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Aging and Trans
Part 3
Mental Health

Thursday 18th August 2016
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Contents

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Chapter 1

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.

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Thursday 18th August 2016

I have used many different sources in this document 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

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.

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 of **aged** is *anyone over the age of 60.* Although medically 65 is the cut-off point.

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 -

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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 part is referring specifically to mental health as I'm aware that the elderly tend to have difficulties or problems with regard to their mental health. I'm referring here to dementia and its multiple secondary aspects.

As you age then mental health becomes more important as physical health starts impacting on your mental health.

I have started this using the following set of actions -

- Causes,
- Symptoms,
- Diagnosis [1],
- Treatment,
- Prognosis [2].

A short list to some of the major sections.

- Depression at page 28,
- Anxiety at page 24,
- Abuse and neglect at page 289,

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[1] the process of determining by examination the nature and circumstances of a diseased condition

[2] a forecasting of the probable course and outcome of a disease, especially of the chances of recovery

Chapter 3

README FIRST

Contents

This chapter gives a quick introduction to the most important parts of ”*Aging and trans - Part 3 - Mental Health*”. The rest of the book is basically a verbose version of this chapter. You should start by reading this chapter, as it summarises all the conditions, giving their name, symptoms, and a link to their treatment. However you should bear in mind that some things are difficult to write a few short sentences over some of the sections, so references are given to the more informative sections. For more detailed information you can read their main entries. It’s arranged in alphabetical order to make it easier to find things.

Abuse

Symptoms

Many different forms, including sexual, physical, psychological, domestic, discriminatory, financial, neglect, family.

Treatment

See Who to contact about elder abuse.

Read more

See Abuse and neglect.

Alzheimer’s disease

Most common type of dementia; accounts for an estimated 60–80% of cases (ALZ.ORG, 2016d).

Symptoms

Difficulty remembering recent conversations, names or events is often an early clinical symptom; apathy and depression [3] are also often early symptoms. Later symptoms include impaired communication, poor judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking (ALZ.ORG, 2016d).

Brain changes

Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles) as well as evidence of nerve cell damage and death in the brain (ALZ.ORG, 2016d).

Read more

See also Alzheimer's disease.

Anxiety

Symptoms

Some of the physical things that might happen are -

- churning stomach or loose bowels,
- dizziness,
- dry mouth,
- fast breathing,
- rapid and/or irregular heartbeat,
- sweating,
- weakened or tense muscles (MENTALHEALTH, 2016a).

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[3] Depression affects people in different ways and can cause a wide variety of symptoms. They range from lasting feelings of sadness and hopelessness, to losing interest in the things you used to enjoy and feeling very tearful. Many people with depression also have symptoms of anxiety. There can be physical symptoms too, such as feeling constantly tired, sleeping badly, having no appetite or sex drive, and complaining of various aches and pains. The severity of the symptoms can vary. At its mildest, you may simply feel persistently low in spirit (read about low mood), while at its most severe depression can make you feel suicidal and that life is no longer worth living.

Anxiety also has a psychological impact, which can include -

- feeling depressed,
- feeling irritable,
- lack of concentration,
- loss of self-confidence,
- trouble sleeping (MENTALHEALTH, 2016a).

Treatment

See Helping yourself.

Read more

See Anxiety.

Corticobasal degeneration

Symptoms

People with corticobasal degeneration develop a range of difficulties with movement, speech, memory and swallowing. Also see Early symptoms, Mid-stage symptoms, and Advanced stages (NHS, 2015e).

Treatment

There's currently no cure for corticobasal degeneration and no treatment to slow it down, but there are lots of things that can be done to help manage the symptoms (NHS, 2015e).

Read more

See Corticobasal degeneration.

Creutzfeldt-Jakob disease

CJD is the most common human form of a group of rare, fatal brain disorders affecting people and certain other mammals. Variant CJD (”mad cow disease”) occurs in cattle, and has been transmitted to people under certain circumstances (ALZ.ORG, 2016d).

Symptoms

Rapidly fatal disorder that impairs memory and coordination and causes behavior changes (ALZ.ORG, 2016d).

In sporadic CJD, the symptoms mainly affect the workings of the nervous system (neurological symptoms) and these symptoms rapidly worsen in the space of a few months.

In variant CJD, symptoms that affect a person’s behaviour and emotions (psychological symptoms) will usually develop first. These are then followed by neurological symptoms around four months later, which get worse over the following few months.

Familial CJD has the same sort of pattern as sporadic CJD, but it often takes longer for the symptoms to progress, usually around two years rather than a few months.

The pattern of iatrogenic CJD is unpredictable, as it depends on how a person became exposed to the infectious protein (prion) that caused CJD (NHS, 2015g).

Brain changes

Results from misfolded prion protein that causes a ”domino effect” in which prion protein throughout the brain misfolds and thus malfunctions (ALZ.ORG, 2016d).

Read more

See also Creutzfeldt-Jakob disease.

Dementia with Lewy bodies (DLB)

Symptoms

People with dementia with Lewy bodies often have memory loss and thinking problems common in Alzheimer's, but are more likely than people with Alzheimer's to have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations [4], and slowness, gait imbalance or other parkinsonian movement features (ALZ.ORG, 2016d).

Brain changes

Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also aggregates in the brains of people with Parkinson's disease, but the aggregates may appear in a pattern that is different from dementia with Lewy bodies.

The brain changes of dementia with Lewy bodies alone can cause dementia, or they can be present at the same time as the brain changes of Alzheimer's disease and/or vascular dementia, with each abnormality contributing to the development of dementia. When this happens, the individual is said to have ”mixed dementia” (ALZ.ORG, 2016d).

Read more

See also Dementia with Lewy bodies - DLB.

Depression

Symptoms

Being depressed can show itself in different ways. It commonly affects how you feel, how you see yourself and your relationships with other people.

Experiencing a number of the symptoms below on most days over the past month or more suggests you, could need help -

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[4] where someone sees, hears, smells, tastes or feels things that don't exist outside their mind

- feeling tired most of the time,
- sleeping badly - difficulty getting to sleep or waking up early and being unable to go back to sleep,
- loss of appetite or eating more than usual,
- weight change over a relatively short time - loss or gain,
- experiencing physical aches and pains and unfounded fears of serious illness,
- feeling apathetic and unable to enjoy things you normally enjoy,
- distancing yourself from people, particularly those close to you,
- being reluctant to engage in usual activities or leave your house,
- losing confidence in yourself and feeling life is pointless,
- being self-critical and feeling guilty,
- being unable to concentrate,
- feeling anxious,
- having suicidal thoughts (AGEUK, 2015).

Treatment

See Treatment.

Read more

See Depression.

Frontotemporal dementia

Includes dementias such as behavioral variant FTD (bvFTD), primary progressive aphasia [5], Pick's disease, corticobasal degeneration and progressive supranuclear palsy (ALZ.ORG, 2016d).

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[5] Aphasia is a condition that affects the brain and leads to problems using language correctly. People with aphasia make mistakes in the words they use, sometimes using the wrong sounds in a word, choosing the wrong word, or putting words together incorrectly. Aphasia also affects speaking and writing in the same way. Many people with the condition find it difficult to understand words and sentences they hear or read.

Symptoms

Typical symptoms include changes in personality and behavior and difficulty with language. Nerve cells in the front and side regions of the brain are especially affected (ALZ.ORG, 2016d).

Brain changes

No distinguishing microscopic abnormality is linked to all cases. People with FTD generally develop symptoms at a younger age (at about age 60) and survive for fewer years than those with Alzheimer's (ALZ.ORG, 2016d).

Read more

See also Frontotemporal dementia.

Huntington's disease

Huntington's disease is a progressive brain disorder caused by a single defective gene on chromosome 4 (ALZ.ORG, 2016d).

Symptoms

Include abnormal involuntary movements, a severe decline in thinking and reasoning skills, and irritability, depression and other mood changes (ALZ.ORG, 2016d).

Brain changes

The gene defect causes abnormalities in a brain protein that, over time, lead to worsening symptoms (ALZ.ORG, 2016d).

Read more

See also Huntington's disease

Mixed dementia

In mixed dementia abnormalities linked to more than one cause of dementia occur simultaneously in the brain. Recent studies suggest that mixed dementia is more common than previously thought (ALZ.ORG, 2016d).

Brain changes

Characterised by the hallmark abnormalities of more than one cause of dementia —most commonly, Alzheimer's and vascular dementia, but also other types, such as dementia with Lewy bodies (ALZ.ORG, 2016d).

Read more

See also Mixed dementia.

Normal pressure hydrocephalus

Symptoms

Symptoms include difficulty walking, memory loss and inability to control urination (ALZ.ORG, 2016d).

Brain changes

Caused by the buildup of fluid in the brain. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid (ALZ.ORG, 2016d).

Read more

See also Normal pressure hydrocephalus.

Parkinson's disease

As Parkinson's disease progresses, it often results in a progressive dementia similar to dementia with Lewy bodies or Alzheimer's (ALZ.ORG, 2016d).

Symptoms

Problems with movement are common symptoms of the disease. If dementia develops, symptoms are often similar to dementia with Lewy bodies (ALZ.ORG, 2016d).

Brain changes

Alpha-synuclein clumps are likely to begin in an area deep in the brain called the substantia nigra. These clumps are thought to cause degeneration of the nerve cells that produce dopamine (ALZ.ORG, 2016d).

Read more

See also Parkinson's disease.

Stress

Symptoms

- frequent headaches, jaw clenching or pain,
- gritting, grinding teeth,
- stuttering or stammering,
- tremors, trembling of lips, hands,
- neck ache, back pain, muscle spasms,
- light headedness, faintness, dizziness,
- ringing, buzzing or ”popping” sounds,
- frequent blushing, sweating,
- cold or sweaty hands, feet,
- dry mouth, problems swallowing,
- frequent colds, infections, herpes sores,
- rashes, itching, hives, ”goose bumps”,
- unexplained or frequent ”allergy” attacks,
- heartburn, stomach pain, nausea,
- excess belching, flatulence,
- constipation, diarrhea, loss of control,
- difficulty breathing, frequent sighing,
- sudden attacks of life threatening panic,

- chest pain, palpitations, rapid pulse,
- frequent urination,
- diminished sexual desire or performance,
- excess anxiety, worry, guilt, nervousness,
- increased anger, frustration, hostility,
- depression, frequent or wild mood swings,
- increased or decreased appetite,
- insomnia, nightmares, disturbing dreams,
- difficulty concentrating, racing thoughts,
- trouble learning new information,
- forgetfulness, disorganization, confusion,
- difficulty in making decisions,
- feeling overloaded or overwhelmed,
- frequent crying spells or suicidal thoughts,
- feelings of loneliness or worthlessness,
- little interest in appearance, punctuality,
- nervous habits, fidgeting, feet tapping,
- increased frustration, irritability, edginess,
- overreaction to petty annoyances,
- increased number of minor accidents,
- obsessive or compulsive behaviour,
- reduced work efficiency or productivity,
- lies or excuses to cover up poor work,
- rapid or mumbled speech,
- excessive defensiveness or suspiciousness,
- problems in communication, sharing,
- social withdrawal and isolation,
- constant tiredness, weakness, fatigue,
- frequent use of over-the-counter drugs,
- weight gain or loss without diet,
- increased smoking, alcohol or drug use,
- excessive gambling or impulse buying (STRESS.ORG, 2016a).

Treatment

Just as stress is different for each of us there is no stress reduction strategy that is a panacea. Jogging and other aerobic exercises, different types of meditation, prayer, yoga and tai chi are great for many people but when arbitrarily imposed on others, prove dull, boring and stressful (STRESS.ORG, 2016b).

Read more

See Stress.

Vascular dementia

Previously known as multi-infarct or post-stroke dementia, vascular dementia is less common as a sole cause of dementia than Alzheimer's, accounting for about 10% of dementia cases (ALZ.ORG, 2016d).

Symptoms

Impaired judgment or ability to make decisions, plan or organise is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's. Occurs from blood vessel blockage or damage leading to infarcts (strokes) or bleeding in the brain. The location, number and size of the brain injury determines how the individual's thinking and physical functioning are affected (ALZ.ORG, 2016d).

Brain changes

Brain imaging can often detect blood vessel problems implicated in vascular dementia. In the past, evidence for vascular dementia was used to exclude a diagnosis of Alzheimer's disease (and vice versa). That practice is no longer considered consistent with pathologic evidence, which shows that the brain changes of several types of dementia can be present simultaneously. When any two or more types of dementia are present at the same time, the individual is considered to have "mixed dementia" (ALZ.ORG, 2016d).

Read more

See also Vascular dementia.

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Chapter 4

Anxiety, depression

Contents

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Anxiety

Anxiety is a type of fear usually associated with the thought of a threat or something going wrong in the future, but can also arise from something happening right now.

Around 1 in 6 people in the UK will experience a mental health problem like anxiety each year, which has steadily increased over the past 20 years. It is also likely that individuals do not seek help for significant levels of anxiety, meaning many remain without diagnosis or treatment (MENTALHEALTH, 2016a).

What are the signs and symptoms of anxiety?

Life is full of potential stressful events and it is normal to feel anxious about everyday things. There can be a single trigger or event that raises anxiety levels, but generally it's a number of things that increase anxiety levels, including exams, work deadlines, how we think we look, going on a first date or whether we feel safe travelling home late at night.

Anxiety has a strong effect on us because it's one of our natural survival responses. It causes our mind and body to speed up to prepare us to respond to an emergency (MENTALHEALTH, 2016a).

Some of the physical things that might happen are -

- rapid and/or irregular heartbeat,
- fast breathing,

- weakened or tense muscles,
- sweating,
- churning stomach or loose bowels,
- dizziness,
- dry mouth (MENTALHEALTH, 2016a).

Anxiety also has a psychological impact, which can include -

- trouble sleeping,
- lack of concentration,
- feeling irritable,
- feeling depressed,
- loss of self-confidence (MENTALHEALTH, 2016a).

It can be hard to break this cycle, but you can learn to feel less worried and to cope with your anxiety so it doesn't stop you enjoying life.

What are the causes of anxiety?

Feelings of anxiety can be caused by lots of things and vary according to what you're worried about and how you act when you feel apprehensive. They depend on lots of things such as -

- your genes,
- how you were brought up,
- your life experiences,
- the way you learn and cope with things (MENTALHEALTH, 2016a).

Just knowing what makes you anxious and why can be the first steps to managing anxiety.

How can anxiety be treated?

Fear and anxiety can affect all of us every now and then. Most people get through passing moments of anxiety with no lasting effect. People experiencing anxiety in their everyday lives often find the personal resources to cope through simple remedies (MENTALHEALTH, 2016a).

Helping yourself

Talking it through

Although it can be difficult to open up about feeling anxious, it can be helpful to talk to friends, family or someone who has had a similar experience.

Although you might feel embarrassed or afraid to discuss your feelings with others, sharing can be a way to cope with a problem and being listened to can help you feel supported (MENTALHEALTH, 2016a).

Face your fear

By breaking the cycle of constantly avoiding situations that make you anxious, you are less likely to stop doing the things you want, or need, to do. The chances are the reality of the situation won't be as bad as you expect, making you better equipped to manage, and reduce, your anxiety (MENTALHEALTH, 2016a).

Know yourself

Make a note of when you feel anxious, what happens and the potential triggers. By acknowledging these and arming yourself with tips to deal with these triggers, you will be better prepared in anxiety-inducing situations (MENTALHEALTH, 2016a).

Relax

Learning relaxation techniques can help you calm feelings of anxiety. Practices like yoga, meditation or massage will relax your breathing and help you manage the way you feel about stressful experiences (MENTALHEALTH, 2016a).

Exercise

Even small increases in physical activity levels can trigger brain chemicals that improve your mood, wellbeing and stress levels. This can act as a prevention and treatment for anxiety as well as lead to improved body-image, self-esteem and self-worth (MENTALHEALTH, 2016a).

Healthy eating

Eat lots of fruit and vegetables and try to avoid too much sugar. Very sweet foods cause an initial sugar 'rush,' followed by a sharp dip in blood sugar levels which can give you anxious feelings. Caffeine can also increase anxiety levels so try to avoid drinking too much tea or coffee too (MENTALHEALTH, 2016a).

Avoid alcohol or drink in moderation

It's very common for people to drink alcohol when they feel nervous to numb their anxiety, however the effect that alcohol has on how you feel is only temporary. When it wears off you feel worse, potentially more anxious, and your brain will be less able to deal with anxiety naturally (MENTALHEALTH, 2016a).

Faith/spirituality

If you are religious or spiritual, it can help you feel connected to something bigger than yourself. It can provide a way of coping with everyday stress. Church and other faith groups can be a valuable support network (MENTALHEALTH, 2016a).

Talking to someone

If you feel anxious all the time, for several weeks or if it feels like your anxiety is taking over your life, then it's a good idea to ask for help.

- **Talking therapies** - Counselling or cognitive behavioural therapy (CBT) are very effective for people with anxiety problems, CBT helps people to understand the link between negative thoughts and mood and how altering their behaviour can enable them to manage anxiety and feel in control.
- **Mindfulness** - is a variation of CBT focusing on changing the relationship between the individual and their thoughts. Using meditation can help people be 'mindful' of their thoughts and break out of a pattern of negative thinking.
- **Guided self-help** - is usually based on CBT methods and aims to help the person understand the nature of their anxiety and equip them with the necessary skills to cope with it. This works by educating the individual to challenge unhelpful thinking, evaluate their symptoms and gradually expose themselves to the source of their anxiety.

- **Medication** - is used to provide short-term help, rather than as a cure for anxiety problems. Drugs may be most useful when they are combined with other treatments or support, such as talking therapies.
- **Support groups** - are designed for individuals to learn a lot about managing anxiety from asking other people who have experienced it. Local support or self-help groups bring together people with similar experiences to share stories, tips and try out new ways of managing their worries. Your doctor, library or local citizens advice bureau will have details of support groups near you (MENTALHEALTH, 2016a).

How do I get help for my anxiety in an emergency?

Anxiety UK run a helpline staffed by volunteers with personal experience of anxiety so you will be speaking with someone who has been there. Call them on **08444 775 774** (Monday - Friday 9.30am - 5.30pm).

The NHS 111 service is staffed by a team of fully trained advisers, supported by experienced nurses and paramedics. They will ask you questions to assess your symptoms, then give you the healthcare advice you need or direct you straightaway to the local service that can help you best. That could be A&E, an out-of-hours doctor, an urgent care centre or a walk-in centre, a community nurse, an emergency dentist or a late-opening chemist.

The Samaritans have trained volunteers able to listen to you any time of the day or night. They can help you talk through whatever is troubling you, find the answers that are right for you, and offer support. You don't have to give your real name or any personal information if you don't want to. Call them on **08457 909090** or email jo@samaritans.org (MENTALHEALTH, 2016a).

Depression

It's easy to blame ourselves, but depression can affect anyone. You might feel guilty or frustrated that you can't find the motivation to keep up with things, and it can be especially hard to spot the symptoms if you've been feeling the same way for a long time. Many people find they also experience anxiety alongside their symptoms, so nausea, breathlessness and headaches are all signs that it might be time to get help.

Depression is common, and in its mildest form most people can lead a healthy and active life with the right treatment and support. On the more severe end, depression can be devastating and even life-threatening, so don't go through it alone. Spotting the signs and getting help early can be vital, so talk to someone about it and visit your General Practitioner, a community-based doctor (GP) for help (DEPRESSIONALLIANCE, 2016c).

Depression is more than simply feeling unhappy or fed up for a few days.

We all go through spells of feeling down, but when you're depressed you feel persistently sad for weeks or months, rather than just a few days.

Some people still think that depression is trivial and not a genuine health condition. They're wrong. Depression is a real illness with real symptoms, and it's not a sign of weakness or something you can "*snap out of*" by "*pulling yourself together*".

The good news is that with the right treatment and support, most people can make a full recovery (NHS, 2014a).

What is depression?

Depression is not just feeling low. If you are depressed, the feelings of sadness and general lack of motivation that we can all experience from time to time are more intense and can persist for weeks or months. The feelings become so bad that they interfere with the way you think and behave and affect your daily life (NHS, 2014a).

Could you be at risk?

