwanted and resentful. Trying to talk about this may help - perhaps find a time when you're both having a better day.

You may find it easier to talk about your feelings with someone else. Sometimes feelings of anger and guilt can build up, especially if you're not able to talk about them. Give yourselves a chance to try to understand how the other person feels and you may be able to avoid your anger and irritation building into an argument (MACMILLAN, 2014ae).

Emotional support

It can be difficult to cope with some of the strong feelings and worries that you have when you're looking after someone with cancer. It helps to be open and honest about how you feel. There is no right or wrong way to do this - do whatever feels right for you.

Some people find it hard to talk about their feelings with the person that they're caring for. They might worry about upsetting them or breaking down in front of them. If you'd like to talk to someone else, you may find it helpful to see a trained counsellor. Ask your GP about how to organise this.

Support groups and online communities can be a good way to talk to people in a similar situation.

It's important to look after yourself too. Try to take regular breaks, eat healthily and find time to do something you enjoy. Let yourself switch off for a while and release tension if you need too. You might find relaxation techniques helpful, especially if you're having trouble sleeping (MACMILLAN, 2013b).

Talking together

The feelings that you have when someone close to you is very ill can be very strong and hard to deal with. Trying to be open about the way you are feeling may help you to feel more in control. If you can't do this with the person you're caring for, try talking with someone else, like a friend or relative. Your feelings may be easier to deal with once you have discussed them.

Many people find it very difficult to be open together in this way, especially when they're faced with a new and stressful situation. Some carers are uncomfortable about discussing their own feelings with the person with cancer because they don't want to upset them. Others can't bear to talk about it because they don't think they'll be able to comfort their friend or loved one, or because they're worried about breaking down and crying in front of them.

Some people are simply not used to talking with each other about their feelings.

There are no right or wrong ways of communicating and often just being there, perhaps giving a hug or holding hands, is enough to show someone that you care. Be prepared for them to talk about their illness if they want to. Often they won't expect you to provide answers but just to listen and understand so they don't feel so alone.

If you both find it hard to talk about your feelings, it may be easier to bring in a third person to help you. This could be a trusted friend, a religious leader, a counsellor or one of the health professionals you've got to know and trust.

We have more information about talking to and supporting someone with cancer (MACMILLAN, 2013b).

Counselling

The emotions you feel may be very tangled and confused. You may find them difficult to talk about and hard to share with your family or friends. Talking to a trained counsellor gives you an opportunity to talk to someone who is outside your situation. They will listen carefully to what you say, and have the skill and understanding to help you explore your feelings and find ways of coping with them.

Your GP will be able to refer you to a counsellor. You could also contact your local support group or hospital support centre as they may be able to put you in touch with a counsellor (MACMILLAN, 2013b).

Join a support group

Support groups are a really good way to talk to others who are in a similar situation. Some groups are specifically for people who are caring for someone with cancer. They give you a chance to talk to and meet up with other carers who understand what you're experiencing. Even if you can't go to their meetings, you might find it helpful to talk on the phone.

You can find more information about what support groups may be available in your local area from your local council (MACMILLAN, 2013b).

Not everyone who's caring has the time to go to a support group. So another way to get support and to share your feelings is to join an online forum. Online forums are good because you can be put in touch with loads of people who are in the same situation as you. The best things about forums are that you -

- can be anonymous,
- can dip in and out when you want,
- don't have to tell people anything you don't want to,
- can make online friends (MACMILLAN, 2013b).

There are plenty of forums for carers and for people affected by cancer. For example, Macmillan's online community has a forum for carers (macmillan.org.uk/community). Choose one that best suits your situation (MACMILLAN, 2013b).

Looking after yourself

It's important that you look after yourself as well as the person you care for. There are many ways you can do this (MACMILLAN, 2013b).

Take breaks

Having some time for yourself can help you to relax and feel able to cope better, which can also help the person you're caring for.

You may be able to arrange for someone to come in regularly so that you can have some time to yourself, even if it's only a few hours a week. If there isn't a relative or friend who can take over for a few hours, there are other ways of getting help - we have more information about how to get more support (MACMILLAN, 2013b).

Make time for you

When you get time off, it's important that you relax or enjoy yourself doing something different. You may feel tempted to spend time off clearing up the house or doing the washing so that you can get ahead on the chores, but this is unlikely to help you feel better in the long run.

However short it is, a regular and complete break doing something you enjoy is likely to make you feel much better.

It might just be an hour looking round the shops, having a coffee with a friend, going to the cinema or taking a grandchild to the swings. The main thing is to do something that you want to do and switch off for a while (MACMILLAN, 2013b).

Eat well

Try to eat healthily. If you can, make time to prepare and sit down for a cooked meal every day. If you don't have time to prepare a meal perhaps you could ask a friend to prepare you one. Remember to treat yourself to your favourite foods sometimes (MACMILLAN, 2013b).

Get some fresh air and exercise

Try to get some fresh air and exercise every day, even if it's only to go for a short walk. This will help keep you more mentally alert, and may help to reduce tiredness and stress (MACMILLAN, 2013b).

Use relaxation techniques

Using techniques such as relaxation and massage help to reduce stress and feel better able to care. You may also like to learn a relaxation technique using relaxation CD's, DVD's or podcasts.

Some people find having a massage particularly helpful and a great way for them to switch off for a short time. It may be that you have a close friend or relative who would like to go with you for a massage at the same time (MACMILLAN, 2013b).

Releasing tension

Sometimes your feelings may get overwhelming and, if you can't cope, it may help to thump a cushion. This doesn't harm anyone and can leave you feeling a lot better.

Practicing deep breathing may help to reduce stress. Fill your whole lungs with air and breathe in and out slowly at regular intervals.

It can also sometimes help to write down your feelings, as this gives you an opportunity to express your emotions rather than bottling them up (MACMILLAN, 2013b).

Sleep

Many people say that when they're caring for someone who is very ill they find it difficult to relax at night. You may be thinking and worrying about the person who's ill and this can keep you awake. It may be that the person you're caring for is having a bad night, which then keeps you awake. Here are some tips which may help you to have a better night's sleep (MACMILLAN, 2013b).

- Read a book before you go to sleep - it will focus your mind on something other than cancer.
- Have a relaxing bath - you could add lavender oil or bath soak to help you relax.
- Have a warm drink.
- Listen to a relaxation CD or your favourite piece of relaxing music.
- Write a diary - if you get all your thoughts out on paper they won't be quite so busy in your head (MACMILLAN, 2013b).

Spiritual and religious support

Some people find that they become more aware of spiritual or religious feelings during stressful times. This may cause them to question their faith, values and beliefs.

If you or the person you're caring for already have a strong faith, this may give you a lot of comfort and support, but it can also be a source of uncertainty.

If you think that it might help you both to talk to someone, such as the hospital or hospice chaplain or a religious leader, don't be put off because you aren't sure what you believe or haven't worshipped regularly. Spiritual and religious leaders are used to dealing with uncertainty. They are usually happy to talk and to give whatever support and comfort they can (MACMILLAN, 2013b).

Practical preparation before and after treatment

Being a carer

What is a carer?

A carer is someone who provides unpaid support to a family member or friend who could not manage without this help. They don't always live with the person they care for, and may have a job or children to look after as well.

Not everyone identifies with the term carer. You may think of yourself as a partner, family member or friend who is just doing their bit to help. But recognising that you are a carer can be a first step in getting the support you might need (MACMILLAN, 2014u).

Caring can mean many things, including -

- providing transport,
- helping with everyday chores,
- being a good listener,
- helping with personal care (MACMILLAN, 2014u).

The person who spends the most time looking after someone with cancer is usually referred to as their main carer. But some people have more than one carer (MACMILLAN, 2014u).

Being there during diagnosis, treatment and after treatment

When someone close to you is diagnosed with cancer, it can be a very difficult time for you too. You probably want to be there to support them, but you might not know what to do.

You may want to talk to them about how they are feeling. There are also practical things you can do to help them cope, whether you're a partner, relative, friend or carer.

If the person has a number of hospital appointments, you could suggest giving them a lift. Or help them plan for the appointments by writing a list of questions down that they can take along with them.

They may need to stay in hospital for a while to have treatment, so you could offer to visit them. Perhaps think about taking them something to pass the time, for example a magazine or an audiobook.

When their main treatment is finished, it will take them time to recover so they will still need support. You could offer to help with things like shopping and cooking (MACMILLAN, 2014u).

How you can help during diagnosis

When someone close to you finds out they have cancer, you probably want to be there for them but you might not know how you can help. There are practical things you can do to support them - whether you're their partner, relative, friend or carer.

You might also find it helpful to read our information to help you talk to someone who has cancer (MACMILLAN, 2014u).

Be there

- Visit them - especially if they live on their own or you're worried they're feeling isolated.
- Make them a cup of tea and just listen.
- Watch TV or a DVD together to take their mind off things.
- If you can't be there in person, just call or write to them to say you're thinking of them.
- If they're not already in contact with Macmillan, suggest that they contact us to find out how we can support them (MACMILLAN, 2014u).

Be there for hospital appointments

- Help plan for appointments - what questions do they have and what do they want to say? Write it down for them to take along on the day.
- Offer to go with them for support and to talk things through.
- Give them a lift - especially if they're having a test or scan.
- During the appointment, write the important things down (MACMILLAN, 2014u).

Be there between appointments

- They might find it helps to organise the information they've been given and to keep track of things like their symptoms and mood. You could order your friend or relative a free Macmillan Organiser from be.macmillan.org.uk The organiser is also available as an app.
- Having more information helps some people feel more in control. We have more information to help you understand cancer and its treatments. But remember that some people don't want to know all the details and prefer to leave everything to their doctors (MACMILLAN, 2014u).

Chapter 5

Advanced cancer

Contents

[git] • Branch: v1.0 @ 71d77a5 • Release: 1.0 (2016-08-18)

Cancer that has come back or spread is sometimes called advanced cancer. Find ways to cope with symptoms, side-effects and the emotional impact of advanced cancer.

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Finding out you have advanced cancer

You're likely to feel a range of strong emotions when you find out you have advanced cancer. It's common to feel shocked and frightened, or angry about your situation. Most people find that these feelings become easier to manage with time.

Talking to others can be very helpful. It's not unusual to find it hard to talk to close family and friends. You might feel like you're trying to protect them. But being open with those closest to you can help them to understand the best way to help you.

If you'd like to talk to someone else, ask your GP to refer you to a counsellor or support group. You could also use the internet to find online communities where other people affected by cancer are sharing their feelings and experiences.

Some people find support by talking to a religious leader or by writing in a diary. Complementary therapies may also help to reduce stress and anxiety. Talk to your GP to find out what services are available near you (MACMILLAN, 2014n).

Coping with the news

It's common to feel overwhelmed by different feelings when your doctor tells you your cancer is advanced. Some people's cancer may be advanced when they are first diagnosed. For others, the cancer may spread or come back after treatment.

Although it is rare for advanced cancer to be cured, people may live with it for a long time - sometimes for years. This may mean having different treatments when they're needed, or sometimes having ongoing treatment to control the cancer. During this time, many people carry on with their day-to-day lives and doing things that are important to them. Sometimes it may not be possible to control the cancer any longer or a person may not be well enough to have treatment. In this case, their cancer doctor or specialist nurse will always make sure they are given treatments to control any symptoms they have.

When you first find out your cancer is advanced, you may feel shocked and find it hard to take in. You may feel frightened about the future, or angry with other people or yourself. With time, these feelings can become more manageable as you start making decisions and plans.

You might find it helpful to talk to others who understand if you're dealing with difficult news. You can visit our Online Community to talk to people in similar situations.

Knowing that your illness may not be curable can give you an opportunity to decide what's important to you, and how you want to live your life. Concentrating on what you can enjoy and achieve can give you pleasure. It may also help you cope if you find you can't meet other goals (MACMILLAN, 2014n).

Coping with feelings

It's natural to have a mix of emotions when coping with advanced cancer, such as fear or anger. These feelings can occur at different times, and they may vary in strength and frequency. However, people often find that over time their feelings become easier to cope with (MACMILLAN, 2014n).

Fear Many people with advanced cancer feel frightened. You may have times when you feel afraid of the illness itself, the symptoms, or the treatment and its possible side-effects. You may worry about the effect it will have on your family. People often worry about the future or about dying (MACMILLAN, 2014n).

Anger It's natural to feel angry if you have advanced cancer. You may feel angry about feeling unwell, going through treatment and having to cope with the side-effects. You could also be angry about the impact the cancer has had on your life. It may have affected your ability to work or your relationships. You may feel frustrated that your plans will be disrupted by tests and treatment, and that your long-term plans have suddenly become uncertain. Living with the uncertainty that comes with advanced cancer is likely to be physically and emotionally demanding (MACMILLAN, 2014n).

Talking about feelings

We all express our feelings in different ways. It's often clear how someone is feeling by their behaviour, what they say and how they say it. Sometimes though, one emotion can disguise another. For example, a person might be frightened but express their fear by being short-tempered and irritable, or angry with those around them. Talking about our feelings can help us understand our behaviour and what's behind it. This isn't always easy.

If you can, find someone you can talk to about how you feel, such as a family member or friend. Some people prefer to talk to someone outside their immediate circle of family and friends. Your GP, palliative care [18] nurse or doctors and nurses at the hospital will usually ask how you are. This will give you the opportunity to talk about your feelings and emotions if you want to. You might find this easy if you already know them and feel comfortable with them. If you would prefer to talk to someone else, they may be able to refer you to someone who's trained to listen, such as a counsellor.

We have more information about the emotions you might be feeling and ways of coping with them. You might also find our section on talking about cancer useful (MACMILLAN, 2014n).

Emotional support

Counselling Counsellors are trained to listen and help people deal with difficult situations. They may be able to help you find your own solutions to the problems you're facing. This can be very helpful, as cancer can affect many aspects of your life. Talking to someone who is supportive and not personally involved in your situation can also help those close to you.

Your GP or hospital doctor may be able to refer you to a counsellor. Or you may prefer to go to someone independent. Find counselling in your area (MACMILLAN, 2014n).

Support and self-help groups However supportive your family and friends are, you may find it useful to spend some time with people who are going through a similar experience to you. There are many support groups for people with cancer and their relatives. Most have been set up by someone who wanted to meet other people in a similar situation, and others are attached to hospitals. Some hospital cancer units or hospices have day centres or drop-in facilities for outpatients.

Groups offer support and friendship, and it can be reassuring to talk over your worries with someone who has been through something similar. It can also be helpful to meet people who have lived with their cancer for a long time and who enjoy life.

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[18] is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments

Not everyone feels comfortable in a group, and it's important to do what's right for you. You know yourself better than anyone else (MACMILLAN, 2014n).

Online support Many people now get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to share your experiences, ask questions, and get and give advice.

You might find it useful to visit our Online Community where you can share your experiences with people who know what you're going through (MACMILLAN, 2014n).

Spiritual and religious issues Some people find they become more aware of religious or spiritual feelings when they're told their cancer has come back or spread. People with a religious faith are often greatly supported by it during their illness.

Even if you haven't attended religious services regularly in the past or aren't sure what you believe, you can still talk to a priest, rabbi, imam or other religious leader. They are used to dealing with uncertainty and won't be shocked. They're not there to preach to you, but to comfort you and help you find peace of mind. If you're in hospital, you can ask for a visit from a hospital chaplain or other religious or spiritual leader.

Some people with advanced cancer find themselves questioning their faith. If you're in this situation, talking to a spiritual leader may help (MACMILLAN, 2014n).

Medicines that can help

Emotional distress can be reduced with the support of family, friends, support groups, counselling or some of the self-help techniques described in this section.

However, sometimes feelings of anxiety and depression start to affect your ability to deal with everything that's happening to you. In this case, your GP or hospital specialist may be able to prescribe antidepressants, anxiety-reducing drugs or sleeping pills. These can help you cope with your situation (MACMILLAN, 2014n).

Decisions about treatment

You can talk about your treatment options with your medical team and think about what feels right for you. It can be helpful to make a list of any questions you'd like to ask at your appointments. A friend or relative could also come with you for support.

If you have concerns about your treatment plan, you could get a second medical opinion. Ask your GP or specialist about how to do this.

You might be asked to take part in Clinical trials. This is a cancer research trial which can help doctors find better ways to treat cancer. You don't have to take part but if you do, and later change your mind, you can leave at any time.

A question that many people want to ask is, 'How long will I live?'. Doctors can't be certain about this but will usually be able to give some guidance based on the type of cancer you have and your particular situation. You may prefer not to ask the question and that's fine. It's important to do what feels right for you (MACMILLAN, 2014h).

Deciding about your treatment for advanced cancer

Some people like to know as much as possible before deciding on any course of treatment. You can talk to your doctors and nurses about what treatments may be suitable, taking into account your own preferences and how treatment may affect you. This will help you decide on the best course of treatment together.

You may be offered surgery, radiotherapy, chemotherapy, hormonal therapies, targeted therapies or a combination of treatments. The treatment that's appropriate for you will depend on the type of cancer and where it is in your body.

The aim of treatment for advanced cancer is usually to try to control the cancer and help you live longer. It may also help improve your symptoms and quality of life. Controlling the cancer might mean shrinking the size of the tumour or stopping it from growing for a while.

Sometimes you may need to have a few treatments before you and your doctor can decide whether to continue with a full course. For example, if you're having chemotherapy to control or shrink the cancer, you may have a scan after two or three treatment cycles. This gives you and your doctors more information about how helpful this particular treatment is. You can carry on with the course of treatment if the scan results show it's working. If the results show the treatment isn't helping, you and your doctor can talk about other treatment options.

However, there may be a time when the treatment has little effect on the cancer, and you may get the side-effects of the treatment without any of the benefits. Making treatment decisions in these circumstances is always difficult, and you may want to talk about it carefully with your cancer specialist (oncologist), specialist nurse and family. If you decide not to have treatment, you will be given supportive (palliative) care, with medicines to control any symptoms.

You may be given general medicines to control pain or feeling sick (nausea). You might also be given cancer treatments to ease symptoms. For example, radiotherapy can help with pain as well as being a cancer treatment. If you choose not to have any cancer treatments, you'll still be offered palliative care, such as painkillers (MACMILLAN, 2014h).

Talking about treatment options

It's usually possible to take a bit of time to think about your treatment options. It can help to discuss it with your family and the doctors and nurses looking after you. Your cancer specialist will have the most information about treatments. In many hospitals, specialist nurses are available to talk to you about all the possible benefits and side-effects of treatment.

Remember that treatment is for your benefit. It's important to make the decision that feels right for you about which treatment, if any, you want to have.

It can be difficult to remember the questions you want to ask your doctor. It may help to make a list before your next appointment. Some people find it useful to record the discussion with their doctor (with their doctor's permission). Recordings can also be helpful for family and friends to listen to, so that you don't have to keep repeating information. Or you could take a family member or friend with you to your appointment. As well as giving support, they may be able to take notes for you, or remind you of any questions you want to ask (MACMILLAN, 2014h).

Questions you could ask your specialist

- What are my treatment options?
- Is this treatment aimed at helping me live longer or controlling my symptoms?
- How long will it be before I feel the benefit of any treatment?
- What are the side-effects?
- Can I carry on working?
- Will I need to stay in hospital and, if so, for how long? (MACMILLAN, 2014h)

Getting a second opinion

Your multidisciplinary team - usually consisting of an clinical oncologist, nurse, physiotherapist, occupational therapist, social worker, dietitian, and sometimes a speech and language therapist, a pathologist, a radiologist, or others (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion (MACMILLAN, 2014h).

If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion (MACMILLAN, 2013d).

Common reasons why people want a second opinion are because -

- they have doubts about their diagnosis,
- they may not understand the information they've been given,
- they're not happy with the treatment that's been recommended,
- they feel that they cannot talk to the doctor or specialist about their diagnosis or treatment (MACMILLAN, 2013d).

Reasons for requesting a second opinion

Although many people are happy that their GP or the MDT has planned the best treatment for them, some people may want a second opinion. The most common reasons for this are -

You may have doubts about your diagnosis Some people ask for a second opinion because they're worried that their GP or consultant may have incorrectly diagnosed their condition. In this case, it's important to ask for a further appointment so that you can talk to your GP or consultant about any issues. It may help to write down your concerns and show them to the doctor. If you're unsure about any test results, remember you should be able to ask for a written copy of them and for your doctor to explain them to you (MACMILLAN, 2013d).

You may not understand the information you've been given Doctors know that many people find it difficult to take information in when they are anxious or upset. You can always ask for another appointment so that you can go through the information again before going for a second opinion. Many hospital consultants have a nurse specialist working with them who you can either see or phone after your appointment if you need more information. It's also a good idea to take a relative or friend with you so they can help you remember what was said (MACMILLAN, 2013d).

You may not be happy with the treatment that's been recommended This could be because you've heard from somebody, read in a newspaper or seen on the internet that another treatment is better. It's important to remember that even if you have the same type of cancer as someone else, the same treatment may not be suitable for you. That's why doctors plan treatment on an individual basis. If you're concerned about your treatment, ask for a further appointment with your original doctor. You can talk to them about your concerns. They should be able to explain to you why they have recommended a particular treatment for you (MACMILLAN, 2013d).

You may not feel you can talk to your doctor or specialist about your diagnosis or treatment Some people ask for a second opinion because they find it difficult to talk to their original doctor or hospital consultant. If you feel like this, try telling them that you're finding it hard to talk with them - often this can help. Or you could ask to see someone else in their team, for example the consultant's registrar, a nurse, or another GP in the practice (MACMILLAN, 2013d).

Advantages and disadvantages of getting a second opinion

Before you decide whether you want a second opinion, you may want to think about some of the advantages and disadvantages (MACMILLAN, 2013d).

Possible advantages

- If both doctors are in agreement about your diagnosis and treatment this will help you feel more confident about their decision.

- You may find that you get on better with a different doctor and have more confidence in what they say.
- You may be offered a treatment that hasn't been suggested before, or a newer treatment that's part of a clinical trial.
- You may be offered a wider choice of treatments by the second doctor, so you can decide which treatment to have (MACMILLAN, 2013d).

Possible disadvantages

- Having a second opinion doesn't mean you'll be seen or treated more quickly than anyone else. Your treatment may be delayed by waiting to see another consultant. The person you see for a second opinion will also need to get information from your first doctor, which can delay treatment. You may need to think carefully about having a second opinion if a delay is likely to be harmful to you or reduce your chances of successful treatment.
- You may find it upsetting being told the same - or different - news about your diagnosis and treatment if it's not what you were hoping for.
- If you're offered a different treatment, you may be asked to decide which treatment to have. Some people find this difficult and worry about whether they will make the right decision. However, it's important to remember that there's no right or wrong decision.
- You may have to travel some distance to a different hospital to see another specialist and you may then need to have your treatment at that hospital. This might not be easy for you or your family and may mean you have extra travelling costs (MACMILLAN, 2013d).

How to get a second opinion

If you want a second opinion from a GP, you can ask to see another GP at your surgery or you could consider changing your surgery. You may want to discuss this with the practice manager.

There are different ways of seeking a second opinion from a hospital consultant or specialist. You can ask your GP to refer you to another consultant or specialist, either on the NHS or privately. Or you can ask your current consultant or specialist to refer you for a second opinion. People often worry that this will upset the specialist or that they will be seen as a bad patient. However, many doctors, consultants or other specialists will be happy to refer you for a second opinion if it will be helpful.

Relatives and carers can also request a second opinion on your behalf, but only with your consent [19]. Some people do their own research to find the name of a consultant they think they'd like to see.

When you are referred for a second opinion, any relevant medical information will be sent to the new doctor or specialist. This information will include your scan, test results and any previous treatments.

If, after your second opinion, you want the second doctor, consultant or specialist to treat you, this will have to be formally arranged with them (MACMILLAN, 2013d).

Preparing for your second opinion appointment

It can help to prepare for your appointment by thinking about what you want to get out of it. You could write down some questions and take them with you. It can also help to have someone else go with you (MACMILLAN, 2013d).

Here are some questions you may want to ask -

- If the second opinion differs from the original one, why?
- Are there other treatments I could have?
- Do I need any treatment?
- What are the side-effects of these other treatments?
- What impact might the treatments have on my life?
- How might other treatments improve my health?
- How long will I need to be treated for?
- Will I need to have my treatment at another hospital? (MACMILLAN, 2013d)

Difficulty getting a referral for a second opinion If for some reason you find it difficult to get a referral for a second opinion, the Patient Advice and Liaison Service (PALS) in your local hospital may be able to help. You can get the phone number of your PALS team from the hospital switchboard. Alternatively, your local Citizens Advice Bureau (CAB) may be able to advise you (MACMILLAN, 2013d).

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[19] the principle that a person must give permission before they receive any type of medical treatment, test or examination. This must be done on the basis of an explanation by a clinician

Useful organisations

We have a list of organisations that may be able to offer you support and information. Our database of useful organisations lists organisations that provide both practical and emotional support, including information on health, benefits and financial help (MACMILLAN, 2013d).

Clinical trials

Current treatments can be helpful for many people with advanced cancer. But cancer doctors are always looking for better ways of treating cancer and controlling its symptoms. One of the ways doctors do this is through cancer research trials, often called clinical trials [20]. Trials help to improve knowledge about cancer and develop new treatments. Any new drug that's developed will go through trials to check it's safe and effective (MACMILLAN, 2014h).

Taking part in a trial

You may be invited to take part in a clinical trial, and there can be many benefits to doing this. If you decide to take part, you will be carefully monitored during and after the study. It's important to bear in mind that some treatments that look promising at first are often later found to be less effective than existing treatments. They may also have side-effects that outweigh the benefits.

If you start taking part in a trial and then change your mind, you can leave the trial at any time. You may then be offered the standard treatment for your situation.

If you decide not to take part in a trial, your decision will be respected and you won't have to give a reason. There will be no change in the way you're treated by the hospital staff, and you'll be offered the standard treatment for your situation (MACMILLAN, 2014h).

See also /nameref{cltr}.

Complementary and alternative therapies

Complementary therapies are most often used alongside conventional therapies such as chemotherapy and radiotherapy. They aren't used to treat cancer, but

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[20] these compare the effects - both wanted and unwanted - of two or more treatments

they can play an important part in reducing anxiety and helping control symptoms.

The term alternative therapy is often used to refer to treatments that are used instead of conventional medical treatments. Some alternative therapists claim that their therapies can cure cancer even if conventional medicines haven't been able to. But no alternative therapies have been proven to cure cancer or slow its growth. Unfortunately there have been cases where false claims made about alternative therapies have led patients to refuse conventional treatments that could have helped them.

Some alternative therapies may do no harm, but some can cause serious side-effects and make people feel unwell. Many alternative therapies can also be expensive. If you decide to use an alternative therapy, it's important to check it's safe and to check the credentials of the therapist offering the treatment.

It's important to tell your doctor if you're using any complementary or alternative therapies. This is because some therapies may make conventional cancer treatments less effective or increase their side-effects (MACMILLAN, 2014h).

Asking about life expectancy (prognosis)

For many people, the most important question to ask is, 'How long will I live?'

Doctors can't be certain what will happen to an individual person, so they may not be able to answer your questions fully. But they can usually give you some guidance based on the type of cancer and your situation. For example, how well the cancer responds to treatment and how quickly the cancer grows will affect how long you might live. Some people will live with their advanced cancer for a long time - sometimes years. For others, the cancer develops more quickly.

Because different things can affect how long you might live, your doctor's guidance may change over time.

Talking to your doctor about this may be an ongoing discussion, rather than a one-off question. For some people it's important to have an idea of how long they might live. Others prefer to focus on their quality of life, and choose to never ask the question.

Your medical team and your loved ones may wait for you to talk about life expectancy, or they may talk about it straight away. If you're not comfortable discussing this, it's fine to say so. It's important to do whatever feels best for you (MACMILLAN, 2014h).

Who can give you information?

It may be difficult to collect your thoughts during your hospital appointments, and you'll probably think of lots of questions between appointments. You may have a specialist nurse who you can contact when you're not at the hospital.

Our cancer support specialists on 0808 808 00 00 can give you information and emotional support. People with cancer and their relatives sometimes find it helpful to talk to someone they don't know and who isn't emotionally involved in their situation (MACMILLAN, 2014h).

Controlling symptoms and side-effects

Your doctors and nurses will ask about any symptoms or side-effects that you may be experiencing. It's important to talk to them about how you feel so that they can give you the right help.

When treatment is no longer controlling a cancer, doctors may focus on treating any troublesome symptoms. This is to help promote the best possible quality of life.

Not everyone experiences pain, but if you do, you can talk to your doctor about the best pain control plan for your situation. There are different medicines and methods of controlling pain. Your doctor or nurse can talk these through with you.

You might notice changes in your eating habits, such as loss of appetite or feeling sick. If you're concerned about this, ask your doctor about seeing a dietitian. A dietitian will help you find ways to eat well.

Some people also find that that they get tired easily. You could try saving your energy for the things that you really want to do and give yourself plenty of time to rest. If you're having difficulty sleeping, you could try breathing or relaxation exercises (MACMILLAN, 2014e).

Possible symptoms and side-effects

Whether or not you're having treatment to control the cancer, your doctors and nurses will regularly check whether you're having any symptoms and side-effects. Some symptoms are only likely to happen with particular types of cancer, and side-effects can be caused by cancer treatments. It's important to let your medical team know about any symptoms or side-effects so they can arrange appropriate help and treatment.

For some people, treatment may no longer be controlling the cancer. In this situation, your doctor may suggest that the aim of treatment changes from trying to shrink the cancer, to easing troublesome or distressing symptoms. This will help you feel better and have the best possible quality of life.

Palliative care teams based in hospitals and the community are experts in helping control symptoms such as pain. Your GP or cancer specialist can refer you to a palliative care team (MACMILLAN, 2014e).

Controlling pain

Not everyone with advanced cancer has pain, but if you do, it can usually be well-controlled with medicines. If you have pain, it's important to let your doctor know so it can be treated. Mild painkillers like paracetamol may work well for you, but sometimes stronger drugs are needed. Your medical team will work with you to develop the best pain control plan for your situation (MACMILLAN, 2014e).

Other treatments can also be used to relieve pain. These include -

- radiotherapy,
- nerve blocks,
- transcutaneous electrical nerve stimulation (TENS) (MACMILLAN, 2014e).

Some people also find Complementary therapies help relieve pain, such as acupuncture or hypnotherapy and relaxation techniques.

Specialist pain clinics offer these methods of pain control. Your GP or cancer specialist can refer you to one. Or they could refer you to a community palliative care team. These teams specialise in pain and symptom control (MACMILLAN, 2014e).

Eating changes

Many people with advanced cancer notice a change in their eating habits. This may be related to a loss of appetite or to changes in the way you smell and taste food. Some cancers or treatments also cause particular problems, such as Difficulty swallowing or Feeling sick.

Even if you're still eating well, you may lose weight and muscle because the cancer can change the way your body uses the energy in your food.

If you're concerned about weight loss or about changes in your eating habits, talk to your nurse or doctor. They will be able to assess the reason for the change. You can also ask to see a dietitian, who can help you find ways to eat well.

People close to you may have concerns if you're eating less, and they may not understand the reasons for this. You might find it helps if you explain why you find it hard to eat (MACMILLAN, 2014e).

If you're living with advanced cancer, it's your quality of life that's important. Think about what food you enjoy and what you can manage. When you're struggling to eat, these tips may help -

- Try having frequent snacks or small meals. These can be more manageable than three large meals a day.
- Choose foods that you enjoy and ignore those that don't appeal to you. You can try them again after a few weeks if your appetite improves or sense of taste returns.
- If you can only manage small amounts, choose foods or drinks that will give you energy and protein so you get the most out of what you eat.
- If you can't face eating, try a nourishing drink. You can make a smoothie by blending or liquidising soft fruits (fresh or frozen) with fortified milk, fruit juice, and ice cream or yoghurt. Your doctor, nurse or dietitian can also prescribe or recommend supplement drinks and puddings for you.
- If you feel you need more help at home with cooking or eating, tell your GP or contact the dietitian at your hospital. They may be able to arrange meals on wheels or a home help for you (MACMILLAN, 2014e).

We have more information about eating well when you have cancer, including a video about healthy diet, recipes and more (MACMILLAN, 2014e).

The writer and broadcaster Ned Sherrin died of oesophageal cancer, and in the last week of his life he's reputed to have only eaten and drank his favourite food and drinks - fish pie and martini's!

When I worked on the cancer ward, a favourite drink of many of our patients was a banana, or frozen and thawed strawberries, with a small wafer-sized ice cream, a couple of ice cubes, all blended with a 'fortisip', a nutritious drink generally prescribed by dieticians. This gave them increased calories, and a chilled and savoury smoothie.

Difficulty swallowing

Chemotherapy, and radiotherapy treatments for a head or neck cancer, can affect the cells in the lining of the throat, which can make it painful to chew or swallow.

An infection in your mouth and throat can also make chewing and swallowing uncomfortable. A common mouth infection is thrush (candidiasis). It shows as white spots on your mouth and tongue, or your tongue and mouth lining become red and swollen. Thrush is treated with anti-fungal tablets. Some people are prescribed these tablets to prevent thrush.

Let your doctor or dietitian know if you're having any difficulties. If you find that drinks make you cough, you should tell your doctor or specialist nurse as soon as possible (MACMILLAN, 2014j).

- You may find that taking painkillers before mealtimes can help you chew and swallow more easily. Your doctor or nurse can advise you about this.
- Keep eating your favourite foods where possible, but make changes to soften them. For example, cover foods in interesting sauces and gravies; finely chop meat and vegetables then casserole or stew them; and cut the crusts off bread for softer sandwiches. If you have a blender, you could liquidise cooked foods.
- There are several balanced food supplements that you may find helpful, for example Build up® or Complan® drinks. You can buy these in your chemist or supermarket. Your doctor may give you a prescription for some of them (MACMILLAN, 2014j).

Feeling sick

Some types of chemotherapy, hormonal therapy and targeted therapy can make you feel sick. Nausea may be caused by radiotherapy to the brain, stomach, bowel or close to the liver. Other drugs, such as painkillers and antibiotics, and physical problems like constipation or liver damage, can also cause nausea.

There are very effective treatments to help prevent and control sickness. Your cancer specialist can prescribe anti-sickness (anti-emetic) drugs for you. Let them know if your anti-sickness drugs are not helping, as there are several different types you can take (MACMILLAN, 2014m).

If feeling sick is putting you off your food, these tips may help -

- Try eating dry food, such as toast or crackers, first thing in the morning before you get up.
- If the smell of cooking makes you feel sick, eat cold meals or food from the freezer that only needs heating up. However, remember to follow the cooking instructions to make sure it's properly cooked.
- If possible, let someone else do the cooking.
- Avoid greasy, fatty or fried foods.

- Try sitting by an open window so there's plenty of fresh air in the room while you eat.
- Sit at a table in an upright position when eating, and stay sitting for a short time after the meal.
- When you feel sick, start by eating light foods such as thin soups or egg custards. Gradually introduce small portions of your favourite foods, slowly building up to a more varied diet.
- Food or drink containing ginger can help reduce feelings of sickness. You could try crystallised ginger, ginger tea or ginger biscuits.
- Sipping a fizzy drink is a popular remedy for feeling sick. Try mineral water, ginger ale, lemonade or soda water, and sip it slowly through a straw.
- Try having drinks between meals rather than with your food.
- You could try wearing sea bands (available from chemists) around your wrists. They use acupressure to help relieve nausea.
- Try to make sure you have regular bowel movements as constipation can make you feel sick (MACMILLAN, 2014m).

Fatigue

You may find you become tired easily, and that your body no longer feels as strong. This could be because of the cancer or because of the side-effects of treatment. If your energy is limited, save it for the things you really want to do. Very often, reorganising your daily activities can be helpful, for example setting aside time to rest every day.

Practical aids can also be useful, such as walking sticks, walking frames or wheelchairs. They may help you move around more than you could on your own. Many shopping centres and supermarkets offer electric wheelchairs. You can check your local area at the National Federation of Shopmobility's website (MACMILLAN, 2014e).

What is fatigue?

Fatigue can be caused by cancer itself or the side effects of treatments. It is when you feel very tired or exhausted most, or all, of the time. Nine out of ten people with cancer (90%) experience fatigue and it affects everyone differently. For some people the effects will be very mild, for others it can be very disruptive. You may get tired very quickly, and not feel better after resting and sleeping. Fatigue can affect all areas of your life. Even reading or watching television can be very tiring. This can be frustrating and overwhelming.

Cancer-related fatigue usually gets better after treatment finishes but, for some people, it continues for months or years. Tell your doctors and nurses about your fatigue and how it affects your life. You may find it helpful to keep a fatigue diary. Your doctor or nurse may be able to tell you about ways you can manage the symptoms or treat the causes. One of the best things you can do to manage your fatigue is to stay physically active (MACMILLAN, 2013m).

Fatigue and cancer Fatigue is a very common problem for people with cancer. Nine out of ten people with cancer (90%) may feel fatigued at some time. Cancer-related fatigue (CRF) may be due to the cancer itself or may be a result of symptoms caused by the cancer. It can also be a side-effect of treatment.

Fatigue can be especially difficult to deal with when you're already trying to cope with cancer. You may feel very tired or exhausted all or most of the time. This can be frustrating and feel overwhelming at times. Many people find their fatigue is as distressing and disabling as the other side-effects of cancer treatment.

Cancer-related fatigue is different from the tiredness and fatigue that someone without cancer may get. People with cancer may get tired much more quickly after less activity. When healthy people get fatigued, it's usually relieved by rest and sleep, whereas cancer-related fatigue isn't. The fatigue usually gets better after treatment finishes, but it may continue for many months, or sometimes years.

It's important to tell your doctors and nurses about your fatigue and how it makes you feel, without playing it down. There are ways they may be able to help. For example, treating the causes of fatigue, such as anaemia or sleeplessness.

There are also things you can do for yourself that may help you cope. Research tells us that one of the best things you can do to help manage your fatigue is to stay active (MACMILLAN, 2013m).

The effects of fatigue Fatigue can affect all areas of your life. You may be too tired to take part in daily activities, relationships and social events. It affects everyone differently and can cause many different symptoms. Some people find their fatigue is very mild and doesn't interfere much with their daily life. But for others, it's very disruptive (MACMILLAN, 2013m).

The different levels of fatigue are described in the fatigue diary. Some of the more common effects of fatigue include -

- Difficulty doing the smallest chores. Even everyday activities such as brushing your hair, showering or cooking can seem impossible.
- A feeling of having no energy, as if you could spend the whole day in bed.
- A feeling of having no strength to do anything.
- Lack of concentration.
- Having trouble thinking, speaking or making decisions.
- Difficulty remembering things.
- Feeling breathless after only light activity.
- Dizziness or a feeling of light-headedness.
- Difficulty sleeping (insomnia).
- Loss of sex drive.
- Feeling more moody and emotional than usual (MACMILLAN, 2013m).

Fatigue can affect the way you think and feel. You may find it impossible to concentrate on anything, which can affect school or your job. If you're having trouble concentrating, it can also affect things that you usually enjoy doing. Even reading or watching TV can be difficult.

Money may become a problem if you need to take time off work or stop working completely.

Fatigue can affect your relationships. You may spend less time with friends and family, or spend more time sleeping. It may make you become impatient with people around you, or you may avoid going out or being with friends because it's too much effort.

Getting help and support from your healthcare team may help to prevent or relieve some of these effects, and improve your quality of life (MACMILLAN, 2013m).

What causes fatigue?

Cancer-related fatigue can be caused by many things. These include -

- The cancer itself.
- Tests and investigations you may need to have.
- Treatments for cancer - including chemotherapy, radiotherapy, hormone therapy, targeted therapies and surgery. CRF usually improves when you have finished treatment but can sometimes be a long-term problem.
- Low levels of red blood cells in your blood (anaemia) due to your cancer or cancer treatments. You may have a blood transfusion to help increase the number of red blood cells.

- The emotional effects of cancer, such as anxiety or depression. These are common emotions when you are first diagnosed with cancer but generally get easier to manage with time.
- Poor appetite due to your cancer or side-effects of treatment.
- Symptoms that cancer may cause such as pain, breathlessness or fluid retention (MACMILLAN, 2013l).

Cancer treatments and fatigue

Before treatment starts, many people already feel tired from the tests and investigations used to diagnose the cancer. They may also be tired from trying to cope with different emotional effects. The cancer itself can also make you feel tired. The treatment for cancer can make the tiredness worse, but it may also improve things if the cancer is making you feel tired. People who are older, have other medical problems, or have more than one type of treatment are more likely to be affected by cancer-related fatigue (MACMILLAN, 2013l).

Surgery Many people feel tired after surgery and need to take things easy for a while. This effect is usually temporary. However, some types of surgery may cause continuing problems with fatigue (for example, if surgery to the stomach leads to problems with absorbing food) (MACMILLAN, 2013l).

Chemotherapy and radiotherapy Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. Radiotherapy treats cancer by using high-energy rays to destroy cancer cells. Fatigue caused by chemotherapy or radiotherapy usually improves after treatment, but sometimes it can be more of a long-term problem. Many people find their normal levels of energy return within 6–12 months of the treatment ending. However, some people find they still feel tired and have low energy levels a year or so later. Sometimes, tiredness can continue for two years or more, although this is far less common (MACMILLAN, 2013l).

Hormonal therapies Hormonal therapies are treatments that can stop or slow the growth of some cancer cells. They either alter the levels of particular hormones in the body or prevent the hormones from being absorbed by cancer cells. These are often given for several years. Some hormonal therapies can cause fatigue (MACMILLAN, 2013l).

Targeted (biological) therapies Targeted therapies use substances that target the growth of cancer cells. Some of them can cause fatigue. Apart from treatment-related anaemia, doctors are still trying to find out exactly why cancer treatments cause fatigue. It's thought that fatigue may occur after having cancer treatment because -

- the body needs extra energy to repair and heal,
- there is a build-up of chemicals as the cancer cells are destroyed,
- the body's immune system is affected (MACMILLAN, 2013l).

Anaemia and fatigue

Anaemia is a possible cause of fatigue in people with cancer. It is a shortage of haemoglobin in the blood. Haemoglobin (or Hb) is found in red blood cells and carries oxygen around the body. As red blood cells circulate in the body, they give energy by carrying oxygen to all of the body's cells.

If the number of red blood cells is low, there is less Hb, so less oxygen reaches the cells. If the level of Hb in your blood drops below normal, you may feel tired and have less energy. Doctors regularly check the levels of blood cells in people who have cancer and cancer treatments (MACMILLAN, 2013l).

People who have anaemia may also find that they -

- are breathless,
- feel dizzy and light-headed,
- have a worsening of angina [21] (chest pain due to heart problems) (MACMILLAN, 2013l).

Causes of anaemia Chemotherapy reduces the production of red blood cells and is a common cause of anaemia. Radiotherapy can also cause anaemia if it's given to an area of the body that contains bone marrow. The bone marrow is where red blood cells are made. Radiotherapy given to the breastbone (sternum), the hip bones or the long bones of the arms and legs is most likely to reduce the production of red blood cells.

If you're having cancer treatment, you may find it helpful to write down your Hb levels in a fatigue diary. This may help you see how they affect your everyday life and your level of fatigue. It's important to let your doctor know if you think your Hb level is making you feel tired. If you are anaemic, your doctor may be able to give you treatment that will make you feel better.

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[21] chest pain that occurs when the blood supply to the muscles of the heart is restricted

Treatment for anaemia depends on the cause. The main treatment is a blood transfusion, which involves a drip (transfusion) of red blood cells given directly into the bloodstream. It can quickly raise the number of red blood cells that circulate the body (MACMILLAN, 2013l).

Eating problems and fatigue

Our bodies get energy from the food we eat. Fatigue can occur if the body doesn't get enough food or if there are changes to the way the body is able to use the food. In cancer, this can happen because -

- you can't eat the same amount of food as you normally do,
- your body needs more energy than it did before,
- your body may not be able to absorb and use all the nutrients from the food (MACMILLAN, 2013l).

If you feel sick (nausea), you may not get enough energy from food because you are likely to be eating less. If you actually are sick (vomit), your body doesn't absorb the food and essential nutrients it needs. This can also make you feel weak and tired, and you may also become dehydrated. If you have nausea or vomiting, your doctor can prescribe anti-sickness (anti-emetic) drugs, which usually help. They should be taken regularly so that the sickness doesn't come back. Some anti-sickness drugs can cause tiredness and may make you feel drowsy. Let your doctor know if this is a problem.

Chemotherapy can cause changes in appetite and taste, which may cause you to eat less. If you find that some foods no longer appeal to you, try something different. Your doctor, nurse or hospital dietitian may be able to help.

It can help to get someone else to prepare food for you. Otherwise, you may find that you use all your energy to cook and then feel too tired to eat. You could also buy some ready-made meals or place an order with an organisation that delivers ready-made meals to your home. Wiltshire Farm Foods deliver frozen meals to homes throughout the UK.

You can also contact your council's social services department to find out if you qualify for their 'meals on wheels' service.

If you don't feel like eating, you could try ready-made, high-calorie drinks. These are available from any chemist. Some are available on prescription. Unflavoured high-energy powders, which add calories to food without adding bulk, are also available on prescription.

The section on Eating problems has more information on coping with eating difficulties caused by cancer or its treatment (MACMILLAN, 2013l).

Cytokines and fatigue

Cytokines are proteins produced by the body. They act as chemical messengers and help regulate a wide variety of functions in the body. Studies have shown that cytokine levels are often raised in people with cancer-related fatigue, and these high levels may actually cause some of the symptoms people have. However, the exact way cytokines cause fatigue is not yet fully understood (MACMILLAN, 2013l).

Pain and fatigue

Many people with cancer don't have pain, but for those who do, it can cause fatigue. Painkillers and other treatments such as relaxation and acupuncture, can help relieve pain and reduce fatigue. The section on controlling cancer Pain, which you may find useful (MACMILLAN, 2013l).

Tips for better rest

Regular, good quality sleep is important when you are feeling tired (MACMILLAN, 2013k).

Keeping to your normal sleeping pattern, even if you want to sleep all the time, can help. There are different things you can do to improve your sleep and rest. You might want to try -

- keeping a bedtime routine,
- reducing light and noise in your bedroom,
- keeping a worry diary to record any thoughts that stop you sleeping,
- getting some exercise - this may help you to sleep better in the long term (MACMILLAN, 2013k).

If you struggle to get to sleep, there are things you can do to help. It's a good idea to have a small snack or a warm drink before bed. But try not to drink stimulating drinks, such as coffee, close to bedtime as this can keep you awake. You might also want to try mental exercises if you can't get to sleep. For example, try to remember the lines of a song, make alphabetical lists or write a letter in your mind.

Your doctor or nurse can give you more advice on how to manage your fatigue (MACMILLAN, 2013k).

Sleep when coping with fatigue

It's very important to try to keep to a normal sleep routine, even though your fatigue may make you feel like sleeping all the time.

There are many ways to overcome fatigue, which your nurse or doctor can discuss with you. In the meantime, the tips below might help you to make the most of your rest periods (MACMILLAN, 2013k).

10 tips for better rest

Good-quality sleep is very important and may help to relieve fatigue, as well as reduce your need to sleep during the day (MACMILLAN, 2013k).

1. Sleep for just long enough to feel refreshed the following day, but don't sleep for longer than you need. Spending too much time in bed is likely to affect the quality of your sleep.
2. Exercise regularly if you can, as this may help you sleep better in the long term.
3. Wake up at the same time every day and go to bed at the same time so you get into a good sleep routine.
4. Keep your bedroom for sleeping. If you wake during the night, go to another room in the house. If you need to sleep during the day, go to your bed to sleep.
5. Reduce light and noise at night-time as this will disturb your sleep. Even occasional loud noises (such as an aircraft flying overhead) affect sleep. If there's too much light, try using a heavier pair of curtains or an eye-mask. If your bedroom is noisy, you could try using ear plugs.
6. Keep the temperature in your bedroom comfortably warm. If your room is very warm or very cold, your sleep may be affected.
7. Have a bedtime snack but avoid stimulants and limit your alcohol intake at night-time. Hunger may disturb sleep. Have a light bedtime snack, warm milk or a hot drink before going to bed if you find it helps you sleep, but avoid food and drinks that contain stimulants such as caffeine for a few hours before bedtime. While alcohol can help people to fall asleep more quickly, the sleep tends to be disturbed. It may also give you a dry mouth and an unpleasant taste that can wake you up, so it's best to limit your intake of alcohol near bedtime.
8. Be aware of how naps affect you. Some people find that daytime naps help them sleep better at night, while others sleep less well after them. Find out what suits you best.

9. Get out of bed if you can't sleep. Rather than lying in bed tossing and turning, get up and watch television or read a book. You could try listening to audiobooks, which are available from most bookshops and libraries, or can be downloaded from the internet. Wait until you feel tired again and then go back to bed.
10. Keep a worry book. If you wake at night and are worrying about things, write them down. You can then work through your list during the day and get support and advice from relatives, friends or from your doctor or nurse (MACMILLAN, 2013k).

Mental exercises to help you sleep

Mental exercises can also help you to sleep. Here are a few mental exercises that you may like to try. They usually take about 10 minutes to do -

- Try to remember the lines of a song or poem.
- Make alphabetical lists of girls' or boys' names, countries, trees or flowers.
- Relive in detail a favourite experience.
- Write a letter in your mind.
- Use a relaxation exercise (MACMILLAN, 2013k).

You can get more information on sleeping well from the Royal College of Psychiatrists, which produces a range of useful information leaflets (MACMILLAN, 2013k).

Managing symptoms of fatigue

There are things you can do to help manage the symptoms of fatigue.

Eating well and drinking lots of fluids can help increase your energy levels. Your doctor or nurse can give you advice on your diet.

Being physically active may also improve your energy levels and increase your appetite. Start slowly and increase the amount of activity you do over time. Try setting yourself small goals that you can achieve, such as walking to the front door. Some exercise, even a small amount, is better than no exercise at all. It's important to get advice from your doctor before you do any new physical activity. They may refer you to a physiotherapist for further advice.

You may find that you feel more stressed when you are having treatment. This can make you feel more tired. Try to make time to relax. There are relaxation techniques you can use to relieve tension and increase your energy. Complementary therapies may also help you cope with fatigue and help you to relax. Speak to you GP about using these therapies.

There aren't any licensed drug treatments for fatigue but they are being researched. Steroid drugs can be helpful for some people. Your cancer specialist can talk about this with you (MACMILLAN, 2013g).

Diet and fatigue Eating well can help to boost your energy levels. Here are some useful hints -

- Keep a diary of what and when you eat every day to see if you have more energy after certain meals.
- Try to take advantage of the times when your appetite is best.
- Drink plenty of fluids.
- If your taste changes, try different foods or eat the foods that taste best to you.
- Ask your doctor or nurse for any booklets or leaflets that give dietary advice.
- Ask your doctor to refer you to a dietitian, who can give you helpful ideas (MACMILLAN, 2013g).

Physical activity and exercise There's good evidence that physical activity, such as gentle strengthening exercises combined with some walking, can actually help to reduce the symptoms of fatigue. Being active may help to boost your appetite, give you more energy and improve your general well-being, so it's important to try to exercise a bit, even if you don't feel like it. It's best to try to get a good balance between being active, exercising and getting plenty of rest.

It's best to choose an activity or exercise that you enjoy. Try to maintain the amount of activity you do. However, if you have fatigue, this may not always be possible. Remember that some exercise is always better than no exercise. Simple goals such as walking from the front door to the back door may be an achievable goal for you. But try to increase your level of activity and build up the amount of exercise you do a bit at a time.

Before you start to do any physical activity or increase the amount you do, it's important to get advice from a healthcare professional.

Always talk to your cancer specialist or GP before you start. They can advise you on the type and amount of exercise that's safe for you. It's also important to discuss any other medical conditions you have, such as high blood pressure, diabetes or lung problems, as these may be affected by physical activity.

You might find it helpful to get advice about exercise from a specialist cancer physiotherapist. Your GP or cancer specialist can arrange a referral for you (MACMILLAN, 2013g).

A physiotherapist can help you -

- build up your physical fitness,
- improve your energy, strength, joint range,
- coordination and balance,
- manage the side-effects of treatment,
- set some realistic goals for keeping active (MACMILLAN, 2013g).

The physiotherapist may suggest referring you for a supervised group exercise programme. These groups are run by healthcare professionals or experienced fitness trainers. Many people find the social side of being in a group enjoyable, and it may also help give you a bit more motivation to exercise (MACMILLAN, 2013g).

General suggestions for exercise It's helpful to set yourself some personal goals using the simple steps below. Try not to do too much, too soon (MACMILLAN, 2013g).

- Plan some activity or light exercise into your day.
- Try some regular, light exercise such as walking, and simple strengthening exercises like standing up and sitting down.
- These have been shown to reduce fatigue, and can help some people sleep better.
- Exercises such as yoga, qigong and tai chi may be particularly good as they involve gentle movement, stretching, breathing and balance.
- If exercise is impossible, try to stay active in your daily routine.
- Pay attention to how your body reacts to activity and exercise. How did you feel? How well did you sleep afterwards?
- Drink plenty of fluids before, during and after exercise.
- Keep a record of your activities so that you and your healthcare team can monitor your progress. You could write them down in the fatigue diary.
- Allow your muscles time to recover after activity by balancing activity with rest.
- Don't exercise if you feel unwell, are in pain or have any other symptoms that worry you, such as feeling breathless. Let your doctor know if you feel unwell or have worrying symptoms (MACMILLAN, 2013g).

Relaxation to help with fatigue Making time for activities that help you relax is very important in dealing with and preventing fatigue. Stress uses up energy and can make you feel more tired.

It's very likely that you will feel more stressed than usual when you start your cancer treatment (MACMILLAN, 2013g). The following suggestions may help you relax -

- Talk to others about anything that is worrying you.
- Try an activity such as reading, seeing friends and listening to music. This may help take your mind off worrying thoughts.
- If you can, try to avoid situations that make you anxious.
- If you can, take regular light exercise such as walking (MACMILLAN, 2013g).

Many people find it hard to relax and unwind, especially if the stresses and strains of the day are difficult to forget. Using specific relaxation techniques can help to relieve tension and boost your energy levels (MACMILLAN, 2013g). There are two types of relaxation exercises -

- physical ones, which work on tension in your body - these include tensing and releasing each part of your body in turn and breathing exercises,
- mental ones, which help to relax your mind - these include imagery exercises (MACMILLAN, 2013g).

You may want to experiment until you find the best exercise for you. You can ask if there is a nurse or other healthcare professional, such as an occupational therapist or psychologist, who can help you find the technique that's best for you. Using relaxation CD's or DVD's can be a good way to learn different exercises.

When you're ready to try a relaxation exercise, find a quiet, warm, dimly lit, relaxing place where you won't be disturbed, then lie or sit in a well-supported position. You'll get the maximum benefit from these techniques if you practise them for 5–15 minutes each day (MACMILLAN, 2013g).

Complementary therapies for fatigue There are a number of different complementary therapies that may help you cope with fatigue. They include -

- meditation,
- acupuncture,
- reflexology,
- aromatherapy,
- massage,
- music therapy (MACMILLAN, 2013g).

You may need to pay for these but they are sometimes available on the NHS. Your GP, specialist nurse or a palliative care nurse may be able to refer you. You may also be able to get them through a cancer support group.

Some doctors have been reluctant for their patients to use complementary therapies, mainly because they have not been properly tested in clinical trials. But many people who use them find that they're relaxing and help improve their general well-being. They can also help people feel more in control of their health and of what's happening to them (MACMILLAN, 2013g).

Please see Complementary therapies for more information about complimentary therapies.

Drug treatments for fatigue At the moment, there aren't any licensed drug treatments to help prevent or improve fatigue. Steroid drugs, such as dexamethasone, can sometimes be helpful. Your specialist can discuss this with you.

Research into other drug treatments is ongoing. You may be asked to take part in a Clinical trials. Your doctor or specialist nurse can give you further information about any drug trials that you may be suitable for (MACMILLAN, 2013g).

Managing everyday activities if you have fatigue

It's important to plan ahead if you have fatigue. Be realistic about what you can do and plan to do things when you usually feel less tired.

You may find some of these suggestions help you deal with everyday tasks -

- Spread housekeeping tasks over the week and ask for help if you can.
- Try shopping online so it is delivered to your home - or ask a relative or friend to do your shopping for you.
- Cook simple meals and eat small meals and snacks throughout the day.
- Have a bath instead of a shower and try to wear clothes that are easy to take off.
- Listen to the radio or an audiobook instead of watching television.
- If you have children, explain that you're feeling tired. Plan activities where you can sit down while spending time with them.
- Avoid driving when you feel tired. Family or friends may be able to drive you instead (MACMILLAN, 2013f).

Remember to ask for help if you need it. Family, friends, neighbours, social workers and occupational therapists may be able to help you manage your tasks (MACMILLAN, 2013f).

Planning your life around fatigue If you have fatigue, planning ahead is important. Plan your day so that you have time to do the things you want to do most.

It's important to be realistic about what you can do. You can use the fatigue diary to write down the times when you feel your best and when you feel most tired. This may help you to plan your activities.

Keeping a note of your energy levels will help you identify the days and times when you have more energy. However, you may have to accept that you won't be able to do everything you used to do. It may help to decide early on which activities you're prepared to give up, at least until you feel more able to do them again.

While some people feel less tired in the mornings, others cope better in the afternoon. Try to plan bigger tasks to fit in with the time of day when you feel least tired. Pace yourself, and plan enough rest and sleep periods. It makes sense to plan a period of rest after a period of activity. Some people also find that they need to rest after meals.

Short naps and rest periods are useful, however, you need to balance them with some activity or exercise. Too much rest isn't always a good thing as your muscles can weaken, which can make your fatigue worse. It's important that any daytime rest doesn't stop you from sleeping at night.

It's also important to plan your days around your treatment. Try to avoid anything energetic or stressful for 24 hours before and after your treatments. If you feel less well on a particular day, it's okay to be less active and to rest more.

Doing things for yourself can be very important, but try not to feel guilty if you have to ask other people to help. Often friends and relatives want to help and are pleased to be asked.

You may also find it helpful to see an occupational therapist from the hospital or from social services. They can help you find ways of saving your energy and may be able to visit you at home (MACMILLAN, 2013f).

Tips to help you manage housekeeping tasks when you have fatigue

- Spread tasks out over the week.
- Do a little bit each day rather than a lot in one go.
- Ask other people to do heavy work where possible.
- Sit down to do chores whenever you can.

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- If you can afford it, employ a cleaner. If not, you can ask for home help from social services. Depending on your circumstances, you may need to pay for this.
- Use long-handled dusters, mops and dustpans where possible to avoid stretching and bending.
- Ask someone to take your rubbish bags out for you.
- Ask someone to cut your grass for you and to tidy the garden (MACMILLAN, 2013f).

Tips to help you manage shopping when you have fatigue Ask others to do your shopping. If you don't have anyone who can do it for you, or you would rather shop yourself, these suggestions may help -

- Make a list before you start.
- Write the shopping list following the layout of the store, so you don't walk around more than necessary.
- Use a shopping trolley for support.
- Use a wheeled shopping bag to carry supplies and shopping.
- Shop at less busy times.
- Ask for help in the shop/supermarket with packing and carrying groceries to the car, or ask them to deliver them to your home.
- Shop with a friend for extra help.
- Do your shopping online and have it delivered at a time that suits you (MACMILLAN, 2013f).

Tips to help you prepare meals when you have fatigue

- Try cooking simpler meals to reduce the amount of time you spend in the kitchen.
- Eat convenience/precooked meals.
- Try eating little and often. Eat small meals and snacks throughout the day.
- If you can, sit while preparing meals.
- Prepare extra dishes or double portions when you're feeling less tired and freeze them for when you need them.
- Use oven dishes you can serve from to save on washing up.
- Don't lift heavy pans. Where possible, dish food out near the stove.
- Ask others to move heavy items to the table.
- Avoid bending and stretching when preparing food.
- Let dishes soak rather than scrubbing them, and leave them to dry on a draining board.
- Use a dishwasher if you have one.

- Use place mats instead of tablecloths - they're easier to put on the table and to clean (MACMILLAN, 2013f).

Tips to help with washing and dressing when you have fatigue

- Have a bath rather than a shower, or sit down in the shower.
- Wear clothes that are easy to put on and take off. Sometimes wearing pyjamas is easier if you're not going out.
- Sit down when getting dressed (MACMILLAN, 2013f).

Tips to help with leisure activities when you have fatigue

- Listen to audiobooks if you feel too tired to read.
- Listen to the radio rather than watching the TV.
- Explain to family and friends that there may be times when you can't see them, or that short phone calls and visits may be better (MACMILLAN, 2013f).

Tips to help with laundry when you have fatigue

- Where possible, use a trolley to move your washing to and from the washing machine.
- Get help to hang up washing.
- Use a foldaway drying rack for smaller items.
- Use a lightweight iron and sit down to iron if you can.
- Wear clothes that don't need to be ironed.
- Slide the iron on to a heatproof pad to avoid lifting it (MACMILLAN, 2013f).

Tips to help with childcare when you have fatigue One of the hardest aspects of fatigue can sometimes be feeling that you're letting your family down. This can be especially upsetting when you have children. No one is suggesting that you must ask others to take over caring for your children. However, there are things that you can do to make things a bit easier -

- Start by explaining to your child(ren) that you're feeling tired and won't be able to do as much with them as before. You may be surprised at how well they respond.
- Plan activities with your children that can be done while sitting down.
- Try planning activities where there are places for you to sit while the children enjoy themselves.
- Try to avoid lifting smaller children. Use a pram or pushchair if you have to transport them from place to place.

- Try to involve your children in some household chores.
- Accept offers of help from people you trust. This may include someone else taking your children to and from school or looking after them occasionally.
- Ask people to babysit from time to time so you can do some of the things you enjoy doing or need to do (MACMILLAN, 2013f).

Tips to help with driving when you have fatigue Driving can be difficult and dangerous if you feel very tired. You may be less alert than normal, and less able to concentrate. Your reaction time will also be reduced. You might find the following tips helpful -

- If you feel very tired it may be better to avoid driving.
- If possible, ask a family member or friend to drive you.
- If you have to get to hospital appointments, ask your nurse or doctor if there is any help available so that you don't have to drive.
- If you have to drive, plan any trips for when you know you usually feel more alert. It may also help to avoid driving at times when the roads are busier than usual.
- If you have to make a long journey, plan to break it up with regular stops or an overnight stay somewhere.
- If you feel yourself falling asleep while driving, stop in a safe place and take a break (MACMILLAN, 2013f).

Managing work if you have fatigue

You may find that you can't continue working due to fatigue, or that you have to reduce the amount of time you spend at work.

It can help to talk to your employer or personnel/human resources (HR) department and let them know that you may need some time off.

Don't feel that you have to work if you're too tired. If you do want to carry on working, you may be able to find ways of making your work less tiring for a while (MACMILLAN, 2013h).

Anyone with cancer is protected by the Equality Act 2010, which prevents employers from victimising or discriminating against people with a disability. The act also states that employers are expected to make reasonable adjustments to support employees in the workplace. You may want to make suggestions for adjustments that could help to support you. Things that your employer can do to help include -

- changing your hours so that you can travel to and from work at less busy times (outside the rush hour),
- asking colleagues to be supportive and to help with some of your work,
- finding you a parking place near to your place of work,
- letting you take short breaks to lie down and rest,
- allowing you to work from home (if this is possible),
- finding you lighter work if your job involves physical exertion or heavy lifting (MACMILLAN, 2013h).

If you're self-employed, it can help to talk to the Department for Work and Pensions about benefits that you may be entitled to claim.

Our sections about work and cancer and self-employment and cancer have more detailed information and useful tips for coping with fatigue at work (MACMILLAN, 2013h).

Emotional support if you have fatigue

If you find it difficult to cope with your fatigue, it might be helpful to talk about how you're feeling.

You may want to talk to a counsellor. They can help you talk about your feelings and help you find ways of dealing with them. Our cancer support specialists can tell you about services in your area or you can ask your GP to refer you.

Other people find it comforting to speak to a religious or spiritual advisor about how they are feeling. You don't need to have any particular faith, as they are used to supporting people of different faiths, or no faith, in times of need.

You may find it helpful to talk to other people in a similar situation. You can meet people by joining a support group. There are cancer support groups all over the UK. Or you may want to join an online support group or chat room. You can talk to other people or just read people's posts. Online support groups are usually available 24-hours a day and are easy to join and leave. On our online community, you can share your thoughts and get support from other people in a similar situation (MACMILLAN, 2013c).

Counselling and fatigue If you find it difficult to cope with your fatigue, or you feel anxious or depressed, you may find counselling helpful. Counsellors are trained to listen, and can help you talk through your feelings and find ways of dealing with them. They won't give advice or answers, but will help you find your own answers. You may find counselling particularly helpful if you aren't able to discuss your feelings and emotions with people close to you.

Many hospitals have counsellors or staff who are specially trained to provide emotional support and counselling. You can ask your hospital doctor or nurse what services are available and ask them to refer you. Some GPs have counsellors in their practice, or they can refer you to one.

If you would like to find out more about counselling, our cancer support specialists can tell you more and let you know about services in your area. Not all counselling services are available on the NHS, so you may need to pay for them (MACMILLAN, 2013c).

Support groups and fatigue Some people find it helps to talk to other people who've had fatigue. You may find talking to other people at the hospital helpful, or you could join a local support group.

Most areas in the UK have cancer support groups. They are sometimes led by a healthcare professional. Other members of the group may be in a similar position to you. Some support groups have counsellors.

Some people find groups helpful and they form close relationships with other members. However, other people get embarrassed or uncomfortable when talking about personal issues with strangers. Don't worry if groups aren't for you (MACMILLAN, 2013c).

Online support and fatigue You may find it helps to join an online support group or chat room. There are a number of online groups for various cancers, where you can chat to other people. If you prefer, you can stay anonymous and just read other people's posts. Online groups and chat rooms can be very supportive, as you'll find that other people have similar thoughts, emotions and experiences to you.

The groups and chat rooms are often available 24-hours a day, so there may be people online you can chat to when you really need support the most. Online groups are easy to join and leave, without any need for personal contact or explanations.

Visit our online community to chat to people in our forums, blog your experiences, make friendships and join support groups. You can share your own thoughts and feelings, and get support from others (MACMILLAN, 2013c).

Spiritual support Some people find comfort in religion during times when they feel anxious or depressed. You may find it helpful to talk to a local minister, hospital chaplain or other spiritual or religious adviser. Don't be put off if you've never talked to one before, or if you don't have any particular faith. They are used to supporting people in times of need (MACMILLAN, 2013c).

Talking to your doctor or nurse about fatigue

Preparing for your appointment Prepare for your next appointment with your doctor or nurse by writing down any questions that you want to ask. Don't be embarrassed to ask them to repeat or explain anything that you don't understand. It may help to take a relative or friend with you and to have a notebook to jot down any information, as it can be difficult to remember what's been said when you have fatigue.

It can sometimes be difficult for your healthcare team to understand how much fatigue is affecting your life and how distressing it is. It's important to describe your symptoms to them. You may need to emphasise to your doctors and nurses the difficulties that fatigue is causing.

Tell them about the activities you find difficult, such as climbing stairs, cooking or bathing. Let them know if anything makes the fatigue better or worse. If you have kept a fatigue diary, you can take it with you and show it to the healthcare professionals looking after you.

Your doctor will look for any causes of your fatigue that can be treated. They may examine you and may organise some blood tests [22].

It can often be difficult to discuss emotions, especially when you are ill, for fear of upsetting yourself and others. Try not to let embarrassment stop you discussing your feelings with your doctors and nurses (MACMILLAN, 2013j).

Here are some specific questions you may like to ask -

- What could be causing my fatigue?
- What treatments may help?
- How can I cope with my fatigue?
- What help is available?
- What can I do to help reduce my fatigue? (MACMILLAN, 2013j)

You may find it helpful to make a note of any questions you might want to ask, and the answers you receive (MACMILLAN, 2013j).

Looking after someone with fatigue

What you can do

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[22] these have a wide range of uses and are one of the most common types of medical test

- Understand the different ways of dealing with fatigue. Reading the information in this section should help.
- Encourage your relative or friend to use the fatigue diary, or help them to fill it in. Write down how fatigue affects their life as well as how it affects yours.
- Use the fatigue diary to find out what times the person you care for has more energy to do things such as shopping or having visitors around. Plan to make the most of these times.
- Try reducing fatigue by helping your relative or friend make simple improvements to their sleep, diet and exercise habits (MACMILLAN, 2013e).

You can go with your relative or friend on their visits to hospital and take the fatigue diary with you. Discuss with the doctors and nurses -

- how the fatigue is affecting both of you,
- what could be causing the fatigue,
- what techniques you've tried to reduce fatigue and what has or hasn't been helpful (MACMILLAN, 2013e).

Caring for another person can be exhausting. You may also become tired if you have lots to worry about. It's important that you also look after yourself and avoid getting too tired.

This can be difficult when you have a lot to do and you don't want to let your relative or friend down.

You may need to involve other people or organisations to help with the caring, especially if you also have an illness that makes you feel tired. Try not to feel guilty if you do need extra help, and try to remember it's not helpful if you both feel tired (MACMILLAN, 2013e).

Cancer-related fatigue

Signs of cancer-related fatigue

Here are some signs of cancer-related fatigue that you and your family/carers can watch for (ACS, 2016). Talk to someone on your cancer care team if you have any of these symptoms -

- You feel tired and it doesn't get better, it keeps coming back, or it becomes severe.
- You're more tired than usual during or after an activity.
- You're feeling tired and it's not related to an activity.

- You put less energy into your personal appearance.
- You're too tired to do the things you normally do.
- Your arms and legs feel heavy and hard to move.
- You have no energy.
- You feel weak.
- Your tiredness doesn't get better with rest or sleep.
- You spend more time in bed and/or sleep more. Or, you may have trouble sleeping.
- You stay in bed for more than 24 hours.
- You become confused.
- You can't concentrate or focus your thoughts.
- You have trouble remembering things.
- Your tiredness disrupts your work, social life, or daily routine.
- You feel sad, depressed, or irritable.
- You feel frustrated, irritable, and upset about the fatigue and its effects on your life (ACS, 2016).

Even though fatigue is a very distressing symptom, doctors and nurses don't focus on it, and patients and caregivers seldom report it.

It may be hard for you to talk about it, but tell your cancer care team about your fatigue. Tell them how it's affecting your life. Someone on your team should be able to help you if they know you're having this problem. Managing fatigue is part of good cancer care. Work with your cancer care team to find and treat the causes of your fatigue (ACS, 2016).

Cancer-related fatigue is different.

Fatigue is being tired - physically, mentally, and emotionally. It means having less energy to do the things you need or want to do.

The fatigue that comes with cancer, called **cancer-related fatigue**, is different from the fatigue of daily life.

Everyday, normal fatigue usually doesn't last long. It often gets better when you rest. Cancer-related fatigue is worse and it causes more distress. It's not the tired feeling people remember having before they had cancer. People describe it as feeling weak, listless, drained, or ”washed out”. Some may feel too tired to eat, walk to the bathroom, or even use the TV remote. It can be hard to think, as well as move your body. Rest does not make it go away, and just a little activity can be exhausting. For some people, this kind of fatigue causes more distress than pain, nausea, vomiting, or depression.

Cancer-related fatigue is worse than everyday fatigue. It lasts longer and sleep doesn't make it better: It's unpredictable. People describe it as overwhelming, affecting every part of their lives.

Cancer-related fatigue can -

- Differ from one day to the next in how bad it is and how much it bothers you,
- Be overwhelming and make it hard for you to feel well,
- Make it hard for you to be with your friends and family,
- Make it hard for you to do things you normally do, including going to work,
- Make it harder for you to follow your cancer treatment plan (ACS, 2016).

Many people with cancer say fatigue is the most distressing side effect of cancer and its treatment - it can have a major effect on a person's quality of life.

Fatigue is the most common side-effect of cancer treatment, and it often hits without warning. Everyday activities - talking on the phone, shopping for groceries, even lifting a fork to eat - can be overwhelming tasks (ACS, 2016).

How long does cancer-related fatigue last?

Cancer-related fatigue can last from months to years. It often continues after treatment ends.

For people getting chemotherapy in cycles, fatigue often gets worse in the first few days and then gets better until the next treatment, when the pattern starts again. For those getting radiotherapy, fatigue usually gets worse as the treatment goes on.

Fatigue can affect your mood, employment, daily routines, self-care, recreation, relationships, and your sense of self (ACS, 2016).

Cancer-related fatigue is reported in 14% to 96% of patients undergoing cancer treatment (Fosså, Dahl, and Loge, 2003), (Miaskowski and Portenoy, 1998), (Irvine et al., 1991), (Vogelzang et al., 1997), (Detmar et al., 2000), (Costantini, Mencaglia, Giulio, et al., 2000), (Cella et al., 2002), and in 19% to 82% of patients post-treatment (Prue et al., 2006), (Bower et al., 2006), (NCI, 2014).

Most people get back to their normal energy levels from between 6 months to a year after the end of cancer treatment. But it can take longer (UK, 2016).

Fatigue or depression?

Some signs of fatigue often look a lot like those of depression, and it's easy to confuse the two. Depression involves an inability to feel pleasure - people who are depressed feel sad or unworthy. They may give up hope. You can have fatigue and not be depressed, although some people have both fatigue and depression.

Sometimes it may be hard to find a label for what you're feeling. Your doctor might want you to see a mental health professional to get another opinion on whether depression is part of the problem. If it is, treatment can help.

Try to tell your doctor exactly how you feel and how it affects the things you do. Only you know if you have fatigue and how it's changing your ability to enjoy life. Talk to your cancer care team so you can find ways to feel better (ACS, 2016).

Complementary therapies

What are complementary and alternative therapies?

Knowing the difference between conventional medical treatments and complementary and alternative therapies can help you to make informed treatment decisions.

- **Conventional medical treatments** are used by doctors to treat people with cancer. Depending on your type of cancer you may have surgery, radiotherapy, chemotherapy, hormonal or targeted therapies. These are scientifically tested and researched treatments. These treatments can cure many cancers, help people to live longer or reduce their symptoms.
- **Complementary therapies** are used alongside, or in addition to, conventional medical treatments. They do not claim to cure cancer. People use them to boost their physical or emotional health. Or to relieve symptoms or side-effects. Some have been scientifically tested to check how effective and safe they are.
- **Alternative therapies** are used instead of conventional medical treatments. They are not tested in the same way as conventional medical treatments. Some claim to treat or cure cancer. But no alternative therapies have been proven to cure cancer or slow its growth and some may be harmful (MACMILLAN, 2014z).

Always tell your doctor about any therapies you're using (MACMILLAN, 2014z).

Conventional medical treatments

These are the medical treatments doctors use to treat people with cancer. Surgery, radiotherapy, chemotherapy, hormonal and targeted therapies are all conventional medical treatments.

Many cancers are cured with these treatments. Even when treatments are unable to cure cancer, they often help people live for longer and/or reduce their symptoms.

Conventional medical treatments for cancer are scientifically tested and researched. This means we know how safe and effective they are and what their possible side-effects are. This is called evidence-based medicine (MACMILLAN, 2014z).

Complementary and alternative therapies

These are sometimes used by people with cancer. They are often grouped together, but there are important differences between them depending on how and why they're used. A therapy can be complementary if it's used in one way and alternative if used in another (MACMILLAN, 2014z).

Complementary therapies These are generally used alongside, or in addition to, conventional medical treatments. Complementary therapists don't claim that they can treat or cure cancer. People generally use complementary therapies to boost their physical or emotional health. Sometimes they may be used to relieve symptoms or the side-effects of conventional medical treatments.

Sometimes, complementary therapy is combined with conventional medicine. This is called integrated or integrative medicine.

Some complementary therapies have been tested in the same way as conventional medical treatments. This is to see how effective and safe they are, and to see if they have side-effects (MACMILLAN, 2014z).

Alternative therapies Alternative therapies are used instead of conventional medical treatments.

Some alternative therapies claim to treat or even to cure cancer. But no alternative therapies have been proven to cure cancer or slow its growth.

Alternative therapies don't go through the same evidence-based testing as conventional medical treatments. Some may even be harmful.

Using an alternative therapy instead of conventional cancer treatment could reduce the chances of curing someone's cancer or of living for longer with it (MACMILLAN, 2014z).