Depression can just happen. But in many cases it can be 'triggered' by significant life events, especially events connected with loss. We tend to think of loss in terms of the distress we feel on losing a partner or close friend. But other types of loss are more common as we grow older too and can affect our self-esteem or how we see our place in the world (AGEUK, 2015).

They include -

- **loss of your job and daily routine when you retire** - you may have been looking forward to retirement but when it comes, find it hard to adjust to the loss of a structure to your day, contact with colleagues and the purpose that working gave to your life.
- **loss of good health** - this could be a chronic [6] condition like arthritis or hearing and sight problems that can get gradually worse; or a sudden

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[6] A health condition or disease that is persistent or otherwise long-lasting in its effects or a disease that comes with time

change in your health that affects your previous sense of 'invincibility' such as having a heart attack. Poor health, particularly having a chronic health condition, is one of the most common factors contributing to depression in later life.
- **loss of independence** - this may come if you have an illness that means you need to depend more on other people or can no longer drive or if you take on a caring role that affects your own social life.
- **loss of a much loved home** - if you need to down-size to a more manageable property or move into sheltered housing or a care home.
- **loss of your social network** - this can happen if you move home, if close friends or family move away or die or if poor health or mobility mean you can no longer take part in activities you've enjoyed for many years and you may end up feeling lonely (AGEUK, 2015).

These situations might make anyone feel blue or a bit down and not everyone who experiences them goes on to develop depression. The important thing is to be aware of how these situations can be triggers for depression (AGEUK, 2015).

Can risk of depression be reduced?

If you are going through difficult times or you are feeling sad, you should seek support and help early on. This can prevent the normal reaction to sadness or a change in circumstances turning into depression. Do not brush how you feel under the carpet and hope it will sort itself out. Symptoms are likely to get worse if you do.

If you suspect a relative is in danger of, or could be suffering from depression, or you find yourself living with someone with depression, then try and talk to them about it. The risk of developing depression increases when people feel alone and unsupported. Consider the following -

- be watchful and offer emotional and practical support particularly if the person does not live nearby,
- look for signs that they are neglecting themselves or perhaps drinking more alcohol than usual,
- express your concerns and let them know what you've observed,
- encourage them to make an appointment with their GP or another professional at the practice they feel comfortable with and offer to go with them (AGEUK, 2015).

Men can find it particularly difficult to talk about or admit to how they feel and so are much less likely to seek help from family, friends or their GP (AGEUK, 2015).

Misconceptions associated with depression

- **Depression is a normal part of ageing** - this is a widespread belief among some professionals and young and old people alike. But depression is not a normal part of ageing. There is a range of effective treatments that can be tried and are effective, regardless of your age. Do not let yourself or your relative accept depression as an inevitable part of life.
- **I should be able to snap out of it myself or feeling like this is a sign of weakness** - commonly held beliefs that prevent many people seeking the much needed support and help they deserve in overcoming depression.
- **I should only bother my family and friends or the doctor with a physical illness** - when physical symptoms dominate, a diagnosis of depression is more likely to be overlooked. So it is important to talk about what is happening in your life and how you feel in yourself as well as any physical aches and pains.
- **A mental health problem is not as deserving of help as a physical health problem** - a common thought but remember doctors are trained to diagnose and treat both mental and physical illness (AGEUK, 2015).

Depression and mental illness can have stigma attached to it and so you are reluctant to admit to a problem that you feel could reflect badly on you or your family - this is a common reason for not seeking help. Depression is a real illness that deserves treatment and can be successfully treated (AGEUK, 2015).

Recognising symptoms

Being depressed can show itself in different ways. It commonly affects how you feel, how you see yourself and your relationships with other people.

Experiencing a number of the symptoms below on most days over the past month or more suggests you, or your relative, could need help -

- feeling tired most of the time,
- sleeping badly - difficulty getting to sleep or waking up early and being unable to go back to sleep,
- loss of appetite or eating more than usual,
- weight change over a relatively short time - loss or gain,
- experiencing physical aches and pains and unfounded fears of serious illness,
- feeling apathetic and unable to enjoy things you normally enjoy,
- distancing yourself from people, particularly those close to you,
- being reluctant to engage in usual activities or leave your house,

- losing confidence in yourself and feeling life is pointless,
- being self-critical and feeling guilty,
- being unable to concentrate,
- feeling anxious,
- having suicidal thoughts (AGEUK, 2015).

Symptoms that also suggest a physical illness - such as tiredness, weight loss, problems sleeping and aches and pains - tend to be more typical in older people who are depressed and can disguise an underlying depression (AGEUK, 2015).

Symptoms

The symptoms of depression can be complex and vary widely between people. But as a general rule, if you are depressed, you feel sad, hopeless and lose interest in things you used to enjoy.

The symptoms persist for weeks or months and are bad enough to interfere with your work, social life, and family life.

There are many other symptoms of depression and you're unlikely to have every one listed below (NHS, 2014a).

Psychological symptoms include -

- continuous low mood or sadness,
- feeling hopeless and helpless,
- having low self-esteem,
- feeling tearful,
- feeling guilt-ridden,
- feeling irritable and intolerant of others,
- having no motivation or interest in things,
- finding it difficult to make decisions,
- not getting any enjoyment out of life,
- feeling anxious or worried,
- having suicidal thoughts or thoughts of harming yourself (NHS, 2014a).

Physical symptoms include -

- moving or speaking more slowly than usual,
- change in appetite or weight (usually decreased, but sometimes increased),
- constipation,

- unexplained aches and pains,
- lack of energy or lack of interest in sex (loss of libido),
- changes to your menstrual cycle,
- disturbed sleep (for example, finding it hard to fall asleep at night or waking up very early in the morning) (NHS, 2014a).

Social symptoms include -

- not doing well at work,
- taking part in fewer social activities and avoiding contact with friends,
- neglecting your hobbies and interests,
- having difficulties in your home and family life (NHS, 2014a).

Depression can come on gradually, so it can be difficult to notice something is wrong. Many people continue to try to cope with their symptoms without realising they are ill. It can take a friend or family member to suggest something is wrong (NHS, 2014a).

Doctors describe depression by how serious it is -

- mild depression has some impact on your daily life,
- moderate depression has a significant impact on your daily life,
- severe depression makes it almost impossible to get through daily life - a few people with severe depression may have psychotic symptoms (NHS, 2014a).

Grief and depression

It can be hard to distinguish between grief and depression. They share many of the same characteristics, but there are important differences between them.

Grief is an entirely natural response to a loss, while depression is an illness.

People who are grieving find their feelings of loss and sadness come and go, but they're still able to enjoy things and look forward to the future.

In contrast, people who are depressed have a constant feeling of sadness. They don't enjoy anything and find it hard to be positive about the future (NHS, 2014a).

Other types of depression

There are different types of depression, and some conditions where depression may be one of the symptoms. These include -

- **Postnatal depression** - Some women develop depression after having a baby. Postnatal depression is treated in similar ways to other forms of depression, with talking therapies and antidepressant medicines.
- **Bipolar disorder** is also known as ”manic depression” - It’s where there are spells of depression and mania [7]. The depression symptoms are similar to clinical depression, but the bouts of mania can include harmful behaviour such as gambling, going on spending sprees and having unsafe sex.
- **Seasonal affective disorder (SAD)** - Also known as ”winter depression”, SAD is a type of depression that has a seasonal pattern usually related to winter (NHS, 2014a).

When to seek help

If you experience symptoms of depression for most of the day, every day for more than two weeks, you should seek help from your GP.

A low mood may improve after a short time (NHS, 2014a).

Living with depression

Depression can make simple, day to day life seem impossible. It can take a huge amount of strength and motivation to manage basic tasks like getting out of bed and leaving the house. Things we take for granted like speaking to friends or reading a book can become exhausting, and some people start to feel anxious or ashamed about not being able to do the things they used to, especially if it means taking time away from work or college (DEPRESSIONALLIANCE, 2016c).

The risk of isolation

It can be hard to explain our thoughts and feelings to others. When depression takes hold some people find themselves overwhelmed by emotions, while others feel cut off from them. This can sometimes make relationships difficult, and many people feel they have to hide what’s happening. The more overwhelming our symptoms, the more isolated and lonely we can become. Left untreated, depression can have a devastating impact on our relationships, our work, our finances and our overall health, so it’s vital to seek help as early as possible (DEPRESSIONALLIANCE, 2016c).

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[7] feeling very high and overactive (less severe mania is known as hypomania)

Managing depression

Most people with depression will get better with the right treatment and support. For some it takes months, for others it's years, and you might find that your symptoms go up and down, particularly during periods of stress or change. For many people, recovery is about being able to manage depression in the long term, so you're more likely to be able to prevent your symptoms from reoccurring in future or can stop them becoming unmanageable if they do. In the depths of depression recovery can seem unimaginable, which is why encouraging someone to get help isn't always straightforward. The good news is that things usually get better, and with the right support most people will go on to lead a healthy and active life (DEPRESSIONALLIANCE, 2016c).

Causes

There is no single cause of depression. You can develop it for different reasons and it has many different triggers.

For some, an upsetting or stressful life event - such as bereavement, divorce, illness, redundancy, and job or money worries - can be the cause.

Often, different causes combine to trigger depression. For example, you may feel low after an illness and then experience a traumatic event, such as bereavement, which brings on depression.

People often talk about a "downward spiral" of events that leads to depression. For example, if your relationship with your partner breaks down, you're likely to feel low, so you stop seeing friends and family and you may start drinking more. All of this can make you feel even worse and trigger depression.

Some studies have also suggested you're more likely to get depression as you get older, and that it's more common if you live in difficult social and economic circumstances (NHS, 2014a).

Stressful events

Most people take time to come to terms with stressful events, such as bereavement or a relationship breakdown. When these stressful events happen, you have a higher risk of becoming depressed if you stop seeing your friends and family and you try to deal with your problems on your own (NHS, 2014a).

Illness

You may have a higher risk of depression if you have a longstanding or life-threatening illness, such as coronary heart disease or cancer.

Head injuries are also an often under-recognised cause of depression. A severe head injury can trigger mood swings and emotional problems.

Some people may have an underactive thyroid (hypothyroidism) resulting from problems with their immune system. In rarer cases a minor head injury can damage the pituitary gland, a pea-sized gland at the base of your brain that produces thyroid-stimulating hormones.

This can cause a number of symptoms, such as extreme tiredness and a loss of interest in sex (loss of libido), which can in turn lead to depression (NHS, 2014a).

Personality

You may be more vulnerable to depression if you have certain personality traits, such as low self-esteem or being overly self-critical. This may be because of the genes you've inherited from your parents, or because of your early life experiences (NHS, 2014a).

Family history

If someone else in your family has suffered from depression in the past, such as a parent or sister or brother, then it's more likely you will too (NHS, 2014a).

Loneliness

Becoming cut off from your family and friends can increase your risk of depression (NHS, 2014a).

Alcohol and drugs

Some people try to cope when life is getting them down by drinking too much alcohol or taking drugs. This can result in a spiral of depression.

Cannabis helps you relax, but there is evidence that it can bring on depression, especially in teenagers.

And don't be tempted to drown your sorrows with a drink. Alcohol is categorised as a "strong depressant" and actually makes depression worse (NHS, 2014a).

Diagnosis

If you experience symptoms of depression for most of the day, every day for more than two weeks, you should seek help from your GP.

It is especially important to speak to your GP if you experience -

- symptoms of depression that are not improving,
- your mood affects your work, other interests, and relationships with your family and friends,
- thoughts of suicide [8] or self-harm [9] (NHS, 2014a).

Sometimes, when people are depressed they find it hard to imagine that treatment can actually help. But the sooner you seek treatment, the sooner your depression will lift.

There are no physical tests for depression, though your GP may examine you and do some urine or blood tests to rule out other conditions that have similar symptoms, such as an underactive thyroid.

The main way in which your GP will tell if you have depression is by asking you lots of questions about your general health and how the way you are feeling is affecting you mentally and physically.

Try to be as open as you can be with the GP. Describing your symptoms and how they are affecting you will really help your GP understand if you have depression and how severe it is.

Any discussion you have with your GP will be confidential. Your GP will only ever break this rule if there's a significant risk of harm to either yourself or others, and if informing a family member or carer would reduce that risk (NHS, 2014a).

Diagnosis and treatment

If your symptoms persist, make an appointment with your GP or if you feel more comfortable, arrange to see one of the practice nurses.

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[8] the act of intentionally ending your life

[9] this is when somebody intentionally damages or injures their body. It's usually a way of coping with or expressing overwhelming emotional distress

Take someone with you for support who you trust or as a second pair of ears to take note of what is discussed and agreed during the consultation.

To help make the most of the consultation and provide a clear view of what is happening to you -

- make a list of all your symptoms, whether they are worse at certain times of the day or on particular occasions, how long you've had them and their effect on your day-to-day life and relationship with others,
- explain any circumstances that could be contributing to these symptoms and the way you feel,
- take a list of all medications you currently take, including any supplements or non-prescription medication,
- be as open and honest as you can; remember anything you say is confidential (AGEUK, 2015).

You should be asked how you've been feeling, for how long and how it is affecting you on a day-to-day basis.

Any physical symptoms you describe may need further investigation, but if no reason for them is found, don't be put off if the GP seems unhelpful or feels nothing more can be done to help you.

If your symptoms have lasted more than a month, depression is a diagnosis that should be considered. Your age on its own should not be seen as the cause of your problems and should not decide the type of treatment you are offered (AGEUK, 2015).

Treatment

In October 2009, NICE (The National Institute for Health and Care Excellence) issued guidance on Treating depression in adults and Treating depression in adults with long-term physical health problems.

The guidance covers diagnosis, treatment options that should be available on the NHS for mild, moderate and severe depression and how to stay well in the future. It also suggests questions you may like to ask about your treatment options and how family and frifends can help in supporting you.

There are several treatments available for depression depending on the severity of your symptoms.

They include -

- advice from your GP or nurse at the practice on managing or coping with symptoms, with the offer of a review within 2 weeks to see if they are helping and to find out how you are,
- joining a physical activity programme that takes account of any health problems you have. Regular exercise is known to improve mood and sense of wellbeing as well as improving physical health,
- joining a peer support group - an opportunity for you to meet with others who have the same condition so you can share your experiences and solutions,
- psychological therapies (talking therapies) such as counselling or CBT,
- anti-depressant medication,
- assessment and support from a member of the community mental health team or local older persons mental health team (AGEUK, 2015).

In your discussion with your GP ask him to explain -

- which treatments may be appropriate in your case. If your GP favours a particular treatment, ask why?
- how the different treatments work and their benefits and risks,
- how soon you can expect to start to feel better,
- how long are you likely to need to continue with treatment,
- how often you need to come back for a review,
- what you can do to help yourself and whether there are any local groups you may find it helpful to contact (AGEUK, 2015).

You can then discuss your preferences and agree which treatment(s) you should try.

If you are considering talking therapy, be sure to mention any cultural, language or religious needs you have or any hearing or sight problems, so they can be addressed when arranging therapy for you.

If you have a health problem or hearing or sight difficulties that could be contributing to how you feel, make sure you are getting the best possible treatment for those too (AGEUK, 2015).

There are many different ways to treat depression, and for most people recovery starts with a visit to the GP. Once your GP understands your symptoms and has reached a diagnosis, you'll need to agree on a treatment together. The treatment your GP suggests will depend on the severity of your symptoms and the local services available, but it's your choice so you'll need to agree on it together as a partnership. The more comfortable and informed you feel about your treatment the more likely it is to help you through recovery (DEPRESSIONALLIANCE, 2016c).

Treatment for depression usually involves a combination of medicines, talking therapies and self-help.

The type of treatment your GP recommends will be based on the type of depression you have. Below is a short description of the types of treatment your GP may recommend (NHS, 2014a).

Mild depression

- **wait and see** - if you're diagnosed with mild depression, your depression may improve by itself. In this case, you'll simply be seen again by your GP after two weeks to monitor your progress. This is known as watchful waiting (NHS, 2014a).
- **exercise** - there is evidence that exercise may help depression and it is one of the main treatments if you have mild depression. Your GP may refer you to a qualified fitness trainer for an exercise scheme (NHS, 2014a).
- **self-help groups** - talking through your feelings can be helpful. You could talk either to a friend or relative, or you can ask your GP to suggest a local self-help group. Your GP may also recommend self-help books and online CBT (NHS, 2014a).

Mild to moderate depression

- **talking therapy** - if you have mild depression that isn't improving, or you have moderate depression, your GP may recommend a talking treatment (a type of psychotherapy). There are different types of talking therapy for depression, including CBT and counselling. Your GP can refer you for talking treatment or in some parts of the country you might be able to refer yourself (NHS, 2014a).

Moderate to severe depression

- **antidepressants** - antidepressants are tablets that treat the symptoms of depression. There are almost 30 different kinds of antidepressant. They have to be prescribed by a doctor, usually for depression that is moderate or severe.
- **combination therapy** - your GP may recommend that you take a course of antidepressants plus talking therapy, particularly if your depression is quite severe. A combination of an antidepressant and CBT usually works better than having just one of these treatments.

- **mental health teams** - if you have severe depression, you may be referred to a mental health team made up of psychologists, psychiatrists, specialist nurses and occupational therapists [10]. These teams often provide intensive specialist talking treatments as well as prescribed medication (NHS, 2014a).

Talking treatments

Cognitive behavioural therapy (CBT)

CBT helps you understand your thoughts and behaviour and how they affect you.

CBT recognises that events in your past may have shaped you, but it concentrates mostly on how you can change the way you think, feel and behave in the present.

It teaches you how to overcome negative thoughts, for example being able to challenge hopeless feelings.

CBT is available on the NHS for people with depression or any other mental health problem that it has been shown to help.

You normally have a short course of sessions, usually six to eight sessions, over 10 to 12 weeks on a one-to-one basis with a counsellor trained in CBT. In some cases, you may be offered group CBT (NHS, 2014a).

Online CBT

Computerised CBT is a form of CBT that works through a computer screen, rather than face-to-face with a therapist.

It's delivered in a series of weekly sessions and should be supported by a healthcare professional. For instance, it's usually prescribed by your GP and you may have to use the surgery computer to access the programme (NHS, 2014a).

Interpersonal therapy (IPT)

interpersonal therapy (IPT) focuses on your relationships with other people and on problems you may be having in your relationships, such as difficulties with communication or coping with bereavement.

There's some evidence that IPT can be as effective as antidepressants or CBT, but more research is needed (NHS, 2014a).

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[10] they help people of all ages to carry out everyday activities which are essential for their own health and wellbeing

Psychodynamic psychotherapy

In psychodynamic (psychoanalytic) psychotherapy, a psychoanalytic therapist will encourage you to say whatever is going through your mind.

This will help you to become aware of hidden meanings or patterns in what you do or say that may be contributing to your problems (NHS, 2014a).

Counselling

Counselling is a form of therapy that helps you think about the problems you are experiencing in your life to find new ways of dealing with them. Counsellors support you in finding solutions to problems, but do not tell you what to do.

Counselling on the NHS usually consists of six to 12 hour-long sessions. You talk in confidence to a counsellor, who supports you and offers practical advice.

Counselling is ideal for people who are basically healthy but need help coping with a current crisis, such as anger, relationship issues, bereavement, redundancy, infertility or the onset of a serious illness (NHS, 2014a).

Getting help

Your first port of call should be your GP, who can refer you for NHS talking treatments for depression available locally.

In some parts of the country, you also have the option of self-referral. This means that if you prefer not to talk to your GP, you can go directly to a professional therapist (NHS, 2014a).

Medicines

Antidepressants

Antidepressants are medicines that treat the symptoms of depression. There are almost 30 different kinds available.

Most people with moderate or severe depression benefit from antidepressants, but not everybody does. You may respond to one antidepressant but not to another, and you may need to try two or more treatments before you find one that works for you.

The different types of antidepressant work about as well as each other. However, side-effects vary between different treatments and people.

When you start taking antidepressants, you should see your GP or specialist nurse every week or two for at least four weeks to see how well they are working. If they are working, you'll need to continue taking them at the same dose for at least four to six months after your symptoms have eased.

If you've had bouts of depression in the past, you may need to continue to take antidepressants for up to five years or longer.

Antidepressants aren't addictive, but you may get some withdrawal symptoms if you stop taking them suddenly or you miss a dose (see below) (NHS, 2014a).