Complementary therapies and cancer

There are many reasons why people choose to use complementary therapies. Some people find they help them cope with the stresses of cancer and its treatments. Many therapies are relaxing, and may lift your spirits when you aren't feeling your best.

Doctors and nurses have researched some complementary therapies in trials. Some results showed that certain therapies helped to relieve particular cancer symptoms or treatment side-effects. Other results showed no effect on symptoms or side-effects. But the therapies researched were found to be safe and most people who tried them found them very supportive.

Complementary therapists usually work with the person as a whole. They don't just work with the part of the body where the cancer is. This is called a holistic approach. Health and social care professionals, such as doctors, nurses and physiotherapists, also aim to take a holistic approach.

Some people say the relationship they develop with their complementary therapist is an added benefit. Having someone who listens to you may help you cope with difficult feelings.

Finding support for yourself in this way can help you feel more in control. Some people may also see complementary therapies as a positive thing to do for their general well-being.

Some complementary therapies are done in a group. This may be a good opportunity to meet other people with similar experiences in a positive setting (MACMILLAN, 2014z).

Complementary therapies may help you -

- feel better and improve your quality of life,
- feel less stressed, tense and anxious,
- sleep better,
- with some of your cancer symptoms,
- with some of the side-effects of your cancer treatment,
- feel more in control (MACMILLAN, 2014z).

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Choosing a complementary therapy

When choosing a complementary therapy it can help to think about what you want to get out of it. Some therapies aim to relax you or make you feel generally better. Whilst others may help you cope with the symptoms of cancer or the side-effects of treatment.

Always tell your doctor if you are thinking about using complementary therapies. Although many complementary therapies are safe to use alongside conventional treatment, some may not be suitable. Your doctor can help you choose a complementary therapy that is safe for you.

You may be able to get some complementary therapies free on the NHS or from some large cancer charities. Private therapists can be expensive so make sure you find out the cost beforehand.

If you want to know about the therapies other people with cancer have found helpful you can contact a local cancer support group or join an online community. The Macmillan Support Line can also give you information on complementary and alternative therapies, and how to find a suitable therapist (MACMILLAN, 2014d).

Things to consider when choosing complementary therapies

When choosing a complementary therapy, it can help to think about -

- what you would like to do,
- how it may benefit you,
- any safety issues,
- how much it costs (MACMILLAN, 2014d).

You can read more by choosing a therapy in the find a therapy section. There are a number of other organisations that can give you information on complementary therapies.

If you'd like to know what other people have found helpful, you can contact a local cancer support group. Or if you have internet access, you can join an online community. Support groups and online communities make it possible for people affected by cancer to give and get support. People can share their experiences of all aspects of their treatment, including complementary therapies. You can join our online community at macmillan.org.uk/community and find a support group near you at macmillan.org.uk/supportgroups.

You can also read interviews with people who have tried complementary therapies at healthtalk.org (MACMILLAN, 2014d).

Your preferences

To decide what feels right for you, it may help to think about what you want from the complementary therapy (MACMILLAN, 2014d).

You may want to -

- feel more relaxed,
- get help with troublesome symptoms or side-effects,
- get help with difficult emotions,
- feel generally better,
- make a positive lifestyle change (MACMILLAN, 2014d).

There are some other things to think about -

- What's available in your area?
- Are treatments free or, if you have to pay, how much can you afford?
- Do you want a one-off treatment or something to do regularly? (MACMILLAN, 2014d)

Safety

Doctors don't usually have a problem with their patients using complementary therapies. But some therapies may not be suitable if you have a particular cancer or are having certain treatments.

Before using a complementary therapy, talk to your cancer doctor or nurse. Find out if it could have any harmful effects for you. It's very important to check whether it could interact with your cancer treatment, make it less effective or increase side-effects.

If you're already having complementary therapy before you start conventional treatment, make sure you tell your cancer doctor or nurse, especially if you're taking herbs, pills or medicines.

If you're having a complementary therapy, it's very important to tell the complementary therapist you have cancer (MACMILLAN, 2014d).

Cost

Some complementary therapies are provided free by the NHS and some larger cancer charities. Ask your doctor or nurse if there are complementary therapies at your hospital, hospice or GP surgery. Some cancer support groups offer therapies free of charge or at a reduced cost.

Therapies that aren't provided by the NHS or a support group can be expensive. The costs can add up over a long period of time. Check the costs beforehand and make sure you're being fairly charged. Some private therapists may offer a reduced cost based on your ability to pay. Some organisations should be able to give you an idea of the usual costs of certain complementary therapies (MACMILLAN, 2014d).

Getting information

Before making any decisions, make sure you have all the information you need about the complementary therapy you're interested in. Talk about it with your cancer doctor or nurse.

Ask to have a consultation with a complementary therapist first to find out what they think their therapy can do for you. We have some ideas on Choosing a complementary therapist and suggestions of what to ask them.

You may find it helpful to take a relative or friend with you for support. It can also help to write down the questions that matter most to you beforehand. Take your time to decide if you want to go ahead with the therapy.

The Macmillan Support Line can give you information on complementary and alternative therapies, and how to find a suitable therapist. They can also help you find a support group offering complementary therapy services in your area.

You can also get information from library books and online.

Be careful when choosing what to read or believe on the internet. Some websites make claims that aren't backed up by evidence and others may be selling products for profit. We have a list of websites that are reliable sources of information (MACMILLAN, 2014d).

Choosing a complementary therapist

It's important to use a registered practitioner. There are several organisations that regulate complementary therapists but registration is not compulsory in the UK. Therapists volunteer to join the register. Those who are members of these organisations have met a required national standard of practice. They may have a quality mark displayed on a certificate of qualification, or in their place of work.

Regulatory organisations will be able to provide you with a list of registered therapists (MACMILLAN, 2014c).

When choosing a therapist, you should -

- always use a qualified therapist who belongs to a professional body - ask the organisation about the level of qualification their practitioners have,
- check if the organisation has a code of practice and ethics, and a disciplinary and complaints procedure (reputable organisations will have these in place),
- ask the practitioner how many years of training they've had and how long they've been practising,
- ask what training they have done around complementary therapies and cancer,
- ask if they have indemnity insurance (in case of harm from complementary therapy side-effects),
- be careful not to be misled by false promises - no trustworthy therapist would ever claim to be able to cure cancer. Remember that some health professionals, such as doctors, nurses and physiotherapists, are trained in complementary therapies - so it's worth checking what services your hospital provides first (MACMILLAN, 2014c).

Massage therapies

Massage therapy

Massage is often offered as part of cancer care in cancer centres, hospices, community health services and some GP surgeries (MACMILLAN, 2014r).

Massage is a form of structured or therapeutic touch. It can be used to -

- relax your mind and body,
- relieve tension,
- improve the flow of fluid (lymph) in the lymphatic system,
- enhance your mood (MACMILLAN, 2014r).

Some studies of people with cancer suggested that massage therapy reduced symptoms such as pain, nausea, anxiety, depression and fatigue.

There are different types of massage therapy. Some are soft and gentle, while others are more active and may be uncomfortable. Your therapist will be able to adjust the pressure for your comfort. Cancer doctors and complementary therapists will usually advise you to try gentle massage and avoid vigorous, deep tissue massage.

Some people worry that massage could cause cancer cells to spread to other parts of their body. Research has not found any evidence of this, but massage therapists will avoid any areas affected by cancer, such as tumour sites or lymph nodes.

Talk to your cancer doctor or nurse if you're worried.

Massage therapists working with people with cancer must be properly trained and qualified. They should have some knowledge of cancer and its treatments. They can sometimes teach relatives or friends how to do basic massages, so that they can support you at home (MACMILLAN, 2014r).

During your therapy it's important to avoid massage -

- directly over a tumour or lymph nodes (glands) affected by cancer (lymph nodes are part of the immune system and help to filter germs and disease),
- to areas that are bruised or sensitive,
- to areas being treated with radiotherapy during and for a few weeks after it finishes,
- around intravenous catheters (such as central lines) and pain relief patches,
- to areas affected by blood clots [23], poor circulation or varicose veins (MACMILLAN, 2014r).

It's also important to be particularly gentle if -

- cancer has spread to your bones,
- you have a low platelet count (platelets are cells that help the blood to clot) (MACMILLAN, 2014r).

If you tend to bleed or bruise easily or have cancer in your bones, speak to your cancer doctor before having massage therapy.

You can contact the GCMT (The Council for Soft Tissue Therapies) to find a trained massage therapist (MACMILLAN, 2014r).

Energy-based therapies

Therapists believe that everyone has a special type of energy that can be worked on. Energy-based therapies aim to improve your physical and emotional health, using little, if any, physical contact (MACMILLAN, 2014l).

You might try -

- Shiatsu and acupressure to ease feelings of pain. The therapist applies gentle pressure, gently stretches or holds areas of the body.

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[23] known as venous thromboembolism (VTE) and is a serious, potentially fatal, medical condition

- Reflexology to ease feelings of stress and anxiety. Some people find it also relieves symptoms such as feeling sick (nausea), tension, pain and fatigue. The therapist applies gentle pressure to specific points on the feet or hands.
- Therapeutic touch, for example Reiki, gives some people valuable support. The practitioner applies gentle pressure to the body or work just above the surface (MACMILLAN, 2014l).

There is no medical evidence that energy-based therapies will treat symptoms, but you may still find them relaxing and calming (MACMILLAN, 2014l).

What are energy-based therapies?

Energy-based therapies are based on the theory that everyone has a special type of energy that can be worked on for health benefits.

There is no medical evidence that energy-based therapies have any effect on the cancer. Some may be used to try to treat symptoms, but there is no medical evidence that they help. Their most common effects are that some people find them relaxing and calming.

Some energy-based therapies rely on little, if any, physical contact for their effects. Others involve touch or body movements.

Energy-based therapies are available in some hospitals. If you are looking for these therapies somewhere other than in hospital, it's important to check that the therapist or practitioner is trained, registered and insured (MACMILLAN, 2014l).

Shiatsu and acupressure

Shiatsu is a Japanese form of massage. It's based on the theory that health depends on the balanced flow of energy through certain channels in the body. Therapists believe placing pressure on these channels helps restore energy balance. They may also gently stretch or hold areas of the body to reduce stiffness and soreness.

Although some people feel shiatsu eases pain and other symptoms, there's very little medical evidence to support this. But many people still find it a relaxing or uplifting experience.

As with other types of massage, it's important to take precautions (MACMILLAN, 2014l).

Reflexology

Reflexology is a form of foot or hand massage related to acupressure. Reflexologists believe different areas on the feet or hands represent, and are connected to, different parts of the body.

They apply gentle pressure to specific points on the feet or hands. The aim is to help you feel more relaxed.

Reflexology has been used to try to improve symptoms related to cancer or treatment, such as feeling sick (nausea), tension, pain and fatigue. So far, medical evidence hasn't proven that it's effective when used in this way. But, some evidence shows that reflexology can help people feel more relaxed and many people use it to help ease stress and anxiety (MACMILLAN, 2014l).

Therapeutic touch

In therapeutic touch, the practitioner uses touch or works just above the surface of the body. They believe this affects an energy field surrounding each person and they can act as a channel through which healing energy flows into the patient. There's no medical evidence to show it helps with symptoms or side-effects.

Some people feel that therapeutic touch gives them valuable support. When it's used in a religious or spiritual way, it's called spiritual or faith healing.

Reiki is another type of therapeutic touch developed in Japan. You sit or lie down and the practitioner gently places their hands on or just above your body. They use a sequence of positions that cover most of the body. You don't need to remove any clothing. Each position is held for about 2–5 minutes or until the practitioner feels the flow of energy has slowed or stopped.

Many organisations can give you more information about therapeutic touch (MACMILLAN, 2014l).

Mind body therapies

Mind-body therapies are based on the belief that what we think and feel can affect our well-being.

Below are some of the most popular mind-body complementary therapies used by people with cancer in the UK (MACMILLAN, 2014s).

- Relaxation can help reduce anxiety and stress.

- Visualisation may help to improve mood or reduce symptoms and side-effects.
- Meditation can help reduce feelings of fear, pain, anxiety and depression.
- Hypnotherapy may help you to make positive lifestyle changes and encourage positive emotions, such as calmness and relaxation.
- Art therapy helps you become more aware of, and let go of, difficult feelings.
- Music therapy can help you to express your feelings and may help to relieve symptoms of pain (MACMILLAN, 2014s).

You can practice these therapies at home, as part of a group or one-to-one with a therapist. Many conventional cancer treatment centres provide mind-body therapies (MACMILLAN, 2014s).

What are mind-body therapies?

Mind-body therapies are based on the belief that what we think and feel can affect our well-being. Like all other complementary or alternative therapies, they have no effect on the cancer. But they are often given as part of support for people with cancer.

Mind-body therapies are available in many conventional cancer treatment centres. They may help you feel less anxious, improve your mood and help you sleep. They can also be used to ease symptoms, such as pain, or to reduce side-effects caused by cancer treatment.

Most mind-body techniques need to be practised regularly for you to get the best results. Many people find that attending group classes helps them stay motivated to practise the techniques.

Some NHS services and support groups offer mind-body therapies. You can ask if they are provided at your hospital or if they can be accessed through your GP.

Call us on 0808 808 00 00 for details of support groups in your area (MACMILLAN, 2014s).

Relaxation

Simple breathing and relaxation exercises can help reduce anxiety and stress. As well as calming your mind, they may also reduce muscle tension. This may have a positive effect on the parts of the nervous system that control blood pressure and the digestive system. Relaxation is sometimes used together with meditation and visualisation.

Almost everyone can use relaxation techniques. You can learn them as part of a group or at home using a CD (MACMILLAN, 2014s).

Here are some organisations that provide relaxation CD's -

- Talking Life,
- Penny Brohn Cancer Care,
- Pain Relief Foundation (MACMILLAN, 2014s).

Visualisation (mental imagery)

This technique involves creating images in your mind while you are in a state of relaxation or meditation. For example, you might imagine that -

- you're lying in a field full of beautiful flowers,
- you're healthy and strong,
- the sun's rays are shining on you, warming you and giving you strength (MACMILLAN, 2014s).

The theory is that by imagining a peaceful scene, you will feel more relaxed. Various studies are looking at whether visualisation can be of any benefit to people with cancer. Some studies have found that women having treatment for breast cancer have improved their mood using visualisation. Other research has shown that, for some people, it can reduce the symptoms of cancer or the side-effects of treatment (MACMILLAN, 2014s).

Meditation

Meditation uses concentration or reflection to deeply relax and calm the mind. This can help reduce feelings of fear, pain, anxiety and depression.

Regular meditation practice can help people feel more in control of themselves and their lives. Many studies have shown that regular meditation lowers blood pressure and reduces the pulse rate, as well as reducing anxiety and stress levels.

You can use CD's to meditate at home or you may find it helpful to meditate in a group until you are familiar with the technique.

You can ask your GP or hospital doctor if they offer meditation or check with a complementary therapy organisation.

Meditation may not be suitable for people who have mental health problems. If you have or have had a mental illness, it's important to get advice from your doctor before considering meditation (MACMILLAN, 2014s).

Hypnotherapy

Many people use hypnotherapy to help them make positive lifestyle changes, such as giving up smoking, or to encourage positive emotions, such as calmness and relaxation.

Some studies have shown that hypnotherapy has helped reduce some side-effects of cancer treatment, such as nausea and vomiting. Some other studies have shown it can help with pain. But there isn't enough reliable evidence for doctors to recommend it as the main treatment for these problems.

A hypnotherapist will work with you to create a more helpful state of mind, during which you will still be aware of your surroundings. The therapist will make suggestions, which are believed to have a helpful effect on the way you deal with certain situations. You are always in control and are able to stop any session by simply opening your eyes.

We have details of organisations who can help you find a hypnotherapist (MACMILLAN, 2014s).

Art therapy

Art therapy is used to help people to express themselves. The art therapist may have training in psychotherapy and will encourage you to communicate your feelings through painting, drawing or sculpting. The aim is to express your feelings rather than produce a work of art.

The therapy can be given one-to-one with the therapist or in groups.

Being creative can sometimes help you become more aware of, and let go of, difficult feelings. These feelings can then be discussed, if appropriate, in counselling or group sessions.

You don't need to be able to draw or paint to take part. You will be encouraged to be spontaneous and doodle.

Art therapy is not widely available for cancer patients on the NHS. We have details of how to find an art therapist near you (MACMILLAN, 2014s).

Music therapy

This therapy uses music to improve quality of life by helping people communicate. You don't need to be able to play an instrument or read music.

Music therapy can be carried out individually or as part of a group.

During the session, you work with a range of easy-to-use instruments to help show your feelings. The aim is to help people who may find it difficult to talk about their feelings to express themselves.

Music therapy has also been shown to help relieve symptoms such as pain. Some studies found that people using music therapy were able to use lower doses of painkillers to control their pain.

Music therapy is not widely available for cancer patients on the NHS. We have details of how to find a music therapist near you (MACMILLAN, 2014s).

Diet and food supplements

You may make changes to your diet to improve your overall health, or to cope with the effects of cancer and its treatment. Nutritional therapies cannot cure cancer. But following a healthy diet is one of the most important changes you can make for your health.

Nutritional therapists work with you to find a diet that suits your needs. They may use detoxing, high-dose vitamins or avoiding certain food groups to try to improve your health. If you're lacking essential vitamins, minerals and essential fatty acids, dietary supplements can help. These can be particularly beneficial for people with cancer who struggle to get the right nutrients.

Always speak to your doctor before taking any nutritional therapies. Some supplements, for example antioxidants, can affect how well your cancer treatment works. Some may even increase the risk of some cancers developing (MACMILLAN, 2014i).

What are diet and food supplements?

Many people make changes to their diet after a cancer diagnosis as a way of staying as healthy as possible. They may also do this to help their body cope with the effects of cancer and its treatments. Giving up smoking, increasing physical activity and following a healthy diet are the most important changes people can make for their health.

For most people, making these types of changes will make the biggest difference to their health. They can be more helpful than making any one particular change.

People often ask about 'superfoods' or foods that boost the immune system. But there isn't any medical evidence that suggests these work.

There still isn't enough clear information to make exact recommendations about what someone with cancer should eat. In general, cancer experts recommend following a healthy, balanced diet. Your healthcare team (this includes your GP, doctors and nurses) are the best people to advise you what, if any, lifestyle changes you can make that may help.

We have more information about healthy eating and cancer and a useful video with tips for healthy eating (MACMILLAN, 2014i).

Nutritional therapists

Nutritional therapists don't aim to cure cancer through diet but try to improve your health. They use methods such as detoxing, high-dose vitamins or avoiding certain food groups.

There's no medical evidence that nutritional therapy can reduce the chance of cancer coming back and no reliable research has shown that it can improve health.

Nutritional therapists assess your general health and recommend a diet that's thought to be specific to your needs. Nutritional therapists are different from dietitians. Dietitians use current medical evidence to give specific advice to people with eating or weight problems as well as advice on healthy eating in general. Your doctor or nurse can refer you to an NHS dietitian (MACMILLAN, 2014i).

Dietary supplements

We need nutrients such as vitamins, minerals and essential fatty acids for our bodies to work properly. The best way to get these is by eating a healthy diet. However, some people with cancer aren't able to get all the nutrients they need from their diet. This may be because of problems with eating or because their bodies aren't able to absorb the nutrients.

If you're concerned about your diet or nutrition, ask your doctor or nurse to refer you to a dietitian. They can give you advice on what to eat and may prescribe nutritional supplements for you. If you aren't able to eat a healthy balanced diet, your doctor may prescribe a daily multivitamin and multi-mineral supplement. This will give you the recommended daily allowance (RDA) of the nutrients you need.

If you're thinking of taking dietary supplements, it's important to talk to your cancer doctor first.

Some people think that if something is good for you in small amounts, taking larger amounts is even better. But this isn't always the case. Nutrients, which are essential for our health in small amounts, can be harmful and cause unpleasant side-effects when taken in large amounts. And some may interact with, or lessen the effectiveness of, cancer treatments.

Despite a lot of research into cancer and dietary supplements, there isn't enough evidence to suggest that taking them can help treat cancer or stop it from coming back. But, research has found that taking certain supplements could increase the risk of some cancers developing (MACMILLAN, 2014i).

Antioxidants Antioxidants such as vitamins A, C and E, coenzyme Q10 and selenium are some of the most commonly taken dietary supplements.

Antioxidants can help to prevent cell damage. Because of this, some doctors have concerns that taking antioxidant supplements during cancer treatment may make cancer treatment less effective. Your cancer doctor may recommend that you don't take antioxidant supplements during your treatment, unless it's as part of a clinical trial.

If you'd like to discuss dietary supplements and get more information, call us on 0808 808 00 00 (MACMILLAN, 2014i).

Psychological and self-help therapies

Having someone to speak to, outside your circle of family and friends, can be a much needed source of support. Speaking to a counsellor or psychologist can help you explore confusing or upsetting emotions.

Group therapy or self-help groups, also give you the opportunity to share your thoughts and feelings. They can also be a good way of finding out how other people affected by cancer coped with their situations.

Sometimes negative thoughts and feelings can affect your everyday activities and behaviour. Therapies such as mindfulness meditation and cognitive behavioural therapy aim to help you break cycles of negative thought. Therapists use techniques that aim to change your thought patterns to be more positive.

Sharing your experience of cancer with other people may greatly benefit you. Hearing your thoughts, feelings and advice can also be a great help to someone in a similar situation. We can help you share your story when you join our Cancer Voices Network (MACMILLAN, 2014v).

What are psychological therapies?

There are several ways to get self help and psychological support. These approaches may be used to help people cope with stress, anxiety and difficult feelings.

You may find that it helps to talk openly and honestly with your family and friends. The healthcare professionals caring for you, who know your situation, can also be a good source of support. You can ask your doctor to put you in touch with the psychological support services at your hospital.

We have more information on the benefits of talking about your illness. Your relatives, friends and carers may find our information on how to talk to someone with cancer useful when they're supporting you (MACMILLAN, 2014v).

Counselling

Many people can get support by talking to close family members or friends. But you may find certain feelings very hard to share with them. It can sometimes be useful to talk to someone from outside your circle of family and friends, who has been trained to listen. Counsellors and psychologists can help you explore your feelings and talk through confusing or upsetting emotions.

Talking one-to-one with a trained counsellor or psychologist can help you find ways of coping with difficult feelings. Some GPs have counsellors within their practice, or they can refer you to a counsellor. Our cancer support specialists on 0808 808 00 00 can give you details of how to find counsellors in your local area (MACMILLAN, 2014v).

Mindfulness meditation

Mindfulness meditation is an approach that can help you change the way you think about different experiences. This can help to reduce stress and anxiety. It helps you to pay attention to the present moment using techniques such as meditation, breathing and yoga. You are encouraged to become aware of your thoughts and feelings, without making judgements about them.

Mindfulness-Based Cognitive Therapy (MBCT) and Mindfulness- Based Stress Reduction (MBSR) are both mindfulness techniques. They use meditation, yoga and breathing techniques along with some cognitive behavioural therapy (CBT) techniques. The aim is to help you change your thought patterns. Cognitive (thinking) therapy focuses on the 'here and now' difficulties. It looks for ways to change your current state of mind so that your thoughts are more positive.

There are a few centres in the UK that offer mindfulness classes on the NHS. They may also be available through your hospital (MACMILLAN, 2014v).

Group therapy

You may be offered the chance to take part in group therapy. This is when a trained therapist (counsellor or other professional) encourages a group of people to share their feelings and experiences with each other.

This is different from a self-help group. The therapist leading the group will be aware of the individual participants' problems and will be able to guide the discussion so that everyone benefits (MACMILLAN, 2014v).

Self-help groups

Organised groups, where people with cancer and their families meet others in a similar situation, can be helpful. This is often the first chance that people have to discuss their experiences with other people living with cancer.

These groups can be a source of information and support, and can provide an opportunity for people to talk about their feelings. Some groups are run by health professionals, doctors and nurses, counsellors or psychotherapists in a hospital. More commonly, people with cancer run the groups. They often offer different techniques and coping strategies, together with relaxation or visualisation. They can also be a good source of practical information and emotional support.

If you're interested in joining a group but are unsure about whether it would help, make some enquiries about it first. Or you could go to a meeting to see what it's like before joining. You may feel more comfortable if you take a relative or friend along with you. But if you feel it's not for you, you don't have to go again. You may find it more helpful and supportive to find someone you can speak with individually on a regular basis (MACMILLAN, 2014v).

Share your experience

Having cancer is a life-changing experience. When treatment finishes, many people find it helps to talk about it and share their thoughts, feelings and advice with other people. Just hearing about how you've coped, what side-effects you had and how you managed them is very helpful to someone in a similar situation.

We can help you share your story. Find more information about becoming a Cancer Voice (MACMILLAN, 2014v).

Physical therapies

Physical therapies aim to achieve feelings of well-being by working the body and mind. There are a number of therapies available to try.

Western medical acupuncture is based on current medical knowledge and evidence-based medicine. It is very similar to traditional acupuncture. This technique involves inserting sterile needles into certain ’trigger points’, just below the skin. This is thought to stimulate the nerves and cause the release of natural chemicals into the body.

Other mind and body physical therapies involve more physical techniques, such as yoga or Tai chi and qi gong. These therapies use gentle, controlled, low-impact movements combined with breathing exercises. They can be done by people of all ages and of varying levels of fitness.

It’s a good idea to speak to your doctor before using any complementary therapies (MACMILLAN, 2014t).

What are physical therapies?

Complementary therapies that work directly on your body, whether by a therapist or by yourself, are called physical therapies. They include acupuncture and mind/body physical therapies (MACMILLAN, 2014t).

Acupuncture

Acupuncture that has its origins in Traditional Chinese Medicine is based on there being a system of energy channels in the body.

Traditional therapists believe that needles inserted into the skin release the flow of energy and restore a healthy balance to the body. Traditional therapists are not registered health professionals. This section is about western medical acupuncture (MACMILLAN, 2014t).

Western medical acupuncture This is based on current medical knowledge and evidence-based medicine. It’s sometimes available within the NHS.

During an acupuncture session, the therapist inserts fine sterile needles just below the skin into certain ’trigger points’. The trigger points are specific places thought to affect the nerves in the skin and muscle. This can send messages to the brain. Stimulating the nerves in this way may release natural chemicals in the body such as endorphins. Endorphins are hormones that give you a feeling of well-being.

An acupuncturist may be a member of a team working in a pain clinic or part of a palliative care (symptom control) team. Some doctors, nurses and physiotherapists are trained in western medical acupuncture.

Some studies show acupuncture has helped reduce sickness in people who have had surgery or chemotherapy. There is also some evidence that acupuncture may help reduce pain in people with cancer, but more research is needed.

There's some evidence that acupuncture may help in treating other problems such as breathlessness and a dry mouth. Acupuncture is also sometimes used to treat menopausal symptoms, but it's not yet clear how effective it is for this.

In general, when carried out by a trained professional, acupuncture is safe and side-effects or complications are rare.

It's not advisable to have acupuncture if you are having treatment, such as chemotherapy, that could affect your blood count. This may result in a lower than normal number of white blood cells, which increases your risk of infection. You should also avoid acupuncture if you have a lower than normal number of platelets (blood cells that help blood to clot). This can increase your risk of bleeding.

If you have, or are at risk of, lymphoedema, you should avoid having acupuncture in the limb that's affected or at risk. Lymphoedema is swelling to part of the body caused by damage to the lymphatic system. Check with your doctor if you're thinking about having acupuncture (MACMILLAN, 2014t).

Mind/body physical therapies

Some types of physical activity, such as yoga, tai chi and qi gong, are designed to work both the body and the mind. In general, they use gentle, controlled, low-impact movements combined with breathing exercises. They can be done by people of all ages and of varying levels of fitness (MACMILLAN, 2014t).

Yoga

There are different types of yoga. They all involve positioning your body in different ways, breathing exercises and some form of meditation or relaxation.

Some types of yoga use very gentle stretching, movement and meditation. Others may involve more vigorous physical movement and dietary changes.

Yoga is generally safe, but people with some types of cancer may need to adapt some of the positions so they're easier to do.

Some people who have cancer find that yoga helps them cope with their illness and feel better generally. A recent study found that people who followed a four-week yoga course after they completed their cancer treatment had fewer problems sleeping and felt less fatigued.

Some small studies have shown that yoga may also be useful in relieving menopausal symptoms such as hot flushes and joint pains, but more research is needed. Some hospitals offer yoga classes. We have more information on how to find a yoga class near you (MACMILLAN, 2014t).

Tai Chi and Qi Gong

Tai chi and qi gong (sometimes spelt 'chi kung') come from Chinese medical traditions. They include parts of mind-body therapies, energy-based therapies and physical therapies.

Both tai chi and qi gong focus on building strength, balance and flexibility through slow, fluid movements. They also use mental imagery and deep breathing.

Together, the physical and mental exercises can help to improve general health and create a feeling of well-being.

You can get more information about tai chi or qi gong from complementary therapy organisations (MACMILLAN, 2014t).

Therapies using herb and plant extracts

Therapies using herbs and plants can be available as a tea or taken as a tablet, cream or ointment. Some common therapies that use herb and plant extracts include -

- Aromatherapy uses natural oils extracted from plants.
- Flower remedies use the essence of flowers.
- Homeopathy uses plant and mineral extracts diluted many times.
- Herbal medicines use plants or mixtures of plant extracts (MACMILLAN, 2014x).

Although plants and herbs are natural, this doesn't always mean they are safe. Some herbs can interfere with cancer treatments by making them less effective or by increasing side-effects.

Always tell your doctor if you are using herb and plant therapies and let your therapist know that you have cancer. Many doctors advise that herbal medicines should be avoided during, and for a few weeks before and after, treatment with chemotherapy or radiotherapy (MACMILLAN, 2014x).

Choosing a therapy that uses herb and plant extracts

Therapies using herbs and plants are widely available in supermarkets, chemists, health food shops, on the internet and from nutritionists, herbalists and homeopaths. They are mainly taken by mouth but can also come as oils and creams.

Flower, plant or herb therapies have no effect on cancer. There is no medical evidence to show that flower, plant or herb therapies help or treat cancer symptoms or side-effects of treatment. But some people feel that they help (MACMILLAN, 2014x).

Aromatherapy

Aromatherapy is the use of natural oils extracted from plants. The oils are thought to be beneficial to your body and mind. They may be used during massage but can also be used in baths and creams, and through diffusers.

You don't always have to remove clothing to have massage or aromatherapy. Having your hand, forearm or head and neck massaged can be very relaxing. Different oils are thought to have different effects.

There is no medical evidence to show that aromatherapy helps with the symptoms of cancer or side-effects of treatment. But many people find it a relaxing and enjoyable experience.

It's important to tell the aromatherapist about any medicines you are taking and give them all your medical details. They use very low-strength oils for people with cancer. But some oils can have physical effects on the body and, for example, may affect blood pressure. Also some oils can have oestrogen-like effects. You should avoid these oils if you have an oestrogen-dependent cancer, which includes some types of breast cancer.

If you are having any type of cancer treatment, always check with your cancer doctor first before you have aromatherapy. Usually it's fine to have aromatherapy and massage during radiotherapy as long as it's not used on the area being treated.

For more detailed information about aromatherapy and to find a trained therapist, contact the Aromatherapy Council (MACMILLAN, 2014x).

Flower remedies

Flower remedies use the essence of flowers diluted many times. You take the remedy as a liquid. They are considered to be safe and some people feel they help reduce anxiety and help them feel better. But no medical evidence has shown this to be true.

Different types of flower remedies are available. You can buy them from health food shops and some chemists.

Flower remedies are often diluted in alcohol, so people who don't drink alcohol may choose not to use them (MACMILLAN, 2014x).

Homeopathy

Homeopathy is used for a number of illnesses. It may be taken with conventional treatment to try to improve the quality of life for people with cancer. There's no reliable medical evidence that homeopathy is effective.

Homeopathy is based on the idea that 'like cures like'. The theory is that some homeopathic medicines cause similar symptoms to the illness being treated, and this triggers the body's natural reaction. So therapists use tiny amounts that cause symptoms similar to those you are already having.

Homeopathic remedies are mostly made of plant and mineral extracts. They come as tablets, liquids or creams, in a very diluted form.

Homeopaths use their remedies to try to relieve symptoms caused by cancer or side-effects of cancer treatments. They're also used to help general well-being.

Some GPs and hospital doctors are trained in homeopathy, and it's sometimes available through the NHS. If you're interested in this type of therapy, you can discuss it with your GP or your cancer doctor.

Homeopathy is safe to use alongside conventional cancer treatments because the remedies are extremely diluted.

There's no evidence that it causes harm (MACMILLAN, 2014x).

Mistletoe (Iscador®, Eurixor®) Mistletoe comes from a group of therapies called anthroposophical medicine. These therapies aim to combine conventional medicine with complementary therapies, including homeopathy and physical therapies.

Mistletoe can be taken by mouth or as injections. It may be given by homeopaths and is sometimes described as a herbal or homeopathic remedy (MACMILLAN, 2014x).

There's no reliable medical evidence that mistletoe is effective in treating cancer. It's claimed that mistletoe may have various effects, which include -

- stimulating the immune system,
- improving the quality of life of people with cancer,
- reducing side-effects of chemotherapy and radiotherapy (MACMILLAN, 2014x).

In general, mistletoe therapy appears to be safe and any side-effects are usually mild.

If mistletoe is taken in large doses, it may cause more serious side-effects. When given as an injection, mistletoe may cause mild swelling, redness, itching and pain around the injection site. Rarely it can cause allergic reactions, which may be serious in some people.

Because mistletoe extracts may stimulate the immune system, they could reduce the effectiveness of some medicines. This includes immunosuppressants, which people take after a donor stem cell or bone marrow transplant. It's important to check with your cancer doctor before using mistletoe extracts (MACMILLAN, 2014x).

Herbal remedies

Herbal remedies use plants or mixtures of plant extracts to treat illness and promote health. Practitioners of Chinese medicine also use herbs as part of Traditional Chinese Medicine. Herbs may be boiled in water and drunk as a tea, mixed in an alcohol solution, or be made into tablets, creams or ointments.

Some herb and plant extracts have been researched in clinical trials, and have been shown to help with certain symptoms or side-effects. Others have been shown to have no effect (MACMILLAN, 2014x).

Commonly used herbs include -

- ginger - used to relieve feelings of sickness (nausea),
- St John's Wort - used to treat a low mood and mild to moderate depression (MACMILLAN, 2014x).

Although plants and herbs are natural, this doesn't automatically mean they are safe. Natural substances can have powerful effects and cause side-effects. Some conventional treatments are made from plant extracts. So, if you choose to take herbal remedies, it's important to use them safely. You need to be aware of any side-effects they may cause.

If you take or are interested in trying herbal remedies, talk to your cancer doctor. They need to know all the medicines you're taking, whether they're prescribed or not, to help them give you the best possible care (MACMILLAN, 2014x).

Taking herbs during cancer treatment

Although we know about some interactions between herbs and cancer treatments, a herbal supplement may have dozens of compounds. All of its active ingredients may not be known. So it's often not possible to know the effects of herbs and possible interactions with other medicines or treatments. Many doctors advise that herbal medicines should be avoided during, and for a few weeks before and after, treatment with chemotherapy or radiotherapy (MACMILLAN, 2014x).

Some herbs can interfere with cancer treatments by making them less effective or by increasing side-effects. For example -

- St John's Wort can reduce the effectiveness of the chemotherapy drug irinotecan.
- Drinking green tea may make the cancer medicine bortezomib (Velcade®) less effective.
- Green tea can also increase the side-effects caused by the chemotherapy drug irinotecan and by the hormonal therapy tamoxifen.
- Garlic and evening primrose oil may affect blood clotting and should be avoided before surgery (MACMILLAN, 2014x).

Some herbs and dietary supplements can interfere with cancer treatments by making them more toxic or less effective. It's important to check with your cancer doctor if you're planning to use herbal remedies or take supplements during, and for a few weeks before and after, cancer treatment.

The Memorial Sloan Kettering Cancer Center is a reliable website that can give you safety information about individual herbs. If you're seeing a herbalist, check that they are registered with an accredited body (MACMILLAN, 2014x).

Do Feelings Affect Cancer?

Many people who are considering using complementary therapies wonder if there is a link between cancer and psychological factors, such as emotions and stress.

Here, we go through some of the questions people have asked and the research that's been done around feelings and cancer (MACMILLAN, 2014x).

Are people with particular personality types more likely to get cancer?

Some people believe that people with certain personality types are more likely to get cancer. Others think that personality may affect how long someone with cancer will live for, or whether they may die from cancer.

One large study has shown no medical evidence that people with certain personality types are more likely to get cancer. The same study showed that personality had no effect on the outcome of those who already have cancer (MACMILLAN, 2014x).

Can stress cause cancer?

Some people believe that their cancer was caused by stress. The stress may have been caused by a traumatic event, or being exposed to stressful situations over a long period of time. It's very difficult to research whether stress can cause cancer. This is because everyone reacts differently to stress.

Stress may increase our risk of cancer because at difficult times in life, some people may start unhealthy behaviours. This can include smoking or drinking too much alcohol. Studies currently show that stress can result in slight changes to the body's immune system. But there's no evidence this causes cancer or affects its growth (MACMILLAN, 2014x).

Can attitude affect cancer?

Some people feel that a positive attitude helps when coping with cancer and its treatments. But a positive attitude means different things to different people - it doesn't mean you have to be cheerful all the time.

Cancer can make people feel helpless and too tired to be positive and 'fight' the cancer. This doesn't mean that their attitude lowers their chance of a good outcome from treatment.

It's important to talk to your doctor or nurse if you feel anxious or depressed. There's help available for your emotional, as well as your physical, well-being. Trying to be positive shouldn't become a burden. Very few people are optimistic all the time, and it's natural and understandable to feel down sometimes (MACMILLAN, 2014x).

Can changing my attitude and level of stress help?

Anything that helps you cope in your own way is valuable. Many of the ideas behind complementary therapies suggest that a change of attitude can affect the outlook. But it would be difficult for medical evidence to show whether a change of attitude alone can help with cancer, symptoms or side-effects. But many people find complementary therapies helpful, and they can contribute to a sense of well-being and better quality of life (MACMILLAN, 2014x).

Eating problems

Many people experience eating problems during or after cancer treatment.

Some eating problems, such as a poor appetite or weight loss, may have been symptoms which led to your diagnosis. Some eating problems may be due to the location of the cancer in your body, causing you to feel sick or have poor digestion. Your doctor may try to improve your food intake before treatment starts.

Eating problems can be caused by some cancer treatments. These can be temporary, but sometimes last longer. If you have treatment to your mouth, throat, stomach or intestine, it will take time to return to a regular eating pattern. Treatment such as radiotherapy to the head and neck area may cause a dry mouth and difficulty swallowing. Chemotherapy and targeted therapies can cause sickness, diarrhoea or constipation, taste changes and soreness to your mouth. You could also be at risk of an infection after cancer treatment and your doctor may suggest avoiding foods with harmful bacteria.

Your doctor can refer you to a dietician who will assess your food needs and advise you on which foods are best for you (MACMILLAN, 2014k).

Being diagnosed with cancer

Everyone's nutritional needs will be different when diagnosed with cancer. Some people will feel well and be able to eat normally. For others, weight loss or a poor appetite may have been symptoms that led to their diagnosis. If you had eating problems before you were diagnosed, you may need some support from your doctor or dietitian. They will try to improve your food intake before you start treatment.

Some eating problems may be related to the cancer itself. Depending on where the tumour is in your body, it can make you feel sick (nausea), be sick (vomit), or it can cause pain or poor digestion. The tumour may also change the way your body uses the food you do eat, so that you don't get all the nutrients you should (MACMILLAN, 2014k).

Cancer treatments and eating problems

Some cancer treatments can cause eating problems. Some problems are temporary and improve when you finish treatment. Others may last longer (MACMILLAN, 2014k).

Surgery

In the short-term, surgery can slow down your digestion. If you have surgery to your mouth, throat, stomach or intestine, it can take some time for you to return to a more regular eating pattern (MACMILLAN, 2014k).

Radiotherapy

Radiotherapy to your head, neck or chest area can cause taste changes, swallowing difficulties, a dry mouth and a very sore mouth and throat. Radiotherapy to the tummy (abdomen) or pelvic areas can make you feel sick (nauseous), or be sick (vomit), or it can cause diarrhoea (MACMILLAN, 2014k).

Chemotherapy

Common side-effects of some chemotherapy treatments can include loss of appetite, taste changes, constipation, diarrhoea, feeling sick or being sick and a sore mouth (MACMILLAN, 2014k).

Targeted (biological) therapy

This can affect your appetite or your ability to eat. Problems might include taste changes, a dry or sore mouth and feeling sick (MACMILLAN, 2014k).

Risk of infection

A possible side-effect of cancer treatment is an increased risk of infection. This is mainly a side-effect of chemotherapy. It happens because the treatment can temporarily lower the number of white blood cells in your body, which help to fight infection. When the number of white blood cells is low, it's called neutropenia.

Most people having chemotherapy will not need to change their diet. If you are on high-dose chemotherapy, you may be advised to avoid foods that contain harmful bacteria and be careful with food hygiene. This is called a 'clean diet' and it can help to reduce your risk of getting an infection. Your specialist nurse will discuss this with you (MACMILLAN, 2014k).

Dietitians

If you have any problems with your diet, you can ask your doctor at the hospital to refer you to a dietitian. In some hospitals, you can refer yourself. Contact the hospital's dietetic department for more information. If you're not in hospital, your GP can refer you to a community dietitian.

Qualified dietitians are experts in assessing the food needs of people who are ill. They can review your diet and look at any specialist dietary requirements you may have. They can advise you on which foods are best for you, and also whether any food supplements would be helpful (MACMILLAN, 2014k).

Other eating problems

Some people with cancer may have particular eating problems that are not covered here. For example -

- People with diabetes.
- People who have a colostomy or ileostomy.
- People who have had all or part of their stomach or bowel removed.
- People who have radiotherapy to their mouth or jaw (MACMILLAN, 2014k).

If this includes you, you may need to follow a specially designed diet. You can get advice about these diets from your doctor, specialist nurse or dietitian. There are also organisations that can help (MACMILLAN, 2014k).

If you have a sore or dry mouth

During your treatment for cancer your mouth may become dry or sore. Soreness or ulceration of the mouth is called mucositis and can be painful. Any damage to your mouth will usually be temporary and your mouth will get better over time.

Radiotherapy or chemotherapy may damage the saliva glands temporarily, so your mouth may become dry.

You can make small changes to the food and drinks you have to improve these side-effects. Drinking plenty of water or non-acidic fruit juices, such as peach nectar can help.

Other tips include - Adding ice to drinks and eating cold food, which is more soothing than hot drinks and food - keep your food moist with sauces and gravies - and cleaning your mouth with a soft brush.

If these changes don't help your symptoms, you can talk to your doctor about your mouth problems. They can prescribe mouthwashes, sprays or painkillers if needed (MACMILLAN, 2014k).

If you have a sore mouth

Soreness and ulceration of the lining of the mouth or throat is called mucositis and can be very painful. It can be caused by chemotherapy, targeted therapies, and radiotherapy to the head and neck. Damage to the cells lining the mouth or throat is usually temporary and most side-effects will go when treatment ends.

Your specialist nurse and doctor will talk to you about mouth care during treatment and they may examine your mouth from time to time. Tell them if your mouth is sore or if it getting worse (MACMILLAN, 2014k).

Tips to help keep your mouth healthy -

- Drink plenty of fluids, especially water. If you find that fresh fruit juices sting your mouth, try less acidic juices instead. For example, you could try peach or pear nectar and blackcurrant or rosehip syrup. Some pre-prepared drinks that taste like fruit juice may also be helpful. These are available from health food shops and some supermarkets. Try milk or milk-based drinks, such as malted drinks, milk shakes and hot chocolate.

- Cold foods and drinks may be more soothing. Try adding crushed ice to drinks and eating ice cream or soft milk jellies. Some people find sucking on ice soothing.
- Very hot or cold drinks may irritate your sore mouth so try having drinks that are lukewarm or at room temperature.
- Try drinking through a straw.
- Avoid salty or spicy food that may sting.
- Avoid rough-textured food, such as toast or raw vegetables, as they can scrape at sore areas.
- Keep your food moist with sauces and gravies.
- Tell your doctor if you have a sore mouth. They can prescribe soothing or antiseptic lotions or sprays for you. You may also need painkillers before mealtimes to help you with swallowing.
- Mouthwashes can be very soothing, but many available in chemists or shops may be too strong for you. Evidence shows that salt-water mouthwashes are just as effective at reducing soreness, or your doctor can prescribe an anaesthetic gel or mouthwash instead. Many hospitals have their own mouth care guidelines for people having chemotherapy or radiotherapy. Your doctor or specialist nurse will be able to advise you.
- Speak to your dentist about support during your cancer treatment. They may recommend high-fluoride or non-foaming toothpaste to help reduce soreness.
- Use a children's soft toothbrush to clean your teeth gently. Avoid toothpicks when cleaning your teeth.
- If you wear dentures, soak them in a denture-cleaning solution overnight and leave them out for as long as you can during the day to prevent them rubbing your gums. If you're having radiotherapy to the jaw area, you may be advised to keep your dentures in as much as possible during the day to help maintain the shape of your gums. However, if your mouth is very sore, it may be more comfortable to not wear your dentures (MACMILLAN, 2014k).

If you have a dry mouth

Radiotherapy to the head and neck area and some chemotherapy drugs can damage the saliva glands, and this may lead to a dry mouth (xerostomia).

Tips if you have a dry mouth -

- If your tongue is 'coated' it may make your food taste unpleasant and might put you off eating. You can clean your tongue with a bicarbonate of soda solution: use one teaspoon of bicarbonate of soda (available from your

chemist) dissolved in a pint (570mls) of warm water. Clean your tongue with a soft toothbrush, foamstick or gauze, dipped in the solution. Check with your clinical nurse specialist for further advice.
- Frequent drinks, even if you just take a few sips at a time, can help keep your mouth moist. You may find fizzy drinks the most refreshing. Keep a glass of water by your bedside and carry water with you whenever you go out.
- Try sucking ice cubes or lollies. You can make lollies by freezing fresh fruit juice in ice-cube trays or in special lolly containers with sticks.
- Keep your food moist with sauces and gravies.
- Avoid chocolate and pastry as they can stick to the roof of your mouth.
- Chewing gum can sometimes stimulate your saliva.
- Tell your doctor about your dry mouth. They can prescribe mouthwashes, lozenges, artificial saliva sprays or gels, if you think they will help.
- Use lip balm or petroleum jelly for dry lips, but do not use any balm on your lips during radiotherapy treatment - speak to your clinical nurse specialist or radiotherapy team about this (MACMILLAN, 2014k).

If you have changes in taste

Some people with cancer find that their taste changes, although this is usually temporary. They may no longer enjoy certain foods, find that all foods taste the same, taste very sweet or salty, or notice a metallic taste in their mouth. Occasionally, they can't taste anything at all (MACMILLAN, 2014k).

If your taste changes, here are some tips for making your food more enjoyable -

- Eat foods that you enjoy and ignore those that don't appeal to you, but try them again after a few weeks as your sense of taste may change again.
- Use seasonings, spices and herbs such as pepper, cumin or rosemary to flavour your cooking. However, if your mouth is sore, you may find that some spices and seasonings make it worse.
- Try marinating meat in fruit juices or wine, or cook it in strong sauces such as curry or sweet and sour.
- Cold meats may taste better served with pickle or chutney.
- Sharp-tasting foods like fresh fruit, fruit juices and bitter boiled sweets can be refreshing and leave a pleasant taste in your mouth.
- If you no longer like tea or coffee, try lemon tea, or perhaps an ice-cold fizzy drink such as lemonade.

- Some people find that cold foods taste better than hot foods. If your sense of taste or smell has changed, it can sometimes help to serve food at room temperature.
- Serve fish, chicken and egg dishes with sauces.
- Use plastic cutlery if you notice a metallic taste in your mouth (MACMILLAN, 2014k).

If you're too tired

Feeling very tired (fatigued) is a common side-effect of cancer treatment. It's often worse towards the end of a course of radiotherapy or chemotherapy and for some weeks after it's finished. You may find you're struggling to cook your meals and are even too tired to eat (MACMILLAN, 2014k).

These suggestions may help you -

- This is the time to use quick convenience foods such as frozen meals, tinned foods and ready meals. Remember though, to defrost frozen foods thoroughly and to cook all foods properly to avoid any risk of food poisoning. Read cooking instructions carefully and stick to them.
- Try to plan ahead. If you have a freezer, prepare food while you are feeling active and freeze it for when you're more tired. You could stock up on convenience foods or use a meal delivery company.
- This is also a good opportunity to give family and friends the chance to help by doing some shopping or cooking for you.
- If you really can't face eating, try a nourishing drink. You can make a smoothie by blending bananas, peaches, strawberries or other soft fruit (fresh or frozen) with fortified milk, fruit juice, ice cream or yoghurt in a liquidiser or blender. See our information on the build-diet for further advice. If needed, your doctor, nurse or dietitian can prescribe or recommend supplement drinks and puddings for you.
- If you feel you need more help at home with your cooking or eating, tell your GP or contact the dietitian at your hospital. They may be able to arrange for you to have meals delivered (meals on wheels) or someone to prepare food for you (MACMILLAN, 2014k).

If you have constipation

Constipation means that you're not able to open your bowels routinely and it can become difficult or painful for you to pass bowel motions. Some chemotherapy drugs, anti-sickness drugs and painkillers can cause constipation (MACMILLAN, 2014k).

Tips to help prevent or reduce constipation -

- Make sure you have plenty of fibre (roughage) in your diet. Good sources of fibre include - wholewheat breakfast cereals like Weetabix®, Shredded Wheat® or muesli; wholemeal bread and flour; brown rice; wholemeal pasta; and fresh fruit and vegetables.
- Make sure you drink plenty of fluids - both hot and cold drinks will help. Aim to drink at least two litres (3.5 pints) a day. This is particularly important if you increase the amount of fibre in your diet, as eating fibre without drinking enough fluids can make constipation worse.
- Popular natural remedies for constipation are prune juice, prunes and syrup of figs.
- Gentle exercise, such as walking, will help keep your bowels moving.
- If the constipation is due to medicines that you're taking, it may be possible to adjust the dose you take. You may need to take laxatives [24] as well. Talk to your doctor who can give you further advice (MACMILLAN, 2014k).

If you have cancer of the bowel, or you think that your bowel may be affected by your cancer treatment, always ask your doctor or specialist nurse for advice on dealing with constipation. A diet with lots of fibre in it may make your symptoms worse (MACMILLAN, 2014k).

If you have diarrhoea

Diarrhoea usually means that you need to pass more bowel motions in a day than is normal for you, and the stools you pass are looser than normal.

It can be caused by chemotherapy, radiotherapy, targeted therapies and surgery. The treatments can affect the healthy cells that line the digestive tract, which causes diarrhoea. Sometimes other medications, such as antibiotics, or an infection can also cause diarrhoea.

Diarrhoea can be a temporary, mild side-effect. But for some people, it can be severe and they will need to see a doctor to help manage it. Tell your doctor if you have diarrhoea or if it is getting worse. They can investigate the cause, and prescribe anti-diarrhoea medicines.

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[24] a type of medicine that can help you empty your bowels if you are having trouble going to the toilet

Sometimes diarrhoea can be severe and it's important to contact the hospital if this happens. If you have more than 4–6 episodes of diarrhoea a day, contact the hospital on the numbers you've been given and speak to a doctor or nurse (MACMILLAN, 2014k).

Some tips to help with diarrhoea -

- Make sure you drink plenty of liquid (up to two litres a day) to replace the fluid lost with the diarrhoea, but avoid alcohol and coffee.
- Eat small, frequent meals made from light foods such as dairy produce, white fish, poultry, well-cooked eggs, white bread, pasta or rice. Eat your meals slowly.
- Eat less fibre (cereals, raw fruits and vegetables) until the diarrhoea improves.
- Avoid greasy, fatty foods such as chips and beefburgers, and spicy foods like chilli peppers.
- Acidophilus or other bacteria found in live yoghurt or live yoghurt drinks may help ease diarrhoea caused by antibiotics. Antibiotics can kill off the healthy bacteria normally found in the bowel, but the bacteria found in live yoghurt may replace them. However, you should avoid live yoghurt while you're having chemotherapy or if your immunity is low (MACMILLAN, 2014k).

If your diarrhoea is caused by radiotherapy or chemotherapy, changing your diet is unlikely to help. It's important that you take the anti-diarrhoea medicines prescribed by your doctor. If you have diarrhoea after surgery for bowel cancer, discuss it with your doctor or specialist nurse before changing your diet (MACMILLAN, 2014k).

If you have wind

How to cope with wind

The amount of wind we produce depends on how healthy bacteria and digestive enzymes in our bowel combine with the foods we eat.

After radiotherapy, some people have more wind because their pelvic floor muscles are weaker. Pelvic radiotherapy may also cause an overgrowth of healthy bacteria in the small bowel, which can cause wind. Some types of bowel surgery may result in problems with wind. It can also be caused by constipation and some medicines. If you find the wind difficult to cope with, talk to your doctor or specialist nurse. If passing wind becomes painful, tell your doctor (MACMILLAN, 2014k).

Here are some helpful tips for coping with wind -

- Eat and drink slowly. Take small mouthfuls and chew your food well.
- Avoid food that you think gives you wind. Beans, pickles and fizzy drinks commonly cause problems.
- A popular natural remedy is to drink two teaspoons of peppermint water dissolved in a small cup of hot water. This can be sweetened with sugar.
- You could try taking charcoal tablets, which you can buy in the chemist.
- Gentle exercise, especially walking, can bring some relief.
- Try to ensure your bowels are opening regularly - wind can be a sign of constipation.
- Your GP can prescribe peppermint oil capsules that may help (MACMILLAN, 2014k).

And when walking still hasn't shifted it, I've used 'Windeze' which was very effective. They are chewable peppermint tablets and work quite quickly.

If you're feeling sick

Some types of chemotherapy, hormonal therapy and targeted therapy can make you feel sick. Nausea may be caused by radiotherapy to the brain, stomach, bowel or close to the liver. Other drugs, such as painkillers and antibiotics, and physical problems like constipation or liver damage, can also cause nausea.

There are very effective treatments to help prevent and control sickness. Your cancer specialist can prescribe anti-sickness (anti-emetic) drugs for you. Let them know if your anti-sickness drugs are not helping, as there are several different types you can take (MACMILLAN, 2014k).

If feeling sick is putting you off your food, these tips may help -

- Try eating dry food, such as toast or crackers, first thing in the morning before you get up.
- If the smell of cooking makes you feel sick, eat cold meals or food from the freezer that only needs heating up. However, remember to follow the cooking instructions to make sure it's properly cooked.
- If possible, let someone else do the cooking.
- Avoid greasy, fatty or fried foods.
- Try sitting by an open window so there's plenty of fresh air in the room while you eat.
- Sit at a table in an upright position when eating, and stay sitting for a short time after the meal.

- When you feel sick, start by eating light foods such as thin soups or egg custards. Gradually introduce small portions of your favourite foods, slowly building up to a more varied diet.
- Food or drink containing ginger can help reduce feelings of sickness. You could try crystallised ginger, ginger tea or ginger biscuits.
- Sipping a fizzy drink is a popular remedy for feeling sick. Try mineral water, ginger ale, lemonade or soda water, and sip it slowly through a straw.
- Try having drinks between meals rather than with your food.
- You could try wearing 'sea bands' (available from chemists) around your wrists. They use acupressure to help relieve nausea.
- Try to make sure you have regular bowel movements as constipation can make you feel sick (MACMILLAN, 2014k).

If you're having problems chewing or swallowing

Swallowing

Chemotherapy, and radiotherapy treatments for a head or neck cancer, can affect the cells in the lining of the throat, which can make it painful to chew or swallow. An infection in your mouth and throat can also make chewing and swallowing uncomfortable. A common mouth infection is thrush (candidiasis). It shows as white spots on your mouth and tongue, or your tongue and mouth lining become red and swollen. Thrush is treated with anti-fungal tablets. Some people are prescribed these tablets to prevent thrush.

Let your doctor or dietitian know if you're having any difficulties. If you find that drinks make you cough, you should tell your doctor or specialist nurse as soon as possible (MACMILLAN, 2014k).

- You may find that taking painkillers before mealtimes can help you chew and swallow more easily. Your doctor or nurse can advise you about this.
- Keep eating your favourite foods where possible, but make changes to soften them. For example, cover foods in interesting sauces and gravies; finely chop meat and vegetables then casserole or stew them; and cut the crusts off bread for softer sandwiches. If you have a blender, you could liquidise cooked foods.
- There are several balanced food supplements that you may find helpful, for example Build up® or Complan® drinks. You can buy these in your chemist or supermarket. Your doctor may give you a prescription for some of them (MACMILLAN, 2014k).

Appetite

Poor appetite

During cancer treatment you may lose your appetite because you feel sick, too tired or because things taste different. These suggestions may help you -

- If you can't face big meals, eat small, frequent meals or snacks instead of three meals a day. If you find certain times of the day are better for you, make the most of these.
- Try to make your food look as attractive as possible. Put small portions on your plate and garnish the food with lemon, tomato or parsley.
- Stimulate your appetite with a small sherry or brandy half an hour before you eat. Some people find a glass of wine with their meals helps their digestion. Check with your doctor that you can have alcohol.
- Keep snacks handy to eat whenever you can. Bags of nuts or crisps, dried fruit or a bowl of grated cheese are quite light and tasty. If these are hard for you to swallow, a yoghurt or fromage frais may be easier. If you've recently had surgery or radiotherapy for Bowel cancer you may need advice about the best foods for you. Discuss this with your specialist nurse, doctor or a dietitian.
- Sweet or savoury nourishing drinks can be used to replace small meals and can be sipped slowly through the day (see our information on the building-up diet).
- Eat your meals slowly, chew the food well and relax for a little while after each meal.
- Sometimes the smell of cooking can be appetising, but occasionally it can put you off eating. If cooking smells spoil your appetite, keep away from the kitchen and ask your family or friends to cook. Or try to eat cold foods that don't need cooking.
- Everyone's appetite changes and you may have good and bad days. Make the most of the good days by eating well and treating yourself to your favourite foods.
- Try to eat your meals in a room where you feel relaxed and where there aren't any distractions.
- It may be possible to stimulate your appetite using medicines such as a low dose of steroids or the hormone medroxyprogesterone. Your doctor may prescribe these for you (MACMILLAN, 2014k).

Big appetite due to medicines

Some medicines, such as steroids, may give you a big appetite and might make you want to eat much more than usual. It's important to try to eat healthy foods such as fruit and vegetables instead of sweets and crisps so you don't put on too much weight (MACMILLAN, 2014k).

If you have heartburn or indigestion

Heartburn is a burning sensation behind the breastbone that can be very painful. It's caused when acid from the stomach irritates the lining of the gullet (oesophagus).

Indigestion is discomfort in the upper part of the tummy (abdomen), occurring particularly after meals. It can happen when stomach acid irritates the lining of the stomach or small bowel. Some drugs (such as steroids or anti-inflammatory painkillers) and some cancer treatments (such as chemotherapy) can also irritate the stomach lining. You may get indigestion if you have a small stomach capacity, don't eat or drink much or if you don't move around very much.

The best way of dealing with heartburn and indigestion depends on its cause. Talk to your doctor as they can often prescribe medicines to help reduce or relieve it for you (MACMILLAN, 2014k).

Here are some tips for coping with heartburn and indigestion -

- Take note of any foods that cause discomfort so you can avoid them. When symptoms have settled, you can try reintroducing them in small quantities one at a time. This makes sure that you are not missing out on vital nutrients.
- Large meals, chocolate, alcohol, fatty and spicy foods, fizzy drinks, chewing gum, hard-boiled sweets, mint, aniseed and dill are all known to commonly cause problems. You may want to limit or avoid these.
- Wear loose clothing around your waist.
- Limit activity for at least 45–60 minutes after eating.
- Antacid medicines can help relieve irritation by neutralising the acid. You can buy them over the counter at your local pharmacy.
- If you smoke, stop or cut down as the chemicals in cigarette smoke may make indigestion worse.
- Try not to lie flat on your back, especially after meals.
- If you get a lot of indigestion at night, avoid eating for 3–4 hours before you go to bed and sleep propped up on pillows.
- Try to achieve and maintain a healthy weight (MACMILLAN, 2014k).

Coping with eating problems

Your feelings about eating problems

You may worry that changes in your eating pattern will affect your relationships with your partner, family and friends. You may be anxious about what people think of you or about being rejected. Or you may feel self-conscious about eating at home or out with family or friends.

Many people find that it helps to talk to someone close to them. If you find it difficult to talk about your feelings with your family, you could speak to your doctor or specialist nurse (MACMILLAN, 2014k).

Getting help with meals

You may not always feel well enough to be able to cook food for yourself or others. If you're the person who usually prepares the meals for your family, it may feel strange to let someone else take charge. Try not to feel guilty about letting someone else do the things you usually do. When you feel better, you can get back into your normal routine.

If you live on your own and need help with cooking or shopping, contact your GP, district nurse or social worker. They may be able to arrange for a home helper, meals on wheels or a local organisation to help you with cooking or shopping (MACMILLAN, 2014k).

Caring for someone with eating problems

If you're the main carer for someone with cancer, it can be upsetting and difficult to know how to deal with the eating problems their cancer or treatments have caused. Mealtimes are often an enjoyable and important part of family and social life. It can be frustrating and worrying when someone you're caring for can't eat very much.

People who are very ill often don't feel like eating. Cancer treatments and medicines can all affect their appetite. Feeling sick and having diarrhoea or constipation can stop them eating. They may feel too tired to eat, have a sore or dry throat or mouth, or find chewing and swallowing difficult. The amount they can eat may change from day to day and their likes and dislikes may also alter (MACMILLAN, 2014k).

Suggestions for carers about coping with food preparation and mealtimes -

- Take time to ask them what they'd like to eat.
- Try to talk openly about their eating problems and the different ways you could both manage it. This can help you both feel more in control of the situation.
- Try to give small meals often, whenever the person feels like eating, rather than at set times of the day.
- Treat them to their favourite foods at the times when you know their appetite is at its best.
- Keep a range of different foods so that you can offer them something at any time of the day. Tinned foods and pre-prepared frozen meals can be as good for them as a meal that takes a long time to prepare.
- If they can't manage solid food, try soft foods such as porridge, bananas, soup, yoghurt or milk-based foods like custard or rice pudding.
- Moist food is often easier to cope with, and will help to prevent a dry mouth.
- If someone's sense of taste or smell has changed, it can sometimes help to serve food cold or at room temperature.
- Use plastic cutlery if the person affected by cancer notices a metallic taste in their mouth.
- If the person you're caring for finds that certain cooking smells make them feel sick, prepare food in a different room if possible. Serve food in a well-ventilated room.
- Be aware of how energy supplements can be used to add energy to everyday meals and drinks. For example, you could try adding fortified milk to tea or coffee (see our information on the building-up diet).
- Try not to worry if they can't always eat what you've cooked. And don't urge or nag them much, as this can be unhelpful.
- Take special care while preparing food when the person you care for may be at risk of infections. The doctors or dietitian at the hospital will be able to advise you about this.
- Make sure you have support and take time to care for yourself (MACMILLAN, 2014k).

Nutritional support/artificial feeding and cancer

Cancer, or the effects of cancer treatments, can sometimes result in malnutrition and weight loss.

Malnutrition is when the body isn't getting enough vitamins, minerals and other nutrients to keep it healthy. This may be because you have a reduced Appetite or difficulty Swallowing.

These problems may only happen for a short time. Changes to your diet or supplementing it with nutritious drinks is sometimes all you need. However, for some people this won't be enough to keep their weight up, or they may be unable to swallow or have difficulty doing so.

If you aren't able to eat or drink enough to maintain your weight, your doctors or dietitian may advise that you have nutritional support (artificial feeding). This can seem overwhelming at first. However, there are many advantages to having nutritional support, which usually helps people overcome their worries (MACMILLAN, 2014k).

Nutritional support is used to help people who aren't able to eat or drink in the usual way. It can -

- prevent weight loss,
- help people who need to put on weight,
- help to overcome weakness or tiredness,
- make sure that people are getting enough liquid,
- ease the pressure of having to eat - for example, if people have problems swallowing and find it difficult to eat (MACMILLAN, 2014k).

Why nutritional support is used

Generally, nutritional support is needed if a person -

- has difficulty swallowing - for example due to cancer of the throat or gullet, or because of a sore mouth due to radiotherapy,
- has unintentional weight loss (usually 10% or more of their body weight) that is not helped by dietary supplements,
- has been unable to eat or drink enough, and dietary supplements haven't helped (MACMILLAN, 2014k).

Types of nutritional support

There are two main types of feeding system -

- Enteral nutrition (EN),
- Parenteral nutrition (PN) (MACMILLAN, 2014k).

Enteral nutrition (EN) is when nutritional fluid is given through a tube going into the stomach or small intestine. It may be given when the digestive system is working well, but you have problems eating enough.

If you only need nutritional support for a short time, the tube may be passed through the nose down into the stomach. If nutritional support is likely to be needed for more than a few weeks, a tube is passed through the skin and muscle of your abdomen straight into the stomach or small bowel.

Parenteral nutrition (PN) is giving nutrients and fluid directly into the bloodstream through a tube going into a vein in the neck, chest or arm. It is sometimes called total parenteral nutrition. It is usually only used for short periods of time.

There are some other types of feeding options. Your doctor will decide which feeding system is best for you based on your individual circumstances (MACMILLAN, 2014k).

Types of nutritional support

Two main types of feeding system are used, known as enteral nutrition (EN) and parenteral nutrition (PN). The type of nutritional support you have depends on a number of factors (MACMILLAN, 2014k).

Enteral nutrition (EN) This is where the nutritional fluid is given into the gut through a tube going into the stomach, or small intestine. There are different ways of giving EN.

EN is best for you if your digestive system is working normally, but you aren't able to eat enough - for example, because of a cancer in the head or neck area (MACMILLAN, 2014k).

Parenteral nutrition (PN) This is where the nutritional fluid is given through a tube that is put into a vein (intravenously). PN aims to provide nutritional support when it isn't possible to take nutrients through your digestive system.

PN is usually used if people are unable to have EN. This may be due to major surgery on the small bowel, a bowel obstruction or a difficulty with inserting the tubes used for EN. Difficulty with inserting EN tubes may happen after some types of surgery to the head, neck or stomach (MACMILLAN, 2014k).

Enteral nutrition (EN)

There are several ways of giving EN. The most common methods used are -

- nasogastric (NG) feeding - a thin tube is passed down the nose and into the stomach

- percutaneous endoscopic gastrostomy (PEG) and radiologically inserted gastrostomy (RIG) feeding - a tube is passed through the skin and muscle of the abdomen into the stomach,
- percutaneous endoscopic jejunostomy (PEJ) feeding - a tube is passed through the skin and muscle of the abdomen into the middle of the small bowel (the jejunum) just below the stomach (MACMILLAN, 2014k).

Nutritional support through a NG or PEG and RIG feeding is often used after surgery to the head, neck, stomach or gullet (oesophagus) (MACMILLAN, 2014k).

Nasogastric (NG) feeding

Nasogastric feeding is usually recommended if you're likely to need nutritional support for only a short time. NG feeding may also be used for people having radiotherapy to the mouth, throat or gullet, if swallowing becomes difficult because of swelling from the treatment (MACMILLAN, 2014k).

How an NG tube is put in You will need to be in a comfortable position, sitting upright. A thin, flexible tube is gently inserted into your nostril, down the back of the throat, down the gullet (oesophagus) and into your stomach. It's important that the person inserting the NG tube checks it is correctly positioned in your stomach.

This is done by drawing some fluid out from the tube using a syringe. As stomach fluid is very acidic, fluid drawn out from the tube is tested for acidity with a pH indicator to show whether or not the tube is in the stomach. Sometimes an X-ray may be necessary to make sure that the tube is correctly placed in the stomach.

Once the tube is correctly positioned, it will be taped to your nose or cheek to keep it in place.

Your dietitian will work out how much liquid food you need to have each day. The hospital staff will give you this through the tube. If you're at home, the liquid food can be prescribed by your GP, who will ask your local pharmacy to supply it for you. You or your carer will be shown how to give the liquid food. A district nurse will also visit you.

Other fluids, such as liquid medicines, can be given through the tube. Medicines can block the tube if they aren't diluted properly and flushed through with plenty of liquid. Your dietitian, doctor, nurses or pharmacist can advise you about which medicines can be given through the tube. They can also show you how to give them properly (MACMILLAN, 2014k).

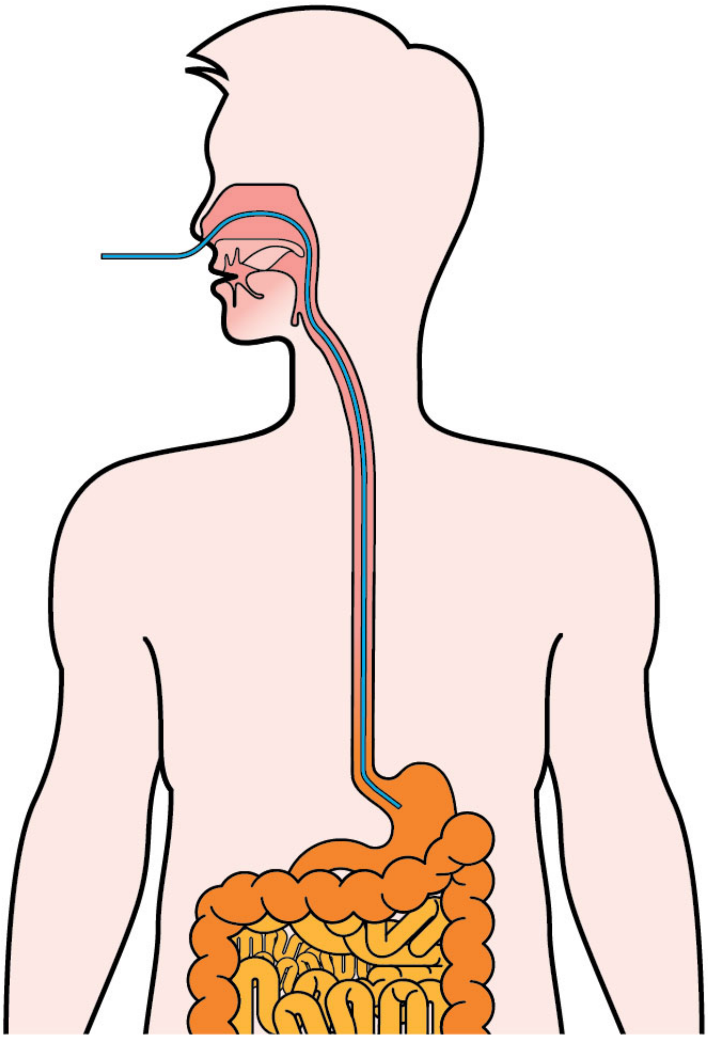

Figure 5.1: The positioning of a nasogastric tube

Possible problems with NG feeding There can be disadvantages and possible complications with any type of nutritional support. With NG feeding these are -

- You may find the insertion of an NG tube uncomfortable and possibly quite distressing. The procedure is usually completed very quickly, although sometimes it can take more than one attempt to get the tube into the right place.
- As the end of the tube comes out through the nostril and is taped to the face, it is obviously visible. You may find this embarrassing and feel self-conscious about it.

- NG tubes can be pulled out of the stomach if they aren't fixed securely. Before each feed, the position of the tube needs to be checked. In hospital the nurses will do this or will show you how to do it. Normally, some fluid is drawn out of the tube and checked with a pH indicator. If you're at home, you, or your carer(s), will need to do this before each feed. Sometimes the tube may fall out completely and will then need to be replaced.
- Occasionally the tube may become dislodged. This can result in the tip of the tube entering the lungs. If checking the position of the tube indicates that it has become dislodged, it should be removed and replaced.
- NG tubes can sometimes become blocked. Water is flushed down the tube at regular intervals to try to prevent this from happening. However, if a blockage occurs and can't be cleared, the tube will need to be removed and a new one put in.
- An NG feed can be inconvenient, as the liquid food often needs to be given slowly into the tube over a number of hours. You won't be able to move around freely during this time. Some people prefer to have their feed given overnight so that they aren't restricted during the day. Your dietitian will talk to you about the best way of giving the feed, so that it doesn't interfere too much with your lifestyle. It may be possible to use a small portable pump to regulate the flow of the feed.
- If the feed is given too quickly it can flow up into the gullet, which can be very unpleasant and may make you feel sick. Medicines can be given to control this, so let your doctor know if this occurs (MACMILLAN, 2014k).

Percutaneous endoscopic gastrostomy (PEG) and radiologically inserted gastrostomy (RIG) feeding

Gastrostomy feeding is recommended if your digestive system is still working well but nutritional support is likely to be needed for more than a few weeks.

Gastrostomy feeding involves surgically creating an opening, known as a fistula, through the abdominal wall. A feeding tube is then passed through the opening and into the stomach.

The feeding tube is held in place with either a stitch, a small inflated balloon around the tube just under the skin, or a flange around the tube just under the skin (MACMILLAN, 2014k).

How a PEG is put in Before a PEG is put in, a doctor or specialist nurse will explain the procedure to you. You will be asked to sign a form saying that you agree (consent) to having the PEG put in, and that you understand why it is being done.

You'll need to have nothing to eat or drink for several hours before the procedure to make sure that your stomach is empty. Your doctor will also give you antibiotics to reduce your risk of getting an infection.

You'll be given a sedative to make you feel sleepy. A flexible tube with a light at the end (an endoscope) is passed into your mouth, down your gullet and then into the stomach. The stomach is inflated with air, and the endoscope is positioned so that the light at the end shines through the abdominal wall to show the position of the stomach.

The skin of the abdominal wall is then cleaned and a local anaesthetic is used to numb the area. A small cut is made through the skin and muscle through which a feeding tube is inserted into the stomach.

Once the tube is in place, the area around the tube (the tube site) is cleaned. A dressing isn't usually necessary unless there is leakage of fluid from the site. The area around the tube needs to be cleaned daily with soap and water and thoroughly dried. The tube needs to be flushed with 30ml of water before and after each feed.

It takes approximately three weeks for the skin to heal around the tube. During this time, you should avoid getting the area wet. It's fine to shower as long as the exit site is protected. It's also fine to wash, but you should avoid having a bath.

Your dietitian will discuss with you how much liquid food you need to have through the tube each day (MACMILLAN, 2014k).

How a RIG is put in A RIG is inserted in a similar way to a PEG, but X-ray scanning equipment is used to position it. An NG tube is inserted (as above). You will then have some local anaesthetic injected to numb an area on your abdomen before a small cut (incision) is made.

Some air is pumped down the NG tube and into the stomach that helps position the RIG tube accurately. The gastrostomy tube is then put directly into the stomach using X-ray guidance.

Once the gastrostomy tube is in place, some dye is flushed into it and an X-ray is taken to make sure it's in the right place. After this the NG tube can be removed. The RIG is held in place with stitches, which are removed about 10 days later (MACMILLAN, 2014k).

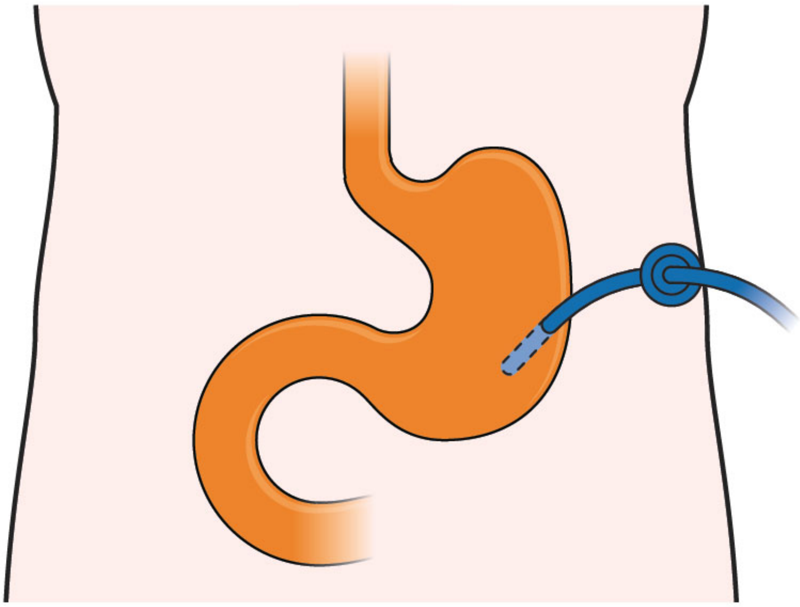

Figure 5.2: A percutaneous endoscopic gastrostomy tube

Benefit of PEG/RIG feeding PEGs and RIGs allow people who can't eat in the usual way to take in enough liquid food and fluids. These tubes can't be seen when people are wearing clothes, but a nasogastric (NG) tube can be (MACMILLAN, 2014k).

Possible problems with PEG/RIG feeding The most common complications with a PEG or RIG tube include -

- a blockage developing in the tube - flushing the tube before and after each feed reduces the chance of this happening,
- infection developing in the tissues around the site (MACMILLAN, 2014k).

It is important to tell your doctor as soon as possible if -

- the skin around the tube becomes red or swollen,
- you notice discoloured fluid coming from around the tube,
- you develop a high temperature or feel unwell (MACMILLAN, 2014k).

If the feed is given too quickly, some people may feel nausea or have a sensation of stomach contents flowing back up the gullet (reflux). Let your doctor know if this happens, as they can give you medicines to help.

As with NG feeding, the feed needs to be given slowly and this can restrict you from being able to move around freely. For this reason, many people prefer to have their feed overnight. Your dietitian can discuss your feeding with you, so that you can minimise the disruption to your daily life.

If you're at home, you should be given the name of a healthcare professional at the hospital so that you can contact them if you develop any problem with your PEG/RIG tube.

PEG/RIG tubes can stay in place for up to two years, but many people have them for much shorter periods. After this, they can be replaced if they are still needed (MACMILLAN, 2014k).

Percutaneous endoscopic jejunostomy (PEJ) feeding Some people may have a percutaneous endoscopic jejunostomy (PEJ), also called a jejunostomy tube. This procedure is similar to a PEG/RIG, but the tube is passed into the middle part of the small bowel (the jejunum) instead of the stomach. A jejunostomy tube may be inserted at the same time as surgery to the gullet or stomach.

The possible problems and care needs are the same as for PEG/RIG tubes. But a PEJ tube needs to be given more slowly, and the water put into the PEJ needs to be sterile, or boiled then cooled (MACMILLAN, 2014k).

Parenteral nutrition (PN)(or total parenteral nutrition) Parenteral nutrition (PN) means giving nutrients and fluid directly into the bloodstream. PN is sometimes referred to as TPN, which means total parenteral nutrition. However, as it is not always possible to provide total nutrition through the bloodstream, TPN is more commonly known as PN (MACMILLAN, 2014k).

How PN is given PN is usually given through a thin tube, which is inserted into a large vein in your neck or chest. The tube is known as a central line. Sometimes it is given through a thin tube in your arm that goes up into a vein in your chest. This is called a PICC line (peripherally inserted central catheter).

Occasionally, a vein in the arm may be used (like having an ordinary drip), but this is less common. It tends to be used if feeding is only necessary for a short period of time (fewer than 10 days) and if you're not on restricted fluids, as fluids need to be more diluted if an arm vein is used.

The doctors will take into account your individual circumstances and decide the best type of feeding for you (MACMILLAN, 2014k).

How the central or PICC line is put in Your central or PICC line will be put in at the hospital by a specially trained nurse or doctor. A central line is usually put in under a general anaesthetic, but sometimes a local anaesthetic may be used. A PICC line is put in using a local anaesthetic.

You will have an X-ray to make sure that the tube is in the right place. You shouldn't feel any pain when the tube is being put in, but you may feel a bit sore for a few days afterwards. A mild painkiller such as paracetamol will help ease this (MACMILLAN, 2014k).

Benefits of PN PN allows nutrition to be given even when the digestive tract isn't working. It can allow the digestive tract to rest so that it can heal - for example, after surgery to the stomach or bowel. It can also be used if you are experiencing severe vomiting or diarrhoea and cannot have enteral feeding (MACMILLAN, 2014k).

Possible problems with PN It's possible for an infection to develop either inside the line or around the exit site. You should tell your doctor if -

- the exit site becomes red or swollen,
- you notice discoloured fluid coming from it,
- you develop a temperature (MACMILLAN, 2014k).

You may be given antibiotics or, if the infection is serious, the tube may have to be removed.

It is possible for a blood clot (thrombosis) to form in your vein at the tip of the central line. If this happens, the tube may have to be removed. You may be given some anti-clotting medicines to prevent this from happening. The medicines are usually added to the feed.

You will have regular blood tests while having PN. This is to check that your levels of sugar, minerals and other substances are normal. PN can sometimes alter your blood sugar levels and you may need insulin to control your sugars if they are too high. Your feed will be specially prepared for you each day according to your blood levels and nutritional needs.

PN is usually started gradually. Your feed will be reduced over a few days when you no longer need it (MACMILLAN, 2014k).

Home feeding Many people can have their nutritional support at home. Having parenteral nutrition is more difficult to deal with than NG or PEG feeding. You may need to be referred to a specialist hospital to be shown how to manage the parenteral feeds at home.

The thought of having nutritional support at home may make you feel anxious. Before you're discharged from hospital, you will be given training in how to manage your particular feeding system. If you have a carer, or carers, they will be given training too.

Home nutritional support will not start until you, and your carer(s) if you have one, feel confident in dealing with the tube and the feeds.

A team of healthcare professionals will also help to support you at home. The support offered to people may vary, but your GP, district nurse and dietitian can help you.

Some NHS trusts work in partnership with specialist home-care companies to ensure that people who go from hospital care to home care receive the support and expertise they need (MACMILLAN, 2014k).

Your feelings Many people feel upset if they need nutritional support or cannot eat or drink as they normally would. You may find having enteral feeding such as an NG tube or a PEG affects how you feel about your body image. These are all normal reactions. It is part of the process many people go through in trying to come to terms with their condition.

Everyone has their own way of coping with difficult situations. It may be helpful to talk to your doctor, specialist nurse or dietitian about how you feel. Some people find it helpful to talk to family or friends, while others prefer to seek help from people outside their situation. Others may prefer to keep their feelings to themselves. There is no right or wrong way of coping, but help is available if you need it. You may wish to contact our cancer support specialists for information about counselling in your area (MACMILLAN, 2014k).

Useful organisations Patients on Intravenous and Nasogastric Nutrition Therapy (PINNT)

PINNT aims to support patients who need artificial nutrition therapy, and their carers, via the website and regional groups. It gives information on nutritional therapies, parenteral and enteral feeding, and has specific information for younger people (MACMILLAN, 2014k).

Pain

What is pain and what causes it?

Pain is an uncomfortable, unpleasant physical sensation. It happens when parts of the body are damaged. Around 5 in 10 people who have treatment for cancer (50%) have some pain.

How people feel and experience pain is very individual. Your pain may be different from someone else's who has had the same treatment or type of cancer as you. Remember, having more pain does not necessarily mean the cancer is worse or more advanced.

You may have pain for a number of reasons. Cancer treatments such as surgery, chemotherapy or radiotherapy can damage body tissue and sometimes nerves, causing you to feel pain. These are physical causes. Your emotions can also affect pain levels. For example, feelings of anxiety or depression may make pain worse. Social or work pressures can also exacerbate pain.

If you have pain, it can almost always be reduced. It's really important to let your doctor or nurse know as soon as you have pain. The earlier treatment is started for pain, the more effective it will be (MACMILLAN, 2013i).

About cancer pain

Up to 5 in 10 people who have treatment for cancer (50%) have some pain. When cancer has come back or spread, about 7 in 10 people (70%) have pain. If you have pain, it's important to tell your doctors and nurses so they can treat it.

Some people may not want to talk about their pain as they feel they are complaining. But the earlier treatment is given for pain, the more effective it is.

The way people feel and experience pain varies. Even people with the same type of cancer can have very different experiences. The amount of pain you have is not related to how severe your cancer is. And having pain doesn't always mean that the cancer is advanced or more serious. Pain doesn't always get worse as the cancer develops. It is important to remember that cancer pain can almost always be reduced (MACMILLAN, 2013i).

What is pain?

Pain is an uncomfortable, unpleasant physical sensation as well as an emotional experience. It happens when parts of the body are damaged. This damage irritates nerve endings, which then send a warning signal to the brain. The brain responds by making us feel pain or discomfort.

Pain is not only a physical sensation. Emotions can make the pain better or worse. If you're anxious, you may feel more pain, and if you're relaxed, you may feel less pain (MACMILLAN, 2013i).

Causes of pain

People with cancer may have pain for a number of reasons.

Physical causes The cancer may press on the tissues around it or on a nerve. Cancer treatments can also damage or injure tissues.

Surgery causes pain, as tissues are cut or damaged. Radiotherapy can also damage tissues. For example, radiotherapy can damage the skin in the area being treated. Chemotherapy can damage the soft tissues in the mouth, causing soreness. The pain usually goes away once the treatments are completed and the damaged tissues have healed.

Sometimes, surgery, radiotherapy and chemotherapy can damage nerves and lead to a type of pain known as neuropathic pain.

Pain isn't always due to cancer. Other health conditions, such as arthritis or diabetes, can cause pain.

If you develop a new ache or pain, or another new symptom, you may worry that the cancer has come back. Or you may think it is getting worse or has spread. These aren't necessarily the reasons for the pain.

It's always best to tell your doctor about any new pain or symptom, so you can get the right treatment. Usually, the earlier treatment is started the easier it is to control pain (MACMILLAN, 2013i).

Emotions and pain Sometimes, emotional stress such as anxiety, depression and tiredness can make your pain feel worse. This doesn't mean that cancer pain is completely due to your emotions. But it's important to get the right help, and this may mean treating emotional stress as well as the physical causes of your pain (MACMILLAN, 2013i).

Social effects on pain Sometimes, social or work pressures that cause stress can make pain worse. For example, not being able to see friends or not being able to work can affect pain levels (MACMILLAN, 2013i).

Different types of pain and how to describe it

There are different types of pain.

- **Acute** pain starts suddenly and is short-term.
- **Chronic** pain is felt over a longer period of time.
- **Neuropathic** (nerve) pain can come and go.
- **Visceral** pain is felt when organs or tissues are damaged.
- **Breakthrough** pain occurs in between regular, scheduled painkillers.
- **Total pain** includes the emotional, social and spiritual factors that also affect a person's pain experience (MACMILLAN, 2013i).

Pain does not feel the same for everyone. Describing your pain clearly will help your doctor or nurse find the best treatment. It's important to tell your healthcare team if you have pain. Try to explain to them where the pain is, what it is like (for example dull, sharp, burning), how bad it is and when you are in pain. It can also help to describe how the pain changes over time and what makes it better or worse.

Keeping a pain diary can help you explain your pain to your doctor or nurse, and it can help them plan the best treatment (MACMILLAN, 2013i).

Pain terms

Your doctors or nurses may talk about your pain in different ways. In this section, we explain the different types of pain you may hear about. We also give suggestions for how you might describe your pain to a doctor or nurse in order to help them treat it (MACMILLAN, 2013i).

Acute pain This is pain that starts suddenly and acts as a warning to the body.

It is always short-term. When the reason for the pain has been treated or the tissues have healed, the pain will disappear (MACMILLAN, 2013i).

Chronic pain This is felt over a longer period of time. It's usually caused by the cancer (tumour) itself. It can sometimes be caused by cancer treatments (MACMILLAN, 2013i).

Neuropathic (nerve) pain This is pain caused by nerve damage. It may be due to the cancer or cancer treatments. The pain can sometimes continue even when the cause has been treated.

Neuropathic pain can come and go. You may describe it using words such as burning, stabbing, shooting, tingling or radiating (spreading out). There are specific medicines and treatments that can help treat neuropathic pain (MACMILLAN, 2013i).

Visceral pain This is pain we feel when our organs or tissues are damaged, injured or inflamed. An example of visceral pain is when the liver becomes enlarged and causes pain and discomfort in the tummy (abdomen) (MACMILLAN, 2013i).

Breakthrough pain This is pain that occurs in between regular, scheduled painkillers. It may happen quite suddenly because of an activity, such as walking or coughing. It may happen when the effect of the regular painkiller wears off. Sometimes, it's not clear why someone has breakthrough pain (MACMILLAN, 2013i).

Total pain Total pain is not just physical pain. Pain can be caused, or made worse, by your emotions or things happening in your life.

Our emotions, behaviours, social activities and spiritual beliefs may all affect how we feel pain. Your healthcare team will consider these things when assessing your pain. Tell them about any worries you have, even if they are not about your illness.

If you have any of these types of pain, tell your healthcare team. They will be able to help control the pain with the right treatment (MACMILLAN, 2013i).

Talking about your pain

Talking about your pain and how you are feeling is very important. Some people think that they just have to accept pain, and that talking about it won't help. But there are ways of managing pain if you tell your healthcare team about it.

Being in pain that is not properly controlled will make you miserable and affect your everyday life. If you are in pain and upset, this will also affect your family. Tell your healthcare team how you are feeling. They can help manage your pain. Feeling less or no pain will help you do the things you want to do. It will also help you stay more positive and active (MACMILLAN, 2013i).

Different types of pain and how to describe it

Describing your pain as well as you can will help your doctors and nurses find the best way of treating it. Here below are some questions that will help you to describe your pain -

Where is the pain? Is the pain in one part of your body, or in more than one place?

You can use diagrams like the one below to mark where your pain is. If you have more than one pain, label them 1, 2, 3, and so on (with 1 being the pain that upsets you most) (MACMILLAN, 2013i).

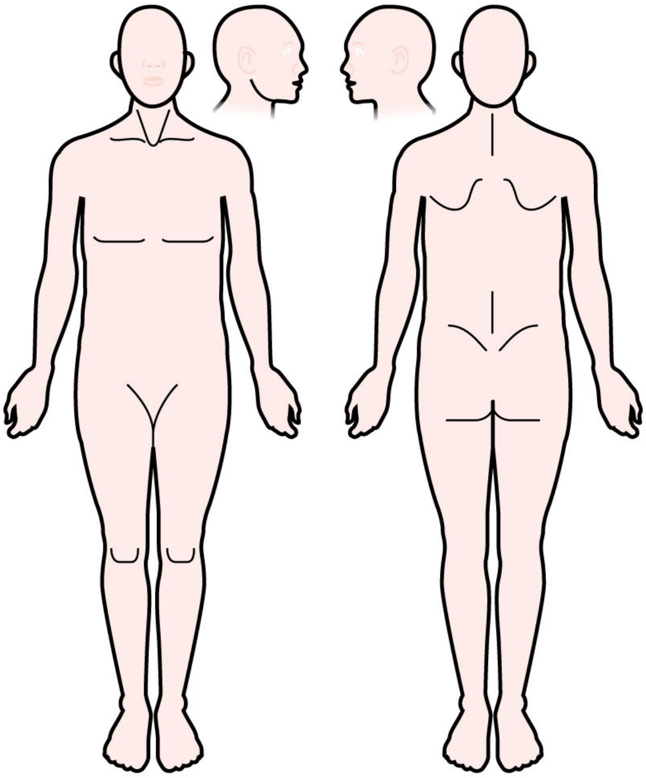

Figure 5.3: Parts of the body to record where your pain is

What is the pain like? You might use words such as these to describe your pain: aching, tender, sharp, hot, burning, nagging, intense, stabbing, tingling, dull, throbbing.

Our pain diary has more words that you may find helpful to describe your pain (MACMILLAN, 2013i).

How bad is your pain? If you measured your pain on a scale of 0 to 10, what number would you rate it? (0 means no pain and 10 means the worst pain you can think of). We have included a scale in our pain diary which you may find it helpful to refer to. It also includes the diagram of the body shown above (MACMILLAN, 2013i).

When are you in pain? Are you in pain all the time? Or does it come and go? Does it get better or worse when you sit still? What happens when you move? Is it better or worse at night? Does it keep you awake or wake you up? (MACMILLAN, 2013i)

Does anything make the pain better or worse? Do you feel better or worse when you're standing, sitting or lying down? Does a heat pad or ice pack help? Is it relieved by painkillers such as paracetamol? Do the painkillers stop the pain or just reduce it, and for how long? Can you reduce the pain yourself by reading, listening to music or watching TV? (MACMILLAN, 2013i)

How does the pain affect your daily life? Does it stop you from bending or stretching? Does it stop you from sitting for very long? Can you sit long enough to eat a meal? Does the pain stop you from concentrating or affect your sleep? Does it stop you from walking for short or long distances?

Don't feel that you're being a nuisance or making a fuss by talking about your pain. Your answers to these questions will help your doctor or nurse plan the best treatments for you (MACMILLAN, 2013i).

Levels of pain and different strengths of painkillers

Pain can be mild, moderate or severe. It can be treated using different strengths of painkiller, depending on your level of pain. To decide which type of painkiller is best, your doctor or nurse may use a tool called the analgesic ladder. The ladder shows each level of pain and the type of painkillers that are best to control it (MACMILLAN, 2013i).

- **Mild pain - Step one** - includes non-opioid drugs for example paracetamol and anti-inflammatory drugs (Brufen®, Neurofen®).

- **Moderate pain - Step two** - includes weak opioid drugs for example dihydrocodeine (DF118 Forte®, DHC Continus®), codeine phosphate or tramadol.
- **Moderate to severe pain - Step three** - includes strong opioid drugs for example morphine, fentanyl and oxycodone (MACMILLAN, 2013i).

Different painkillers do different things and are sometimes used in combination. For example, non-opioid painkillers are often used alongside weak or strong opioids. Other medicines, known as adjuvant drugs may also be used to control pain. Examples are bisphosphonates and steroids.

If you experience any side-effects, tell your doctor or nurse. You should also talk to them before taking any other medicines (MACMILLAN, 2013i).

Levels of pain control

Different types of painkillers are effective for mild, moderate or severe pain. This is explained in an analgesic ladder, which is a tool doctors and nurses often use to find the best medicines for your pain. Examples of non-opioids, weak opioids, strong opioids and other medicines are explained below.

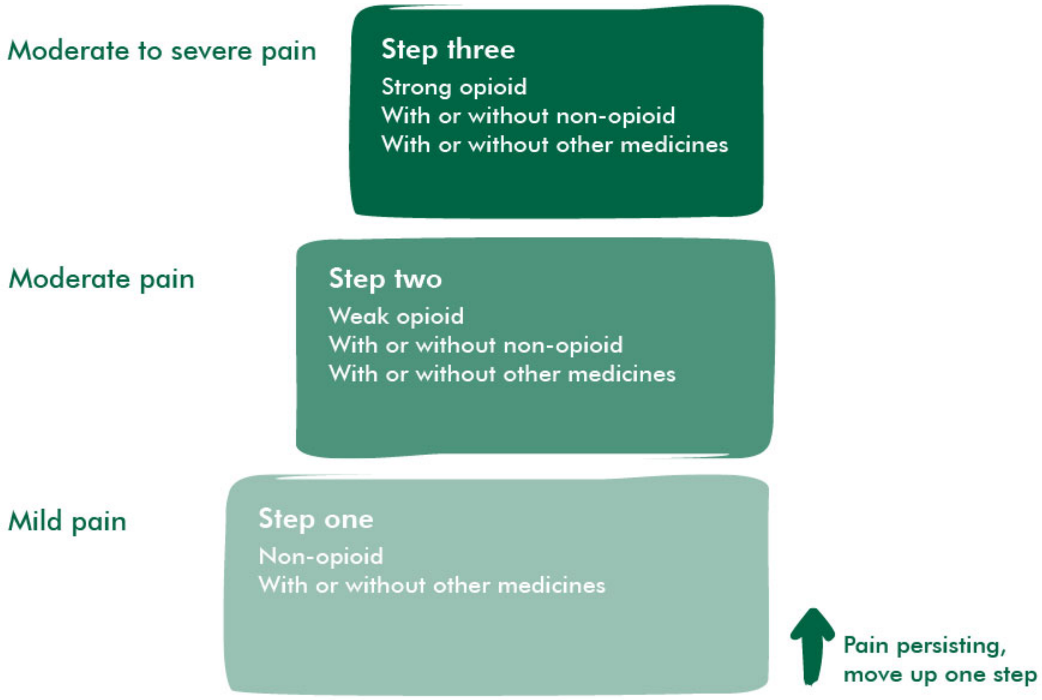

Figure 5.4: The analgesic ladder (steps of pain control)

How the analgesic ladder is used

If your pain is not controlled by a painkiller from step one on the analgesic ladder, your nurse or doctor will prescribe a painkiller from step two.

For example, if you're taking a mild painkiller such as paracetamol but are still getting pain, your doctor should prescribe a weak opioid from step two. This may be a painkiller such as dihydrocodeine, codeine phosphate or tramadol. If the pain still isn't controlled or it increases, your doctor could then prescribe a strong opioid from step three, such as morphine.

You don't have to start with painkillers from the mild group - if you have moderate or severe pain when you first see your doctor, you can start by taking painkillers from step two or step three.

Often, non-opioid painkillers are used at the same time as weak or strong opioid painkillers, as they work in different ways.

For example, a strong painkiller such as morphine can be used with a mild painkiller such as paracetamol or ibuprofen.

At each step of the analgesic ladder, other medicines can also be used to control pain. These include bisphosphonates, steroids and drugs for nerve pain. Although they are not painkillers, they can be used for certain types of pain.

There is more information about how non-opioid, weak opioid and strong opioid drugs are given below (MACMILLAN, 2013i).

If you are prescribed any medication from Step 3, the opioids, you should also ask for a laxative, as Step 3 medications have a very strong side-effect of constipating you! And with some medications, like codeine phosphate from Step 2 for the same reason. Ask your doctor about which laxatives are suitable for that particular medication that they are prescribing.

Step one: Non-opioid drugs for mild pain

Mild pain is treated with painkillers such as paracetamol, and anti-inflammatory drugs.

Paracetamol can be used for most types of mild pain. It can be bought from a chemist or supermarket. It has few side-effects, but it's important not to take more than the recommended dose. Higher doses can damage the liver. Paracetamol does not reduce inflammation.

Anti-inflammatory drugs such as ibuprofen (Brufen®, Neurofen®) help reduce inflammation and swelling. They are good for treating pain in the skin, muscle or bone. Ibuprofen can be bought from a pharmacist or supermarket. Other anti-inflammatory medicines need to be prescribed by a doctor.

Check with your doctor or nurse before taking these types of medicines. They do not always work for everyone and may not mix well with other medicines. Anti-inflammatory drugs can cause indigestion and may irritate the lining of the stomach, so it's important to take them after a meal or snack.

Your doctor may prescribe another medicine to help protect your stomach. If you've had previous problems with stomach ulcers [25], your doctor may advise you not to take anti-inflammatory drugs at all.

When taking these drugs, always check the recommended dose on the packet and never take a higher dose.

Remember that other medicines or tablets that you can buy from a pharmacy or supermarket may also contain paracetamol or anti-inflammatory drugs such as aspirin or ibuprofen. These should not be taken as well as other pain medicines unless advised by your doctor. Check with your pharmacist before buying any other medicines (MACMILLAN, 2013i).

Step two: Weak opioid drugs for moderate pain

Moderate pain is treated with weak opioid drugs such as dihydrocodeine (DF118 Forte®, DHC Continus®), codeine phosphate or tramadol.

These are often combined with paracetamol in a single tablet (for example, co-codamol contains codeine and paracetamol, and co-dydramol contains dihydrocodeine and paracetamol). Combination painkillers have brand names such as Tylex®, Remedeine®, Solpadol®, Kapake® and Tramacet®. Most are only available on prescription from a doctor. There is a limit to the number of tablets that can be taken in one day. If your pain isn't controlled, it's important to let your doctor know so that you can be switched to stronger painkillers.

Some weak opioids may cause side-effects such as constipation, nausea or drowsiness (MACMILLAN, 2013i).

Codeine phosphate is very often given in hospital for diarrhoea, its very common side-effect of causing constipation being used here.

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[25] painful sores that appear in the mouth

Step three: Strong opioid drugs for moderate to severe pain

Moderate to severe pain is treated with strong opioids, such as morphine, fentanyl and oxycodone.

With this type of painkiller, it's important for your doctor to find the most effective dose for you. Two people with the same type of cancer may need different doses of the same drug, even if they're at the same stage of their illness. It's common to start at a low dose and increase it gradually to a dose that controls your pain.

If your pain increases or decreases, the dose of your painkiller can be changed. You may only need a small increase in dose to get your pain under control again. But if your pain is bad, your doctors may increase the dose by a larger amount.

It can take a few days to adjust to taking a strong opioid painkiller.

Strong painkillers have side-effects. If you have side-effects, tell your doctor or nurse. A different type of strong painkiller may be better for you and not cause side-effects.

Other painkillers may be used with strong opioids. For example, paracetamol or anti-inflammatory drugs such as ibuprofen. If your doctor or specialist nurse suggests this, it is important to take these as well as your strong painkiller (MACMILLAN, 2013i).

Who can help you manage your pain

Different healthcare professionals may help to manage your pain. You'll see some of them in the hospital and others at home or in the local community. They include -

- GPs, who can monitor your pain and suggest treatments,
- district nurses, who can help you with your medicines and manage your pain at home,
- physiotherapists, who can advise you on how to make moving less painful,
- occupational therapists, who can arrange special equipment to make you more comfortable,
- counsellors or psychologists, who can help you with worries or emotions that may worsen pain,
- pharmacists, who can give advice about your painkillers and over-the-counter medicines,
- specialist palliative care teams, made up of professionals who are experts in managing pain,

- hospice staff, who can treat your pain when you spend time in a hospice,
- Marie Curies nurses, who help people with advanced cancer to stay at home,
- anaesthetists, some of whom are pain relief experts and treat pain with specialist techniques,
- pain teams, which are based in hospitals and made up of pain experts (MACMILLAN, 2013i).

Who can help?

Various healthcare professionals may be involved in managing your pain (MACMILLAN, 2013i).

GP When you are at home, your GP can tell you about medicines or other treatments you may need to control your pain. They can monitor you regularly to see what has helped. They can arrange for a district nurse to visit. They can also refer you to a specialist palliative care team or other people who can help you (MACMILLAN, 2013i).

District Nurse A district nurse can visit you at home to help you manage your pain. They can make sure your pain relief is working and help you with your medicines. They can contact the GP to renew prescriptions and advise you about pain treatments (MACMILLAN, 2013i).

Physiotherapist A physiotherapist may be able to show you different ways of moving so that your pain isn't made worse.

They can also arrange a wheelchair for you if that will help you move more easily (MACMILLAN, 2013i).

Occupational therapist An occupational therapist may be able to give you equipment to make you more comfortable. For example, special cushions or mattresses for when you are sitting or lying down. They can arrange handrails and ramps for your home to help you move around more easily. They can also suggest ways to help improve your energy and be more active (MACMILLAN, 2013i).

Counsellor or psychologist Some people find it helpful to see a counsellor or psychologist. They can help you find ways of coping with the pain. They can also help you with any worries or emotions that may be making your pain worse (MACMILLAN, 2013i).

Pharmacist A pharmacist will know about any medicines you have been prescribed. They can check your prescription, advise you about your medicines and explain how they may affect you. Tell your pharmacist if you are buying any over-the-counter medicines. They can tell you whether it is safe to take them with your prescribed painkillers (MACMILLAN, 2013i).

Specialist palliative care team Specialist palliative care doctors and nurses are experts in helping people who are in pain. They help to manage the symptoms of cancer and other life-changing conditions. The palliative care team may also include a physiotherapist, an occupational therapist and a counsellor. Some teams also have a psychologist. This is a person trained to help you think about what other things in your life may be causing you pain. Specialist palliative care teams can be based in hospitals or the community.

Hospital teams only work in the hospital. They can help you with your pain control if you're attending an outpatient clinic or if you're an inpatient. They will make sure your GP knows what is happening. They can also refer you to a community palliative care team to look after you when you are at home.

Community teams work from a local hospice or somewhere outside the hospital, for example from a GP surgery. Community teams have doctors and nurses who can visit you in your own home. They give advice and guidance on pain and other symptoms. They can also provide emotional support (MACMILLAN, 2013i).

Hospices Sometimes it can help to spend a few days or weeks in a hospice having your pain, symptoms and other problems treated. Your community specialist palliative care team or GP can arrange this for you. In the hospice, the doctors and nurses can often adjust the dose of painkillers, or give you new ones, more quickly than if you were at home. Once your pain is controlled, you can go home again. At home, your GP and community specialist palliative care team can continue to help you. Your GP will know about community palliative care and hospice services in your area (MACMILLAN, 2013i).

Marie Curie nurses Marie Curie nurses help people with advanced cancer to stay in their own homes. They can help manage symptoms, including pain.

They will stay in your home for a period of time during the day and/or night. Your district nurse or specialist palliative care team will be able to give you more information about Marie Curie nurses in your area (MACMILLAN, 2013i).

Anaesthetists Anaesthetists give drugs during and after operations. Some are also experts in pain relief and can help treat cancer pain. They may be part of a pain team (see below). If you have a treatment called a nerve block, you may have an anaesthetist do it (MACMILLAN, 2013i).

Pain team Many hospitals have pain teams. The doctors and nurses who work in these teams are specially trained to help people in pain.

Most teams include an anaesthetist. Some teams have a psychologist. Your GP or specialist palliative care team can refer you to a pain team. This is very useful if your pain is difficult to control or you need a nerve block.

It's important that you and your family know who is supervising your pain control and who you should contact if you have pain or other symptoms. If you don't know who this is, ask your GP.

You should always be able to get help and advice, by telephone or in person, whenever you need it. This includes during the day and night (MACMILLAN, 2013i).

Storing and remembering your medicines

It's important to store your medicines properly and take them at the right times to ensure they work as well as possible. Here are some practical tips.

- Storing painkillers - keep them in their labeled bottle or packet, in a cool, dry place, and out of children's reach.
- Checking dates - check the label to make sure your drugs are not out of date.
- Remembering to take your medicines - write a note, set an alarm or get someone to remind you. A schedule where you can mark off each dose may help.
- Pill organisers - these can help you keep track of medicines. You can label the box with the times you need to take them.
- Travelling with medicines - remember to take your medicines with you and make sure you have enough to cover the whole time away. Take a list of your medicines, copies of prescriptions and your doctor's telephone number in case these are needed.

- Pain diary - keeping a note of what helps with your pain will help you and your medical team to control it (MACMILLAN, 2013i).

Being organised with your medicines

Here are some practical tips to help you look after your medicines properly and remember to take them at the right time (MACMILLAN, 2013i).

Storing painkillers It's very important to store painkillers carefully. Make sure that they are properly labelled, and keep them in a cool, dry place. Keep them out of the reach of children and lock them away if necessary.

Keep medicines in their labelled bottles or packets, so you don't mix them up. Don't take them if they are out of date. You can check the bottle or packet for a date.

Always return any unused medicines to a pharmacist, who can dispose of them properly. Don't put them in the bin or down the toilet (MACMILLAN, 2013i).

Remembering to take your medicines If you're worried about forgetting to take your medicine, write a note to yourself and put it somewhere you will see it. You could ask your partner, relative or friend to remind you to take them. Or you could set an alarm on your computer or mobile phone to remind you.

Keeping a pain diary (see below) may help you keep track of when to take your drugs (MACMILLAN, 2013i).

If you are taking several different drugs, you may find it helpful to write down -

- the drugs you're taking,
- what they're for,
- their doses,
- the time of day you need to take them (MACMILLAN, 2013i).

Your doctor, nurse or pharmacist can help you do this. They may give you a chart to write on. Make sure it has space for you to check and mark each dose as you take it.

It's best to make things as simple as possible. If you find it hard to remember to take medicines several times a day, talk to your doctor. There may be other types of the same drug that you can take less often (MACMILLAN, 2013i).

Pill organisers You may find it easier to have your drugs arranged in a container or box. This is called a pill organiser or dosette box. You can label it with the times you need to take them (MACMILLAN, 2013i).

Travelling with your medicines When you are away from home, remember to take your medicines with you. If you are travelling on a plane, keep them in a zipped bag in your hand luggage. Take a list of your medicines, copies of your prescription and the telephone number of your doctor. Don't forget there may be a time difference if travelling abroad. Make sure you have enough painkillers and other medicines to cover the whole time away. Taking a few extra may be a good idea, in case there is a delay for any reason.

Some countries limit the amount of particular drugs that can be taken into the country. There are restrictions about taking drugs like morphine into some countries (MACMILLAN, 2013i).

Pain diary You may find it useful to keep a pain diary of how well your pain and other symptoms are being controlled. You can also use it to record which painkillers you take and how well they work. This will help your medical team too. They will be able to see whether the doses of any of your painkillers need changing. If you don't want to keep a pain diary, you can still write down times when the pain was bad and what helped (MACMILLAN, 2013i).

Painkillers and how they are taken

Painkillers are medicines to manage pain. They are also known as analgesics. There are many types available and different ways of taking them.

Painkillers are usually taken by mouth as a tablet or capsule. If you find swallowing difficult, you can often get them in liquid form or as pills that dissolve in water.

You may be given painkillers in other ways such as skin patches, gels, nasal sprays or suppositories. Buccal and sublingual medicines dissolve in the mouth and act quickly, so they're often used for breakthrough pain. Injections and drips can also be used. If you need strong painkillers over a period of time, a small pump called a syringe driver is used, which releases a dose of painkiller at a constant rate.

Always tell your doctor or nurse if you have pain, or if your pain gets worse (MACMILLAN, 2013i).

Painkillers for controlling cancer pain

There are many painkillers available to treat different types and levels of pain. Painkilling drugs are known as analgesics. Your medical team will aim to find the right combination of painkillers for you.

Some people with cancer have constant pain, so they need to take painkillers regularly to keep the pain under control.

If you are prescribed painkillers, it's important to take them at regular intervals. This is to make sure the medicines are as effective as possible. Your medicines will be most effective if you follow the schedule.

It's important not to let pain increase until it becomes severe. Tell your doctor or nurse if your pain gets worse. Severe pain can cause fear, anxiety and difficulty sleeping. These things can make the pain worse and more difficult to control.

Not everyone who has cancer pain has advanced cancer. But if your cancer is advanced, we have a video about pain control for people with advanced cancer that you may find helpful (MACMILLAN, 2013i).

Ways of taking painkillers

Painkillers are mostly taken by mouth - either as tablets or capsules. For people who find it hard to swallow, many oral medicines are available as liquids and some can be dissolved in water. Sometimes, painkillers may be given in other ways -

Skin patches These are stuck onto the skin. They are useful when your pain is under control. They only need to be changed every few days (MACMILLAN, 2013i).

Gels Some painkillers can be rubbed onto the skin to help relieve pain in one area (MACMILLAN, 2013i).

Buccal and sublingual medicines These enter the bloodstream through the tissues in the mouth, so they don't have to be swallowed. They are usually used for controlling breakthrough pain, as they work quickly (MACMILLAN, 2013i).

Nasal medicines Some painkillers can be sprayed into the nose. These work best for breakthrough pain (MACMILLAN, 2013i).

Suppositories These are inserted into the back passage of your bottom (also known as the rectum) (MACMILLAN, 2013i).

Feeding tube If you have a feeding tube such as a PEG (percutaneous endoscopic gastrostomy) or RIG (radiologically inserted gastrostomy), some liquid or soluble painkillers can be given through the tube (MACMILLAN, 2013i).

Injection Many painkillers can be given by injection, either into a muscle or more usually under the skin (MACMILLAN, 2013i).

Infusion Some painkillers can be given by infusion over a period of time. There are different ways of giving painkillers by infusion:

- Subcutaneous infusion - This involves giving a continuous dose of a drug or drugs into a fine needle that is placed just under the skin. A small portable pump called syringe driver is used to give the drugs.
- Intravenous infusion using a patient-controlled analgesia (PCA) - A PCA pump can be used to give pain relief after surgery. The pump has a button on a handset that you press to give yourself a set dose of a painkiller. If you need surgery, your doctors will give you more information about PCA (MACMILLAN, 2013i).
  The PCA pumps are programmed to only give you a certain dosage an hour, this ensures that you cannot overdose yourself unwittingly.

Epidural and intrathecal analgesia. These may be used to relieve pain after surgery. They are also used during labour, when a woman is giving birth. Sometimes, they can be used to help people with cancer pain. An anaesthetist will manage this type of pain control. Your doctors or an anaesthetist will tell you more about epidural or intrathecal analgesia if you need them (MACMILLAN, 2013i).

Syringe drivers for giving pain control

Many strong painkillers (strong opioids) can be given by a syringe driver.

A syringe driver is a small, portable pump that can be used to give you a continuous dose of your painkiller and other medicines through a syringe. You may use one if you're being sick or you can't swallow. Your doctor or nurse will let you know if you need a syringe driver.

A syringe driver is battery powered. The painkiller is put into the syringe, and the syringe is put into the driver. It is attached by a long tube to a fine needle or cannula that is placed just under the skin. A small dose of the drug is then released at a constant rate for as long as you need it. The syringe is usually changed every 24 hours by a nurse.

Syringe drivers are portable so you can move around as usual. They can clip onto a belt, or fit into a pocket, bag or bum bag. Or they can be placed in a specially designed holster (holder) that fits under your arm. Other medicines, such as anti-sickness medicines, can also be given through the syringe driver.

Some people worry that if they have advanced cancer and need a syringe driver, this could shorten their life. This isn't true. A syringe driver is simply a different way of giving drugs at the dose you need to control your symptoms (MACMILLAN, 2013i).

Common questions about painkilling drugs

Common questions about painkillers are: *When should I take the?* and *Do I have to take them regularly?* Sometimes, people delay taking painkillers until pain is severe or don't take them regularly. This can make pain more difficult to control and means you're in pain when you don't need to be.

The aim of painkillers is to provide constant pain relief, so it's important to take them regularly.

Some people ask; *If I'm given a strong painkiller, does that mean that my cancer is advanced?* If you're given a strong painkiller, this doesn't mean the cancer is worse. Another common question is; *Will I become addicted to painkillers?* This is very unlikely.

If you need to take a strong opioid painkiller, you may ask if there is a right dose you should take or if you can stop taking them. The right dose is the one that controls your pain. You should never suddenly stop taking them without medical advice as this can cause withdrawal symptoms.

If you're unsure or concerned about taking painkillers, speak to your doctor. They will give you advice (MACMILLAN, 2013i).

Facts about painkillers

People have different beliefs about painkillers, especially strong ones such as morphine.

Some people may feel scared or worried about having these painkillers. This may stop them taking the painkillers as advised by their doctor, which makes the pain harder to control. It can help to know some of the facts about painkilling drugs when you start taking them (MACMILLAN, 2013i).

When should I take my painkillers? You should start taking your painkillers when you have pain. Many people believe that they should delay using painkillers for as long as possible, and that they should only get help when pain becomes unbearable. But if you do this, it can mean you are in pain when you don't need to be. It can also make the pain more difficult to control. There is no need to save painkillers until you're very ill or your pain is severe (MACMILLAN, 2013i).

Do I have to take my painkillers regularly? If you have painkillers, take them regularly as prescribed by your doctor. The aim is for pain control to be constant. If you've been given painkillers for breakthrough pain, don't wait for it to get really bad before you take them.

It's important to let your doctors and nurses know if your painkillers are not helping, or if you get breakthrough pain. Depending on the type of painkiller you are taking, you may need to have your regular dose adjusted, or you may need to have a different painkiller. Remember that it can sometimes take time to get the right painkiller and dose (MACMILLAN, 2013i).

What does it mean if I'm given a strong painkiller? If you have severe pain you may be given a strong painkiller, such as morphine. This doesn't mean that the cancer is more serious. The dose can also be changed if the pain gets better or worse. If you have a strong painkiller, this doesn't mean you will always need to take it. If your pain improves, you may be able to take a milder painkiller (MACMILLAN, 2013i).

Will my painkillers be given with any other medicines? You may be given other medicines to take with your painkillers. These may include anti-depressants, muscle relaxants or anti-epileptics (drugs that prevent fits or seizures, but are also used for neuropathic pain). These medicines will help to control your pain in a different way from your painkillers (MACMILLAN, 2013i).

Will I become addicted to painkillers? Many people who are prescribed strong opioid painkillers such as morphine ask if they will get addicted to it, or if they will become confused and unable to look after themselves. This is unlikely to happen. People who become addicted to drugs usually initially choose to take them, and then keep taking them because they have a psychological need. For example, they may crave feeling disconnected or 'high' when they take them. This is very different from someone who is in physical pain and needs to take the drug to control their pain (MACMILLAN, 2013i).

What is the right dose of a strong opioid painkiller? Unlike many other drugs, there is no standard dose for morphine or other strong opioid painkillers. The right dose is the one that controls your pain, and this varies from person to person (MACMILLAN, 2013i).

Is there a maximum dose of a strong painkiller you can take? If morphine or other strong opioids are taken as prescribed, you will not overdose. There is no maximum dose for strong opioid painkillers. However, suddenly increasing the dose is dangerous, so never increase the dose or take extra doses without talking to your doctor first (MACMILLAN, 2013i).

Can I stop taking a strong opioid painkiller? If you're taking morphine or another strong opioid painkiller, it's important that you don't suddenly stop taking it. This is because as well as controlling pain, strong painkillers have other physical effects. If they are stopped suddenly, you may get withdrawal effects. These include diarrhoea, cramping pains in the stomach and bowel, sickness, sweating, restlessness and agitation (MACMILLAN, 2013i).

Other types of drugs used in pain control

Some drugs are prescribed with painkillers to help control pain. These are often known as adjuvant drugs. They work in different ways. Below are some of the drugs used.

- Bisphosphonates strengthen bones affected by cancer and reduce bone pain.
- Denosumab injections reduce bone pain and the risk of fractures if cancer has spread to the bones.
- Steroid tablets can reduce swelling and pain caused by a tumour pressing on a part of the body.
- Anti-epileptic and anti-depressant drugs can reduce pain caused by nerve damage.

- Antibiotics can help if pain is caused by an infection.
- Muscle relaxants can be given if muscle spasms are making pain worse (MACMILLAN, 2013i).

You may have other medicines that are not mentioned here.

It may take a while to find the drugs that work best for you. Talk to your doctor or nurse if you are still in pain or have side-effects (MACMILLAN, 2013i).

Adjuvant drugs

You may be prescribed other medicines to take with your painkillers. These are often known as adjuvant drugs (MACMILLAN, 2013i).

Bisphosphonates

People who have pain from cancer that has spread to the bones may find drugs called bisphosphonates helpful. As well as helping to reduce pain, bisphosphonates can also strengthen the affected bones. You can have them as a drip into a vein, usually once a month, or as tablets. An example of this type of drug is zoledronic acid (MACMILLAN, 2013i).

Denosumab

This is a treatment that reduces bone breakdown. It may be used to lower the risk of fractures and relieve bone pain if cancer has spread to the bones. You have it as an injection just under the skin every four weeks (MACMILLAN, 2013i).

Steroids

Steroids are usually given by mouth as tablets. They can reduce swelling and pain caused by a tumour pressing on a part of the body. There are many types of steroids. Usually people are given prednisolone or dexamethasone (MACMILLAN, 2013i).

Anti-epileptic and anti-depressant drugs

Some anti-epileptic drugs (such as gabapentin, pregabalin or carbamazepine) and some low-dose anti-depressants (such as amitriptyline) can help reduce pain caused by nerve damage. This type of pain is called neuropathic pain. These medicines are usually taken by mouth as tablets or capsules.

The dose of these medicines may need to be gradually increased over a few days or weeks to control the pain. This means it's important to continue taking them, even if they don't work immediately.

Some people worry that if they are given anti-depressants for nerve pain, it's because their doctor thinks they're depressed. This is not the reason. Research has shown that low doses of anti-depressants are effective for nerve pain. Higher doses are needed to treat depression.

Some people find that the anti-depressant amitriptyline can make them feel sleepier or slightly 'hungover'. If this happens to you, tell your doctor or nurse. Take the dose at night to stop you feeling drowsy during the day (MACMILLAN, 2013i).

Antibiotics

When pain is caused by an infection, for example an infected wound, your doctor may prescribe antibiotics to treat the infection (MACMILLAN, 2013i).

Muscle relaxants

If muscle spasms are making your pain worse, you may have a short course of a muscle relaxant drug. This could be diazepam (Valium®), baclofen (Lioresal®), hyoscine butylbromide (Buscopan®) or clonazepam (Rivotril®). They help relax the muscles.

You may have other medicines that are not mentioned here.

Ask your doctor or specialist nurse if you have any questions or are unsure about any of your prescribed medicines.

It is important you are as pain-free as possible. Sometimes, it may take a little while to find the drugs that suit you best and relieve your pain. Talk to your doctor or nurse if you are still in pain or side-effects are bothering you (MACMILLAN, 2013i).

When cancer treatments are used for pain control

Cancer treatments can help relieve pain caused by cancer. They include surgical and medical treatments (MACMILLAN, 2013i).

- Surgery can be used to remove part or all of a tumour. This reduces pain by relieving pressure on organs or a nerve. Surgery may involve inserting a stent (a hollow tube) if you have a blockage in a tube-shaped organ such as the gullet. This relieves the obstruction and can reduce pressure.
- Radiotherapy can be used to shrink a tumour. A special type of radiotherapy known as Radioisotope therapy can also be used to control bone pain.
- Chemotherapy and targeted therapies reduce pain by shrinking the tumour.
- Hormonal therapy may be used to treat certain cancers and help reduce pain.
- Nerve blocks relieve pain by blocking pain messages from getting to the brain.
- Radiofrequency ablation (RFA) uses heat to destroy cancer cells. It's sometimes used to relieve bone pain caused by small secondary bone tumours (MACMILLAN, 2013i).

Your doctor or specialist nurse will be able to advise you about which method of pain control is most suitable for you (MACMILLAN, 2013i).

Controlling pain with cancer treatments

Sometimes, surgical and medical treatments that are used to treat cancer can also be used to help relieve cancer pain (MACMILLAN, 2013i).

Surgery

Some people may have an operation to remove part, or all, of a tumour. This can help to relieve pressure on organs or a nerve. Sometimes, laser treatment can be used to reduce the size of a tumour. Or a surgeon can insert a stent. This is a narrow tube that is put inside a duct or tube-like organ, such as the gullet. It can help to reduce pressure and relieve a blockage by keeping the duct or organ open. These treatments can sometimes help to relieve or improve cancer pain (MACMILLAN, 2013i).

Radiotherapy

This treatment uses high-energy rays such as X-rays. It is sometimes used to shrink a tumour. It can reduce pain and other symptoms. Radiotherapy can be used to control pain in the bones - especially the spine, thigh bones (femur), pelvis and ribs.

Usually only one or two sessions of radiotherapy are needed. The treatment doesn't work straight away. It usually takes 7–10 days to reduce your pain. You will need to keep taking your other painkillers during this time. The dose of radiotherapy used to treat pain is low, and the treatment has very few side-effects other than tiredness for a while.

Sometimes, a special type of radiotherapy known as radioisotope therapy may be used to help control bone pain. This can be used if there is pain in more than one bone (MACMILLAN, 2013i).

Chemotherapy

Chemotherapy and targeted therapies can shrink tumours to help reduce pain. Your doctor can tell you whether they may help you. Ask how likely they are to work and what the side-effects may be. This will help you decide whether the treatment would be helpful for you (MACMILLAN, 2013i).

Hormonal therapy

Hormones can be used to treat cancer. They may also help to reduce pain for some types of cancer, such as breast and prostate cancer. Your doctor can tell you whether hormonal therapies may help your pain (MACMILLAN, 2013i).

Nerve blocks

Nerve blocks may help relieve pain by preventing pain messages getting to the brain.

Nerves can be blocked using drugs such as local anaesthetics (sometimes given with steroids) or other chemicals such as alcohol or phenol. Local anaesthetics produce a short-lasting block. Although alcohol or phenol give a longer-lasting block, they are less commonly used because of the side-effects they cause.

Nerve blocks involve specialist techniques and are carried out by a pain specialist. This is usually an anaesthetist. Your GP or hospital specialist can refer you to a pain team (MACMILLAN, 2013i).

Other treatments for bone pain

Radiofrequency ablation (RFA) uses heat to destroy cancer cells. It can help to relieve pain that hasn't responded to radiotherapy. It is usually only used to treat small secondary bone tumours.

There may be other treatments that can help strengthen bones and relieve bone pain. You can ask your doctor or specialist nurse about these. They will be able to tell you more (MACMILLAN, 2013i).

Controlling pain without drugs

There are various non-drug treatments or complementary therapies that may help with pain. Some people find these very helpful, however they don't work for everyone.

These non-drug treatments or complementary therapies can be used on their own or with painkillers. If you decide to use a complementary therapy, always talk to your doctor first. Complementary therapies should not replace any treatments prescribed by your doctor.

Some treatments or therapies aim to help you cope better with pain, for example by teaching you techniques that relax and de-stress your body and mind. Others use physical therapies to relieve the pain (MACMILLAN, 2013i).

There are many different treatments and therapies available -

- TENS machine,
- Acupuncture,
- Cognitive-behavioural therapy (CBT),
- Physiotherapy and exercise,
- Relaxation,
- Hypnotherapy,
- Meditation,
- Massage therapy,
- Visualisation (MACMILLAN, 2013i).

If you do use any complementary therapies you should always use a qualified therapist. The British Complementary Medicine Association (BCMA) has details of qualified therapists (MACMILLAN, 2013i).

TENS machine

A TENS machine is a battery-powered device with wires. The wires are attached to sticky pads, which are put on the surface of your skin (usually near the area of your pain). It sends a small electrical current into your body that feels like a tingling sensation. Some people say that using a TENS machine has helped ease their pain. You should always continue with your prescribed painkillers as a TENS machine alone is not effective.

It is important to check with your healthcare team before using a TENS machine. They are not suitable for everyone.

TENS machines may be available for short-term loan on the NHS. Pain teams, physiotherapists and many palliative care teams can advise you on whether TENS is suitable for you and how to use it. You can also buy a TENS machine from a pharmacy (MACMILLAN, 2013i).

Acupuncture

Acupuncture uses fine needles that are inserted just under the skin at certain pressure points on the body. It is not painful as the needles are so tiny. It's thought that acupuncture may work by stimulating the body to produce endorphins. Endorphins are natural substances produced in the body, which are similar to morphine and help to reduce pain.

Acupuncture can help some people with cancer pain. It may also help relieve other cancer symptoms, such as feeling sick. Some specialist NHS pain and palliative care teams offer acupuncture. Your GP or cancer specialist can refer you. You may have to pay for this (MACMILLAN, 2013i).

Cognitive-behavioural therapy (CBT)

CBT is a therapy that helps people change the way they feel, by changing the way they think and behave. This may help someone feel more in control of their illness. Some people say this has helped them with their pain. It cannot make the pain go away, but it may help someone to cope with the pain, and think about it in a different way. You can have CBT on a one-to-one basis with a trained therapist, or in group sessions. If you think it may help, ask your healthcare team about CBT (MACMILLAN, 2013i).

Physiotherapy and exercise

Pain may stop you from using the part of your body that hurts. This may lead to muscle or joint stiffness. You may be able to see a physiotherapist who will help treat the problem with gentle massage and exercise. This may help to relieve the pain.

Physiotherapists can also advise you on any exercise you can do at home to help improve your pain. Check with your doctor or physiotherapist whether it is safe to exercise and what type of activity may help (MACMILLAN, 2013i).

Relaxation

Learning to relax and let go of your fears and anxieties can also help control pain. Even if you can only do this for a short time each day, it will help. There are two main types of relaxation exercises -

- Physical exercises - These release tension in your body. A technique called progressive muscle relaxation involves learning to tense and relax particular groups of muscles in the body. You can learn to relax and contract stomach muscles, neck muscles and other muscles individually or together. When you know how, you can start using the technique during stressful periods to help reduce tension and therefore pain. When you have learned the basic technique, you can use it to help with pain relief during more difficult times.
- Mental exercises - For example, visualisation. This means seeing pictures in your head (see visualisation below). It can help relax your mind. Mental exercises can be helpful if you find that anxiety is making your pain worse (MACMILLAN, 2013i).

To practice relaxation, find a quiet, warm, dimly lit, relaxing place. Make sure you will not be disturbed. Lie or sit in a well-supported position. These techniques are most helpful if you practise them for 5–15 minutes each day. Using relaxation tapes can help. You may want to try different things until you find the best sort of relaxation exercise for you. You can ask your doctor if there is a healthcare professional who can help you. This might be an occupational therapist or psychologist (MACMILLAN, 2013i).

Hypnotherapy

Hypnosis is a form of deep relaxation. It can help you to think about your pain differently. It will help you to focus your thoughts and feelings on something other than pain. You can learn how to hypnotise yourself. This is called self-hypnosis. It can help you change the way you think about pain and help you cope with difficult treatments or situations. Your GP may have a list of local therapists who provide hypnotherapy, or you can contact the National Register of Hypnotherapists and Psychotherapists (MACMILLAN, 2013i).

Meditation

There are many different types of meditation. They all aim to calm your mind so that you become at peace with yourself. To meditate, sit quietly and be aware of your breathing, without trying to control it. If you have a thought, try to ignore it and only focus on your breathing. If you prefer, you can put an object in front of you and focus on that instead.

Some hospices or hospitals have people who can help you meditate. Ask your doctor, specialist nurse or palliative care team about it.

If you're being treated for any mental illnesses, check with your doctor before using meditation (MACMILLAN, 2013i).

Massage therapy

Massage therapy is when someone strokes or applies gentle pressure to your body. It may help improve your mood and help you relax. Some people find it reduces pain.

Gentle massage can help relieve aching backs or limbs. Rubbing the painful area may help to reduce the number of pain messages reaching the brain. It also helps the muscles relax. Use unscented oils and lotions to keep your skin soft and supple.

Check with your doctor to see whether massage may help and if it is suitable for you (MACMILLAN, 2013i).

Visualisation

Visualisation is when you bring happy, relaxing pictures into your mind. Remembering pleasant sounds, sights, tastes or smells may help you to feel more relaxed. It may help to distract you from the symptoms of pain and discomfort. Someone who has had special training can help you to practise visualisation. Check with your healthcare team about finding a trained therapist (MACMILLAN, 2013i).

What else can help with pain?

There are many things you can do to make your pain easier to cope with. Even small changes to your routine can make a difference.

Try to make sure you're as comfortable as possible. Sit or lie in a position that doesn't cause pain. Changing position regularly, using special pillows and having equipment to help with moving can also help.

You might want to try using heat or cold to relieve pain. Heat pads and warm baths can ease aches and stiffness, whilst an ice pack may relieve inflammation and swelling.

Other things can help distract you from the pain, such as watching TV, reading or listening to music. Having family or friends for short, regular visits can be something to look forward to. Some people also find that art or music therapy reduces feelings of anxiety and helps them to relax.

Talking to family members or friends can often help to relieve worry or anxiety. Often they can also help you find the information and support you need (MACMILLAN, 2013i).

What else can help with controlling pain?

Many people assume that drugs or other treatments are the only way to control cancer pain. In fact, they are only one part of treatment.

Sometimes, simple ways of making you feel better are overlooked. There are a lot of things that you and other people can do to make you feel better (MACMILLAN, 2013i).

Staying as comfortable as possible The way you sit or lie down can affect your pain. Try to be in a comfortable position. Remember, what may feel comfortable at first may be painful 15 or 20 minutes later. Family or friends can help you change position as often as you need. This will also reduce the risk of your skin becoming sore because of being in one position for a long time.

Bedding may need to be tidied or changed. You may feel a lot better when you get back into a cool bed with fresh bed linen.

Other things that can help are -

- v-shaped pillows or supports that help reduce backache and neck pain,
- a bed cradle to keep the weight of blankets off weak or painful limbs,
- a special mattress and cushions,

- equipment to help with movement and sitting (MACMILLAN, 2013i).

Your district nurse can help you get these things, or tell you where to get them (MACMILLAN, 2013i).

Using heat or cold Heat pads and warm baths can help relieve aches and pains. They may help relax muscles and reduce joint stiffness. Ice packs can help relieve pain where there is inflammation and swelling. Some people find that alternating heat with cold helps them.

Always take care to protect your skin from burns when using heat pads and ice packs. Heat pads should be used with a fleece cover. Ice packs should be wrapped in a towel before you place them near the skin. Heat shouldn't be used on body areas that are already inflamed or swollen, as it can make the swelling worse (MACMILLAN, 2013i).

Distraction Watching TV, reading, playing computer games, listening to music or chatting to a friend are ways of using your mind to think of something else. Sitting in a chair or lying in bed with nothing to do can become depressing. Short periods of entertainment can help you feel better and help you cope better with your pain. Short, regular visits from friends and relatives may help. And it's good to have something nice like this to look forward to (MACMILLAN, 2013i).

Music or art therapy This is using music or art to reduce anxiety and relax you. It may help you to express your feelings in a creative way. You don't have to be musical or artistic. Music or art therapists often run classes at hospitals or hospices. Going out and meeting other people while enjoying an activity may also help to distract you from any pain, and help you to feel as good as possible (MACMILLAN, 2013i).

Practical support and information

You may be anxious about your treatment or worried about coping at home. You may be having financial problems or emotional difficulties. Often, friends or relatives can help by getting information from doctors and nurses for you, or by researching services that can help. Sometimes, there is little that they can say or do, but just having them there to listen and understand can be a huge relief.

Getting help with the things that worry you can help you cope better with pain. If you are less stressed, this can make pain easier to control (MACMILLAN, 2013i).

Getting emotional and practical support

Pain can affect many aspects of your life. It doesn't just affect your body; it also affects thoughts and feelings. Having pain can be overwhelming. You may not feel like this all the time, but getting the right emotional and practical support can make it easier to cope.

Feeling better emotionally may make your physical pain feel better. Talking about your feelings to someone close can help. Or you could talk to your GP or our cancer support specialists. They can help you to find local support groups or counseling organisations.

Pain can sometimes cause people to question their faith or spirituality, even if they're not religious. This can be very emotional and may make your pain worse. Speaking to a religious or spiritual leader could help.

If you're finding it difficult to control your pain, tell your healthcare team. They can recommend medical and non-medical treatments. If you have other symptoms, treating these can also make managing pain easier.

A number of organisations and schemes also offer practical support to people with cancer (MACMILLAN, 2013i).

Your feelings and cancer pain

Having cancer can affect every part of your life. Being in pain not only affects your body. It also interferes with your thoughts and feelings. People can have lots of emotions when they are in pain. You may feel -

- angry,
- hopeless,
- frustrated,
- anxious,
- isolated,
- fearful,
- depressed,
- like you've lost control (MACMILLAN, 2013i).

Being in pain may stop you from doing the things you enjoy. You may not be able to go out as much. Or you may not be able to do normal daily tasks any more, or go to work. Feelings can change from day to day. Sometimes, they can all become overwhelming. But you are not alone in feeling like this.

There are many people and organisations that can help you. Some non-medical treatments may also help. Ask your doctor or specialist palliative care nurse which ones may help.

If you feel okay emotionally, your physical pain may feel better. It can help to talk about your feelings. You could talk to your partner, a close friend or relative. If you don't talk about your feelings, the people close to you may not realise you are in pain. They may not understand why you are angry or upset.

If you don't want to talk to anyone you know about your feelings, talk to your GP or specialist palliative care nurse. They can help by putting you in contact with a counsellor. Or you can speak to our cancer support specialists on 0808 808 00 00. They can give you contact details of local support groups or counselling organisations.

Sometimes, your GP may suggest you take an anti-depressant or a sedative drug such as diazepam. This can help improve your mood or reduce anxiety. Don't feel bad about this. It is common to be prescribed one of these. Many people with cancer or cancer pain find these medicines help them cope (MACMILLAN, 2013i).

Spiritual help

Illness can force people to take life more seriously, to question the meaning of life and to stop taking things for granted. Some people who have religious beliefs may find themselves questioning their faith. Even people who are not religious may experience spiritual turmoil. People often ask questions such as, '*Is there life after death?*' and '*Why should the people I love suffer?*' Questions like these, which relate to basic beliefs about life, can cause great emotional and spiritual upset. This can worsen the experience of physical pain.

Some people find comfort in religion at this time. It may help to talk to a local minister, hospital chaplain or other religious or spiritual leader. If you don't feel that this is right for you, it may help to talk to family and friends, a counsellor or someone from a cancer support organisation. Our cancer support specialists can give you details of organisations that provide counselling (MACMILLAN, 2013i).

Control of other cancer symptoms

People with cancer may have many symptoms. Some are caused by the cancer, and some are caused by cancer treatments. Trying to cope with other symptoms may make it more difficult to cope with pain. Often, other symptoms can be relieved by medical or non-medical treatments, or by a combination of both. If your other symptoms are well controlled, this can help you deal more effectively with your pain.

Talk to your healthcare team if you have other symptoms. They will be able to advise you on how to deal with them (MACMILLAN, 2013i).

Practical support

If your pain means that you can't move around easily, you may need specialist equipment or people to help you in your daily life.

The British Red Cross has an office in every county. They have volunteers who can help you in many ways. This may be with shopping, posting letters or changing library books. They may be able to take you to an appointment at the hospital. The British Red Cross can also lend equipment like wheelchairs and commodes (portable toilets).

The Disabled Living Foundation runs an information service. It also has specialist advisers and occupational therapists. They can give advice on aids and specialist equipment, including special cutlery, walking aids and wheelchairs. Scope also gives information and advice to disabled people.

If you have mobility (movement) problems because of your cancer or pain, you may find the Blue Badge scheme useful. This provides parking concessions (allowances) for people with mobility problems. It means that you, or someone with you, can park close to where you want to go. For example, you can park next to the entrance of a shop. This will make it easier for you to go out. To apply for a badge, contact your local council. A healthcare professional, welfare rights adviser or social worker can help you apply.

Some areas have good neighbour schemes. The schemes organise help for people in the local area. This could be help with shopping, befriending or offering transport. The schemes are usually run by the social services or local community organisations. Some are only available to people living alone. Look for 'council for voluntary service' or 'good neighbour schemes' in the phone book or online (MACMILLAN, 2013i).

Clinical trials

What does a clinical trial involve?

Volunteers for clinical trials can involve healthy people or patients. Clinical trials are done for many reasons. For example they may look at new treatments to see if they are more effective than the standard treatments already available. Or compare different ways of diagnosing an illness. There are also trials that look at prevention, screening and quality of life (MACMILLAN, 2015i).

In cancer care treatment trials are the most common type of trial. They may be carried out to -

- test new treatments, such as chemotherapy drugs and targeted therapies,
- look at new combinations of existing treatments, or change the way they are given, to make them more effective or to reduce side-effects,
- compare the effectiveness of drugs used to control symptoms,
- find out how cancer treatments work,
- see which treatments are the most cost-effective (MACMILLAN, 2015i).

Clinical trials provide the evidence that is needed for doctors and patients so they know which treatments are the safest and most effective.

This information is for people with cancer, who may have the option of joining a clinical trial as part of their cancer treatment. We refer to these people as patients (MACMILLAN, 2015i).

Treatment trials

Treatment trials are the most common type of trial. In cancer care, they may be done to -

- test new treatments such as new chemotherapy drugs and targeted therapies,
- look at new combinations of existing treatments, or change the way they are given, in order to make them more effective or to reduce side-effects,
- compare the effectiveness of drugs used for symptom control,
- discover which treatments have fewer side-effects,
- find out more about how cancer treatments work,
- see which treatments have the least impact on peoples' everyday lives,
- see which treatments are the most cost-effective (MACMILLAN, 2015i).

Treatment trials are the only reliable way of finding out whether a different operation, type of chemotherapy, targeted therapy or radiotherapy is better than what is already available.

If doctors already knew that a new treatment was better than the standard treatment, there would be no need for a clinical trial. Patients would be offered the treatment routinely as part of their care (MACMILLAN, 2015i).

The treatment being tested may aim to -

- improve survival (how long people live after treatment),
- relieve the symptoms of cancer,
- reduce the side-effects of treatment,
- improve quality of life or sense of well-being for people with cancer (MACMILLAN, 2015i).

Many drugs that are now commonly used in cancer care have been previously tested in clinical trials. Without ongoing research, it wouldn't be possible to add to our knowledge about effective treatments (MACMILLAN, 2015i).

Prevention trials

Prevention trials look at whether a specific treatment may help to prevent a specific type of cancer. For example, trials have looked at whether people with a higher risk of cancer, because of their family history, would benefit from taking medicine to reduce their risk (MACMILLAN, 2015i).

Screening trials

Screening trials look at new ways of testing a person for a specific cancer. These trials are often aimed at finding cancer early when the chance of a cure may be highest. They may be carried out in the general population. Or in people who are at a higher risk of cancer because of their family history (MACMILLAN, 2015i).

Diagnostic trials

Diagnostic trials look at new ways of accurately finding a cancer - perhaps using new scans or tests. These trials usually include people who may have symptoms of cancer (MACMILLAN, 2015i).

Quality of life trials

Quality of life trials look at ways of improving a person's sense of well-being. Many quality of life trials are combined with treatment trials. This is because doctors want to know what effect a particular treatment has on a person's everyday life. They often include questionnaires, which people complete at different stages during the trial. These may look at the psychological and financial impact of the treatment on both patients and their carers. For example, a trial might look at whether someone has to take time off work to care for you while you have treatment (MACMILLAN, 2015i).

Clinical trial design

If you take part in a trial you may hear terms such as -

- controlled trials,
- placebo,
- randomisation,
- blind and double blind trials (MACMILLAN, 2015b).

In most controlled trials, one group of patients will have the standard treatment for their cancer type. The other group will have the trial treatment which is being tested. The results are then compared to see which treatment works and if the side-effects are worse or better.

Sometimes when there isn't a standard treatment available, one of the groups is given a placebo treatment instead. This looks the same as the treatment being studied but it contains no medicine. It is also called an inactive treatment.

To decide who goes into each group in a fair way, a computer places patients into treatment groups. This is called randomisation.

You may not be told which treatment group you are in. This is called a blind trial. In some trials called double blind trials, neither the patient nor the doctor will know which treatment they are getting (MACMILLAN, 2015b).

Controlled trials

In most trials, one group of patients will have the trial treatment and one group will have the standard treatment. The people having the trial treatment are called the trial group and the people having the standard treatment are the control group (MACMILLAN, 2015b).

The results of both groups are compared to -

- see if there is any benefit from the new treatment,
- see if the side-effects are better, worse or different,
- measure how much of the improvement in the patients is due to the new treatment and how much would have happened by chance or is due to standard treatment (MACMILLAN, 2015b).

Sometimes standard treatment is to ’watch and wait’. This means that no treatment is given unless the cancer starts to develop or cause symptoms (MACMILLAN, 2015b).

Placebo

In some situations, where there is no standard treatment to compare with the trial treatment, patients may be given a placebo. A placebo is a treatment that looks the same as the treatment being studied. It contains no medicine and is also known as an inactive treatment.

Placebos may be used when a therapy, such as a targeted therapy, is being added to the standard treatment to see whether this gives better results. One group of people will be given the standard treatment plus the trial therapy, and one group of people will be given the standard treatment plus a placebo. People who take part in a trial that uses a placebo won’t know whether they’re getting the actual treatment or the placebo. In some trials (known as double-blind) the doctors won’t know either.

Comparing people’s responses to the placebo and to the treatment being tested tells the researchers whether a treatment is having any real benefit (MACMILLAN, 2015b).

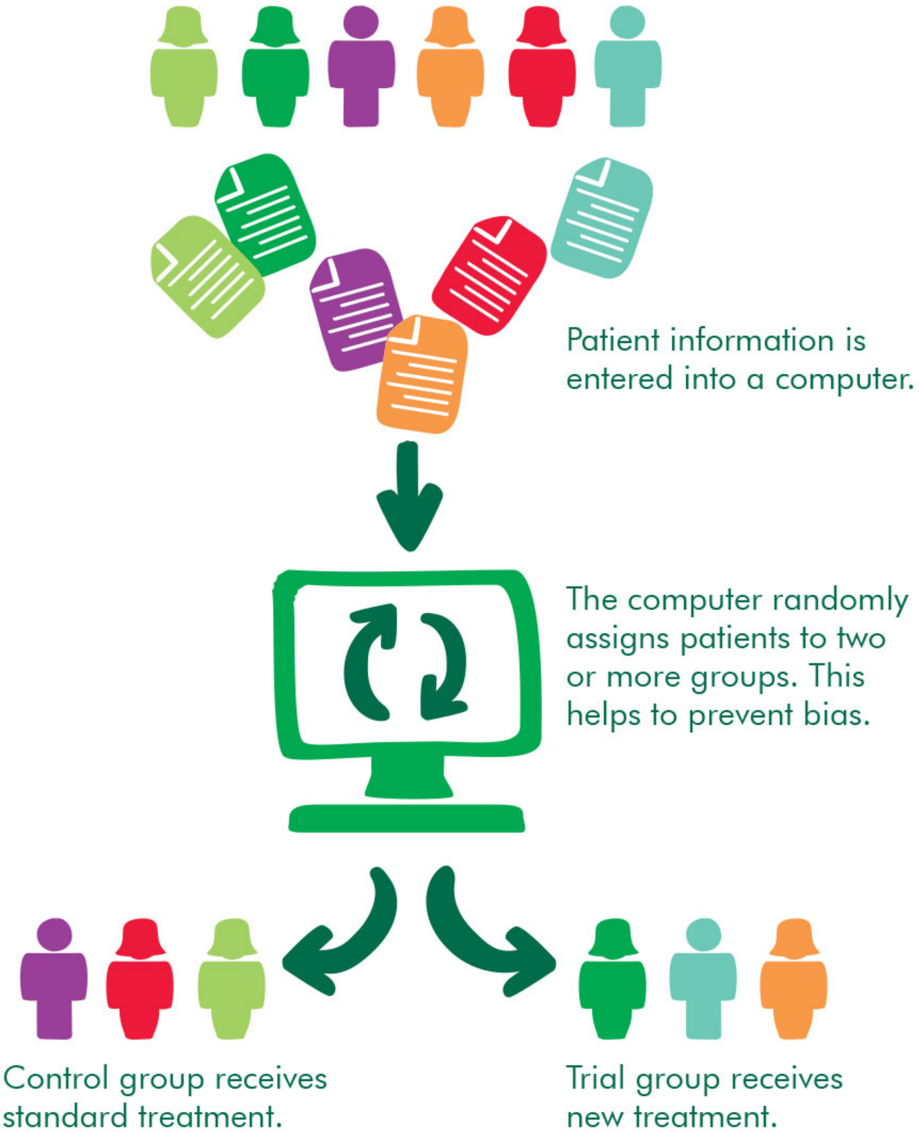
Randomisation

Most phase 3 and some phase 2 trials are randomised. In a randomised trial, a computer programme is used to put patients into treatment groups. This means that if you agree to take part, neither you nor your doctors will be able to choose which treatment you’re given.

Trials are often randomised because if the researchers or doctors were to decide who should get which treatment, they might be influenced by what they know about their patients. This means they might put people who they think are more or less likely to respond to a new treatment into a particular group. This is known as introducing bias and it could affect the accuracy of the research results.

Bias can be prevented if people are put into treatment groups by a computer. The computer can match the groups so that they are similar. For example, they can be matched so that each group has a similar mix of patients of different ages, gender or state of health. If one group does better than another group, it's therefore more likely to be because of the treatment (MACMILLAN, 2015b).

The illustration below shows how the process works.



Blind trials and double-blind trials

If you take part in a trial of a new drug, you may not be told which treatment group you are in. This is called a blind trial. The medicine used will look the same, whether it's the new treatment, standard treatment or a placebo.

Some randomised trials are called double-blind trials. This means that neither you nor the doctor treating you will know which treatment you're getting. Your doctor opens a specially coded treatment pack and only the trial organisers know which drug it contains. In an emergency, your doctor can find out from the trial co-ordinators which treatment you're having. Or the pharmacy department at the hospital will be able to break the code.

Blind trials or double-blind trials aim to reduce any bias. For example, knowing you're having a new treatment might make you feel more positive or negative. This could influence what you report to the researchers. Similarly, if your medical team knew that you were having a new treatment for which they had high hopes, this might affect how they judged your response to it (MACMILLAN, 2015b).

Entry criteria

All clinical trials have strict guidelines about who can take part. These are known as entry criteria or eligibility criteria. Anyone who wants to take part in a clinical trial must meet these criteria. For example, some trials may include people with a specific type of cancer or a particular stage of cancer. Staging takes into account the cancer's size, its position in the body and whether it has begun to spread.

All trials also have exclusion criteria. These explain who cannot take part. Exclusion criteria help to ensure the safety of people taking part and make sure the results are as accurate as possible (MACMILLAN, 2015b).

Examples of exclusion criteria sometimes include -

- having another health condition,
- taking particular medicines,
- having had particular treatments in the past (MACMILLAN, 2015b).

Your cancer specialist can tell you whether you're suitable for a specific trial (MACMILLAN, 2015b).

Benefits and risks of clinical trials

There are benefits and risks to taking part in a clinical trial. But the trials are made to be as low-risk as possible while making the benefits as great as possible for anyone who takes part (MACMILLAN, 2015a).

You can speak to your doctor before deciding whether to take part in a trial and ask them any questions you might have. You may want to know -

- more about the trial,
- what you will need to do (MACMILLAN, 2015a).

You may also want to think about practical issues around taking part in a trial. You might have to visit the hospital more often, which could mean extra travel costs.

During and after the trial you'll be followed up carefully. This means you may need to have regular tests. For some patients this is reassuring. Others would prefer not to have more hospital visits and not take part in the trial.

There is no right or wrong decision about taking part in a trial. To help you decide, you could talk to family or friends, or write down a list of the pros and cons (MACMILLAN, 2015a).

Benefits and risks of taking part in a trial

Clinical trials are designed to make the risks as low as possible and the benefits as great as possible for all the people who take part, whichever treatment they get (MACMILLAN, 2015a).

Benefits Taking part in a trial means that you may be given a new treatment that works better than the standard treatment. The new treatment might not otherwise be available yet because it does not have its license. You'll also be helping doctors find out which treatments may benefit future patients.

When you take part in a trial, you'll be followed up very carefully during and after the study. Your doctors will probably want you to have regular tests, such as blood tests, and you may be asked some extra questions about how you're feeling. This means that any changes in your health - whether or not they are related to the treatment you're having - can be noticed and dealt with as soon as possible. Some patients find this reassuring. Others would prefer not to have more hospital visits and therefore would rather not take part in trials (MACMILLAN, 2015a).

Potential risks With any clinical trial, there is always a small risk that the treatment could harm you or that you could experience side-effects that are unpleasant or unexpected. During the trial, researchers make every effort to minimise these risks (MACMILLAN, 2015a).

Practical issues Taking part in a trial may mean going to your hospital or GP more often than you would normally, so bear this in mind before you agree to take part. Attending the hospital can be tiring and the extra travel may cost a lot of money. Ask your doctor how many extra visits will be needed and think about how convenient this will be for you. You can also ask whether the research trial will pay for your additional travel costs, and how you can claim (MACMILLAN, 2015a).

Making a decision If you are finding it difficult to decide whether or not to join a clinical trial, it may be helpful to talk things through with your doctor or nurse. You might also find it helpful to speak with your family and friends as they may be able to help talk things through with you. Sometimes something as simple as writing a list of pros and cons can be helpful.

It is important to know there is no right or wrong decision. Any decision you make will be the right one for you at that time. If you need more support, you can call the Macmillan Support Line on 0808 808 00 00 to talk to our cancer support specialists (MACMILLAN, 2015a).

Also see Decisions about treatment for further information about decision making.

Questions to ask

Here are some questions you might like to ask before deciding whether to take part in a trial. Your doctor or nurse will probably answer most of these when they tell you about the trial. Most of these will be covered in the written information you are given about the trial (MACMILLAN, 2015a).

General questions

- What is the trial called?
- What is the aim of the trial and how will it help people?
- Why have I been invited to take part?
- What are the treatment choices in the trial?

- What are the benefits of the trial for me?
- What are the possible risks?
- How long is the trial expected to last?
- Can I withdraw from the trial at any time?
- The answer should always be yes.
- What happens if I leave the trial early?
- How long will it be before the results of the trial are known?
- Will I be informed of the results? (MACMILLAN, 2015a)

Remember that it may be some time before the results are available. It's not unusual for trials to take many years before the results are available. While doctors may see quite soon whether people respond to a new treatment, it will take much longer to see how long the response will last (MACMILLAN, 2015a).