Selective serotonin reuptake inhibitors (SSRIs)

If your GP thinks you would benefit from taking an antidepressant, you'll usually be prescribed a modern type called a selective serotonin reuptake inhibitor (SSRI). Examples of commonly used SSRI antidepressants are Seroxat (paroxetine), Prozac (fluoxetine) and Cipramil (citalopram).

They help increase the level of a natural chemical in your brain called serotonin, which is thought to be a "good mood" chemical.

SSRIs work just as well as older antidepressants and have fewer side-effects.

They can, however, cause nausea and headaches, as well as a dry mouth and problems having sex. However, all these negative effects usually improve over time.

Some SSRIs aren't suitable for children under the age of 18. Research shows that the risk of self-harm and suicidal behaviour may increase if they're taken by under-18s. Fluoxetine is the only SSRI that can be prescribed for under-18s, and even then only when a specialist has given the go-ahead (NHS, 2014a).

Tricyclic antidepressants (TCAs)

This group of antidepressants is used to treat moderate to severe depression.

Tricyclic antidepressants (TCAS), which includes Imipramil (imipramine) and amitriptyline, have been around for longer than SSRIs. They work by raising the levels of the chemicals serotonin and noradrenaline in your brain. These both help lift your mood.

They're generally quite safe, but it's a bad idea to smoke cannabis if you are taking TCAS because it can cause your heart to beat rapidly.

Side-effects of TCAS may include a dry mouth, blurred vision, constipation, problems passing urine, sweating, light-headedness and excessive drowsiness, but vary from person to person.

The side-effects usually ease after seven to 10 days, as your body gets used to the medication (NHS, 2014a).

Other antidepressants

New antidepressants, such as Efexor (venlafaxine), Cymbalta or Yentreve (duloxetine) and Zispin Soltab (mirtazapine), work in a slightly different way from SSRIs and TCAS.

Venlafaxine and duloxetine are known as serotonin-noradrenaline reuptake inhibitor (SNRI)s. Like TCAS, they change the levels of serotonin and noradrenaline in your brain.

Studies have shown that an SNRI can be more effective than an SSRI, though they're not routinely prescribed as they can lead to a rise in blood pressure (NHS, 2014a).

Withdrawal symptoms

Antidepressants are not addictive in the same way that illegal drugs and cigarettes are, but when you stop taking them you may have some withdrawal symptoms, including -

- upset stomach,
- flu-like symptoms,
- anxiety,
- dizziness,
- vivid dreams at night,
- sensations in the body that feel like electric shocks (NHS, 2014a).

In most cases these are quite mild and last no longer than a week or two, but occasionally they can be quite severe. They seem to be most likely to occur with paroxetine (Seroxat) and venlafaxine (Efexor).

Withdrawal symptoms occur very soon after stopping the tablets, so can easily be told apart from symptoms of depression relapse, which tend to occur after a few weeks (NHS, 2014a).

Other treatments

St John's wort

St John's wort is a herbal treatment that some people take for depression. It's available from health food shops and pharmacies.

There's some evidence that it may help mild to moderate depression, but it's not recommended by doctors. This is because the amount of active ingredients varies among individual brands and batches, so you can never be sure what sort of effect it will have on you.

Taking St John's wort with other medications, such as anticonvulsants, anticoagulants, antidepressants and the contraceptive pill, can also cause serious problems.

You shouldn't take St John's wort if you are pregnant or breastfeeding, as we don't know for sure that it's safe.

Also, St John's wort can interact with the contraceptive pill, reducing its contraceptive effect (NHS, 2014a).

Electric shock treatment

I have assisted a patient in my care to have ECT, pre-treatment, during treatment, and post-treatment. I found the patient's confusion post-treatment quite upsetting, and the Doctor giving the treatments lack of knowledge about how ECT works surprising! I now consider ECT to be barbaric and a relic of Victorian England, and that it should never be used now in the 21st century.

electroconvulsive therapy (ECT) is a treatment that involves sending an electric current through the brain from electrodes placed on your head, this will trigger an epileptic seizure to relieve the symptoms of some mental health problem.

The treatment is given under a general anaesthetic [11] and using muscle relaxants, so that your muscles only twitch slightly, and your body does not convulse during the seizure (MIND, 2016b).

What problems can ECT treat?

ECT is mainly used if you -

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

- have severe, life-threatening depression,
- have not responded to medication or talking treatments,
- have found it helpful in the past and have asked to receive it again,
- have severe postnatal depression (MIND, 2016b).

It may sometime be used if you -

- are experiencing a manic or psychotic episode which is severe or is lasting a long time,
- are catatonic (MIND, 2016b).

It may also be used when it is important to have an immediate effect; for example, because you are so depressed that you are unable to eat or drink, and are in danger of kidney failure (MIND, 2016b).

You may be given a series of ECT sessions. It is usually given twice a week for three to six weeks (NHS, 2014a).

Is ECT effective?

No-one is sure how ECT works, but it is known to change patterns of blood flow in the brain, and also change the way energy is used in parts of the brain that are thought to be involved in depression. It may cause changes in brain chemistry, although how these are related to symptoms is not understood.

The ECT Accreditation Service (run by the Royal College of Psychiatrists) reported on a survey of 78 ECT clinics in England and Wales in 2012-2013. This reported the results of 1895 courses of treatment in 1789 people -

- improved ('minimally', 'much' or 'very much') - 1712,
- no change - 113,
- worse - 28 (MIND, 2016b).

Why is ECT controversial?

The history of ECT In the past (1950s to 1970s), ECT was used far more than it is now. It was done without anaesthetic and often without consent [12], and far more treatments were given than is common now. Many people experienced it as more of a punishment than a treatment.

Some people think it is still administered in the same way, and it has also been depicted in quite barbaric ways on film. So people often have a false impression of what ECT is really like now (MIND, 2016b).

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[12] 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

Adverse effects

The main side-effect is memory loss (which is also common after seizures caused by epilepsy). This is usually short-term, but can be very significant, disabling and long-lasting in some people and is a cause of anxiety (MIND, 2016b).

Personal experiences

People's experience of ECT varies enormously. Some people find it the most useful treatment they have had, and would ask for it again if they needed treatment for depression. Others feel violated by it, and would do anything to avoid having it again (MIND, 2016b).

How do I decide to have ECT?

Deciding whether or not to have ECT may be very difficult. Usually you will only be offered it if you are very depressed, which in itself makes it difficult to take in information and make decisions based on what you have been told. But you have the right to full information about the treatment, and to decide for yourself whether or not you wish to receive it.

Generally, unless you are unable to make a decision for yourself, it is your decision whether you accept the treatment or not.

You may find it helpful to discuss it with a trusted friend or family member, or a mental health advocate [13]. You can contact POhWER or Rethink Mental Illness to find out about advocacy services in your area (MIND, 2016b).

Advantages of ECT -

- When it works, it works quickly.
- It can prevent death if you are so depressed you are unable to talk, and you have stopped eating and drinking and looking after yourself.
- If you have depression after childbirth, it can lift these feelings quickly so that you are able to care for and enjoy your baby.
- It may lift suicidal feelings (but there is no evidence that it prevents suicide) (MIND, 2016b).

Disadvantages of ECT -

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[13] An advocate is another person that helps you express your views and wishes, and helps make sure your voice is heard

- Even if it has worked, often the effects don't last long, and it can't address any underlying despair or life problems you may have, or prevent future depression.
- Some people find it overwhelmingly negative and may feel worse after treatment, especially if they regret having consented to it, or were given it without consent.
- Side-effects, especially memory loss, which is usually short lived, but may be very significant in some cases (MIND, 2016b).

It is important that you are offered other types of treatments in the period following ECT so that you can make the most of any improvement it has given you. These might include talking treatments or arts therapies which you may have been too depressed to make use of before, as well as medication (MIND, 2016b).

When should I avoid having ECT?

Before a course of ECT treatments, you will need a full medical examination. You will be asked about -

- your medical history - if you have any physical problems, these should be treated, as far as possible, before you have ECT. If you have heart or circulation problems, or breathing problems, both the ECT itself and the anaesthetic may be more dangerous for you.
- whether you are pregnant - ECT may be used in pregnancy, but the anaesthetist may not be happy about giving a general anaesthetic to a pregnant woman, except in a medical emergency.
- any medicine you are taking - some prescribed drugs affect your response to ECT -
  - some antidepressants (such as fluoxetine) may cause the seizure to last longer than normal,
  - some drugs, including benzodiazepine tranquillisers, make it more difficult to induce a seizure so that a higher dose of electric current has to be used.
- any drug allergies (MIND, 2016b).

NICE guidance

The National Institute for Health and Care Excellence (NICE) says that before you are offered ECT, doctors should consider the risks of the treatment. These include -

- the risk of general anaesthetic,
- other medical conditions you might have,

- possible adverse effects, especially memory loss,
- the risks of not having treatment (MIND, 2016b).

Extra caution should be used as the risks of ECT may be higher in the following groups, for -

- pregnant women,
- older people,
- children and young people (it should not be used for depression in children under the age of 12) (MIND, 2016b).

After each ECT session, you should be assessed, and you should not receive any more ECT if you -

- have had a positive response so that more treatment is unnecessary,
- show signs of serious adverse effects, such as memory loss (MIND, 2016b).

If you have had ECT for depression before and it did not help, you should only be given it again if -

- you and your doctors are sure that all other possible treatments have been tried,
- you have discussed the possible benefits and harms with the doctor and also with a friend or family member, if you want them to be included (MIND, 2016b).

Can I be given ECT without my consent?

Making an informed choice and giving consent You have the right to make an informed decision about whether or not to accept the treatment a doctor suggests. To consent properly you need enough information to be able to weigh up the risks and benefits of having it (MIND, 2016b).

You should be given full information, in language you can understand, about -

- the expected benefits,
- any side-effects and the risk of harm,
- how the treatment will be given,
- alternative treatments,
- the alternative of having no treatment at all (MIND, 2016b).

It can be hard to take in a lot of new information in one go, so you can ask for medical staff to explain it to you more than once if necessary.

You should be given 24 hours to think about it and ECTAS recommends that you have a friend, relative or advocate with you, when you are given the information, so that they can go over it with you again. ECTAS also recommends that, if your relatives or close friends disagree with your treatment, this should be recorded in your notes, together with the reasons for going ahead with it (MIND, 2016b).

If you agree to the treatment you will have to sign a written consent form.

Once you have signed a consent form, you should be informed that you can change your mind at any stage in the treatment and that, if you do, the treatment will be stopped. You should also be told how you can tell staff if you have changed your mind. At each stage of the treatment, the doctor should confirm with you that you are continuing to consent (MIND, 2016b).

Questions for your doctor If ECT is recommended, you (or your friend or relative) might want to ask the following questions -

- What is the reason for suggesting ECT?
- What are the risks of ECT?
- How could ECT help?
- What are the side-effects?
- Are there any long-term effects?
- Have I been offered every available alternative treatment?
- What treatment will I be offered in addition to, and after, ECT?
- What is the risk that I will feel worse afterwards?
- How many treatments are suggested?
- How will the dosage be decided?
- What will happen to me if I refuse this treatment? (MIND, 2016b)

If you are subject to the Mental Health Act 1983, ECT can normally be given only if you consent to it and a second opinion appointed doctor (SOAD) or approved clincian (i.e. approved by the Welsh Ministers) certifies that you've consented (and have the capacity to do so) (MIND, 2016b).

Treatment without consent

You may be given ECT without your consent if you need emergency treatment or if you don't have capacity to consent to it (MIND, 2016b).

Emergency treatment The Mental Health Act sometimes allows ECT to be given without your consent in an emergency, but only if the treatment is immediately necessary for any of the following -

- to save your life,

- to prevent your condition seriously worsening (and the treatment doesn't have unfavourable physical or psychological consequences that can't be reversed) (MIND, 2016b).

If you do not have capacity If you cannot give consent, treatment may be given under the Mental Health Act or (less commonly) under the Mental Capacity Act.

Under some sections of the Mental Health Act

You can be treated without your consent if -

- you are unable to understand the information about ECT and cannot give informed consent,
- you have not previously made an advance decision [14] or there is a decision made by an attorney [15], deputy [16] or the Court of Protection [17] refusing ECT treatment, and
- a second opinion specialist who is not involved in your care also agrees that it should be given (MIND, 2016b).

Under the Mental Capacity Act 2005

You may be treated without your consent if -

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[14] An advance decision is a statement of instructions about what medical treatment you want to refuse in case you lose the capacity to make these decisions in the future. It is legally binding

[15] An attorney is a person over the age of 18 whom you have appointed to make decisions on your behalf about your welfare and/or your property and financial affairs. You need an attorney if you are unable to make such decisions yourself. If you do not have the capacity to appoint an attorney, the Court of Protection may appoint a deputy to perform this role.

- A health and welfare attorney makes decisions about things like your daily routine, your medical care, where you live and, if you specially request this, whether you should have life-sustaining treatment.
- A property and financial affairs attorney makes decisions about things like paying bills, collecting benefits and selling your home

[16] A deputy is a person the Court of Protection appoints to make decisions for you once you have lost capacity to make them yourself. A deputy usually makes decisions about finances and property. The court can appoint a deputy to take healthcare and personal care decisions, though this is relatively rare

[17] The Court of Protection makes decisions and appoints deputies to act on your behalf if you are unable to make decisions about your personal health, finance or welfare

- you are assessed as lacking capacity to consent (under the Mental Capacity Act 2005), and
- you have not previously made an advance decision refusing ECT treatment, and
- it is considered to be in your best interests to receive the treatment (MIND, 2016b).

Advance decisions about ECT

If you are clear you do not wish to receive ECT even if your life is in danger, your advance decision needs to meet special conditions. If you have already made a valid and applicable advance decision refusing ECT, or your attorney under a Lasting Power of Attorney, or a court-appointed deputy, or a Court has refused ECT on your behalf, then the ECT should not be given to you.

In all cases your family should also be consulted if appropriate (MIND, 2016b).

What is the treatment like?

Do I have to be an inpatient? Not necessarily. You usually receive ECT as an inpatient in a hospital, but outpatient treatment is possible (MIND, 2016b).

If you are an outpatient, you will need to have someone with you to accompany you home - you should not return alone to an empty house. You (or your friend or family member who is with you) should be asked to confirm that -

- you will be accompanied home and have someone with you for 24 hours after treatment,
- you will not drive during your course of treatment, or until the psychiatrist has told you it's OK,
- you will not drink alcohol for at least 24 hours, or until you have been told it's OK,
- you will not sign any legal documents for at least 24 hours or until you have been told it's OK (MIND, 2016b).

What is the ECT clinic like? The ECT Accreditation Service sets standards for the administration of ECT, and there is a list of participating clinics, and the standards they have met, on the Royal College of Psychiatrists website (MIND, 2016b).

The ECT treatment centre should consist of a suite of three rooms -

- a waiting area, which should be comfortable and provide a relaxing environment,
- a treatment room, which should have the equipment required for monitoring and resuscitation in addition to the ECT machine,
- a recovery room (MIND, 2016b).

The suite should be organised so that the rooms are separate and you are able to move easily from one room to the next, and cannot observe other people in adjacent rooms (MIND, 2016b).

Clinic staff The staff should consist of -

- nurses, including -
  - a trained nurse manager in overall charge of the ECT session,
  - a nurse, who you know and trust, who is with you during all stages of treatment,
  - a nurse trained in resuscitation (MIND, 2016b).
- a medical team including -
  - a senior psychiatrist,
  - a senior anaesthetist,
  - an assistant to the anaesthetist (MIND, 2016b).

What happens during the procedure?

ECT is carried out under a general anaesthetic and with a muscle relaxant. Because of the anaesthetic, you must not eat or drink anything (except a few sips of water) for at least six hours beforehand (MIND, 2016b).

You should wear loose, comfortable clothing

- You should not be wearing any hairspray, creams, make-up or nail polish, or have any metal slides or grips in your hair, or piercings.
- Let the team know if you have had cosmetic dentistry such as veneers, implants or piercings
- You will lie on a bed, and your jewellery, shoes and any dentures will be removed and kept safe for you.
- Once you are comfortable, you will be given a general anaesthetic, via an injection.
- While you are unconscious, you will receive an injection of muscle relaxant to minimise the convulsions caused by the electric current. Because of the muscle relaxant, you will be given oxygen, and the anaesthetist will look after your breathing, using a face mask and a pressure bag.

- Two padded electrodes will be placed on your temples, either one on each side of your head (bilateral ECT), or both on the same side (unilateral ECT) (see below for more information).
- A mouth guard will be placed in your mouth, to stop you biting your tongue.
- The ECT machine will deliver a series of brief, high-voltage, electrical pulses - about 60 to 70 pulses a second, for three to five seconds, causing you to have a seizure, or fit. This will cause you to stiffen slightly, and there may be twitching movements in the muscles of your face, hands and feet. The seizure should last 20 to 50 seconds (MIND, 2016b).

What is bilateral or unilateral ECT?

- Bilateral means that one electrode is placed on each temple so that the whole brain is stimulated
- Unilateral means that both electrodes are place on one temple, so that only one side of the brain is stimulated (MIND, 2016b).

Both types cause a seizure of the whole brain.

Bilateral ECT may be more effective, but unilateral is sometimes thought to cause fewer memory problems. However, with unilateral you may need a higher dose of electricity to cause the seizure, and this may increase the likelihood of memory loss with this method, so that it is not in fact very different from bilateral.

Bilateral placement is more commonly used. You may receive unilateral ECT if you have had unpleasant side-effects after bilateral, or if you have responded well to unilateral ECT in the past (MIND, 2016b).

How strong is the electric current?

The strength of electric current needed to produce a fit is called the 'seizure threshold'. This varies from person to person -

- it is higher in men than in women,
- it may be affected by medication you may recently have taken,
- it increases with age, meaning that older people need a stronger electric current,
- it depends on the exact position of the electrodes on your head,
- it depends on the amount of anaesthetic you have been given (MIND, 2016b).

The 'dose' of electric current given to you will be adjusted to take all of these things into account.

- if the dose is too low (below the threshold), there will be no benefit from the ECT,
- the higher the dose, the greater the risk of unpleasant side-effects, so it's important that the dose is kept as close as possible to the threshold (MIND, 2016b).

What happens immediately after?

After the seizure, the mouth guard is removed and you will be turned on your side. The anaesthetist will provide oxygen until the muscle relaxant wears off (after a few minutes) and you start breathing on your own again. You will slowly come round, although you may feel very groggy.

You may sleep for a while after treatment.

You will need to recover from the general anaesthetic as well as the ECT treatment itself (MIND, 2016b).

How many treatments will I have?

You should not normally be prescribed more than two treatments at one time, although a maximum number (usually 12) may be prescribed beforehand. You should be assessed after each treatment to see if another one is necessary, or is inadvisable.

The treatments should normally take place twice a week, although three treatments may be given in one week if you have a severe or life-threatening illness.

After a course of treatment you should be seen by the mental health team at least once a month for three months (MIND, 2016b).

What are the side-effects?

Memory loss

This is the most important side-effect of ECT, and the one which causes most concern.

It is usually a short-term effect, and most people find their memories gradually return as they recover from ECT.

However, for some people, memory loss can mean both losing personal memories, and having difficulty remembering new information. Some people have been so badly affected that they have lost key skills or knowledge, such as expertise needed to continue their professional work or career.

Guidelines say that you should have a standard test of your memory and thinking abilities as part of your assessment before treatment and after each treatment session. (MIND, 2016b).

Immediate side effects

Other side-effects that may occur immediately after treatment are -

- drowsiness (you may sleep for a while),
- confusion,
- headache,
- feeling sick,
- aching muscles,
- loss of appetite (MIND, 2016b).

Very rarely, people may experience prolonged fits, especially if they are taking drugs or have medical conditions which lower the 'seizure threshold'.

Some of the symptoms listed above may subside quickly, but some may last for weeks, months, or even permanently.

Some people have also -

- had injuries to their teeth or jaw, or other muscles, but physical injury from the convulsions should be minimised by the muscle relaxant,
- become very confused between treatments, and on rare occasions may become restless or agitated (MIND, 2016b).

The general anaesthetic (as for any procedure where it is used) carries a risk of illness and a very small risk of death, separate from the ECT treatment itself (MIND, 2016b).