Practical questions

You may also want to ask some practical questions to make sure you're happy with any demands that the trial will make on you -

- How much of my time will be needed?
- Will I need to take time off work?
- Will I need extra help from family and friends?
- Will my fares to and from the trial centre be paid?
- If so, how can I claim the costs back?
- What extra tests or appointments will I have?
- Will I have to collect the drug from the hospital?
- Will the drug be sent to me by post or will I get it through my GP?
- Will I have to fill in questionnaires or keep a diary? Sometimes questionnaires are simple tick-box lists, or you may be asked to record your answers online (MACMILLAN, 2015a).

Safety in clinical trials

If you decide to take part in a clinical trial, you are protected in lots of ways -

- The UK's Medicines and Healthcare products Regulatory Agency (MHRA) makes sure clinical trials meet high standards of practice and that all serious side-effects are reported.
- All clinical trials have to be approved by a research ethics committee. These are independent groups made up of a mixture of health professionals and non-medical people. They ensure patients are given all the information they need.

- Data monitoring committees monitor the safety of a clinical trial and how well a treatment is working. They can stop a trial if it is causing harm to a person.
- All clinical trials have some form of insurance to compensate patients in the unlikely event something goes wrong (MACMILLAN, 2015f).

How safe are clinical trials?

Understandably, anyone who enters a clinical trial will want to know that it's safe for them to do so. There are a number of ways people are protected before and during a trial (MACMILLAN, 2015f).

Medicines and Healthcare products Regulatory Agency (MHRA)

The UK's MHRA makes sure trials meet international standards of good practice, which are there to protect the people taking part. All serious side-effects must be reported (MACMILLAN, 2015f).

Research ethics committees

All research in the UK involving people, whether done in the NHS or the private sector, has to be approved by an ethics committee.

These are independent groups that put the rights, safety, dignity and well-being of research participants at the centre of their decision-making. They make sure that patients are fully informed, and check that any information given is clear and accurate. They also ensure that patients are compensated if anything goes wrong.

The research ethics committee looks at each research proposal and gives an opinion about the trial and whether the research is ethical.

The committees cover a local area and must be made up of a mix of health professionals and non-medical people. They often include patients, lawyers and members of the public. Having non-medical people is important as they can look at the trial from an 'outsider's' point of view (MACMILLAN, 2015f).

The research ethics committee is independent of research sponsors, funders and investigators. It checks that -

- the researchers are qualified to do the trial,
- the trial is well planned,
- the likely benefits are greater than the possible risks,

- patients are recruited to the trial correctly (MACMILLAN, 2015f).

Patients and members of the public are becoming more involved with research teams. They bring the patient's perspective of illness and treatment, which can help the researcher's understanding.

For example, they comment on the possibility of people wanting to participate in a trial and what aspects of the trial might put people off taking part.

Patients and members of the public can also suggest new areas for research and help to write information about clinical trials for the public (MACMILLAN, 2015f).

Monitoring trials and stopping rules

Before a trial begins, a data monitoring committee is usually set up to monitor patient safety and the effectiveness of the treatment during the trial.

The data monitoring committee along with the research ethics committee can stop a trial if they are concerned that a new drug or treatment is causing harm to a person. For example, they can stop a trial if there are severe side-effects. This is unlikely to happen in phase 3 or 4 trials because new drugs or treatments are well tested during phases 1 and 2.

Trials can also be stopped early if the results of the new treatment appear to be much better than the standard treatment. The new treatment can then be used instead of the standard treatment so that everyone in the trial can benefit from it.

Sometimes patients will then move from being in the control group, to the new treatment group (MACMILLAN, 2015f).

Insurance

The drugs used in clinical trials are made to the highest standards of purity and quality. Drug companies are insured so that if a patient is harmed by an unforeseen event due to the drug, compensation can be paid. It's very rare for patients to be seriously harmed by trial drugs, although some may cause unpleasant side-effects.

Trials funded by the Department of Health, the UK Medical Research Council or medical charities may not have this kind of insurance, but a payment would be made if something did go wrong.

All trials will have a legal sponsor. One of the sponsor's roles is to make sure that there are arrangements, such as insurance, to protect those taking part against damage or loss.

However, individual NHS trusts are responsible for insuring themselves against harm caused by local trials. Research ethics committees will refuse approval for trials where there is no insurance or provision for compensation (MACMILLAN, 2015f).

Taking part in a clinical trial

Before deciding if you want to take part in a clinical trial, your doctors will tell you about the treatment you will have and what you will have to do during the trial.

You should feel comfortable that you have all the information you need and feel able to ask any questions. You may want to talk to your family or friends about the trial before making a decision.

If you decide you want to take part in the trial, you will be asked to sign a consent form. You can't be entered into a trial without giving your consent.

If you decide not to take part in the trial, you can tell your doctor or nurse. You don't have to give a reason and you will be offered the standard treatment for your type of cancer.

If you give your consent to take part in a trial and then change your mind, you can leave it at any time without giving a reason.

All your medical records are confidential and your name won't be used when the results are published (MACMILLAN, 2015g).

Information and giving consent

Before you go into a trial, a doctor, nurse or other researcher will ask for your permission. They can't enter you into the trial if you don't give your written consent, after you have had plenty of time to think about it (MACMILLAN, 2015g).

To help you decide whether you want to take part, the researchers should tell you -

- what the trial is trying to find out,
- what the trial will involve and what you'll have to do (MACMILLAN, 2015g).

There are guidelines for researchers that explain what information people need to help them decide whether to take part in a clinical trial. But there's a lot of discussion about how much people really want to know, and this varies from person to person.

It's important that you have enough information to make an informed decision. You should feel able to ask any questions that will help you to make a decision. Before you decide, you should also feel that you have been given enough time to think about the trial and what it will mean to you.

Someone from your medical team will be able to answer any questions you may have. They will go through the possible benefits and risks of joining the trial. They should also discuss any other treatments that may be appropriate in your situation. You may want to talk about it with your family or friends, and think about any practical aspects, such as extra appointments and tests.

You will be given a patient information leaflet about the trial. You can take this away and read it in your own time before you are formally invited to take part (MACMILLAN, 2015g).

If you decide to take part If you decide that you want to take part, you may be asked to give your consent verbally to the person carrying out the trial, who will write it in your notes. You'll then be asked to sign a consent form that says that you agree to take part. Your doctor will also sign the consent form. You'll be given a copy to keep (MACMILLAN, 2015g).

If you decide not to take part If you decide not to take part in the trial, you can tell your doctor or nurse. Your decision will be respected and you don't have to give a reason. There will be no change in the way that the hospital staff treat you, and you'll be offered the standard treatment for your type of cancer (MACMILLAN, 2015g).

Who is responsible for your care?

During the trial your cancer specialist and GP are still the people in charge of your care, making the day-to-day decisions with you about your treatment (MACMILLAN, 2015g).

Withdrawing from a trial

Remember that even if you give your consent to a trial, you can leave it at any time without giving a reason. If you're having a new treatment as part of a trial and then leave the trial, you may not be able to continue having the new treatment. In this situation you'll be given the appropriate standard treatment for your type of cancer.

If you are thinking of leaving a trial it's a good idea to discuss it with your specialist or your research nurse (MACMILLAN, 2015g).

Confidentiality

If you agree to take part in a clinical trial, your GP will only be told if you give your consent. It can sometimes help for your GP to know you're in a trial as they're responsible for your day-to-day health at home. If you have any queries or problems during the trial, you should talk to the specialist doctor responsible for it, or your research nurse. Your medical records concerning the trial are confidential.

Sometimes, a representative of a relevant drug company or staff from the trials office who are co-ordinating the trial may look at your records to check that all the necessary information is collected accurately. No one who looks at your notes can give information to anyone outside the healthcare team looking after you. In the same way, when the results are published you will not be named (MACMILLAN, 2015g).

Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial, you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients (MACMILLAN, 2015g).

How are clinical trials carried out?

Before new cancer treatments or drugs are given to people in trials they are first tested in laboratories using cancer cells. They then go through 3 stages (phases) of being tested in trials before they are approved for use (MACMILLAN, 2015e).

Different phases of a clinical trial

Treatment-related clinical trials are usually carried out in a series of steps or phases.

Potential new cancer drugs or treatments are first tested in the laboratory (pre-clinical trials) before they're given to people in trials. If it seems they may help to treat a particular cancer, they are tested in what are called phase 1 trials. If these are successful, the drug is used in phase 2 trials and then phase 3 trials. Phase 4 trials test drugs that are already licensed.

Feasibility studies and pilot studies may be carried out before a planned clinical trial. A feasibility study is designed to see how possible a clinical trial is. For example, it will look at how easy it will be to recruit people to the trial, how many people the trial might need and how long the trial could take to complete.

Pilot studies are a smaller 'test' version of the main clinical trial. They are done before the main study to check whether the ideas behind the trial and the suggested methods (the 'trial design') work in practice.

Researchers who run trials involving patients have to offer a treatment they believe is at least as good as, or possibly better than, the best treatment that is currently available. The trials have to be carried out following strict rules and guidelines, see Safety in clinical trials (MACMILLAN, 2015e).

Phase 1 trials

Phase 1 trials test a possible new cancer treatment or drug that has only been tested on cancer cells in the laboratory. This is the first stage in which the drug or potential treatment is used in patients (MACMILLAN, 2015e).

Phase 1 trials may involve chemotherapy or targeted therapies.

A phase 1 trial aims to find out -

- whether the medicine has an effect on the body,
- how much of the medicine can be given safely without causing serious side-effects,
- what side-effects the medicine causes (MACMILLAN, 2015e).

How does the trial work? The first patients are given a small dose of the drug that is expected to be safe. If none of the patients have any side-effects, the next group will be given a higher dose. The dose is gradually increased with each group. This is called dose-escalation.

The researchers look carefully at the effects of the drug until they find the dose at which side-effects are acceptable. This is known as the maximum tolerated dose.

For targeted therapies, it may be necessary to test a biopsy specimen first. This is to see whether the patient is likely to benefit from the new treatment. A biopsy is a sample of cells that may have been removed when you were diagnosed. The cells can be looked at and tested under a microscope to find out whether the patient is likely to benefit from the new treatment.

In a phase 1 trial, it's likely that most people won't benefit from the new treatment. But it's possible that some people will.

Finding out the best dose and the side-effects of the drug is a very important stage before testing how effective the drug is. Sometimes, phase 1 studies include different ways of giving the new drug or medicine. For example, patients may be given the same drug by injection or as tablets (MACMILLAN, 2015e).

Who can take part? Phase 1 trials involve very few patients. These trials are only open to people whose cancer has come back or spread. They have already had treatment and there is currently no other standard treatment available.

It's difficult to know whether a new medicine will cause harmful side-effects, so people in this type of trial need to be selected and checked very carefully. For example, people need to be feeling reasonably well to take part in these sorts of trials. This is because the trials are specifically looking at side-effects. It would not be safe or fair to have people who were already feeling unwell taking medicines which might possibly make them feel worse - particularly with no proof yet that the medicine is effective (MACMILLAN, 2015e).

Where do the trials take place? Phase 1 trials are usually carried out in clinical research units. These are often based at specialist hospitals, rather than in local hospitals. Sometimes, this may involve some travelling to and from the hospital (MACMILLAN, 2015e).

How long does the trial last? Phase 1 trials can take from several months to a year to finish.

At the end of the trial, the research team will know the major side-effects of the treatment and whether it has any effect on the cancer. If the treatment is shown to be safe and looks like it does have an effect on the cancer, it will then be tested in phase 2 trials. Not all treatments tested in phase 1 trials make it to phase 2 (MACMILLAN, 2015e).

Phase 2 trials

A phase 2 trial aims to find out -

- whether the drug works well enough to be tested in a larger, phase 3 trial,
- which types of cancer it might be best used to treat,
- more about the side-effects and how best to manage them,
- more about the best dose to use (MACMILLAN, 2015e).

Phase 2 trials have more patients, usually about 20–40 people, and may last a couple of years. These patients will be closely followed up to see whether their cancer is responding. If the cancer shrinks, it's known as a response to the treatment.

The trial will also look further at any side-effects caused by the treatment. Although the new treatment would have been tested in a phase 1 trial, it's still possible that it will cause side-effects that haven't been seen before. This is because it is being tested in a larger group of patients (MACMILLAN, 2015e).

Phase 3 trials

A phase 3 trial aims to compare what looks like promising new treatments with standard treatments. It also gives more information about the side-effects that the new treatment may cause.

Sometimes, a phase 3 trial may test whether a new treatment will be as good as the standard treatment but cause fewer side-effects. For example, a new way of giving radiotherapy may be tested and compared to the standard radiotherapy treatment.

Sometimes a new treatment will be tested when no standard treatment currently exists. In these trials, the new treatment may be compared with the current routine 'standard of care' that would be given. This routine care might involve regular appointments to see how well the person is and to treat any symptoms. This is sometimes called observation or best supportive care.

Sometimes phase 3 trials may involve a placebo.

Phase 3 trials are large and may include hundreds, or sometimes thousands, of patients from many different hospitals, often from several countries. They may take many years to complete (MACMILLAN, 2015e).

A phase 3 trial aims to find out -

- how long patients stay free of cancer - this is known as disease-free survival,
- the number of people who are alive, with or without signs of cancer - this is known as overall survival,
- whether the cancer grows more slowly,
- how the treatment affects patients' quality of life (MACMILLAN, 2015e).

Phase 3 trials usually involve a Randomisation process.

Manufacturers of drugs that have been shown to be safe and effective in phase 3 trials can then apply for the drug to be granted a licence. This is known as a marketing authorisation. Licensed drugs are then available to be used in healthcare.

Most licences are granted by the European Medicines Agency (EMA) as the licence covers all countries in the European Union.

The Medicines and Healthcare products Regulatory Agency (MHRA) can grant a licence for a drug to be used just in the UK. Drugs that are licensed may be further researched in phase 4 trials (MACMILLAN, 2015e).

Phase 4 trials

Phase 4 trials are carried out after a drug has been shown to be effective and has been granted a licence. They aim to find out -

- how well the drug works when it's used more widely,
- the long-term risks and benefits of the drug,
- more about possible rare side-effects and the safety of the drug (MACMILLAN, 2015e).

Understanding clinical trial results

It can take many years before the results of a clinical trial are known (MACMILLAN, 2015h).

In many trials, researchers will want to know how effective a treatment has been. If the cancer has stopped growing, become smaller or disappeared, it is known as a response. You may hear your doctors talking about a complete response, a partial response or stable disease -

- **Complete response** - all the cancer has disappeared. It is not usually thought of as a cure until there has been no sign of it returning for several years,
- **Partial response** - the cancer has decreased in size by at least 30%,
- **Stable disease** - the cancer has decreased in size by less than 30% (MACMILLAN, 2015h).

Other trials look at the long-term side-effects of a treatment or how long people live for after their treatment.

You can usually find out the results of your clinical trial by speaking to your specialist (MACMILLAN, 2015h).

Why trial results take a long time to be published

It can sometimes take many years to get the results of a trial. This may be because many thousands of people need to take part to show a small but important difference between treatments.

If a trial is looking at how long people live after their cancer treatment, they need to be monitored for many years - often five years, but sometimes 10 years or more. Researchers continue to collect this information during this time. The information is collected from the hospital, national records or a patient's GP.

Patients' names are removed so individual people will not be identified in the study results (MACMILLAN, 2015h).

Understanding trial results

Researchers need to collect information (called outcomes or endpoints) to help them decide which treatment is most effective and safest.

In a Phase 2 trials, the first outcome that researchers look for is how effective the treatment has been in treating the cancer.

In solid tumours (not blood cancers like lymphomas, leukaemias and myelomas), if the cancer has stopped growing, shrunk or disappeared, it's known as a response (MACMILLAN, 2015h).

You may hear your doctors use different phrases to describe your response to treatment, such as a complete or partial response, or stable disease -

- A complete response is defined as the disappearance of all of the detectable cancer for at least four weeks. Clearly this is a very good result, but a complete response doesn't always mean a cure. It takes several years with

no sign of the cancer returning (recurrence) before it can be thought of as cured,
- A partial response is a decrease in cancer size by at least 30% for at least four weeks, without any signs of growth elsewhere in the body,
- Stable disease is when the cancer has shrunk in size, but by less than 30%, and there are no signs of growth elsewhere in the body (MACMILLAN, 2015h).

These definitions also help doctors to describe the effects of the drugs on the tumours in a standard way.

Some trials look at long-term outcomes of treatment. In a Phase 3 trials, researchers are often looking at how long people live after the treatment (survival). Doctors and researchers monitor whether more people are cured, or live longer, with the new treatment (MACMILLAN, 2015h).

Finding out results

The results of most clinical trials will be published in medical journals. However, a final report of a trial may not be published until many years after people were treated. If you don't read medical journals, you may not get to know the results.

But sometimes they are published in newspapers or discussed on TV or the radio, especially if the results are presented at doctors' conferences.

Researchers are expected to think about how people taking part in their trial will be told the results. If this isn't explained to you when you join the trial, ask the research team.

Generally the best way to find out results is to ask your specialist. However, more patients are now being contacted directly when results of trials are available (MACMILLAN, 2015h).

Finding out about current clinical trials

To be able to take part in a trial, your cancer specialist or GP has to refer you to the doctor in charge of the trial. It can sometimes be difficult to find a trial to take part in. Your cancer specialist or specialist nurse should be able to tell you about trials in your area, and they may know of other trials that might be suitable for you. Not all hospitals have the facilities or expertise to take part in some trials, so you may have to travel to a different hospital.

If you've been invited to take part in a clinical trial, you may be introduced to a research nurse. They can tell you all about the trial and answer your questions.

If you'd like to find out about other trials that may be suitable, our cancer support specialists on 0808 808 00 00 can give you information about current trials available nationwide (MACMILLAN, 2015c).

You can search for trials in the UK on websites such as -

- Cancer Research UK,
- UK Clinical Trials Gateway (MACMILLAN, 2015c).

Taking part in a clinical trial abroad

It can sometimes be possible to take part in a trial abroad. This may mean that you have to pay for the treatment as well as your travel costs, which can be very expensive. Try to get as much information as possible about the trials from trustworthy sources and websites. It's a good idea to be cautious of trials run by small clinics rather than research hospitals. Also, be careful to avoid trials offering 'miracle cures', often at great expense, as these are unlikely to help you.

You can discuss any trials with your cancer specialist, who can give you further advice. Trials conducted abroad may not be regulated in the same strict way that trials in the UK are.

You can search for trials abroad on websites such as the US website National Cancer Institute. This website also lists UK trials (MACMILLAN, 2015c).

Influencing future research

New clinical trials are being set up all the time. Some are started by the government-funded Medical Research Council (MRC) or the National Cancer Research Institute (NCRI). Others are started by charities such as Cancer Research UK. Clinical trials are also set up by international organisations or drug companies.

Many of these organisations have patient groups that help to decide on areas that need further research. Cancer specialists are very aware of the gaps in their understanding of the diagnosis and treatment of cancer, but patients, their families and friends may see other aspects of their care that need further research. If you have any thoughts about research that might be useful, talk to your doctor or nurse.

The organisation INVOLVE has information and advice about how you can get involved with research (MACMILLAN, 2015c).

Chapter 6

Cancer

Contents

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This section refers to any form of non-genderised cancer, i.e. it can occur in women or men.

Bladder cancer

Bladder cancer is where a growth of abnormal tissue, known as a tumour, develops in the bladder lining. In some cases, the tumour spreads into the surrounding muscles.

The most common symptom of bladder cancer is blood in your urine, which is usually painless.

If you notice blood in your urine, even if it comes and goes, you should visit your GP, so the cause can be investigated (NHS, 2015a).

Symptoms

Blood in your urine is the most common symptom of bladder cancer. The medical name for this is haematuria and it's usually painless. You may notice streaks of blood in your urine or the blood may turn your urine brown. The blood isn't always noticeable and it may come and go (NHS, 2015a).

Less common symptoms of bladder cancer include -

- a need to urinate on a more frequent basis,
- sudden urges to urinate,
- a burning sensation when passing urine (NHS, 2015a).

If bladder cancer reaches an advanced stage and begins to spread, symptoms can include -

- pelvic pain,
- bone pain,
- unintentional weight loss,
- swelling of the legs (NHS, 2015a).

When to seek medical advice

If you ever have blood in your urine - even if it comes and goes - you should visit your GP, so the cause can be investigated (NHS, 2015a).

Having blood in your urine doesn't mean you definitely have bladder cancer. There are other, more common, causes including -

- a urinary tract infection, such as cystitis,
- a kidney infection,
- kidney stones,
- urethritis,
- an enlarged prostate gland, in men (NHS, 2015a).

Causes

Bladder cancer is caused by changes to the cells of the bladder. It's often linked with exposure to certain chemicals, but the cause isn't always known (NHS, 2015a).

Increased risk

Several factors have been identified that can significantly increase your risk of developing bladder cancer (NHS, 2015a).

Smoking Smoking is the single biggest risk factor for bladder cancer. This is because tobacco contains cancer-causing (carcinogenic) chemicals.

If you smoke for many years, these chemicals pass into your bloodstream and are filtered by the kidneys into your urine. The bladder is repeatedly exposed to these harmful chemicals, as it acts as a store for urine. This can cause changes to the cells of the bladder lining, which may lead to bladder cancer.

It's estimated that just over a third of all cases of bladder cancer are caused by smoking. People who smoke may be up to four times more likely to develop bladder cancer than non-smokers (NHS, 2015a).

Exposure to chemicals Exposure to certain industrial chemicals is the second biggest risk factor. Previous studies have estimated that this may account for around 25% of cases (NHS, 2015a).

Chemicals known to increase the risk of bladder cancer include -

- aniline dyes,
- 2-Naphthylamine,
- 4-Aminobiphenyl,
- xenylamine,
- benzidine,
- o-toluidine (NHS, 2015a).

Occupations linked to an increased risk of bladder cancer are manufacturing jobs involving -

- dyes,
- textiles,
- rubbers,
- paints,
- plastics,
- leather tanning (NHS, 2015a).

Some non-manufacturing jobs have also been linked to an increased risk of bladder cancer. These include taxi or bus drivers, as a result of their regular exposure to the chemicals present in diesel fumes. The link between bladder cancer and these types of occupations was discovered in the 1950s and 1960s. Since then, regulations relating to exposure to cancer-causing chemicals have been made much more rigorous and many of the chemicals listed above have been banned.

However, these chemicals are still linked with cases of bladder cancer now, as it can take up to 30 years after initial exposure to the chemicals before the condition starts to develop (NHS, 2015a).

Other risk factors Other factors that can increase your risk of bladder cancer include -

- radiotherapy to treat previous cancers near the bladder, such as bowel cancer,
- previous treatment with certain chemotherapy medications, such as cyclophosphamide and cisplatin,
- previous surgery to remove part of the prostate gland, during treatment for benign prostate enlargement,
- having diabetes - bladder cancer is thought to be linked to certain treatments for type 2 diabetes,
- having a tube in your bladder (an indwelling catheter [26]) for a long time, because you have nerve damage that has resulted in paralysis,
- long-term or repeated urinary tract infections (UTIs),
- long-term bladder stones,
- having an early menopause (before the age of 42),
- an untreated infection called schistosomiasis, which is caused by a parasite that lives in fresh water - this is very rare in the UK (NHS, 2015a).

How does bladder cancer spread?

Bladder cancer usually begins in the cells of the bladder lining. In some cases, it may spread into surrounding bladder muscle. If the cancer penetrates this muscle, it can spread to other parts of the body, usually through the lymphatic system.

If bladder cancer spreads to other parts of the body, such as other organs, it's known as metastatic bladder cancer (NHS, 2015a).

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[26] a flexible tube used to drain the bladder and collect urine

Diagnosis

If you have symptoms of bladder cancer, such as blood in your urine, you should see your GP.

Your GP may ask about your symptoms, family history and whether you've been exposed to any possible causes of bladder cancer, such as smoking.

In some cases, your GP may request a urine sample, so it can be tested in a laboratory for traces of blood, bacteria or abnormal cells.

Your GP may also carry out a physical examination of your rectum and vagina, as bladder cancer sometimes causes a noticeable lump that presses against them.

If your doctor suspects bladder cancer, you'll be referred to a hospital for further tests.

In 2015, the National Institute for Health and Care Excellence (NICE) published guidelines to help GPs recognise the signs and symptoms of bladder cancer and refer people for the right tests faster. Find out who should be referred for further tests for suspected bladder cancer (NHS, 2015a).

At the hospital

Some hospitals have specialist clinics for people with blood in their urine (haematuria), while others have specialist urology departments for people with urinary tract problems (NHS, 2015a).

Cystoscopy If you're referred to a hospital specialist and they think you might have bladder cancer, you should first be offered a cystoscopy [27].

This procedure allows the specialist to examine the inside of your bladder by passing a cystoscope through your urethra [28]. A cystoscope is a thin tube with a camera and light at the end.

Before having a cystoscopy, a local anaesthetic gel is applied to your urethra so you don't feel any pain. The gel also helps the cystoscope to pass into the urethra more easily.

The procedure usually takes about five minutes (NHS, 2015a).

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[27] a medical procedure used to examine the inside of the bladder using an instrument called a cystoscope

[28] the tube through which you urinate

Imaging scans You may be offered a computerised tomography (CT) [29] scan or an magentic resonance imaging (MRI) [30] scan if the specialist feels they need a more detailed picture of your bladder.

An intravenous (IV) urogram may also be used to look at your whole urinary system before or after treatment for bladder cancer.

During this procedure, dye is injected into your bloodstream and X-rays [31] are used to study it as it passes through your urinary system (NHS, 2015a).

Transurethral resection of a bladder tumour (TURBT)

If abnormalities are found in your bladder during a cystoscopy, you should be offered an operation known as transurethral resection of a bladder tumour (TURBT). This is so any abnormal areas of tissue can be removed and tested for cancer (a biopsy).

TURBT is carried out under general anaesthetic.

Sometimes, a sample of the muscle wall of your bladder is also taken to check whether the cancer has spread, but this may be a separate operation within six weeks of the first biopsy.

You should also be offered a dose of chemotherapy after the operation. This may help to prevent the bladder cancer returning, if the removed cells are found to be cancerous (NHS, 2015a).

Staging and grading

Once these tests have been completed, it should be possible to tell you the grade of the cancer and what stage it is.

Staging is a measurement of how far the cancer has spread. Lower-stage cancers are smaller and have a better chance of successful treatment.

Grading is a measurement of how likely a cancer is to spread. The grade of a cancer is usually described using a number system ranging from G1 to G3. High-grade cancers are more likely to spread than low-grade cancers (NHS, 2015a).

The most widely used staging system for bladder cancer is known as the TNM system, where -

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[29] computerised tomography

[30] magentic resonance imaging

[31] a quick and painless procedure commonly used to produce images of the inside of the body

- **T** - stands for how far into the bladder the **tumour** has grown,
- **N** - stands for whether the cancer has spread into nearby lymph **nodes**,
- **M** - stands for whether the cancer has spread into another part of the body (**metastasis**), such as the lungs (NHS, 2015a).

T stages The T staging system is as follows -

- TIS or CIS (carcinoma in situ) - a very early high-grade cancer confined to the innermost layer of the bladder lining,
- Ta - the cancer is just in the innermost layer of the bladder lining,
- T1 - the cancerous cells have started to grow into the connective tissue beyond the bladder lining (NHS, 2015a).

Bladder cancer up to the T1 stage is usually called early bladder cancer or non-muscle-invasive bladder cancer (NHS, 2015a).

If the tumour grows larger than this, it's usually called muscle-invasive bladder cancer and is categorised as -

- T2 - the cancer has grown through the connective tissue, into the bladder muscle,
- T3 - the cancer has grown through the layer of muscles, into the surrounding layer of fat (NHS, 2015a).

If the tumour grows larger than the T3 stage, it's considered to be advanced bladder cancer and is categorised as -

- T4 - the cancer has spread outside the bladder, into surrounding organs (NHS, 2015a).

N stages The N staging system is as follows -

- N0 - there are no cancerous cells in any of your lymph nodes,
- N1 - there are cancerous cells in just one of your lymph nodes in your pelvis,
- N2 - there are cancerous cells in two or more lymph nodes in your pelvis,
- N3 - there are cancerous cells in one or more of your lymph nodes (known as common iliac nodes) deep in your groin (NHS, 2015a).

M stages There are only two options in the M system -

- M0 - where the cancer hasn't spread to another part of the body,
- M1 - where the cancer has spread to another part of the body, such as the bones, lungs or liver (NHS, 2015a).

The TNM system can be difficult to understand, so don't be afraid to ask your care team questions about your test results and what they mean for your treatment and outlook (NHS, 2015a).

Treatment

The treatment options for bladder cancer largely depend on how advanced the cancer is.

Treatments usually differ between early stage, non-muscle-invasive bladder cancer and more advanced muscle-invasive bladder cancer (NHS, 2015a).

Multidisciplinary teams (MDTs)

All hospitals use MDTs to treat bladder cancer. These are teams of specialists that work together to make decisions about the best way to proceed with your treatment (NHS, 2015a).

Members of your MDT may include -

- a urologist - a surgeon specialising in treating conditions affecting the urinary tract,
- a clinical oncologist - a specialist in chemotherapy and radiotherapy,
- a pathologist - a specialist in diseased tissue,
- a radiologist - a specialist in detecting disease using imaging techniques (NHS, 2015a).

You should be given the contact details for a clinical nurse specialist, who will be in contact with all members of your MDT. They'll be able to answer questions and support you throughout your treatment.

Deciding what treatment is best for you can be difficult. Your MDT will make recommendations, but remember that the final decision is yours.

Before discussing your treatment options, you may find it useful to write a list of questions to ask your MDT (NHS, 2015a).

Non-muscle-invasive bladder cancer

If you've been diagnosed with non-muscle-invasive bladder cancer (stages CIS, Ta and T1), your recommended treatment plan depends on the risk of the cancer returning or spreading beyond the lining of your bladder (NHS, 2015a).

This risk is calculated using a series of factors, including -

- the number of tumours present in your bladder,
- whether the tumours are larger than 3cm (one inch) in diameter,
- whether you've had bladder cancer before,
- the grade of the cancer cells (NHS, 2015a).

These treatments are discussed in more detail below.

Low-risk Low-risk non-muscle-invasive bladder cancer is treated with TURBT. This procedure may be performed during your first cystoscopy, when tissue samples are taken for testing (see Diagnosis bladder cancer).

TURBT is carried out under a general anaesthetic. The surgeon uses an instrument called a cystoscope to locate the visible tumours and cut them away from the lining of the bladder. The wounds are sealed (cauterised) using a mild electric current, and you may be given a catheter to drain any blood or debris from your bladder over the next few days.

After surgery, you should be given a single dose of chemotherapy, directly into your bladder, using a catheter. The solution is kept in your bladder for around an hour before being drained away.

Most people are able to leave hospital less than 48 hours after having TURBT and are able to resume normal physical activity within two weeks.

You should be offered follow-up appointments at three months and nine months to check your bladder, using a cystoscopy. If your cancer returns after six months, and is small, you may be offered a treatment called fulguration. This involves using an electric current to destroy the cancer cells (NHS, 2015a).

Intermediate-risk People with intermediate-risk non-muscle-invasive bladder cancer should be offered a course of at least six doses of chemotherapy. The liquid is placed directly into your bladder, using a catheter, and kept there for around an hour before being drained away.

You should be offered follow-up appointments at three months, nine months, 18 months, then once every year. At these appointments, your bladder will be checked using a cystoscopy. If your cancer returns within five years, you'll be referred back to a specialist urology team.

Some residue of the chemotherapy medication may be left in your urine after treatment, which could severely irritate your skin. It helps if you urinate while sitting down and that you're careful not to splash yourself or the toilet seat. After passing urine, wash the skin around your genitals with soap and water.

If you're sexually active, it's important to use a barrier method of contraception, such as a condom. This is because the medication may be present in your semen or vaginal fluids, which can cause irritation.

You also shouldn't try to get pregnant or father a child while having chemotherapy for bladder cancer, as the medication can increase the risk of having a child with birth defects (NHS, 2015a).

High-risk People with high-risk non-muscle-invasive bladder cancer should be offered a second TURBT operation, within six weeks of the initial investigation (see Diagnosis bladder cancer). A CT scan or an MRI scan may also be required (NHS, 2015a).

Your urologist and clinical nurse specialist will discuss your treatment options with you, which will either be -

- a course of Bacillus Calmette-Guérin (BCG) treatment - using a variant of the BCG vaccine,
- an operation to remove your bladder (cystectomy) (NHS, 2015a).

The BCG vaccine is passed into your bladder through a catheter and left for two hours before being drained away. Most people require weekly treatments over a six-week period. Common side-effects of BCG include -

- a frequent need to urinate,
- pain when urinating,
- blood in your urine (haematuria),
- flu-like symptoms, such as tiredness, fever and aching,
- urinary tract infections (NHS, 2015a).

If BCG treatment doesn't work, or the side-effects are too strong, you'll be referred back to a specialist urology team.

You should be offered follow-up appointments every three months for the first two years, then every six months for the next two years, then once a year. At these appointments, your bladder will be checked using a cystoscopy.

If you decide to have a cystectomy, your surgeon will need to create an alternative way for urine to leave your body (urinary diversion). Your clinical nurse specialist can discuss your options for the procedure and how the urinary diversion will be created.

After having a cystectomy, you should be offered follow-up appointments including a CT scan at six and 12 months, and blood tests once a year. Men require an appointment to check their urethra once a year for five years (NHS, 2015a).

Muscle-invasive bladder cancer

The recommended treatment plan for muscle-invasive bladder cancer depends on how far the cancer has spread. With T2 and T3 bladder cancer, treatment aims to cure the condition if possible, or at least control it for a long time (NHS, 2015a).

Your urologist, oncologist and clinical nurse specialist will discuss your treatment options with you, which will either be -

- an operation to remove your bladder (cystectomy) - see above,
- radiotherapy with a radiosensitiser (NHS, 2015a).

Your oncologist should also discuss the possibility of having chemotherapy before either of these treatments (neoadjuvant therapy), if it's suitable for you (NHS, 2015a).

Radiotherapy with a radiosensitiser Radiotherapy is given by a machine that beams the radiation at the bladder (external radiotherapy). Sessions are usually given on a daily basis for five days a week over the course of four to seven weeks. Each session lasts for about 10 to 15 minutes.

A radiosensitiser should also be given alongside radiotherapy for muscle-invasive bladder cancer. This is a medicine which affects the cells of a tumour, to enhance the effect of radiotherapy. It has a much smaller effect on normal tissue (NHS, 2015a).

As well as destroying cancerous cells, radiotherapy can also damage healthy cells, which means it can cause a number of side-effects. These include -

- diarrhoea,
- inflammation of the bladder (cystitis),
- tightening of the vagina (in women), which can make having sex painful,
- erectile dysfunction (in men),
- loss of pubic hair,
- infertility,
- tiredness,
- difficulty passing urine (NHS, 2015a).

Most of these side-effects should pass a few weeks after your treatment finishes, although there's a chance they'll be permanent.

Having radiation directed at your pelvis usually means you'll be infertile for the rest of your life. However, most people treated for bladder cancer are too old to have children, so this isn't usually a problem.

After having radiotherapy for bladder cancer, you should be offered follow-up appointments every three months for the first two years, then every six months for the next two years, and every year after that. At these appointments, your bladder will be checked using a cystoscopy.

You may also be offered CT scans of your abdomen, pelvis and chest after six months, one year and two years. A CT scan of your urinary tract may be offered every year for five years (NHS, 2015a).

Surgery or radiotherapy?

Your MDT may recommend a specific treatment because of your individual circumstances.

For example, someone with a small bladder or many existing urinary symptoms is better suited to surgery. Someone who has a single bladder tumour with normal bladder function is better suited for treatments that preserve the bladder.

However, your input is also important, so you should discuss which treatment is best for you with your MDT.

There are pros and cons of both surgery and radiotherapy (NHS, 2015a).

The pros of having a radical cystectomy include -

- treatment is carried out in one go,
- you won't need regular cystoscopies after treatment, although other less invasive tests may be needed (NHS, 2015a).

The cons of having a radical cystectomy include -

- it can take up to three months to fully recover,
- a risk of general surgical complications, such as pain, infection and bleeding,
- a risk of complications from the use of general anaesthetic,
- an alternative way of passing urine out of your body needs to be created, which may involve an external bag,
- a high risk of erectile dysfunction in men (estimated at around 90%) as a result of nerve damage,
- after surgery, some women may find sex uncomfortable, as their vagina may be smaller,
- a small chance of a fatal complication, such as a heart attack, stroke or deep vein thrombosis (DVT) (NHS, 2015a).

The pros of having radiotherapy include -

- there's no need to have surgery, which is often an important consideration for people in poor health,
- your bladder function may not be affected, as your bladder isn't removed,
- there's less chance of causing erectile dysfunction (around 30%) (NHS, 2015a).

The cons of having radiotherapy include -

- you'll require regular sessions of radiotherapy for four to seven weeks,
- short-term side-effects are common, such as diarrhoea, tiredness and inflammation of the bladder (cystitis),
- a small chance of permanently damaging the bladder, which could lead to problems urinating,
- women may experience a narrowed vagina, making sex difficult and uncomfortable (NHS, 2015a).

Chemotherapy

In some cases, chemotherapy may be used during treatment for muscle-invasive bladder cancer. Instead of medication being put directly into your bladder, it's put into a vein in your arm. This is called intravenous chemotherapy and can be used -

- before radiotherapy and surgery to shrink the size of any tumours,
- in combination with radiotherapy before surgery (chemoradiation),
- to slow the spread of incurable advanced bladder cancer (palliative chemotherapy) (NHS, 2015a).

There isn't enough evidence to say whether chemotherapy is an effective treatment when it's given after surgery to prevent the cancer returning. It's usually only used this way as part of a clinical trial.

Chemotherapy is usually given over a few consecutive days at first. You'll then have a few weeks off to allow your body to recover before the treatment begins again. This cycle will be repeated for a few months.

As the chemotherapy medication is being injected into your blood, you'll experience a wider range of side-effects than if you were having chemotherapy directly into the bladder. These side-effects should stop after the treatment has finished.

Chemotherapy weakens your immune system, making you more vulnerable to infection. It's important to report any symptoms of a potential infection, such as a high temperature, persistent cough or reddening of the skin, to your MDT. Avoid close contact with people who are known to have an infection (NHS, 2015a).

Other side-effects of chemotherapy can include -

- nausea,
- vomiting,
- hair loss,
- lack of appetite,
- tiredness (NHS, 2015a).

Locally advanced or metastatic bladder cancer

The recommended treatment plan for locally advanced or metastatic bladder cancer depends on how far the cancer has spread. Your oncologist should discuss your treatment options with you, which may include -

- a course of chemotherapy,
- treatments to relieve cancer symptoms (NHS, 2015a).

Chemotherapy If you receive a course of chemotherapy, you'll be given a combination of drugs to help relieve the side-effects of treatment. Treatment may be stopped if chemotherapy isn't helping, or a second course may be offered (NHS, 2015a).

Relieving cancer symptoms You may be offered treatment to relieve any cancer symptoms. This may include -

- radiotherapy to treat painful urination, blood in urine, frequently needing to urinate or pain in your pelvic area,
- treatment to drain your kidneys, if they become blocked and cause lower back pain [32] (NHS, 2015a).

Palliative care

If you cancer is at an advanced stage and can't be cured, your MDT should discuss how the cancer will progress and which treatments are available to ease the symptoms.

You can be referred to a palliative care team, who can provide support and practical help, including pain relief (NHS, 2015a).

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[32] a common problem that affects most people at some point in their life

Complications

A diagnosis of bladder cancer, and some treatments for the condition, can have a significant impact on your life (NHS, 2015a).

Emotional impact

The emotional impact of living with bladder cancer can be huge. Many people report experiencing a kind of ”rollercoaster” effect. For example, you may feel down at receiving a diagnosis, up when the cancer is removed, and down again as you try to come to terms with the after-effects of your treatment (NHS, 2015a).

This type of emotional disruption can sometimes trigger feelings of depression. Signs that you may be depressed include -

- having continuous feelings of sadness or hopelessness,
- no longer taking pleasure in the things you enjoy (NHS, 2015a).

Contact your GP for advice if you think you may be depressed. There’s a range of relatively successful treatments for depression, including antidepressant medication [33] and therapies such as cognitive behavioural therapy (CBT) (NHS, 2015a).

Urinary diversion

If your bladder is removed, an alternative way of passing urine out of your body will be created during the operation. This is called urinary diversion.

There are various types of urinary diversion, which are described below. In some cases, you may be able to make a choice based on your personal preferences. However, certain treatment options will not be suitable for everyone.

Your MDT can provide information on the most suitable options for you (NHS, 2015a).

Urostomy A urostomy is carried out during a radical cystectomy. A small section of the small bowel is removed and connected to your ureters (the two tubes that normally carry urine out of the kidneys).

The surgeon then creates a small hole in the surface of your abdomen and the open end of the removed bowel is placed in this hole, creating an opening known as a stoma.

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[33] a type of medication used to treat clinical depression or prevent it recurring

A special waterproof bag is placed over the stoma to collect urine. A stoma nurse will teach you how to care for your stoma, and how and when to change the bag.

The Urostomy Association is a UK-based charity that provides information and assistance to people who have recently had, or are about to have, a urostomy (NHS, 2015a).

Continent urinary diversion Continent urinary diversion is similar to a urostomy, but without an external bag. Instead, a section of your bowel is used to create a pouch inside your body that stores urine.

The ureters are connected to the pouch and the pouch is connected to an opening in the abdominal wall. A valve in the opening (stoma) prevents urine leaking out.

The pouch is emptied using a thin, flexible tube (catheter). Most people need to empty their pouch about four or five times a day (NHS, 2015a).

Bladder reconstruction In some cases it may be possible to create a new bladder, known as a neobladder. This involves removing a section of your bowel and reconstructing it into a balloon-like sac, before connecting it to your urethra at one end and your ureters at the other end. However, bladder reconstruction isn't suitable for everyone.

You'll be taught how to empty your neobladder by relaxing the muscles in your pelvis, while tightening the muscles in your abdomen at the same time.

Your neobladder won't contain the same types of nerve endings as a real bladder, so you won't get the distinctive sensation that tells you to pass urine. Some people experience a feeling of fullness inside their abdomen, while others have reported they feel like they need to pass wind.

Because of the loss of normal nerve function, most people with a neobladder experience some episodes of urinary incontinence [34], which usually occurs during the night, while they're asleep.

You may find it useful to empty your neobladder at set times during the day, including before you go to bed, to help prevent incontinence (NHS, 2015a).

Sexual problems

Erectile dysfunction Contact your MDT if you lose the ability to obtain or maintain an erection after a radical cystectomy. It may be possible for you to be

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[34] the unintentional passing of urine

treated with a type of medicine known as phosphodiesterase type 5 inhibitors (PDE5). PDE5s work by increasing the blood supply to your penis.

PDE5s are sometimes combined with a device called a vacuum pump, which consists of a cylinder connected to a pump. The penis is placed inside the cylinder and the air is pumped out. This creates a vacuum that causes blood to flow into the penis. A rubber ring is then placed around the base of the penis, which allows an erection to be maintained for around 30 minutes (NHS, 2015a).

Narrowing of the vagina Both radiotherapy and cystectomy can cause a woman's vagina to become shortened and narrowed, which can make penetrative sex painful or difficult.

There are two main treatment options available if you have a narrowed vagina. The first is to apply hormonal cream to the area, which should help to increase moisture inside your vagina.

The second is to use vaginal dilators. These are plastic cone-shaped devices of various sizes that are designed to gently stretch your vagina and make it more supple.

It's usually recommended that you use dilators for a 5 to 10-minute period every day, starting with the dilator that fits in easiest first and gradually increasing the size, as your vagina stretches over the following weeks.

Many women find this an embarrassing issue to discuss, but the use of dilators is a well-recognised treatment for narrowing of the vagina. Your specialist cancer nurse should be able to provide more information and advice.

You may find that the more often you have penetrative sex, the less painful it becomes. However, it may be several months before you feel emotionally ready to be intimate with a sexual partner (NHS, 2015a).

Prevention

It's not always possible to prevent bladder cancer, but some risk factors have been identified, which may increase your risk of developing the condition (NHS, 2015a).

Stopping smoking

If you smoke, giving up is the best way to reduce your risk of developing bladder cancer and preventing it from recurring.

If you decide to stop smoking, your GP will be able to refer you to the NHS Stop Smoking Service, which provides dedicated help and advice about the best ways to give up smoking.

You can also call the NHS Smokefree helpline on 0300 123 1044 (England only). The specially trained helpline staff will offer you free expert advice and encouragement.

If you're committed to giving up smoking, but don't want to be referred to a stop smoking service, your GP should be able to prescribe medical treatment to help with any withdrawal symptoms you may experience after giving up (NHS, 2015a).

Workplace safety

Your risk of bladder cancer could be increased if your job involves exposure to certain chemicals. Occupations linked to an increased risk of bladder cancer are manufacturing jobs involving -

- rubber,
- dyes,
- textiles,
- plastic,
- leather tanning,
- diesel fumes (NHS, 2015a).

Nowadays, there are rigorous safety protocols in place designed to minimise your risk of exposure, and chemicals known to increase the risk of bladder cancer have been banned. If you're uncertain about what these protocols involve, talk to your line manager or health and safety representative.

If you're concerned that your employer may be disregarding recommendations about workplace safety, you should contact the Health and Safety Executive for advice (NHS, 2015a).

Diet

There's some evidence to suggest that a diet high in fruit and vegetables and low in fat can help to prevent bladder cancer.

Even though this evidence is limited, it's a good idea to follow this type of healthy diet, as it can help to prevent other types of cancer, such as bowel cancer, as well as serious health conditions, including high blood pressure (hypertension), stroke and heart disease.

A low-fat, high-fibre diet is recommended, including plenty of fresh fruit and vegetables (five portions a day) and whole grains. Limit the amount of salt you eat to no more than 6g (0.2oz) a day (one teaspoon) because too much can increase your blood pressure.

You should try to avoid foods that contain saturated fat, as it can increase your cholesterol levels (NHS, 2015a).

Foods high in saturated fat include -

- meat pies,
- sausages and fatty cuts of meat,
- butter,
- ghee (a type of butter often used in Indian cooking),
- lard,
- cream,
- hard cheese,
- cakes and biscuits,
- foods that contain coconut or palm oil (NHS, 2015a).

However, a balanced diet should include a small amount of unsaturated fat, because this will actually help to control your cholesterol levels (NHS, 2015a).

Foods high in unsaturated fat include -

- oily fish,
- avocados,
- nuts and seeds,
- sunflower, rapeseed, olive and vegetable oils (NHS, 2015a).

Bowel cancer

Bowel cancer is a general term for cancer that begins in the large bowel. Depending on where the cancer starts, bowel cancer is sometimes called colon or rectal cancer.

Cancer can sometimes start in the small bowel (small intestine), but small bowel cancer is much rarer than large bowel cancer.

Bowel cancer is one of the most common types of cancer diagnosed in the UK, with around 40,000 new cases diagnosed every year.

About 1 in every 20 people in the UK will develop bowel cancer in their lifetime (NHS, 2014a).

Symptoms

The three main symptoms of bowel cancer are blood in the stools (faeces), a change in bowel habit, such as more frequent, looser stools, and abdominal (tummy) pain.

However, these symptoms are very common. Blood in the stools is usually caused by haemorrhoids (piles), and a change in bowel habit or abdominal pain is often the result of something you have eaten.

In the UK, an estimated 7 million people have blood in the stools each year. Even more people have temporary changes in their bowel habits and abdominal pain. Most people with these symptoms do not have bowel cancer.

As the vast majority of people with bowel cancer are over the age of 60, these symptoms are more important as people get older. These symptoms are also more significant when they persist in spite of simple treatments (NHS, 2014a).

Most patients with bowel cancer present with one of the following symptom combinations -

- a persistent change in bowel habit, causing them to go to the toilet more often and pass looser stools, usually together with blood on or in their stools,
- a persistent change in bowel habit without blood in their stools, but with abdominal pain,
- blood in the stools without other haemorrhoid symptoms, such as soreness, discomfort, pain, itching, or a lump hanging down outside the back passage,
- abdominal pain, discomfort or bloating always provoked by eating, sometimes resulting in a reduction in the amount of food eaten and weight loss (NHS, 2014a).
- bleeding from your bottom and/or blood in your faeces,
- a change in bowel habit lasting three weeks or more,
- unexplained weight loss,
- extreme tiredness for no obvious reason,
- a pain or lump in your tummy (BOWELCANCERUK, 2016).
- a lump that your doctor can feel in your back passage or abdomen (more commonly on the right side),
- a feeling of needing to strain in your back passage (as if you need to pass a bowel motion), even after opening your bowels,
- pain in your back passage,
- a lower than normal level of red blood cells (anaemia) (CANCERRESEARCHUK, 2015a).

The symptoms of bowel cancer can be subtle and don't necessarily make you feel ill (NHS, 2014a).

When to seek medical advice

Try the bowel cancer symptom checker for advice on what treatments you can try to see if your symptoms get better, and when you should see your GP to discuss whether any tests are necessary.

Your doctor will probably perform a simple examination of your tummy and bottom to make sure you have no lumps, as well as a simple blood test to check for iron deficiency anaemia [35] - this can indicate whether there is any bleeding from your bowel you haven't been aware of.

In some cases, your doctor may decide it is best to have a simple test in hospital to make sure there is no serious cause for your symptoms.

Make sure you return to your doctor if your symptoms persist or keep coming back after stopping treatment, regardless of their severity or your age (NHS, 2014a).

Bowel obstruction

In some cases, bowel cancer can stop digestive waste passing through the bowel. This is known as a bowel obstruction (NHS, 2014a).

Symptoms of a bowel obstruction can include -

- severe abdominal pain, which may initially come and go,
- not being able to pass stools when you go to the toilet,
- noticeable swelling or bloating of the tummy,
- vomiting (NHS, 2014a).

A bowel obstruction is a medical emergency. If you suspect your bowel is obstructed, you should see your GP quickly. If this isn't possible, go to the accident and emergency (A&E) department of your nearest hospital (NHS, 2014a).

Causes

Cancer occurs when the cells in a certain area of your body divide and multiply too rapidly. This produces a lump of tissue known as a tumour.

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[35] a condition where a lack of iron in the body leads to a reduction in the number of red blood cells

Most cases of bowel cancer first develop inside clumps of cells on the inner lining of the bowel. These clumps are known as polyps [36]. However, if you develop polyps, it does not necessarily mean you will get bowel cancer.

Exactly what causes cancer to develop inside the bowel is still unknown. However, research has shown several factors may make you more likely to develop it. These factors are outlined below (NHS, 2014a).

Age

Your chances of developing bowel cancer increase as you get older. Almost 9 out of 10 cases of bowel cancer in the UK are diagnosed in people over the age of 60 (NHS, 2014a).

Family history

Having a family history of bowel cancer can increase your risk of developing the condition yourself, particularly if a close relative (mother, father, brother or sister) was diagnosed with bowel cancer below the age of 50.

If you are particularly concerned that your family's medical history may mean you are at an increased risk of developing bowel cancer, it may help to speak to your GP.

If necessary, your GP can refer you to a genetics specialist, who can offer more advice about your level of risk and recommend any necessary tests to periodically check for the condition (NHS, 2014a).

Diet

A large body of evidence suggests a diet high in red and processed meat can increase your risk of developing bowel cancer.

For this reason, the Department of Health advises people who eat more than 90g (cooked weight) a day of red and processed meat cut down to 70g a day.

There is also evidence that suggests a diet high in fibre could help reduce your bowel cancer risk (NHS, 2014a).

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[36] small growths on the inner lining of the colon (large bowel) or rectum. They are common, affecting 15%–20% of the UK population, and don't usually cause symptoms

Smoking

People who smoke cigarettes are more likely to develop bowel cancer, other types of cancer, and other serious conditions, such as heart disease (NHS, 2014a).

Alcohol

Drinking alcohol has been shown to be associated with an increased risk of bowel cancer, particularly if you regularly drink large amounts (NHS, 2014a).

Obesity

Being overweight or obese [37] is linked to an increased risk of bowel cancer, particularly in men.

If you are overweight or obese, losing weight may help lower your chances of developing the condition (NHS, 2014a).

Inactivity

People who are physically inactive have a higher risk of developing bowel cancer.

You can help reduce your risk of bowel and other cancers by being physically active every day (NHS, 2014a).

Digestive disorders

Some conditions affecting the bowel may put you at a higher risk of developing bowel cancer. For example, bowel cancer is more common in people who have had severe Crohn's disease [38] or ulcerative colitis [39] for many years.

If you have one of these conditions, you will usually have regular check-ups to look for signs of bowel cancer from about 10 years after your symptoms first develop.

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[37] a person who's very overweight, with a lot of body fat. Generally, men with a waist circumference of 94cm (37in) or more and women with a waist circumference of 80cm (about 31.5in) or more

[38] a long-term condition that causes inflammation of the lining of the digestive system

[39] a long-term condition, where the colon and rectum become inflamed

Check-ups will involve examining your bowel with a colonoscope - a long, narrow flexible tube that contains a small camera - that is inserted into your rectum.

The frequency of the colonoscopy examinations will increase the longer you live with the condition, and will also depend on factors such as how severe your ulcerative colitis is and if you have a family history of bowel cancer (NHS, 2014a).

Genetic conditions

There are two rare inherited conditions that can lead to bowel cancer. They are -

- **familial adenomatous polyposis (FAP)** - a condition that triggers the growth of non-cancerous polyps inside the bowel,
- **hereditary non-psolyposis colorectal cancer (HNPCC)**, also known as Lynch syndrome - an inherited gene fault (mutation) that increases your bowel cancer risk (NHS, 2014a).

Although the polyps caused by FAP are non-cancerous, there is a high risk that, over time, at least one will turn cancerous. Most people with FAP will have bowel cancer by the time they are 50.

As people with FAP have such a high risk of getting bowel cancer, they are often advised by their doctor to have their large bowel removed before they reach the age of 25.

Families affected can find support and advice from FAP registries such as The Polyposis Registry provided by St Mark's Hospital, London.

Removing the bowel as a precautionary measure is also usually recommended in people with HNPCC because the risk of developing bowel cancer is so high (NHS, 2014a).

Diagnosis

When you first see your GP, they will ask about your symptoms and whether you have a family history of bowel cancer.

They will then usually carry out a simple examination of your abdomen (tummy) and your bottom, known as a digital rectal examination (DRE) [40].

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[40] a type of physical examination during which a doctor or nurse inserts a finger into your rectum (back passage) to feel for abnormalities

This is a useful way of checking whether there are any lumps in your tummy or back passage. The tests can be uncomfortable, and most people find an examination of the back passage a little embarrassing, but they take less than a minute.

If your symptoms suggest you may have bowel cancer or the diagnosis is uncertain, you will be referred to your local hospital initially for a simple examination called a flexible sigmoidoscopy.

In 2015, the National Institute for Health and Care Excellence (NICE) published guidelines to help GPs recognise the signs and symptoms of bowel cancer and refer people for the right tests faster.

To find out if you should be referred for further tests for suspected bowel cancer, read the NICE 2015 guidelines on suspected cancer: recognition and referral (NHS, 2014a).

Flexible sigmoidoscopy

A flexible sigmoidoscopy is an examination of your rectum and some of your large bowel using a device called a sigmoidoscope.

A sigmoidoscope is a long, thin, flexible tube attached to a very small camera and light. It is inserted into your rectum and up into your bowel.

The camera relays images to a monitor, and can also be used to take biopsies [41], where a small tissue sample is removed for further analysis.

It is better for your lower bowel to be as empty as possible when sigmoidoscopy is performed, so you may be asked to carry out an enema - a simple procedure to flush your bowels - at home beforehand. This should be used at least two hours before you leave home for your appointment.

A sigmoidoscopy can feel uncomfortable, but it only takes a few minutes and most people go home straight after the examination (NHS, 2014a).

More detailed tests

Most people with bowel cancer can be diagnosed by flexible sigmoidoscopy. However, some cancers can only be diagnosed by a more extensive examination of the colon.

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[41] a medical procedure that involves taking a small sample of body tissue so it can be examined under a microscope

The two tests used for this are colonoscopy and computerised tomography (CT) [42] colonography. These tests are described in more detail below (NHS, 2014a).

Colonoscopy A colonoscopy is an examination of your entire large bowel using a device called a colonoscope, which is like a sigmoidoscope but a bit longer.

Your bowel needs to be empty when a colonoscopy is performed, so you will be advised to eat a special diet for a few days beforehand and take a laxative on the morning of the examination.

You will be given a sedative to help you relax during the test, after which the doctor will insert the colonoscope into your rectum and move it along the length of your large bowel. This is not usually painful, but can feel uncomfortable.

The camera relays images to a monitor, which allows the doctor to check for any abnormal areas within the rectum or bowel that could be the result of cancer. As with a sigmoidoscopy, a biopsy may also be performed during the test.

A colonoscopy usually takes about an hour to complete, and most people can go home once they have recovered from the effects of the sedative.

After the procedure, you will probably feel drowsy for a while, so you will need to arrange for someone to accompany you home. It is best for elderly people to have someone with them for 24-hours after the test. You will be advised not to drive for 24-hours.

In a small number of people, it may not be possible to pass the colonoscope completely around the bowel, and it is then necessary to have CT colonography (NHS, 2014a).

CT colonography CT colonography, also known as a ”virtual colonoscopy”, involves using a computerised tomography (CT) scanner [43] to produce three-dimensional images of the large bowel and rectum.

During the procedure, gas is used to inflate the bowel using a thin, flexible tube placed in your rectum. CT scans are then taken from a number of different angles.

As with a colonoscopy, you may need to have a special diet for a few days and take a laxative before the test to ensure your bowels are empty when the test is carried out.

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[42] uses X-rays and a computer to create detailed images of the inside of the body

[43] uses X-rays and a computer to create detailed images of the inside of the body

This test can help identify potentially cancerous areas in people who are not suitable for a colonoscopy because of other medical reasons.

A CT colonography is a less invasive test than a colonoscopy, but you may still need to have colonoscopy or flexible sigmoidoscopy at a later stage so any abnormal areas can be removed or biopsied (NHS, 2014a).

Further tests

If a diagnosis of bowel cancer is confirmed, further testing is usually carried out to check if the cancer has spread from the bowel to other parts of the body. These tests also help your doctors decide on the most effective treatment for you (NHS, 2014a).

These tests can include -

- **a CT scan of your abdomen and chest** - this will check if the rest of your bowel is healthy and whether the cancer has spread to the liver or lungs,
- **a magnetic resonance imaging (MRI) scan** [44] - this can provide a detailed image of the surrounding organs in people with cancer in the rectum (NHS, 2014a).

Staging and grading

Once the above examinations and tests have been completed, it should be possible to determine the stage and grade of your cancer.

Staging refers to how far your cancer has advanced. Grading relates to how aggressive your cancer is and how likely it is to spread.

This is important, as it helps your treatment team choose the best way of curing or controlling the cancer.

A number of different staging systems are used by doctors. A simplified version of one of the common systems used is outlined below (NHS, 2014a).

- **stage 1** - the cancer is still contained within the lining of the bowel or rectum,
- **stage 2** - the cancer has spread beyond the layer of muscle surrounding the bowel and may have penetrated the surface covering the bowel or nearby organs,

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[44] a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body

- **stage 3** - the cancer has spread into nearby lymph nodes,
- **stage 4** - the cancer has spread beyond the bowel into another part of the body, such as the liver (NHS, 2014a).

There are three grades of bowel cancer -

- **grade 1** - a cancer that grows slowly and has a low chance of spreading beyond the bowel,
- **grade 2** - a cancer that grows moderately and has a medium chance of spreading beyond the bowel,
- **grade 3** - a cancer that grows rapidly and has a high chance of spreading beyond the bowel (NHS, 2014a).

If you are not sure what stage or grade of cancer you have, ask your doctor (NHS, 2014a).

Treatment

Surgery is usually the main treatment for bowel cancer, and may be combined with chemotherapy, radiotherapy or biological treatments, depending on your particular case.

The treatments recommended for you will depend on which part of your bowel is affected and how far the cancer has spread, but surgery is usually the main treatment.

If it's detected early enough, treatment can cure bowel cancer and stop it coming back. Unfortunately, a complete cure is not always possible and there is sometimes a risk that the cancer could recur at a later stage.

In more advanced cases that cannot be removed completely by surgery, a cure is highly unlikely.

However, symptoms can be controlled and the spread of the cancer can be slowed using a combination of surgery, chemotherapy, radiotherapy and biological treatments where appropriate (NHS, 2014a).

Your treatment team

If you are diagnosed with bowel cancer, you will be cared for by a multidisciplinary team, which will include a specialist cancer surgeon, an oncologist (a radiotherapy and chemotherapy specialist), a radiologist, and a specialist nurse.

When deciding what treatment is best for you, your care team will consider the type and size of the cancer, your general health, whether the cancer has spread to other parts of your body, and how aggressive the cancer is (NHS, 2014a).

Surgery for colon cancer

If colon cancer is at a very early stage, it may be possible to remove just a small piece of the lining of the colon wall. This is known as local excision.

If the cancer spreads into muscles surrounding the colon, it will usually be necessary to remove an entire section of your colon. This is known as a colectomy (NHS, 2014a).

There are two ways a colectomy can be performed -

- **an open colectomy** - where the surgeon makes a large cut (incision) in your abdomen and removes a section of your colon,
- **a laparoscopic (keyhole) colectomy** - where the surgeon makes a number of small incisions in your abdomen and uses special instruments guided by a camera to remove a section of colon (NHS, 2014a).

During surgery, nearby lymph nodes are also removed. It is usual to join the ends of the bowel together after bowel cancer surgery, but very occasionally this is not possible and a stoma is needed.

Both open and laparoscopic colectomies are thought to be equally effective at removing cancer and have similar risks of complications.

However, laparoscopic colectomies have the advantage of a faster recovery time and less postoperative pain. It is becoming the routine way of doing most of these operations.

Laparoscopic colectomies should be available in all hospitals that carry out bowel cancer surgery, although not all surgeons perform this type of surgery. Discuss your options with your surgeon to see if this method can be used (NHS, 2014a).

Surgery for rectal cancer

There are a number of different types of operation that can be carried out to treat rectal cancer, depending on how far the cancer has spread.

Some of the main techniques used are described below (NHS, 2014a).

Local resection If you have a very small, early-stage rectal cancer, your surgeon may be able to remove it in an operation called a local resection (transanal resection).

The surgeon puts an endoscope in through your back passage and removes the cancer from the wall of the rectum (NHS, 2014a).

Total mesenteric excision In many cases, however, a local resection is not possible. Instead, a larger area of the rectum will need to be removed.

This area will include a border of rectal tissue free of cancer cells, as well as fatty tissue from around the bowel (the mesentery). This type of operation is known as total mesenteric excision (TME).

Removing the mesentery can help ensure all the cancerous cells are removed, which can lower the risk of the cancer recurring at a later stage.

Depending on where in your rectum the cancer is located, one of two main TME operations may be carried out. These are outlined below (NHS, 2014a).

Low anterior resection Low anterior resection is a procedure used to treat cases where the cancer is in the upper section of your rectum.

The surgeon will make an incision in your abdomen and remove the upper section of your rectum, as well as some surrounding tissue to make sure any lymph glands containing cancer cells are also removed.

They will then attach your colon to the lowest part of your rectum or upper part of the anal canal. Sometimes they turn the end of the colon into an internal pouch to replace the rectum.

You will probably require a temporary stoma to give the joined section of bowel time to heal (NHS, 2014a).

Abdominoperineal resection Abdominoperineal resection is used to treat cases where the cancer is in the lowest section of your rectum.

In this case, it will be necessary to remove the whole of your rectum and surrounding muscles to reduce the risk of the cancer regrowing in the same area.

This involves removing and closing the anus and removing its sphincter muscles, so there is no option except to have a permanent stoma after the operation.

Bowel cancer surgeons always do their best to avoid giving people permanent stomas wherever possible (NHS, 2014a).

Stoma surgery

Where a section of the bowel is removed and the remaining bowel joined, the surgeon may sometimes decide to divert your stool away from the join to allow it to heal.

The stool is temporarily diverted by bringing a loop of bowel out through the abdominal wall and attaching it to the skin - this is called a stoma. A bag is worn over the stoma to collect the stool.

When the stoma is made from the small bowel (ileum) it is called an ileostomy, and when it is made from the large bowel (colon) it is called a colostomy.

A specialist nurse, known as a stoma care nurse, can advise you on the best site for a stoma prior to surgery.

The nurse will take into account factors such as your body shape and lifestyle, although this may not be possible where surgery is performed in an emergency.

In the first few days after surgery, the stoma care nurse will advise on the care necessary to look after the stoma and the type of bag suitable.

Once the join in the bowel has safely healed, which can take several weeks, the stoma can be closed during further surgery.

In some people, for various reasons, rejoining the bowel may not be possible or may lead to problems controlling bowel function, and the stoma may become permanent.

Before having surgery, the care team will advise you about whether it may be necessary to form an ileostomy or colostomy, and the likelihood of this being temporary or permanent.

There are patient support groups available that provide support for patients who have just had or are about to have a stoma. You can get more details from your stoma care nurse, or visit the groups online for further information (NHS, 2014a).

These include -

- Colostomy Association,
- Ileostomy and Internal Pouch Support Group - this organisation provides a unique visiting service for anyone wishing to speak with someone who has been through similar surgery (NHS, 2014a).

Side-effects of surgery

Bowel cancer operations carry many of the same risks as other major operations, including bleeding, infection, developing blood clots, or heart or breathing problems.

The operations all carry a number of risks specific to the procedure. One risk is that the joined up section of bowel may not heal properly and leak inside your abdomen. This is usually only a risk in the first few days after the operation.

Another risk is for people having rectal cancer surgery. The nerves that control urination and sexual function are very close to the rectum, and sometimes surgery to remove a rectal cancer can damage these nerves.

After rectal cancer surgery, most people need to go to the toilet to open their bowels more often than before, although this usually settles down within a few months of the operation (NHS, 2014a).

Radiotherapy

There are two main ways radiotherapy can be used to treat bowel cancer. It can be given before surgery to shrink rectal cancers and increase the chances of complete removal, or be used to control symptoms and slow the spread of cancer in advanced cases (palliative radiotherapy) (NHS, 2014a).

Radiotherapy given before surgery for rectal cancer can be performed in two ways -

- **external radiotherapy** - where a machine is used to beam high-energy waves at your rectum to kill cancerous cells,
- **internal radiotherapy (brachytherapy)** - where a radioactive tube is inserted into your anus and placed next to the cancer to shrink it (NHS, 2014a).

External radiotherapy is usually given daily, five days a week, with a break at the weekend. Depending on the size of your tumour, you may need one to five weeks of treatment. Each session of radiotherapy is short and will only last for 10 to 15 minutes.

Internal radiotherapy can usually be performed in one session before surgery is carried out a few weeks later.

Palliative radiotherapy is usually given in short daily sessions, with a course ranging from 2 to 3 days, up to 10 days (NHS, 2014a).

Short-term side-effects of radiotherapy can include -

- feeling sick,
- fatigue,
- diarrhoea,
- burning and irritation of the skin around the rectum and pelvis - this looks and feels like sunburn,
- a frequent need to urinate,
- a burning sensation when passing urine (NHS, 2014a).

These side-effects should pass once the course of radiotherapy has finished. Tell your care team if the side-effects of treatment become particularly troublesome. Additional treatments are often available to help you cope with the side- effects better (NHS, 2014a).

Long-term side-effects of radiotherapy can include -

- a more frequent need to pass urine or stools,
- blood in your urine and stools,
- infertility,
- erectile dysfunction (NHS, 2014a).

If you want to have children, it may be possible to store a sample of your sperm or eggs before treatment begins so they can be used in fertility treatments in the future (NHS, 2014a).

Chemotherapy

There are three ways chemotherapy can be used to treat bowel cancer -

- before surgery - used in combination with radiotherapy to shrink the tumour,
- after surgery - to reduce the risk of the cancer recurring,
- palliative chemotherapy - to slow the spread of advanced bowel cancer and help control symptoms (NHS, 2014a).

Chemotherapy for bowel cancer usually involves taking a combination of medications that kill cancer cells. They can be given as a tablet (oral chemotherapy), through a drip in your arm (intravenous chemotherapy), or as a combination of both.

Treatment is given in courses (cycles) that are two to three weeks long each, depending on the stage or grade of your cancer.

A single session of intravenous chemotherapy can last from several hours to several days.

Most people having oral chemotherapy take tablets over the course of two weeks before having a break from treatment for another week.

A course of chemotherapy can last up to six months, depending on how well you respond to the treatment. In some cases, it can be given in smaller doses over longer periods of time (maintenance chemotherapy) (NHS, 2014a).

Side-effects of chemotherapy can include -

- fatigue,
- feeling sick,
- vomiting,
- diarrhoea,
- mouth ulcers [45],
- hair loss with certain treatment regimens, but this is generally uncommon in the treatment of bowel cancer,
- a sensation of numbness, tingling or burning in your hands, feet and neck (NHS, 2014a).

These side-effects should gradually pass once your treatment has finished. It usually takes a few months for your hair to grow back if you experience hair loss.

Chemotherapy can also weaken your immune system, making you more vulnerable to infection.

Inform your care team or GP as soon as possible if you experience possible signs of an infection, including a high temperature (fever) or a sudden feeling of being generally unwell.

Medications used in chemotherapy can cause temporary damage to men's sperm and women's eggs. This means that for women who become pregnant or for men who father a child, there is a risk to the unborn baby's health.

It is therefore recommended you use a reliable method of contraception while having chemotherapy treatment and for a period after your treatment has finished (NHS, 2014a).

Biological treatments

Biological treatments, including cetuximab, bevacizumab and panitumumab, are a newer type of medication also known as monoclonal antibodies.

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[45] painful sores that appear in the mouth

Monoclonal antibodies are antibodies that have been genetically engineered in a laboratory. They target special proteins found on the surface of cancer cells, known as epidermal growth factor receptors (EGFR).

As EGFRs help the cancer grow, targeting these proteins can help shrink tumours, and improve the effect and outcome of chemotherapy.

Biological treatments are therefore usually used in combination with chemotherapy when the cancer has spread beyond the bowel (metastatic bowel cancer).

These treatments are not available to everyone with bowel cancer. The National Institute for Health and Care Excellence (NICE) has specific criteria that need to be met before these can be prescribed (NHS, 2014a).

Cetuximab is only available on the NHS when -

- surgery to remove the cancer in the colon or rectum has been carried out or is possible,
- bowel cancer has spread to the liver and cannot be removed surgically,
- a person is fit enough to undergo surgery to remove the cancer from the liver if this becomes possible after treatment with cetuximab (NHS, 2014a).

Cetuximab, bevacizumab and panitumumab are available on the NHS through a government scheme called the Cancer Drugs Fund. All these medications are also available privately, but are very expensive (NHS, 2014a).

Living with bowel cancer

See Living with cancer.

Kidney cancer

Kidney cancer is the eighth most common cancer in adults in the UK, with just over 10,100 people diagnosed each year.

In around half of all cases of kidney cancer there are no symptoms, and the condition is detected during tests for other unrelated conditions (NHS, 2015c).

Symptoms

Most cases of kidney cancer don't cause any symptoms in the early stages.

The most common symptoms of mid- to advanced-stage kidney cancer are -

- blood in your urine (haematuria) - the amount of blood is usually high enough to change the colour of your urine to a reddish or dark brown colour,
- a persistent pain in your side, just below the ribs,
- a lump or swelling in the area of your kidneys (on either side of the body) (NHS, 2015c).

However, in around half of all cases the cancer causes no symptoms and is only detected during a routine ultrasound scan [46] (NHS, 2015c).

Less common symptoms of kidney cancer include -

- extreme tiredness (fatigue) or anaemia,
- unintentional weight loss,
- a high temperature of 38'C (100.4'F) or above,
- night sweats,
- a general sense of feeling unwell,
- swelling of the veins in the testicles (in men),
- loss of appetite,
- high blood pressure (hypertension) (NHS, 2015c).

When to seek medical advice

See your GP immediately if you have pain or a swelling or lump in your kidney area (on either side of your body, just below your ribcage).

You should also see your GP if you have blood in your urine. Although it's highly unlikely to be caused by kidney cancer, it could be a symptom of a less serious condition that still requires treatment, such as a kidney stone or bladder stone (NHS, 2015c).

Causes

The exact cause of kidney cancer is unknown, but there are risk factors that can increase the chances of developing the condition.

The three main risk factors for kidney cancer are -

- obesity,
- smoking,
- family history and genetics (NHS, 2015c).

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[46] this is sometimes called a sonogram, and is a procedure that uses high-frequency sound waves to create an image of part of the inside of the body

Obesity

Obesity is a significant risk factor for kidney cancer.

A study carried out by Cancer Research UK in 2011 found that around a quarter of kidney cancer cases are associated with being overweight or obese (25% of cases in men and 22% in women).

There's a strong link between someone's body mass index (BMI) [47] and their risk of developing kidney cancer. You can read more about how BMI is calculated, and work out your BMI using the healthy weight calculator.

A BMI score of 25 or above has been shown to increase a person's chances of developing kidney cancer. Those with a a BMI score of 30 or above are at particularly high risk.

This may be because overweight or obese people, particularly women, have higher levels of a hormone called oestrogen in their body. It's thought that excess levels of oestrogen may stimulate the growth of cancerous cells.

Cases of kidney cancer have been increasing over the last 40 years, which has been linked to rising obesity levels (NHS, 2015c).

Smoking

Smoking is also a significant risk factor for developing kidney cancer, and the more you smoke the greater the risk.

For example, research has shown that if you regularly smoke 10 cigarettes a day, you're one-and-a-half times more likely to develop kidney cancer compared to a non-smoker. This increases to twice as likely if you smoke 20 or more cigarettes a day.

It's not clear why smoking increases your chances of developing kidney cancer (NHS, 2015c).

Family history and genetics

If you have a close family member (parents, brothers, sisters or a child) who's been diagnosed with kidney cancer, you're about twice as likely to develop kidney cancer yourself (NHS, 2015c).

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[47] it is a measure of body fat based on your weight in relation to your height, and applies to most adult men and women aged 20 and over

Examples of inherited genetic conditions and syndromes that increase your risk of developing kidney cancer include -

- **tuberous sclerosis** - a rare genetic condition that causes multiple non-cancerous (benign) tumours to grow in the body; it's autosomal dominant, which means you only have to inherit the faulty gene from one parent to get it; about one in every 100 people with tuberous sclerosis will develop kidney cancer,
- **hereditary papillary kidney cancer** - a rare form of cancer caused by faulty genes inherited from your parents; it's autosomal dominant and causes small, slow-growing, cancerous tumours to develop in the kidneys, which can sometimes spread,
- **hereditary leiomyomatosis and renal cell carcinoma (HLRCC)** - a rare, autosomal dominant form of cancer, where cancerous tumours develop from smooth muscle tissue (leiomyomatas); people with HLRCC have a 10–16% increased risk of developing kidney cancer,
- **Von Hippel-Lindau syndrome** - a rare genetic syndrome that causes small non-cancerous tumours to develop inside the nervous system; VHL is also autosomal dominant and about 4 out of 10 people who have it develop kidney cancer,
- **Birt-Hogg-Dubé syndrome** - an inherited syndrome that causes non-cancerous tumours to develop in the hair follicles of the skin; they usually occur on the face, neck and torso (NHS, 2015c).

Other possible risk factors

There are also a number of other possible risk factors for developing kidney cancer, including -

- **mild painkillers** - some mild painkillers have been linked to an increased risk of developing kidney cancer; NSAIDs, such as ibuprofen, may slightly increase the risk, although occasional use or low doses are unlikely to be harmful,
- **kidney disease** - if you have kidney failure and need to have regular dialysis (treatment to replicate the functions of the kidneys), your risk of developing kidney cysts and kidney cancer is increased,
- **high blood pressure (hypertension)** - high blood pressure is a known risk factor for kidney disease, and you're up to twice as likely to develop kidney cancer if you have raised blood pressure (NHS, 2015c).

Diagnosis

In many cases, kidney cancer is diagnosed after routine scans and check-ups, as the condition doesn't always have obvious symptoms (NHS, 2015c).

Seeing your GP

You should see a GP if you have any symptoms of kidney cancer, such as blood in your urine or a constant pain below your ribs.