Longer term effects

Longer term effects include -

- apathy (loss of interest in things),
- loss of creativity, drive and energy,
- difficulty concentrating,
- loss of emotional responses,
- difficulty learning new information (MIND, 2016b).

What alternatives are there?

If the NICE guidelines are being followed, you will only be offered ECT (in most cases) if you have tried other treatments and found them unsuccessful, unhelpful or unacceptable, or you are so unwell you are unable to engage with them.

These should have included -

- antidepressant drugs,
- talking therapies,
- arts therapies (MIND, 2016b).

This doesn't mean you have to try ECT; you can choose to try other treatment again. There may be new drugs, or better access to different talking treatments, since you last tried a treatment (MIND, 2016b).

Other physical treatments

Transcranial magnetic stimulation (TMS)

This is another physical treatment which is considered to be comparable to ECT. It stimulates the brain using magnetic fields. It is approved as a treatment for migraine.

NICE guidance says that Transcranial magnetic stimulation (TMS) is safe, but there is not sufficient evidence that it is effective for depression for it to be offered in NHS hospitals, unless you are taking part in research. It is available for depression in some private hospitals.

The advantages of TMS are that it does not require a general anaesthetic, and does not normally cause a seizure, so is much less likely than ECT to cause memory loss (MIND, 2016b).

Neurosurgery

If nothing else has helped, including ECT, and you are still severely depressed, you may be offered neurosurgery for mental disorder, deep brain stimulation, or vagus nerve stimulation (MIND, 2016b).

For most people, ECT is good for relieving severe depression, but the beneficial effect tends to wear off after several months.

Some people get unpleasant side-effects, including short-term headaches, memory problems, nausea and muscle aches (NHS, 2014a).

Lithium

If you've tried several different antidepressants and had no improvement, your doctor may offer you a type of medication called lithium in addition to your current treatment.

There are two types of lithium: lithium carbonate and lithium citrate. Both are usually effective, but if you are taking one that works for you, it's best not to change.

If the level of lithium in your blood becomes too high, it can become toxic [18]. You will therefore need blood tests every three months to check your lithium levels while you're on the medication.

You'll also need to avoid eating a low-salt diet because this can also cause the lithium to become toxic. Ask your GP for advice about your diet (NHS, 2014a).

Recovery and wellbeing

Recovery from depression can mean different things. For some people its about being able to take care of yourself, leave the house in the morning and feel pleasure when you speak to friends. For others it means returning to work, having an active social life and picking up the hobbies you thought you'd lost. For most, it's about accepting the condition and finding ways to manage it in the long term, as much as we might wish it would disappear. Some people even find that recovery brings surprising benefits, and you might discover that you're more understanding of others, more appreciative of the small things in life and are be more supportive when others are in trouble (DEPRESSIONALLIANCE, 2016c).

Living with depression

There are some key steps you can take to lift your mood and help your recovery from depression (NHS, 2014a).

Take your medication

It is important to take your medication as prescribed, even if you start to feel better.

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[18] Capable of causing injury or death, especially by chemical means; poisonous

If you stop your medication too soon, you could have a relapse of your depression. If you have any questions or concerns about the medication you're taking, talk to your doctor or pharmacist.

It may help to read the information leaflet that comes with your medication to find out about possible interactions with other drugs or supplements. Check with your doctor first if you plan to take any over-the-counter remedies such as painkillers, or any nutritional supplements. These can sometimes interfere with antidepressants (NHS, 2014a).

Exercise and diet

Exercise and a healthy diet can make a tremendous difference to how quickly you recover from depression. And they will both improve your general health, too.

Research suggests that exercise may be as effective as antidepressants at reducing depression symptoms.

Being physically active can lift your mood, reduce stress and anxiety, boost the release of endorphins (your body's feel-good chemicals) and improve self-esteem. Also, exercising may be a good distraction from negative thoughts, and it can improve social interaction.

It also helps your mood to have a healthy diet. In fact, eating healthily seems to be just as important for maintaining your mental health as it is for preventing physical health problems (NHS, 2014a).

Mindfulness

It can be easy to rush through life without stopping to notice much. Paying more attention to the present moment - to your own thoughts and feelings, and to the world around you - can improve your mental wellbeing. Some people call this awareness 'mindfulness', and you can take steps to develop it in your own life.

The National Institute for Health and Clinical Excellence (NICE) recommends 'mindfulness based cognitive therapy' for people who are currently well but have experienced three or more previous episodes of depression. It may help to prevent a future episode of depression. Read the NICE 2009 guidelines on Depression in Adults (NHS, 2014a).

Talking about it

Sharing a problem with someone else or with a group can give you support and an insight into your own depression. Research shows that talking can help people recover from depression and cope better with stress.

You may not feel comfortable about discussing your mental health and sharing your distress with others. If so, writing about how you feel or expressing your emotions through poetry or art are other ways to help your mood (NHS, 2014a).

Smoking, drugs and alcohol

It may be tempting to smoke or drink to make you feel better. Cigarettes and booze may seem to help at first, but they make things worse in the long run.

Be extra cautious with cannabis. You might see it as harmless, but research has revealed a strong link between cannabis use and mental illness, including depression (NHS, 2014a).

The evidence shows that if you smoke cannabis you -

- make your depression symptoms worse,
- feel more tired and uninterested in things,
- are more likely to have depression that relapses earlier and more frequently,
- will not have as good a response to antidepressant medicines,
- are more likely to stop using antidepressant medicines,
- are less likely to recover fully (NHS, 2014a).

If you drink or smoke too much or use drugs, get advice and support from your GP, or read these articles about getting help if you want to stop smoking, taking drugs or drinking too much alcohol (NHS, 2014a).

Work and finances

If your depression is caused by working too much or is affecting your ability to do your job, you may need time off to recover. However, there is evidence that taking prolonged time off work can make depression worse. There's also quite a lot of evidence that going back to work can help you recover from depression.

It's important to avoid too much stress, and this includes work-related stress. If you're employed, you may be able to work shorter hours or work in a more flexible way, particularly if job pressures seem to trigger your symptoms. Under the Equality Act (2010) all employers must make reasonable adjustments to make the employment of people with disabilities possible. This can include people with a diagnosis of mental illness (NHS, 2014a).

If you can't work as a result of your depression, you may be eligible for a range of benefits, depending on your circumstances. These include -

- Statutory sick pay,
- Incapacity Benefit,
- Disability Living Allowance,
- Attendance Allowance,
- Carer's Allowance,
- Council Tax Benefit,
- Housing Benefit (NHS, 2014a).

Looking after someone with depression

It's not just the person with depression who is affected by their illness. The people close to them are too.

If you're caring for someone with depression, your relationship with them and family life in general can become strained. You may feel at a loss as to what to do. Finding a support group and talking to others in a similar situation might help.

If you're having relationship or marriage difficulties, it might help to contact a relationship counsellor who can talk things through with you and your partner.

Men are less likely to ask for help than women and are also more likely to turn to alcohol or drugs when depressed (NHS, 2014a).

Coping with bereavement

Losing someone close to you can be a trigger for your depression.

When someone you love dies, the emotional blow can be so powerful that you feel it's impossible to ever recover. However, with time and the right help and support, it is possible to start living your life again (NHS, 2014a).

Depression and suicide

The majority of suicide cases are linked with mental disorders, and most of them are triggered by severe depression (NHS, 2014a).

Warning signs that someone with depression may be considering suicide are -

- making final arrangements, such as giving away possessions, making a will or saying goodbye to friends,
- talking about death or suicide - this may be a direct statement, such as ”*I wish I was dead*”, but often depressed people will talk about the subject indirectly, using phrases like ”*I think dead people must be happier than us*” or ”*Wouldn't it be nice to go to sleep and never wake up*”,
- self-harm, such as cutting their arms or legs, or burning themselves with cigarettes,
- a sudden lifting of mood, which could mean that a person has decided to commit suicide and feels better because of this decision (NHS, 2014a).

If you are feeling suicidal or are in the crisis of depression, contact your GP as soon as possible. They will be able to help you.

If you can't or don't want to contact your GP, call the Samaritans on 116 123, 24-hours a day, seven days a week. Alternatively, visit the Samaritans website or email jo@samaritans.org (NHS, 2014a).

For more information see Suicide and also Self-harm.

Helping a suicidal friend or relative

If you see any of the above warning signs -

- get professional help for the person,
- let them know they are not alone and that you care about them,
- offer your support in finding other solutions to their problems (NHS, 2014a).

If you feel there is an immediate danger, stay with the person or have someone else stay with them, and remove all available means of committing suicide, such as medication. Over-the-counter drugs such as painkillers can be just as dangerous as prescription medication. Also, remove sharp objects and poisonous household chemicals such as bleach (NHS, 2014a).

Support from family and friends

It may be helpful, if you agree, for a family member coming along with you to the GP so they can ask any questions about how best to help and support you. It can be weeks before the treatment makes you feel better and so support from family and friends to keep appointments or take medication can be vital to a successful outcome. Their reassurance that things will get better with time, along with regular phone calls or visits and offers of practical help can all contribute to your recovery (AGEUK, 2015).

Keeping well in the future

It is important to do all you can to stay well. Be sure to continue with any prescribed medication. If you are now taking regular exercise, have learned some relaxation techniques, are getting out more and have developed new friendships and interests, keeping them up is important to your long term health and well-being.

Should your symptoms seem to be returning, let friends and family know and make an appointment to see your GP so any problems can be nipped in the bud (AGEUK, 2015).

About talking treatments

Our later years of life can bring rest, relaxation and fulfilment, but they can also bring real challenges.

Talking treatments involve talking to someone who is specially trained to help us manage our thoughts and feelings and the effect they have on our behaviour and mood.

As we get older many of us face illness, disability or have to cope with the loss of friends and family. Even without these difficulties, many of us can feel worried as we approach retirement, or have trouble adapting to life once we've stopped working. These worries can easily lead to feelings of unhappiness, anxiety and stress (AGEUK, 2015).

Whatever the reasons, if you or someone you know has -

- negative thoughts or emotions,
- a low mood and is unable to be cheered up,
- less energy than they used to,
- feelings of anxiety or helplessness (AGEUK, 2015).

Then they could most probably benefit from a talking treatment.

Talking treatments are available to all of us, for free, through the NHS.

Take the first step and ask your GP about talking treatments today. You can also find a local talking treatment near you on the NHS website.

Older people as a group are drastically under-represented as users of talking treatments. This might be because there has been a stigma attached to seeing a 'therapist' or receiving 'counselling'. However, a quarter us will experience anxiety or feel low at some point in our life; it doesn't mean we're weaker or less able to cope.

Taking steps to feel better is, in fact, the most important thing you can do to treat a mental health problem (AGEUK, 2015).

Help and support

If you're suffering from depression, it's important to make use of the help and support available to you.

If you want to learn more about depression and the treatments available, you may wish to contact Mind [19]. They offer information and support to people with depression and their families through their website, information materials and infoline.

You can also find information about depression on the NHS Choices website in the Health A-Z section.

Your local Age UK may offer a range of services to help you meet new people and learn new skills such as computing. They may also run lunch clubs, arrange social outings and classes to help you keep fit and have volunteers who can visit you at home if you find it difficult to get out.

If you are offering support to a family member with depression it can be both rewarding and stressful. Information is out there which can support carers and enable them to discuss any difficulties they are experiencing. Local carer support groups offer a handy support network.

Carers Direct [20], Carers UK [21] and the Carers Trust [22] provide information and advice and details of local support groups for carers (AGEUK, 2015).

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[19] Mind is the leading mental health charity for England and Wales

[20] An online and telephone service providing information, advice and support for carers

[21] Carers UK is a membership led national organisation set up by carers for carers

[22] Carers Trust is a new charity formed in April 2012 by the merger of The Princess Royal Trust for Carers and Crossroads Care. It provides information, advice and support services for people across the UK caring for a family member or friend at home

Tips for coping with depression

If you're feeling depressed, it can be helpful to try some coping strategies.

David Richards, professor of mental health services research at the University of Exeter, offers these self-help tips for dealing with depression (NHS, 2016e).

Stay in touch

Don't withdraw from life. Socialising can improve your mood. Keeping in touch with friends and family means you have someone to talk to when you feel low (NHS, 2016e).

Be more active

Take up some form of exercise. There's evidence that exercise can help lift your mood. If you haven't exercised for a while, start gently by walking for 20 minutes every day (NHS, 2016e).

Face your fears

Don't avoid the things you find difficult. When people feel low or anxious, they sometimes avoid talking to other people. Some people can lose their confidence about going out, driving or travelling.

If this starts to happen, facing up to these situations will help them become easier (NHS, 2016e).

Don't drink too much alcohol

For some people, alcohol can become a problem. You may drink more than usual as a way of coping with or hiding your emotions, or just to fill time. But alcohol won't help you solve your problems and could also make you feel more depressed (NHS, 2016e).

Try to eat a healthy diet

Some people don't feel like eating when they're depressed and are at risk of becoming underweight. Others find comfort in food and can put on excess weight.

Antidepressants can also affect your appetite.

If you're concerned about weight loss, weight gain or how antidepressants are affecting your appetite, talk to your GP (NHS, 2016e).

Have a routine

When people feel down, they can get into poor sleep patterns, staying up late and sleeping during the day. Try to get up at your normal time and stick to your routine as much as possible.

Not having a routine can affect your eating. You may stop cooking regular meals, eat snacks throughout the day instead or miss breakfast because you're still in bed (NHS, 2016e).

Seeking help for depression

If you're still feeling down or depressed after a couple of weeks, talk to your GP or call NHS 111.

If you start to feel that your life isn't worth living or about harming yourself, get help straight away. These are signs that you need to talk to someone urgently.

Various treatments are available for depression, including talking therapies, antidepressants and self-help.

You can also contact helplines, such as Samaritans on 116 123, for 24-hour confidential, non-judgemental emotional support.

If you've had depression or anxiety in the past, even if they weren't formally diagnosed, get help immediately. You're more likely to have an episode of depression if you've had one before (NHS, 2016e).

Five steps to wellbeing

Good mental health isn't just about being free from depression. We can all benefit from taking a positive and proactive approach to our wellbeing, and this can help us to get better, stay well and even prevent mild depression from happening in the first place.

The 'Five Steps to Wellbeing' are simple actions we can do in our everyday lives to help us feel good and function well. The five steps are - Connect, Be Active, Take Notice, Keep Learning and Give, and were developed by the New Economics Foundation. In the depths of depression it's unlikely we'll feel well enough to manage all these, but when we're feeling stronger they can help us stay well and to live life to the fullest. Boosting our wellbeing isn't just important for our own health; our workplaces, communities, friends and family will benefit from small changes we can all make for a healthier lifestyle (DEPRESSIONALLIANCE, 2016a).

Connect

With the people around you. With family, friends, colleagues and neighbours, or at home, work, school and in your local community. Think of these as the cornerstones of your life and invest time in developing them. Do you and your workmates share a common interest? Do you know your neighbour? Keep in touch, make that call, write that letter, send that text, feel a valued sense of belonging. Building connections will support and enrich you everyday (DEPRESSIONALLIANCE, 2016a).

Be active

Go for a walk or run. Step outside. Nature is good for us - being in green open spaces increases our sense of wellbeing and relaxation. Cycle to the shops. Play a game. Get muddy in the garden. If you find it hard on your own, talk to a friend, family member or work-mate and help motivate each other. Go to your local library and see what activities are on offer in your area.

Don't forget to eat well - nutrition is a key part of keeping active and keeping mentally and physically healthy. It doesn't have to be boring or expensive: lots of fresh produce and Omega-3 rich foods. Exercising can give you a boost and doing it with others can help you to feel connected. Most importantly, discover a physical activity you enjoy and that suits your level of mobility and fitness (DEPRESSIONALLIANCE, 2016a).

Take notice

Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Take time to breath, unwind: yoga, meditation, listening to music, reading a book - time on your own. Reflecting on your experiences will help you appreciate what matters to you (DEPRESSIONALLIANCE, 2016a).

Keep learning

Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Get creative: draw, compose music, write poetry, act, dance, paint, cook, knit. Set a challenge you will enjoy achieving. Learning new things can make you more confident as well as being fun and a chance to connect with other people in your community or at work (DEPRESSIONALLIANCE, 2016a).

Give

Do something nice for a friend, or a stranger. Thank someone. Smile. Look out, as well as in. Volunteer your time. Start a group. Search on the internet for your local voluntary action service. Explore local timebanks. Look in your library or community centre for ways to get involved. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you (DEPRESSIONALLIANCE, 2016a).

The concept of wellbeing

The concept of wellbeing comprises two main elements: feeling good and functioning well. Feelings of happiness, contentment, enjoyment, curiosity and engagement are characteristic of someone who has a positive experience of their life. Equally important for wellbeing is our functioning in the world. Experiencing positive relationships, having some control over one's life and having a sense of purpose are all important attributes of wellbeing (Thompson et al., 2008).

Chapter 5

Memory problems?

Contents

If you’re concerned about memory problems, do consult your GP as soon as possible. But it’s also worth bearing in mind that more than half of patients referred to memory clinics for confirmation of a dementia diagnosis turn out not to have the condition, according to recent figures from the University of Sheffield. So what else could be causing the issue (Murphy, 2016)?

Its your menopause

60% of menopausal women experience memory problems due to fluctuating hormone levels, according to a University of California study (Greendale et al., 2009). And these difficulties tend to be most evident in the year immediately following a woman's final period, say researchers at the University of Rochester (Weber, Rubin and Maki, 2013).

The good news, though, is that the effect is temporary: memory skills tend to return to pre-menopausal levels in the years after the menopause. "*The most important thing that women need to be reassured of is that these problems, while frustrating, are normal and, in all likelihood, temporary*," says Dr Miriam Weber, who led the Rochester study (Weber, Rubin and Maki, 2013), (Murphy, 2016).

Perimenopause

Consistent with transitioning women's perceived memory difficulties, perimenopause was associated with a decrement in cognitive performance, characterised by women not being able to learn as well as they had during premenopause. Improvement rebounded to premenopausal levels in postmenopause, suggesting that menopause transition-related cognitive difficulties may be time-limited. Hormone initiation prior to the final menstrual period had a beneficial effect whereas initiation after the final menstrual period had a detrimental effect on cognitive performance (Greendale et al., 2009).

You've been under a lot of stress

Long-term stress can lead to brain structure changes that may erode short-term memory skills, says a study at The Ohio State University (Crane, 2016). Mice who had been repeatedly exposed to stress - in the form of bullying by a bigger mouse - were unable to locate the escape hole in a maze they'd previously mastered. Mice who hadn't been bullied managed to find the exit without a problem.

The stressed mice also experienced measurable brain changes, including inflammation caused by the immune system's response to the outside pressure. You'll be pleased to hear they'd made a full recovery within 28 days, though (Murphy, 2016).

You're overweight

Need another good reason to lose a few pounds? Being overweight is associated with poor episodic memory, says a recent University of Cambridge study (Chekea, Simonsa and Claytona, 2015). Fifty adults of varying sizes were asked to complete a test that involved hiding items around a complex environment over two days and later recalling when and where they'd hidden them. People with a high BMI [23] tended to fare significantly worse.

The researchers' conclusion? *'Although only a small study, its results support existing findings that excess body weight may be associated with changes to the structure and function of the brain and its ability to perform certain cognitive tasks optimally'* (Murphy, 2016).

You had a bad night

Just one restless night can have a dramatic effect on your memory skills, according to a US study (Fenn et al., 2014). Participants were shown images of a simulated burglary, then asked to recall the details the following day. Those who'd been kept awake for 24 hours - and even those who'd had up to five hours of sleep - were more likely to mix up the information.

"*People who repeatedly get low amounts of sleep every night could be more prone in the long run to develop these forms of memory distortion,*" says the study's co-author Dr Kimberly Fenn. "*It's not just a full night of sleep deprivation that puts them at risk*" (Fenn et al., 2014), (Murphy, 2016).

You're getting too much sleep

Yes, there is such a thing! Women who slept for nine hours or more on average performed just as badly in cognitive tests as those who slept for less than five hours, in a recent Harvard study (Devore et al., 2014). Researchers estimated that both 'under-sleepers' and 'over-sleepers' were mentally two years older than those who enjoyed seven to eight hours of slumber each night (Murphy, 2016).

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[23] body mass index - a measure that uses your height and weight to work out if your weight is healthy. The BMI calculation divides an adult's weight in kilograms by their height in metres squared. For example, A BMI of 25 means 25kg/m2

Your diet's to blame

Foods laden with sugar and fat appear to reduce levels of a natural brain chemical, called BDNF, which is crucial for learning and memory skills, say researchers at the University of California (Gómez-Pinilla, 2008).

Meanwhile, a diet rich in omega-3 fatty acids - found in oily fish and walnuts, for example - is associated with many brain-boosting benefits.

But it's not just what you eat that impacts your memory; when you eat it makes a difference, too. Regularly indulging in late-night snacks, which means your body is busy digesting food while you're asleep, can damage the hippocampus - the part of the brain where memories are formed - according to another recent US study (Murphy, 2016).

You're dehydrated

Can't remember where you left your keys? Try drinking a glass of water. Even very mild dehydration can alter our ability to think clearly and remember simple things, say researchers at the University of Connecticut (Poitras, 2012).

The feeling of thirst doesn't really kick in until we're already one or two per cent dehydrated - and that can be enough to impair our powers of recall (Murphy, 2016).

Six common causes of forgetfulness

Getting a bit absent-minded? Don't worry, it doesn't mean you've got dementia - here's our guide to the top six reasons for becoming forgetful (Westcott, 2015).

Trouble remembering phone numbers? Dither over simple decisions? Problems following recipes? You're not alone - particularly if you're over 50. And with the constant flow of stories about Alzheimer's disease and dementia in the press and online, it's not surprising that such mental slips raise the question, '*Could it be dementia?*'

Well, the good news is that such everyday trials are usually just part of the normal cognitive changes that affect us all as we age.

Dementia is far more than ordinary forgetfulness or occasional foggy thinking, says Professor June Andrews, who is director of the Dementia Services Development Centre at the University of Stirling. "*You need to start worrying only if you* *experience a significant, progressive downturn in your mental capacity*", she says. "*It's normal to misremember phone numbers, for instance, but not to forget how to use your mobile or what it's for*".

Even if you do experience more serious symptoms, don't despair. Numerous other medical problems have symptoms that make people think they have dementia. The most common are outlined below (Westcott, 2015).

Vitamin B12 deficiency

- **Dementia-like symptoms include** - bad judgment and low mood.

Vitamin B12 plays a vital role in maintaining the brain and nervous system. It's found in meat, poultry, eggs and milk. But age-related changes in stomach acid, certain medications (including proton pump inhibitors used to treat reflux, antibiotics, metformin used to treat Type-2 diabetes) and excess alcohol can all deplete the body's stores.

Left untreated, a vitamin B12 deficiency can lead to brain shrinkage and symptoms such as Confusion, apathy, depression, poor memory and judgment. Other problems, though, can include numbness, pins and needles, disturbed vision and unsteadiness on your feet (Westcott, 2015).

Next steps

You should first ask your doctor for a blood test. Taking a supplement could help. An Oxford University study found that taking a combination of vitamin B12 (0.5mg/day), plus folic acid (0.8mg/day) and vitamin B6 (20mg/day) for two years significantly slowed brain shrinkage in those with mild cognitive decline (Westcott, 2015).

Depression

- **Dementia-like symptoms include** - poor concentration and apathy.

Depression may affect more than one in five people over 65, according to figures from Age UK - often without them realising it. (The figures also show women are more prone to depression than men.)

"*Many people wrongly think the overriding symptom is sadness*," observes Dr James Warner, who is national professional adviser for old age psychiatry at independent health regulator the Care Quality Commission. "*But memory problems,* *trouble concentrating, struggling to get things done and loss of interest in activities can be just as prominent."*

Depression is linked with cognitive problems in two out of five older people. "*However, while someone who is depressed may meet an acquaintance and forget their name, they will know who they are,*" explains Dr Warner. "*Someone with dementia, on the other hand, will be unable to identify the person behind the name."*

People with depression can also experience what doctors call 'delayed verbal recall', a problem remembering words, and may speak more slowly. "*With dementia, though, this goes further,*" says Dr Warner. "*Sufferers frequently forget words for common objects. For example, they may describe a cup as "that thing you put tea into"*" (Westcott, 2015).

Next steps

Again, you should see your GP - depression is, of course, a real illness that can be treated successfully.

Antidepressants, exercise, reminiscence therapy and advice on stress-management are all options. And in a recent review in the International Journal of Geriatric Psychiatry, CBT was reported to help improve planning and problem-solving skills, as well as lifting mood, in older people with depression and cognition problems (Westcott, 2015).

Urinary tract infection (UTI)

- **Dementia-like symptoms include** - hallucinations and restlessness.

For many, this common bacterial infection can bring on a fever, create an urgent need to pee or make it uncomfortable to do so. But older sufferers - whose immune systems may no longer respond to such infections, who may have less sensitive pain receptors and could already have problems going to the loo - may not notice anything unusual.

Apart, that is, from delirium [24]. Often a result of the dehydration a Urinary Tract Infection (UTI) causes, its effects include lack of awareness of surroundings, inability to follow a conversation or speak clearly, vivid, scary dreams, seeing people or things that aren't there, restlessness, wandering, slowness and mood changes.

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[24] an acute, transient and reversible state of confusion, usually the result of other organic processes (infection, drugs, dehydration etc.), the onset is acute and the cognition of the patient can be highly fluctuant over a short period of time

"*But what distinguishes these problems from dementia,*" says Dr Trisha Macnair, specialty doctor in medicine for the elderly with Surrey Community Health, "*is that they tend to come on quickly [hours, days or weeks], rather than developing over years.*"

Other UTI symptoms to look out for include cloudy, unpleasant-smelling urine, a general feeling of being unwell or nausea. Our thirst-sensation is blunted with age, so guard against dehydration in general by drinking plenty of tea and water (Westcott, 2015).

Next steps

A course of antibiotics, drinking lots of water, a healthy diet and rest usually bring fast relief.

Cranberry tablets (which contain compounds thought to stop bacteria sticking to the urinary tract's walls) or probiotics may help keep UTIs at bay if you're prone to them (Westcott, 2015).

Thyroid problem

- **Dementia-like symptoms include** - failing memory and fatigue.

"*The thyroid, a small butterfly-shaped gland in your neck, produces hormones that regulate most bodily functions, including mood and cognition. And, like dementia, symptoms of thyroid problems can creep up relatively slowly,*" points out Dr Warner, who is also consultant psychiatrist at the Central North West London Foundation Trust.

An underactive thyroid is more common in women and is estimated to affect one in 20 people aged 60-plus.

Difficulty thinking, poor working memory (the kind used to follow the steps in an instruction manual), slowed reactions and low mood are some clues. Other tell-tale signs that may distinguish it from dementia, however, include weight gain, over-sensitivity to cold, dry skin, hair loss and constipation.

An overactive thyroid can trigger poor attention, concentration and memory for words, anxiety, restlessness, palpitations, over-sensitivity to heat and weight loss (Westcott, 2015).

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Next steps

A simple blood test can identify if your thyroid is pumping out too few or too many hormones. Medication usually sorts things out within weeks. Occasionally, other treatment, including surgery, may be needed for an overactive thyroid (Westcott, 2015).

Parkinson's Disease

- **Dementia-like symptoms include** - slow reactions and short attention span.

It's not widely known, but mild cognitive impairment can be a sign of this nervous-system condition.

"*Like dementia, Parkinson's is a long time developing*," explains Dr Warner. "*What we call non-motor symptoms often present up to ten years before classic symptoms, such as a 'masked' [unexpressive] face, tremor*[25] *and difficulty moving*."

Problems with attention and concentration, for example, can make things such as reading a newspaper difficult, while slower thought processes can affect how long it takes you to make decisions or respond in a conversation (Westcott, 2015).

Next steps

Parkinson's UK has a non-motor symptoms questionnaire that you can take to your GP to help them scrutinise your symptoms. Visit parkinsons.org.uk or call 0808 800 0303 (Westcott, 2015).

Medication overload

- **Dementia-like symptoms include** - confusion.

Getting older invariably means taking an increasing number of medicines and, when they're combined, they can cause cognitive symptoms that resemble long-term mental issues.

Some drugs cause problems by themselves. "*Anticholinergics - prescribed to treat asthma, incontinence, insomnia, gastrointestinal problems, muscle spasms and high*

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[25] a type of uncontrollable shake or tremble of part of the body

blood pressure - may cause confusion by blocking acetylcholine, a brain messenger chemical involved in memory and learning," says Dr Warner. Feeling light-headed, having a dry mouth, constipation, bladder problems or blurred vision are other possible side effects.

"*Sleeping pills and 'opiate' painkillers for conditions such as arthritis and back pain can also damage alertness,*" he adds (Westcott, 2015).

There is a medical term for this condition which is known as 'poly-pharmacy'.

Next steps

Always take medications exactly as prescribed. Gen up on side-effects and possible cross-reactions by reading in-pack instructions for prescription and over-the-counter medications, including herbal and dietary supplements.

If you're uncertain, check with your GP or pharmacist. Make sure medications are reviewed regularly to check they are still appropriate for your needs (Westcott, 2015).

Chapter 6

Common dementia and its types

Contents

If you're becoming increasingly forgetful, particularly if you're over the age of 65, it may be a good idea to talk to your GP about the early signs of dementia.

As you get older, you may find that memory loss becomes a problem. It's normal for your memory to be affected by age, stress, tiredness, or certain illnesses and medications. This can be annoying if it happens occasionally, but if it's affecting your daily life or is worrying you or someone you know, you should seek help from your GP (NHS, 2015a).

Early warning signs

New habits?

Strange new habits such as always cutting up an apple for breakfast but never eating it can be a sign of a new compulsive behaviour and this in turn can indicate early onset dementia.

If you or someone you know is behaving unusually in this way, ask yourself why you or they are doing it. If there's a good answer, i.e. I keep meaning to eat it but I just don't seem to have the time, then it might not be a compulsive behaviour.

The key to compulsive behaviours, however, is that they can't be stopped easily. So if the behaviour continues, it might be time to visit your GP for a check-up (Green, 2015).

Dramatic changes in social behaviour?

A formerly polite and reserved person who becomes crass and rude to friends and family could be showing the early signs of brain changes caused by dementia. Many brain disorders affect moral and social behaviour, which is governed by the right side of the brain, making people say things they wouldn't usually dream of uttering, or making them behave in socially unacceptable ways such as shouting, swearing or stealing things, or making inappropriate sexual advances. Dementia is one such disease and while not all dementia patients will overtly change their moral behaviour, it is a sign to look out for (Green, 2015).

At a loss for words?

Surprise birthday parties and extravagant gifts aside, if you're regularly finding it difficult to find words to express yourself, you may be showing an early sign of dementia. This is particularly evident if you or the individual can't find a way around the lack of that word - instead of finding a different way to say the same thing, they will continue to search for that one word that's missing. Similarly, this lack of knowledge of a certain word can also make following a story difficult (Green, 2015).

What is dementia?

Dementia is a common condition. Your risk of developing dementia increases as you get older, and the condition usually occurs in people over the age of 65.

Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities. This includes problems with -

- memory loss,
- thinking speed,
- mental agility,
- language,
- understanding,
- judgement (NHS, 2015a).

People with dementia can become apathetic or uninterested in their usual activities, and have problems controlling their emotions. They may also find social situations challenging, lose interest in socialising, and aspects of their personality may change.

A person with dementia may lose empathy (understanding and compassion), they may see or hear things that other people do not (hallucinations), or they may make false claims or statements.

As dementia affects a person's mental abilities, they may find planning and organising difficult. Maintaining their independence may also become a problem. A person with dementia will therefore usually need help from friends or relatives, including help with decision making.

Your GP will discuss the possible causes of memory loss with you, including dementia. Other symptoms can include -

- increasing difficulties with tasks and activities that require concentration and planning,

- depression,
- changes in personality and mood,
- periods of mental confusion,
- difficulty finding the right words (NHS, 2015a).

Most types of dementia can't be cured, but if it is detected early there are ways you can slow it down and maintain mental function (NHS, 2015a).

Risk factors for dementia

Researchers have discovered several important factors that affect our risk of developing dementia. These include age and genetics, but also medical conditions and lifestyle choices. A person's risk of developing dementia depends upon a combination of all of these risk factors. Some of them, such as age or the genes we have inherited from our parents, are beyond our control. Others are things we can change, such as our lifestyle choices - for example, whether we smoke and how much we exercise (Llewellyn and Bayer, 2016).

Ageing

Age is the strongest known risk factor for dementia. Whilst it is possible to develop the condition earlier - at least 1 in 20 people with dementia developed it at age under 65 - the chances of developing dementia rise significantly as we get older. Above the age of 65, a person's risk of developing Alzheimer's disease or vascular dementia doubles roughly every 5 years. It is estimated that dementia affects one in 14 people over 65 and one in six over 80 (Llewellyn and Bayer, 2016).

This may be due to factors associated with ageing, such as -

- higher blood pressure,
- increased risk of cardiovascular diseases (eg heart disease and stroke),
- changes to nerve cells, DNA and cell structure,
- loss of sex hormones after mid-life changes,
- the weakening of the body's natural repair systems,
- changes in the immune system (Llewellyn and Bayer, 2016).

Gender

Women are more likely to develop Alzheimer's disease than men. This is the case even if we allow for the fact that women on average live longer. The reasons for this are still unclear. It has been suggested that Alzheimer's disease in women is linked to a lack of the hormone oestrogen after the menopause. However, controlled trials of hormone replacement therapy (HRT, which replaces female hormones) have not been shown to reduce the risk of developing Alzheimer's. The age at which HRT is started, however, may affect the outcome. HRT (prescribed mainly to help with symptoms of the menopause) is not recommended as a way for women to help reduce their risk of dementia.

For most dementias other than Alzheimer's disease, men and women have much the same risk. For vascular dementia, men are actually at slightly higher risk than women. This is because men are more prone to stroke and heart disease, which can cause vascular and mixed dementia (Llewellyn and Bayer, 2016).

Ethnicity

There is some evidence that people from certain ethnic communities are at higher risk of dementia than others. For example, South Asian people (from countries such as India and Pakistan) seem to develop dementia - particularly vascular dementia - more often than white Europeans. South Asians are well known to be at a higher risk of stroke, heart disease and diabetes, and this is thought to explain the higher dementia risk.

Similarly, people of African or African-Caribbean origin seem to develop dementia more often. They are known to be more prone to diabetes and stroke. All of these effects are probably down to a mix of differences in diet, smoking, exercise and genes (Llewellyn and Bayer, 2016).

Genetics

Scientists have known for some time that the genes we inherit from our parents can affect whether or not we will develop certain diseases. The role of genes in the development of dementia is not yet fully understood, but researchers have made important advances in recent years.

More than 20 genes have been found that do not directly cause dementia but affect a person's risk of developing it. For example, inheriting certain versions (variants) of the gene apolipoprotein E (APOE) increases a person's risk of developing Alzheimer's disease. Having a close relative (parent or sibling) with Alzheimer's disease increases your own chances of developing the disease very slightly compared to someone with no family history. However, it does not mean that dementia is inevitable for you.

It is also possible to inherit genes that directly cause dementia, although these are much rarer than the risk genes like APOE. In affected families there is a very clear pattern of inheritance of dementia from one generation to the next. This pattern is seen in families with familial Alzheimer's disease (a very rare form of Alzheimer's which appears usually well before the age of 60) and genetic frontotemporal dementia. If a person has the faulty gene then each of their children has a 50% chance of inheriting it and so developing the dementia (Llewellyn and Bayer, 2016).

Medical conditions and diseases

Cardiovascular factors

There is very strong evidence that conditions that damage the heart, arteries or blood circulation all significantly affect a person's chances of developing dementia. These are known as cardiovascular risk factors. The main ones for dementia are -

- **type 2 diabetes** - in mid-life or later life,
- **high blood pressure** - in mid-life,
- **high total blood cholesterol levels** - in mid-life,
- **obesity** - in mid-life (Llewellyn and Bayer, 2016).

These conditions are avoidable risk factors for dementia and also for cardiovascular diseases (stroke and heart disease, such as abnormal heart rhythm). Having cardiovascular disease or type 2 diabetes increases a person's risk of developing dementia by up to two times (Llewellyn and Bayer, 2016).

These cardiovascular conditions are most strongly linked to vascular dementia. This is because vascular dementia is caused by problems with blood supply to the brain.

Recent research suggests that many people with dementia have mixed dementia, or they have Alzheimer's disease with some vascular damage in the brain. The cardiovascular risk factors and diseases should be considered as risk factors for mixed dementia and not just vascular dementia. In some cases (eg diabetes or high mid-life cholesterol) they are known risk factors for Alzheimer's disease as well (Llewellyn and Bayer, 2016).

Depression

People who have had periods of depression - whether in mid-life or later life - also seem to have increased rates of dementia. Whether depression is a risk factor that in part causes dementia is not clear, and the answer probably differs with age. There is some evidence that depression in middle age does lead to a higher dementia risk in older age. In contrast, depression in later life, i.e. when a person is in their 60s or older, may be an early symptom of dementia rather than a risk factor for it (Llewellyn and Bayer, 2016).

Other conditions

Other medical conditions that can increase a person's chances of developing dementia include Parkinson's disease, multiple sclerosis and HIV. Down's syndrome and other learning disabilities also increase a person's risk of dementia.

A number of other conditions have been linked to dementia in some studies, but evidence on them is still emerging. These conditions include chronic kidney disease, hearing loss, anxiety and sleep apnoea (where breathing stops for a few seconds or minutes during sleep). There is also growing evidence that loneliness and social isolation may increase someone's risk of dementia. In many of these cases, more research is needed to show the strength and 'direction' of this link (i.e. what causes what) (Llewellyn and Bayer, 2016).

Lifestyle factors

There is overwhelming evidence that our lifestyle choices affect our risk of developing dementia. This is especially true of activities linked to cardiovascular health, so 'What's good for your heart is good for your head'.

Studies of large groups show that dementia risk is lowest in people who have several healthy behaviours in mid-life. These behaviours include regular physical exercise, not smoking, drinking alcohol only in moderation (if at all), and maintaining a healthy diet and weight. The dementia risk is lowest in people who do three or more of these, not just one or two. Trials also suggest that practising healthy behaviours in combination seems to work better than adopting one or two.

This section summarises the scientific evidence from population studies or - less often - trials on the main lifestyle risk factors for developing dementia (Llewellyn and Bayer, 2016).

Physical inactivity -

This is one of the strongest lifestyle risk factors for developing dementia. It is also closely linked to an increased risk of heart disease, stroke and type 2 diabetes. These cardiovascular and metabolic effects of being inactive are well known, but physical inactivity also has direct effects on the structure and function of the brain (Llewellyn and Bayer, 2016).

Smoking -

Smoking tobacco has an extremely harmful effect on the heart, lungs and vascular system, including the blood vessels in the brain. Smoking significantly increases the risk of developing dementia later in life, especially Alzheimer's disease (as well as type 2 diabetes, stroke and heart disease) (Llewellyn and Bayer, 2016).

Unhealthy diet -

An unhealthy diet can affect a person's risk of developing many illnesses, including dementia, but also cardiovascular disease and type 2 diabetes. A poor diet is one that contains too much saturated fat, which raises cholesterol, narrows the arteries and leads to weight gain. An unhealthy diet also includes too much salt (which contributes to high blood pressure and stroke) and too much sugar (an additional factor in weight gain and type 2 diabetes) (Llewellyn and Bayer, 2016).

Excessive alcohol -

Regularly drinking above the NHS recommended levels of alcohol increases a person's risk of developing dementias such as Alzheimer's disease and vascular dementia. Excessive alcohol consumption at higher levels over a long period of time also increases the risk of developing Korsakoff's syndrome [26] and alcoholic dementia [27] (Llewellyn and Bayer, 2016).

Many specialists used to think that low to moderate levels of drinking - a few units each week - reduces the risk of dementia (mainly because it may help to keep the heart healthy). Although this 'protective effect' remains controversial,

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[26] a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1)

[27] a form of dementia caused by long-term, excessive consumption of alcoholic beverages, resulting in neurological damage and impaired cognitive function

most specialists now no longer think that alcohol at low or moderate levels reduces your dementia risk (Llewellyn and Bayer, 2016).