Your GP will examine you and, if they think your symptoms need further assessment, refer you to a specialist urologist (a doctor who specialises in conditions that affect the urinary tract).

If you notice blood in your urine, your GP will usually carry out a blood test and take a urine sample. The results will help rule out other possible causes, such as infection or kidney stones.

In 2015, the National Institute for Health and Care Excellence (NICE) published guidelines to help GPs recognise the signs and symptoms of renal (kidney) cancer and refer people for the right tests faster. To find out if you should be referred for further tests for suspected kidney cancer, read the NICE 2015 guidelines on Suspected Cancer: Recognition and Referral.

If you need to be referred urgently, you'll usually be seen within two weeks (NHS, 2015c).

Further tests

If your GP refers you to a hospital specialist, further tests will help determine whether you have kidney cancer (NHS, 2015c).

Ultrasound scan An ultrasound scan uses high-frequency sound waves to create an image of an organ in the body. It can often detect changes in the shape of the kidney that might be caused by a cancerous tumour.

An ultrasound scan may be needed if the cause of the blood in your urine can't be found (NHS, 2015c).

Computerised tomography scan You may also be referred for a computerised tomography (CT) scan [48]. During a CT scan, a series of detailed images of the inside of your body are taken and put together by a computer.

If you have a CT scan, you may be given a special dye to drink, or it may be injected. The dye makes the results of the CT scan clearer (NHS, 2015c).

Image-guided biopsy In some cases of kidney cancer, an image-guided biopsy is carried out. It's a minor surgical procedure performed under local anaesthetic. This means you'll be awake during the procedure, but the area surrounding the affected kidney will be numbed, so that you don't feel anything.

During an image-guided biopsy, a radiologist or surgeon will use an ultrasound or CT scan to guide a needle through your skin and into your kidney. A small tissue sample will be removed from your kidney and examined under a microscope to check for cancerous cells (NHS, 2015c).

Magnetic resonance imaging (MRI) scan You may also need to have a magnetic resonance imaging (MRI) scan, which can be used to produce detailed images of your kidneys. The images can help identify a tumour and determine its size (NHS, 2015c).

Cystoscopy A cystoscopy is a medical procedure that uses an instrument called a cystoscope to examine the inside of your bladder and urinary system.

This procedure doesn't look at the kidneys, but it can rule out or confirm whether any bleeding is coming from problems in the bladder (NHS, 2015c).

Intravenous pyelogram (IVP) An intravenous pyelogram (IVP) test involves injecting a dye into your bloodstream. X-rays are taken after a short time, with the dye highlighting any growths present in the kidneys (NHS, 2015c).

Staging and grading

If kidney cancer is confirmed, it's usually possible to determine its grade and stage.

The stage describes how far the cancer has spread, and the grade describes how aggressive the cancer is and how quickly it's likely to spread.

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[48] uses X-rays and a computer to create detailed images of the inside of the body

Both the stage and grade of your kidney cancer will help determine your recommended treatment and the likelihood of achieving a cure.

Healthcare professionals use the TNM system to stage kidney cancer -

- **T** - indicates how large the tumour has grown (a tumour is a lump of cancerous tissue),
- **N** - indicates whether nearby lymph nodes are affected (lymph nodes are small, oval-shaped glands found throughout the body, which help protect against infection),
- **M** - indicates whether the cancer has spread to another part of the body (M stands for metastases, which is the medical term for cancer that has spread) (NHS, 2015c).

The stages of tumour size are -

- T1a - where the tumour is less than 4cm (about 1.6 inches) in diameter,
- T1b - where the tumour is 4–7cm (about 1.6–2.8 inches) in diameter,
- T2 - where the tumour is larger than 7cm (2.8 inches) in diameter, but hasn't spread out of the kidney,
- T3a - where the tumour has spread into the adrenal gland or the layer of fat surrounding the kidney,
- T3b - where the tumour has spread into the renal vein (the vein that carries blood back from the kidney to the heart) or into the vena cava (the vein that carries blood back from the top half of the body),
- T3c - where the tumour has spread past the diaphragm (the sheet of muscle that separates the top part of the abdomen from the bottom part),
- T4 - where the tumour has spread beyond the tough layer of tissue that surrounds and protects the kidney (NHS, 2015c).

There are three lymph node stages -

- N0 - where no lymph nodes have been affected,
- N1 - where there are cancer cells in one lymph node,
- N2 - where there are cancer cells in two or more lymph nodes (NHS, 2015c).

M0 means that the cancer hasn't spread to another part of the body. M1 means that the cancer has spread.

Kidney cancer is graded using a scale of one to four. The higher the grade, the more aggressive the cancer (NHS, 2015c).

Treatment

The treatment of kidney cancer depends on the size and spread of the cancer. Surgery is the most common first course of action, with the aim of removing the cancer cells.

Unlike most other cancers, chemotherapy isn't very effective in treating kidney cancer. However, there are non-surgical treatments available, such as radiotherapy or targeted drug therapies.

The main treatments for kidney cancer are covered in detail below and include -

- Nephrectomy,
- Embolisation,
- Radiotherapy,
- Targeted therapies,
- Immunotherapy (NHS, 2015c).

Your treatment plan

You can expect to be cared for by the MDT, often comprising a specialist cancer surgeon, an oncologist (who specialises in radiotherapy and chemotherapy), a radiologist, a nephrologist (a kidney specialist) and a specialist nurse.

You'll be given a key worker, usually the specialist nurse, who will be responsible for coordinating your care.

Your team will recommend what they think is the best treatment option, but the final decision will be yours (NHS, 2015c).

When deciding what treatment is best for you, your doctors will consider -

- the stage and grade of your cancer (how big it is and how far it's spread),
- your age and general health (NHS, 2015c).

If the cancer hasn't spread out of your kidney (T1 or T2 kidney cancer), it can usually be cured by removing some or all of the kidney.

If the cancer has spread out of your kidney (T3 or T4 kidney cancer), a complete cure may not be possible. However, it should be possible to slow the cancer's progression and treat any symptoms (NHS, 2015c).

Surgical treatments

Nephrectomy A nephrectomy is an operation to remove a kidney.

If the tumour is less than 4cm (1.5 inches) in diameter, it may only be necessary to remove some of your kidney. This is known as a partial nephrectomy. A partial nephrectomy may also be required if your remaining kidney is in poor health.

If the tumour is more than 4cm in diameter, your entire kidney will need to be removed. Even if the cancer has spread beyond your kidney, you may still benefit from having your kidney removed.

Removing the kidney can help resolve the pain, and make other types of non-surgical treatment more effective.

It's possible to live a normal life with only one kidney, because the other kidney will be able to compensate.

During a nephrectomy, the surgeon may also remove nearby lymph nodes to make sure the cancer hasn't spread beyond the kidney (NHS, 2015c).

There are two ways that both a partial and open nephrectomy can be performed. They are an -

- **open nephrectomy** - where the kidney is removed through a large incision in your abdomen (stomach),
- **laparoscopic or keyhole nephrectomy** - where a series of smaller incisions are made in your abdomen, and the kidney is removed using small surgical instruments (NHS, 2015c).

Both techniques have advantages and disadvantages.

A laparoscopic nephrectomy has a considerably quicker recovery time than an open nephrectomy.

However, the procedure requires surgeons with specialised training, so you may have to wait longer to receive treatment than you would if you decided to have an open nephrectomy.

Some types of kidney cancer, where the tumour is located in the centre of the kidney, may not be suitable for a laparoscopic nephrectomy.

One of the main disadvantages of an open nephrectomy is that it's a major surgical procedure that can place a considerable strain on the body. This means it may not be suitable for people who are particularly frail or unwell.

You should discuss the pros and cons of both procedures with your surgical team (NHS, 2015c).

Embolisation If you're unable to have a nephrectomy, you may benefit from an alternative operation known as embolisation.

During embolisation, the surgeon will insert a small tube called a catheter into your groin, then use X-ray images to guide the catheter into the blood supply of your kidney. A substance will then be injected through the catheter to block the blood supply to your kidney.

By blocking blood supply to the kidney, any tumours that are present will become starved of oxygen and nutrients, causing them to shrink (NHS, 2015c).

Non-surgical treatments for advanced kidney cancer

Kidney cancer is one of the few types of cancer that's less responsive to chemotherapy (where powerful medication is used to kill cancerous cells).

However, a number of clinical trials are under way that are looking at new combinations of chemotherapy medications that appear to be benefiting some people.

There are also a number of different non-surgical treatments that can slow the spread of the cancer and help control its symptoms (NHS, 2015c).

Radiotherapy Radiotherapy can't usually cure kidney cancer, but it can slow down its progress and help reduce pain. You should only need a few minutes of radiotherapy every day, for a number of days.

When radiotherapy is used to control the symptoms of cancer rather than cure it, the side-effects tend to be mild. Possible side-effects may include fatigue (tiredness), nausea and vomiting (NHS, 2015c).

Cryotherapy Cryotherapy involves killing cancer cells by freezing them. It may be used if a person isn't fit enough for surgery, or if their tumour is small.

Cryotherapy is usually classed as either percutaneous (where needles are passed through the skin) or laparoscopic (where needles are placed directly into the kidney through a small incision).

Side-effects include bleeding around the kidney and injury to the tube that carries urine from the kidney to the bladder (the ureter) (NHS, 2015c).

Radiofrequency ablation Radiofrequency ablation (RFA) uses heat generated by radio waves to kill cancer cells. This is a percutaneous treatment, meaning no incision is needed.

This treatment is only available at specialist centres. It's mainly used if you're not strong enough for surgery or your kidney cancer is in the early stages.

RFA can't be used if the cancer is too close to other organs, such as the bowel.

Side-effects include bleeding in the treatment area, a collection of blood (haematoma) near the kidney, and problems passing urine due to the narrowing of the tube that joins the kidney to the bladder (the ureter) (NHS, 2015c).

Targeted therapies

A number of new medicines have been developed for the treatment of kidney cancer. These are -

- Sunitinib,
- Pazopanib,
- Axitinib,
- Sorafenib,
- Temsirolimus,
- Everolimus,
- bevacizumab (NHS, 2015c).

These medicines are sometimes referred to as ”targeted therapies” because they're designed to target and interrupt the functions needed by cancer to grow and spread.

At present, only sunitinib, pazopanib and axitinib have been recommended by the National Institute for Health and Care Excellence (NICE). They're available on the NHS for people who are still relatively healthy and have advanced kidney cancer, or kidney cancer that's spread to other parts of their body.

Sorafenib, temsirolimus, everolimus and bevacizumab aren't currently recommended by NICE (NHS, 2015c).

Sunitinib Sunitinib is the most commonly prescribed treatment for kidney cancer. It's a type of medication known as a tyrosine kinase inhibitor. Tyrosine kinase is an enzyme (protein) that helps cancer cells to grow. Sunitinib works by blocking protein kinase, stopping cancer from growing.

Sunitinib is taken as a capsule with or without food. You take it once a day for four weeks before having a two-week break. This six-week cycle is repeated for as long as the treatment is effective.

It's very important that you take sunitinib in the exact dosage that's been prescribed for you. Never stop taking medication for cancer without first consulting your specialist (NHS, 2015c).

Common side-effects of sunitinib include -

- nausea,
- diarrhoea,
- high blood pressure (hypertension),
- hair discolouration,
- mouth soreness,
- skin discolouration,
- skin rashes or blisters (NHS, 2015c).

Pazopanib Like sunitinib, pazopanib is a tyrosine kinase inhibitor that can be used to slow down or stop the growth of cancer cells in the kidneys. It also prevents cancer cells developing blood vessels, which they need to grow.

Pazopanib is taken as a tablet once a day with a glass of water. You should take it about the same time each day, either at least an hour before eating or two hours afterwards. It's important that you take it in the exact dosage that your specialist has prescribed for you (NHS, 2015c).

Common side-effects of pazopanib include -

- nausea,
- diarrhoea,
- high blood pressure,
- hair discolouration,
- abnormal liver function (NHS, 2015c).

Axitinib Axitinib may be recommended for treating advanced kidney cancer if sunitinib and/or pazopanib have stopped working or haven't been effective.

Like sunitinib and pazopanib, axitinib is a tyrosine kinase inhibitor that blocks tyrosine kinase and stops cancer growing.

Axitinib is taken as a tablet with a glass of water twice a day, about 12 hours apart. Your specialist may start you on a low dose which, depending on how you feel, may be increased after two weeks. It's very important that you take the exact dose that's been prescribed for you (NHS, 2015c).

Common side-effects of axitinib include -

- diarrhoea,
- nausea and vomiting,
- loss of appetite,
- tiredness,
- a decrease in thyroid hormone level (hypothyroidism),

- headaches,
- weight loss,
- loss of fertility (NHS, 2015c).

Sorafenib Sorafenib is another tyrosine kinase inhibitor that blocks the protein, tyrosine kinase, which encourages cancer cells to grow. It also prevents cancer cells developing blood vessels which they need to grow.

Sorafenib is taken as tablet twice a day (at the same time each day) with a glass of water. It can also be taken with a meal, but make sure the food is low-fat, because high-fat foods make it less effective.

Again, it's very important that you take sorafenib as instructed by your doctor at the exact dosage prescribed for you (NHS, 2015c).

Common side-effects of sorafenib include -

- diarrhoea,
- fatigue,
- nausea and vomiting,
- hair thinning (in around one in four people),
- increased risk of bleeding - such as nosebleeds or bleeding gums,
- loss of fertility,
- flushed skin (NHS, 2015c).

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Temsirolimus Temsirolimus is sometimes used to treat advanced kidney cancer. It's a type of medication known as an mTOR inhibitor, which blocks a protein called mTOR, that's usually active in cancer cells, making them reproduce and multiply. Temsirolimus also prevents blood vessels developing, which cancer cells need to grow.

Temsirolimus is a liquid that's delivered directly into the bloodstream, either through a tube that's put into a vein in your arm (catheter), or a tube into a large vein in your chest (a central line). The treatment takes 30–60 minutes and you have it once a week in hospital. Before each dose, an antihistamine is usually given to prevent an allergic reaction (NHS, 2015c).

Common side-effects of temsirolimus include -

- red, dry, itchy skin,
- nausea and vomiting,
- lack of appetite,
- diarrhoea,

- a sore mouth or mouth ulcers,
- sleeping problems,
- loss of fertility (NHS, 2015c).

Everolimus Everolimus is a medication for advanced kidney cancer that's returned during or following treatment. It stops some of the signals produced within cells that make them grow and divide. Everolimus prevents the mTOR protein working properly, which plays an important role in the growth of cancer cells.

Everolimus is taken as a tablet once a day at the same time each day. It should be swallowed whole with a glass of water, rather than being chewed or crushed. It can be taken with or without food. It's very important that everolimus is taken using the exact dosage and method prescribed (NHS, 2015c).

Common side-effects of everolimus include -

- a sore mouth,
- tiredness,
- a rash or itchy, dry skin,
- loss of appetite,
- nausea and vomiting,
- a lack of periods in women (this may be temporary),
- loss of fertility (NHS, 2015c).

Immunotherapy

As well as medications that prevent, disrupt and slow down the growth and development of kidney cancer (kinase and mTOR inhibitors), there are also treatments that work by encouraging the immune system to attack cancer cells. This type of treatment is known as immunotherapy.

Bevacizumab is a medication that's given intravenously (into a vein, through a drip). It blocks a protein called endothelial growth factor (VEGF), which helps cancer to grow. Bevacizumab is usually used in combination with an immunotherapy treatment called interferon. Interferon is taken as an injection just under the skin (subcutaneously), three times a week. It encourages your immune system to attack and destroy the cancer cells.

Another medication called aldesleukin is sometimes used to treat kidney cancer that's spread. It's similar to a natural protein the body produces called interleukin-2 (IL-2), which is part of the immune system. IL-2 activates lymphocytes (a type of white blood cell), which fight illnesses and infections.

Aldesleukin works in a number of ways. It interferes with how cancer cells grow and multiply, it stimulates the immune system into attacking cancer cells, and it makes cancer cells send out chemicals that attract immune system cells. Like interferon, aldesleukin is usually given as a subcutaneous injection.

Immunotherapy treatments are now rarely used to treat advanced kidney cancer. This is because targeted therapies tend to be more effective in controlling the condition, and immunotherapy can sometimes cause serious side-effects (NHS, 2015c).

Prevention

As the causes of kidney cancer aren't fully understood, it's not possible to completely prevent it.

However, leading a healthy lifestyle may help reduce your chances of developing the condition.

Combining a healthy diet and regular exercise will help you avoid becoming overweight or obese, which are both significant risk factors for kidney cancer.

If you're overweight or obese, you can lose weight and maintain a healthy weight by combining regular physical activity with a calorie-controlled diet (NHS, 2015c).

Diet

A low-fat, high-fibre diet that includes whole grains and plenty of fresh fruit and vegetables (at least five portions a day) is recommended for a healthy heart.

You should also limit the amount of salt in your diet to no more than 6g (0.2oz or 1 teaspoon) a day. Too much salt will increase your blood pressure (NHS, 2015c).

Avoid eating foods high in saturated fat because it will increase your cholesterol level. High-fat foods include -

- meat pies,
- sausages and fatty cuts of meat,
- butter,
- ghee - a type of clarified butter often used in Indian cooking,
- lard,
- cream,
- hard cheese,
- cakes and biscuits,

- foods that contain coconut or palm oil (NHS, 2015c).

There's some evidence that eating a diet that has plenty of oily fish (at least one portion a week) may help reduce the risk of kidney cancer. Examples of oily fish include -

- salmon,
- mackerel,
- sardines,
- trout,
- herring (NHS, 2015c).

Oily fish also contains vitamin D, which can reduce the risk of some cancers. You can also get vitamin D from sunlight or by taking supplements (NHS, 2015c).

Exercise

It's recommended that adults should do a minimum of 150 minutes (2 hours and 30 minutes) of moderate-intensity aerobic activity, such as cycling or brisk walking, every week.

The exercise should be strenuous enough to increase your heart rate and you should feel slightly out of breath afterwards (NHS, 2015c).

Examples of activities you could incorporate into your exercise programme include -

- brisk walking,
- hill climbing,
- running,
- cycling,
- swimming (NHS, 2015c).

If you find it difficult to do 150 minutes of exercise a week, start at a level you feel comfortable with.

However, you should visit your GP for a health check if you've never exercised before or you're returning to exercise after a long period of time (NHS, 2015c).

Giving up smoking

If you smoke, giving up is the most effective way of preventing kidney cancer, as well as a number of other serious health conditions, such as stroke, heart attack and lung cancer.

Your GP can help if you want to stop smoking, by giving you information and advice, and prescribing medication.

The NHS Smokefree website also has useful information and advice about giving up smoking. Alternatively, you can call the free Smokefree national helpline on 0300 123 1044 (NHS, 2015c).

Alcohol

There's evidence to suggest that drinking a moderate amount of alcohol, such as 4–5 glasses of wine a month, will help reduce your risk of developing kidney cancer. The reasons for this aren't fully understood.

However, you shouldn't exceed the recommended limits for alcohol, because excessive drinking will place you at risk of developing liver disease, liver cancer, and high blood pressure (hypertension) (NHS, 2015c).

- men and women are advised not to regularly drink more than 14 units a week,
- spread your drinking over three days or more if you drink as much as 14 units a week (NHS, 2015c).

A unit of alcohol is equal to about half a pint of normal-strength lager or a pub measure (25ml) of spirits. A small (125ml) glass of wine contains 1.5 units of alcohol.

See also Drinking and Alcohol - Trans and Aging - Part 1 - General Health

Lung cancer

Lung cancer is one of the most common and serious types of cancer. Around 44,500 people are diagnosed with the condition every year in the UK (NHS, 2015d).

Symptoms

Symptoms of lung cancer develop as the condition progresses and there are usually no signs or symptoms in the early stages.

The main symptoms of lung cancer are listed below. If you have any of these, you should see your GP -

- a cough that doesn't go away after two or three weeks,

- a long-standing cough that gets worse,
- persistent chest infections [49],
- coughing up blood [50],
- an ache or pain when breathing or coughing,
- persistent breathlessness,
- persistent tiredness or lack of energy,
- loss of appetite or unexplained weight loss (NHS, 2015d).

Less common symptoms of lung cancer include -

- changes in the appearance of your fingers, such as becoming more curved or their ends becoming larger (this is known as finger clubbing),
- a high temperature (fever) of 38'C (100.4'F) or above,
- difficulty swallowing or pain when swallowing,
- wheezing,
- a hoarse voice,
- swelling of your face or neck,
- persistent chest or shoulder pain (NHS, 2015d).

Causes

Most cases of lung cancer are caused by smoking, although people who have never smoked can also develop the condition (NHS, 2015d).

Smoking

Smoking cigarettes is the single biggest risk factor for lung cancer. It's responsible for more than 85% of all cases.

Tobacco smoke contains more than 60 different toxic substances, which can lead to the development of cancer. These substances are known to be carcinogenic (cancer-producing).

If you smoke more than 25 cigarettes a day, you are 25 times more likely to get lung cancer than a non-smoker (NHS, 2015d). While smoking cigarettes is the biggest risk factor, using other types of tobacco products can also increase your risk of developing lung cancer and other types of cancer, such as oesophageal cancer and mouth cancer. These products include -

- cigars,

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[49] an infection of the lungs or airways

[50] small amounts of bright red blood, or frothy blood-streaked sputum (saliva and phlegm)

- pipe tobacco,
- chewing tobacco (NHS, 2015d).

Smoking cannabis has also been linked to an increased risk of lung cancer. Most cannabis smokers mix their cannabis with tobacco. While they tend to smoke less than tobacco smokers, they usually inhale more deeply and hold the smoke in their lungs for longer.

It's been estimated that smoking four joints (homemade cigarettes mixed with cannabis) may be as damaging to the lungs as smoking 20 cigarettes.

Even smoking cannabis without mixing it with tobacco is potentially dangerous. This is because cannabis also contains substances that can cause cancer (NHS, 2015d).

Passive smoking

If you don't smoke, frequent exposure to other people's tobacco smoke (passive smoking) can increase your risk of developing lung cancer.

For example, research has found that non-smoking women who share their house with a smoking partner are 25% more likely to develop lung cancer than non-smoking women who live with a non-smoking partner (NHS, 2015d).

Radon

Radon is a naturally occurring radioactive gas that comes from tiny amounts of uranium present in all rocks and soils. It can sometimes be found in buildings.

If radon is breathed in, it can damage your lungs, particularly if you're a smoker. Radon is estimated to be responsible for about 3% of all lung cancer deaths in England (NHS, 2015d).

Occupational exposure and pollution

Exposure to certain chemicals and substances used in several occupations and industries has been linked to a slightly higher risk of developing lung cancer. These chemicals and substances include -

- arsenic,
- asbestos,
- beryllium,
- cadmium,

- coal and coke fumes,
- silica,
- nickel (NHS, 2015d).

Research also suggests that being exposed to large amounts of diesel fumes for many years may increase your risk of developing lung cancer by up to 50%. One study has shown that your risk of developing lung cancer increases by about a third if you live in an area with high levels of nitrogen oxide gases (mostly produced by cars and other vehicles) (NHS, 2015d).

Diagnosis

See your GP if you have symptoms of lung cancer, such as breathlessness or a persistent cough.

Your GP will ask about your general health and what symptoms you've been experiencing. They may examine you and ask you to breathe into a device called a spirometer, which measures how much air you breathe in and out.

You may be asked to have a blood test to rule out some of the possible causes of your symptoms, such as a chest infection.

In 2015, the National Institute for Health and Care Excellence (NICE)] published guidelines to help GPs recognise the signs and symptoms of lung cancer and refer people for the right tests faster. To find out if you should be referred for further tests for suspected lung cancer, read the NICE 2015 guidelines on Suspected Cancer: Recognition and Referral (NHS, 2015d).

Chest X-ray

A chest X-ray is usually the first test used to diagnose lung cancer. Most lung tumours show up on X-rays as a white-grey mass.

However, chest X-rays can't give a definitive diagnosis because they often can't distinguish between cancer and other conditions, such as a lung abscess (a collection of pus that forms in the lungs).

If your chest X-ray suggests you may have lung cancer, you should be referred to a specialist (if you haven't already) in chest conditions such as lung cancer. A specialist can carry out more tests to investigate whether you have lung cancer and, if you do, what type it is and how much it's spread (NHS, 2015d).

CT scan

A computerised tomography (CT) scan is usually carried out after a chest X-ray. A CT scan uses X-rays and a computer to create detailed images of the inside of your body.

Before having a CT scan, you'll be given an injection of a contrast medium. This is a liquid containing a dye that makes the lungs show up more clearly on the scan. The scan is painless and takes 10–30 minutes to complete (NHS, 2015d).

PET-CT scan

A PET-CT scan (which stands for positron emission tomography-computerised tomography [51]) may be carried out if the results of the CT scan show you have cancer at an early stage.

The PET-CT scan can show where there are active cancer cells. This can help with diagnosis and treatment.

Before having a PET-CT scan, you'll be injected with a slightly radioactive material. You'll be asked to lie down on a table, which slides into the PET scanner. The scan is painless and takes around 30–60 minutes (NHS, 2015d).

Bronchoscopy and biopsy

If the CT scan shows there might be cancer in the central part of your chest, you'll have a bronchoscopy. A bronchoscopy is a procedure that allows a doctor or nurse to remove a small sample of cells from inside your lungs.

During a bronchoscopy, a thin tube called a bronchoscope is used to examine your lungs and take a sample of cells (biopsy). The bronchoscope is passed through your mouth or nose, down your throat and into the airways of your lungs.

The procedure may be uncomfortable, but you'll be given a mild sedative beforehand to help you relax and a local anaesthetic to make your throat numb. The procedure is very quick and only takes a few minutes (NHS, 2015d).

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[51] scans are used to produce detailed three-dimensional images of the inside of the body

Other types of biopsy

If you're not able to have one of the biopsies described above, or you've had one and the results weren't clear, you may be offered a different type of biopsy. This may be a type of surgical biopsy such as a thoracoscopy or a mediastinoscopy, or a biopsy carried out using a needle inserted through your skin.

These types of biopsy are described below (NHS, 2015d).

Percutaneous needle biopsy A percutaneous needle biopsy involves removing a sample from a suspected tumour to test it at a laboratory for cancerous cells.

The doctor carrying out the biopsy will use a CT scanner to guide a needle to the site of a suspected tumour through the skin. A local anaesthetic is used to numb the surrounding skin, and the needle is passed through your skin and into your lungs. The needle will then be used to remove a sample of tissue for testing (NHS, 2015d).

Thoracoscopy A thoracoscopy is a procedure that allows the doctor to examine a particular area of your chest and take tissue and fluid samples.

You're likely to need a general anaesthetic before having a thoracoscopy. Two or three small cuts will be made in your chest to pass a tube (similar to a bronchoscope) into your chest. The doctor will use the tube to look inside your chest and take samples. The samples will then be sent away for tests.

After a thoracoscopy, you may need to stay in hospital overnight while any further fluid in your lungs is drained out (NHS, 2015d).

Mediastinoscopy A mediastinoscopy allows the doctor to examine the area between your lungs at the centre of your chest (mediastinum).

For this test, you'll need to have a general anaesthetic and stay in hospital for a couple of days. The doctor will make a small cut at the bottom of your neck so they can pass a thin tube into your chest.

The tube has a camera at the end, which enables the doctor to see inside your chest. They'll also be able to take samples of your cells and lymph nodes at the same time. The lymph nodes are tested because they're usually the first place that lung cancer spreads to (NHS, 2015d).

Staging

Once the above tests have been completed, it should be possible to work out what stage your cancer is, what this means for your treatment and whether it's possible to completely cure the cancer (NHS, 2015d).

Non-small-cell lung cancer Non-small-cell lung cancer (the most common type) usually spreads more slowly than small-cell lung cancer and responds differently to treatment.

The stages of non-small-cell lung cancer are outlined below (NHS, 2015d).

Stage 1 The cancer is contained within the lung and hasn't spread to nearby lymph nodes. Stage 1 can also be divided into two sub-stages -

- stage 1A - the tumour is less than 3cm in size (1.2 inches),
- stage 1B - the tumour is 3–5cm (1.2–2 inches) (NHS, 2015d).

Stage 2 Stage 2 is divided into two sub-stages: 2A and 2B (NHS, 2015d).

In stage 2A lung cancer, either -

- the tumour is 5–7cm,
- the tumour is less than 5cm and cancerous cells have spread to nearby lymph nodes (NHS, 2015d).

In stage 2B lung cancer, either -

- the tumour is larger than 7cm,
- the tumour is 5–7cm and cancerous cells have spread to nearby lymph nodes,
- the cancer hasn't spread to lymph nodes, but has spread to surrounding muscles or tissue,
- the cancer has spread to one of the main airways (bronchus),
- the cancer has caused the lung to collapse,
- there are multiple small tumours in the lung (NHS, 2015d).

Stage 3 Stage 3 is divided into two sub-stages: 3A and 3B (NHS, 2015d).

In stage 3A lung cancer, the cancer has either spread to the lymph nodes in the middle of the chest or into the surrounding tissue. This can be -

- the covering of the lung (the pleura),
- the chest wall,

- the middle of the chest,
- other lymph nodes near the affected lung (NHS, 2015d).

In stage 3B lung cancer, the cancer has spread to either of the following -

- lymph nodes on either side of the chest, above the collarbones,
- another important part of the body, such as the gullet (oesophagus), windpipe (trachea), heart or into a main blood vessel (NHS, 2015d).

Stage 4 In stage 4 lung cancer, the cancer has either spread to both lungs or to another part of the body (such as the bones, liver or brain), or the cancer has caused fluid-containing cancer cells to build up around your heart or lungs (NHS, 2015d).

Small-cell lung cancer Small-cell lung cancer is less common than non-small-cell lung cancer. The cancerous cells responsible for the condition are smaller in size when examined under a microscope than the cells that cause non-small-cell lung cancer (NHS, 2015d).

Small-cell lung cancer only has two possible stages -

- limited disease - the cancer has not spread beyond the lung,
- extensive disease - the cancer has spread beyond the lung (NHS, 2015d).

Lung cancer screening

There's currently no national screening programme for lung cancer in the UK.

This is because current tests for lung cancer aren't simple, quick or sensitive enough to outweigh the risks associated with screening (such as radiation exposure during X-rays) (NHS, 2015d).

Treatment

Treatment for lung cancer is carried out by a team of specialists who will work together to provide the best possible treatment.

This team contains all the specialists required to make a proper diagnosis, to stage your cancer and to plan the best treatment. If you want to know more, ask your specialist about this (NHS, 2015d).

The type of treatment you'll receive for lung cancer depends on several factors, including -

- the type of lung cancer you have (non-small-cell or small-cell cancer),
- the size and position of the cancer,
- how far advanced your cancer is (the stage),
- your overall health (NHS, 2015d).

Deciding what treatment is best for you can be difficult. Your cancer team will make recommendations, but the final decision will be yours.

The main treatment options include surgery, radiotherapy and chemotherapy. Depending on your type of cancer and how advanced it is, you may receive a combination of these treatments (NHS, 2015d).

Your treatment plan

Your treatment plan depends on whether you have non-small-cell lung cancer or small-cell lung cancer (NHS, 2015d).

Non-small-cell lung cancer If you have non-small-cell lung cancer that's confined to one lung and you're in good general health, you'll probably have surgery to remove the cancerous cells. This may be followed by a course of chemotherapy to destroy any cancer cells that may have remained in the body.

If the cancer hasn't spread too far but surgery isn't possible (for example, if your general health means you have an increased risk of developing complications), radiotherapy to destroy the cancerous cells will usually be recommended. In some cases, this may be combined with chemotherapy (known as chemoradiotherapy).

If the cancer has spread too far for surgery or radiotherapy to be effective, chemotherapy is usually recommended. If the cancer starts to grow again after initial chemotherapy treatment, another course of treatment may be recommended.

In some cases, a treatment called biological or targeted therapy may be recommended as an alternative to chemotherapy, or after chemotherapy. Biological therapies are medications that can control or stop the growth of cancer cells (NHS, 2015d).

Small-cell lung cancer Small-cell lung cancer is usually treated with chemotherapy, either on its own or in combination with radiotherapy. This can help to prolong life and relieve symptoms.

Surgery isn't usually used to treat this type of lung cancer. This is because the cancer has often already spread to other areas of the body by the time it's diagnosed. However, if the cancer is found very early, surgery may be used. In these cases, chemotherapy or radiotherapy may be given after surgery to help reduce the risk of the cancer returning (NHS, 2015d).

Surgery

There are three types of lung cancer surgery -

- **Lobectomy** - where one or more large parts of the lung (called lobes) are removed. Your doctors will suggest this operation if the cancer is just in one section of one lung.
- **Pneumonectomy** - where the entire lung is removed. This is used when the cancer is located in the middle of the lung or has spread throughout the lung.
- **Wedge resection or segmentectomy** - where a small piece of the lung is removed. This procedure is only suitable for a small number of patients, as it is only used if your doctors think your cancer is small and limited to one area of the lung. This is usually very early-stage non-small-cell lung cancer (NHS, 2015d).

People are naturally concerned that they won't be able to breathe if some or all of a lung is removed, but it's possible to breathe normally with one lung. However, if you have breathing problems before the operation, such as breathlessness, it's likely that these symptoms will continue after surgery (NHS, 2015d).

Tests before surgery Before surgery can take place, you'll need to have a number of tests to check your general state of health and your lung function. These may include -

- an electrocardiogram (ECG) - electrodes are used to monitor the electrical activity of your heart,
- spirometry - you'll breathe into a machine called a spirometer, which measures how much air your lungs can breathe in and out (NHS, 2015d).

How it's performed Surgery is usually performed by making a cut (incision) in your chest or side, and removing a section or all of the affected lung. Nearby lymph nodes may also be removed if it's thought that the cancer may have spread to them.

In some cases, an alternative to this approach, called video-assisted thoracoscopic surgery (VATS), may be suitable. VATS is a type of keyhole surgery, where small incisions are made in the chest. A small fibre-optic camera is inserted into one of the incisions, so the surgeon can see images of the inside of your chest on a monitor (NHS, 2015d).

After the operation You'll probably be able to go home 5 to 10 days after your operation. However, it can take many weeks to recover fully from a lung operation.

After your operation, you'll be encouraged to start moving about as soon as possible. Even if you have to stay in bed, you'll need to keep doing regular leg movements to help your circulation and prevent blood clots from forming. A physiotherapist will show you breathing exercises to help prevent complications.

When you go home, you'll need to exercise gently to build up your strength and fitness. Walking and swimming are good forms of exercise that are suitable for most people after treatment for lung cancer. Talk to your care team about which types of exercise are suitable for you (NHS, 2015d).

Complications As with all surgery, lung surgery carries a risk of complications. These are estimated to occur in one out of five cases. These complications can usually be treated using medication or additional surgery, which may mean you need to stay in hospital for longer (NHS, 2015d).

Complications of lung surgery can include -

- inflammation or infection of the lung (pneumonia),
- excessive bleeding,
- a blood clot in the leg (deep vein thrombosis), which could potentially travel up to the lung (pulmonary embolism) (NHS, 2015d).

Radiotherapy

Radiotherapy is a type of treatment that uses pulses of radiation to destroy cancer cells. There are a number of ways it can be used to treat people with lung cancer.

An intensive course of radiotherapy, known as radical radiotherapy, can be used to try to cure non-small-cell lung cancer if the person isn't healthy enough for surgery. For very small tumours, a special type of radiotherapy called stereotactic radiotherapy may be used instead of surgery.

Radiotherapy can also be used to control the symptoms and slow the spread of cancer when a cure isn't possible (this is known as palliative radiotherapy).

A type of radiotherapy known as prophylactic cranial irradiation (PCI) is also sometimes used during the treatment of small-cell lung cancer. PCI involves treating the whole brain with a low dose of radiation. It's used as a preventative measure because there's a risk that small-cell lung cancer will spread to your brain (NHS, 2015d).

The three main ways that radiotherapy can be given are described below -

- **Conventional external beam radiotherapy** - a machine is used to direct beams of radiation at affected parts of your body.
- **Stereotactic radiotherapy** - a more accurate type of external beam radiotherapy where several high-energy beams are used to deliver a higher dose of radiation to the tumour, while sparing the surrounding healthy tissue as much as possible.
- **Internal radiotherapy** - a catheter (thin tube) is inserted into your lung. A small piece of radioactive material is placed inside the catheter and positioned against the site of the tumour before being removed after a few minutes (NHS, 2015d).

For lung cancer, external beam radiotherapy is used more often than internal radiotherapy, particularly if it's thought that a cure is possible. Stereotactic radiotherapy may be used to treat tumours that are very small, as it's more effective than standard radiotherapy alone in these circumstances.

Internal radiotherapy only tends to be used as a palliative treatment when the cancer is blocking or partly blocking your airway (NHS, 2015d).

Courses of treatment A course of radiotherapy treatment can be planned in several different ways.

Radical radiotherapy is usually given five days a week, with a break at weekends. Each session of radiotherapy lasts 10–15 minutes and the course usually lasts four to seven weeks.

Continuous hyperfractionated accelerated radiotherapy (CHART) is an alternative method of delivering radical radiotherapy. CHART is given three times a day for 12 days in a row.

For stereotactic radiotherapy, fewer treatment sessions are needed because a higher dose of radiation is delivered with each treatment. People having conventional radical radiotherapy are likely to have around 20–32 treatment sessions, whereas stereotactic radiotherapy typically only requires anything from 3 to 10 sessions.

Palliative radiotherapy usually only requires one to five sessions to control your symptoms (NHS, 2015d).

Side-effects Side-effects of radiotherapy to the chest include -

- chest pain,
- fatigue,
- persistent cough that may bring up blood-stained phlegm (this is normal and nothing to worry about),
- difficulties swallowing (dysphagia [52]),
- redness and soreness of the skin, which looks and feels like sunburn,
- hair loss on your chest (NHS, 2015d).

Side-effects should pass once the course of radiotherapy has been completed (NHS, 2015d).

Chemotherapy

Chemotherapy uses powerful cancer-killing medication to treat cancer. There are several different ways that chemotherapy can be used to treat lung cancer. For example, it can be -

- given before surgery to shrink a tumour, which can increase the chance of successful surgery (this is usually only done as part of a clinical trial),
- given after surgery to prevent the cancer returning,
- used to relieve symptoms and slow the spread of cancer when a cure isn't possible,
- combined with radiotherapy (NHS, 2015d).

Chemotherapy treatments are usually given in cycles. A cycle involves taking the chemotherapy medication for several days, then having a break for a few weeks to let your body recover from the effects of the treatment.

The number of cycles of chemotherapy you need will depend on the type and the grade of your lung cancer. Most people require four to six courses of treatment over three to six months.

Chemotherapy for lung cancer involves taking a combination of different medications. The medications are usually delivered through a drip into a vein (in-

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[52] swallowing difficulties

travenously), or into a tube connected to one of the blood vessels in your chest. Some people may be given capsules or tablets to swallow instead (NHS, 2015d).

Side-effects Side-effects of chemotherapy can include -

- fatigue,
- nausea,
- vomiting,
- mouth ulcers,
- hair loss (NHS, 2015d).

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These side-effects should gradually pass once your treatment has finished, or you may be able to take other medicines to make you feel better during your chemotherapy.

Chemotherapy can also weaken your immune system, making you more vulnerable to infection. Tell your care team or GP as soon as possible if you have possible signs of an infection, such as a high temperature (fever) of 38'C (100.4'F) or more, or you suddenly feel generally unwell (NHS, 2015d).

Other treatments

As well as surgery, radiotherapy and chemotherapy, there are a number of other treatments that are sometimes used to treat lung cancer. These are described below (NHS, 2015d).

Biological therapies Biological therapies are newer medications. They're sometimes recommended as an alternative treatment to chemotherapy for non-small-cell cancer that has spread too far for surgery or radiotherapy to be effective.

Examples of biological therapies include erlotinib and gefitinib. These are also called growth factor inhibitors because they work by disrupting the growth of the cancer cells.

Biological therapies are only suitable for people who have certain proteins in their cancerous cells. Your doctor may be able to request tests on a small sample of cells removed from your lung (biopsy) to determine whether these treatments are likely to be suitable for you (NHS, 2015d).

Radiofrequency ablation Radiofrequency ablation is a new type of treatment that can treat non-small-cell lung cancer diagnosed at an early stage.

The doctor carrying out the treatment uses a computerised tomography (CT) scanner to guide a needle to the site of the tumour. The needle will be pressed into the tumour and radio waves will be sent through the needle. These waves generate heat, which kills the cancer cells.

The most common complication of radiofrequency ablation is that a pocket of air gets trapped between the inner and outer layer of your lungs (pneumothorax). This can be treated by placing a tube into the lungs to drain away the trapped air (NHS, 2015d).

Cryotherapy Cryotherapy is a treatment that can be used if the cancer starts to block your airways. This is known as endobronchial obstruction, and it can cause symptoms such as -

- breathing problems,
- a cough,
- coughing up blood (NHS, 2015d).

Cryotherapy is performed in a similar way to internal radiotherapy, except that instead of using a radioactive source, a device known as a cryoprobe is placed against the tumour. The cryoprobe can generate very cold temperatures, which help to shrink the tumour (NHS, 2015d).

Photodynamic therapy Photodynamic therapy (PDT) is a treatment that can be used to treat early-stage lung cancer when a person is unable or unwilling to have surgery. It can also be used to remove a tumour that's blocking the airways.

Photodynamic therapy is carried out in two stages. Firstly, you'll be given an injection of a medication that makes the cells in your body very sensitive to light.

The next stage is carried out 24–72 hours later. A thin tube will be guided to the site of the tumour, and a laser will be beamed through it. The cancerous cells, which are now more sensitive to light, will be destroyed by the laser beam.

Side-effects of photodynamic therapy can include inflammation of the airways and a build-up of fluid in the lungs. Both these side-effects can cause symptoms of breathlessness and lung and throat pain. However, these symptoms should gradually pass as your lungs recover from the effects of the treatment (NHS, 2015d).

Will the NHS fund an unlicensed medication if my doctor wants to prescribe it for me?

Your doctor can prescribe a medicine outside its licensed use if they're willing to take personal responsibility for this "off-licence" use of the medication.

Your local CCG may need to be involved, as it would have to decide whether to support your doctor's decision and pay for the medication from NHS budgets (NHS, 2015d).

Living with lung cancer

Lung cancer can affect your daily life in different ways, depending on what stage it's at and the treatment you're having (NHS, 2015d).

Although not all these steps work for everybody, there are several ways you can find support to help you cope -

- talk to your friends and family,
- talk to other people in the same situation,
- know about your condition,
- don't try to do too much,
- make time for yourself (NHS, 2015d).

Lung cancer specialist nurses

Your specialist team should have at least one lung cancer nurse specialist (CNS) working with them.

Ask your specialist to make sure you see a specialist nurse, who can support you and provide information about other sources of advice and support (NHS, 2015d).

Breathlessness Breathlessness is common in people who have lung cancer, whether it is a symptom of the condition or a side-effect of treatment (NHS, 2015d).

In many cases, breathlessness can be improved with some simple measures such as -

- breathing in slowly through your nose and out through your mouth (after treatment for lung cancer, you may see a physiotherapist, who can teach you some simple breathing exercises),

- making daily activities easier - for example, using a trolley when you go shopping or keeping things you often need downstairs so you don't need to regularly walk up and down the stairs,
- using a fan to direct cool air towards your face,
- eating smaller and more frequent meals, and taking smaller mouthfuls (NHS, 2015d).

If measures like these aren't enough to control your breathlessness, you may need further treatment. There are a number of medications that can help improve breathlessness. Home oxygen treatment may be an option in more severe cases.

If your breathlessness is caused by another condition, such as a chest infection or a fluid build-up around the lungs (a pleural effusion), treating this underlying cause may help your breathing (NHS, 2015d).

Pain Some people with lung cancer have pain, while others never have any. About one in three people who are treated for cancer experience some pain.

Pain isn't related to the severity of the cancer - it varies from person to person. What causes cancer pain isn't thoroughly understood, but there are ways of treating it so the pain can be controlled.

People with advanced lung cancer may need treatment for pain as their cancer progresses. This can be part of palliative care (see below), and is often provided by doctors, nurses and other members of the palliative care team. You can have palliative care at home, in hospital, in a hospice or other care centre (NHS, 2015d).

Emotional effects and relationships Having cancer can lead to a range of emotions. These may include shock, anxiety, relief, sadness and depression.

People deal with serious problems in different ways. It's hard to predict how living with cancer will affect you.

Being open and honest about how you feel and what your family and friends can do to help you may put others at ease. But don't feel shy about telling people that you need some time to yourself, if that's what you need (NHS, 2015d).

Talk to others Your GP or specialist nurse may be able to reassure you if you have questions, or you may find it helpful to talk to a trained counsellor, psychologist or specialist phone helpline. Your GP surgery will have information on these.

You may find it helpful to talk about your experience of lung cancer with others in a similar position at a local support group. Patient organisations have local groups where you can meet other people who have been diagnosed with lung cancer and had treatment.

If you have feelings of depression, talk to your GP - they can provide advice and support (NHS, 2015d).

Money and financial support If you have to reduce or stop work because of cancer, you may find it hard to cope financially. If you have cancer or you're caring for someone with cancer, you may be entitled to financial support.

- If you have a job but can't work because of your illness, you are entitled to Statutory Sick Pay from your employer.
- If you don't have a job and can't work because of your illness, you may be entitled to Employment and Support Allowance.
- If you're caring for someone with cancer, you may be entitled to Carer's Allowance.
- You may be eligible for other benefits if you have children living at home or you have a low household income (NHS, 2015d).

It's a good idea to find out early on what help is available to you. You could ask to speak to the social worker at your hospital, who can give you the information you need (NHS, 2015d).

Free prescriptions People being treated for cancer are entitled to apply for an exemption certificate giving free prescriptions for all medication, including treatment for unrelated conditions.

The certificate is valid for five years and you can apply for a certificate by speaking to your GP or cancer specialist (NHS, 2015d).

Palliative care If you have a lot of symptoms caused by lung cancer, your GP and healthcare team will need to give you support and pain relief. This is called palliative care. Support is also available for your family and friends.

As your cancer progresses, your doctor should work with you to establish a clear management plan based on your (and your carer's) wishes. This includes whether you'd prefer to go to hospital, a hospice, or be looked after at home as you become progressively more ill.

It will take account of what services are available to you locally, what's clinically advisable and your personal circumstances (NHS, 2015d).

Prevention

If you smoke, the best way to prevent lung cancer and other serious conditions is to stop smoking as soon as possible.

However long you have been smoking, it's always worth quitting. Every year you don't smoke decreases your risk of getting serious illnesses, such as lung cancer. After 10 years of not smoking, your chances of developing lung cancer falls to half that of someone who smokes.

NHS Smokefree can offer advice and encouragement to help you quit smoking. You can call them on 0300 123 1044, or visit their website.

Your GP or pharmacist can also give you help and advice about giving up smoking (NHS, 2015d).

Diet

Research suggests that eating a low-fat, high-fibre diet, including at least five portions a day of fresh fruit and vegetables and plenty of whole grains, can reduce your risk of lung cancer, as well as other types of cancer and heart disease (NHS, 2015d).

Exercise

There's strong evidence to suggest that regular exercise can lower the risk of developing lung cancer and other types of cancer.

Adults should do at least 150 minutes (2 hours and 30 minutes) of moderate-intensity aerobic activity each week (NHS, 2015d).

Mouth cancer

Mouth cancer, also known as oral cancer, is where a tumour develops on the surface of the tongue, mouth, lips or gums.

Tumours can also occur in the salivary glands, tonsils and the pharynx (the part of the throat from your mouth to your windpipe) but these are less common (NHS, 2014d).

Types of mouth cancer

A cancer that develops on the inside or outside layer of the body is called a carcinoma and these types of cancer are categorised by the type of cells the cancer starts in.

Squamous cell carcinoma is the most common type of mouth cancer, accounting for nine out of 10 cases. Squamous cells are found in many places around the body, including the inside of the mouth and under the skin (NHS, 2014d).

Less common types of mouth cancer include -

- **oral malignant melanoma** - where the cancer starts in cells called melanocytes, which help give skin its colour,
- **adenocarcinomas** - cancers that develop inside the salivary glands (NHS, 2014d).

Symptoms

Mouth cancer can develop on most parts of the mouth, including the lips, gums and occasionally, the throat (NHS, 2014d).

The most common symptoms of mouth cancer include -

- red or white patches in the mouth or throat,
- a lump,
- ulcers (NHS, 2014d).

Other symptoms may include -

- persistent pain in the mouth,
- pain or dysphagia,
- changes in your voice, or speech problems,
- swollen lymph nodes (glands) in your neck,
- unexplained weight loss,
- bleeding or numbness in the mouth,
- a tooth, or teeth, that becomes loose for no obvious reason,
- difficulty moving your jaw (NHS, 2014d).

When to seek medical advice

Many of the symptoms listed above can be caused by less serious conditions, such as minor infections.

But it's strongly recommended that you visit your GP if any of the symptoms listed above have lasted for more than three weeks. It's especially important to seek medical advice if you're a heavy drinker or smoker (NHS, 2014d).

Dental check-ups

Mouth cancer tends not to cause any noticeable symptoms during the initial stages of the disease.

This is why it is important to have regular dental check-ups, particularly if you are a smoker, a heavy drinker or a betel chewer, because a dentist may often be able to detect the condition during an examination.

You should have a dental check-up at least every year. However, more frequent check-ups may be recommended if you have a history of tooth decay [53] or gum disease [54] (NHS, 2014d).

Causes

The two leading causes of mouth cancer in the UK are drinking too much alcohol and smoking.

Both alcohol and tobacco are carcinogenic, which means they contain chemicals that can damage the DNA in cells and lead to cancer. The risk of mouth cancer increases significantly in somebody who is both a heavy smoker and heavy drinker.

Exactly what triggers the changes in DNA that lead to mouth cancer and why only a small number of people develop mouth cancer is still uncertain (NHS, 2014d).

How mouth cancer spreads

There are two ways mouth cancer can spread -

- **directly** - the cancer can spread out of the mouth and into nearby tissues, such as surrounding skin or into the back of the jaw,
- **via the lymphatic system** - the lymphatic system is a series of glands found throughout your body which produce many specialised cells needed by your immune system to fight infection (NHS, 2014d).

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[53] occurs when acid is produced from plaque, which builds up on your teeth

[54] a very common condition where the gums become swollen, sore or infected

Mouth cancer that spreads to another part of the body is known as metastatic oral cancer (NHS, 2014d).

Other risk factors

Other risk factors for mouth cancer may include -

- chewing tobacco or other smokeless tobacco products like snus,
- chewing betel nuts with or without tobacco,
- a poor diet,
- the HPV,
- poor oral hygiene (NHS, 2014d).

Smokeless tobacco

There is a range of smokeless tobacco products including -

- chewing tobacco,
- snuff - powdered tobacco designed to be sniffed gently,
- snus - a type of smokeless tobacco popular in Sweden, which is placed under your upper lip (NHS, 2014d).

Smokeless tobacco products are not harmless and many increase your risk of developing mouth cancer, as well as other cancers, such as liver cancer, pancreatic cancer and oesophageal cancer (NHS, 2014d).

Betel nuts

Betel nuts are mildly addictive seeds taken from the betel palm tree, and are widely used in many southeast Asian ethnic communities, such as people of Indian and Sri Lankan origin.

They have a stimulant effect similar to coffee. Betel nuts also have a carcinogenic effect, which can increase the risk of mouth cancer. This risk is made worse as many people enjoy chewing betel nuts along with tobacco.

Due to the tradition of using betel nuts, rates of mouth cancer are much higher in ethnic Indian and Sri Lankan communities than in the population at large (NHS, 2014d).

Diet

There is evidence that a poor diet may increase your risk of some types of mouth cancer.

A healthy, balanced diet with plenty of fruit and vegetables is thought to reduce your risk of developing mouth cancer (NHS, 2014d).

Human papilloma virus (HPV)

The HPV is a family of viruses that affect the skin and moist membranes that line your body, such as those in your cervix, anus, mouth and throat.

You can contract an HPV infection by having sexual contact with a person already infected - you do not have to have 'full sex'; just close skin-to-skin contact.

There is evidence that in rare cases, certain types of HPV can cause abnormal tissue growth inside the mouth, triggering mouth cancer (NHS, 2014d).

Poor oral hygiene

There is evidence that poor oral hygiene, such as having tooth decay, gum disease, not brushing your teeth regularly and having ill-fitted dentures (false teeth) can increase your risk of mouth cancer (NHS, 2014d).

Diagnosis

If you have symptoms of mouth cancer, your GP will carry out a physical examination and ask about your symptoms.

If mouth cancer is suspected, you will be referred to hospital for further tests or to speak to a specialist head and neck surgeon.

In 2015, the National Institute for Health and Care Excellence (NICE) published guidelines to help GPs recognise the signs and symptoms of mouth cancer and refer people for the right tests faster. To find out if you should be referred for further tests for suspected mouth cancer, read the NICE 2015 guidelines on Suspected Cancer: Recognition and Referral (NHS, 2014d).

Biopsy

It may be necessary to remove a small sample of affected tissue to check for the presence of cancerous cells. This procedure is known as a biopsy.

There are three main methods used to carry out a biopsy in cases of suspected mouth cancer (NHS, 2014d).

Punch biopsy A punch biopsy may be used if the suspected affected area of tissue is in an easily accessible place, such as your tongue or the inside of your mouth.

The area is first injected with a local anaesthetic to numb it. The doctor will then cut away a small section of affected tissue and remove it with tweezers.

The procedure is not painful, but can feel a little uncomfortable (NHS, 2014d).

Fine needle aspiration (FNA) A fine needle aspiration (FNA) is a type of biopsy used if it is suspected a swelling in your neck is the result of mouth cancer.

Your neck is numbed and a needle is used to draw out a small sample of tissue and fluids from the lump. The sample is then checked for cancerous cells.

FNA is not painful but it can be uncomfortable and cause bruising (NHS, 2014d).

Panendoscopy A panendoscope is used if the suspected tissue is at the back of your throat or inside one of your nasal cavities.

This is a long thin tube with a camera and a light which is guided through the nose, then used to remove a small section of tissue for the biopsy.

The panendoscope can also check whether cancer has spread from your mouth to further down your throat, such as your larynx (voice box), oesophagus (gullet) or trachea (windpipe) (NHS, 2014d).

Further tests

If the biopsy confirms cancer you will need further tests to check what stage it has reached.

If the cancer is diagnosed late it can have spread from your mouth into the lymphatic system - a series of glands throughout your body which produce many of the specialised cells needed by your immune system.

Once the cancer reaches the lymphatic system, it is capable of spreading to any other part of your body, including your bones, blood and organs.

However, it's uncommon for mouth cancer to spread further than the lymph nodes near your mouth, although in some cases it may also spread to surrounding bones, such as the jaw bone, and in some cases your lungs.

Therefore, the tests will examine your lymph nodes, bones and the tissue near the site of your initial tumour to check for the presence of other tumours (NHS, 2014d).

These tests may include -

- an X-ray,
- a magnetic resonance imaging (MRI) scan,
- a computerised tomography (CT) scan,
- a positron emission tomography [55] (PET) scan (NHS, 2014d).

Further biopsies on nearby lymph nodes may also be carried out (NHS, 2014d).

Staging and grading

Once these tests have been completed it should be possible to tell what stage and grade your cancer is -

- staging is a measure of how far the cancer has spread,
- the grade describes how aggressive the cancer is and how fast it is likely to spread in future (NHS, 2014d).

This will help determine whether you have -

- early mouth cancer (usually curable),
- intermediate mouth cancer (may be curable),
- or advanced mouth cancer (not usually curable, but it is usually possible to slow the spread of the cancer and extend lifespan) (NHS, 2014d).

There are three grades of mouth cancer: low-grade (the slowest), moderate-grade and high-grade (the most aggressive).

Grading your cancer helps the doctor decide how quickly you need to be treated (NHS, 2014d).

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[55] scans are used to produce detailed three-dimensional images of the inside of the body

Treatment

Your treatment will depend on the type and size of the cancer, the grade and how far it's spread - as well as your general health (NHS, 2014d).

Your treatment plan

If the cancer hasn't spread beyond the mouth or the oropharynx (the bit of your throat at the back of your mouth), a complete cure may be possible using a combination of surgery, radiotherapy and chemotherapy.

If the cancer has spread to other parts of the body, then a cure is unlikely but it will be possible to slow the progress of the cancer and help relieve symptoms by using surgery, radiotherapy and chemotherapy.

Deciding what treatment is best for you can be difficult. Your care team will make recommendations, but the final decision will be yours.

Before going to hospital to discuss your treatment options, you may find it useful to write a list of questions to ask the specialist. For example, what are the advantages and disadvantages of particular treatments (NHS, 2014d).

Before treatment begins Radiotherapy makes the teeth more sensitive and vulnerable to infection so before treatment begins, you'll be given a full dental examination and any necessary work will be carried out.

If you smoke or drink, stopping will increase the chances of your treatment being successful.

Your specialist nurse and your GP can provide help and support if you are finding it difficult to quit smoking and drinking (NHS, 2014d).

Surgery

For mouth cancer, the aim of surgical treatment is to remove any affected tissue while minimising damage to the rest of the mouth (NHS, 2014d).

Photodynamic therapy (PDT) If the cancer is in its very early stages, it may be possible to remove any tumours using a type of laser surgery known as photodynamic therapy (PDT). PDT involves taking a medicine that makes your tissue sensitive to the effects of light. A laser is then used to remove the tumour (NHS, 2014d).

Other forms of surgery If your cancer is more advanced, it may be necessary to remove part of your mouth lining and, in some cases, facial skin, which can be replaced using skin grafted from your forearm or chest.

If your tongue is affected, part of the tongue will have to be removed. This is known as a partial glossectomy. The tongue is then reconstructed using grafted tissue.

If the cancer has spread to your jawbone it will need to be surgically removed. The jawbone can be replaced by taking bone from another part of your body and grafting it in place.

Occasionally, other bones, such as cheekbones, may have to be removed to completely remove the cancer.

These can be replaced with plastic prosthetic bones which are are usually very realistic, leaving your physical appearance largely unaffected.

During surgery, your surgeon may also remove lymph nodes near the site of the initial tumour. This is often done as a preventative measure in case they contain small numbers of cancerous cells that can't be detected (NHS, 2014d).

Radiotherapy

Radiotherapy uses doses of radiation to kill cancerous cells. It may be possible to remove the cancer using radiotherapy alone, but it is usually used after surgery to prevent the cancer from recurring.

The treatment is normally given every day over the course of three to seven weeks, depending on the size of the cancer and how far it has spread (NHS, 2014d).

While it kills cancerous cells, radiotherapy can also affect healthy tissue, and it has a number of side-effects, including -

- sore, red skin (like sunburn),
- mouth ulcers,
- sore mouth and throat,
- dry mouth,
- loss of, or changes in taste,
- loss of appetite,
- tiredness,
- feeling sick,
- stiff jaw,
- bad breath (NHS, 2014d).

Any side-effects will be monitored by your care team and treated where possible.

The side-effects of radiotherapy can be distressing, but most of them will pass once the radiotherapy is complete (NHS, 2014d).

Internal radiotherapy Internal radiotherapy - also called brachytherapy - is often used to treat cancers of the tongue that are in their early stages. It involves placing radioactive implants directly into the tumour while you are under a general anaesthetic.

They will be left for between one and eight days during which time the cancer cells will receive a much higher dose of radiation than the rest of your mouth.

Visits by friends and family will need to be restricted due to radiation and pregnant women and children won't be able to visit you.

The radioactive implants will cause your mouth to become swollen, and you will experience some pain five to 10 days after the implants are removed (NHS, 2014d).

Chemotherapy

Chemotherapy is sometimes used in combination with radiotherapy when the cancer is widespread, or if it is thought there is a significant risk of the cancer returning.

Chemotherapy involves the use of powerful cancer-killing medicines. These medicines damage the DNA of the cancerous cells, interrupting their ability to reproduce.

Medicines used in chemotherapy can sometimes damage healthy tissue as well as the cancerous tissue (NHS, 2014d).

Adverse side-effects are common and include -

- fatigue (tiredness),
- sore mouth,
- mouth ulcers,
- feeling sick,
- being sick,
- hair loss (NHS, 2014d).

The side-effects should stop once the treatment has finished.

Chemotherapy also weakens your immune system and makes you more vulnerable to infection (NHS, 2014d).

Cetuximab

Cetuximab is a new type of medication, known as a biologic, used to treat advanced cases of mouth cancer. It is usually used in combination with radiotherapy or chemotherapy.

Cetuximab targets proteins on the surface of cancer cells, known as epidermal growth factor receptors. These receptors help the cancer to grow, so by targeting these proteins, cetuximab prevents the cancer from spreading (NHS, 2014d).

The National Institute for Health and Care Excellence (NICE) ruled that cetuximab did not represent a cost-effective treatment in most cases and has recommended it only be used in people who -

- are in a good state of health (likely to make a good recovery if treated),
- are unable to have chemotherapy for medical reasons (for example, because they have kidney disease or are pregnant) (NHS, 2014d).

Complications

Complications of treatment for mouth cancer can include dysphagia (difficulty swallowing), speech problems and emotional disruption (NHS, 2014d).

Difficulty swallowing

Dysphagia is the medical term for difficulty swallowing. It is easy to take your ability to swallow food and liquid for granted, but in reality the process relies on a complex interaction of muscles, which can be easily disrupted.

Surgery and radiotherapy can affect your tongue, mouth or throat, resulting in dysphagia. Dysphagia is a potentially serious problem because, aside from the risk of malnutrition, there is a chance that small particles of food could enter your airways and become lodged in your lungs. This can trigger a chest infection, known as aspiration pneumonia.

If you are having problems swallowing, a speech and language therapist (SLT) will need to assess your swallowing reflex. One way an SLT can do this is to perform a test known as a videofluoroscopy, which involves adding a special dye to liquid and food that you swallow. The dye highlights your swallowing reflexes and by using X-rays your SLT can see if there is a risk of food entering your lungs.

If this is the case, it may be necessary in the short term to provide you with a feeding tube, which will be directly connected to your stomach. The SLT will teach you exercises so you can ”relearn” how to swallow properly.

Your ability to swallow will improve as you learn the exercises and the damaged tissue is allowed to heal. However, there is a chance your swallowing reflex will never fully recover.

In some circumstances, you may have to alter your diet to make swallowing easier. A dietitian can give you dietary advice (NHS, 2014d).

Speech

Much like swallowing, your ability to speak clearly is governed by a complex interaction of muscles, bones and tissue, including your tongue, teeth, lips and soft palate (a section of tissue found at the back of the mouth).

Radiotherapy and surgery can affect this process and make it difficult to pronounce certain sounds. In severe cases, you may have problems making yourself understood.

An SLT will help you improve your verbal communication skills by teaching you a series of exercises that develop your range of vocal movements and teach you new ways of producing sounds (NHS, 2014d).

Emotional impact

The emotional impact of living with mouth cancer can be significant. Many people report experiencing a roller-coaster effect.

For example, you may feel down when you receive a diagnosis, but feel up when the cancer responds to treatment. Then you may feel down again as you try to come to terms with the side-effects and after effects of your treatment (NHS, 2014d).

This type of emotional disruption can sometimes trigger depression. Signs that you may be depressed include -

- feeling down or hopeless during the past month,
- no longer taking pleasure in the things you used to enjoy (NHS, 2014d).

For more information about depression see {Depression - Aging and trans - Part 3 - Mental Health}.

Living with mouth cancer

Having mouth cancer doesn't necessarily mean you'll have to give up work, but you may need quite a lot of time off, and you may not be able to carry on like you did before treatment.

If you have cancer you're covered by the Disability Discrimination Act. This means that your employer is not allowed to discriminate against you because of your illness. They have a duty to make "reasonable adjustments" to help you cope. Examples of these include -

- allowing you time off for treatment and medical appointments,
- allowing flexibility with working hours, the tasks you have to perform or your working environment (NHS, 2014d).

The definition of what is "reasonable" depends on the situation. For example, how much it would affect your employer's business.

It will help if you give your employer as much information as possible about how much time you will need off and when. Talk to your human resources department if you have one. Your union or staff association representative should also be able to give you advice.

If you're having difficulties with your employer, you may be able to receive help from your union or your local Citizens Advice Bureau (NHS, 2014d).

See also Living with cancer.

Caring for others with mouth cancer

Being a carer is not an easy role. When you are busy responding to the needs of others it can deplete your reserves of emotional and physical energy and make it easy for you to neglect your own health and mental wellbeing. Research on carers' health shows that high numbers of carers suffer health effects through caring. If you are trying to combine caring with a paid job or looking after a family, this can cause even more stress.

If you are caring for someone else, it is important to look after yourself and get as much help as possible. It is in your best interests and those of the person you are caring for (NHS, 2014d).

Look after your health Eat regularly and healthily. If you do not have time to sit down for every meal, try to make time to sit down for at least one of your day's meals. Instead of relying on fast food snacks, go for healthier options, such as fruit (NHS, 2014d).

Look after your emotional health As well as exhaustion, isolation and worries about the person you are caring for, it is understandable if there are times when you feel resentful and then guilty for feeling like this. These feelings are natural (NHS, 2014d).

Look for support Friends and family may not always understand what you are going through and it can be helpful to talk to people in the same situation. Carers Direct has a lot of useful information on its website and runs a helpline on 0300 123 1053 (NHS, 2014d).

Skin cancer (Melanoma)

Melanoma is a type of skin cancer that can spread to other organs in the body.

The most common sign of melanoma is the appearance of a new mole or a change in an existing mole. This can happen anywhere on the body, but the back, legs, arms and face are most commonly affected.

In most cases, melanomas have an irregular shape and more than one colour. They may also be larger than normal moles and can sometimes be itchy or bleed.

An "ABCDE checklist" has been developed for people to tell the difference between a normal mole and a melanoma (NHS, 2014e).

Here we are covering a type of melanoma known as superficial spreading melanoma, this is the most common type of melanoma. About 70 out of 100 of all melanomas in the UK (70%) are this type. They are most common in middle aged people. To start with, they tend to grow outwards rather than downwards into the skin. Doctors call this the radial growth phase. The melanoma is not usually at risk of spreading to other parts of the body until it begins to grow downwards into the deeper layers of skin and beyond. So if you have a mole that is getting bigger, particularly if it has an irregular edge, it is important to go and get it checked (CANCERRESEARCHUK, 2015b).

Other types of melanoma are summarised below.

Nodular melanoma

Nodular melanoma is a fast-developing type of melanoma, most common in middle-aged people. It may not develop from an existing mole and can appear in areas of skin that aren't regularly exposed to the sun (NHS, 2014e). So it is most often found on the chest or back. It begins to grow downwards, deeper into the skin, quite quickly if it is not removed. There is often a raised area on the skin surface with this type of melanoma. Nodular melanomas are often very dark brownish black, or black, in colour. They can come up in areas of skin that have not received a great deal of sun. And they may not necessarily develop from a mole which was already there (CANCERRESEARCHUK, 2015b).

Lentigo maligna melanoma

Lentigo maligna melanoma is most common in elderly people and those who have spent a lot of time outdoors. It is common on the face and tends to grow slowly over a number of years (NHS, 2014e). About 10 in 100 melanomas (10%) are this type. They develop from very slow growing pigmented areas of skin called lentigo maligna or Hutchinson's melanotic freckle. The lentigo maligna is flat and grows outwards in the surface layers of the skin. So it may gradually get bigger over several years and may change shape. If it becomes a lentigo maligna melanoma, it starts to grow down into the deeper layers of the skin and may form lumps (nodules) (CANCERRESEARCHUK, 2015b).

Acral lentiginous melanoma

Acral lentiginous melanoma is a rare type of melanoma that usually appears on the palms of the hands and the soles or big toenails of the feet. This is the most common type of melanoma in people with dark skin (NHS, 2014e). It can also grow under the nails. It is much more common on the feet than on the hands (CANCERRESEARCHUK, 2015b).

Amelanotic melanoma

Amelanotic means without melanin. Melanomas tend to be dark in colour, amelanotic melanomas usually have no, or very little colour. Occasionally they are pink or red, or have light brown or gray around the edges. Less than 5 out of 100 melanomas (5%) are amelanotic. Other types of melanoma such as acral lentiginous can lack colour and are amelanotic melanomas. They are often difficult to diagnose because of their lack of colour and may be mistaken for other conditions of the skin. Treatment is the same as for other types of melanoma (CANCERRESEARCHUK, 2015b).

Other types of melanoma

Melanoma can occur anywhere in the body, including in the internal organs. Melanoma of the skin is also called cutaneous malignant melanoma. Cutaneous is another word for the skin.

One area where melanoma can occur, although it is rare, is inside the eye. There are melanocytes in the iris (the coloured bit around the pupil) and also in a lining inside the eye called the choroid layer. If these melanocytes (the pigment producing cells) become cancerous, then this is a melanoma. If melanoma starts in the iris, a dark spot may show. But if it is anywhere else in the eye, it will only be seen if a specialist examines the eye (CANCERRESEARCHUK, 2015b).

Symptoms

The first sign of a melanoma is often a new mole or a change in the appearance of an existing mole.

Normal moles are usually round or oval, with a smooth edge, and no bigger than 6mm (1/4 inch) in diameter.

See your GP as soon as possible if you notice changes in a mole, freckle or patch of skin, especially if the changes happen over a few weeks or months (NHS, 2014e).

Signs to look out for include a mole that is -

- getting bigger,
- changing shape,
- changing colour,
- bleeding or becoming crusty,
- itchy or painful (NHS, 2014e).

A helpful way to tell the difference between a normal mole and a melanoma is the ABCDE checklist -

- **A** - Asymmetrical - melanomas have two very different halves and are an irregular shape.
- **B** - Border - melanomas have a notched or ragged border.
- **C** - Colours - melanomas will be a mix of two or more colours.
- **D** - Diameter - melanomas are larger than 6mm (1/4 inch) in diameter.

- **E** - Enlargement or elevation - a mole that changes size over time is more likely to be a melanoma (NHS, 2014e).

Melanomas can appear anywhere on your body, but they most commonly appear on the back, legs, arms and face. They may sometimes develop underneath a nail.

In rare cases, melanoma can develop in the eye. Noticing a dark spot or changes in vision can be signs, although it is more likely to be diagnosed during a routine eye examination (NHS, 2014e).

Causes

Most skin cancer is caused by ultraviolet (UV) light damaging the DNA in skin cells. The main source of UV light is sunlight (NHS, 2014e).

Sunlight contains three types of UV light -

- ultraviolet A (UVA),
- ultraviolet B (UVB),
- ultraviolet C (UVC) (NHS, 2014e).

UVC is filtered out by the Earth's atmosphere, but UVA and UVB damage skin over time, making it more likely for skin cancers to develop. UVB is thought to be the main cause of skin cancer.

Artificial sources of light, such as sunlamps and tanning beds, also increase your risk of developing skin cancer. Repeated sunburn, either by the sun or artificial sources of light, increases the risk of melanoma in people of all ages (NHS, 2014e).

Moles

You are at an increased risk of melanoma if you have lots of moles on your body, especially if they are large (over 5mm) or unusually shaped.

Having just one unusually shaped or very large mole increases your risk of melanoma by 60%.

For this reason, it's important to monitor moles for changes and avoid exposing them to the sun (NHS, 2014e).

Family history

Research suggests that if you have two or more close relatives who have had non-melanoma skin cancer, your chances of developing the condition may be increased (NHS, 2014e).

Increased risk

Certain things are believed to increase your chances of developing all types of skin cancer, including -

- pale skin that does not tan easily,
- red or blonde hair,
- blue eyes,
- older age,
- a large number of freckles,
- an area of skin previously damaged by burning or radiotherapy treatment,
- a condition that suppresses your immune system - such as HIV,
- medicines that suppress your immune system (immunosuppressants) - commonly used after organ transplants,
- exposure to certain chemicals - such as creosote and arsenic,
- a previous diagnosis of skin cancer (NHS, 2014e).

Diagnosis

A diagnosis of melanoma will usually begin with an examination of your skin. Your GP will refer you to a specialist if they suspect melanoma.

Some GPs take digital photographs of suspected tumours so they can email them to a specialist for assessment.

As melanoma is a relatively rare condition, many GPs will only see a case every few years. It's important to monitor your moles and return to your GP if you notice any changes. Taking photos to document any changes will help with diagnosis (NHS, 2014e).

Seeing a specialist

In 2015, the National Institute for Health and Care Excellence (NICE) published guidelines to help GPs recognise the signs and symptoms of malignant melanoma and refer people for the right tests faster. To find out if you should be referred for further tests for suspected malignant melanoma, read the NICE 2015 guidelines on Suspected Cancer: Recognition and Referral.

You will be referred to a dermatology clinic or hospital for further testing if melanoma is suspected. You should see a specialist within two weeks of seeing your GP.

The dermatologist or plastic surgeon will examine the mole and the rest of your skin. They may also remove the mole and send it for testing (biopsy) to check whether the mole is cancerous. A biopsy is usually carried out under local anaesthetic, meaning the area around the mole will be numbed and you won't feel any pain.

If cancer is confirmed, you will usually need a further operation, most often carried out by a plastic surgeon, to remove a wider area of skin (NHS, 2014e).

Further tests

Further tests will be carried out if there is a concern the cancer has spread into other organs, bones or your bloodstream (NHS, 2014e).

Sentinel lymph node biopsy If melanoma spreads, it will usually begin spreading through channels in the skin (called lymphatics) to the nearest group of glands (called lymph nodes). Lymph nodes are part of the body's immune system, helping to remove unwanted bacteria and particles from the body.

Sentinel lymph node biopsy is a test to determine whether microscopic amounts of melanoma (less than would show up on any X-ray or scan) might have spread to the lymph nodes. It is usually carried out by a specialist plastic surgeon, while you are under general anaesthetic.

A combination of blue dye and a weak radioactive chemical is injected around your scar. This is usually done just before the wider area of skin is removed. The solution follows the same channels in the skin as any melanoma.

The first lymph node this reaches is known as the ”sentinel” lymph node. The surgeon can locate and remove the sentinel node, leaving the others intact. The node is then examined for microscopic specks of melanoma (this process can take several weeks).

If the sentinel lymph node is clear of melanoma, it's extremely unlikely that any other lymph nodes are affected. This can be reassuring because if melanoma spreads to the lymph nodes, it's more likely to spread elsewhere.

If the sentinel lymph node contains melanoma, there is a risk that other lymph nodes in the same group will contain melanoma.

Your surgeon should discuss the pros and cons of having a sentinel lymph node biopsy before you agree to the procedure. Sentinel lymph node biopsy does not cure melanoma, but is used to investigate the outlook of your condition.

An operation to remove the remaining lymph nodes in the group may be recommended. This is known as a completion lymph node dissection or completion lymphadenectomy (NHS, 2014e).

Other tests you may have include -

- a computerised tomography (CT) scan,
- a magnetic resonance imaging (MRI) scan,
- a positron emission tomography-computerised tomography (PET) scan
- blood tests (NHS, 2014e).

Treatment

Surgery is the main treatment for melanoma, although it often depends on your individual circumstances.

People with melanoma skin cancer should be cared for by a team of specialists that often includes a dermatologist, a plastic surgeon, an oncologist (a radiotherapy and chemotherapy specialist), a pathologist and a specialist nurse (NHS, 2014e).

When helping you decide on your treatment, the team will consider -

- the type of cancer you have,
- the stage of your cancer (how big it is and how far it has spread),
- your general health (NHS, 2014e).

Your team will recommend what they believe to be the best treatment option, but the final decision will be yours.

Before going to hospital to discuss your treatment options, you may find it useful to write a list of questions to ask the specialist. For example, you may want to find out what the advantages and disadvantages of particular treatments are (NHS, 2014e).

Melanoma stages

Health professionals use a staging system to describe how far melanoma has grown into the skin (the thickness) and whether it has spread. The type of treatment you receive will depend on what stage the melanoma has reached (NHS, 2014e).