Head injuries -

A severe blow to the head - especially being knocked out - increases the risk of later dementia such as Alzheimer's disease. About a fifth of professional boxers go on to develop a different form of dementia. This used to be known as dementia pugilistica but is now known as chronic traumatic encephalopathy. This is thought to be caused by protein deposits formed in the brain as a result of head injury. Recent evidence suggests that professional American footballers, who often have repeat mild head injuries, may also be at risk of chronic traumatic encephalopathy (Llewellyn and Bayer, 2016).

How to reduce your risk of developing dementia

There are lots of things you can do to reduce your chances of developing dementia. You can adopt a healthy lifestyle at any time. It's never too early, but starting in mid-life is a good time if you've not already done so. Many people use significant changes in their lives - for example, children moving out, a health scare, divorce or starting the menopause - as a trigger to live more healthily.

You will find it easier to adopt a healthier lifestyle (e.g. exercising more or eating better) if you can build it into your normal daily routine. Getting your friends and family to support you - or better yet, join you - also makes it more fun and therefore makes you more likely to continue (Llewellyn and Bayer, 2016).

Be physically active

Regular moderate physical exercise is one of the best ways to reduce your risk of dementia, raise your cardiovascular health and improve your mental wellbeing. 'Regular' means exercising five times each week for 30 minutes each time. You can build up to this gradually. 'Moderate' exercise means doing an activity that leaves you a bit out of breath, raises your heart rate and may make you slightly sweaty. Exercising like this brings many health benefits even if you're not losing weight. Activities could include brisk walking, cycling, swimming or dancing. You don't have to go to a gym or run a marathon. You could join a walking group, try a class at your leisure centre, or go dancing with friends. Try cycling to work, walking the children to school, getting off the bus two stops earlier and walking or taking the stairs instead of the lift. There are now lots of wearable gadgets or smartphone apps which record how active you've been (Llewellyn and Bayer, 2016).

Stop smoking

If you do smoke, stop! It is better to stop smoking sooner (or better still, to never start) but it is never too late to quit. Even if you stop smoking in later life it will benefit your overall health and may reduce your risk of dementia. NHS Stop Smoking advisers can provide information, advice and support on how to quit. You might be able to refer yourself, or talk to your GP or local pharmacy for advice. Many people now use e-cigarettes, which provide nicotine without the harmful tobacco smoke, to help them quit smoking (Llewellyn and Bayer, 2016).

Eat healthily

A healthy balanced diet includes lots of fruit and vegetables. Aim for five portions a day. Fresh, frozen and tinned fruit and vegetables all count. A healthy diet also has fish at least twice a week, including oily fish (e.g. mackerel, salmon, sardines) which contains healthy polyunsaturated (omega-3) fatty acids and vitamin D. Adding starchy foods (e.g. potatoes, brown rice, pasta, bread) and protein (e.g. meat, fish, eggs, beans) will also help you maintain a balanced diet. Following a 'Mediterranean' kind of diet is good for your cardiovascular health and may reduce your dementia risk. This diet is high in vegetables, fruit and cereals. Fats are mainly unsaturated (eg olive oil) with very little saturated fat (eg cakes, biscuits, butter, most cheeses). A Mediterranean diet also has some fish, poultry, eggs and dairy, but only a small amount of red or processed meat. To eat healthily, limit sugary treats such as fizzy drinks and sweets and keep an eye on your salt intake, especially salt hidden in bread, pizza and ready meals. Read the labels on foods to see what they contain or look for healthier (reduced fat or salt) options. Speak to your doctor or pharmacist if you are thinking of taking a vitamin or mineral supplement (Llewellyn and Bayer, 2016).

Maintain a healthy weight

Keeping to a healthy weight will reduce your risk of type 2 diabetes, stroke and heart disease - and hence probably of dementia. As well as weight, keep an eye on your waistline, as fat round your middle is particularly unhealthy. A good starting point is to follow the advice on physical exercise and maintain a healthy diet. Keep a diary of your food intake and exercise for each day - you are more likely to lose weight if you burn off what you eat. Visit the NHS Live Well pages for ideas, such as eating smaller portions at mealtimes. Alcohol contains hidden calories, so be aware of how much you drink. You could also consider joining a local weight loss group. If you've tried to make changes without success, your GP can also offer advice (Llewellyn and Bayer, 2016).

Drink alcohol within recommended levels (if at all)

If you do drink, keep below the recommended NHS levels. These changed in 2016 and are now a maximum of 14 units each week for men and women, spread over three or more days. This is the same as four or five large glasses of wine over the week, or seven pints of beer or lager with lower alcohol content. To check how much you're drinking, record your units over the week - and be honest. If you want to cut down, set yourself a limit for each time you drink (and keep to it). You can also try smaller glasses, drinks with lower alcohol content, drinking with food, or alternating soft and alcoholic drinks. If you really find it a struggle to cut down, talk to your GP about what support is available (Llewellyn and Bayer, 2016).

Keep mentally active

If you can keep your mind stimulated you are likely to reduce your risk of dementia. Regular mental activity throughout a person's lifetime seems to increase the brain's ability. This helps build up a 'cognitive reserve' and allows the brain to cope better with disease. (This link between brain activity and dementia is sometimes described as '**Use it or lose it**'.) Keeping mentally active could help to delay the symptoms of dementia by several years. It could even mean that you never get it. You could try learning a new language, doing puzzles (e.g. word searches, crosswords, Sudoku), playing cards, reading challenging books or writing letters. Find something enjoyable which stimulates your mind, do it regularly and keep doing it. There is not yet enough evidence to add computer 'brain training' games to this list, in spite of claims made by some manufacturers. Benefits from brain training are so far modest. They might make you better at a specific task, as practised within the game, but broader benefits for your mind or daily life are so far largely unproven. None has been shown to reduce the risk of developing dementia, although there is lots of research and new studies reporting all the time (Llewellyn and Bayer, 2016).

Be social

There is emerging evidence that keeping socially engaged and having a supportive social network may reduce your dementia risk. It will also make you less prone to depression and more resilient. Try to visit family and friends, look after grandchildren, travel or volunteer. You may like to try joining a social/activity club or a group at a place of worship (Llewellyn and Bayer, 2016).

Take control of your health

Managing your health can reduce your dementia risk. If you are invited for an NHS Health Check (in England), make sure you go. At this free mid-life 'MOT', a health professional will talk to you and measure your cardiovascular risk factors (e.g. blood pressure, weight, cholesterol). If necessary, you can then agree a plan to reduce your own risk of cardiovascular disease and dementia. In Wales, visit the Add to your life website for a self-assessment (see 'Useful websites'). In Northern Ireland, contact Northern Ireland Chest, Heart and Stroke (see 'Other useful organisations'). You can keep track of your weight or measure your blood pressure at home at any time with a simple monitor. If you feel that you might be getting depressed, seek treatment early (Llewellyn and Bayer, 2016).

Long term condition?

If you are already living with a long-term condition (e.g. diabetes, heart disease or high blood pressure) it's important to keep this under control. Follow professional advice about taking medicines - even if you feel well - and on lifestyle, such as diet and exercise (Llewellyn and Bayer, 2016).

Assessment and diagnosis

If you are worried that you are getting more forgetful, or you have been feeling confused, anxious or low for a while, it is a good idea to visit your GP. If you are concerned that someone close to you has been experiencing these difficulties, or has been behaving out of character, you may like to suggest that they visit their GP and that you accompany them for the appointment.

The changes listed above may be caused by several conditions, but they may also be an indication of dementia. The term 'dementia' describes a set of symptoms that occur when the brain is damaged by certain diseases, such as Alzheimer's disease or a series of small strokes (Taylor and Llife, 2014).

Each person will experience dementia differently, but there will usually be problems with -

- day-to-day memory,
- concentrating, planning or organising,
- language (e.g. struggling to find the right word),
- judging distances and seeing objects properly (not caused by poor eyesight),
- orientation (e.g. confusion about the day or month, or where they are) (Taylor and Llife, 2014).

These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. For example, the person or their family may notice that they now struggle to use the phone or regularly forget to take their medicine.

A person with dementia may also experience changes in their mood or behaviour.

Assessment for possible dementia is not a single step but a process that takes time. It often starts with the person or family members realising that there is something wrong. Assessment proceeds through various stages and tests, and ends with sharing of the diagnosis. For the person and those close to them, this journey is often an uncertain, anxious and emotional one (Taylor and Llife, 2014).

Why get a diagnosis?

A thorough and timely assessment for possible dementia is essential, in order to -

- rule out other conditions that may have similar symptoms and may be treatable, including depression, chest and urinary tract infections, severe constipation, and vitamin and thyroid deficiencies,
- rule out other possible causes of confusion (e.g. poor sight or hearing), emotional changes and upsets (e.g. moving house or bereavement), or the side-effects of certain drugs or combinations of drugs,
- provide a person with dementia with an explanation for their symptoms, removing uncertainty and allowing them to begin to adjust,
- allow a person with dementia to access treatment as well as information, advice and support (emotional, practical, legal and financial),

- allow a person with dementia to plan and make arrangements for the future (Taylor and Llife, 2014).

If the outcome of the assessment is a diagnosis of dementia, it is important that the type (e.g. Alzheimer's disease or vascular dementia) is also diagnosed. Knowing the dementia type will help to understand symptoms, predict how the dementia might progress, and suggest how best to manage it. For example, certain drugs will be prescribed for Alzheimer's disease (but not vascular dementia), although these do not cure the condition (Taylor and Llife, 2014).

Making a diagnosis

Making a diagnosis of dementia is often difficult, particularly in the early stages. This is because there is no one simple test and early symptoms can be similar to those of lots of other common conditions, as mentioned above. A thorough assessment will often accurately diagnose the type of dementia, and people will usually be told the type, though this may only be confirmed after death if a post-mortem is done.

Most discussion about a persons possible diagnosis of dementia comes from their GP, although the assessment may take place in hospital (Taylor and Llife, 2014).

Assessment by a GP

In the case of suspected dementia, the first person to consult is the GP. A person may see the GP in their surgery, or the GP may prefer to make a home visit. If they suspect the person has dementia, it is often easier to assess and observe their behaviour in their home. The exact problems then become clearer, as the person is in a familiar environment. The GP will assess the person through the following procedures -

- **Taking a medical history** - The GP will spend some time talking to the person and someone who knows them well. (The doctor may contact a family member by phone if they cannot attend in person.) They will ask about how and when the symptoms started and how they are affecting the person's life. The GP will look at the person's medical history and those of other family members. They will also review the medicines the person is taking.
- **Physical examinations and tests** - The GP may carry out a physical examination, particularly if a stroke or Parkinson's disease is suspected.

They will also take samples (blood and possibly urine) to send off for tests. These may identify other conditions that are causing the symptoms.
- **Tests of mental abilities** - The GP will ask the person a series of questions or give them a short pen-and-paper test. These are designed to test thinking, memory and orientation (Taylor and Llife, 2014).

At the end of the assessment, the GP should explain their findings and discuss what action needs to be taken. Depending on their expertise and training, they may feel able to make a diagnosis at this stage, although this is uncommon. If it is dementia, the GP is more likely to be able to diagnose this if the condition is more advanced or the dementia is a common type such as Alzheimer's.

More often, the GP will decide that further assessment is needed to make sure. In such cases they will generally refer the person to a memory assessment service, memory clinic or other specialist service within a community mental health team. These services all have teams of different professionals, and are set up to assess people with memory problems, especially those with suspected dementia (Taylor and Llife, 2014).

Referral to a specialist

The GP is the usual person to make a referral to a specialist. If the person or their carer feels that a referral would be helpful and the GP does not suggest it, they should ask about it. A specialist such as a consultant will have more knowledge and experience of dementia than a GP. They will have more time allocated for the appointment and access to more specialised investigations, such as brain scans and in-depth mental testing. After referral, the person should have to wait no longer than 4–6 weeks to see a specialist.

The GP will make the referral to a consultant working in a particular specialty. Which specialty they refer them to may depend on the age of the person, their symptoms, and what is available in the area they live in. The main types of consultant are explained below.

- **Old age psychiatrists** - are psychiatrists who specialise in the mental health of older people, including dementia. They may sometimes also offer support to younger people with dementia.
- **General adult psychiatrists** - specialise in diagnosing and treating a wide range of mental health problems. A younger person (under 65) may be referred to such a psychiatrist to help with the diagnosis.
- **Geriatricians** - specialise in physical illnesses and disabilities associated with old age, and in the care of older people. If the person being assessed is frail or in poor general health, they may be referred to one of these spe-

cialists to see whether their symptoms are due to a physical illness. They may have a physical illness as well as dementia.
- **Neurologists** - specialise in diseases of the brain and nervous system. Some neurologists [28] have particular experience in diagnosing dementia. They tend to see younger people and those with less common types of dementia (Taylor and Llife, 2014).

The consultant usually works in a specialist team, alongside a number of doctors at various stages of training in that particular specialty. Although the person may not always see their consultant, they are ultimately responsible for the case and will discuss it with the doctor the person has seen. The consultant also usually works with other professionals, including mental health nurses, psychologists, occupational therapists, social workers and dementia advisers (professionals who provide information, advice and guidance to people with dementia and their carers) (Taylor and Llife, 2014).

Assessment

An assessment for possible dementia can be confusing and daunting, and a diagnosis of dementia is life-changing. Many memory services offer people who are about to go through assessment and diagnosis the chance to talk things over with a professional beforehand.

This pre-diagnostic counselling will help the person (and those close to them) understand why they have been referred, learn about the assessment process, give consent (or not) to go ahead, and prepare them for the possible outcomes. It is also an opportunity for the person and those supporting them to share what they already know about dementia, express their feelings and raise any concerns.

Assessment may take place in the home, in an outpatient's department at a hospital, in a day hospital over several weeks or, very occasionally, while the person stays in hospital as an inpatient. The specialist will carry out their assessment via the following steps -

- **Taking a medical history** - As with the GP, the specialist will talk to the person being assessed and those close to them for up to 90 minutes.
- **Physical examinations and tests** - A physical examination and/or tests will be undertaken, if they have not already been carried out by the GP. In many cases the blood tests will already have been done before referral.

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[28] a doctor who specialises in conditions of the nervous system, in conditions that affect the brain and spinal cord

- **Tests of mental abilities** - The person will have a more detailed assessment of memory and other thinking processes. This assessment consists of a range of pen-and-paper tests and questions. These will test things like memory, orientation, language and visuospatial skills (e.g. copying shapes). These tests can be very good at helping to determine the type of problem a person may have, particularly in the early stages. The assessment can also be used as a baseline to measure any changes over time, which can help with making a diagnosis. The test is often given by a trained professional such as a mental health nurse or occupational therapist. In more complicated cases the person will be assessed by a clinical psychologist or neuropsychologist (professionals whose specialty includes the diagnosis of mental health problems).
- **Scans** - The person might be sent for a brain scan. Depending on where they live, this may involve a wait of several weeks. There are several types of brain scan -
  - computerised tomography (CT), computerised axial tomography scan (CAT scan) and magnetic resonance imaging (MRI) scans are widely used. They all show structural changes to brain tissue.
  - single photon emission computerised tomography (SPECT) and positron emission tomography (PET) scans are less widely used. They show changes in brain activity (Taylor and Llife, 2014).

CT and MRI scans can identify conditions with similar symptoms to dementia such as a brain bleed, tumour or build-up of fluid inside the brain. If the person has dementia, these scans may show that the brain has shrunk in certain areas. MRI in particular may also show changes caused by diseased blood vessels in the brain, indicating stroke or possible vascular dementia. A scan showing no unexpected changes in the brain does not rule out conditions such as Alzheimer's disease. This is because in the early stages of the disease the changes can be difficult to distinguish from those seen in normal ageing.

SPECT and other more specialised scans can show areas where brain activity (blood flow or metabolism) is reduced. These scans are mostly used if the diagnosis of dementia type is still unclear after a CT or MRI scan.

To make the diagnosis, the consultant will bring together all the information from the history, symptoms, physical exam, tests and any scans. The combined picture will often allow a diagnosis to be made. If the diagnosis is dementia, the consultant should also be able to determine the type.

In some cases the consultant may diagnose mild cognitive impairment rather than dementia, especially if the symptoms are mild or could indicate depression. Mild cognitive impairment is when the person has problems with memory or thinking but these are not severe enough to be diagnosed as dementia. The specialist may then discharge the person back to their GP and ask the GP to re-refer them if they are significantly worse after a further 6–12 months. Sometimes the brain scan will not show any significant changes and a further scan is arranged (Taylor and Llife, 2014).

Getting the most from a consultation

If possible, someone who knows the person being assessed well should go with them to the consultation. Whether you are attending the appointment for yourself or for someone you are supporting, it may be useful to do the following -

- Write down any questions or worrying symptoms beforehand to bring up with the GP or specialist. Try to include details of when symptoms first started. It can be difficult to remember everything you want to say during a consultation.
- During the consultation, write down any important points the doctor makes.
- Ask the doctor (or any other professional) to explain any words or phrases you do not understand.
- Ask the doctor to write down any medical terms, especially if English is not your first language.
- If a professional refers to ’memory problems’ when giving a diagnosis, and you’re unclear what they mean, you might want to ask, ’*Do you mean I have dementia?*’ or ’*Is that the same as Alzheimer’s?*’, for example. Make sure you are clear what type of dementia has been diagnosed.
- A specialist should offer to send you a copy of the letter they will write to the GP. This letter will include details of the diagnosis. You can ask them to provide a more personalised letter, containing clear information about the diagnosis and care needs (Taylor and Llife, 2014).

Receiving the diagnosis

At the end of a consultation the doctor will explain if they can make any tentative diagnosis based on the information they have so far. When all the test results are known, a separate appointment will usually be made for the consultant, and often other professionals in the team, to give the final diagnosis. Very occasionally, the consultant will send a report to the person’s GP, who will then give the diagnosis.

A diagnosis of dementia should be communicated sensitively but honestly, in a way that is tailored to the needs of the individual. The person being assessed has the right to be told their diagnosis and should be asked if they wish to know the outcome. (Very occasionally, a person chooses not to know; this is their right too.) If relevant, the doctor should also ask the person if they are happy for the person attending with them to be told, although this question should already have been raised in any pre-diagnostic counselling. It is usually in everyone's interests for the diagnosis to be shared with those close to the person.

Occasionally the doctor will decide not to tell the person with dementia their diagnosis. It may be that the doctor thinks that the person would not understand the diagnosis, perhaps because the dementia is at a late stage. Or the doctor may feel that the person would find this knowledge too distressing. For example, they may be struggling with a very serious illness, have had a recent bereavement, or already been very upset by the assessment process so far. The doctor should discuss what is in the person's best interests with anyone supporting the person.

Doctors differ in how they communicate a diagnosis of dementia and the words they use. Some doctors will refer to 'memory problems' instead of using the word 'dementia'. What is important is that the doctor uses language that the person understands and takes things at a pace that works for them. Professionals should answer any questions the person has in a sensitive but honest and straightforward way.

Following a diagnosis of dementia there is lot to adjust to and a great deal of information to take in. The final diagnosis meeting will usually cover how the dementia is likely to progress and any treatments (drug or non-drug) as part of a care plan.

Most memory services also offer sessions, running for several weeks after diagnosis, at which the person and those close to them can talk through the next steps in more detail and receive further written information. These sessions usually cover medication, living well, driving, benefits, local support services, planning ahead and more (Taylor and Llife, 2014).

Ongoing assessment

Once a diagnosis of dementia is confirmed, any medication has been started, and any post-diagnostic sessions have been completed, the person will generally be discharged from the memory service back to their GP. (An exception may be that there is a need for ongoing specialist support for specific symptoms or behaviours.) As the dementia progresses, the GP may refer the person with dementia back to a specialist for help in assessing changes, and for advice on ways to deal with certain difficulties such as changes in behaviour. The GP remains responsible for the general health of the person with dementia.

Prescription of drugs for Alzheimer's disease will be started by the specialist and then routine prescribing will usually transfer to the GP. A review of these drugs is generally carried out every six months by the specialist or GP.

Someone diagnosed with dementia can seek support from their GP, or local support groups, if they feel they need it (Taylor and Llife, 2014).