The melanoma stages can be described as -

- Stage 0 - the melanoma is on the surface of the skin.
- Stage 1A - the melanoma is less than 1mm thick.
- Stage 1B - the melanoma is 1–2mm thick, or the melanoma is less than 1mm thick and the surface of the skin is broken (ulcerated) or its cells are dividing faster than usual (mitotic activity).
- Stage 2A - the melanoma is 2–4mm thick, or the melanoma is 1–2mm thick and is ulcerated.
- Stage 2B - the melanoma is thicker than 4mm, or the melanoma is 2–4mm thick and ulcerated.
- Stage 2C - the melanoma is thicker than 4mm and ulcerated.
- Stage 3A - the melanoma has spread into one to three nearby lymph nodes, but they are not enlarged; the melanoma is not ulcerated and has not spread further.
- Stage 3B - the melanoma is ulcerated and has spread into one to three nearby lymph nodes but they are not enlarged, or the melanoma is not ulcerated and has spread into one to three nearby lymph nodes and they are enlarged, or the melanoma has spread to small areas of skin or lymphatic channels, but not to nearby lymph nodes.
- Stage 3C - the melanoma is ulcerated and has spread into one to three nearby lymph nodes and they are enlarged, or the melanoma has spread into four or more lymph nodes nearby.
- Stage 4 - the melanoma cells have spread to other areas of the body, such as the lungs, brain or other parts of the skin (NHS, 2014e).

Stage 1 melanoma Treating stage 1 melanoma will involve surgically removing the melanoma and a small area of skin around it - this is known as surgical excision.

Surgical excision is usually carried out under local anaesthetic. This means you will be awake but the area around the melanoma will be numbed, so you won't feel pain. In some cases, general anaesthetic is used, which means you will be asleep during the procedure.

If a surgical excision is likely to leave a significant scar, it may be done in combination with a skin graft. A skin graft involves removing a patch of healthy skin, usually taken from a part of your body where scarring cannot be seen, such as your back. It is then connected, or grafted, to the affected area. Skin grafts or flaps are used when the area of skin being removed is too big to close using a direct method.

Once the melanoma has been removed, there is little possibility it will return and no further treatment should be required. You will probably be asked to come for follow-up appointments before being discharged (NHS, 2014e).

Stage 2 and 3 melanoma As with stage 1 melanomas, any affected areas of skin will be removed. The remaining skin is either closed directly, or a skin graft or flap may be carried out if necessary (NHS, 2014e).

Sentinel node biopsy Sentinel node biopsy, which is not a mandatory procedure, will be discussed with you. If you decide to go ahead with the procedure and the results show no spread to nearby lymph nodes, it is unlikely you will have further problems with this melanoma.

If the test confirms melanoma has spread to nearby nodes, your specialist will discuss with you whether further surgery is required. Additional surgery involves removing the remaining nodes, known as a completion lymph node dissection or completion lymphadenectomy (NHS, 2014e).

Lymph nodes If the melanoma has spread to nearby lymph nodes, you may need further surgery to remove them. Your doctor will have felt a lump in your lymph nodes and the diagnosis of melanoma is usually confirmed using a needle biopsy (fine needle aspiration). Removing the affected nodes requires a procedure called a block dissection, performed under general anaesthetic.

While the surgeon will try to ensure the rest of your lymphatic system can function normally, there is a risk that the removal of lymph nodes will disrupt the lymphatic system, leading to a build-up of fluids in your limbs. This is known as lymphoedema (NHS, 2014e).

Follow-up Once the melanoma has been removed, you will need follow-up appointments to see how you are recovering and to watch for any sign of the melanoma returning.

You may be offered treatment to try to prevent the melanoma returning. This is called adjuvant treatment. There is not much evidence that adjuvant treatment helps prevent melanoma from coming back, so this is only offered as part of a Clinical trials (NHS, 2014e).

Stage 4 melanoma It may not be possible to cure melanoma if it has -

- been diagnosed at its most advanced stage,
- spread to another part of your body (metastasis),
- come back in another part of your body after treatment (recurrent cancer) (NHS, 2014e).

Treatment is available and given in the hope that it can slow the cancer's growth, reduce any symptoms you may have and possibly extend your life expectancy.

You may be able to have surgery to remove other melanomas that have occurred away from the original site (NHS, 2014e).

You may also be able to have other treatments to help with symptoms. These include -

- radiotherapy,
- drug treatments (NHS, 2014e).

Radiotherapy Radiotherapy may be used after an operation to remove your lymph nodes, and can also be used to help relieve the symptoms of advanced melanoma.

Radiotherapy uses controlled doses of radiation to kill cancer cells. It is given at the hospital as a series of 10–15 minute daily sessions, with a rest period over the weekend (NHS, 2014e).

The side-effects of radiotherapy include -

- tiredness,
- nausea,
- loss of appetite,
- hair loss,
- sore skin (NHS, 2014e).

Many side-effects can be prevented or controlled with medicines your doctor can prescribe, so let them know about any that you experience. After treatment has finished, the side-effects of radiotherapy should gradually reduce (NHS, 2014e).

Drug treatment In recent years there have been major advancements in treating melanoma. The medications used to treat melanoma are changing as new formulations are being introduced into clinics (NHS, 2014e).

The medications currently being used include -

- vemurafenib,
- ipilimumab,

- nivolumab (NHS, 2014e).

However, not everyone is suitable for these drugs. Your specialist will discuss an appropriate treatment with you, and many people are entered into clinical trials. See also Clinical trials.

Some of the available medications are discussed below (NHS, 2014e).

Chemotherapy Chemotherapy involves using anti-cancer (cytotoxic) drugs to kill the cancer. It is normally used to treat melanoma that has spread to parts of the body and is mainly given to help relieve symptoms of advanced melanoma.

Several different chemotherapy drugs are used to treat melanoma and are occasionally given in combination. The drugs most commonly used for melanoma are dacarbazine and temozolomide. However, many different types of drugs can be used. Your specialist can discuss with you which drugs are the most suitable.

Chemotherapy is usually given as an outpatient treatment, which means you will not have to stay in hospital overnight. Dacarbazine is given through a drip and temozolomide is given in tablet-form. Chemotherapy sessions are usually given once every three to four weeks, with gaps between treatment intended to give your body and blood time to recover.

The main side-effects of chemotherapy are caused by their influence on the rest of the body. Side-effects include infection, nausea and vomiting, tiredness and sore mouth. Many side-effects can be prevented or controlled with medicines that your doctor can prescribe (NHS, 2014e).

Electrochemotherapy Electrochemotherapy is a possible treatment for melanoma. It may be considered if -

- surgery isn't suitable or hasn't worked,
- radiotherapy and chemotherapy haven't worked (NHS, 2014e).

The procedure involves giving chemotherapy intravenously (directly into a vein). Short, powerful pulses of electricity are then directed to the tumour using electrodes.

These electrical pulses allow the medicine to enter the tumour cells more effectively and cause more damage to the tumour. The procedure is usually carried out using general anaesthetic but some people may be able to have local anaesthetic.

Depending on how many tumours need to be treated, the procedure can take up to an hour to complete. The main side-effect is some pain where the electrode was used, which can last for a few days and may require painkillers.

It usually takes around six weeks for results to appear and the procedure usually needs to be repeated. Your specialist can give you more detailed information about this treatment option.

Read the NICE (2013) guidelines on Electrochemotherapy for metastases in the skin (NHS, 2014e).

Immunotherapy Immunotherapy uses drugs (often derived from substances that occur naturally in the body) that encourage your body's immune system to work against the melanoma. Two such treatments in regular use for melanoma are interferon-alpha and interleukin-2. Both are given as an injection (into the blood, under the skin, or into lumps of melanoma).

Side-effects include flu-like symptoms, such as chills, a high temperature, joint pain and fatigue (NHS, 2014e).

Vaccines There is ongoing research into producing a vaccine for melanoma, either to treat advanced melanoma or to be used after surgery in patients who have a high risk of the melanoma coming back.

Vaccines are designed to focus the body's immune system so it recognises the melanoma and can work against it. Vaccines are usually given as an injection under the skin every few weeks, often over a period of months.

As more research is needed into vaccines, they are only given as part of a clinical trial (NHS, 2014e).

Monoclonal antibodies Our immune systems make antibodies all the time, usually as a way of controlling infections. They are substances that recognise something which doesn't belong in the body and help to destroy it. Antibodies can be produced in the laboratory and can be made to recognise and lock onto specific targets, either in the cancer or in specific parts of the body.

Antibodies produced in the laboratory are usually called monoclonal antibodies (NHS, 2014e).

Ipilimumab Ipilimumab is a monoclonal antibody that has been licensed for use in the UK since 2011. It works like an accelerator for the immune system, allowing the body to work against all sorts of conditions, including cancer.

In December 2012, NICE recommended ipilimumab as a possible treatment for people with previously treated advanced melanoma that has spread or cannot be surgically removed (NHS, 2014e).

Signalling inhibitors Signalling inhibitors are drugs that work by disrupting the messages (signals) a cancer uses to co-ordinate its growth. There are hundreds of these signals, and it is difficult to know which ones need to be blocked. Most of the signals have short, technical names. Two that are of current interest in relation to melanoma are BRAF and MEK.

There are drugs available that can interfere with these signals, but most are currently only widely available as part of clinical trials.

NICE recommends a signalling inhibitor called vemurafenib as a possible treatment for melanoma that has spread or cannot be surgically removed (NHS, 2014e).

Clinical trials All new treatment for cancer (and other diseases) is first given to patients in a clinical trial.

A clinical trial or study is an extremely rigorous way of testing a drug on people. Patients are monitored for any effects of the drug on the cancer, as well as side-effects. Many people with melanoma are offered entry into clinical trials, but some people are suspicious of the process (NHS, 2014e).

There are a few key things to know about clinical trials -

- Overall, patients in clinical trials do better than those on routine treatment, even when receiving a drug that would be given routinely.
- All clinical trials are highly regulated.
- All new treatments will first become available through clinical trials (NHS, 2014e).

Even where a new drug fails to offer any benefits over existing treatment, the knowledge that we gain from the trial is valuable for future patients.

If you are asked to take part in a trial, you will be given an information sheet and, if you want to take part, you will be asked to sign a consent form. You can refuse or withdraw from a clinical trial without it affecting your care (NHS, 2014e).

Deciding against treatment for Stage 4 melanoma Many of the treatments described above have unpleasant side-effects that can affect your quality of life. You may decide against having treatment if it is unlikely to significantly extend your life expectancy, or if you do not have symptoms causing you pain or discomfort.

This is entirely your decision and your healthcare team will respect it. If you decide not to receive treatment, pain relief and nursing care will be made available when you need it. This is called palliative care (NHS, 2014e).

Chapter 7

Female-only cancers

Contents

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Cervical cancer

Cervical cancer is a type of cancer that develops in a woman's cervix [56].

Cancer of the cervix often has no symptoms in its early stages. If you do have symptoms, the most common is unusual vaginal bleeding, which can occur after sex, in between periods or after the menopause.

Abnormal bleeding doesn't mean that you definitely have cervical cancer, but it should be investigated by your GP as soon as possible. If your GP thinks you might have cervical cancer, you should be referred to see a specialist within two weeks (NHS, 2015b).

Symptoms

The symptoms of cervical cancer aren't always obvious, and it may not cause any symptoms at all until it's reached an advanced stage.

This is why it's very important that you attend all of your cervical screening appointments (NHS, 2015b).

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[56] the lowermost part of the uterus, where it connects with the vaginal wall

Unusual bleeding

In most cases, vaginal bleeding is the first noticeable symptom of cervical cancer. It usually occurs after having sex.

Bleeding at any other time, other than your expected monthly period, is also considered unusual. This includes bleeding after the menopause (when a woman's monthly periods stop).

Visit your GP for advice if you experience any type of unusual vaginal bleeding (NHS, 2015b).

Other symptoms

Other symptoms of cervical cancer may include pain and discomfort during sex and an unpleasant smelling Vaginal discharge (NHS, 2015b).

Advanced cervical cancer

If the cancer spreads out of your cervix and into surrounding tissue and organs, it can trigger a range of other symptoms, including -

- constipation,
- blood in your urine (haematuria),
- loss of bladder control (urinary incontinence),
- bone pain,
- swelling of one of your legs,
- severe pain in your side or back caused by swelling in your kidneys, related to a condition called hydronephrosis,
- changes to your bladder and bowel habits,
- loss of appetite,
- weight loss,
- tiredness and a lack of energy (NHS, 2015b).

When to seek medical advice

You should contact your GP if you experience -

- bleeding after sex (postcoital bleeding),
- bleeding outside of your normal periods,
- new bleeding after the menopause (NHS, 2015b).

Vaginal bleeding is very common and can have a wide range of causes, so it doesn't necessarily mean you have cervical cancer. However, unusual vaginal bleeding is a symptom that needs to be investigated by your GP (NHS, 2015b).

Causes

In almost all cases, cervical cancer is the result of a change in cell DNA caused by the HPV.

Cancer begins with a change in the structure of the DNA that's present in all human cells. DNA provides the cells with a basic set of instructions, including when to grow and reproduce.

A change in the DNA's structure is known as a mutation. It can alter the instructions that control cell growth, which means the cells continue growing instead of stopping when they should. If the cells reproduce uncontrollably, they produce a lump of tissue called a tumour (NHS, 2015b).

Human papilloma virus (HPV)

More than 99% of cervical cancer cases occur in women who have been previously infected with HPV. HPV is a group of viruses, rather than a single virus. There are more than 100 different types.

HPV is spread during sexual intercourse and other types of sexual activity (such as skin-to-skin contact of the genital areas, or using sex toys) and is thought to be very common. It's estimated that 1 in 3 women will develop a HPV infection within two years of starting to have regular sex, and about 4 in 5 women will develop the infection at some point in their lives.

Some types of HPV don't cause any noticeable symptoms and the infection will pass without treatment. Other types of HPV can cause genital warts, although these types aren't linked to an increased risk of causing cervical cancer.

About 15 types of HPV are considered high-risk for cervical cancer. The two types known to have the highest risk are HPV 16 and HPV 18, which cause about 7 out of every 10 cervical cancers.

High-risk types of HPV are thought to contain genetic material that can be passed into the cells of the cervix. This material begins to disrupt the normal workings of the cells, which can eventually cause them to reproduce uncontrollably, leading to the growth of a cancerous tumour.

As most types of HPV don't cause any symptoms, you or your partner could have the virus for months or years without knowing it (NHS, 2015b).

Cervical intraepithelial neoplasia (CIN)

Cancer of the cervix usually takes many years to develop. Before it does, the cells in the cervix often show changes known as cervical intraepithelial neoplasia (CIN) or, less commonly, cervical glandular intraepithelial neoplasia (CGIN).

CIN and CGIN are pre-cancerous conditions. Pre-cancerous conditions don't pose an immediate threat to a person's health, but they can potentially develop into cancer in the future.

However, even if you develop CIN or CGIN, the chances of it developing into cervical cancer are very small, and if the changes are discovered during cervical screening, treatment is highly successful.

The progression from becoming infected with HPV to developing CIN or CGIN and then developing cervical cancer is very slow, often taking 10 to 20 years (NHS, 2015b).

Increased risk

The fact that HPV infection is very common but cervical cancer is relatively uncommon suggests that only a very small proportion of women are vulnerable to the effects of an HPV infection. There appear to be additional risk factors that affect a woman's chance of developing cervical cancer. These include -

- **smoking** - women who smoke are twice as likely to develop cervical cancer than women who don't; this may be caused by the harmful effects of chemicals found in tobacco on the cells of the cervix,
- **having a weakened immune system** - this can occur as a result of taking certain medications, such as immunosuppressants, which are used to stop the body rejecting donated organs, or as a result of a condition such as HIV or AIDS,
- **taking the oral contraceptive pill for more than five years** - women who take the pill are thought to have twice the risk of developing cervical cancer than those who don't, although it's not clear why,
- **having children (the more children you have, the greater your risk)** - women who have two children have twice the risk of getting cervical cancer compared with women who don't have any children (NHS, 2015b).

The reason for the link between cervical cancer and childbirth is unclear. One theory is that the hormonal changes that occur during pregnancy may make the cervix more vulnerable to the effects of HPV (NHS, 2015b).

The spread of cervical cancer

If cervical cancer is undiagnosed and untreated, it will slowly spread out of the cervix and into the surrounding tissue and organs. The cancer can spread down to the vagina and the surrounding muscles that support the bones of the pelvis. Alternatively, it can spread upwards, blocking the tube that runs from your kidneys to your bladder (ureters).

The cancer can then spread into your bladder, rectum (back passage) and eventually into your liver, bones and lungs. Cancerous cells can also spread through your lymphatic system. The lymphatic system is a series of nodes (glands) and channels spread throughout your body in a similar way to the blood circulation system.

The lymph nodes produce many of the specialised cells needed by your immune system (the body's natural defence against infection and illness). If you have an infection, the nodes in your neck or under your armpits can become swollen.

In some cases of early cervical cancer, the lymph nodes close to the cervix contain cancerous cells. In some cases of advanced cervical cancer, lymph nodes in the chest and abdomen can be affected (NHS, 2015b).

Diagnosis

If cervical cancer is suspected, you'll be referred to a gynaecologist (a specialist in treating conditions of the female reproductive system).

Referral will be recommended if the results of your cervical screening test suggest that there are abnormalities in the cells of your cervix. However, in most cases, the abnormalities don't mean you have cervical cancer.

You may also be referred to a gynaecologist if you have abnormal vaginal bleeding, or if your GP has noticed a growth inside your cervix during an examination.

The sexually transmitted infection (STI) chlamydia [57] is one of the most common reasons why women experience unusual vaginal bleeding. Your GP may recommend that you're tested for it first before being referred. Testing for chlamydia

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[57] a bacterial infection

involves taking a small tissue sample from your cervix, or carrying out a urine test (NHS, 2015b).

Colposcopy

If you've had an abnormal cervical screening test result, or your symptoms suggest that you may have cervical cancer, your gynaecologist will usually carry out a colposcopy [58]. This is an examination to look for abnormalities in your cervix.

During a colposcopy, a small microscope with a light source at the end (colposcope) is used. As well as examining your cervix, your gynaecologist may remove a small tissue sample (biopsy) so that it can be checked under a microscope for cancerous cells (NHS, 2015b).

Cone biopsy

In some cases, a minor operation called a cone biopsy may also be carried out. The operation is carried out in hospital, usually under a local anaesthetic.

During a cone biopsy, a small, cone-shaped section of your cervix will be removed so that it can be examined under a microscope for cancerous cells. You may experience vaginal bleeding for up to four weeks after the procedure. You may also have period-like pains (NHS, 2015b).

Further testing

If the results of the biopsy suggest you have cervical cancer and there's a risk that the cancer may have spread, you'll probably need to have some further tests to assess how widespread the cancer is. These tests may include -

- **a pelvic examination carried out under general anaesthetic** - your womb, vagina, rectum and bladder will be checked for cancer,
- **blood tests** - these can be used to help assess the state of your liver, kidneys and bone marrow,
- **computerised tomography (CT) scan** - scans are taken of the inside of your body and a computer is used to assemble them into a detailed three-dimensional image; the CT scan can help to identify cancerous tumours and show whether cancerous cells have spread,

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[58] a procedure to find out whether there are abnormal cells on or in a woman's cervix or vagina

- **magnetic resonance imaging (MRI) scan** - this type of scan uses strong magnetic fields and radio waves to produce detailed pictures of the inside of your body; it can also be used to check whether cancer has spread,
- **chest X-ray** - this will indicate whether cancer has spread to your lungs,
- **positive emission tomography (PET) scan** [59] (NHS, 2015b).

Staging

After all of the tests have been completed and your test results are known, it should be possible to tell you what stage cancer you have. Staging is a measurement of how far the cancer has spread. The higher the stage, the further the cancer has spread. The staging for cervical cancer is as follows -

- **stage 0 (pre-cancer)** - there are no cancerous cells in the cervix, but there are biological changes that could trigger cancer in the future; this is called cervical intraepithelial neoplasia (CIN) or carcinoma in situ (CIS),
- **stage 1** - the cancer is still contained inside the cervix,
- **stage 2** - the cancer has spread outside of the cervix into the surrounding tissue, but hasn't reached the tissues lining the pelvis (pelvic wall) or the lower part of the vagina,
- **stage 3** - the cancer has spread into the lower section of the vagina and/or into the pelvic wall,
- **stage 4** - the cancer has spread into the bowel, bladder or other organs, such as the lungs (NHS, 2015b).

Treatment

Treatment for cervical cancer depends on how far the cancer has spread.

As cancer treatments are often complex, hospitals use MDTs to treat cervical cancer and tailor the treatment programme to the individual.

MDTs are made up of a number of different specialists who work together to make decisions about the best way to proceed with your treatment (NHS, 2015b).

Your cancer team will recommend what they think the best treatment options are, but the final decision will be yours. In most cases, the recommendations will be -

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[59] a specialised scan, where a mildly radioactive substance is injected into your veins so the cancerous tissue shows up more clearly; it's often combined with a CT scan and is used to see if the cancer has spread, or to check how well a person is responding to treatment

- **early cervical cancer** - surgery to remove some or all of the womb, radiotherapy, or a combination of the two,
- **advanced cervical cancer** - radiotherapy and/or chemotherapy, although surgery is also sometimes used (NHS, 2015b).

The prospect of a complete cure is good for cervical cancer diagnosed at an early stage, although the chances of a complete cure decrease the further the cancer has spread.

In cases where cervical cancer isn't curable, it's often possible to slow its progression, prolong lifespan and relieve any associated symptoms, such as pain and vaginal bleeding. This is known as palliative care.

The different treatment options are discussed in more detail below (NHS, 2015b).

Removing abnormal cells

If your screening results show that you don't have cervical cancer, but there are biological changes that could turn cancerous in the future, a number of treatment options are available. These include -

- **large loop excision of the transformation zone (LLETZ)** - the abnormal cells are cut away using a fine wire and an electrical current,
- **cone biopsy** - the area of abnormal tissue is removed during surgery,
- **laser therapy** - a laser is used to burn away the abnormal cells (NHS, 2015b).

Surgery

There are three main types of surgery for cervical cancer. They are -

- **radical trachelectomy** - the cervix, surrounding tissue and the upper part of the vagina are removed, but the womb is left in place,
- **hysterectomy** - the cervix and womb are removed; depending on the stage of the cancer, it may also be necessary to remove the ovaries and fallopian tubes,
- **pelvic exenteration** - a major operation in which the cervix, vagina, womb, bladder, ovaries, fallopian tubes and rectum are removed (NHS, 2015b).

Radical trachelectomy A radical trachelectomy is usually only suitable if cervical cancer is diagnosed at a very early stage. It's usually offered to women who want to preserve their child-bearing potential.

During the procedure, the surgeon will make a number of small incisions (cuts) in your abdomen. Specially designed instruments will be passed through the incisions and used to remove your cervix and the upper section of your vagina. Lymph nodes from your pelvis may also be removed. Your womb will then be reattached to the lower section of your vagina.

Compared with a hysterectomy or pelvic exenteration, the advantage of this type of surgery is that your womb remains intact, which means that you may still be able to have children. However, it's important to be aware that the surgeons carrying out this operation can't guarantee you'll still be able to have children.

If you do have children after the operation, your child would have to be delivered by caesarean section. It's also usually recommended that you wait 6 to 12 months after having surgery before trying for a baby, so that your womb and vagina have time to heal.

Radical trachelectomy is a highly skilled procedure. It's only available at a number of specialist centres in the UK, so it may not be available in your area and you may have to travel to another city to be treated (NHS, 2015b).

Hysterectomy A hysterectomy is usually recommended for early cervical cancer. This may be followed by a course of radiotherapy to help prevent the cancer coming back (NHS, 2015b).

Two types of hysterectomies are used to treat cervical cancer. They are -

- **simple hysterectomy** - where the cervix and womb are removed and, in some cases, the ovaries and fallopian tubes are also removed; this is only appropriate for very early stage cervical cancers,
- **radical hysterectomy** - where the cervix, womb, surrounding tissue and lymph nodes, ovaries and fallopian tubes are all removed; this is the preferred option in advanced stage one and some early stage two cervical cancers (NHS, 2015b).

Short-term complications of a hysterectomy include infection, bleeding, blood clots and accidental injury to your ureter, bladder or rectum.

The risk of long-term complications is small, but they can be troublesome. They include -

- the risk that your vagina can become shortened and drier, which can make sex painful,
- urinary incontinence,
- swelling of your arms and legs, caused by a build-up of fluid (lymphoedema),

- your bowel becomes obstructed because of a build-up of scar tissue - this may require further surgery to correct (NHS, 2015b).

As your womb is removed during a hysterectomy, you'll no longer be able to have children.

If your ovaries are removed, it will also trigger the menopause if you haven't already experienced it (NHS, 2015b).

Pelvic exenteration A pelvic exenteration is a major operation that's usually only recommended when cervical cancer returns after what was thought to be a previously successful course of treatment. It's offered if the cancer returns to the pelvis, but hasn't spread beyond this area (NHS, 2015b).

A pelvic exenteration involves two phases of treatment -

- the cancer is removed, plus your bladder, rectum, vagina and the lower section of your bowel,
- two holes called stomas are created in your abdomen - the holes are used to pass urine and faeces out of your body into collection pouches called colostomy bags (NHS, 2015b).

Following a pelvic exenteration, your vagina can be reconstructed using skin and tissue taken from other parts of your body. This means you'll be able to have sex after the procedure, although it may be several months until you feel well enough to do so (NHS, 2015b).

Radiotherapy

Radiotherapy may be used on its own or combined with surgery for early stage cervical cancer. It may be combined with chemotherapy for advanced cervical cancer, where it can be used to control bleeding and pain (NHS, 2015b).

There are two ways that radiotherapy can be delivered. These are -

- **externally** - a machine beams high-energy waves into your pelvis to destroy cancerous cells,
- **internally** - a radioactive implant is placed inside your vagina and cervix (NHS, 2015b).

In most cases, a combination of internal and external radiotherapy will be used. A course of radiotherapy usually lasts for around five to eight weeks.

As well as destroying cancerous cells, radiotherapy can sometimes also harm healthy tissue. This means it can cause significant side-effects many months, and even years, after treatment.

However, the benefits of radiotherapy often tend to outweigh the risks. For some people, radiotherapy offers the only hope of getting rid of the cancer.

Side-effects of radiotherapy are common and can include -

- diarrhoea,
- pain when urinating,
- bleeding from your vagina or rectum,
- feeling very tired (fatigue),
- feeling sick (nausea),
- sore skin in your pelvis region similar to sunburn,
- narrowing of your vagina, which can make having sex painful,
- infertility,
- damage to the ovaries, which will usually trigger an early menopause (if you haven't already experienced it),
- bladder and bowel damage, which could lead to incontinence (NHS, 2015b).

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Most of these side-effects will resolve within about eight weeks of finishing treatment, although in some cases they can be permanent. It's also possible to develop side-effects several months, or even years, after treatment has finished.

If infertility is a concern for you, it may be possible to surgically remove eggs from your ovaries before you have radiotherapy, so that they can be implanted in your womb at a later date. However, you may have to pay for this.

It may also be possible to prevent an early menopause by surgically removing your ovaries and replanting them outside the area of your pelvis that will be affected by radiation. This is known as an ovarian transposition.

Your MDT can provide more information about the possible options for treating infertility and whether you're suitable for an ovarian transposition (NHS, 2015b).

Chemotherapy

Chemotherapy can be combined with radiotherapy to try to cure cervical cancer, or it can be used as a sole treatment for advanced cancer to slow its progression and relieve symptoms (palliative chemotherapy).

Chemotherapy involves using either a single chemotherapy medication called cisplatin or a combination of different chemotherapy medications to kill the cancerous cells.

Chemotherapy is usually given using an intravenous drip on an outpatient basis, so you'll be able to go home once you've received your dose (NHS, 2015b).

As with radiotherapy, these medications can also damage healthy tissue. Side-effects are therefore common and can include -

- nausea and vomiting,
- diarrhoea,
- feeling tired all the time,
- reduced production of blood cells, which can make you feel tired and breathless (anaemia) and vulnerable to infection because of a lack of white blood cells,
- mouth ulcers,
- loss of appetite,
- hair loss - your hair should grow back within three to six months of your course of chemotherapy being completed, although not all chemotherapy medications cause hair loss (NHS, 2015b).

Some types of chemotherapy medication can damage your kidneys, so you may need to have regular blood tests to assess the health of your kidneys (NHS, 2015b).

Follow-up

After your treatment has been completed and the cancer has been removed, you'll need to attend regular appointments for testing. This will usually involve a physical examination of your vagina and cervix (if it hasn't been removed).

As there's a risk of cervical cancer returning, these examinations will be used to look for signs of this. If anything suspicious is found, a further biopsy can be carried out.

If cervical cancer does return, it usually returns around 18 months after a course of treatment has been completed.

Follow-up appointments are usually recommended every four months after treatment has been completed for the first two years, and then every six to 12 months for a further three years (NHS, 2015b).

Your multidisciplinary team (MDT)

Members of your MDT may include -

- a surgeon,
- a clinical oncologist (a specialist in chemotherapy and radiotherapy),
- a medical oncologist (a specialist in chemotherapy only),
- a pathologist (a specialist in diseased tissue),
- a radiologist (a specialist in imaging scans),

- a gynaecologist (a doctor who specialises in treating conditions that affect the female reproductive system),
- a social worker,
- a psychologist,
- a specialist cancer nurse, who'll usually be your first point of contact with the rest of the team (NHS, 2015b).

Complications

Complications of cervical cancer can occur as a side-effect of treatment or as the result of advanced cervical cancer (NHS, 2015b).

Side-effects

Early menopause If your ovaries are surgically removed or they're damaged during treatment with radiotherapy, it will trigger an early menopause (if you haven't already had it). Most women experience the menopause in their early fifties (NHS, 2015b).

The menopause is caused when your ovaries stop producing the hormones oestrogen and progesterone. This leads to the following symptoms -

- you no longer have monthly periods or your periods become much more irregular,
- hot flushes,
- vaginal dryness,
- loss of sex drive,
- mood changes,
- stress incontinence (leaking urine when you cough or sneeze),
- night sweats,
- thinning of the bones, which can lead to brittle bones (osteoporosis) (NHS, 2015b).

These symptoms can be relieved by taking a number of medications that stimulate the production of oestrogen and progesterone. This treatment is known as hormone replacement therapy [60](HRT) (NHS, 2015b).

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[60] a treatment used to relieve symptoms of the menopause. It replaces female hormones that are at a lower level as you approach the menopause

Narrowing of the vagina Radiotherapy to treat cervical cancer can often cause your vagina to become narrower, which can make having sex painful or difficult.

There are two main treatment options if you have a narrowed vagina. The first is to apply hormonal cream to your vagina. This should increase moisture within your vagina and make having sex easier.

The second is to use a vaginal dilator, which is a tampon-shaped device made of plastic. You insert it into your vagina and is designed to help make it more supple. It's usually recommended that you insert the dilator for 5 to 10 minutes at a time on a regular basis during the day over the course of 6 to 12 months.

Many women find discussing the use of a vaginal dilator embarrassing, but it's a standard and well-recognised treatment for narrowing of the vagina. Your specialist cancer nurse or radiographers in the radiotherapy department should be able to give you more information and advice.

You may find that the more times you have sex, the less painful it becomes. However, it may be several months before you feel emotionally ready to be intimate with a sexual partner (NHS, 2015b).

Lymphoedema If the lymph nodes in your pelvis are removed, it can sometimes disrupt the normal workings of your lymphatic system.

One of the functions of the lymphatic system is to drain away excess fluid from the body's tissue. A disruption to this process can lead to a build-up of fluid in the tissue known as lymphoedema. This can cause certain body parts to become swollen - usually the legs, in cases of cervical cancer.

There are exercises and massage techniques that can reduce the swelling. Wearing specially designed bandages and compression garments can also help (NHS, 2015b).

Emotional impact The emotional impact of living with cervical cancer can be significant. Many people report experiencing a "rollercoaster" effect.

For example, you may feel down when you receive a diagnosis, but feel better when removal of the cancer has been confirmed. You may then feel down again as you try to come to terms with the after-effects of your treatment.

This type of emotional disruption can sometimes trigger depression. Typical signs of depression include feeling sad, hopeless and losing interest in things you used to enjoy.

Contact your GP if you think you may be depressed. There are a range of effective treatments available, including antidepressant medication and talking therapies, such as cognitive behavioural therapy (CBT).

You may also find Jo's Cervical Cancer Trust a useful resource. It's the UK's only charity dedicated to women affected by cervical cancer.

Local cancer support groups may also be available in your area for women affected by cancer. Your specialist cancer nurse should be able to provide contact details (NHS, 2015b).

Advanced cervical cancer

Some of the complications that can occur in advanced cervical cancer are discussed below.

Pain If the cancer spreads into your nerve endings, bones or muscles, it can often cause severe pain.

A number of effective painkilling medications can usually be used to control the pain. Depending on the levels of pain, they can range from paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, to more powerful opiate-based painkillers, such as codeine and morphine.

Tell your care team if the painkillers you're prescribed aren't effective in reducing your pain. You may need to be prescribed a stronger medication. A short course of radiotherapy may also be effective in controlling the pain.

Macmillan nurses, who work both in hospitals and in the community, can also provide expert advice about pain relief (NHS, 2015b).

Kidney failure Your kidneys remove waste material from your blood. The waste is passed out of your body in urine through tubes called the ureters. Kidney function can be monitored by a simple blood test called serum creatinine level.

In some cases of advanced cervical cancer, the cancerous tumour can press against the ureters, blocking the flow of urine out of the kidneys. The build-up of urine inside the kidneys is known as hydronephrosis and can cause the kidneys to become swollen and stretched.

Severe cases of hydronephrosis can cause the kidneys to become scarred, which can lead to loss of most or all of the kidneys' functions. This is known as kidney failure (NHS, 2015b).

Kidney failure can cause a wide range of symptoms, including -

- tiredness,
- swollen ankles, feet or hands, caused by water retention,
- shortness of breath,
- feeling sick,
- blood in your urine (haematuria) (NHS, 2015b).

Treatment options for kidney failure associated with cervical cancer include draining urine out of the kidneys using a tube inserted through the skin and into each kidney (percutaneous nephrostomy). Another option is to widen the ureters by placing a small metal tube called a stent inside them (NHS, 2015b).

Blood clots As with other types of cancer, cervical cancer can make the blood ”stickier” and more prone to forming clots. Bed rest after surgery and chemotherapy can also increase the risk of developing a clot.

Large tumours can press on the veins in the pelvis, which slows the flow of blood and can lead to a blood clot developing in the legs (NHS, 2015b).

Symptoms of a blood clot in your legs include -

- pain, swelling and tenderness in one of your legs (usually your calf),
- a heavy ache in the affected area,
- warm skin in the area of the clot,
- redness of the skin, particularly at the back of your leg, below the knee (NHS, 2015b).

A major concern in these cases is that the blood clot from the leg vein will travel up to the lungs and block the supply of blood. This is known as a pulmonary embolism and can be fatal.

Blood clots in the legs are usually treated using a combination of blood-thinning medication, such as heparin or warfarin, and compression garments designed to help encourage the flow of blood through the limbs (NHS, 2015b).

Bleeding If the cancer spreads into your vagina, bowel or bladder, it can cause significant damage, resulting in bleeding. Bleeding can occur in your vagina or rectum (back passage), or you may pass blood when you urinate.

Minor bleeding can often be treated using a medication called tranexamic acid, which encourages the blood to clot and stop the bleeding. Radiotherapy can also be highly effective in controlling bleeding caused by cancer.

Major bleeding may be treated temporarily by vaginal packing (using gauze to stem the bleeding) and later by surgery, radiotherapy or by cutting off blood supply to the cervix (NHS, 2015b).

Fistula A fistula is an uncommon but distressing complication that occurs in around 2% of cases of advanced cervical cancer.

A fistula is an abnormal channel that develops between two sections of the body. In most cases involving cervical cancer, the fistula develops between the bladder and the vagina. This can lead to a persistent discharge of fluid from the vagina. A fistula can sometimes develop between the vagina and rectum.

Surgery is usually required to repair a fistula, although it's often not possible in women with advanced cervical cancer, because they're usually too frail to withstand the effects of surgery.

In such cases, treatment often involves using medication, creams and lotions to reduce the amount of discharge and protect the vagina and surrounding tissue from damage and irritation (NHS, 2015b).

Vaginal discharge Another uncommon, but distressing, complication of advanced cervical cancer is an unpleasant-smelling discharge from your vagina.

The discharge can occur for a number of reasons, such as the breakdown of tissue, the leakage of bladder or bowel contents out of the vagina, or a bacterial infection of the vagina.

Treatment options for vaginal discharge include an antibacterial gel called metronidazole and wearing clothing that contains charcoal. Charcoal is a chemical compound that's very effective in absorbing unpleasant smells (NHS, 2015b).

Palliative care

If your doctors can't do any more to treat your cancer, your care will focus on controlling your symptoms and helping you to be as comfortable as possible. This is called palliative care.

Palliative care also includes psychological, social and spiritual support for you and your family or carers.

There are different options for terminal care in the late stages of cancer. You may want to think about whether you'd like to be cared for in hospital, in a hospice or at home, and discuss these issues with your doctor. Some organisations who provide care for people with cancer include -

- Macmillan Cancer Support - which has specially trained nurses who help to look after people with cancer at home. To be referred to a Macmillan nurse, ask your hospital doctor or GP, or call 0808 808 00 00,

- Marie Curie Cancer Care - have specially trained nurses who help to look after people with cancer at home. They also run hospices for people with cancer,
- Hospice UK - provides information about hospice care [61] and how to find a hospice.

Living with cervical cancer

The impact of cervical cancer on your daily life will depend on the stage of cancer and the treatment you're having.

Many women with cervical cancer have a radical hysterectomy. This is a major operation that takes around 6 to 12 weeks to recover from. During this time, you need to avoid strenuous tasks and lifting, such as lifting children or heavy shopping bags.

You won't be able to drive for 3 to 8 weeks after the operation. Most women will also need 8 to 12 weeks off work to recover after having a radical hysterectomy.

Some of the treatments for cervical cancer can make you very tired, particularly chemotherapy and radiotherapy. Because of this, you may need to take a break from some of your normal activities for a while.

Don't be afraid to ask for practical help from family and friends if you need it. Practical help may also be available from your local authority. Ask your doctor or nurse about who to contact (NHS, 2015b).

Work

See Living with cancer.

Your sex life

Many women feel nervous about having sex soon after treatment for cervical cancer, but it's perfectly safe. Sex won't make the cancer come back and your partner can't catch cancer from you.

If you want to, you can resume your normal sex life within a few weeks of finishing radiotherapy or having surgery. This will give your body time to heal.

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[61] based on the same principles as palliative care. Hospice care is initiated at the very end of life, when death is expected within six months. Hospice care is very often provided in the home, on specialised hospital hospice units or in free-standing hospice facilities

If you're having chemotherapy, male partners should wear a condom when you have sex, because it's not clear if having sex after chemotherapy can have an effect on them.

Some women find sex difficult after being treated for cervical cancer, because the side-effects of some treatments can include vaginal dryness and narrowing of the vagina. In these cases, there are treatments that can help, such as vaginal dilators (NHS, 2015b).

Prevention

There's no single way to completely prevent cervical cancer, but there are things that can reduce your risk (NHS, 2015b).

Safer sex

Most cases of cervical cancer are linked to an infection with certain types of HPV. HPV can be spread through unprotected sex, so using a condom can reduce your risk of developing the infection. However, the virus isn't just passed on through penetrative sex - it can be transmitted during other types of sexual contact, such as skin-to-skin contact between genital areas and by using sex toys.

Your risk of developing an HPV infection increases the earlier you start having regular sex and with the more sexual partners you have, although women who have only had one sexual partner can also develop it (NHS, 2015b).

Cervical screening

Regular cervical screening is the best way to identify abnormal changes in the cells of the cervix at an early stage.

Women who are 25–49 years of age are invited for screening every three years. Women who are 50–64 years of age are invited every five years. For women who are 65 years of age or older, only those who haven't been screened since they were 50, or those who have had recent abnormal tests, are offered screening.

Make sure that your GP surgery has your up-to-date contact details, so that you continue getting screening invitations.

It's important that you attend your cervical screening tests, even if you've been vaccinated for HPV, because the vaccine doesn't guarantee protection against cervical cancer.

If you've been treated for abnormal cervical cell changes, you'll be invited for screening more frequently for several years after treatment. How regularly you need to go will depend on how severe the cell change is.

Although it can identify most abnormal cell changes in the cervix, cervical screening isn't always 100% accurate. Therefore, you should report symptoms such as unusual vaginal bleeding to your GP, even if you've recently been tested (NHS, 2015b).

Cervical cancer vaccination

The NHS cervical cancer vaccination programme uses a vaccine called Gardasil. Gardasil protects against four types of HPV, including the two strains responsible for more than 70% of cervical cancers in the UK (HPV16 and HPV18). It also prevents genital warts.

Girls are offered the childhood immunisation programme. The vaccine is given to girls when they're 12–13 years old, with three doses given over a six-month period.

Although the HPV vaccine can significantly reduce the risk of cervical cancer, it doesn't guarantee that you won't develop the condition. You should still attend cervical screening tests, even if you've had the vaccine (NHS, 2015b).

Avoid smoking

You can reduce your chances of getting cervical cancer by not smoking. People who smoke are less able to get rid of the HPV infection from the body, which can develop into cancer.

If you decide to give up smoking, your GP can refer you to the NHS Stop Smoking Service, which gives you help and advice on the best ways to stop smoking.

You can also call the NHS Smoking Helpline (0300 123 1044) and speak to specially trained staff who will provide free expert advice and encouragement.

If you want to give up smoking, but you don't want to be referred to a stop smoking service, your GP should be able to prescribe medical treatment to help with any withdrawal symptoms that you may experience after giving up (NHS, 2015b).

Female breast cancer

Breast cancer is the most common type of cancer in the UK.

In 2011, just under 50,000 women were diagnosed with invasive breast cancer. Most women who get it (8 out of 10) are over 50, but younger women, and in rare cases, men, can also get breast cancer.

If it's treated early enough, breast cancer can be prevented from spreading to other parts of the body (NHS, 2014b).

The breasts

The breasts are made up of fat, connective tissue and thousands of tiny glands called lobules, which produce milk. When a woman has a baby, the milk is delivered to the nipple through tiny tubes called ducts, which allow her to breastfeed.

The body is made up of billions of tiny cells, which usually grow and multiply in an orderly way. New cells are only produced when and where they're needed. In cancer, this orderly process goes wrong and cells begin to grow and multiply uncontrollably (NHS, 2014b).

Symptoms

The first symptom of breast cancer most women notice is a lump or an area of thickened tissue in their breast.

Most breast lumps (90%) aren't cancerous, but it's always best to have them checked by your doctor.

You should see your GP if you notice any of the following -

- a lump or area of thickened tissue in either breast (NHS, 2014b).
  - can you feel a lump?
  - either in the breast, upper chest or armpit?
  - is there a lumpy area?
  - or unusual thickening of the breast tissue that doesn't go away?
  - is there any unusual pain?
  - either in part of the breast or the armpit? (BREASTCANCERNOW, 2016).
- a change in the size or shape of one or both breasts,
- discharge (liquid) that comes from the nipple without squeezing (BREASTCANCERCARE, 2014), (which may be streaked with blood) (NHS, 2014b).
  - any unusual discharge?

  - one or both nipples might have a discharge (BREASTCANCERNOW, 2016).
- a lump or swelling in either of your armpits (BREASTCANCERCARE, 2014)
- dimpling on the skin of your breasts (NHS, 2014b).
  - any change in size or shape?
  - for example, one breast might become larger or lower than the other.
  - any change in colour?
  - e.g. the breast may look red or inflamed.
  - any change in skin texture?
  - such as puckering or dimpling of the skin of the breast (BREASTCANCERNOW, 2016).
- a rash or crusting on or around your nipple,
  - any rash or crusting of the nipple or surrounding area (BREASTCANCERNOW, 2016).
- your nipple becoming inverted (pulled in) or changing its position or shape (BREASTCANCERCARE, 2014).
  - what about the appearance or the direction of the nipple?
  - e.g. one might become inverted (turned in) when it normally points out (BREASTCANCERNOW, 2016).
- constant pain in your breast or your armpit,
- redness or a rash on the skin and/or around the nipple (BREASTCANCERCARE, 2014).

It's as simple as **TLC**

- **T** - TOUCH your breasts. Can you feel anything unusual?
- **L** - LOOK for changes. Is there any change in shape or texture?
- **C** - CHECK anything unusual with your doctor (BREASTCANCERNOW, 2016).

Breast pain isn't usually a symptom of breast cancer.

How do I check my breasts?

There's no right or wrong way to check your breasts for any changes. Try to get used to looking at and feeling your breasts regularly. You can do this in the bath or shower, when you use body lotion, or when you get dressed. There's really no need to change your everyday routine. Just decide what you are comfortable with and what suits you best.

Remember to check all parts of your breast, your armpits and up to your collarbone.

Everyone's breasts look and feel different.

Some people have lumpy breasts, or one breast larger than the other, or breasts that are different shapes. Some have one or both nipples pulled in (inverted), which can be there from birth or happen when the breasts are developing.

When you check your breasts, try to be aware of any changes that are different for you (BREASTCANCERCARE, 2014).

Breast awareness

It's important to be breast aware, so you can pick up any changes as soon as possible. Get to know what is normal for you. For instance, your breasts may look or feel different at different times of your life. This will make it much easier to spot potential problems (NHS, 2014b).

Causes

The causes of breast cancer aren't fully understood, making it difficult to say why one woman may develop breast cancer and another may not.

However, there are risk factors that are known to affect your likelihood of developing breast cancer. Some of these you can't do anything about, but there are some you can change (NHS, 2014b).

Age

The risk of developing breast cancer increases with age. The condition is most common among women over 50 who have been through the menopause. About 8 out of 10 cases of breast cancer occur in women over 50.

All women who are 50–70 years of age should be screened for breast cancer every three years as part of the NHS Breast Screening Programme. Women over the age of 70 are still eligible to be screened and can arrange this through their GPor local screening unit (NHS, 2014b).

Family history

If you have close relatives who have had breast cancer or ovarian cancer, you may have a higher risk of developing breast cancer. However, because breast cancer is the most common cancer in women, it's possible for it to occur in more than one family member by chance.

Most cases of breast cancer aren't hereditary (they don't run in families), but particular genes, known as BRCA1 and BRCA2, can increase your risk of developing both breast and ovarian cancer. It's possible for these genes to be passed on from a parent to their child. A third gene (TP53) is also associated with increased risk of breast cancer.

If you have, for example, two or more close relatives from the same side of your family, such as your mother, sister or daughter, who have had breast cancer under the age of 50, you may be eligible for surveillance for breast cancer or for genetic screening to look for the genes that make developing breast cancer more likely. If you're worried about your family history of breast cancer, discuss it with your GP (NHS, 2014b).

Predictive genetic tests for cancer risk genes

Cancer is not usually inherited, but some types - mainly breast, ovarian, colorectal and prostate cancer - can be strongly influenced by genes and can run in families.

We all carry certain genes that are normally protective against cancer - they correct any DNA damage that naturally occurs when cells divide.

Inheriting faulty versions or ”variants” of these genes significantly raises your risk of developing cancer, because the altered genes cannot repair the damaged cells, which can build up and form a tumour.

BRCA1 and **BRCA2** are two examples of genes that raise your cancer risk if they become altered. Having a variant BRCA gene greatly increases a woman's chance of developing breast cancer and ovarian cancer. This was the reason Angelina Jolie had preventative breast cancer surgery, followed by ovarian cancer surgery. They also increase a man's chance of developing male breast cancer and prostate cancer.

BRCA genes are not the only cancer risk genes. Researchers recently identified more than 100 new gene variants associated with an increased risk of breast, prostate and ovarian cancer. Individually, these new gene variants only slightly increase the risk of cancer, but a combination could mean a high risk overall.

If you or your partner have a high-risk cancer gene, such as an altered version of **BRCA1**, it can be passed on to any children you have (NHS, 2015g).

What to do if you're worried Speak to your GP if cancer runs in your family and you're worried you may get it too. They may refer you to a local genetics service for an NHS genetic test, which will tell you if you have inherited one of the cancer risk genes.

This type of testing is known as predictive genetic testing. It's ”predictive” because a positive result means you have a greatly increased risk of developing cancer. It doesn't mean you have cancer or are definitely going to develop it.

You may be eligible for this NHS test if the faulty gene has already been identified in one of your relatives, or if there is a strong family history of cancer in your family (NHS, 2015g).

Pros and cons of having a predictive genetic test Not everyone who is eligible for the NHS test will want to have it. It's a personal decision, and should only be made after you've had genetic counselling sessions and talked through what having the test means, how you may feel and how you will cope (NHS, 2015g).

Advantages

- **a positive result means you can take steps to manage your risk of developing cancer** - you can make certain lifestyle changes to lower your risk, have regular screening and have preventative treatment (see Managing your risk, below),
- **knowing the result may reduce any stress and anxiety** that comes from not knowing (NHS, 2015g).

Disadvantages

- **the results of some genetic tests are inconclusive** - doctors may identify a variation in a gene, but not know what effect it may have,
- **a positive result may cause permanent anxiety** - some people would rather not know about their risk and only want to be told if they actually develop cancer (NHS, 2015g).

What testing involves There are usually two steps to genetic testing -

- **A relative with cancer has a diagnostic blood test** to see if they have a cancer risk gene (this normally must happen before any healthy relatives are tested). Their result will be ready four to eight weeks later,

- **If your relative's test is positive, you can have the predictive genetic test** to see if you have the same faulty gene. Your GP will refer you to your local genetics service for the blood test (you'll need a copy of your relative's test results). The result will take up to two weeks to come through after a blood sample is taken, but this may not happen at your first appointment. This test is fully predictive as a "clear" negative test, which will mean you have not inherited the family high risk of cancer (NHS, 2015g).

The charity Breakthrough Breast Cancer explains the importance of these two steps -

- "*Without looking at the genes of an affected relative first, testing a healthy individual would be like reading through an entire book looking for a spelling mistake without knowing where the mistake is, or if there is a mistake at all.*"
- When there are no affected relatives available, full testing of BRCA1 and BRCA2 may be possible for those with at least a 10% chance of having a genetic fault. This usually means having a very strong family history of early onset breast and particularly ovarian cancer. It takes four to eight weeks to get the result, but this is not fully predictive as a negative test, so cannot rule out that the problem in relatives is due to a different gene (NHS, 2015g).

What a positive result means If your predictive genetic test result is positive, it means you have a faulty gene that raises your risk of developing cancer.

It doesn't mean you are guaranteed to get cancer - your genes only partly influence your future health risks. Other factors, such as your medical history, lifestyle and your environment, also play a role.

If you have one of the faulty BRCA genes, there is a 50% chance you will pass this on to any children you have and a 50% chance that each of your siblings also has it.

You may want to discuss your results with other members of your family, who may also be affected. The genetics clinic will discuss with you how a positive or negative result will affect your life and your relationships with your family.

You can read more about this in the beginner's guide to BRCA1 and BRCA2 produced by The Royal Marsden NHS Foundation Trust.

Insurance companies cannot ask you to disclose the results of predictive genetic tests for the majority of policies, but this may change in the future (NHS, 2015g).

Managing your risk If your test result is positive, you have a range of options to manage your risk. Risk-reducing surgery is not the only option.

Ultimately, there's no right or wrong answer about what you should do - it's a decision only you can make (NHS, 2015g).

Regularly examining your breasts If you have the faulty BRCA1/2 gene, it's a good idea to be aware of changes in your breasts. Read more about being breast cancer aware.

This advice applies to men with a faulty BRCA2 gene too, as they are also at increased risk of breast cancer (although to a lesser extent) (NHS, 2015g).

Screening In the case of breast cancer, annual breast screening in the form of mammograms and MRI scans can also monitor your condition and catch cancer early, if it does develop.

Detecting breast cancer at an early stage means it may be easier to treat. The chance of making a full recovery from breast cancer, especially if it is detected early, is relatively high compared with other forms of cancer.

Unfortunately, there's currently no reliable screening test for ovarian cancer or prostate cancer. Read more about screening for prostate cancer. However, annual prostate-specific antigen - a marker for prostate cancer. The higher the number, the greater the chance of prostate cancer, but this is not definite (PSA) tests for prostate cancer may benefit men who carry the faulty BRCA2 gene (NHS, 2015g).

Lifestyle changes Changes in your lifestyle can sometimes reduce your individual cancer risk. These include taking plenty of exercise and eating a healthy diet.

If you have a faulty BRCA gene, be aware of other factors that could increase your risk of breast cancer. It's recommended that you avoid -

- the oral contraceptive pill [62] if you are over 35,
- combined hormone replacement therapy (HRT) if you're over 50,
- drinking more than the maximum recommended daily limits of alcohol,
- being overweight (NHS, 2015g).

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[62] it contains artificial versions of the female hormones oestrogen and progesterone, which women produce naturally in their ovaries

The National Institute for Health and Care Excellence (NICE) also recommends that women with a family history of breast cancer breastfeed their children, if possible (NHS, 2015g).

Medication (chemoprevention) NICE has recommended treatment with tamoxifen or raloxifene for a specific group of women who have a high risk of developing breast cancer. These medicines can reduce the risk of breast cancer for up to 20 years from five years of taking them.

For more information, read the article: Drugs to be offered to women at high risk of breast cancer, which also explains the side-effects these medicines can cause.

Read the full NICE 2013 guidelines on familial breast cancer (NHS, 2015g).

Risk-reducing surgery Risk-reducing surgery means removing all the tissue (such as the breasts or ovaries) that could become cancerous. Carriers of a faulty BRCA gene may wish to consider a preventative mastectomy.

Women who have risk-reducing mastectomies reduce their risk of developing breast cancer by around 90%. However, a mastectomy is a major operation and recovering from it can be physically and emotionally difficult.

Surgery can also be used to reduce ovarian cancer risk. Women who have their ovaries removed before the menopause not only dramatically reduce their risk of developing ovarian cancer, but also reduce their risk of developing breast cancer by up to 50%. However, this will trigger an early menopause and mean you're not able to have your own children (unless you store eggs or embryos). Read more about surgery to remove the ovaries, including the risks and after-effects.

The risk of ovarian cancer in women who carry a BRCA gene fault does not begin to rise significantly until about the age of 40. Therefore, carriers of the faulty gene who are younger than 40 usually wait to have this operation (NHS, 2015g).

Telling close relatives Your genetics unit will not approach your relatives about your result - it will usually be up to you to tell your family.

You may be given a standard letter to share with relatives, which explains your test result and contains all the information they need to be referred for the test themselves.

However, not everyone will want to have the genetic test. Women who are closely related to you (such as your sister or daughter) can have cancer screening without having genetic testing (NHS, 2015g).

Planning a family Cancer risk genes can be passed on to any children you have. If your predictive genetic test is positive and you want to start a family, you have several options. You can -

- **have your children without any intervention**, and risk your child inheriting the faulty gene,
- **adopt a baby**,
- **use donor eggs or donor sperm** (depending on who carries the faulty gene) to avoid passing on the faulty gene,
- **have prenatal testing**, which is a test done in pregnancy that reveals whether your baby has the faulty gene. You can then plan to continue or terminate the pregnancy, depending on the test result,
- **have pre-implantation genetic diagnosis** - a technique used to select embryos that have not inherited the faulty gene. However, there is no guarantee this technique will result in a successful pregnancy, and funding for it on the NHS may not be available to all patients (NHS, 2015g).

Paying for private testing If there isn't a strong family history of cancer in your family and the faulty gene hasn't otherwise been identified in any of your relatives, you won't be eligible for the NHS genetic test.

You'll have to pay for it privately if you still wish to have the test. Consider this carefully, because -

- if you don't have any family history of cancer, it's unlikely you have one of the faulty genes,
- the tests can be expensive, potentially costing up to £500–2,000 or more,
- there's no guarantee they will predict whether you'll develop cancer,
- you may not be offered genetic counselling to help you make a decision and support you once you get your results (NHS, 2015g).

About BRCA1 and BRCA2 If you have a fault (mutation) in one of the BRCA genes, your risk of developing breast cancer and ovarian cancer is greatly increased.

Women with the faulty BRCA1 gene, for example, have a 60–90% lifetime risk of breast cancer and a 40–60% risk of ovarian cancer. In other words, out of every 100 women with the faulty BRCA1 gene, between 60 and 90 will develop breast cancer in their lifetime and between 40 and 60 will develop ovarian cancer.

The faulty BRCA genes affect around 1 in every 400 people, but people of Ashkenazi Jewish descent are at a much higher risk (as many as 1 in 40 may carry the faulty gene).

For more information, The Royal Marsden NHS Foundation Trust has produced a beginner's guide to BRCA1 and BRCA2 (NHS, 2015g).

Previous diagnosis of breast cancer

If you've previously had breast cancer or early non-invasive cancer cell changes in breast ducts, you have a higher risk of developing it again, either in your other breast or in the same breast again (NHS, 2014b).

Previous benign breast lump

A Breast lump doesn't mean you have breast cancer, but certain types of lump may slightly increase your risk of developing it. Certain benign changes in your breast tissue, such as atypical ductal hyperplasia (cells growing abnormally in ducts), or lobular carcinoma in situ (abnormal cells inside your breast lobes), can make getting breast cancer more likely (NHS, 2015g).

Breast lump Breast lumps are common and have a number of different causes.

Although most lumps aren't breast cancer, any unusual changes to the breasts should be checked by a GP as soon as possible. If your GP finds a lump on examination, they will routinely refer you to be seen by a hospital specialist.

There are several types of benign (non-cancerous) breast lump, most of which are harmless and are caused by hormonal changes that occur at different times in a woman's life, such as during the menstrual cycle (NHS, 2014c).

Common types of benign breast lump include -

- a **fibroadenoma** - a firm lump that moves around easily in the breast and is more common in younger women,
- a **breast cyst** - a smooth, firm fluid-filled lump most commonly seen in women aged 30 to 60,
- a **breast abscess** - a painful collection of pus that forms under the skin of the breast, usually as the result of a bacterial infection (NHS, 2014c).

Causes Most breast lumps are caused by benign (non-cancerous) conditions, although occasionally a breast lump can be a symptom of breast cancer.

It's important to see your GP as soon as possible if you notice a lump in your breast so they can refer you for tests to confirm the cause.

Some of the main causes of breast lumps and their symptoms are outlined below (NHS, 2014c).

1. **Benign breast lumps**
   There are a number of different benign causes of breast lumps. Most benign breast lumps are harmless and may not necessarily require any treatment (NHS, 2014c).
   (a) **Fibroadenosis**
   Fibrocystic breast disease, also known as fibroadenosis, is a term used to describe a group of benign conditions that affect the breast. The symptoms of fibroadenosis can include -
      - breast pain (mastalgia or mastodynia),
      - increase in breast size,
      - lumpiness of the breast (nodularity), particularly just before or during a period (NHS, 2014c).

   Fibroadenosis can develop in one or both breasts, or can affect just part of one breast. The symptoms can also vary significantly between women, with some women finding them slightly annoying and others finding them very painful. The pain and lumpiness will usually disappear after your period.
   The cause of fibroadenosis is not well understood. However, it may be the result of the breast tissue responding abnormally to hormonal changes that occur with the menstrual cycle (NHS, 2014c).
   (b) **Fibroadenomas**
   Fibroadenomas are smooth, well-rounded solid lumps of tissue that sometimes develop outside the milk ducts (the tiny tubes in the breast that carry milk). They are particularly common in young women.
   They are sometimes described as ”breast mice” because they can easily move around within the breast.
   Fibroadenomas can disappear on their own, but they sometimes remain and grow larger, particularly during pregnancy. They don’t usually resolve after your period.
   It’s not clear what causes fibroadenomas, but it is thought they may occur because of an abnormal response to the hormone oestrogen. This is because they are common in women who haven’t been through the menopause and postmenopausal women who are having hormone replacement therapy (HRT) (NHS, 2014c).
   (c) **Breast cysts**
   Breast cysts are fluid-filled sacs that develop within the breast tissue and can cause smooth, firm lumps to develop. They are more common in women aged 30 to 60.

   Cysts vary in size. Some can be tiny, while others can grow to several centimetres in diameter. Single or multiple cysts can occur in one or both breasts.
   Cysts often do not cause any symptoms, although some women may experience pain in addition to any lumps.
   As with fibroadenomas, hormones are thought to play a role in the development of breast cysts because they are particularly common in pre-menopausal women and postmenopausal women having HRT (NHS, 2014c).

   (d) **Breast abscesses**
   A breast abscess is a painful collection of pus that forms inside the breast.
   In addition to a painful lump, symptoms of a breast abscess can include a high temperature (fever) and inflammation (redness and swelling) of the skin over the affected area. Most breast abscesses are caused by a bacterial infection. The bacteria usually enter the breast through small cracks or breaks in the skin of the nipple, which can sometimes develop during breastfeeding (NHS, 2014c).

   (e) **Other benign causes**
   Other benign causes of breast lumps include -

   - **mastitis** - where breast tissue becomes painful and inflamed,
   - **fat necrosis** - a hard, irregular lump often caused by trauma or bruising to the breast; for example, after surgery on the breast,
   - a **lipoma** - a fatty growth that causes a lump,
   - an **intraductal papilloma** - a wart-like growth in a milk duct, which may also cause nipple discharge (NHS, 2014c).

2. **Breast cancer**
   Although the vast majority of breast lumps are benign, a lump in one of the breasts can sometimes be a sign of Female breast cancer and Male breast cancer.
   A lump is more likely to be a sign of breast cancer if it -

   - is clearly defined,
   - feels firm,
   - doesn't move around,
   - persists after your period or develops after the menopause (in women) (NHS, 2014c).

   Breast cancer can also cause some other symptoms, such as discharge from your nipples, dimpling on the skin of your breasts, and changes in the appearance of your nipple (such as becoming sunken into your breast).

> The risk of breast cancer increases with age, but is most common in women and men over the age of 50. Having a family history of the condition may also mean your risk is increased (NHS, 2014c).

Breast density

Your breasts are made up of thousands of tiny glands (lobules), which produce milk. This glandular tissue contains a higher concentration of breast cells than other breast tissue, making it denser. Women with dense breast tissue may have a higher risk of developing breast cancer because there are more cells that can become cancerous.

Dense breast tissue can also make a breast scan (mammogram) difficult to read, because it makes any lumps or areas of abnormal tissue harder to spot. Younger women tend to have denser breasts. As you get older, the amount of glandular tissue in your breasts decreases and is replaced by fat, so your breasts become less dense (NHS, 2014b).

Exposure to oestrogen

The female hormone, oestrogen, can sometimes stimulate breast cancer cells and cause them to grow. The ovaries, where your eggs are stored, begin to produce oestrogen when you start puberty, to regulate your periods.

Your risk of developing breast cancer may rise slightly with the amount of oestrogen your body is exposed to. For example, if you started your periods at a young age and experienced the menopause at a late age, you'll have been exposed to oestrogen over a longer period of time. In the same way, not having children, or having children later in life, may slightly increase your risk of developing breast cancer because your exposure to oestrogen is uninterrupted by pregnancy (NHS, 2014b).

Being overweight or obese

If you've experienced the menopause and are overweight or obese, you may be more at risk of developing breast cancer. This is thought to be linked to the amount of oestrogen in your body, because being overweight or obese after the menopause causes more oestrogen to be produced (NHS, 2014b).

Being tall

If you're taller than average, you're more likely to develop breast cancer than someone who's shorter than average. The reason for this isn't fully understood, but it may be due to interactions between genes, nutrition and hormones (NHS, 2014b).

Alcohol

Your risk of developing breast cancer can increase with the amount of alcohol you drink. See Effects of alcohol - Trans and Aging - Part 1 - General Health. Research shows that for every 200 women who regularly have two alcoholic drinks a day, there are three more women with breast cancer, compared with women who don't drink at all (NHS, 2014b).

Radiation

Certain medical procedures that use radiation, such as X-rays and computerised tomography (CT) scans, may slightly increase your risk of developing breast cancer.

If you had radiotherapy to your chest area for Hodgkin lymphoma when you were a child, you should have already received a written invitation from the Department of Health for a consultation with a specialist to discuss your increased risk of developing breast cancer. See your GP if you weren't contacted, or if you didn't attend a consultation.

If you currently need radiotherapy for Hodgkin lymphoma, your specialist should discuss the risk of breast cancer before your treatment begins (NHS, 2014b).

Hormone replacement therapy (HRT)

Hormone replacement therapy (HRT) is associated with a slightly increased risk of developing breast cancer. Both combined HRT and oestrogen-only HRT can increase your risk of developing breast cancer, although the risk is slightly higher if you take combined HRT.

It's estimated that there will be an extra 19 cases of breast cancer for every 1,000 women taking combined HRT for 10 years. The risk continues to increase slightly the longer you take HRT, but returns to normal once you stop taking it (NHS, 2014b).

Contraceptive pill and cancer risk

Research has shown that women who use oral contraception (the pill) have a slight, but significant, increased risk of developing breast cancer.

However, the risk starts to decrease once you stop taking the pill, and your risk of breast cancer is back to normal 10 years after stopping (NHS, 2014b).

Diagnosis

You may be diagnosed with breast cancer following routine breast screening, or you may have symptoms that you've seen your GP about (NHS, 2014b).

Seeing your GP

See your GP as soon as possible if you notice any symptoms of breast cancer, such as an unusual lump in your breast or any change in the appearance, feel or shape of your breasts.

Your GP will examine you and, if they think your symptoms need further assessment, they'll refer you to a specialist breast cancer clinic.

In 2015, the National Institute for Health and Care Excellence (NICE) published guidelines to help GPs recognise the signs and symptoms of breast cancer and refer people for the right tests faster. To find out if you should be referred for further tests for suspected breast cancer, read the NICE 2015 guidelines on Suspected Cancer: Recognition and Referral (NHS, 2014b).

Tests at the breast cancer clinic

If you have suspected breast cancer, either because of your symptoms or because your mammogram has shown an abnormality, you'll be referred to a specialist breast cancer clinic for further tests (NHS, 2014b).

Mammogram and breast ultrasound If you have symptoms and have been referred by your GP, you'll have a mammogram to produce an X-ray of your breasts. You may also need an ultrasound scan.

If your cancer was detected through the NHS Breast Screening Programme, you may need another mammogram or ultrasound scan.

If you're under 35 years of age, your doctor may suggest that you only have a breast ultrasound scan. This is because younger women have denser breasts, which means a mammogram isn't as effective as ultrasound in detecting cancer.

Ultrasound uses high-frequency sound waves to produce an image of the inside of your breasts, showing any lumps or abnormalities. Your doctor may also suggest a breast ultrasound if they need to know whether a lump in your breast is solid or contains liquid (NHS, 2014b).

Biopsy A biopsy is where a sample of tissue cells is taken from your breast and tested to see if it's cancerous. You may also need a scan and a needle test on lymph nodes in your armpit (axilla) to see whether these are also affected.

Biopsies can be taken in different ways, and the type you have will depend on what your doctor knows about your condition. Different methods of carrying out a biopsy are discussed below.

Needle aspiration may be used to test a sample of your breast cells for cancer or to drain a benign cyst (a small fluid-filled lump). Your doctor will use a small needle to extract a sample of cells, without removing any tissue.

Needle biopsy is the most common type of biopsy. A sample of tissue is taken from a lump in your breast using a large needle. You'll have a local anaesthetic, which means you'll be awake during the procedure, but your breast will be numb.

Your doctor may suggest that you have a guided needle biopsy (usually guided by ultrasound or X-ray, but sometimes MRI is used) to obtain a more precise and reliable diagnosis of cancer and to distinguish it from any non-invasive change, particularly ductal carcinoma in situ (DCIS).

Vacuum-assisted biopsy, also known as mammotome biopsy, is another type of biopsy. During the procedure, a needle is attached to a gentle suction tube, which helps to obtain the sample and clear any bleeding from the area (NHS, 2014b).

Further tests for breast cancer

If a diagnosis of breast cancer is confirmed, more tests will be needed to determine the stage and grade of the cancer, and to work out the best method of treatment (NHS, 2014b).

Scans and X-rays Computerised tomography (CT) scans, or chest X-ray and liver ultrasound scans, may be needed to check whether the cancer has spread to your lungs or liver. An MRI scan of the breast may be needed to clarify or to assess the extent of the condition within the breast.

If your doctor thinks that the cancer could have spread to your bones, you may need a bone scan. Before having a bone scan, a substance containing a small amount of radiation, known as an isotope, will be injected into a vein in your arm. This will be absorbed into your bone if it's been affected by cancer. The affected areas of bone will show up as highlighted areas on the bone scan, which is carried out using a special camera (NHS, 2014b).

Tests to determine specific types of treatment You'll also need tests that show whether the cancer will respond to specific types of treatment. The results of these tests can give your doctors a more complete picture of the type of cancer you have and how best to treat it. The types of test you could be offered are discussed below.

In some cases, breast cancer cells can be stimulated to grow by hormones that occur naturally in your body, such as oestrogen and progesterone.

If this is the case, the cancer may be treated by stopping the effects of the hormones, or by lowering the level of these hormones in your body. This is known as ”hormone therapy”.

During a hormone receptor test, a sample of cancer cells will be taken from your breast and tested to see if they respond to either oestrogen or progesterone. If the hormone is able to attach to the cancer cells (using a hormone receptor), they're known as ”hormone receptor positive”.

While hormones can encourage the growth of some types of breast cancer, other types are stimulated by a protein called human epidermal growth factor receptor 2 (HER2).

These types of cancer can be diagnosed using a HER2 test, and treated with medication to block the effects of HER2. This is known as ”biological” or ”targeted” therapy (NHS, 2014b).

Stage and grade of breast cancer

Stage of breast cancer When your breast cancer is diagnosed, the doctors will give it a stage. The stage describes the size of the cancer and how far it has spread.

Ductal carcinoma in situ (DCIS) is sometimes described as Stage 0. Other stages of breast cancer describe invasive breast cancer (see below) (NHS, 2014b).

- **Stage 1** - the tumour measures less than 2cm and the lymph nodes in the armpit aren't affected. There are no signs that the cancer has spread elsewhere in the body,
- **Stage 2** - the tumour measures 2–5cm or the lymph nodes in the armpit are affected, or both. There are no signs that the cancer has spread elsewhere in the body,
- **Stage 3** - the tumour measures 2–5cm and may be attached to structures in the breast, such as skin or surrounding tissues. The lymph nodes in the armpit are affected. However, there are no signs that the cancer has spread elsewhere in the body.
- **Stage 4** - the tumour is of any size and the cancer has spread to other parts of the body (metastasis) (NHS, 2014b).

This is a simplified guide. Each stage is divided into further categories: A, B and C. If you're not sure what stage you have, ask your doctor (NHS, 2014b).

TNM staging system The TNM staging system may also be used to describe breast cancer, as it can provide accurate information about the diagnosis. T describes the size of the tumour, N describes whether cancer has spread to the lymph nodes, and M gives an indication of whether the cancer has spread to other parts of the body (NHS, 2014b).

Grade of breast cancer The grade describes the appearance of the cancer cells.

- **Low grade (G1)** - the cells, although abnormal, appear to be growing slowly,
- **Medium grade (G2)** - the cells look more abnormal than low-grade cells.
- **High grade (G3)** - the cells look even more abnormal and are more likely to grow quickly (NHS, 2014b).

Treatment

If you have cancer you should be assigned a MDT - a team of specialists who work together to provide the best treatment and care.

The main treatments for breast cancer are -

- surgery
- radiotherapy,
- chemotherapy,
- hormone therapy,
- biological therapy (targeted therapy) (NHS, 2014b).

You may have one of these treatments, or a combination. The type or combination of treatments you have will depend on how the cancer was diagnosed and the stage it's at.

Breast cancer diagnosed at screening may be at an early stage, but breast cancer diagnosed when you have symptoms may be at a later stage and require a different treatment. Your healthcare team will discuss with you which treatments are most suitable (NHS, 2014b).

Choosing the right treatment for you

When deciding what treatment is best for you, your doctors will consider -

- the stage and grade of your cancer (how big it is and how far it's spread),
- your general health,
- whether you've experienced the menopause (NHS, 2014b).

You should be able to discuss your treatment with your care team at any time and ask questions (NHS, 2014b).

Treatment overview

Surgery is usually the first type of treatment for breast cancer. The type of surgery you undergo will depend on the type of breast cancer you have.

Surgery is usually followed by chemotherapy or radiotherapy or, in some cases, hormone or biological treatments. Again, the treatment you'll have will depend on your type of breast cancer.

Your doctor will discuss the most suitable treatment plan with you. Chemotherapy or hormone therapy will sometimes be the first treatment (NHS, 2014b).

Secondary breast cancer Most breast cancers are discovered in the condition's early stages. However, a small proportion of women discover that they have breast cancer after it's spread to other parts of the body (known as metastasis).

If this is the case, the type of treatment you have may be different. Secondary cancer, also called ”advanced” or ”metastatic” cancer, isn't curable and treatment aims to achieve remission (where the cancer shrinks or disappears, and you feel normal and able to enjoy life to the full) (NHS, 2014b).

Surgery There are two main types of breast cancer surgery. They are -

- surgery to remove the cancerous lump (tumour), known as breast-conserving surgery,
- surgery to remove the whole breast, which is called a mastectomy [63] (NHS, 2014b).

In many cases, a mastectomy can be followed by reconstructive surgery to try to recreate a bulge to replace the breast that was removed.

Studies have shown that breast-conserving surgery followed by radiotherapy is as successful as total mastectomy at treating early-stage breast cancer (NHS, 2014b).

Breast-conserving surgery Breast-conserving surgery ranges from a lumpectomy or wide local excision, where just the tumour and a little surrounding breast tissue is removed, to a partial mastectomy or quadrantectomy, where up to a quarter of the breast is removed (NHS, 2014b).

If you have breast-conserving surgery, the amount of breast tissue you have removed will depend on -

- the type of cancer you have,
- the size of the tumour and where it is in your breast,
- the amount of surrounding tissue that needs to be removed,
- the size of your breasts (NHS, 2014b).

Your surgeon will always remove an area of healthy breast tissue around the cancer, which will be tested for traces of cancer. If there's no cancer present in the healthy tissue, there's less chance that the cancer will reoccur. If cancer cells are found in the surrounding tissue, more tissue may need to be removed from your breast.

After having breast-conserving surgery, you will usually be offered radiotherapy to destroy any remaining cancer cells (NHS, 2014b).

Mastectomy A mastectomy is the removal of all the breast tissue, including the nipple. If there are no obvious signs that the cancer has spread to your lymph nodes, you may have a mastectomy, where your breast is removed, along with a sentinel lymph node biopsy (see below).

If the cancer has spread to your lymph nodes, you will probably need more extensive removal (clearance) of lymph nodes from the axilla (under your arm) (NHS, 2014b).

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[63] an operation to remove the breast

Reconstruction Breast reconstruction is surgery to make a new breast shape that looks as much as possible like your other breast. Reconstruction can be carried out at the same time as a mastectomy (immediate reconstruction), or it can be carried out later (delayed reconstruction). It can be done either by inserting a breast implant or by using tissue from another part of your body to create a new breast (NHS, 2014b).

Lymph node surgery To find out if the cancer has spread, a procedure called a sentinel lymph node biopsy may be carried out.

The sentinel lymph nodes are the first lymph nodes that the cancer cells reach if they spread. They're part of the lymph nodes under the arm (axillary lymph nodes). The position of the sentinel lymph nodes varies, so they're identified using a combination of a radioisotope and a blue dye.

The sentinel lymph nodes are examined in the laboratory to see if there are any cancer cells present. This provides a good indicator of whether the cancer has spread.

If there are cancer cells in the sentinel nodes, you may need further surgery to remove more lymph nodes from under the arm (NHS, 2014b).

Radiotherapy Radiotherapy uses controlled doses of radiation to kill cancer cells. It's usually given after surgery and chemotherapy to kill any remaining cancer cells.

If you need radiotherapy, your treatment will begin about a month after your surgery or chemotherapy, to give your body a chance to recover. You'll probably have radiotherapy sessions three to five days a week, for three to six weeks. Each session will only last a few minutes (NHS, 2014b).

The type of radiotherapy you have will depend on your cancer and surgery type. Some women may not need to have radiotherapy at all. The types available are -

- **breast radiotherapy** - after breast-conserving surgery, radiation is applied to the whole of the remaining breast tissue,
- **chest wall radiotherapy** - after a mastectomy, radiotherapy is applied to the chest wall,
- **breast boost** - some women may be offered a boost of high-dose radiotherapy in the area where the cancer was removed; however, the boost may affect the appearance of the breast, particularly if you have large breasts, and can sometimes have other side-effects, including hardening of the breast tissue (fibrosis),

- **radiotherapy to the lymph nodes** - where radiotherapy is aimed at the armpit (axilla) and the surrounding area to kill any cancer that may be present in the lymph nodes (NHS, 2014b).

The side-effects of radiotherapy include -

- irritation and darkening of the skin on your breast, which may lead to sore, red, weepy skin,
- fatigue,
- lymphoedema (NHS, 2014b).

Chemotherapy Chemotherapy involves using anti-cancer (cytotoxic) medication to kill the cancer cells. It's usually used after surgery to destroy any cancer cells that haven't been removed. This is called adjuvant chemotherapy.

In some cases, you may have chemotherapy before surgery, which is often used to shrink a large tumour. This is called neo-adjuvant chemotherapy.

Several different medications are used for chemotherapy and three are often given at once. The choice of medication and the combination will depend on the type of breast cancer you have and how much it's spread.

Chemotherapy is usually given as an outpatient treatment, which means you won't have to stay in hospital overnight. The medications are usually given through a drip straight into the blood through a vein.

In some cases, you may be given tablets that you can take at home. You may have chemotherapy sessions once every two to three weeks, over a period of four to eight months, to give your body a rest in between treatments (NHS, 2014b).

The main side-effects of chemotherapy are caused by their influence on normal, healthy cells, such as immune cells. Side-effects include -

- infections,
- loss of appetite,
- nausea and vomiting,
- tiredness,
- hair loss,
- sore mouth (NHS, 2014b).

Many side-effects can be prevented or controlled with medicines that your doctor can prescribe.

Chemotherapy medication can also stop the production of oestrogen in your body, which is known to encourage the growth of some breast cancers.

If you haven't experienced the menopause, your periods may stop while you're undergoing chemotherapy treatment. After you've finished the course of chemotherapy, your ovaries should start producing oestrogen again.

However, this doesn't always happen and you may enter an early menopause. This is more likely in women over 40 years old, because they're closer to menopausal age. Your doctor will discuss with you the impact that any treatment will have on your fertility.

Chemotherapy for secondary breast cancer If your breast cancer has spread beyond the breast and lymph nodes to other parts of your body, chemotherapy won't cure the cancer, but it may shrink the tumour, relieve your symptoms and help lengthen your life (NHS, 2014b).

Hormone treatment Some breast cancers are stimulated to grow by the hormones oestrogen or progesterone, which are found naturally in your body.

These types of cancer are known as hormone-receptor-positive cancers. Hormone therapy works by lowering the levels of hormones in your body or by stopping their effects.

The type of hormone therapy you'll have will depend on the stage and grade of your cancer, which hormone it's sensitive to, your age, whether you've experienced the menopause and what other type of treatment you're having.

You'll probably have hormone therapy after surgery and chemotherapy, but it's sometimes given before surgery to shrink a tumour, making it easier to remove.

Hormone therapy may be used as the only treatment for breast cancer if your general health prevents you from having surgery, chemotherapy or radiotherapy.

In most cases, you'll need to take hormone therapy for up to five years after having surgery. If your breast cancer isn't sensitive to hormones, hormone therapy will have no effect (NHS, 2014b).

Tamoxifen Tamoxifen stops oestrogen from binding to oestrogen-receptor-positive cancer cells. It's taken every day as a tablet or liquid. It can cause several side-effects, including -

- tiredness,
- changes to your periods,
- nausea and vomiting,
- hot flushes,
- aching joints,

- headaches,
- weight gain (NHS, 2014b).

Aromatase inhibitors If you've experienced the menopause, you may be offered an aromatase inhibitor. This type of medication works by blocking aromatase, a substance that helps produce oestrogen in the body after the menopause. Before the menopause, oestrogen is made by the ovaries (NHS, 2014b).

Three aromatase inhibitors may be offered. These are anastrozole, exemestane and letrozole. These are taken as a tablet once a day. Side-effects include -

- hot flushes and sweats,
- lack of interest in sex (loss of libido),
- nausea and vomiting,
- tiredness,
- aching joints and bone pain,
- headaches,
- skin rashes (NHS, 2014b).

Ovarian ablation or suppression In women who haven't experienced the menopause, oestrogen is produced by the ovaries. Ovarian ablation or suppression stops the ovaries working and producing oestrogen.

Ablation can be carried out using surgery or radiotherapy. It stops the ovaries working permanently and means you'll experience the menopause early.

Ovarian suppression involves using a medication called goserelin, which is a luteinising hormone-releasing hormone agonist (LHRHa). Your periods will stop while you're taking it, although they should start again once your treatment is complete.

If you're approaching the menopause (around the age of 50), your periods may not start again after you stop taking goserelin (NHS, 2014b).

Goserelin is taken as an injection once a month and can cause menopausal side-effects, including -

- hot flushes and sweats,
- mood swings,
- trouble sleeping (NHS, 2014b).

Biological therapy (targeted therapy) Some breast cancers are stimulated to grow by a protein called human epidermal growth factor receptor 2 (HER2).

These cancers are called HER2-positive. Biological therapy works by stopping the effects of HER2 and by helping your immune system to fight off cancer cells.

If you have high levels of the HER2 protein and are able to have biological therapy, you'll probably be prescribed a medicine called trastuzumab. Trastuzumab, also known by the brand name Herceptin, is usually used after chemotherapy (NHS, 2014b).

Trastuzumab Trastuzumab is a type of biological therapy known as a monoclonal antibody. Antibodies occur naturally in your body and are made by your immune system to destroy harmful cells, such as viruses and bacteria. The trastuzumab antibody targets and destroys cancer cells that are HER2-positive.

Trastuzumab is usually given intravenously, through a drip. It's also sometimes available as an injection under the skin (a subcutaneous injection).

You will have the treatment in hospital. Each treatment session takes up to one hour and the number of sessions you need will depend on whether you have early or more advanced breast cancer. On average, you'll need a session once every three weeks for early breast cancer, and weekly sessions if your cancer is more advanced.

Trastuzumab can cause side-effects, including heart problems. This means that it's not suitable if you have a heart problem, such as angina, uncontrolled high blood pressure (hypertension) or heart valve disease. If you need to take trastuzumab, you'll have regular tests on your heart to make sure it's not causing any problems (NHS, 2014b).

Other side-effects of trastuzumab may include -

- an initial allergic reaction to the medication, which can cause nausea, wheezing, chills and fever,
- diarrhoea,
- tiredness,
- aches and pains (NHS, 2014b).

Clinical trials A great deal of progress has been made in breast cancer treatment, and more women now live longer and have fewer side-effects from treatment.

These advances were discovered in clinical trials, where new treatments and treatment combinations are compared with standard ones.

All cancer trials in the UK are carefully overseen to ensure they're worthwhile and safely conducted. In fact, participants in clinical trials can do better overall than those in routine care.

If you're asked to take part in a trial, you'll be given an information sheet and, if you want to take part, you'll be asked to sign a consent form. You can refuse or withdraw from a clinical trial without it affecting your care (NHS, 2014b).

Psychological help Dealing with cancer can be a huge challenge, for both patients and their families. It can cause emotional and practical difficulties. Many women have to cope with the removal of part or all of a breast, which can be very upsetting.

It often helps to talk about your feelings or other difficulties with a trained counsellor or therapist. You can ask for this kind of help at any stage of your illness.

There are various ways to find help and support. Your hospital doctor, specialist nurse or GP can refer you to a counsellor. If you're feeling depressed, talk to your GP. A course of antidepressant drugs may help, or your GP can arrange for you to see a counsellor or psychotherapist.

It can help to talk to someone who's been through the same thing as you. Many organisations have helplines and online forums. They can also put you in touch with other people who've had cancer treatment (NHS, 2014b).

Complementary therapies Complementary therapies are holistic therapies that can promote physical and emotional wellbeing. They're given alongside conventional treatments and include relaxation techniques, massage, aromatherapy and acupuncture.

Complementary therapy can help some women cope with diagnosis and treatment, and provide a break from the treatment plan.

Your hospital or breast unit may be able to provide access to complementary therapies or suggest where you can get them. It's important to speak to your breast cancer specialist nurse about any complementary therapy you wish to use, to make sure it doesn't interfere with your conventional treatment (NHS, 2014b).

Living with breast cancer

Breast cancer can affect your daily life in different ways, depending on what stage it's at and what treatment you're having.

How women cope with their diagnosis and treatment varies from person to person. There are several forms of support if you need it. Not all of them work for everybody, but one or more of them should help. You could -

- talk to your friends and family; they can be a powerful support system,
- communicate with other people in the same situation,
- find out as much as possible about your condition,
- avoid doing too much or overexerting yourself,
- make time for yourself (NHS, 2014b).

Recovery

Most women with breast cancer have an operation as part of their treatment. Getting back to normal after surgery can take some time. It's important to take things slowly and give yourself time to recover.

During this time, avoid lifting things - for example, children or heavy shopping bags - and avoid heavy housework. You may also be advised not to drive.

Some other treatments, particularly Radiotherapy and Chemotherapy, can make you very tired. You may need to take a break from some of your normal activities for a while. Don't be afraid to ask for practical help from family and friends (NHS, 2014b).

Follow-up

After your treatment has finished, you'll be invited for regular check-ups, usually every three months for the first year.

If you've had early breast cancer, your healthcare team will agree a care plan with you after your treatment has finished. This plan contains the details of your follow-up. You will receive a copy of the plan, which will also be sent to your GP.

During the check-up, your doctor will examine you and may carry out blood tests or X-rays to see how your cancer is responding to treatment. You should also be offered a mammogram every year for the first five years after your treatment (NHS, 2014b).

Long-term complications Although it's rare, your treatment for breast cancer may cause new problems, such as -

- pain and stiffness in your arms and shoulders may occur after surgery, and the skin in these areas may be tight,
- lymphoedema - this may occur if surgery or radiotherapy damages the lymphatic drainage system in the armpit (NHS, 2014b).

Talk to your healthcare team if you experience these or any other long-term effects of treatment (NHS, 2014b).

Your body and breasts after treatment

Dealing with changes to your body A diagnosis of breast cancer may change how you think about your body. All women react differently to the bodily changes that happen as a result of breast cancer treatment. Some women react positively, but others find it more difficult to cope. It's important to give yourself time to come to terms with any changes to your body (NHS, 2014b).

Early menopause Although most cases of breast cancer occur in women over 50 who have experienced the menopause, some younger women have to cope with an early menopause brought on by cancer treatment.

Symptoms can include hot flushes, vaginal dryness and loss of sexual desire. Talk to your healthcare team about any symptoms you have and they'll be able to help (NHS, 2014b).

Prosthesis A breast prosthesis is an artificial breast, which can be worn inside your bra to replace the breast that's been removed.

Soon after a mastectomy, you'll be given a lightweight foam breast to wear until the area affected by surgery or radiotherapy has healed. After it's healed, you'll be offered a silicone prosthesis. Prostheses come in many different shapes and sizes, and you should be able to find one that suits you (NHS, 2014b).

Reconstruction If you didn't have immediate breast reconstruction (carried out at the time of a mastectomy), you can have reconstruction later. This is called a delayed reconstruction.

There are two main methods of breast reconstruction - reconstruction using your own tissue and reconstruction using an implant. The type that's most suitable for you will depend on many factors, including the treatment you've had, any ongoing treatment and the size of your breasts. Talk to your healthcare team about which reconstruction is suitable for you (NHS, 2014b).

Relationships and sex

Relationships with friends and family It's not always easy to talk about cancer, either for you or your family and friends. You may sense that some people feel awkward around you or avoid you.

Being open about how you feel and what your family and friends can do to help may put them at ease. However, don't be afraid to tell them that you need some time to yourself, if that's what you need (NHS, 2014b).

Your sex life Breast cancer and its treatment can affect your sex life. It's common for women to lose interest in sex after breast cancer treatment. Your treatment may leave you feeling very tired. You may feel shocked, confused or depressed about being diagnosed with cancer. You may be upset by the changes to your body or grieve the loss of your breasts or, in some cases, your fertility.

It's understandable that you may not feel like having sex while coping with all this. Try to share your feelings with your partner. If you have problems with sex that aren't getting better with time, you may want to speak to a counsellor or sex therapist (NHS, 2014b).

Money and financial support

If you have to reduce or stop work because of your cancer, you may find it difficult to cope financially. If you have cancer or you're caring for someone with cancer, you may be entitled to financial support, for example -

- if you have a job but can't work because of your illness, you're entitled to Statutory Sick Pay from your employer,
- if you don't have a job and can't work because of your illness, you may be entitled to Employment and Support Allowance,
- if you're caring for someone with cancer, you may be entitled to Carer's Allowance,
- you may be eligible for other benefits if you have children living at home, or if you have a low household income (NHS, 2014b).

Find out what help is available to you as soon as possible. The social worker at your hospital will be able to give you the information you need (NHS, 2014b).

Free prescriptions People being treated for cancer are entitled to apply for an exemption certificate, giving them free prescriptions for all medication, including medicine for unrelated conditions.

The certificate is valid for five years, and you can apply for it through your GP or cancer specialist (NHS, 2014b).

Talk to other people

Your GP or nurse may be able to answer any questions you have about your cancer or treatment. You may find it helpful to talk to a trained counsellor or psychologist, or to someone at a specialist helpline. Your GP surgery will have information on these.

Some people find it helpful to talk to other people who have breast cancer, either at a local support group or in an internet chatroom (NHS, 2014b).

Prevention

As the causes of breast cancer aren't fully understood, it's not known if it can be prevented altogether.

Some treatments are available to reduce the risk in women who have a higher risk of developing the condition than the general population (NHS, 2014b).

Diet and lifestyle

Regular exercise and a healthy, balanced diet are recommended for all women because they can help prevent many conditions, including heart disease, diabetes and many forms of cancer.

Studies have looked at the link between breast cancer and diet and, although there are no definite conclusions, there are benefits for women who maintain a healthy weight, exercise regularly and who have a low intake of saturated fat and alcohol. Use the healthy weight calculator to check if you're a healthy weight.

It's also been suggested that regular exercise can reduce your risk of developing breast cancer by as much as a third. If you have been through the menopause, it's particularly important that you're not overweight or obese. This is because these conditions cause more oestrogen to be produced, which can increase the risk of breast cancer (NHS, 2014b).

Breastfeeding

Studies have shown that women who breastfeed are statistically less likely to develop breast cancer than those who don't. The reasons aren't fully understood, but it could be because women don't ovulate as regularly while they're breastfeeding and oestrogen levels remain stable (NHS, 2014b).

Treatments to reduce your risk

If you have an increased risk of developing breast cancer, treatment is available to reduce your risk.

Your level of risk is determined by factors such as your age, your family's medical history and the results of genetic tests.

You will usually be referred to a specialist genetics service if it's thought you have an increased risk of breast cancer. Healthcare professionals working at these services should discuss treatment options with you.

The two main treatments are surgery to remove the breasts (mastectomy) or medication. These are described in more detail below (NHS, 2014b).

Mastectomy A mastectomy is surgery to remove the breasts. It can be used to treat breast cancer and reduce the chances of developing the condition in the small number of women from high-risk families.

By removing as much breast tissue as possible, a mastectomy can reduce your risk of breast cancer by up to 90%.

However, like all operations, there's a risk of complications, and having your breasts removed can have a significant effect on your body image and sexual relationships.

If you want to, you can usually choose to have a breast reconstruction either during the mastectomy operation, or at a later date. During breast reconstruction surgery, your original breast shape is recreated using either breast implants or tissue from elsewhere in your body.

An alternative is to use breast prostheses. These are artificial breasts that can be worn inside your bra (NHS, 2014b).

Medication In June 2013, the National Institute for Health and Care Excellence (NICE) announced that two medications, called tamoxifen and raloxifene, would be available on the NHS for women who have an increased risk of developing breast cancer.

Either tamoxifen or raloxifene can be used in women who've been through the menopause, but only tamoxifen should be used in women who haven't.

These medications may not be suitable if in the past you've had blood clots or womb cancer, or if you have an increased risk of developing these problems in the future.

Women who've already had a mastectomy to remove both breasts won't be offered these medications, because their risk of developing breast cancer is very small.

A course of treatment with tamoxifen or raloxifene will usually involve taking a tablet every day for five years (NHS, 2014b).

Raloxifene can cause side-effects including -

- flu-like symptoms,
- hot flushes, and
- leg cramps (NHS, 2014b).

Side-effects of tamoxifen can include -

- hot flushes,
- sweats,
- changes to your periods,
- nausea,
- vomiting (NHS, 2014b).

Your chances of giving birth to a child with birth defects increase while you're taking tamoxifen, so you'll be advised to stop taking it at least two months before trying for a baby. The medication can also increase your risk of blood clots, so you should stop taking it six weeks before having any planned surgery.

Tamoxifen and raloxifene aren't currently licensed for the purpose of reducing the risk of breast cancer in women with an increased risk of developing the condition. However, they can still be used if you understand the benefits and risks, and your doctor believes the treatment will be helpful (NHS, 2014b).

Ovarian cancer

In the UK, around 7,100 women are diagnosed with ovarian cancer each year.

It's the fifth most common cancer among women after Female breast cancer, Bowel cancer, Lung cancer and cancer of the uterus (womb).

Ovarian cancer is most common in women who have been through the menopause (usually over the age of 50), although it can affect women of any age (NHS, 2015f).

Types

Epithelial ovarian cancer About 90 out of 100 tumours of the ovary (90%) are epithelial. Epithelial ovarian cancer means the cancer started in the surface layer covering the ovary (CANCERRESEARCHUK, 2016a).

There are various types of epithelial cancers of the ovary -

- Serous,
- Endometrioid,
- Clear cell,
- Mucinous,
- Undifferentiated or unclassifiable (CANCERRESEARCHUK, 2016a).

Serous epithelial ovarian cancer is the most common type, making up about two thirds of the cases diagnosed. Doctors now think that most high grade serous ovarian cancers actually start in cells at the far end of the fallopian tube, rather than the surface of the ovary. These early cancer cells then spread to the ovary and grow.

About 10 in 100 epithelial ovarian cancers (10%) are undifferentiated or unclassifiable. These tumours have cells that are very undeveloped, so it is not possible to tell which type of cell the cancer started from.

Researchers are investigating in clinical trials whether the rarer types of epithelial ovarian cancer need to be treated any differently to the serous type. But at the moment, they are generally treated in the same way. The main treatments are surgery and chemotherapy.

A small number of ovarian cancers are a type called primary peritoneal carcinoma. The cancer develops from cells that form the membrane around abdominal organs (CANCERRESEARCHUK, 2016a).

Germ cell and other rare ovarian tumours Around 1 or 2 out of 100 ovarian cancers (1% to 2%) are germ cell cancers. They start from the egg making cells of the ovary. As well as these, there are also non cancerous (benign) forms of germ cell tumour, which doctors sometimes call dermoid cysts or mature teratoma (CANCERRESEARCHUK, 2016a).

Borderline ovarian tumours Borderline ovarian tumours are different to ovarian cancer because they do not grow into the supportive tissue of the ovary (the stroma). They are also called tumours of low malignant potential. About 10 out of 100 epithelial ovarian tumours (10%) are borderline tumours.

Borderline ovarian tumours grow slowly and most are diagnosed at an early stage, when the abnormal cells are still within the ovary. Abnormal cells can sometimes break away from the tumour and settle elsewhere in the body, usually the abdomen. These do not usually grow into the underlying tissue.

Borderline ovarian tumours are treated in a different way to ovarian cancers and are usually cured with surgery alone (CANCERRESEARCHUK, 2016a).

Symptoms

The symptoms of ovarian cancer can be difficult to recognise, particularly in its early stages.

This is because they are often the same as symptoms of other less serious conditions, such as irritable bowel syndrome (IBS) or pre-menstrual syndrome (PMS) (NHS, 2015f).

However, three main symptoms are more frequent in women diagnosed with ovarian cancer. They are -

- increased abdominal size and persistent bloating (not bloating that comes and goes),
- persistent pelvic and abdominal pain,
- difficulty eating and feeling full quickly, or feeling nauseous (NHS, 2015f).

Other symptoms, such as back pain, needing to pass urine more frequently than usual, and pain during sex may be the result of other conditions in the pelvic area. However, they may be present in some women with ovarian cancer. If you have these types of symptoms, try keeping a diary to record how many of these symptoms you have over a longer period. Bear in mind that ovarian cancer is rare in women under 40 years of age.

See your GP if you have these symptoms regularly (on most days for three weeks or more). Although it's unlikely they're being caused by a serious problem, it's best to check.

If you've already seen your GP and the symptoms continue or get worse, you should go back and explain this. You know your body better than anyone (NHS, 2015f).

Causes

Several possible causes of ovarian cancer have been identified, along with risks that may make developing the condition more likely.

Cancer begins with a change (mutation) in the structure of the DNA in cells, which can affect how they grow. This means that cells grow and reproduce uncontrollably, producing a lump of tissue called a tumour.

In ovarian cancer, cells in the ovary start to change and grow abnormally. If the cancer isn't identified at an early stage, it can spread to the abdomen and pelvis, including other parts of the female reproductive system (NHS, 2015f).

Increased risk

The exact cause of epithelial ovarian cancer (the main type) isn't known, but certain things may increase your risk of developing it (NHS, 2015f).

Age Your risk of ovarian cancer increases with age, with most cases occurring after the menopause. More than 8 out of 10 cases of ovarian cancer occur in women who are over 50 years of age (NHS, 2015f).

Family history If you have two or more close relatives (mother, sister or daughter) who developed ovarian cancer or Female breast cancer, your risk of also developing the condition may be increased.

If your relatives developed cancer before the age of 50, it's more likely it was the result of an inherited faulty gene. BRCA1 and BRCA2 are faulty genes that are linked to ovarian cancer. They're also known to increase the risk of breast cancer. Having relatives with ovarian cancer doesn't mean you definitely have a faulty gene in the family - the cancer could have happened by chance. Only 1 in 10 (10%) of ovarian cancers are thought to be caused by a faulty gene (NHS, 2015f).

You may be at a high risk of having a faulty gene if you have -

- one relative diagnosed with ovarian cancer at any age and at least two close relatives with breast cancer whose average age is under 60; all of these relatives should be on the same side of your family (either your mother's OR father's side),
- one relative diagnosed with ovarian cancer at any age and at least one close relative diagnosed with breast cancer under the age of 50; both of these relatives should come from the same side of your family,
- two relatives from the same side of the family diagnosed with ovarian cancer at any age (NHS, 2015f).

If you're at a higher risk of having a faulty gene, your GP can refer you for tests to check for faulty BRCA1 and BRCA2 genes (NHS, 2015f).

Ovulation and fertility Every time an egg is released into the reproductive system, the surface of the ovary breaks to let it out. The surface of the ovary is damaged during this process and needs to be repaired. Each time this happens, there's a greater chance of abnormal cell growth during the repair.

This may be why the risk of ovarian cancer decreases if you take the contraceptive pill [62], or have multiple pregnancies or periods of breastfeeding. At these times, eggs aren't released.

There's no strong evidence to show that women who have infertility treatment have an increased risk of developing ovarian cancer. However, it's thought that infertility itself may increase ovarian cancer risk and research into this area is being carried out (NHS, 2015f).

Hormone replacement therapy (HRT) Women who take hormone replacement therapy [60] (HRT) have been shown to have a small increased risk of developing ovarian cancer. However, if HRT is stopped, after five years the risk is reduced to the same level as women who've never taken HRT (NHS, 2015f).

Endometriosis Endometriosis [64] may also increase your risk of ovarian cancer. In endometriosis, the cells that usually line the womb grow elsewhere in the body.

These endometrial cells behave as if they were in the womb, so thickening and bleeding that usually occurs during menstruation occurs in other parts of the body. There's no way for this endometrial tissue to leave the body so it becomes trapped, leading to pain, swelling and bleeding in that area (NHS, 2015f).

Diagnosis

See your GP as soon as possible if you have any Symptoms of ovarian cancer.

Your GP will gently feel your tummy (abdomen) and ask you about your symptoms, general health and whether there's a history of ovarian or Female breast cancer in your family.

They may carry out an internal examination and may take a blood sample or refer you for an ultrasound scan.

If needed, you may also be referred to a specialist (a gynaecologist or gynaecological oncologist) at a hospital.

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[64] a common condition in which small pieces of the womb lining are found outside the womb

In 2015, the National Institute for Health and Care Excellence (NICE) published guidelines to help GPs recognise the signs and symptoms of ovarian cancer and refer people for the right tests faster. To find out if you should be referred for further tests for suspected ovarian cancer, read the NICE 2015 guidelines on Suspected Cancer: Recognition and Referral (NHS, 2015f).

Blood test (CA125)

You may have a blood test to look for a protein called CA125 in your blood. CA125 is produced by some ovarian cancer cells. A very high level of CA125 may indicate that you have ovarian cancer.

However, CA125 isn't specific to ovarian cancer and it can be raised in conditions including endometriosis, fibroids [65], pelvic inflammatory disease [66] and pregnancy, so a raised CA125 level doesn't definitely mean you have ovarian cancer.

The Lab Tests Online UK website has more information on the CA125 test.

The National Institute for Health and Care Excellence (NICE) has produced guidance that recommends testing for CA125 if you frequently experience -

- bloating,
- feeling full quickly and/or loss of appetite,
- pelvic or abdominal pain,
- needing to urinate urgently and/or frequently (NHS, 2015f).

Read the full NICE guidance about the recognition and initial management of ovarian cancer.

If you experience unexplained weight loss, fatigue or changes in your bowel habits, such as diarrhoea or constipation, you may also be tested for CA125.

If you're 50 or over and you've experienced symptoms that could suggest irritable bowel syndrome [67] (IBS) in the last 12 months, such as bloating, abdominal pain or changes in your bowel habits, your GP should test your CA125 level.

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[65] non-cancerous growths that develop in or around the womb (uterus)

[66] an infection of the female upper genital tract, including the womb, fallopian tubes and ovaries

[67] a common, long-term condition of the digestive system. It can cause bouts of stomach cramps, bloating, diarrhoea and/or constipation

Around half of all women with early stage ovarian cancer have a raised level of CA125 in their blood. If your CA125 level is raised, you'll be referred for an ultrasound scan (NHS, 2015f).

Ultrasound scan

An ultrasound scan uses high-frequency sound waves to create an image of your ovaries. You may have an internal ultrasound where the ultrasound probe is inserted into your vagina, or you may have an external ultrasound, where the probe is put next to your stomach.

The image produced can show the size and texture of your ovaries, plus any cysts or other swellings that are present (NHS, 2015f).

Further tests

If you've been diagnosed with ovarian cancer, you may have further tests to see how large the cancer is and if it's spread. This is called staging (NHS, 2015f).

Other tests you may have include -

- a chest X-ray,
- a CT scan or MRI scan,
- abdominal fluid aspiration - a thin needle is passed into your abdomen, so that a fluid sample can be taken and tested for cancerous cells,
- laparoscopy [68] - a thin tube with a camera on the end is inserted through a small incision in your lower abdomen, so that your ovaries can be examined; a small tissue sample may also be taken from your ovaries for testing (a biopsy) (NHS, 2015f).

Staging helps your doctors to decide on the best kind of treatment for your condition. However, it's important to remember that the stage of your ovarian cancer alone cannot predict how your condition will progress (NHS, 2015f).

Stages and grades of ovarian cancer

Staging If your test results indicate that you have ovarian cancer, it will be given a stage. The stage describes the size of the cancer and how far it has spread. The four commonly used stages of ovarian cancer are -

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[68] a type of surgical procedure that allows a surgeon to access the inside of the abdomen (tummy) and pelvis without having to make large incisions in the skin

- **stage 1** - where the cancer only affects one or both of the ovaries,
- **stage 2** - where the cancer has spread from the ovary and into the pelvis or womb,
- **stage 3** - where the cancer has spread to the lining of the abdomen, the surface of the bowel and the lymph nodes in the pelvis,
- **stage 4** - where the cancer has spread to other parts of the body, such as the liver, spleen or lungs (NHS, 2015f).

This is a simplified guide. Each stage is further divided into categories A, B and C. Ask your doctor if you're not sure what stage you have (NHS, 2015f).

Grading The grade of cancer refers to the appearance of cells under a microscope. The grades are as follows -

- **low grade** - although abnormal, cells appear to be slow-growing,
- **moderate grade** - cells look more abnormal than low-grade cells,
- **high grade** - cells look very abnormal and are likely to be fast-growing (NHS, 2015f).

Treatment

If you have cancer, a team of specialists will work together to provide you with the best possible treatment and care.

This is known as a multidisciplinary team. It will often consist of specialist cancer surgeons (gynaecological oncologists), a medical oncologist (chemotherapy specialist) and a specialist cancer nurse. Other members may include a radiologist, pathologist, physiotherapist, dietitian and an occupational therapist (NHS, 2015f).

When deciding which treatment is best for you, your doctors will consider -

- the stage of your cancer (its size and how far it's spread),
- your general health,
- whether fertility is an issue (NHS, 2015f).

You can discuss treatment with your care team and ask questions at any time.

Surgery and chemotherapy are the two main treatments for ovarian cancer (NHS, 2015f).

Advanced ovarian cancer

Ovarian cancer is often diagnosed at an advanced stage (3 or 4) when it has spread to other parts of the abdomen (tummy). Advanced cancer may not be curable. The goal of treatment will be to put the tumour into remission, so it shrinks or disappears (NHS, 2015f).

Surgery Most women with ovarian cancer will be considered for surgery. It sometimes isn't possible to confirm the stage of the cancer until surgery is carried out (NHS, 2015f).

Your doctor will discuss what will happen during surgery. It will probably involve removing -

- both ovaries and the fallopian tubes (a bilateral salpingo-oophorectomy),
- the womb (a total abdominal hysterectomy),
- the omentum - a fatty layer of tissue within the abdomen (an omentectomy) (NHS, 2015f).

The surgeon may also remove the lymph nodes from your pelvis and abdomen, and samples of nearby tissue, to find out whether the cancer has spread.

If it has spread, the surgeon will try to remove as much of it as possible. This is known as ”debulking surgery”.

If the cancer is confined to one or both ovaries, you may only need to have the ovary or ovaries removed, leaving your womb intact. This means you may still be able to carry a pregnancy.

You will probably be ready to go home three to seven days after your operation, but it can take many weeks to fully recover.

When you go home, you'll need to exercise gently to build up your strength and fitness. Walking and swimming are good exercises that are suitable for most people after treatment for ovarian cancer. Discuss the types of exercise that are suitable for you with your doctor or physiotherapist (NHS, 2015f).

Chemotherapy Chemotherapy involves using anti-cancer (cytotoxic) medication to kill cancer cells. It's often given after surgery for ovarian cancer. In some cases, it can be given before surgery to help shrink the tumour and make it easier to remove. This is called ”neoadjuvant chemotherapy”.

Several different medicines can be used in chemotherapy. A combination is often given. The choice of medicine and how and when it's given depends on the stage of your cancer and how much it has spread. The most common treatment for ovarian cancer is a platinum-containing medicine (carboplatin), which is used alone or in combination with another medicine called paclitaxel.

Chemotherapy is usually given as a drip into the vein, but is sometimes given as tablets. Some studies have looked at giving chemotherapy directly into the abdomen - called ”intraperitoneal chemotherapy”. It is not currently established routine practice in the UK, but it's being assessed in clinical trials.

You will usually have chemotherapy as an outpatient, but you may sometimes need a short stay in hospital. It's usually given in cycles, with a period of treatment followed by a period of rest, to allow the body to recover. Most women have six cycles of chemotherapy (NHS, 2015f).

Is chemotherapy working? Over the course of your chemotherapy, you'll have tests to monitor how the cancer is responding to treatment. This can be done in a number of ways. For example -

- if you had higher than normal levels of the protein CA125 in your blood when diagnosed, you may have blood tests to see whether the levels are falling,
- if you had a tumour visible on a CT scan or ultrasound scan when diagnosed, you may have repeated scans to see whether it has shrunk,
- you may have another small operation, known as ”second-look surgery”, which is carried out in the same way as a laparoscopy (NHS, 2015f).

After your chemotherapy treatment, if all of your tests are clear of cancer, you'll be in remission. This means the cancer is under control (NHS, 2015f).

Side-effects of chemotherapy Side-effects of chemotherapy include -

- infections,
- loss of appetite,
- nausea and vomiting,
- tiredness,
- hair loss,
- sore mouth (NHS, 2015f).

Many side-effects can be prevented or controlled with medicines your doctor can prescribe (NHS, 2015f).

Chemotherapy for recurring cancer Ovarian cancer can come back (relapse) after treatment. If this happens, you may have another course of chemotherapy. This is called ”second-line treatment” (NHS, 2015f).

Radiotherapy Radiotherapy uses high energy X-rays. Like chemotherapy, it works by targeting rapidly growing cancer cells.

Radiotherapy isn't usually used to treat ovarian cancer. However, the MDT may occasionally recommend it to treat ovarian cancer under very specific circumstances, such as treating pain and bleeding from a localised tumour mass (NHS, 2015f).

Clinical trials In recent years, much progress has been made in ovarian cancer treatment. More women are living longer and experiencing fewer side-effects. These advances were discovered through clinical trials, where new medicines and combinations of medicines are compared with standard treatment.

All cancer trials in the UK are subject to careful monitoring, to ensure the trial is worthwhile and safely conducted. Participants in clinical trials can often do better overall than in routine care.

If you're asked about taking part in a trial, you'll be offered an information sheet. If you wish to take part, you'll be asked to give your consent (permission) by signing a form. You're always free to refuse or withdraw from a clinical trial without it affecting your care (NHS, 2015f).

Psychological help Dealing with cancer can be a huge challenge for patients and their families. It can bring emotional and practical difficulties.

It often helps to talk about your feelings or other difficulties with a trained counsellor or therapist. You can ask for this kind of help at any stage of your illness. There are various ways to find help and support. For example -

- your hospital doctor, specialist nurse or GP can refer you to a counsellor; talk to your GP if you're feeling depressed; a course of antidepressants may help, or your GP can arrange for you to see a counsellor or psychotherapist,
- it can help to talk to someone who's been through the same thing as you; many organisations have helplines and online forums; they can also put you in touch with other people who have had cancer treatment (NHS, 2015f).

Living with ovarian cancer

How ovarian cancer will affect your daily life depends on the stage your condition is at and what treatment you're having (NHS, 2015f).

How women cope with the diagnosis and treatment varies from person to person. There are several forms of support, if you need it. Not all types of support work for everybody, but one or more should prove helpful -

- Talk to your friends and family, as they can be a powerful support system.
- Communicate with other women in the same situation.
- Find out about your condition.
- Set reasonable goals.
- Take time out for yourself (NHS, 2015f).

Recovery and follow-up

Many women with ovarian cancer have a hysterectomy. This is a major operation, and takes around 6–12 weeks to recover from.

During this time, you'll have to avoid lifting things, such as children and heavy shopping bags, and doing heavy housework. You won't be able to drive for 3–8 weeks after the operation. Most women need 4–12 weeks off work after a hysterectomy.

If your ovaries have been removed and you haven't already been through the menopause, you'll experience the menopause after your treatment. You may decide to take hormone replacement therapy (HRT) to control your symptoms. Your GP will help you decide what's best for you.

Some treatments for ovarian cancer, particularly chemotherapy, can make you feel very tired. You may need a break from your normal activities for a while. Don't be afraid to ask for practical help from family and friends if you need it.

Practical help may also be available from your local authority. Ask your doctor or nurse who to contact.

After your treatment has finished, you'll be invited for regular check-ups to see how well you are responding to treatments. These are usually every 2–3 months to begin with (NHS, 2015f).

Sex and relationships

Relationships with friends and family Having cancer isn't always easy to talk about, either for you or your family and friends. You may sense that some people avoid you or feel awkward around you.

Being open about how you feel and what your family and friends can do to help may put them at ease. However, don't feel shy about telling them you need some time to yourself (NHS, 2015f).

Your sex life Ovarian cancer and its treatment can affect your sex life in several ways (NHS, 2015f).

Early menopause If you haven't already been through the menopause, removing your ovaries means you'll have an early menopause. You're likely to have symptoms of the menopause, which can include vaginal dryness and loss of sexual desire (NHS, 2015f).

Not feeling like sex It's common for women to lose interest in sex after treatment for ovarian cancer. Your treatment may leave you feeling very tired, and you may feel shocked, confused or depressed about being diagnosed with cancer.

You may also feel grief about the loss of your fertility. It's understandable that you may not feel like having sex while coping with all this. Share your feelings with your partner. If your feelings about sex aren't improving with time, you may want to consider speaking to a counsellor or sex therapist (NHS, 2015f).

Also see Living with cancer.

Dealing with dying If you're told that nothing more can be done to treat your ovarian cancer, care will focus on controlling your symptoms and helping you feel as comfortable as possible. This is called palliative care. It also includes psychological, social and spiritual support for you and your family or carers (NHS, 2015f).

Prevention

There's currently no reliable screening test for ovarian cancer. However, there are a number of things that may help to prevent ovarian cancer (NHS, 2015f).

Stopping ovulation and the contraceptive pill

Each time you ovulate, your ovaries are damaged by the egg as it breaks through the surface of the ovary and is released into your reproductive system.

The cells that make up the surface of your ovaries divide and multiply rapidly to repair the damage caused by the egg. It's this rapid cell growth that can occasionally go wrong and result in ovarian cancer (NHS, 2015f).

Anything that stops the process of ovulation can help to minimise your chances of developing ovarian cancer. This includes -

- pregnancy and breastfeeding,
- the contraceptive pill,
- hysterectomy surgery (removal of the ovaries) (NHS, 2015f).

Diet and lifestyle

Research into ovarian cancer has found that the condition may be linked to being overweight or obese. Losing weight through regular exercise and a healthy, balanced diet may help to lower your risk of getting ovarian cancer. Aside from this, regular exercise and a healthy, low-fat diet are extremely beneficial to your overall health, and can help to prevent all forms of cancer and heart disease (NHS, 2015f).

Screening for ovarian cancer

At present, there's no screening method for ovarian cancer that is reliable enough to be used by all women in the UK. Clinical trials into this are continuing.

You may be eligible for screening if you're at high risk of developing the condition due to a strong family history, or if you've inherited a specific abnormal gene.

If you're at high risk, your GP can refer you to your local genetics service or family cancer clinic. You may be screened for ovarian cancer when you're over the age of 35, or when you're five years away from the age at which your youngest relative was diagnosed with the condition. From this point, you'll be screened again once a year (NHS, 2015f).

The screening tests for ovarian cancer are the same as those routinely used to diagnose it. The tests are -

- a blood test for higher-than-normal levels of CA125 (a protein produced by cancer cells),
- a transvaginal ultrasound - where an ultrasound probe is inserted into your vagina so that the size and texture of your ovaries can be seen, as well as any ovarian cysts that may be present (NHS, 2015f).

The tests are used together to produce results that are as accurate as possible. However, as these screening methods are still in the process of being tested, there's no guarantee they'll identify every case of ovarian cancer.

A cervical screening test, previously known as a smear test, can't detect ovarian cancer (NHS, 2015f).

Womb cancer

Cancer of the womb (uterus) is a common cancer that affects the female reproductive system. It's also called uterine cancer and endometrial cancer.

Abnormal vaginal bleeding is the most common symptom of womb cancer.

If you have been through the menopause, any vaginal bleeding is considered abnormal. If you have not yet been through the menopause, unusual bleeding may include bleeding between your periods.

You should see your GP as soon as possible if you experience any unusual vaginal bleeding. While it's unlikely to be caused by womb cancer, it's best to be sure.

Your GP will examine you and ask about your symptoms. They will refer you to a specialist for further tests if they suspect you may have a serious problem, or if they are unsure about a diagnosis (NHS, 2015i).

Symptoms

The most common symptom of womb cancer is abnormal bleeding from the vagina, although most people with abnormal bleeding don't have cancer. Bleeding may start as light bleeding accompanied by a watery discharge, which may get heavier over time. Most women diagnosed with womb cancer have been through the menopause, so any vaginal bleeding will be unusual (NHS, 2015i).
In women who haven't been through the menopause, unusual vaginal bleeding may consist of -

- periods that are heavier than usual,
- vaginal bleeding in between normal periods (NHS, 2015i).

Less common symptoms include pain in the lower abdomen (tummy) and pain during sex (NHS, 2015i). If womb cancer reaches a more advanced stage, it may cause additional symptoms. These include -

- pain in the back, legs, or pelvis,
- loss of appetite,

- tiredness,
- nausea (NHS, 2015i).

When to seek medical advice

If you have postmenopausal vaginal bleeding, or notice a change in the normal pattern of your period, visit your GP.

Only 1 in 10 cases of unusual vaginal bleeding after the menopause are caused by womb cancer, so it's unlikely your symptoms will be caused by this condition (NHS, 2015i).

However, if you have unusual vaginal bleeding, it's important to get the cause of your symptoms investigated. The bleeding may be the result of a number of other potentially serious health conditions, such as -

- endometriosis - where tissue that behaves like the lining of the womb is found on the outside of the womb,
- fibroids - non-cancerous growths that can develop inside the uterus,
- polyps in the womb lining (NHS, 2015i).

Other types of gynaecological cancer can also cause unusual vaginal bleeding, particularly cervical cancer (NHS, 2015i).

Causes

It's not known exactly what causes womb cancer, but certain things can increase your risk of developing it.

Cancer begins with a change (mutation) in the structure of the DNA in cells, which can affect how they grow. This means cells grow and reproduce uncontrollably, producing a lump of tissue called a tumour.

If left untreated, cancer can grow and spread to other parts of your body, either directly or through the blood and lymphatic system (NHS, 2015i).

Increased risk

A number of things have been identified that increase the risk of developing womb cancer. Some of these are discussed below (NHS, 2015i).

Age

The risk of developing womb cancer increases with age. The majority of cases occur in women aged 40 to 74, with only 1% of cases being diagnosed in women under 40 (NHS, 2015i).

Oestrogen

The risk of developing womb cancer is linked to the body's exposure to oestrogen. Oestrogen is one of the hormones that regulates the reproductive system in women (NHS, 2015i).

- **oestrogen** stimulates the release of eggs from your ovaries and causes the cells of the womb lining to divide,
- **progesterone** gets the lining of your uterus ready to receive the egg from the ovaries (NHS, 2015i).

The levels of oestrogen and progesterone in your body are usually balanced with each other. If oestrogen isn't kept in balance by progesterone, the level in the body can increase. This is called unopposed oestrogen.

After the menopause, the body stops producing progesterone. However, there are still small amounts of oestrogen being produced. This unopposed oestrogen causes the cells of the endometrium to divide, which can increase the risk of womb cancer (NHS, 2015i).

Hormone replacement therapy (HRT)

Because of the link between increased levels of unopposed oestrogen and womb cancer, oestrogen-only hormone replacement therapy (HRT) should only be given to women who have had their womb surgically removed (hysterectomy).

In all other cases, both oestrogen and progesterone (combination HRT) must be used in HRT to reduce the risk of womb cancer (NHS, 2015i).

Being overweight or obese

As oestrogen can be produced in fatty tissue, being overweight or obese increases the level of oestrogen in your body. This significantly increases your chances of developing womb cancer.

Women who are overweight are three times more likely to develop womb cancer compared with women who are a healthy weight. Very obese women are six times more likely to develop endometrial cancer compared with women who are a healthy weight.

One way to assess whether your weight is healthy is to calculate your body mass index (BMI). In the UK, people with a BMI of between 25 and 30 are overweight, and those with an index above 30 are obese (NHS, 2015i).

Reproductive history

Women who have not had children are at a higher risk of womb cancer. This may be because the increased levels of progesterone and decreased levels of oestrogen that occur during pregnancy have a protective effect on the lining of the womb (NHS, 2015i).

Tamoxifen

Women who are treated with tamoxifen (a hormone treatment for breast cancer) can be at an increased risk of developing womb cancer. However, this risk is outweighed by the benefits that tamoxifen provides in preventing breast cancer.

It's important to visit your GP if you're taking tamoxifen and experience any abnormal vaginal bleeding (NHS, 2015i).

Diabetes

Women with diabetes are twice as likely to develop womb cancer as women without the condition.

Diabetes causes an increase in the amount of insulin in your body, which in turn can raise your oestrogen levels.

Many women with type 2 diabetes are also overweight, which further increases the risk (NHS, 2015i).

Polycystic ovarian syndrome (PCOS)

Women with polycystic ovarian syndrome (PCOS) are at a higher risk of developing womb cancer, as they have high levels of oestrogen in their bodies.

Women with PCOS have multiple cysts in the ovary, which can cause symptoms such as irregular or light periods, or no periods at all, as well as problems getting pregnant, weight gain, acne, and excessive hair growth (hirsutism) (NHS, 2015i).

Endometrial hyperplasia

Endometrial hyperplasia is when the lining of the womb becomes thicker. Women with the condition may be at an increased risk of developing womb cancer (NHS, 2015i).

Diagnosis

You should visit your GP if you have abnormal vaginal bleeding. While it's unlikely to be caused by womb cancer, it's best to be sure.

Your GP will probably carry out a physical examination of your pelvic area, including your vagina, womb, ovaries, and bladder. They will ask about your symptoms, when they happen, and how often.

You may be referred to a specialist in conditions of the female reproductive organs (a gynaecologist) for further tests. Some of these tests are outlined below.

In 2015, the National Institute for Health and Care Excellence (NICE) published guidelines to help GPs recognise the signs and symptoms of gynaecological cancer and refer people for the right tests faster. To find out if you should be referred for further tests for suspected endometrial cancer, read the NICE 2015 guidelines on Suspected Cancer: Recognition and Referral (NHS, 2015i).

Transvaginal ultrasound (TVU)

Another test you may have is called a transvaginal ultrasound (TVU). TVU is a type of ultrasound scan that uses a small scanner in the form of a probe.

This is placed directly into the vagina to obtain a detailed picture of the inside of the uterus. The probe can feel a little uncomfortable, but shouldn't be painful.

The TVU checks whether there are any changes to the thickness of the lining of your uterus that could be caused by the presence of cancerous cells (NHS, 2015i).

Biopsy

If the results of the TVU detect changes in the thickness of the lining of the uterus, you will usually have a biopsy to confirm the diagnosis.

In a biopsy, a small sample of cells is taken from the lining of the womb (the endometrium). The sample is then checked at a laboratory for the presence of cancerous cells (NHS, 2015i).

The biopsy can be carried out in several ways, including -

- **aspiration biopsy** - a small flexible tube is inserted into your vagina and up into your womb, and then sucks up a small sample of cells,
- **hysteroscopy** - this allows the doctor to look at the inside of the womb using a thin type of telescope called a hysteroscope, which is inserted through your vagina and into your womb, allowing the doctor to look at the lining of the womb and take a sample from it (NHS, 2015i).

In some cases, a hysteroscopy may be used before dilatation and curettage (D&C). D&C is a minor surgical procedure carried out under general anaesthetic, where some tissue from the womb lining is removed. The tissue is then sent off to a laboratory for further testing (NHS, 2015i).

Blood test

A blood test can sometimes help diagnose womb cancer. This is because some cancerous tumours release certain chemicals into your blood, known as tumour markers, which can be detected during a blood test.

However, this type of test isn't very reliable. The presence of these chemicals doesn't mean you definitely have womb cancer. Some people with womb cancer don't have these chemicals in their blood (NHS, 2015i).

Tests if you have womb cancer

If you're diagnosed with womb cancer, you may have further tests to help determine the stage of the cancer. Staging the cancer will allow the doctors to work out how large the cancer is, whether or not it has spread, and the best treatment options for you (NHS, 2015i).

These tests may include -

- a chest X-ray - where radiation is used to check if the cancer has spread to the lungs,
- magnetic resonance imaging (MRI) scan - to check if the cancer has spread,
- a computerised tomography (CT) scan - to check if the cancer has spread,
- further blood tests - these are usually done to check your general health and how well some of your organs are functioning (NHS, 2015i).

Treatment

Surgery is the main treatment for womb cancer, although different methods can be used depending on your personal circumstances (NHS, 2015i).

The stages of womb cancer and the main treatment options are outlined below.

Stages of womb cancer

Health professionals use a staging system to describe how far womb cancer has advanced. These stages are -

- **stage 1** - the cancer is still contained inside the womb (uterus),
- **stage 2** - the cancer has spread to the neck of the womb (the cervix),
- **stage 3** - the cancer has spread outside the womb into nearby tissues in the pelvis or the lymph nodes,
- **stage 4** - the cancer has spread to the soft tissues of the abdomen, or into other organs, such as the bladder, bowel, liver, or lungs (NHS, 2015i).

Your chances of surviving womb cancer depend on the stage at which it's diagnosed.

If womb cancer is diagnosed at stage 1, the outlook is good and around 95% of women live for at least five more years. Many women with stage 1 womb cancer are cured.

If womb cancer is diagnosed at stage 2, you have around a 77% chance of living at least five more years.

If the condition is diagnosed at stage 3, you have a 40% chance of living at least another five years.

Around one in four womb cancers are diagnosed at stage 4. By this point, you only have a 15% chance of living at least five more years (NHS, 2015i).

Treatment overview

The main treatment for womb cancer is to remove the womb (hysterectomy), together with the ovaries and fallopian tubes. This is sometimes followed by radiotherapy or chemotherapy to try to kill any possible remaining cancer cells, depending on the stage and grade of the cancer (NHS, 2015i).

Treatment for women who haven't been through the menopause Having a hysterectomy means you will no longer be able to get pregnant. Younger women who haven't already reached the menopause may not want to have their womb and ovaries removed if they wish to have children.

In this case, under very specific circumstances it may be possible to treat the cancer using hormone therapy (NHS, 2015i).

Treating advanced cancer Advanced womb cancer requires a different course of treatment, usually depending more on chemotherapy.

Advanced cancer may not be curable, but the treatment aims to achieve a remission, where the cancer shrinks, making you feel normal and able to enjoy life to the full.

Even if there's no chance of a cure, surgery may be carried out to remove as much of the cancer as possible.

Radiotherapy, chemotherapy or hormone therapy can reduce symptoms such as pain by shrinking the cancer or slowing its growth (NHS, 2015i).

Surgery

Surgery for stage 1 womb cancer If you have stage 1 cancer, you'll probably have a hysterectomy. This involves removing both ovaries and the fallopian tubes in a procedure called a bilateral salpingo-oophorectomy (BSO), as well as the uterus (hysterectomy).

The surgeon may also take samples from the lymph nodes in the pelvis and abdomen and other nearby tissue. These will be sent to the laboratory to see whether the cancer has spread.

The most common hysterectomy technique involves using one large cut across your tummy to access the womb and remove it.

It's sometimes possible to use a technique called a laparoscopic hysterectomy, also known as a keyhole hysterectomy. This involves using several small cuts so a special type of telescope (laparoscope) and other surgical instruments can be used.

This means the surgeon can see inside your body and remove your womb through your vagina with little scarring.

You'll probably be ready to go home three to five days after your operation, or less if you had keyhole surgery. But it can take many weeks to recover fully.

After your operation, you'll be encouraged to start moving about as soon as possible. This is very important, and even if you have to stay in bed you'll need to keep doing regular leg movements to help your circulation and prevent blood clots. You'll be shown exercises by the nurses or physiotherapist to help prevent complications.

When you go home, you'll need to exercise gently to build up your strength and fitness. Discuss with your doctor or physiotherapist which types of exercise would be suitable for you (NHS, 2015i).

Surgery for stage 2 or 3 womb cancer If you have stage 2 or 3 womb cancer and the cancer has spread to the cervix or nearby lymph nodes in the pelvis, you may have a radical or total hysterectomy.

This involves the additional removal of the cervix and the top of your vagina, as well as the removal of the pelvic lymph nodes. You may also need radiotherapy or chemotherapy treatment after surgery to reduce the risk of the cancer returning (NHS, 2015i).

Surgery for advanced cancer (stage 4) If you have advanced womb cancer, you may have surgery to remove as much of the cancer as possible. This is called debulking surgery.

This won't cure the cancer, but it may ease some of the symptoms. Your doctor will discuss whether debulking surgery is suitable for you (NHS, 2015i).

Radiotherapy

A course of radiotherapy will be recommended if your treatment team thinks there's a significant risk the cancer could return in the pelvis. Radiotherapy may also be used to slow the spread of cancer when a surgical cure is not possible (NHS, 2015i).

There are two types of radiotherapy used to treat womb cancer -

- **internal radiotherapy** (also known as brachytherapy) - where a plastic tube is inserted inside the uterus and radiation treatment is passed down the tube into the womb,
- **external radiotherapy** - where a machine is used to deliver pulses of radiation to your pelvis (NHS, 2015i).

A course of external radiotherapy is usually given to you as an outpatient for five days a week with a break at the weekend. The treatment takes a few minutes. The whole course of radiotherapy may last approximately four weeks depending on the stage and position of the womb cancer.

Some women have internal radiotherapy (brachytherapy) as well as external radiotherapy. During brachytherapy, the device that delivers radiation is placed in your vagina.

There are different types of brachytherapy, involving either low, medium, or high dose rates. With low dose rate methods the radiation is delivered more slowly, so the device has to stay inside you for longer. You'll have to stay in hospital while you have the treatment. Your doctor will discuss this with you.

Radiotherapy has some side-effects. Skin in the treated area can become red and sore, and hair loss may occur. Radiotherapy to the pelvic area can affect the bowel and cause sickness and diarrhoea. As your course of treatment progresses, you're likely to get very tired. Most of these side effects will go away when your treatment finishes, although around 5% of women continue with long-term treatment effects, such as diarrhoea and rectal bleeding (NHS, 2015i).

Chemotherapy

If you have stage 3 or 4 womb cancer, you may be given a course of chemotherapy. Chemotherapy can be used after surgery to try to prevent the return of the cancer. In cases of advanced cancer, it may be used to slow the spread of the cancer and relieve symptoms.

Chemotherapy is usually given as an injection into the vein (intravenously). You'll usually be able to go home the same day you have chemotherapy, but sometimes you may need a short stay in hospital.

Chemotherapy is usually given in cycles, with a period of treatment being followed by a period of rest to allow the body to recover (NHS, 2015i).

Side-effects of chemotherapy can include -

- nausea,
- vomiting,
- hair loss,
- fatigue (NHS, 2015i).

There is also an increased risk of an infection developing in your bloodstream (sepsis [69]), as your body's ability to fight infection is reduced by chemotherapy.

The side-effects should stop once treatment has finished (NHS, 2015i).

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[69] a potentially life-threatening condition, triggered by an infection or injury

Hormone therapy

Some womb cancers are affected by the female hormone oestrogen. These cancers may respond to treatment with hormone therapy. Your doctor will discuss whether this is a possible treatment for your womb cancer.

Hormone therapy usually replaces a hormone called progesterone, which naturally occurs in your body. Artificial progesterone is used and is usually given as tablets.

It's mainly used to treat advanced-stage womb cancers, or cancer that has come back, and can help shrink the tumour and control any symptoms.

The treatment may have some side-effects, including mild nausea, mild muscle cramps, and weight gain. Your doctor will discuss these with you (NHS, 2015i).

Clinical trials

A lot of progress has been made in the treatment of womb cancer, and more women are living longer with fewer side-effects. Some of these advances were discovered through clinical trials, where new treatments and combinations of treatments are compared with standard treatment.

All cancer clinical trials in the UK are carefully monitored to make sure the trial is worthwhile and safely conducted. Participants in clinical trials often do better overall than those in routine care.

If you're invited to take part in a trial, you'll be given an information sheet. If you wish to take part, you'll be asked to sign your consent. You're always free to refuse or withdraw from a clinical trial without it affecting your care (NHS, 2015i).

Living with womb cancer

A diagnosis of cancer is a challenge for most people. How cancer affects your daily life depends on the stage of your cancer and the treatments used (NHS, 2015i).

There are many ways to get help coping with cancer. Not all of them work for everybody, but one or more should prove helpful -

- keep talking to your friends and family - they can be a powerful support system,

- communicate with others in the same situation,
- learn about your condition,
- set reasonable goals,
- take time out for yourself (NHS, 2015i).

After treatment

Women with womb cancer usually have a hysterectomy. This can be a major operation, and recovery may take from 6 to 12 weeks.

During this time you will have to avoid lifting things (for example, children and heavy shopping bags) and doing heavy housework. You won't be able to drive for between three and eight weeks after the operation.

Most women need 4 to 12 weeks off work after a hysterectomy. The recovery time will depend on the type of surgery you have, whether or not any problems develop, and what type of work you will return to.

Some of the treatments for endometrial cancer, particularly radiotherapy, can make you very tired. You may need to take a break from some of your normal activities for a while. Don't be afraid to ask for practical help from family and friends if you need it (NHS, 2015i).

Follow-up After your course of treatment has finished, you'll probably be invited back for regular check-ups. At the check-up, your doctor will examine you (this is likely to include an internal examination) and possibly carry out blood tests or scans to see how your cancer is responding to treatment (NHS, 2015i).

Relationships and sex

Relationships with friends and family Knowing how to talk to your friends and family about your cancer can be difficult, and they may find it hard to talk to you, too. People deal with serious problems in different ways.

It's hard to predict how a diagnosis of cancer will affect you. Being open and honest about how you feel and what your family and friends can do to help may put them at ease. But don't feel shy about telling people that you want some time to yourself, if that's what you need (NHS, 2015i).

Your sex life Womb cancer and its treatment can affect your sex life. This can happen in several ways -

- **early menopause** - if you haven't already had the menopause, removing the ovaries means you'll go through an early menopause; symptoms can include vaginal dryness and loss of sexual desire,
- **changes to your vagina** - radiotherapy for endometrial cancer can make your vagina narrower and less flexible. Sometimes the vagina gets so narrow that having sex becomes difficult. To stop this happening, you should be offered a set of vaginal dilators, which are plastic cones you put into your vagina to stretch it. You can also stretch your vagina by having sex, or by using your fingers or a vibrator,
- **not wanting to have sex** - it's common for women to lose interest in sex after treatment for womb cancer. Your treatment may leave you feeling very tired. You may feel shocked, confused or depressed about being diagnosed with cancer, and you also may be grieving the loss of your fertility (NHS, 2015i).

It's understandable that you may not feel like having sex while having to cope with all this. Try to share your feelings with your partner. If you feel you have problems with sex that aren't getting better with time, you may want to speak to a counsellor or a sex therapist (NHS, 2015i).

Talk to others

Being diagnosed with cancer can be hard, both for patients and their families. You'll need to deal with the emotional and practical difficulties.

With womb cancer, you have to cope physically with recovering from a hysterectomy, as well as the possible emotional impact of losing your womb.

Younger women may have to face the fact they won't be able to have children and all the grief and anger that may cause (NHS, 2015i).

Often, it can help to discuss your feelings and other difficulties with a trained counsellor or therapist. You can ask for this kind of help at any stage of your illness. There are various ways to find help and support -

- your hospital doctor, specialist nurse or GP can refer you to a counsellor,
- if you're struggling with feelings of depression, talk to your GP - a course of antidepressant drugs may be helpful, or your GP can arrange for you to get help from a counsellor or psychotherapist,
- it may be helpful to talk to someone who's had the same experience as you - many organisations have telephone helplines and forums that may be useful to you, and they can put you in touch with other people who have been through cancer treatment (NHS, 2015i).

Money and financial support

See Living with cancer.

Dealing with dying

If you're told nothing more can be done to treat your womb cancer, your care will focus on controlling your symptoms and helping you to be as comfortable as possible. This is called palliative care. Palliative care also includes psychological, social and spiritual support for you and your family or carers (NHS, 2015i).

Chapter 8

Male-only cancers

Contents

Male breast cancer

Male breast cancer is a rare cancer that forms in the breast tissue of men. Though breast cancer is most commonly thought of as a woman's disease, male breast cancer does occur.

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Male breast cancer is most common in older men, though it can occur at any age.

Men diagnosed with male breast cancer at an early stage have a good chance for a cure. Still, many men delay seeing their doctors if they notice one of the usual signs or symptoms, such as a breast lump. For this reason, many male breast cancers are diagnosed when the disease is more advanced (MAYOCLINIC, 2015).

Symptoms

Signs and symptoms of male breast cancer can include -

- A painless lump or thickening in your breast tissue,
- Changes to the skin covering your breast, such as dimpling, puckering, redness or scaling,
- Changes to your nipple, such as redness or scaling, or a nipple that begins to turn inward,
- Discharge from your nipple (MAYOCLINIC, 2015).

When to see a doctor

Make an appointment with your doctor if you have any persistent signs or symptoms that worry you (MAYOCLINIC, 2015).

Causes

It's not clear what causes male breast cancer.

Doctors know that male breast cancer occurs when some breast cells divide more rapidly than healthy cells do. The accumulating cells form a tumour that may spread (metastasize) to nearby tissue, to the lymph nodes or to other parts of the body (MAYOCLINIC, 2015).

Where breast cancer begins in men

Everyone is born with a small amount of breast tissue. Breast tissue consists of milk-producing glands (lobules), ducts that carry milk to the nipples, and fat.

During puberty, women begin developing more breast tissue, and men do not. But because men are born with a small amount of breast tissue, they can develop breast cancer.

Types of breast cancer diagnosed in men include -

- **Cancer that begins in the milk ducts (ductal carcinoma)** - nearly all male breast cancer is ductal carcinoma,
- **Cancer that begins in the milk-producing glands (lobular carcinoma)** - this type is rare in men because they have few lobules in their breast tissue,
- **Cancer that spreads to the nipple (Paget's disease of the nipple)** - rarely, male breast cancer forms in the milk ducts and spreads to the nipple, causing crusty, scaly skin around the nipple (MAYOCLINIC, 2015).

Inherited genes that increase breast cancer risk

Some men inherit abnormal (mutated) genes from their parents that increase the risk of breast cancer. Mutations in one of several genes, especially a gene called *BRCA2*, put you at greater risk of developing breast and prostate cancers.

These genes normally make proteins that keep cells from growing abnormally - which helps prevent cancer. But mutated genes aren't as effective at protecting you from cancer.

Meeting with a genetic counselor and undergoing genetic testing can determine whether you carry gene mutations that increase your risk of breast cancer - and if you can pass this gene along to your children, both boys and girls. Discuss the benefits and risks of genetic testing with your doctor (MAYOCLINIC, 2015).

Risk factors

Factors that increase the risk of male breast cancer include -

- **Older age** - Your risk of male breast cancer increases as you age. The peak incidence of male breast cancer occurs between the ages of 68 and 71,
- **Exposure to oestrogen** - If you take oestrogen-related drugs, such as those used as part of a sex-change procedure or for hormone therapy for prostate cancer, your risk of breast cancer is increased,
- **Family history of breast cancer** - If you have a close family member with breast cancer, you have a greater chance of developing the disease,
- **Klinefelter's syndrome** - This genetic syndrome occurs when a boy is born with more than one copy of the X chromosome. Klinefelter's syndrome causes abnormal development of the testicles. As a result, men with this syndrome produce lower levels of certain male hormones (androgens) and more female hormones (oestrogens),

- **Liver disease** - Certain conditions, such as cirrhosis of the liver, can reduce male hormones and increase female hormones, increasing your risk of breast cancer,
- **Obesity** - Fat cells convert androgens into oestrogen. A higher number of fat cells in your body may result in increased estrogen and higher risk of breast cancer,
- **Radiation exposure** - If you've received radiation treatments to your chest, such as those used to treat cancers in the chest, you're more likely to develop breast cancer later in life,
- **Testicle disease or surgery** - Having inflamed testicles (orchitis) or surgery to remove a testicle (orchiectomy) can increase your risk of male breast cancer (MAYOCLINIC, 2015).

Diagnosis

Start by seeing your GP if you notice any unusual signs or symptoms that worry you. If your doctor thinks you may have breast cancer, you may be referred to a doctor who specialises in treating cancer (oncologist).

Because appointments can be brief, and because there's often a lot of ground to cover, it's a good idea to be well prepared. Here's some information to help you get ready and what to expect from your doctor (MAYOCLINIC, 2015).

What you can do

- Be aware of any pre-appointment restrictions, such as not eating solid food for a period of time before your appointment.
- Write down your symptoms, including any that may seem unrelated to the reason why you scheduled the appointment.
- Write down your key medical information, including other conditions.
- Write down key personal information, including any recent life changes.
- Make a list of all your medications, vitamins and supplements.
- Ask a relative or friend to accompany you, to help you remember what the doctor says.
- Write down questions to ask your doctor (MAYOCLINIC, 2015).

Your time with your doctor is limited, so preparing a list of questions can help you make the most of your time together. List your questions from most important to least important in case time runs out (MAYOCLINIC, 2015).

For male breast cancer, some basic questions to ask your doctor include -

- What type of breast cancer do I have?
- What is the stage of my cancer?
- Has my cancer spread beyond the breast?
- Can my cancer be cured?
- Will I need more tests?
- What are my treatment options?
- What are the potential side-effects of each option?
- Is there a treatment option you feel is best for me?
- How long will cancer treatment last?
- How will cancer treatment affect my daily life?
- I have these other health conditions. How can I best manage them together?
- Should I see a specialist? What will that cost, and will my insurance cover it?
- Are there any brochures or other printed material that I can take with me? What websites do you recommend? (MAYOCLINIC, 2015)

In addition to the questions that you've prepared to ask your doctor, don't hesitate to ask questions that occur to you during your appointment (MAYOCLINIC, 2015).

What to expect from your doctor

Your doctor is likely to ask you a number of questions. Being ready to answer them may make time to go over points you want to spend more time on. You may be asked -

- What symptoms are you experiencing? How severe are they?
- When did you first begin experiencing symptoms? Are they continuous or occasional?
- Have any of your relatives been diagnosed with cancer? If so, what type of cancer and at what age were the family members diagnosed? (MAYOCLINIC, 2015)

Your doctor may conduct a number of diagnostic tests and procedures, such as -

- **Clinical breast exam** - The doctor uses his or her fingertips to examine your breasts and surrounding areas for lumps or other changes. Your doctor assesses how large the lumps are, how they feel, and how close they are to your skin and muscles,
- **Imaging tests** - Mammogram and ultrasound can detect suspicious masses in your breast tissue,

- **Biopsy** - A fine needle is inserted into the breast to remove tissue for analysis in the laboratory. Test results can reveal whether you have breast cancer and if so, the type of breast cancer you have (MAYOCLINIC, 2015).

Determining the extent of the cancer

Determining the extent (this is also known as 'staging') of your cancer helps your doctor evaluate treatment options. Biopsy, blood tests and imaging tests can be used to stage male breast cancer.

The stages of male breast cancer are -

- **Stage I** - The tumour is no more than 2 centimetres (cm) in diameter (about 3/4 inch) and hasn't spread to the lymph nodes,
- **Stage II** - The tumour may be up to 5 cm (about 2 inches) in diameter and may have spread to nearby lymph nodes. Or the tumour may be larger than 5 cm but no cancer cells are found in the lymph nodes,
- **Stage III** - The tumour may be larger than 5 cm (about 2 inches) in diameter and may involve several nearby lymph nodes. Lymph nodes above the collarbone may also contain cancer cells,
- **Stage IV** - Cancer at this stage has spread beyond the breast to distant areas, such as the bone, brain, liver or lungs (MAYOCLINIC, 2015).

Treatment

To determine your male breast cancer treatment options, your doctor considers your cancer's stage, your overall health and your preferences. Male breast cancer treatment often involves surgery and may also include other treatments (MAYOCLINIC, 2015).

Surgery

The goal of surgery is to remove the tumour and surrounding breast tissue. The procedures include -

- **Removal of breast tissue and surrounding lymph nodes (modified radical mastectomy)** - The surgeon removes all of your breast tissue, including the nipple and areola, and some underarm lymph nodes.
- **Removal of one lymph node for testing (sentinel lymph node biopsy)** - The doctor identifies the lymph node most likely to be the first place your cancer cells would spread. That lymph node is removed and

analysed. If no cancer cells are found, there is a good chance that your breast cancer hasn't spread beyond your breast tissue (MAYOCLINIC, 2015).

Radiotherapy

Radiotherapy uses high-energy beams to kill cancer cells. In male breast cancer, radiotherapy may be used after surgery to eliminate any remaining cancer cells in the breast, chest muscles or armpit.

During radiotherapy, radiation comes from a large machine that moves around your body, directing the energy beams to precise points on your chest (MAYOCLINIC, 2015).

Chemotherapy

Chemotherapy uses medications to kill cancer cells. These medications may be administered through a vein in your arm (intravenously), in pill form or by both methods.

Your doctor might recommend chemotherapy after surgery to kill any cancer cells that might have spread outside your breast. Chemotherapy may also be an option for men with advanced breast cancer (MAYOCLINIC, 2015).

Hormone therapy

Most men with male breast cancer have tumours that rely on hormones to grow (hormone-sensitive). If your cancer is hormone-sensitive, your doctor may recommend hormone therapy.

Hormone therapy for male breast cancer often involves the medication tamoxifen, which is also used for women. Other hormone therapy medications used in women with breast cancer haven't been shown to be effective for men (MAYOCLINIC, 2015).

Support

Receiving a cancer diagnosis can be shocking and upsetting. With time you'll find ways to cope with the stress and challenges of cancer and cancer treatment. Until then, you might find it helpful to consider -

- **Talking with someone** - you may feel comfortable discussing your feelings with a friend or family member, or you might prefer meeting with a formal support group. Support groups for the families of cancer survivors also are available.

- **Prayer or meditation** - you can pray or mediate on your own or receive guidance from a spiritual adviser or from an instructor.
- **Exercise** - gentle exercise may help boost your mood and make you feel better. Ask your doctor to recommend appropriate exercise.
- **Creative activities** - certain activities, such as art, dance and music, may help you feel less distressed. Some cancer centers have specially trained professionals who can guide you through these activities.
- **Relaxation exercises** - relaxation exercises help refocus your mind and help you relax. Relaxation exercises include guided imagery and progressive muscle relaxation. You can do relaxation exercises on your own, with an instructor or by listening to a recording that guides you through the exercises (MAYOCLINIC, 2015).

Prostate cancer

Prostate cancer is the most common cancer in men in the UK, with over 40,000 new cases diagnosed every year.

Prostate cancer usually develops slowly, so there may be no signs you have it for many years.

Symptoms often only become apparent when your prostate is large enough to affect the urethra.

When this happens, you may notice things like an increased need to urinate, straining while urinating and a feeling that your bladder has not fully emptied.

These symptoms shouldn't be ignored, but they do not mean you definitely have prostate cancer. It is more likely that they are caused by something else, such as benign prostatic hyperplasia (BPH) or prostate enlargement) (NHS, 2015h).

Symptoms

Prostate cancer does not normally cause symptoms until the cancer has grown large enough to put pressure on the urethra (NHS, 2015h).

This normally results in problems associated with urination. Symptoms can include -

- needing to urinate more frequently, often during the night,
- needing to rush to the toilet,

- difficulty in starting to pee (hesitancy),
- straining or taking a long time while urinating,
- weak flow,
- feeling that your bladder has not emptied fully (NHS, 2015h).

Many men's prostates get larger as they get older due to a non-cancerous condition known as prostate enlargement or BPH.

Symptoms that the cancer may have spread include bone and back pain, a loss of appetite, pain in the testicles and unexplained weight loss (NHS, 2015h).

Causes

It is not known exactly what causes prostate cancer, although a number of things can increase your risk of developing the condition (NHS, 2015h).

These include -

- **Age** - risk rises as you get older and most cases are diagnosed in men over 50 years of age.
- **Ethnic group** - prostate cancer is more common among men of African-Caribbean and African descent than in men of Asian descent.
- **Family history** - having a brother or father who developed prostate cancer under the age of 60 seems to increase the risk of you developing it. Research also shows that having a close female relative who developed breast cancer may also increase your risk of developing prostate cancer.
- **Obesity** - recent research suggests that there may be a link between obesity and prostate cancer.
- **Exercise** - men who regularly exercise have also been found to be at lower risk of developing prostate cancer.
- **Diet** - research is ongoing into the links between diet and prostate cancer. There is evidence that a diet high in calcium is linked to an increased risk of developing prostate cancer (NHS, 2015h).

In addition, some research has shown that prostate cancer rates appear to be lower in men who eat foods containing certain nutrients including lycopene, found in cooked tomatoes and other red fruit, and selenium, found in brazil nuts. However, more research is needed (NHS, 2015h).

Diagnosis

If you have symptoms that could be caused by prostate cancer, you should visit your GP.

There is no single, definitive test for prostate cancer, so your GP will discuss the pros and cons of the various tests with you to try to avoid unnecessary anxiety (NHS, 2015h).

Your doctor is likely to -

- ask for a urine sample to check for infection,
- take a blood sample to test your level of PSA,
- examine your prostate (digital rectal examination (DRE)) (NHS, 2015h).

In 2015, the National Institute for Health and Care Excellence (NICE) published guidelines to help GPs recognise the signs and symptoms of prostate cancer and refer people for the right tests faster. To find out if you should be referred for further tests for suspected prostate cancer, read the NICE 2015 guidelines on Suspected Cancer: Recognition and Referral (NHS, 2015h).

PSA testing

PSA is a protein produced by the prostate gland. All men have a small amount of PSA in their blood, and it increases with age.

Prostate cancer can increase the production of PSA, and so a PSA test looks for raised levels of PSA in the blood that may be a sign of the condition in its early stages.

However, PSA testing is not a specific test for prostate cancer. Most men who have prostate cancer will not have a raised PSA level. More than 65% of men with a raised PSA level will not have cancer, as PSA levels rise in all men as they get older (NHS, 2015h).

Digital rectal examination (DRE)

The next step is a DRE, which can be done by your GP.

During a DRE, your GP will insert a lubricated and gloved finger into your rectum. The rectum is close to your prostate gland, so your GP can check to feel if the surface of the gland has changed. This will feel a little uncomfortable, but should not be painful.

Prostate cancer can make the gland hard and bumpy. However, in most cases, the cancer causes no changes to the gland and a DRE may not be able to detect the cancer.

DRE is useful in ruling out prostate enlargement caused by BPH, as this causes the gland to feel firm and smooth (NHS, 2015h).

Biopsy

Your GP will assess your risk of having prostate cancer based on a number of factors, including your PSA levels, the results of your DRE, and your age, family history and ethnic group. If you are at risk, you should be referred to hospital to discuss the options of further tests.

The most commonly used test is a transrectal ultrasound-guided biopsy (TRUS). A biopsy may also be taken during a cystoscopy examination or through the skin behind the testicles (perineum).

During a TRUS biopsy, an ultrasound probe (a machine that uses sound waves to build a picture of the inside of your body) is inserted into your rectum. This allows the doctor or specialist nurse to see exactly where to pass a needle through the wall of your rectum to take small samples of tissue from your prostate.

The procedure can be uncomfortable and sometimes painful, so you may be given a local anaesthetic to minimise any discomfort. As with any procedure, there may be complications, including bleeding and infection.

Although it is more reliable than a PSA test, the TRUS biopsy can have problems. It can miss up to one in five cancers, because the location of the cancer is unknown when it is carried out. The doctors can see the prostate using the ultrasound scan, but not the tumour(s) if they are present.

You may need another biopsy if your symptoms persist, or your PSA level continues to rise. Your doctor may request an MRI scan of the prostate before another biopsy.

The TRUS biopsy can also find small low-risk cancers that do not need treatment, but may cause you anxiety. Many men often choose to undergo surgery or radiotherapy that may not benefit them but causes side-effects, such as incontinence and erectile dysfunction.

The samples of tissue from the biopsy are studied in a laboratory. If cancerous cells are found, they can be studied further to see how quickly the cancer will spread. This process is known as ”staging and grading” and helps doctors to decide which treatment is the most appropriate (NHS, 2015h).

Further testing

If there is a significant chance the cancer has spread from your prostate to other parts of the body, further tests may be recommended (NHS, 2015h).

These include -

- A magnetic resonance imaging (MRI) or computerised tomography (CT) scan - these scans build a detailed picture of the inside of your body.
- An isotope bone scan - this can tell if the cancer has spread to your bones. A small amount of radiation dye is injected into the vein and collects in parts of the bone where there are any abnormalities (NHS, 2015h).

Testing for prostate cancer

There is currently no screening programme for prostate cancer in the UK. This is because it has not been proved that the benefits would outweigh the risks (NHS, 2015h).

PSA screening

Routinely screening all men to check their PSA levels is a controversial subject in the international medical community (NHS, 2015h).