After diagnosis

Receiving a diagnosis of dementia can be a difficult and emotional time. The diagnosis may come as a shock or it might provide answers to the problems you, or someone close to you, have been having. It can be hard to come to terms with it and know what to do next. Some people might even feel a sense of relief from knowing what is wrong and what steps to take. This section looks at things to consider after a diagnosis of dementia, including possible treatments, planning for the future, sources of support, and how to live well with the condition.

Support after a diagnosis is very important. The person with the diagnosis and their close family should be able to talk things over with a range of professionals. They might want to ask questions about the diagnosis and what it means for them. They should take some time to think about and discuss the future. Information on the help and support available, and on how to stay physically and mentally well, can also help.

A diagnosis of dementia shouldn't stop people being in control of their lives or doing many of the things they enjoy. They should be supported to remain independent, active and engaged, and fully involved in making decisions and choices for themselves, for as long as they can (Solomons and Walton, 2014).

Coming to terms with a diagnosis

Coming to terms with a diagnosis may take a long time. The person might experience a range of emotions, including shock, anger, fear, or even relief at having their symptoms explained. This is normal, and feelings may change from one day to the next. The person's friends and family are also likely to experience a range of emotions and their own difficulties coming to terms with what is happening.

It can help people to talk about their diagnosis, and how they feel about it, with family and friends. Talking about things openly and honestly can help them to think about how they can support each other, and look at ways for the person to carry on living an independent and active life. Talking can also help the person think about the future.

The person may want to talk about their diagnosis with others as well. This could be a counsellor, a health or social care professional, or other people with dementia. In some areas there will be post-diagnosis support groups. This will help the person, and those close to them, come to terms with the diagnosis and look at ways to live well with dementia. Someone might also be offered counselling, giving them an opportunity to talk through their diagnosis and their needs. The local memory service or GP can give more information about post-diagnosis support groups and counselling.

Who to tell about a diagnosis, and how much to say and when, are all up to the individual. They may be worried about how others might react. Some people only tell their close family; others tell friends as well. Some people tell neighbours or members of their community. Whatever the person decides to do, it should be what they feel is right for them (Solomons and Walton, 2014).

Treatments

Although there is no cure for dementia, drug treatments may help to alleviate some of the symptoms. Non-drug treatments can also help someone to manage their condition, and support them to live well after a diagnosis (Solomons and Walton, 2014).

Drug treatments

Someone with mild to moderate Alzheimer's disease may be prescribed donepezil (eg Aricept), rivastigmine (e.g. Exelon) or galantamine (e.g. Reminyl). These are called acetylcholinesterase inhibitors. They do not cure Alzheimer's, but may relieve memory problems and improve alertness for a while. Someone with moderate Alzheimer's disease who can't take an acetylcholinesterase inhibitor may be offered memantine (e.g. Ebixa). Memantine is also given for severe dementia.

For someone with vascular dementia, the doctor should offer drugs that treat the underlying conditions (e.g. high blood pressure). These may help to slow the progression of dementia.

If someone has dementia with Lewy bodies, the doctor may offer one of the acetylcholinesterase inhibitors to help alleviate distressing symptoms such as hallucinations or delusions.

Someone with the behavioural variant of frontotemporal dementia may be prescribed an antidepressant (Solomons and Walton, 2014).

Non-drug treatments

There are a range of non-drug approaches that can help people with any type of dementia to live well. These include talking therapies, such as counselling, which help someone address and come to terms with their diagnosis. Cognitive behavioural therapy, which helps people to change how they think ('cognition') and what they do ('behaviour') may be offered for depression.

A person with dementia may also benefit from cognitive rehabilitation (which aims to reduce the impact of poor memory on a person's quality of life [29]) and cognitive stimulation (involving activities and exercises designed to improve memory and communication skills). Other popular activities include life story work, creative activities (e.g. art), music-based activities or aromatherapy. The GP, memory service or local Alzheimer's Society can tell people what is available in the local area and what might work for them (Solomons and Walton, 2014).

Living well

Staying healthy

Having dementia shouldn't make someone feel ill or unwell. Any physical illness can make a difference to a person's ability to cope. It may also make them more confused or forgetful. If the person with dementia does feel ill or unwell, they should speak to their GP. Having regular check-ups with the GP is important. People with other long-term health conditions (e.g. diabetes) also need to ensure these are managed well.

Having dementia puts someone at increased risk of developing Depression. If they regularly feel low, anxious or irritable, they should speak to their GP; treatments for depression are available (Solomons and Walton, 2014).

Anyone with a diagnosis who is taking more than four medicines should ask their GP for a medication review. Medication can cause side-effects that can affect wellbeing, such as dizziness or increased confusion.

A person with dementia should have regular dental check-ups to help maintain good oral health. They should also have regular sight and hearing check-ups, as problems with these can affect how well they manage their dementia.

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[29] 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

Eating a balanced diet and drinking plenty of fluids are important for maintaining physical and mental wellbeing. A person with dementia should eat a variety of foods; a dietitian can provide advice on eating and drinking. The person's GP can make a referral.

Exercise can have a significant impact on wellbeing. It is good for both physical and mental health. Exercise could include walking, chair exercises, gardening or tai chi, and can be adapted to meet a person's needs. The most effective exercises are ones that the person enjoys and that they can incorporate into their everyday routine. See also Exercise and physical activity https://www.alzheimers.org.uk/factsheet/529

Staying socially involved and physically and mentally active is important. Remaining involved and active can help a person with dementia to maintain their skills and independence, and reduce loneliness. It may also help to improve sleep patterns and potentially prevent depression. Activities can be anything that the person finds enjoyable and wants to do. They should be incorporated into their everyday routine.

It may help to adapt an activity to make it easier, or to try new activities that may be more enjoyable. It is important that the person and those around them don't worry too much about the 'result' of the activity, but instead focus on the process and the enjoyment the person gets from it (Solomons and Walton, 2014). For more information see Staying involved and active https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=115

Maintaining independence

Having dementia makes everyday life more difficult, and a person with the condition may need to change how they do things. There are a variety of assistive technologies and gadgets that can help, which a person with a diagnosis may want to consider using. These could include memory aids (e.g. clocks, calendars and medication prompts) and telecare (e.g. falls sensors). It is important that the person is shown how to use these aids properly, so they can get the best out of them. The person's local disabled living centre or Alzheimer's Society office can provide more information about this. Assistive technology can also help people remain safer in their homes.

It can help to think about changes that can be made in the home environment to enhance independence and safety. For example, it can be helpful to increase light levels and remove trip hazards such as loose rugs. The local fire service can offer a free home safety visit.

An occupational therapist occupational therapist (OT) can provide more information on staying independent and safe at home. The GP or social services can arrange a referral to an occupational therapist (Solomons and Walton, 2014).

Planning ahead

Someone who has received a diagnosis of dementia may want to spend some time thinking about the future and their wishes. As the condition progresses, it will become more difficult for them to make decisions about their health, care (including end-of-life care) and finances.

Mental capacity is the ability to make decisions for yourself. People who cannot do this are said to 'lack capacity'. Planning ahead allows the person with dementia to make choices and decisions in advance about their future care, in case there is a time when they cannot make these decisions for themselves. A person with dementia should discuss their wishes with family and other people close to them (Solomons and Walton, 2014).

Wills

A will allows someone to choose who inherits their money and possessions when they die. It is still possible to make or change a will after a diagnosis of dementia, as long as the person can show that they understand the decision they are making, and the implications that any changes will have. A solicitor can help with making or updating a will (Solomons and Walton, 2014).

Lasting Power of Attorney

Making a Lasting Power of Attorney (LPA) allows a person with dementia to give someone they trust (the attorney) authority to make certain decisions on their behalf. This is often a family member or close friend. All decisions made by the attorney must be in the person's best interests. There are two different types of lasting power of attorney (LPA) -

- **Health and welfare LPA** - The attorney can make decisions about the person's healthcare (e.g. medical treatment) and welfare (e.g. where they live). These powers can only be used if the person can no longer make these decisions for themselves.
- **Property and affairs LPA** - The attorney has the power to manage the person's money, property and affairs on their behalf. This could include

paying bills, collecting income and benefits, accessing bank accounts and even selling a house (Solomons and Walton, 2014).

The attorney will not immediately get to take control when the LPA is made. In order for the LPA to be used, it first needs to be registered with the Office of the Public Guardian. The attorney can only make decisions on the person's behalf once the LPA has been registered, and when they can act may depend on how the LPA has been set up.

Anyone wanting to set up an LPA will need to have the mental capacity to do so. A solicitor can be paid to help with setting it up, but this isn't compulsory.

Lasting Powers of Attorney aren't yet available in Northern Ireland because the law is different (Solomons and Walton, 2014).

Advance statements

An advance statement is a record of a person's preferences and priorities for the future. It could cover where they wish to live or how they like to do day-to-day things (e.g. preferring a bath over a shower). It will be used if someone becomes unable to make decisions for themselves. An advance statement isn't legally binding, but it should be taken into account when deciding what is in the person's best interests. If the person does set up an advance statement, they should tell people about it and keep it somewhere safe (Solomons and Walton, 2014).

Advance decisions

An advance decision ensures that a person has a say in their future medical care, by enabling them to refuse - in advance - specific medical treatments or procedures. This is in case the person becomes unable to make these decisions for themselves. Decisions might include whether the person would be resuscitated if their heart stopped. An advance decision is legally binding. Anyone who would like to set one up should speak to their GP. It is important to review an advance decision regularly, and revise it as necessary, so that it continues to reflect the person's views. In Northern Ireland advance decisions are known as advance directives (Solomons and Walton, 2014).

Financial matters

Someone who has just received a diagnosis of dementia may want to check that their financial affairs are in order. It is important that all their essential details can be easily found. These could include details of bank accounts, tax, benefits, pension, mortgage or rent documents, insurance policies and their will.

Putting things in order as early as possible can help the person to feel prepared for the future. It will also mean that when things become more difficult to manage, they know that everything is arranged as they want it (Solomons and Walton, 2014).

Benefits

A person with a diagnosis of dementia may be eligible for a range of benefits. The local benefits agency, Citizens Advice Bureau or Age UK can carry out a benefits check to see what they may be entitled to.

The main benefits that may be relevant are Attendance allowance (AA) for people 65 and over, or Personal independence payment (PIP) for those under 65. PIP replaced Disability living allowance (DLA) from June 2013. These benefits aren't based on a person's financial situation or national insurance contributions. They are also tax-free (Solomons and Walton, 2014).

Driving

A diagnosis of dementia doesn't automatically mean that someone needs to stop driving immediately. However, they must tell the Driving and Vehicle Licensing Agency (DVLA) in Great Britain or the Driving and Vehicle Licensing Northern Ireland (DVLNI) about the diagnosis. They must also let their car insurance company know. The DVLA or DVLNI will request a report from the person's doctor and may also ask the person to take a driving assessment. These will be used by the DVLA or DVLNI to decide whether the person can continue to drive.

As dementia progresses, there will be a time when the person will need to stop driving. Having to stop driving can be very difficult, and can take a lot of adjustment (Solomons and Walton, 2014).

Working

Someone may receive a diagnosis of dementia while they are still working. This doesn't necessarily mean that they will need to give up work straight away, but there are some things they may want to think about (Solomons and Walton, 2014).

- **Talking to the employer** - It may help for the person to talk to their employer about the diagnosis. In some jobs, there may be a legal obligation to tell the employer: this will be in the person's contract. Once this conversation has taken place, the employer is obliged to make 'reasonable adjustments' to support the person to keep working if they want to.
- **Thinking about the future** - The person may want to take some time to consider the future, and to seek advice on their rights, pension and work-related benefits entitlements.
- **Leaving work** - The person may decide to retire early or stop working. If they do, they should seek advice about their pension.
- **Benefits** - Someone of working age may be eligible for a range of benefits. This will depend on their individual circumstances. A full benefits check will help the person find out what they are entitled to (Solomons and Walton, 2014).

It's important that a person with a diagnosis seeks advice about working and dementia. They can speak to their human resources department, trade union (if they have one), the Advisory, Conciliation and Arbitration Service (ACAS), the local Citizens Advice Bureau or the disability employment adviser at Jobcentre Plus (Solomons and Walton, 2014).

Support and services

After a diagnosis of dementia, someone may be unsure what to do next or where to go for help. Asking for support can be difficult, and the person may feel they don't need it. However, it can help for them to look into what's available in their area, should they need support now or in the future.

Information, advice and support are available from a range of places.

- **The NHS** provides services such as the local GP or memory service. There are a range of other NHS professionals who may be able to help, including occupational therapists and counsellors.
- **Charities and not-for-profit organisations** can provide support, advice and information for people with dementia and their carers. These can be national or local. They may run a range of local services including dementia adviser or dementia support worker services, support groups, activity groups and telephone helplines. The local Alzheimer's Society office can tell people what is available in their area.
- **Social services and social care** can help work out the care and support needs of a person with dementia and their carer. They can also arrange for care and support to be provided. For more information about this, the per-

son or their carer can contact their local social services department. Anyone wishing to have their needs assessed should ask about a community care assessment. Carers can have their needs assessed too: they need to ask for a carer's assessment. Information and advice from social services are free.

- **Private companies** can provide care and support services at home. There may be a charge for these services. Details of local registered companies can be found by contacting social services, the UK Homecare Association or the website of the local regulator: the Care Quality Commission (CQC) in England, Care and Social Services Inspectorate Wales (CSSIW), or the Regulation and Quality Improvement Authority (RQIA) in Northern Ireland. The availability of some services varies between areas of the UK (Solomons and Walton, 2014).

The memory clinic, social services, local Alzheimer's Society office or other local voluntary organisations can provide information on what is available in the person's local area. Some services may be available for free, but others may have a cost (Solomons and Walton, 2014).

Services for younger people with dementia

Someone under 65 who has been diagnosed with dementia may want services that are specifically designed for younger people with dementia. These may include specialist support groups, advocacy, counselling and day centres. The person's family may also benefit from specialist support.

The provision of specialist services for younger people with dementia is patchy, but the number of services is rising. The memory clinic, GP or Alzheimer's Society office can provide information on what services and support are available locally (Solomons and Walton, 2014).

Dementia

What is dementia?

Dementia is a progressive disorder that affects how your brain works and in particular the ability to remember, think and reason.

It is not a disease in itself - but a group of symptoms that may accompany a number of diseases that affect the brain.

The most common of these is Alzheimer's disease. Another is Vascular dementia which can develop following a stroke or mini stroke or if there is blood vessel damage that interrupts the flow of blood to your brain. Other types of dementia include - Dementia with Lewy bodies - DLB and Frontotemporal dementia.

Dementia is not a consequence of growing old but the risk of having dementia increases with age.

In 2014, of the estimated that 850,000 people who were living with dementia in the UK, 773,502 were aged 65 and over (AGEUK, 2016).

Common symptoms of dementia

In most cases, the symptoms that characterise dementia come on gradually and get worse over time, often over a number of years.

Symptoms can vary according to the disease causing them and from person to person. They affect your daily life and are more than just occasional lapses. Symptoms of dementia include -

- Struggling to remember things that happened recently, even though you can easily remember things from longer ago,
- Struggling to follow conversations, particularly in groups,
- Forgetting the names of people or things,
- Struggling to follow a story on television or in a book, or understand magazine and newspaper articles,
- Having trouble remembering the day or date,
- Having trouble remembering where you put something, or where things are kept,
- Being unaware that you are repeating yourself or losing the thread of what you are saying in mid-sentence,
- Difficulty completing familiar tasks,
- Struggling to do things you used to find easy,
- Feeling confused even in a familiar place,
- Having problems controlling your mood, or controlling your emotions (AGEUK, 2016).

Both the person with dementia and those around them may not even notice the signs or take them seriously for quite some time (AGEUK, 2016).

Seeking further advice

If problems like these start to affect your daily life, it is worth sharing your concerns and making an appointment to discuss them with your GP.

If you are worried about someone else, try to encourage them to see their GP. You could offer to go with them for support if they seem a bit reluctant (AGEUK, 2016).

Could you be at risk?

There does not appear to be a single cause of dementia. Research to date suggests a combination of factors affect your overall risk of developing it.

You cannot do anything about factors such as your age or genetics but you can make changes to your lifestyle.

Age

This is the most significant risk factor and chances of developing dementia increase with age (AGEUK, 2016).

Genetics

This seems to be more significant if you develop dementia under the age of 65. In the majority of cases the significance of inheritance seems small. If a parent or other relative develops it, your own chances are only a little higher than if there were no cases in your family (AGEUK, 2016).

Lifestyle

People who follow a healthy lifestyle that protects their heart and blood vessels and who enjoy active and fulfilling lives have been shown to have a lower risk of dementia. Therefore aim to -

- eat a varied diet with plenty of fruit and vegetables,
- eat less salty and fatty foods, particularly avoiding those high in saturated fat,
- drink alcohol in moderation,
- stop smoking,
- take regular exercise,

- enjoy an active life with plenty of outside interests that exercise body and mind,
- ask your GP to check your blood pressure and cholesterol,
- keep your blood glucose well controlled if you have diabetes (AGEUK, 2016).

Diagnosis and treatment

Memory problems can have many underlying causes and are associated with some physical illnesses. These include thyroid problems, urinary tract infections and constipation. They can also be a side-effect of medication or due to stress, tiredness or depression. If your GP considers these but rules them out, there are a number of ways to assess your symptoms further.

As a first step, your GP will chat to you to find out more about you and your symptoms. This can include exploring how they are affecting your daily life. Your GP may carry out some recognised tests to check your thinking and memory. If a family member or someone who knows you well can be there too, it can be helpful for moral support and to support what you are saying.

Your GP may feel able to make a decision based on their findings but is likely to refer you for a fuller assessment to a memory clinic or consultant with more specialist knowledge. If you believe this would be helpful but the GP does not suggest it, ask if you can be referred as you have a right to ask for a second opinion.

Staff at the memory clinic may want to carry out further tests, including a brain scan, to get a clearer picture that will help them reach a diagnosis (AGEUK, 2016).

Difficulty of diagnosis

Making a diagnosis of dementia and confirming which type you have can be difficult, particularly in the early stages. Each person will experience it in their own way and their condition will progress at a different rate.

If you would like more specialist information, the Alzheimer's Society and Alzheimer's Research UK provide information on all types of dementia and have helplines that you can call for advice and support. There is also information about dementia in the health A-Z section of the NHS Choices website.

Your consultant should explain their findings, discuss next steps with you and answer any questions you may have. You can choose not to know your diagnosis. You can also choose who else can know about your diagnosis.

If you receive a diagnosis, it is important to know who will be responsible for managing your care in the short and longer term and who you can contact with any questions or worries (ageuk, 2016).

Treatment

There are drug treatments and non-drug treatments that can either help slow down progression of the dementia or help with some of the symptoms.

The National Institute for Health and Care Excellence (NICE) has issued guidance on supporting people with dementia and their carers. This includes information about the types of medication that can help some people with Alzheimer's disease. These medications address symptoms that affect memory and thinking and can slow their rate of progression.

The NICE guidance also discusses the role of non-drug treatments such as cognitive stimulation therapy. This can help people who have mild or moderate dementia with symptoms that affect their thinking or memory. It involves doing activities that require some thought and problem-solving but in a fun way and can be provided by health or social care staff who have had appropriate training.

Other non-drug treatments can help with help with symptoms that affect mood or behaviour, such as reminiscence therapy, massage, music and other therapies. These treatments can foster a sense of wellbeing in many people with dementia.

Everyone experiences dementia in their own way. The key is to understand the individual and their life history and see if this understanding can help you identify triggers for particular types of behaviour.

NICE has also developed a Quality Standard for Dementia Care. It describes standards that the NHS should be working towards when developing services for people with dementia and their carers (ageuk, 2016).

Help and support

If you wish to discuss your symptoms and concerns before visiting your GP, while awaiting the results of any investigations or if you are recently diagnosed with dementia you may wish to contact one of the dementia charities - Dementia UK, Alzheimer's Research UK, or the Alzheimer's Society. They may be able to answer your questions about medication available and offer information or advice to support you if you are living with or caring for someone with dementia.

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The Alzheimer's Society has over 240 local groups who can offer practical and emotional support and signpost to local services (AGEUK, 2016).