There are several reasons for this -

- PSA tests are unreliable and can suggest prostate cancer when no cancer exists (a false-positive result). This means that many men often have invasive and sometimes painful biopsies for no reason. Also, up to 15% of men with prostate cancer have normal PSA levels (a false-negative result), so many cases may be missed.
- The PSA test can find aggressive prostate cancer that needs treatment, but it can also find slow-growing cancer that may never cause symptoms or shorten life. Some men may therefore face difficult decisions about treatment.
- Treating prostate cancer in its early stages can be beneficial in some cases. But the side-effects of the various treatments are potentially so serious that men may choose to delay treatment until it is absolutely necessary.
- Although screening has been shown to reduce a man's chance of dying from prostate cancer, it would mean many men receive treatment unnecessarily (NHS, 2015h).

More research is needed to determine whether a screening programme would provide men with more benefit than harm (NHS, 2015h).

One European study showed deaths from prostate cancer could be reduced by 20% if there was a screening programme, but this needs to be balanced against the harms of -

- **overdiagnosis** - people being diagnosed with a cancer that will never cause symptoms or death during their lifetime,
- **overtreatment** - people being treated unnecessarily for tumours that would be unlikely to be harmful (NHS, 2015h).

To save one life from prostate cancer, 27 men would have to be diagnosed with it. A recent large study in America found no reduction in the number of deaths (NHS, 2015h).

Improving the test

As there are many reasons why PSA levels may be high at any one time, researchers are trying to make the PSA test, or a variation of it, more accurate. This includes looking at how PSA levels change over time and comparing the PSA level to prostate size.

Researchers are also looking at whether new imaging tests, such as MRI scans, or other blood and urine tests, can be used to decide which men with an elevated PSA should have a biopsy.

Instead of a national screening programme, there is an informed choice programme called prostate cancer risk management for healthy men aged 50 or over who ask their GP about PSA testing. It aims to give men good information on the pros and cons of a PSA test.

If you're a man aged 50 or over and decide to have your PSA levels tested after talking to your GP, they will be able to arrange for it to be carried out for free on the NHS.

If results show you have a raised level of PSA, your GP may suggest further tests (NHS, 2015h).

Should I have a PSA test?

Because the results of the PSA test are not as reliable as doctors would like, other tests and investigations are needed to diagnose prostate cancer.

A PSA test cannot identify prostate cancer on its own, and changes in PSA levels alone are not a good reason to start treatment.

If you are thinking about asking for a PSA test, it is important that you first discuss whether it is right for you with your GP so you understand what the results might mean.

The Prostate Cancer Risk Management Programme has information on the risks and benefits of the PSA test to help you decide whether or not to have it (NHS, 2015h).

Treatment

Your treatment for prostate cancer will depend on your individual circumstances.

For many men with prostate cancer, no treatment will be necessary. Active surveillance or ”watchful waiting” will mean keeping an eye on the cancer and starting treatment only if the cancer shows signs of getting worse or causing symptoms.

When treatment is necessary, the aim is to cure or control the disease so it doesn't shorten life expectancy and affects everyday life as little as possible. Sometimes, if the cancer has already spread, the aim is not to cure it, but to prolong life and delay symptoms (NHS, 2015h).

Your cancer care team

People with cancer should be cared for by a MDT. This is a team of specialists who work together to provide the best care and treatment.

The team often consists of a specialist cancer surgeon, an oncologist (a radiotherapy and chemotherapy specialist), a radiologist, pathologist, radiographer and a specialist nurse. Other members may include a physiotherapist, dietitian and occupational therapist. You may also have access to clinical psychology support (NHS, 2015h).

When deciding what treatment is best for you, your doctors will consider -

- the type and size of the cancer,
- what grade it is,
- your general health,
- whether the cancer has spread to other parts of your body (NHS, 2015h).

Good prostate cancer care

Your MDT will be able to recommend what they feel are the best treatment options, but ultimately the decision is yours (NHS, 2015h).

The National Institute for Health and Care Excellence (NICE) has made recommendations about treatments offered to men with the three main stages of prostate cancer -

- localised prostate cancer (cancer that is just in the prostate gland),
- locally advanced prostate cancer (cancer that has spread beyond the prostate capsule, but is still connected to the prostate gland),
- relapsed (cancer that has returned after treatment) and metastatic prostate cancer (cancer that has spread outside the prostate gland, with no remaining link to the original cancer in the prostate gland) (NHS, 2015h).

Staging of prostate cancer

Doctors will use the results of your prostate examination, biopsy and scans to identify the ”stage” of your prostate cancer (how far the cancer has spread). The stage of the cancer will determine which types of treatments will be necessary (NHS, 2015h).

A widely used method of staging is a number staging system. The stages are -

- **Stage 1** - the cancer is very small and completely within the prostate gland,
- **Stage 2** - the cancer is within the prostate gland, but is larger,
- **Stage 3** - the cancer has spread from the prostate and may have grown into the tubes that carry semen,
- **Stage 4** - the cancer has spread into the lymph nodes or another part of the body, including the bladder, rectum or bones; about 20–30% of cases are diagnosed at this stage (NHS, 2015h).

If prostate cancer is diagnosed at an early stage, the chances of survival are generally good. About 90% of men diagnosed at stages 1 or 2 will live at least five more years and 65–90% will live for at least 10 more years.

If you are diagnosed with stage 3 prostate cancer, you have a 70–80% of chance of living for at least five more years.

However, if you are diagnosed when your prostate cancer has reached stage 4, there is only a 30% chance you will live for at least five more years (NHS, 2015h).

Watchful waiting Watchful waiting is often recommended for older men when it is unlikely that the cancer will affect your natural life span.

If the cancer is in its early stages and not causing symptoms, you may decide to delay treatment, and wait to see if any symptoms of progressive cancer develop.

If this happens, pain medication and hormone medication (see below) to control prostate cancer are usually used (NHS, 2015h).

Watchful waiting may also be recommended for people with a higher risk of prostate cancer if -

- your general health means you are unable to receive any form of treatment,
- your life expectancy means you will die with the cancer rather than from it (NHS, 2015h).

In this case, hormone treatment may be started if there are symptoms caused by the prostate cancer (NHS, 2015h).

Active surveillance Active surveillance aims to avoid unnecessary treatment of harmless cancers, while still providing timely treatment for men who need it.

When they are diagnosed, we know that around half to two-thirds of men with low-risk prostate cancer do not need treatment. Surveillance is a safe strategy that provides a period of observation to gather extra information over time to see whether the disease is changing.

Active surveillance involves you having regular PSA tests and often several biopsies to ensure any signs of progression are found as early as possible. Sometimes, MRI scans may also be carried out. If these tests reveal the cancer is changing or progressing, you can then make a decision about further treatment.

About one in three men who undergo surveillance will later have treatment. This does not mean they made the wrong initial decision. Good evidence shows that active surveillance is safe over an average of six years. Men undergoing active surveillance will have delayed any treatment-related side-effects, and those who eventually need treatment will be reassured that it was necessary (NHS, 2015h).

Radical prostatectomy A radical prostatectomy is the surgical removal of your prostate gland. This treatment is an option for curing localised prostate cancer and locally-advanced prostate cancer.

Like any operation, this surgery carries some risks, and there may be some side-effects. These are outlined below (NHS, 2015h).

- Some men have problems with urinary incontinence. This can range from leaking small drips of urine, to leaking larger amounts. However, for most men, this usually clears up within three to six months of the operation. About two in every 10 men have long-term problems requiring the use of pads.

- Some men have problems getting an erection (erectile dysfunction). For some men, this improves with time, but around half of men will have long-term problems.
- In extremely rare cases, problems arising after surgery can be fatal. For example, one in 1,000 men under 65 years old and one in 200 men over 65 will die following a radical prostatectomy (NHS, 2015h).

For many men, having a radical prostatectomy will get rid of the cancer cells. However, for around one in three men, the cancer cells may not be fully removed, and the cancer cells may return some time after the operation.

Studies have shown that radiotherapy after prostate removal surgery may increase the chances of a cure, although research is still being carried out into when it should be used after surgery.

After a radical prostatectomy, you will no longer ejaculate during sex. This means that you will not be able to have a child through sexual intercourse. You may want to ask your doctors about storing a sperm sample before the operation, so it can be used later for in-vitro fertilisation (IVF) [70] (NHS, 2015h).

Radiotherapy Radiotherapy involves using radiation to kill cancerous cells. This treatment is an option for curing localised prostate cancer and locally-advanced prostate cancer. Radiotherapy can also be used to slow the progression of metastatic prostate cancer and relieve symptoms.

Radiotherapy is normally given as an outpatient at a hospital near you. It is done in short sessions for five days a week, for four to eight weeks. There are short-term and long-term side effects associated with radiotherapy.

You may receive hormone therapy before undergoing radiotherapy to increase the chance of successful treatment. Hormone therapy may also be recommended after radiotherapy to reduce the chances of cancerous cells returning (NHS, 2015h).

Short-term effects of radiotherapy can include -

- discomfort around the rectum and anus (the opening through which stools pass out of your body),
- diarrhoea,
- loss of pubic hair,
- tiredness,
- cystitis - an inflammation of the bladder lining, which can cause you to urinate frequently; urination may be painful (NHS, 2015h).

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[70] one of several techniques available to help people with fertility problems have a baby

Possible long-term side-effects can include -

- an inability to obtain an erection - this affects about one- to two-thirds of men,
- urinary incontinence - this affects about one or two in every 10 men,
- back passage problems (diarrhoea, bleeding, discomfort) - these affect between five and 20 in every 100 men (NHS, 2015h).

As with radical prostatectomy, there is a one-in-three chance the cancer will return. In these cases, medication is usually used to control the cancer instead of surgery. This is because there is a higher risk of complications from surgery in men who have previously had radiotherapy.

Some hospitals now offer new minimally invasive treatments if radiotherapy fails to work, sometimes as part of a clinical trial. These new treatments are called high-intensity focused ultrasound (HIFU) and cryotherapy. These treatments have fewer side-effects, but the long-term outcomes are not yet known (NHS, 2015h).

Brachytherapy Brachytherapy is a form of radiotherapy where the radiation dose is delivered inside the prostate gland. It is also known as internal or interstitial radiotherapy.

The radiation can be delivered using a number of tiny radioactive seeds that are surgically implanted into the tumour. This is called low dose-rate brachytherapy.

The radiation can also be delivered through hollow, thin needles placed inside the prostate. This is calld high dose-rate brachytherapy.

This method has the advantage of delivering a high dose of radiation to the prostate, while minimising damage to other tissues. However, the risk of sexual dysfunction and urinary problems is the same as with radiotherapy, although the risk of bowel problems is slightly lower (NHS, 2015h).

Hormone therapy Hormone therapy is often used in combination with radiotherapy. For example, you may receive hormone therapy before undergoing radiotherapy to increase the chance of a successful treatment. Hormone therapy may also be recommended after radiotherapy to reduce the chances of cancerous cells returning.

Hormone therapy alone should not normally be used to treat localised prostate cancer in men who are fit and willing to receive surgery or radiotherapy. This is because it does not cure the cancer on its own. Hormone therapy can be used to slow the progression of advanced prostate cancer and relieve symptoms.

Hormones control the growth of cells in the prostate. In particular, prostate cancer needs the hormone testosterone to grow. The purpose of hormone therapy is to block the effects of testosterone, either by stopping its production or by stopping your body being able to use testosterone (NHS, 2015h).

Hormone therapy can be given as -

- injections to stop your body making testosterone, called luteinising hormone-releasing hormone (LHRH) agonists,
- tablets to block the effects or reduce the production of testosterone, called anti-androgen treatment,
- combined LHRH and anti-androgen treatment (NHS, 2015h).

The main side-effects of hormone treatment are caused by their effects on testosterone. They usually go away when treatment stops. They include loss of sex drive and erectile dysfunction (this is more common with LHRH agonists than anti-androgens) (NHS, 2015h).

Other possible side-effects include -

- hot flushes,
- sweating,
- weight gain,
- swelling and tenderness of the breasts (NHS, 2015h).

An alternative to hormone therapy is to surgically remove the testicles, called orchidectomy. The operation does not cure prostate cancer, but by removing the testosterone, it controls the growth of the cancer and its symptoms. However, many men prefer to have hormone treatment to block the effects of testosterone (NHS, 2015h).

Trans-urethral resection of the prostate (TURP) During TURP, a thin metal wire with a loop at the end is inserted into your urethra and pieces of the prostate are removed.

This is carried out under general anaesthetic or a spinal anaesthetic (epidural).

This is done to relieve pressure from the urethra to treat any problematic symptoms you may have with urination. It does not cure the cancer (NHS, 2015h).

High intensity focused ultrasound (HIFU) HIFU is sometimes used to treat men with localised prostate cancer that has not spread beyond their prostate.

An ultrasound probe inserted into the rectum releases high-frequency sound waves through the wall of the rectum. These sound waves kill cancer cells in the prostate gland by heating them to a high temperature.

The risk of side-effects from HIFU is usually lower than other treatments.

However, possible effects can include impotence (in five to 10 in every 100 men) or urinary incontinence (in less than one in every 100 men). Back passage problems are rare.

Fistulas (an abnormal channel between the urinary system and rectum) are also rare, affecting less than one in every 500 men. This is because the treatment targets the cancer area only and not the whole prostate.

However, HIFU treatment is still going through clinical trials for prostate cancer. In some cases, doctors can carry out HIFU treatment outside of clinical trials. HIFU is not widely available and its long-term effectiveness has not yet been conclusively proven (NHS, 2015h).

Cryotherapy Cryotherapy is a method of killing cancer cells by freezing them. It is sometimes used to treat men with localised prostate cancer that has not spread beyond their prostate gland.

Tiny probes called cryoneedles are inserted into the prostate gland through the wall of the rectum. They freeze the prostate gland and kill the cancer cells, but some normal cells also die (NHS, 2015h).

The aim is to kill cancer cells while causing as little damage as possible to healthy cells. The side-effects of cryotherapy can include -

- erectile dysfunction - this can affect between two and nine in every 10 men,
- incontinence - this affects less than one in 20 men (NHS, 2015h).

It is rare for cryotherapy to cause rectal problems or fistulas.

Cryotherapy is still undergoing clinical trials for prostate cancer. In some cases, doctors can carry out cryotherapy treatment outside of clinical trials. It is not widely available and its long-term effectiveness has not yet been conclusively proven (NHS, 2015h).

Treating advanced prostate cancer If the cancer has reached an advanced stage, it is no longer possible to cure it. However, it may be possible to slow its progression, prolong your life and relieve symptoms (NHS, 2015h).

Treatment options include -

- radiotherapy,
- hormone treatment,
- chemotherapy (NHS, 2015h).

If the cancer has spread to your bones, medicines called bisphosphonates may be used. Bisphosphonates help reduce bone pain and bone loss (NHS, 2015h).

Chemotherapy Chemotherapy is mainly used to treat prostate cancer that has spread to other parts of the body (metastatic prostate cancer) and which is not responding to hormone therapy.

Chemotherapy destroys cancer cells by interfering with the way they multiply. Chemotherapy does not cure prostate cancer, but can keep it under control and reduce symptoms (such as pain) so everyday life is less affected.

The main side-effects of chemotherapy are caused by their effects on healthy cells, such as immune cells. They include infections, tiredness, hair loss, sore mouth, loss of appetite, nausea and vomiting. Many of these side-effects can be prevented or controlled with other medicines, which your doctor can prescribe for you (NHS, 2015h).

Steroids Steroid tablets are used when hormone therapy no longer works because the cancer is resistant to it. This is called hormone-refractory cancer.

Steroids can be used to try to shrink the tumour and stop it from growing. The most effective steroid treatment is dexamethasone (NHS, 2015h).

Other medical treatments There are a number of new medications that could be used if hormones and chemotherapy fail. Your medical team can tell you if these are suitable and available for you.

NICE has recently issued guidance on medications called abiraterone and enzalutamide. Both abiraterone and enzalutamide may be used to treat men with metastatic prostate cancer that no longer responds to the chemotherapy drug docetaxel (NHS, 2015h).

Deciding against treatment As many of the treatments above have unpleasant side-effects that can affect your quality of life, you may decide against treatment. This make be especially true if you are at an age when you feel that treating the cancer is unlikely to significantly extend your life expectancy.

This is entirely your decision, and your MDT will respect it.

If you decide not to have treatment, your GP and hospital team will still give you support and pain relief. This is called palliative care. Support is also available for your family and friends (NHS, 2015h).

Living with prostate cancer

Depending of the type of prostate cancer you have, your life may be affected in different ways.

Unlike many other types, most prostate cancers get worse slowly. Men may have it for years without symptoms. During this time, men with low-risk prostate cancer (which has not spread beyond the prostate gland) may not need treatment.

About one in five men with prostate cancer have fast-growing cancer. Men whose cancer is more likely to spread may decide to have surgery or radiotherapy, which aims to cure the cancer. However, these treatments can have side-effects (NHS, 2015h).

Impact on everyday activities

If you have no symptoms, prostate cancer should have little or no effect on your everyday activities. You should be able to work, care for your family, carry on your usual social and leisure activities, and look after yourself. However, you may be understandably worried about your future. This may make you feel anxious or depressed, and affect your sleep.

If your prostate cancer progresses, you may not feel well enough to do all the things you used to. After an operation or other treatment, such as radiotherapy or chemotherapy, you will probably feel tired and need time to recover.

If you have advanced prostate cancer that has spread to other parts of your body, you may have symptoms that slow you down and make it difficult to do things. You may have to reduce your working hours or stop working altogether.

Whatever stage your prostate cancer has reached, try to give yourself time to do the things you enjoy and spend time with those who care about you (NHS, 2015h).

Complications of prostate cancer

Erection problems If you have erectile dysfunction, speak to your GP. It may be possible to treat you with a type of medicine known as phosphodiesterase type 5 inhibitors (PDE5). PDE5s work by increasing the blood supply to your penis.

The most commonly used PDE5 is sildenafil (Viagra). Other PDE5s are available if sildenafil is not effective.

Another alternative is a device called a vacuum pump. It is a simple tube connected to a pump. You place your penis in the tube and then pump out all the air. This creates a vacuum, which causes the blood to rush to your penis. You then place a rubber ring around the base of your penis. This keeps the blood in place and allows you to maintain an erection for around 30 minutes (NHS, 2015h).

Urinary incontinence If your urinary incontinence is mild, you may be able to control it by learning some simple exercises. Pelvic floor exercises can strengthen your control over your bladder (NHS, 2015h).

To carry out pelvic floor exercises -

- Sit or lie comfortably with your knees slightly apart.
- Squeeze or lift at the front as if you were trying to stop the passage of urine, then squeeze or lift at the back as if you were trying to stop the passage of wind.
- Hold this contraction for as long as you can (at least two seconds, increasing up to 10 as you improve).
- Relax for the same amount of time before repeating (NHS, 2015h).

If your urinary incontinence is more severe, it may be possible to treat it with surgery. This would involve implanting an artificial sphincter - a sphincter is a muscle used to control the bladder (NHS, 2015h).

Relationships Being diagnosed with prostate cancer often brings families and friends closer, although it can put pressure on relationships too.

Most people want to help, though they may not know what to do. A few people find it hard to talk to someone with prostate cancer, and may try to avoid them. Being open and honest about how you feel and what your family and friends can do to help may put others at ease. But do not feel shy about telling people that you need some time to yourself, if that is what you need (NHS, 2015h).

Talk to others If you have questions, your doctor or nurse may be able to reassure you, or you may find it helpful to talk to a trained counsellor, psychologist or specialist telephone helpline. Your GP surgery will have information on these.

Some men find it helpful to talk to other men with prostate cancer at a local support group or through an internet chat room (NHS, 2015h).

See also Living with cancer.

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Chapter 9

Miscellaneous

Contents

Depression

See Depression - Aging and Trans - Part 3 - Mental Health

Nipple discharge

Nipple discharge can be caused by a wide range of conditions, most of which are harmless or easily treated.

Some of the main causes of nipple discharge are described below.

See your GP if you're unsure of the cause of your discharge or you're embarrassed or worried, especially if the discharge is bloodstained or clear and only comes from one nipple, or if you're a man with nipple discharge (NHS, 2015e).

Pregnancy

For women, one of the most obvious explanations for fluid leaking from the nipple is that you're pregnant or currently breastfeeding, as this can cause a milky discharge to come from both nipples.

In pregnancy, the breasts may start to produce milk from as early as the second trimester, and some women continue to produce milk up to two years after stopping breastfeeding (NHS, 2015e).

Non-pregnancy causes

If pregnancy has been ruled out, it's likely that your nipple discharge is caused by one of the following conditions -

- **duct papilloma** - a harmless growth inside your breast duct (the tube that carries milk from the gland to the nipple) that typically causes bloodstained discharge from one breast,
- **duct ectasia** - a harmless, age-related breast change that can result in a cheesy or discoloured discharge from both breasts,
- **breast or nipple abscess** - a painful collection of pus forming in the breast tissue or around the nipple, usually as a result of bacterial infection (NHS, 2015e).

These conditions are explained in more detail below, to give you a better idea of whether you may be affected. However, it's important to see your GP for a proper diagnosis so a more serious cause such as breast cancer can be ruled out (NHS, 2015e).

Duct papilloma

If the discharge is bloodstained and from a single breast, the cause is likely to be a duct papilloma.

A papilloma is a harmless wart-like growth, usually about 1–2cm in size, found inside one of the breast ducts. The papilloma is usually just behind the nipple and can cause fluid or blood to seep out of the nipple.

You'll usually just have one papilloma, and a simple procedure to remove it will often be recommended.

Although the discharge may be alarming, rest assured that papilloma is not cancer and is very unlikely to turn into cancer (NHS, 2015e).

Duct ectasia

If the discharge is brown, green or cheesy, it's likely you have a harmless condition called duct ectasia.

Duct ectasia tends to affect women approaching the menopause. As the breasts age, the milk ducts behind the nipple get shorter and wider, and may produce a discharge. This is a normal, age-related change and nothing to worry about.

A lump can sometimes be felt behind the nipple, which is just scar tissue or perhaps a dilated duct, and the nipple sometimes becomes inverted.

This condition is harmless and tends to clear up without treatment. It doesn't increase your risk of developing breast cancer in the future. However, it's important to go back to your GP if you develop any new symptoms (NHS, 2015e).

An abscess

If the discharge contains pus, the cause will probably be a breast abscess or abscess around the nipple. The surrounding skin will be red, warm and swollen.

Breast abscesses are often linked to mastitis - a condition that causes breast pain and swelling (inflammation) and usually affects women who are breastfeeding.

If you have been to see your GP because of mastitis, you may already have been given antibiotics. If your breast is still hard, red and painful, your GP should refer you to a specialist to check for a breast abscess.

If the diagnosis is confirmed, a simple procedure to drain the abscess may be recommended (NHS, 2015e).

More unusual causes

Less common causes of nipple discharge are -

- the contraceptive pill - discharge can be a temporary side-effect of starting the pill (some women also get breast tenderness and breast enlargement),
- fluctuating hormones from puberty or the menopause,
- previous breastfeeding - some women continue to produce milk up to two years after they've stopped breastfeeding,
- stimulation of the nipples - for example, through sex,
- medication that causes raised levels of the milk-producing hormone prolactin - this includes SSRI antidepressants and tranquillisers,
- a type of non-cancerous brain tumour called a prolactinoma, which causes raised levels of prolactin,
- a hormone problem - such as an underactive thyroid gland or Cushing's syndrome,
- a clogged milk duct called a galactocele - which is usually associated with childbirth and can cause a milky or creamy discharge along with a painless lump,
- an early form of breast cancer called carcinoma in situ, which is found inside the milk ducts and hasn't yet spread (it's usually picked up during breast cancer screening) (NHS, 2015e).

Is it breast cancer?

In the vast majority of cases, nipple discharge isn't a sign of breast cancer. However, discharge from the breast can very occasionally be a symptom of cancer, so it's not something you should ever ignore (NHS, 2015e).

Nipple discharge is more likely to be a symptom of cancer if -

- you also have a breast lump or changes to the skin of your breast,
- the discharge is bloody and only comes from one nipple,
- the discharge occurs without any pressure on your breast or nipple,
- you're over 50 (NHS, 2015e).

See your GP if you're worried you might have breast cancer. While this is unlikely, it's best to be sure by getting a proper diagnosis (NHS, 2015e). See also Female breast cancer.

Palliative care

Palliative care is a specialised form of medicine that aims to enhance the quality of life of patients and their families who are faced with serious illness. It focuses on increasing comfort through prevention and treatment of distressing symptoms. In addition to expert symptom management, palliative care focuses on clear communication, advance planning, and coordination of care.

Palliative care encompasses the whole self, caring for the physical, emotional, and spiritual needs of patients and their families.

It provides relief from pain and other symptoms of illness such as fatigue, nausea, shortness of breath, and loss of appetite. The goal is to prevent and relieve these symptoms so you can get on with daily life (Morrow, 2015).

Palliative care is care given to improve the quality of life of patients who have a serious or life-threatening disease, such as cancer. The goal of palliative care is to prevent or treat, as early as possible, the symptoms and side-effects of the disease and its treatment, in addition to the related psychological, social, and spiritual problems. The goal is not to cure. Palliative care is also called comfort care, supportive care, and symptom management (NCI, 2010).

The principles of palliative care

The basis of palliative care revolves around what the patient determines to be quality of life. When developing a palliative plan, a team of caregivers will help you to meet your care needs while considering your cultural and personal beliefs, relationships and personal situation.

- Death is a natural stage of life.
- Care does not speed up or delay death.
- Medical procedures and tests are kept to a minimum, unless they are expected to provide relief of your symptoms.
- Care provides you and your family with skills that will help you to cope with your illness and death.
- You know best if pain or other symptoms are being adequately relieved.
- Pain and symptom-relief medications are dosed to provide you with the best results without unacceptable side-effects.
- Food and fluids are not forced or artificially provided. If you want to eat or drink, you can.
- It helps you to live your life as actively as you want until your death.
- It emphasises advanced care planning so your wishes continue to be met if you are no longer able to communicate them (Raymaakers, 2016).

When is palliative care used in cancer care?

Palliative care is given throughout a patient's experience with cancer. It should begin at diagnosis and continue through treatment, follow-up care, and the end of life (NCI, 2010).

What is the difference between palliative care and hospice care?

Although hospice care has the same principles of comfort and support, palliative care is offered earlier in the disease process. As noted above, a person's cancer treatment continues to be administered and assessed while he or she is receiving palliative care. Hospice care is a form of palliative care that is given to a person when cancer therapies are no longer controlling the disease. It focuses on caring, not curing. When a person has a terminal diagnosis (usually defined as having a life expectancy of 6 months or less) and is approaching the end of life, he or she might be eligible to receive hospice care (NCI, 2010).

Where do cancer patients receive palliative care?

Cancer centres and hospitals often have palliative care specialists on staff. They may also have a palliative care team that monitors and attends to patient and family needs. Cancer centres may also have programmes or clinics that address specific palliative care issues, such as lymphoedema, pain management, sexual functioning, or psychosocial issues.

A patient may also receive palliative care at home, either under a doctor's care or through a hospice, or at a facility that offers long-term care (NCI, 2010).

What issues are addressed in palliative care?

Palliative care can address a broad range of issues, integrating an individual's specific needs into care. The physical and emotional effects of cancer and its treatment may be very different from person to person. For example, differences in age, cultural background, or support systems may result in very different palliative care needs (NCI, 2010).

Comprehensive palliative care will take the following issues into account for each patient -

Physical Common physical symptoms include pain, fatigue, loss of appetite, nausea, vomiting, shortness of breath, and insomnia. Many of these can be relieved with medicines or by using other methods, such as nutrition therapy [71] as taught by dieticians, physical therapy [72] as taught by physiotherapists, or deep breathing techniques. Also, chemotherapy, radiotherapy, or surgery may be used to shrink tumours that are causing pain and other problems (NCI, 2010).

Emotional and coping Palliative care specialists can provide resources to help patients and families deal with the emotions that come with a cancer diagnosis and cancer treatment. Depression, anxiety, and fear are only a few of the concerns that can be addressed through palliative care. Experts may provide counselling, recommend support groups, hold family meetings, or make referrals to mental health professionals (NCI, 2010).

Practical Cancer patients may have financial and legal worries, employment concerns, and concerns about completing advance directives. To ease the burden, the palliative care team may assist in coordinating the appropriate services. For example, the team may direct patients and families to resources that can help with financial counselling, understanding medical forms or legal advice, or identifying local and national resources, such as transportation or housing agencies (NCI, 2010).

Spiritual With a cancer diagnosis, patients and families often look more deeply for meaning in their lives. Some find the disease brings them more faith, whereas others question their faith as they struggle to understand why cancer happened to them. An expert in palliative care can help people explore their beliefs and values so that they can find a sense of peace or reach a point of acceptance that is appropriate for their situation (NCI, 2010).

Palliative Care vs Hospice Care

The terms ”palliative care” and ”hospice care” cannot be used interchangeably. Hospice care is only one type of palliative care that can be provided in the last six

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[71] Treatment based on nutrition. It includes checking a person’s nutrition status, and giving the right foods or nutrients to treat conditions such as those caused by diabetes, heart disease, and cancer. It may involve simple changes in a person’s diet, or intravenous or tube feeding. Nutrition therapy may help patients recover more quickly and spend less time in the hospital. Also called medical nutrition therapy

[72] The use of exercises and physical activities to help condition muscles and restore strength and movement. For example, physical therapy can be used to restore arm and shoulder movement and build back strength after breast cancer surgery

months of life. Traditional palliative care can be offered any time in the course of an illness and ideally should begin at the time of diagnosis (Morrow, 2015).

How is palliative care given at the end of life?

Making the transition from curative treatment to end-of-life care is a key part of palliative care. A palliative care team can help patients and their loved ones prepare for physical changes that may occur near the end of life and address appropriate symptom management for this stage of care. The team can also help patients cope with the different thoughts and emotional issues that arise, such as worries about leaving loved ones behind, reflections about their legacy and relationships, or reaching closure with their life. In addition, palliative care can support family members and loved ones emotionally and with issues such as when to withdraw cancer therapy, grief counselling, and transition to hospice care (NCI, 2010).

How do people talk about palliative care or decide what they need?

Patients and their loved ones should ask their doctor about palliative care. In addition to discussing their needs for symptom relief and emotional support, patients and their families should consider the amount of communication they need. What people want to know about their diagnosis and care varies with each person. It's important for patients to tell their doctor about what they want to know, how much information they want, and when they want to receive it (NCI, 2010).

Is there any research that shows palliative care is beneficial?

Yes. Research shows that palliative care and its many components are beneficial to patient and family health and well-being. A number of studies in recent years have shown that patients who have their symptoms controlled and are able to communicate their emotional needs have a better experience with their medical care. Their quality of life and physical symptoms improve.

In addition, the Institute of Medicine 2007 report Cancer Care for the Whole Patient cites many studies that show patients are less able to adhere to their treatment and manage their illness and health when physical and emotional problems are present (NCI, 2010).

Palliative chemotherapy

The primary goal of chemotherapy is to shrink tumours and stop the growth of cancer. If it's been determined that cancer cannot be cured, chemotherapy may still be beneficial to shrink tumour size enough to alleviate the physical symptoms of cancer and to slow the progress of cancer enough to extend life.

The idea of palliative chemotherapy [73] is relatively new. It's only in recent years that the alleviation of symptoms has become an important component of clinical trials for cancer research. The use of chemotherapy in advanced, late-stage cancer remains a controversial subject in the medical community and patients and their loved ones are often stuck in the middle, wondering whether to pursue aggressive treatment or focus on comfort measures only. It's important to understand the benefits and risks of palliative chemotherapy.

For palliative purposes, most oncologists prefer to try the treatment with the least risk of side-effects that would negatively impact quality of life. This means that hormone therapy may be tried before toxic chemotherapies (Morrow, 2016a).

Non-curative chemotherapy for prolonging life and reducing symptoms is called palliative chemotherapy. Palliative chemotherapy is often given to patients with advanced cancer in hopes of making patients more comfortable toward the end of life. It is sometimes given in combination with other cancer treatments.

The type of palliative chemotherapy a patient receives depends on the patient's type of cancer and prognosis. Palliative chemotherapy is usually for patients with non-small-cell lung cancer, pancreatic cancer, or colon cancer (Grack, 2013).

Benefits and Risks of Palliative Chemotherapy

Chemotherapy, no matter what its intended purpose is, isn't risk-free. It's also notorious for causing distressing side-effects. The risks versus potential benefits and the affect on quality of life must be considered.

The best indicator of risk versus benefit is your performance status (see table below). If your performance status is restricted, you will be more likely to develop serious side-effects, such as chemotherapy toxicity.

Tumour size and sites of metastasis, meaning sites that the primary cancer has spread to, should also be considered. Larger tumours and cancers that have multiple sites of metastasis will be less likely to respond to palliative chemotherapy.

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[73] chemotherapy for prolonging life and reducing symptoms

It's also important to consider how palliative chemotherapy will affect your quality of life. The components of quality of life may look slightly different from person to person but typically include physical well-being as well as emotional, social, and spiritual well-being. If the chances of palliative chemotherapy providing you with increased physical comfort are good, you have a reasonably high functioning level and a strong support system for your emotional and spiritual health, you might decide to proceed with the treatment. If, however, the chances of developing serious side-effects are high, the burden of ongoing treatments and tests is heavy, and you are emotionally and spiritually drained, the likelihood of palliative chemotherapy improving your quality of life is probably poor (Morrow, 2016a).

Score	Status
100	Normal: no complaints, no evidence of disease
90	Able to carry on normal activity; minor symptoms
80	Normal activity with effort; some symptoms
70	Cares for self; unable to carry on normal activities
60	Requires occasional assistance; cares for most needs
50	Requires considerable assistance and frequent care
40	Disabled: requires special care and assistance
30	Severely disabled: hospitalized but death not imminent
20	Very sick: active supportive care needed
10	Moribund: fatal processes are progressing rapidly
0	Death (Karnofsky et al., 1948)

Table 9.1: Karnofsky Performance Scale

Palliative radiotherapy

Palliative radiotherapy [74] is one form of palliative therapy, treatment for the symptoms of a medical problem that doesn't treat the problem itself. It's considered comfort care and is mainly intended to improve a patient's quality of life.

People who have cancer may receive palliative radiotherapy - not to cure or even treat the cancer but, instead, to relieve the symptoms, especially pain, that it's causing.

Typically the radiation is used to shrink a tumour or tumours that are causing the symptoms (Morrow, 2016b).

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[74] radiotherapy treatment to shrink a cancer, slow down its growth, or control symptoms

How can palliative radiotherapy help people with cancer?

Some common reasons for considering palliative radiotherapy for people with cancer include -

- **Pain relief** - palliative radiotherapy is especially helpful in treating pain caused by tumours that have invaded bone. It can also relieve pain caused by tumours pressing on nerves.
- **Spinal cord compression** - a serious and painful condition, spinal cord compression is caused by tumours pressing on the spine and spinal cord. Palliative radiotherapy may bring welcome relief.
- **Superior vena cava obstruction** - tumour obstruction of the superior vena cava (the second-largest vein in the body, carrying blood to the heart from the upper body) causes swelling in the face, shortness of breath, and a feeling of fullness in the head. Shrinking of the tumour using palliative radiotherapy may improve the patient's blood flow.
- **Bleeding** - some tumours can cause troublesome bleeding. Haemoptysis, or coughing up blood, can be caused by tumours in the airway. Bleeding due to tumours in the rectum, vagina, or urinary tract may also be uncomfortable enough to treat with palliative radiotherapy.
- **Obstruction of the airway or oesophagus** - tumours that are obstructing the airway or oesophagus, making breathing or eating difficult, are often treated with palliative radiotherapy (Morrow, 2016b).

Types of palliative radiotherapy

There are three ways to deliver radiotherapy, including palliative radiotherapy -

- **External-beam radiation therapy** - this type of radiation is delivered to the outside of the body by a special radiation machine.
- **Internal radiation therapy** - internal radiation is delivered by radioactive material placed inside the body near the tumour.
- **Systemic radiation therapy** - systemic radiation is delivered throughout the body via the bloodstream. An example of this is radioactive iodine that is used to treat certain types of thyroid cancers (Morrow, 2016b).

Side-effects of palliative radiotherapy

Radiotherapy effectively kills tumour cells but unfortunately affects healthy cells, too. Destruction of healthy cells may cause side-effects. Some common side-effects of radiotherapy include -

- weakness,
- fatigue,
- nausea,

- diarrhoea,
- radiation cystitis (irritation and pain in the bladder),
- skin burns, irritation, and infections,
- damage and infections in the lining of the mouth,
- fever (Morrow, 2016b).

Expert palliative care by the cancer team can help with management of uncomfortable side-effects.

Most side-effects of palliative radiotherapy will resolve within weeks of the last radiation treatment (Morrow, 2016b).

Quality of life

Quality of life is an internationally validated framework developed by Dr. Robert Schalock. This is represented by eight domains that provide an indication of an individual's quality of life in three broad areas -

- Independence,
- Social participation,
- Well-being (communitylivingbc, 2010).

The eight domains are -

- **emotional well-being** - contentment, self-concept, lack of stress,
- **interpersonal relations** - interactions, relationships, supports,
- **material well-being** - financial status, employment, housing,
- **personal development** - education, personal competence, performance,
- **physical well-being** - health and health care, activities of daily living, leisure,
- **self-determination** - autonomy / personal control, personal goals, choices,
- **social inclusion** - community integration and participation, roles, supports,
- **rights** - legal, human (respect, dignity, equality) (communitylivingbc, 2010).

Vaginal discharge

It's normal and healthy to produce a clear or white discharge from your vagina. This mucus is produced naturally from the neck of the womb, known as the cervix.

The amount of vaginal discharge varies throughout your menstrual cycle (brown discharge is usually the end of your period) and most pregnant women will get a ”pregnancy discharge”.
Healthy discharge doesn’t have a strong smell or colour. You may feel an uncomfortable wetness, but you shouldn’t have any itching or soreness around your vagina (NHS, 2014f).

How do I know if my discharge is unhealthy?

Any sudden change to your discharge may indicate a vaginal infection. You should be aware of how your discharge naturally varies throughout your cycle and what isn’t normal, but obvious warning signs of infection are -

- a change in colour or consistency,
- a sudden bad smell,
- an unusually large amount of discharge,
- another symptom alongside the discharge, such as itching outside your vagina or pain in your pelvis or tummy,
- unexpected bleeding from the vagina (NHS, 2014f).

If you’re not sure whether your discharge is normal and are worried about it, see your GP or nurse (NHS, 2014f).

Common causes of abnormal discharge

There are many possible causes of abnormal vaginal discharge, but it’s usually a sign of infection. The infection is often caused by something that upsets the natural balance of bacteria or yeast in your vagina, such as washing inside the vagina, or it may be sexually transmitted.
The most common causes are -

- thrush - a fungal infection that commonly affects the vagina,
- bacterial vaginosis - a bacterial infection of the vagina,
- trichomoniasis - a STI caused by a tiny parasite,
- gonorrhoea or chlamydia - STIs caused by bacteria,
- genital herpes - an STI caused by the herpes simplex virus (NHS, 2014f).

The guide below may help you identify the cause of your discharge. However, it’s important to see your GP for a proper diagnosis and advice on how to treat the infection (NHS, 2014f).

Watery or white vaginal discharge with intense itchiness If your discharge is thin and watery, or thick and white (like cottage cheese), you may have thrush. This common fungal infection causes intense itchiness and sore-

ness around your vagina. The discharge may smell slightly yeasty, but doesn't have a strong smell.
Almost all women get thrush from time to time and it's not sexually transmitted. It's easily treated with antifungal medicine, which can be bought over the counter from your pharmacist (NHS, 2014f).

White or grey fishy-smelling discharge If your vaginal discharge is grey or develops a strong fishy smell, particularly after sexual intercourse, you could have bacterial vaginosis (BV). BV is an imbalance in the normal bacteria found in your vagina. It doesn't usually cause itching or irritation.
Like thrush, BV is very common and isn't sexually transmitted. It's easily treated with antibiotics. See your GP for a prescription (NHS, 2014f).

Green, yellow or frothy discharge Trichomoniasis is a common STI caused by a tiny parasite. It can make your vaginal discharge frothy, yellow or green. You may have a lot of discharge, which may also have an unpleasant fishy smell. Other possible symptoms are soreness, swelling and itching around the vagina, and pain when passing urine.
Trichomoniasis is easily treated with an antibiotic called metronidazole, which your GP will prescribe. If you have trichomoniasis, visit a local genitourinary medicine clinic (GUM) or sexual health clinic as it can exist alongside other STIs (NHS, 2014f).

Abnormal discharge with pain or bleeding See your GP or go to a GUM as soon as possible if your vaginal discharge is abnormal and you have -

- pain in your pelvis,
- pain when you urinate,
- bleeding between periods or after sex (NHS, 2014f).

You may have chlamydia or gonorrhoea (both STIs). Gonorrhoea can make your discharge turn green, although often the pain or bleeding are more noticeable. Both conditions are treated with antibiotics.
Untreated gonorrhoea or chlamydia may spread upwards and lead to pelvic inflammatory disease, a serious infection of the womb, fallopian tubes or ovaries (NHS, 2014f).

Abnormal discharge with blisters around the genitals Genital herpes can cause painful, red blisters or sores to appear around your genitals, as well as an abnormal vaginal discharge. See your GP or go to a GUM clinic as soon as possible. You may be offered a course of antiviral tablets, which stop the herpes virus multiplying, but the symptoms may have a tendency to return (NHS, 2014f).

Young girls and post-menopausal women

It's unusual for young girls to have abnormal vaginal discharge before they've gone through puberty. If this happens, they should see a GP. A common cause is a type of vulvitis (inflammation of the vulval area), caused by a streptococcal infection (NHS, 2014f).

Abnormal discharge is also unusual in older women. If you've gone through the menopause and suddenly notice an abnormal vaginal discharge, see your doctor as soon as possible. Possible causes include -

- a STI,
- cervical polyps - non-cancerous growths in the womb or lining of the cervix (neck of the womb),
- an intrauterine device (IUD) (NHS, 2014f).

It's also important to rule out cervical cancer or endometrial cancer (NHS, 2014f).

Cleaning your vagina

The vagina is self-cleansing, so there is no need to wash inside it (called douching). Douching can upset the natural balance of bacteria and fungi in your vagina and lead to thrush or bacterial vaginosis.

Vaginal soreness and abnormal vaginal discharge can also be caused by overusing perfumed soaps, bubble baths and shower gels. Never clean your vagina with anything strongly perfumed. Use a mild soap and warm water to gently wash around your genitals (NHS, 2014f).

Chapter 10

Recent research

Alcohol and cancer

There is strong evidence that alcohol causes cancer at seven sites in the body and probably others. These sites and cancers are the oropharynx, larynx, oesophagus, liver, colon, rectum and breast. Current estimates suggest that alcohol-attributable cancers at these sites make up 5.8% of all cancer deaths world-wide. Confirmation of specific biological mechanisms by which alcohol increases the incidence of each type of cancer is not required to infer that alcohol is a cause (Connor, 2016).

Glossary

A

angina chest pain that occurs when the blood supply to the muscles of the heart is restricted 155, 419

antidepressant medication a type of medication used to treat clinical depression or prevent it recurring 294, 389

B

back pain a common problem that affects most people at some point in their life 293, 428, 462

biopsies a medical procedure that involves taking a small sample of body tissue so it can be examined under a microscope 304, 335, 354, 410, 465, 469

biopsy a medical procedure that involves taking a small sample of body tissue so it can be examined under a microscope 10, 273, 285, 305, 319, 334, 335, 343, 353, 366, 367, 369, 380, 386, 410, 414, 415, 432, 444, 445, 459, 464, 466, 468

blood clots known as venous thromboembolism (VTE) and is a serious, potentially fatal, medical condition 181, 311, 340, 383, 390, 426, 448

blood tests these have a wide range of uses and are one of the most common types of medical test . . . 170, 223, 264, 289, 367, 386, 421, 435, 445, 451, 459

body mass index it is a measure of body fat based on your weight in relation to your height, and applies to most adult men and women aged 20 and over 316

C

catheter a flexible tube used to drain the bladder and collect urine . . . 283, 288, 289, 295

cervix the lowermost part of the uterus, where it connects with the vaginal wall 375

chemotherapy a type of cancer treatment, with medicine used to kill cancer cells. It kills the cancer cells by damaging them, so they can't reproduce and spread 16, 21, 43, 48, 65, 66, 75, 76, 88, 106, 139, 145, 149, 150, 153–156, 174, 175, 193, 195, 197, 198, 200–204, 206–210, 212, 225, 226, 247, 248, 258, 259, 272, 283, 285, 287–290, 292, 293, 307, 312–314, 321, 323, 338, 339, 342, 343, 355, 357, 358, 367, 371, 382, 384–386, 390, 392, 393, 412, 413, 415–417, 419, 427, 433–437, 446–449, 460, 467, 473–475, 483, 485

chest infections an infection of the lungs or airways 331

chlamydia a bacterial infection 379, 489, 490

clinical trials these compare the effects - both wanted and unwanted - of two or more treatments 145, 163, 197, 258, 259, 263, 264, 266–268, 272, 277, 278, 323, 371, 373, 419, 420, 427, 435, 436, 439, 450, 473, 485

cognitive behavioural therapy it is a talking therapy that can help you manage your problems by changing the way you think and behave 79, 189, 190, 294, 389

colostomy a surgical procedure to divert one end of the large intestine (colon) through an opening in the abdominal wall (tummy) 64, 66, 202, 310, 384

colposcopy a procedure to find out whether there are abnormal cells on or in a woman's cervix or vagina 380

complementary therapy When a non-mainstream practice is used together with conventional, western-style, medicine 48, 175, 177–180, 185, 194, 249, 420

computerised tomography (CT) uses X-rays and a computer to create detailed images of the inside of the body 305

computerised tomography (CT) scan uses X-rays and a computer to create detailed images of the inside of the body 319, 334, 344, 354, 367, 380, 445

computerised tomography (CT) scanner uses X-rays and a computer to create detailed images of the inside of the body 305

consent the principle that a person must give permission before they receive any type of medical treatment, test or examination. This must be done on the basis of an explanation by a clinician 144, 220, 269–271, 373, 420, 436, 450

contraceptive pill it contains artificial versions of the female hormones oestrogen and progesterone, which women produce naturally in their ovaries 401, 430, 439, 480

coughing up blood small amounts of bright red blood, or frothy blood-streaked sputum (saliva and phlegm) 331, 344

Crohn’s disease a long-term condition that causes inflammation of the lining of the digestive system 302

cystoscopy a medical procedure used to examine the inside of the bladder using an instrument called a cystoscope 284, 285, 288, 289, 291, 319, 464

D

digital rectal examination (DRE) a type of physical examination during which a doctor or nurse inserts a finger into your rectum (back passage) to feel for abnormalities 303

dysphagia swallowing difficulties 342, 349, 358

E

early menopause when a woman stops having periods and is no longer able to get pregnant naturally 66, 283, 385, 387, 402, 417, 422, 438, 452

endometriosis a common condition in which small pieces of the womb lining are found outside the womb 430, 431, 441

F

fatigue extreme tiredness 42, 151–164, 166–171, 180, 182, 183, 312, 313, 315, 323, 326, 342, 343, 357, 372, 385, 416, 431, 449, 487

fibroids non-cancerous growths that develop in or around the womb (uterus) 431, 441

G

general anaesthetic a state of controlled unconsciousness caused by medications sending you to sleep in a controlled way 74, 223, 285, 288, 291, 335, 357, 366, 368, 369, 371, 445, 472

gum disease a very common condition where the gums become swollen, sore or infected 350, 352

H

hormone replacement therapy a treatment used to relieve symptoms of the menopause. It replaces female hormones that are at a lower level as you approach the menopause 387, 401, 405, 430, 437, 442

hospice care based on the same principles as palliative care. Hospice care is initiated at the very end of life, when death is expected within six months. Hospice care is very often provided in the home, on specialised hospital hospice units or in free-standing hospice facilities 392, 482–484

hot flushes a sudden feeling of heat which seems to come from nowhere and spreads through your body 111, 194, 387, 417, 418, 422, 426, 472

I

ileostomy where the small bowel (small intestine) is diverted through an opening in the tummy (abdomen) . . . 66, 202, 310

in-vitro fertilisation (IVF) one of several techniques available to help people with fertility problems have a baby . . . 470

infertility when a couple cannot get pregnant (conceive), despite having regular unprotected sex . . . 64–66, 290, 312, 385, 430

iron deficiency anaemia a condition where a lack of iron in the body leads to a reduction in the number of red blood cells . . . 300

irritable bowel syndrome a common, long-term condition of the digestive system. It can cause bouts of stomach cramps, bloating, diarrhoea and/or constipation . . . 431

L

laparoscopy a type of surgical procedure that allows a surgeon to access the inside of the abdomen (tummy) and pelvis without having to make large incisions in the skin . . . 432, 435

laxative a type of medicine that can help you empty your bowels if you are having trouble going to the toilet . . . 207, 305

local anaesthetic involves numbing an area of the body using a type of medication called a local anaesthetic . 75, 220, 223, 248, 284, 319, 334, 335, 353, 366, 368, 371, 380, 410, 464

lymphoedema excess fluid build-up in your arm caused by blockage of the lymph nodes under your arm 66, 73, 75, 76, 193, 369, 383, 388, 416, 422, 482

M

magnetic resonance imaging (MRI) scan a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body . . . 306, 319, 354, 367, 381, 445

mastectomy an operation to remove the breast . 74, 78, 106, 402, 414, 415, 422, 425, 426

mouth ulcers painful sores that appear in the mouth . . 313, 327, 343, 356, 357, 386

N

nutrition therapy Treatment based on nutrition. It includes checking a person's nutrition status, and giving the right foods or nutrients to treat conditions such as those caused by diabetes, heart disease, and cancer. It may involve simple changes in a person's diet, or intravenous or tube feeding. Nutrition therapy may help patients recover more quickly and spend less time in the hospital. Also called medical nutrition therapy . . . 483

O

obese a person who's very overweight, with a lot of body fat. Generally, men with a waist circumference of 94cm (37in) or more and women with a waist circumference of 80cm (about 31.5in) or more 302, 316, 328, 407, 424, 439, 442, 443

occupational therapist a person who provides support to people whose health prevents them doing the activities that matter to them 74, 162–164, 234–236, 251, 433, 467

P

palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments . . 137, 140, 148, 163, 193, 234–237, 250, 252, 256, 293, 346, 347, 373, 382, 391, 438, 453, 474, 480–484, 488

palliative chemotherapy chemotherapy for prolonging life and reducing symptoms 485, 486

palliative radiotherapy radiotherapy treatment to shrink a cancer, slow down its growth, or control symptoms 486–488

pelvic inflammatory disease an infection of the female upper genital tract, including the womb, fallopian tubes and ovaries 431, 490

periods the part of the menstrual cycle when a woman bleeds from her vagina for a few days. In most women this happens every 28 days or so . . 17, 96, 327, 375, 376, 387, 407, 417, 418, 426, 440, 443, 490

physical therapy The use of exercises and physical activities to help condition muscles and restore strength and movement. For example, physical therapy can be used to restore arm and shoulder movement and build back strength after breast cancer surgery 483

physiotherapist a person who helps to restore movement and function when someone is affected by injury, illness or disability. It can also help to reduce your risk of injury or illness in the future . . 57, 74, 159, 161, 176, 180, 193, 234–236, 250, 251, 340, 345, 433, 434, 448, 467

polyps small growths on the inner lining of the colon (large bowel) or rectum. They are common, affecting 15%–20% of the UK population, and don't usually cause symptoms 301, 303, 441, 491

positive emission tomography (PET) scan a specialised scan, where a mildly radioactive substance is injected into your veins so the cancerous tissue shows up more clearly; it's often combined with a CT scan and is used to see if the cancer has spread, or to check how well a person is responding to treatment . . . 381

positron emission tomography scans are used to produce detailed three-dimensional images of the inside of the body . . . 354

positron emission tomography-computerised tomography scans are used to produce detailed three-dimensional images of the inside of the body . . . 334, 367

Q

quality of life The individuals's ability to enjoy normal life activities. Quality of life is an important consideration in medical care. Some medical treatments can seriously impair quality of life without providing appreciable benefit, whereas others greatly enhance quality of life 8, 48, 139, 146–149, 153, 173, 176, 186, 196, 197, 200, 258–260, 275, 373, 474, 480, 481, 484–486, 488

R

radiotherapy a treatment involving the use of high-energy radiation. It's commonly used to treat cancer 21, 48, 65, 66, 140, 145, 149, 150, 153–155, 174, 175, 181, 195, 197, 198, 200–211, 215, 217, 225, 226, 247–249, 259, 274, 283, 287, 290–293, 296, 307, 311, 312, 321, 323, 338–344, 355–359, 365, 367, 370, 371, 382–388, 392, 412, 413, 415–417, 422, 436, 446–449, 451, 452, 460, 467, 470, 471, 473, 475, 483, 487

S

sepsis a potentially life-threatening condition, triggered by an infection or injury . . . 449

T

tooth decay occurs when acid is produced from plaque, which builds up on your teeth . . . 350, 352

U

ulcerative colitis a long-term condition, where the colon and rectum become inflamed . . . 302, 303

ulcers painful sores that appear in the mouth . . . 233, 349

ultrasound scan this is sometimes called a sonogram, and is a procedure that uses high-frequency sound waves to create an image of part of the inside of the body . . . 315, 318, 409, 410, 430, 432, 435, 444, 464

urethra the tube through which you urinate 284, 289, 295, 461, 472

urinary incontinence the unintentional passing of urine . . 295, 376, 383, 469, 471, 473, 476

X

X-ray a quick and painless procedure commonly used to produce images of the inside of the body . 15, 217, 220, 223, 285, 319, 323, 333, 334, 337, 354, 358, 366, 409, 410, 421, 432, 436, 445

Acronyms

B

BPH benign prostatic hyperplasia 461–463

C

CRF cancer-related fatigue 152, 153

CT computerised tomography . . 285, 289, 291, 305, 306, 319, 334, 335, 380, 432, 435, 465

D

DRE digital rectal examination 463, 464

F

FAP familial adenomatous polyposis 303

G

GP General Practitioner, a community-based doctor 16, 18–20, 25, 28, 33, 41, 43, 47, 55, 58, 59, 69, 71, 72, 92, 93, 95, 100, 103, 104, 107, 110, 114, 119, 120, 124–126, 135, 137–139, 141–143, 148, 149, 160, 161, 163, 168, 169, 178, 180, 185, 188, 190, 196, 202, 206, 209, 213, 217, 224, 234–237, 248, 250, 252, 255, 256, 265, 266, 270, 271, 276, 277, 280, 281, 284, 294, 297, 300, 301, 303, 304, 313, 315, 318, 329, 330, 333, 343, 346–348, 350, 352, 355, 363, 365, 366, 375–377, 379, 389, 393–395, 397–400, 404, 408, 409, 420, 421, 424, 428–431, 436, 437, 439, 440, 443, 444, 452, 457, 462–464, 466, 474–476, 478–480, 489–491

GUM genitourinary medicine clinic 490

H

HNPCC hereditary non-psolyposis colorectal cancer 303

HPV human papilloma virus 104, 351, 352, 377–379, 393, 394

M

MDT multidisciplinary team - usually consisting of an clinical oncologist, nurse, physiotherapist, occupational therapist, social worker, dietitian, and sometimes a speech and language therapist, a pathologist, a radiologist, or others 141, 287, 291–295, 321, 381, 385, 386, 412, 436, 467, 474

MRI magentic resonance imaging . . . 285, 289, 401, 410, 411, 432, 464–466, 469

P

PSA prostate-specific antigen - a marker for prostate cancer. The higher the number, the greater the chance of prostate cancer, but this is not definite 401, 463–467, 469

S

STI sexually transmitted infection 379, 489–491

T

TURBT transurethral resection of a bladder tumour 285, 288, 289

Bibliography

ACS (2016) *Cancer-related fatigue* URL: http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/fatigue/feeling-tired-vs-cancer-related-fatigue (cit. on pp. 171–174)

BOWELCANCERUK (2016) *Symptoms* URL: https://www.bowelcanceruk.org.uk/symptoms/ (cit. on p. 299)

Bower, J.E. et al. (2006) "Fatigue in long-term breast carcinoma survivors: a longitudinal investigation" in: *Cancer* 106.4, pp. 751–758 DOI: http://dx.doi.org/10.1002/cncr.21671 URL: http://www.ncbi.nlm.nih.gov/pubmed/16400678 (cit. on p. 173)

BREASTCANCERCARE (2014) *Signs and symptoms of breast cancer* URL: https://www.breastcancercare.org.uk/information-support/have-i-got-breast-cancer/signs-symptoms-breast-cancer (cit. on pp. 395–397)

BREASTCANCERNOW (2016) *What are the signs and symptoms of breast cancer?* URL: http://breastcancernow.org/about-breast-cancer/what-are-the-signs-and-symptoms-of-breast-cancer (cit. on pp. 395–396)

CANCERRESEARCHUK (2015a) *Bowel cancer symptoms* URL: http://www.cancerresearchuk.org/about-cancer/type/bowel-cancer/about/bowel-cancer-symptoms (cit. on p. 299)

— (2015b) *Types of melanoma* URL: http://www.cancerresearchuk.org/about-cancer/type/melanoma/about/types-of-melanoma (cit. on pp. 361–363)

— (2016a) *Types of ovarian cancer* URL: http://www.cancerresearchuk.org/about-cancer/type/ovarian-cancer/about/types-of-ovarian-cancer (cit. on pp. 427–428)

— (2016b) *What is a side-effect?* URL: http://www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/cancer-drugs/side-effects/what-is-a-side-effect (cit. on pp. 26–27)

Cella, D. et al. (2002) "Fatigue in cancer patients compared with fatigue in the general United States population" in: *Cancer* 94.2, pp. 528–538 DOI: http://dx.

doi.org/10.1002/cncr.10245 URL: http://www.ncbi.nlm.nih.gov/pubmed/11900238 (cit. on p. 173)

COMMUNITYLIVINGBC (2010) *What is Quality of Life?* URL: http://www.communitylivingbc.ca/projects/quality-of-life/what-is-quality-of-life/ (cit. on p. 488)

Connor, J. (2016) “Alcohol consumption as a cause of cancer” in: *Addiction* Online Version of Record published before inclusion in an issue DOI: 10.1111/add.13477 URL: http://dx.doi.org/10.1111/add.13477 (cit. on p. 492)

Costantini, M., E. Mencaglia, P.D. Giulio, et al. (2000) “Cancer patients as ’experts’ in defining quality of life domains. A multicentre survey by the Italian Group for the Evaluation of Outcomes in Oncology (IGEO)” in: *Quality of Life Research* 9.2, pp. 151–159 URL: http://www.ncbi.nlm.nih.gov/pubmed/10983479 (cit. on p. 173)

Detmar, S.B. et al. (2000) “How are you feeling? Who wants to know? Patients’ and oncologists’ preferences for discussing health-related quality-of-life issues” in: *Journal of Clinical Oncology* 18.18, pp. 3295–3301 URL: http://www.ncbi.nlm.nih.gov/pubmed/10986063 (cit. on p. 173)

Fosså, S.D., A.A. Dahl, and J.H. Loge (2003) “Fatigue, anxiety, and depression in long-term survivors of testicular cancer” in: *Journal of Clinical Oncology* 21.7, pp. 1249–1254 URL: http://www.ncbi.nlm.nih.gov/pubmed/12663711 (cit. on p. 173)

Grack, A.V. (2013) *Chemotherapy: what is it, and how is it used?* URL: http://www.stopcancerfund.org/tz-general-treatment-issues/chemotherapy-what-is-it-and-how-is-it-used/ (cit. on p. 485)

Irvine, D.M. et al. (1991) “A critical appraisal of the research literature investigating fatigue in the individual with cancer” in: *Cancer Nursing* 14.4, pp. 188–199 URL: http://www.ncbi.nlm.nih.gov/pubmed/1913633 (cit. on p. 173)

Karnofsky, D. et al. (1948) “The use of nitrogen mustards in the palliative treatment of carcinoma” in: *Cancer* 1, pp. 634–656 (cit. on p. 486)

LIVEWELL (2015) *Coping with a cancer diagnosis* URL: http://www.nhs.uk/Livewell/cancer/Pages/coping-with-cancer-diagnosis.aspx (cit. on pp. 22–26)

MACMILLAN (2013a) *Difficulty sleeping* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/other-side-effects/difficulty-sleeping.html#46206 (cit. on pp. 107–114)

— (2013b) *Emotional support* URL: https://www.macmillan.org.uk/information-and-support/coping/your-emotions/someone-close-has-cancer/emotional-support.html (cit. on pp. 125–129)

— (2013c) *Emotional support if you have fatigue* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness/emotional-support-fatigue.html (cit. on pp. 168–170)

MACMILLAN (2013d) *Getting a second opinion* URL: http://www.macmillan.org.uk/information-and-support/treating/treatment-decisions/who-will-be-involved-in-my-treatment-decision/getting-a-second-opinion.html (cit. on pp. 141–145)

— (2013e) *Looking after someone with fatigue* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness/looking-after-someone-with-fatigue.html (cit. on p. 171)

— (2013f) *Managing everyday activities if you have fatigue* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness/tips-manage-everyday-activities-fatigue.html (cit. on pp. 163–167)

— (2013g) *Managing symptoms of fatigue* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness/tips-manage-symptoms-fatigue.html (cit. on pp. 160–163)

— (2013h) *Managing work if you have fatigue* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness/tips-manage-work-fatigue.html (cit. on pp. 167–168)

— (2013i) *Pain* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/pain/index.html (cit. on pp. 225–257)

— (2013j) *Talking to your doctor or nurse about fatigue* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness/talking-doctor-nurse-fatigue.html (cit. on p. 170)

— (2013k) *Tips for better rest* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness/tips-for-better-rest.html (cit. on pp. 157–159)

— (2013l) *What causes fatigue?* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness/what-causes-fatigue.html (cit. on pp. 42, 154–157)

— (2013m) *What is fatigue?* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness/what-is-fatigue.html (cit. on pp. 152–153)

— (2013n) *When to contact your healthcare team after treatment* URL: http://www.macmillan.org.uk/information-and-support/coping/your-emotions/dealing-with-your-emotions/when-to-contact-healthcare-team-after-treatment.html (cit. on pp. 60–64)

— (2013o) *Worrying about cancer coming back* URL: http://www.macmillan.org.uk/information-and-support/coping/your-emotions/dealing-with-your-emotions/worrying-about-cancer-coming-back.html (cit. on pp. 56–60)

— (2013p) *Your feelings when someone close to you has cancer* URL: https://www.macmillan.org.uk/information-and-support/coping/your-emotions/someone-close-has-cancer/your-feelings.html (cit. on pp. 114–118)

MACMILLAN (2014a) *Cancer and cell types* URL: http://www.macmillan.org.uk/information-and-support/understanding-cancer/cancer-and-cell-types.html (cit. on pp. 13–15)

— (2014b) *Cancer symptoms* URL: http://www.macmillan.org.uk/information-and-support/understanding-cancer/signs-and-symptoms.html (cit. on pp. 16–18)

— (2014c) *Choosing a complementary therapist* URL: http://www.macmillan.org.uk/information-and-support/coping/complementary-therapies/complementary-therapies-explained/choosing-a-complementary-therapist.html (cit. on pp. 179–180)

— (2014d) *Choosing a complementary therapy* URL: http://www.macmillan.org.uk/information-and-support/coping/complementary-therapies/complementary-therapies-explained/choosing-a-complementary-therapy.html (cit. on pp. 177–179)

— (2014e) *Controlling symptoms and side-effects* URL: http://www.macmillan.org.uk/information-and-support/coping/advanced-cancer/coping-with-advanced-cancer/controlling-symptoms-side-effects.html (cit. on pp. 147–149, 151)

— (2014f) *Coping with family life and work* URL: http://www.macmillan.org.uk/information-and-support/coping/your-emotions/managing-day-to-day-life/coping-family-life-work.html (cit. on pp. 90–92)

— (2014g) *Dealing with your emotions* URL: http://www.macmillan.org.uk/information-and-support/coping/your-emotions/dealing-with-your-emotions.html (cit. on pp. 34–41)

— (2014h) *Decisions About Treatment* URL: http://www.macmillan.org.uk/information-and-support/coping/advanced-cancer/coping-with-advanced-cancer/decisions-about-treatment.html (cit. on pp. 139–141, 145–147)

— (2014i) *Diet and food supplements* URL: http://www.macmillan.org.uk/information-and-support/coping/complementary-therapies/complementary-therapies-explained/diet-food-supplements.html (cit. on pp. 187–189)

— (2014j) *Difficulty swallowing* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/eating-problems/problems-chewing-swallowing.html (cit. on p. 150)

— (2014k) *Eating problems* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/eating-problems (cit. on pp. 200–217, 219–224)

— (2014l) *Energy-based therapies* URL: http://www.macmillan.org.uk/information-and-support/coping/complementary-therapies/complementary-therapies-explained/energy-based-therapies.html (cit. on pp. 181–183)

MACMILLAN (2014m) *Feeling sick* URL: http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/eating-problems/feeling-sick.html (cit. on pp. 150–151)

— (2014n) *Finding Out You Have Advanced Cancer* URL: http://www.macmillan.org.uk/information-and-support/coping/advanced-cancer/coping-with-advanced-cancer/finding-out.html (cit. on pp. 135–138)

— (2014o) *How is cancer treated?* URL: http://www.macmillan.org.uk/information-and-support/understanding-cancer/how-is-it-treated.html (cit. on pp. 15–16)

— (2014p) *How your feelings can affect you physically* URL: http://www.macmillan.org.uk/information-and-support/coping/your-emotions/managing-day-to-day-life/your-feelings-affect-physically.html (cit. on pp. 42–45)

— (2014q) *Lifestyle and diet* URL: http://www.macmillan.org.uk/information-and-support/coping/your-emotions/managing-day-to-day-life/lifestyle-and-diet.html (cit. on pp. 95–97)

— (2014r) *Massage therapies* URL: http://www.macmillan.org.uk/information-and-support/coping/complementary-therapies/complementary-therapies-explained/massage-therapies.html (cit. on pp. 180–181)

— (2014s) *Mind body therapies* URL: http://www.macmillan.org.uk/information-and-support/coping/complementary-therapies/complementary-therapies-explained/mind-body-therapies.html (cit. on pp. 183–187)

— (2014t) *Physical therapies* URL: http://www.macmillan.org.uk/information-and-support/coping/complementary-therapies/complementary-therapies-explained/physical-therapies.html (cit. on pp. 192–194)

— (2014u) *Practical preparation before and after treatment* URL: http://www.macmillan.org.uk/information-and-support/organising/practical-preparation-for-treatment/looking-after-someone (cit. on pp. 130–131)

— (2014v) *Psychological and self-help therapies* URL: http://www.macmillan.org.uk/information-and-support/coping/complementary-therapies/complementary-therapies-explained/psychological-self-help-therapies.html (cit. on pp. 189–191)

— (2014w) *Symptoms And Common Cancers* URL: http://www.macmillan.org.uk/information-and-support/understanding-cancer/symptoms-and-common-cancers.html (cit. on pp. 20–21)

— (2014x) *Therapies using herb and plant extracts* URL: http://www.macmillan.org.uk/information-and-support/coping/complementary-therapies/complementary-therapies-explained/therapies-using-herb-plant-extracts.html (cit. on pp. 194–200)

MACMILLAN (2014y) *Tip - asking for help* URL: http://www.macmillan.org.uk/information-and-support/coping/your-emotions/managing-day-to-day-life/tip-asking-for-help.html (cit. on pp. 92–95)

— (2014z) *What are complementary and alternative therapies?* URL: http://www.macmillan.org.uk/information-and-support/coping/complementary-therapies/complementary-therapies-explained/complementary-alternative-therapies.html (cit. on pp. 174–176)

— (2014aa) *What is cancer?* URL: http://www.macmillan.org.uk/information-and-support/understanding-cancer/what-is-cancer.html (cit. on pp. 10–13)

— (2014ab) *What you can do* URL: http://www.macmillan.org.uk/information-and-support/coping/your-emotions/dealing-with-your-emotions/what-you-can-do.html (cit. on pp. 45–50)

— (2014ac) *Why do cancers come back?* URL: http://www.macmillan.org.uk/information-and-support/understanding-cancer/why-do-cancers-come-back.html (cit. on pp. 21–22)

— (2014ad) *Your feelings after cancer treatment* URL: http://www.macmillan.org.uk/information-and-support/coping/your-emotions/dealing-with-your-emotions/your-feelings-after-cancer-treatment.html (cit. on pp. 51–55)

— (2014ae) *Your feelings when you're looking after someone with cancer* URL: https://www.macmillan.org.uk/information-and-support/coping/your-emotions/someone-close-has-cancer/feelings-looking-after-someone.html (cit. on pp. 119–125)

— (2014af) *Your sex life and sexuality* URL: http://www.macmillan.org.uk/information-and-support/coping/relationships/your-sex-life-and-sexuality/index.html (cit. on pp. 97–106)

— (2015a) *Benefits and risks of clinical trials* URL: http://www.macmillan.org.uk/information-and-support/treating/clinical-trials/can-and-should-i-take-part/benefits-and-risks.html (cit. on pp. 264–266)

— (2015b) *Clinical trial design* URL: http://www.macmillan.org.uk/information-and-support/treating/clinical-trials/what-does-a-clinical-trial-involve/types-of-clinical-trials.html (cit. on pp. 260–263)

— (2015c) *Finding out about current clinical trials* URL: http://www.macmillan.org.uk/information-and-support/treating/clinical-trials/can-and-should-i-take-part/finding-out-about-current-trials.html (cit. on p. 278)

— (2015d) *Getting diagnosed* URL: http://www.macmillan.org.uk/information-and-support/understanding-cancer/getting-diagnosed.html (cit. on pp. 18–20)

— (2015e) *How are clinical trials carried out?* URL: http://www.macmillan.org.uk/information-and-support/treating/clinical-trials/what-does-a-clinical-trial-involve/how-are-clinical-trials-carried-out.html (cit. on pp. 271–275)

MACMILLAN (2015f) *Safety in clinical trials* URL: http://www.macmillan.org.uk/information-and-support/treating/clinical-trials/can-and-should-i-take-part/safety-in-clinical-trials.html (cit. on pp. 267–269)

— (2015g) *Taking part in a clinical trial* URL: http://www.macmillan.org.uk/information-and-support/treating/clinical-trials/can-and-should-i-take-part/taking-part-in-a-trial.html (cit. on pp. 269–271)

— (2015h) *Understanding clinical trial results* URL: http://www.macmillan.org.uk/information-and-support/treating/clinical-trials/what-does-a-clinical-trial-involve/understanding-results.html (cit. on pp. 275–277)

— (2015i) *What does a clinical trial involve?* URL: http://www.macmillan.org.uk/information-and-support/treating/clinical-trials/what-does-a-clinical-trial-involve/what-are-clinical-trials.html (cit. on pp. 258–260)

— (2016) *Cancer and body image concerns* URL: http://www.macmillan.org.uk/information-and-support/coping/changes-to-appearance-and-body-image/body-image-after-treatment/index.html (cit. on pp. 64–90)

MAYOCLINIC (2015) *Male breast cancer* URL: http://www.mayoclinic.org/diseases-conditions/male-breast-cancer/basics/definition/con-20025972 (cit. on pp. 455–461)

MEDICINENET (2016) *Definition of Quality of life* URL: http://www.medicinenet.com/script/main/art.asp?articlekey=11815 (cit. on p. 8)

Miaskowski, C. and R.K. Portenoy (1998) “Update on the assessment and management of cancer-related fatigue” in: *Principles and Practice of Supportive Oncology Updates* 1.2, pp. 1–10 (cit. on p. 173)

Morrow, A. (2015) *Palliative Care Overview* URL: https://www.verywell.com/palliative-care-overview-1132621 (cit. on pp. 481, 484)

— (2016a) *Palliative Chemotherapy Basics* URL: https://www.verywell.com/what-is-palliative-chemotherapy-1132013 (cit. on pp. 485–486)

— (2016b) *What Is Palliative Radiation Therapy for Cancer?* URL: https://www.verywell.com/palliative-radiation-therapy-1132351 (cit. on pp. 486–488)

NCI (2010) *Palliative Care in Cancer* URL: http://www.cancer.gov/about-cancer/advanced-cancer/care-choices/palliative-care-fact-sheet (cit. on pp. 481–484)

— (2014) *Fatigue (PDQ®)–Health Professional Version* URL: http://www.cancer.gov/about-cancer/treatment/side-effects/fatigue/fatigue-hp-pdq (cit. on p. 173)

NHS (2014a) *Bowel cancer* URL: http://www.nhs.uk/conditions/Cancer-of-the-colon-rectum-or-bowel/Pages/Introduction.aspx (cit. on pp. 33, 298–314)

— (2014b) *Breast cancer* URL: http://www.nhs.uk/Conditions/Cancer-of-the-breast-female/Pages/Introduction.aspx (cit. on pp. 395–398, 404, 407–426)

— (2014c) *Breast lump* URL: http://www.nhs.uk/conditions/Breast-lump/Pages/Introduction.aspx (cit. on pp. 404–407)

NHS (2014d) *Mouth cancer* URL: http://www.nhs.uk/conditions/cancer-of-the-mouth/pages/introduction.aspx (cit. on pp. 27–28, 348–361)

— (2014e) *Skin cancer (melanoma)* URL: http://www.nhs.uk/Conditions/Malignant-melanoma/Pages/Introduction.aspx (cit. on pp. 361–373)

— (2014f) *Vaginal discharge* URL: http://www.nhs.uk/Conditions/vaginal-discharge/Pages/Introduction.aspx (cit. on pp. 489–491)

— (2015a) *Bladder cancer* URL: http://www.nhs.uk/Conditions/Cancer-of-the-bladder/Pages/Introduction.aspx (cit. on pp. 280–298)

— (2015b) *Cervical cancer* URL: http://www.nhs.uk/Conditions/Cancer-of-the-cervix/Pages/Introduction.aspx (cit. on pp. 375–394)

— (2015c) *Kidney cancer* URL: http://www.nhs.uk/Conditions/Cancer-of-the-kidney/Pages/Introduction.aspx (cit. on pp. 314–330)

— (2015d) *Lung cancer* URL: http://www.nhs.uk/conditions/cancer-of-the-lung/Pages/Introduction.aspx (cit. on pp. 330–348)

— (2015e) *Nipple discharge* URL: http://www.nhs.uk/conditions/nipple-discharge/Pages/Introduction.aspx (cit. on pp. 478–480)

— (2015f) *Ovarian cancer* URL: http://www.nhs.uk/conditions/cancer-of-the-ovary/Pages/Introduction.aspx (cit. on pp. 426, 428–440)

— (2015g) *Predictive genetic tests for cancer risk genes* URL: http://www.nhs.uk/conditions/predictive-genetic-tests-cancer/Pages/Introduction.aspx (cit. on pp. 398–404)

— (2015h) *Prostate cancer* URL: http://www.nhs.uk/conditions/cancer-of-the-prostate/Pages/Introduction.aspx (cit. on pp. 461–476)

— (2015i) *Uterine cancer* URL: http://www.nhs.uk/conditions/Cancer-of-the-uterus/Pages/Introduction.aspx (cit. on pp. 440–453)

PRUE, G. et al. (2006) "Cancer-related fatigue: A critical appraisal" in: *European Journal of Cancer* 42.7, pp. 846–863 DOI: http://dx.doi.org/10.1016/j.ejca.2005.11.026 URL: http://www.ncbi.nlm.nih.gov/pubmed/16460928 (cit. on p. 173)

RAYMAAKERS, K. (2016) *What Is Palliative and Hospice Care?* URL: https://www.verywell.com/what-is-palliative-and-hospice-care-2252248 (cit. on p. 481)

UK, CANCER RESEARCH (2016) *What is cancer fatigue?* URL: http://www.cancerresearchuk.org/about-cancer/coping-with-cancer/coping-physically/fatigue/what-is-cancer-fatigue (cit. on p. 173)

VOGELZANG, N.J. et al. (1997) "Patient, caregiver, and oncologist perceptions of cancer-related fatigue: results of a tripart assessment survey. The Fatigue Coalition" in: *Seminars in Hematology* 34.3, pp. 4–12 URL: http://www.ncbi.nlm.nih.gov/pubmed/9253778 (cit. on p. 173)

WHO (1948) *WHO definition of Health* URL: http://www.who.int/about/definition/en/print.html (cit. on p. 7)

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