Social care, practical and emotional support

The nature of dementia means your condition will change over time. It is important that the health professional responsible for your care tells you about the range of local services that can help you and family members who care for you as your needs change.

This includes social services should you need help with personal care and day-to-day activities and voluntary groups that can provide both practical and emotional support to you and your family.

Caring is a very demanding job. So if you care for someone with dementia you can ask social services for an assessment to identify your need for support. You may be eligible for regular respite or longer respite breaks (AGEUK, 2016).

Financial Support

If you have difficulty managing personal care or day-to-day tasks or need watching over to make sure you are all right, you may be able to claim a non means-tested benefit - Personal Independence Payment (PIP) if you are under 65 years old or Attendance Allowance if you are aged 65 and over (AGEUK, 2016).

Alzheimer's disease

Alzheimer's disease is the most common type of dementia, affecting an estimated 850,000 people in the UK (NHS, 2016a). Most common type of dementia; accounts for an estimated 60–80% of cases (ALZ.ORG, 2016d). Dementia is a progressive neurological disease which affects multiple brain functions, including memory.

The exact cause of Alzheimer's disease is unknown, although a number of things are thought to increase your risk of developing the condition. These include -

- increasing age,
- a family history of the condition,
- previous severe head injuries,
- lifestyle factors and conditions associated with cardiovascular disease (NHS, 2016a).

It's becoming increasingly understood that it's very common to have both changes of Alzheimer's and vascular dementia together (mixed dementia) (NHS, 2016a).

Causes

Alzheimer's disease is caused by parts of the brain shrinking (atrophy), which affects the structure and function of particular brain areas.

It's not known exactly what causes this process to begin. However, in the brains of people with Alzheimer's disease, scientists have found amyloid plaques (abnormal deposits of protein), neurofibrillary tangles (containing tau) and imbalances in a chemical called acetylcholine.

It's also common to have a degree of vascular damage in the brain.

These reduce the effectiveness of healthy neurons (nerve cells that carry messages to and from the brain), gradually destroying them.

Over time, this damage spreads to several areas of the brain. The first areas affected are responsible for memories (NHS, 2016a).

Increased risk

Although it's still unknown what triggers Alzheimer's disease, several factors are known to increase your risk of developing the condition (NHS, 2016a).

Age -

Age is the single most significant factor in the development of Alzheimer's disease. The likelihood of developing the condition doubles every five years after you reach 65 years of age.

However, it's not just older people who are at risk of developing Alzheimer's disease. Around 1 in 20 people with the condition are under 65. This is called early onset Alzheimer's disease and it can affect people from around the age of 40. (NHS, 2016a).

Family history -

The genes you inherit from your parents can contribute to your risk of developing Alzheimer's disease, although the actual increase in risk is small if you have a close family member with the condition.

However, in a few families, Alzheimer's disease is caused by the inheritance of a single gene, and the risks of the condition being passed on are much higher.

If several of your family members have developed dementia over the generations, it may be appropriate to seek genetic counselling for information and advice about your chances of developing Alzheimer's disease when you are older (NHS, 2016a).

Down's syndrome -

People with Down's syndrome are at a higher risk of developing Alzheimer's disease.

This is because the genetic fault that causes Down's syndrome can also cause amyloid plaques to build up in the brain over time, which can lead to Alzheimer's disease in some people (NHS, 2016a).

Head injuries -

People who have had a severe head injury have been found to be at higher risk of developing Alzheimer's disease (NHS, 2016a).

Cardiovascular disease -

Research shows that several lifestyle factors and conditions associated with cardiovascular disease can increase the risk of Alzheimer's disease (NHS, 2016a).

These include -

- smoking,
- obesity,
- diabetes,
- high blood pressure,
- high cholesterol (NHS, 2016a).

You can help reduce your risk by -

- stopping smoking,
- eating a healthy, balanced diet,
- leading an active life, both physically and mentally,
- losing weight if you need to,
- drinking less alcohol,
- having regular health checks as you get older (NHS, 2016a).

Brain changes

Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles) as well as evidence of nerve cell damage and death in the brain (ALZ.ORG, 2016d).

Symptoms

The symptoms of Alzheimer's disease progress slowly over several years. Sometimes these symptoms are confused with other conditions and may initially be put down to old age.

The rate at which the symptoms progress is different for each individual and it's not possible to predict exactly how quickly it will get worse.

In some cases, infections, medications, strokes or delirium can be responsible for symptoms getting worse. Anyone with Alzheimer's disease whose symptoms are rapidly getting worse should be seen by a doctor, so these can be managed (NHS, 2016a).

Difficulty remembering recent conversations, names or events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired communication, poor judgment, disorientation, confusion, behaviour changes and difficulty speaking, swallowing and walking (ALZ.ORG, 2016d).

Stages of Alzheimer's disease

Generally, the symptoms of Alzheimer's disease are divided into three main stages (NHS, 2016a).

Early symptoms -

In the early stages, the main symptom of Alzheimer's disease is memory lapses. For example, someone with early Alzheimer's disease may -

- forget about recent conversations or events, or misplace items,
- forget the names of places and objects, or have trouble thinking of the right word,
- repeat themselves regularly, such as asking the same question several times,
- show poor judgement or find it harder to make decisions,

- become less flexible and more hesitant to try new things (NHS, 2016a).

There are often signs of mood changes, such as increasing anxiety or agitation, or periods of confusion (NHS, 2016a).

Middle-stage symptoms -

As Alzheimer's disease develops, memory problems will get worse. Someone with the condition may find it increasingly difficult to remember the names of people they know and may struggle to recognise their family and friends (NHS, 2016a).

Other symptoms may also develop, such as -

- increasing confusion and disorientation - for example, getting lost, or wandering and not knowing what time of day it is,
- obsessive, repetitive or impulsive behaviour,
- delusions (believing things that are untrue) or feeling paranoid and suspicious about carers or family members,
- problems with speech or language, known as aphasia,
- disturbed sleep,
- changes in mood, such as frequent mood swings, depression and feeling increasingly anxious, frustrated or agitated,
- difficulty performing spatial tasks, such as judging distances,
- hallucinations (NHS, 2016a).

By this stage, someone with Alzheimer's disease usually needs support to help them with their everyday living. For example, they may need help eating, washing, getting dressed and using the toilet (NHS, 2016a).

Later symptoms -

In the later stages of Alzheimer's disease, the symptoms become increasingly severe and distressing for the person with the condition, as well as their carers, friends and family.

Hallucinations and delusions may come and go over the course of the illness, but can get worse as the condition progresses. Sometimes people with Alzheimer's disease can be violent, demanding and suspicious of those around them (NHS, 2016a).

A number of other symptoms may also develop as Alzheimer's disease progresses, such as -

- difficulty eating and swallowing, known as dysphagia [30],
- difficulty changing position or moving around without assistance,
- considerable weight loss - although some people eat too much and put on weight,
- unintentional urinary incontinence or bowel incontinence [31],
- gradual loss of speech,
- significant problems with short- and long-term memory (NHS, 2016d).

In the severe stages of Alzheimer's disease, people may need full-time care and assistance with eating, moving and using the toilet.

Diagnosis

It's best to see your GP if you're worried about your memory or think you may have dementia.

If you're worried about someone else, encourage them to make an appointment and perhaps suggest going with them. It's often very helpful having a friend or family member there.

A timely diagnosis gives you the best chance to adjust, prepare and plan for the future, as well as accessing treatments and support that may help (NHS, 2016a).

Seeing your GP

Memory problems aren't just caused by dementia - they can also be caused by -

- depression or anxiety [32],
- stress,
- medications,
- alcohol or drugs,
- other health problems - such as hormonal disturbances or nutritional deficiencies (NHS, 2016a).

Your GP can carry out some simple checks to try to find out what the cause may be. They can then refer you to a specialist for assessment, if necessary.

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[30] Dysphagia is the medical term for swallowing difficulties. Some people with dysphagia have problems swallowing certain foods or liquids, while others can't swallow at all.

[31] an inability to control bowel movements, resulting in involuntary soiling. It's also sometimes known as faecal incontinence

[32] anxiety is a feeling of unease, such as worry or fear, that can be mild or severe

Your GP will ask about your concerns and what you or your family have noticed. They'll also check other aspects of your health, and carry out a physical examination. They may also organise some blood tests and ask about any medication you're taking to rule out other possible causes of your symptoms.

You'll usually be asked some questions and carry out some memory, thinking, and pen and paper tasks to check how different areas of your brain are functioning. This can help your GP decide if you need to be referred to a specialist for more assessments (NHS, 2016a).

Referral to a specialist -

Your GP may refer you to a specialist memory assessment service to help with your diagnosis. Memory clinics are staffed by professionals from multiple disciplines who are experts in diagnosing, caring for and advising people with dementia and their families (NHS, 2016a).

Memory clinic staff can include the following, depending on your local area -

- **a nurse** - usually a trained mental health nurse who specialises in diagnosing and caring for people with dementia,
- **a psychologist** - a healthcare professional who specialises in the assessment and treatment of mental health conditions,
- **a psychiatrist** - a qualified medical doctor who has training in treating mental health conditions,
- **a neurologist** - a specialist in treating conditions that affect the nervous system (the brain and spinal cord),
- **a geriatrician** - a doctor with specialist training in the care of older people,
- **a social worker** - a trained member of staff able to advise and assist with accessing social services within the local area,
- **an occupational therapist** - a member of staff with specialist skills in assessing and supporting people with dementia and their families with adjusting to disabilities (NHS, 2016a).

There's no simple and reliable test for diagnosing Alzheimer's disease, but the staff will listen to the concerns of both you and your family about your memory or thinking. They will assess your skills and arrange more tests to rule out other conditions (NHS, 2016a).

Assessing your mental abilities -

A specialist will usually assess your mental abilities using a special series of questions.

One widely used test is the mini mental state examination (MMSE). This involves being asked to carry out activities such as memorising a short list of objects correctly and identifying the current day of the week, month and year. Different memory clinics may also use other, longer tests.

The MMSE isn't used to diagnose Alzheimer's disease, but it's useful to initially assess areas of difficulty that a person with the condition may have. This helps specialists to make decisions about treatment and whether more tests are necessary (NHS, 2016a).

Tests -

To rule out other possible causes of your symptoms and look for possible signs of damage caused by Alzheimer's disease, your specialist may recommend having a brain scan. This could be a -

- **computerised tomography (CT) scan** - where several X-rays [33] of your brain are taken at slightly different angles and a computer is used to put the images together, see CT scan.
- **magnetic resonance imaging (MRI) scan** - where a strong magnetic field and radio waves are used to produce detailed images of the inside of your brain, see MRI scan (NHS, 2016a).

Some specialist centres offer scans which look at brain function and particular protein deposits. However, at the moment, these are mostly experimental and only used if the diagnosis is unclear (NHS, 2016a).

After diagnosis

It may take several appointments and tests over months, or even years, before a diagnosis of Alzheimer's disease can be confirmed.

For some people, a diagnosis of Alzheimer's disease is a huge shock, especially as it's not unusual for people with dementia to have less awareness of their difficulties.

For others, the diagnosis can be very important in helping them and their families to make sense of symptoms they've been concerned about for a long time.

If you've just been given a diagnosis of dementia, you may be feeling numb, scared and unable to take everything in. It may be helpful to have the diagnosis explained again to help make sense of the idea over time. It might help to talk

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[33] a quick and painless procedure commonly used to produce images of the inside of the body

things through with family and friends, and to seek support from the Alzheimer's Society.

It takes time to adapt to a diagnosis of dementia, for both you and your family. Some people find it helpful to seek information and plan for the future, but others may need a longer period to process the news.

However, as dementia is a progressive illness, the weeks to months after a diagnosis is often a good time to think about legal, financial and healthcare matters for the future (NHS, 2016a).

Prevention

As the exact cause of Alzheimer's disease is still unknown, there's no way to prevent the condition. However, there are steps you can take that may help to delay the onset of dementia (NHS, 2016a).

Reducing your risk of cardiovascular disease

Cardiovascular disease has been linked with an increased risk of Alzheimer's disease and vascular dementia (NHS, 2016a).

You may be able to reduce your risk of developing these conditions - as well as other serious problems, such as strokes and heart attacks - by taking steps to improve your cardiovascular health, including -

- stopping smoking,
- not drinking large amounts of alcohol,
- eating a healthy, balanced diet, including at least five portions of fruit and vegetables every day,
- exercising for at least 150 minutes (2 hours and 30 minutes) every week by doing moderate-intensity aerobic activity (such as cycling or fast walking) – this will improve both your physical and mental health,
- make sure your blood pressure is checked and controlled through regular health tests,
- if you have diabetes, make sure you keep to the diet and take your medication (NHS, 2016d).

Staying mentally active

There's some evidence to suggest that rates of dementia are lower in people who remain as mentally, physically and socially active as possible throughout their lives, as well as among those who enjoy a wide range of different activities and hobbies (NHS, 2016d).

It may be possible to reduce your risk of Alzheimer’s disease and other types of dementia by -

- reading,
- writing for pleasure,
- learning foreign languages,
- playing musical instruments,
- taking part in adult education courses,
- playing tennis,
- playing golf,
- swimming,
- group sports, such as bowling,
- walking,
- Interventions such as ”brain training” computer games have been shown to improve cognition over a short period, but research hasn’t yet demonstrated whether this can prevent dementia (NHS, 2016d).

Future research

Research into Alzheimer’s disease is continuing. As more is revealed about the condition, other ways to treat or prevent it may be found.

Participation in research is important and helps to improve dementia care and support for people with dementia, plus their carers and families.

You can read about ongoing dementia research on the Alzheimer’s Research UK website. You can also ask your local memory clinic about projects taking place.

The National Institute for Health and Care Excellence (NICE) has advised that there isn’t evidence to support the use of the following to prevent dementia -

- statins,
- hormone replacement therapy - when chemicals are taken to replace those that your body no longer produces,
- vitamin E - found in a variety of foods, such as olive oil, nuts and seeds,
- non-steroidal anti-inflammatory drugs (NSAIDs) (NHS, 2016d).

Vascular dementia

Vascular dementia is the second most common type of dementia (after Alzheimer's disease), affecting around 150,000 people in the UK.

The word 'dementia' describes a set of symptoms that can include memory loss and difficulties with thinking, problem-solving or language. In vascular dementia, these symptoms occur when the brain is damaged because of problems with the supply of blood to the brain (PASSMORE, MAKIN and KEHOE, 2014).

Causes

Vascular dementia is caused by reduced blood flow to the brain, which damages and eventually kills the brain cells (NHS, 2015v).

To be healthy and function properly, brain cells need a constant supply of blood to bring oxygen and nutrients. Blood is delivered to the brain through a network of vessels called the vascular system. If the vascular system within the brain becomes damaged - so that the blood vessels leak or become blocked - then blood cannot reach the brain cells and they will eventually die.

This death of brain cells can cause problems with memory, thinking or reasoning. Together these three elements are known as cognition [34]. When these cognitive problems are bad enough to have a significant impact on daily life, this is known as vascular dementia (PASSMORE, MAKIN and KEHOE, 2014).

This death of some brain cells can happen for a number of reasons, including -

- **narrowing of the small blood vessels deep inside the brain** - this is known as subcortical vascular dementia, or small vessel disease,
- **a stroke** (where the blood supply to part of the brain is suddenly cut off, usually as the result of a blood clot) - this is sometimes called post-stroke dementia, or single-infarct dementia,
- **lots of mini-strokes** - that cause tiny, but widespread, damage to the brain - this is known as multi-infarct dementia (NHS, 2015v).

In some people, the damage to the brain may be caused by Alzheimer's disease in addition to one of these conditions. This is known as mixed dementia (NHS, 2015v).

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[34] a generic term embracing the mental activities associated with thinking, learning, and memory

Who's most at risk?

Things that can increase your chances of developing vascular dementia in later life include -

- high blood pressure (hypertension),
- smoking,
- poor diet,
- high blood cholesterol,
- lack of exercise,
- being overweight or obese,
- diabetes,
- excessive alcohol consumption,
- an irregular heartbeat (atrial fibrillation) (NHS, 2015v).

These problems can result in damage to the blood vessels in and around the brain, or cause blood clots to develop inside them (NHS, 2015v).

Can I reduce my risk?

By making healthy lifestyle changes - such as stopping smoking and exercising regularly - and treating any health conditions you have, you may be able to reduce your risk of developing vascular dementia.

This may also help slow down or stop the progression of vascular dementia if you are diagnosed in the early stages (NHS, 2015v).

However, there are some things you can't change that can increase your risk of vascular dementia, such as

- **your age** - the risk of vascular dementia increases as you get older, with people over 65 most at risk (NHS, 2015v), A person's risk of developing the condition doubles approximately every five years over the age of 65. Vascular dementia under the age of 65 is uncommon and affects fewer than 8,000 people in the UK. Men are at slightly higher risk of developing vascular dementia than women (Passmore, Makin and Kehoe, 2014).
- **major conditions** - A person who has had a stroke, or who has diabetes or heart disease, is approximately twice as likely to develop vascular dementia. Sleep apnoea, a condition where breathing stops for a few seconds or minutes during sleep, is also a possible risk factor. Someone can reduce their risk of dementia by keeping these conditions under control, through taking prescribed medicines (even if they feel well) and following professional advice about their lifestyle. There is some evidence that a history of depression also increases the risk of vascular dementia. Anyone who

thinks they may be depressed should seek their doctor's advice early (Passmore, Makin and Kehoe, 2014).

- **Cardiovascular disease** - and therefore vascular dementia - is linked to high blood pressure, high cholesterol and being overweight in mid-life. Someone can reduce their risk of developing these by having regular check-ups (over the age of 40), by not smoking, and by keeping physically active. It will also help to eat a healthy balanced diet and drink alcohol only in moderation. Aside from these cardiovascular risk factors, there is good evidence that keeping mentally active throughout life reduces dementia risk. There is some evidence for the benefits of being socially active too (Passmore, Makin and Kehoe, 2014).
- **genetic factors** - Researchers think there are some genetic factors behind the common types of vascular dementia, and that these are linked to the underlying cardiovascular diseases. Someone with a family history of stroke, heart disease or diabetes has an increased risk of developing these conditions. Overall, however, the role of genes in the common types of vascular dementia is small (Passmore, Makin and Kehoe, 2014).
- **your ethnicity** - People from certain ethnic groups are more likely to develop cardiovascular disease and vascular dementia than others. Those from an Indian, Bangladeshi, Pakistani or Sri Lankan background living in the UK have significantly higher rates of stroke, diabetes and heart disease than white Europeans. Among people of African-Caribbean descent, the risk of diabetes and stroke - but not heart disease - is also higher. These differences are thought to be partly inherited but mainly due to lifestyle factors such as diet, smoking and exercise (Passmore, Makin and Kehoe, 2014).

In rare cases, unavoidable genetic conditions can also increase your risk of vascular dementia.

For example, small vessel disease can occur as the result of an inherited disorder called cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL).

This is caused by a faulty gene that makes the blood vessels in the brain more susceptible to changes (NHS, 2015v).

Types of vascular dementia

There are several different types of vascular dementia. They differ in the cause of the damage and the part of the brain that is affected. The different types of vascular dementia have some symptoms in common and some symptoms that differ. Their symptoms tend to progress in different ways (Passmore, Makin and Kehoe, 2014).

Stroke-related dementia

A stroke happens when the blood supply to a part of the brain is suddenly cut off. In most strokes, a blood vessel in the brain becomes narrowed and is blocked by a clot. The clot may have formed in the brain, or it may have formed in the heart (if someone has heart disease) and been carried to the brain. Strokes vary in how severe they are, depending on where the blocked vessel is and whether the interruption to the blood supply is permanent or temporary (Passmore, Makin and Kehoe, 2014).

Post-stroke dementia

A major stroke occurs when the blood flow in a large vessel in the brain is suddenly and permanently cut off. Most often this happens when the vessel is blocked by a clot. Much less often it is because the vessel bursts and bleeds into the brain. This sudden interruption in the blood supply starves the brain of oxygen and leads to the death of a large volume of brain tissue.

Not everyone who has a stroke will develop vascular dementia, but about 20% of people who have a stroke do develop this post-stroke dementia within the following six months. A person who has a stroke is then at increased risk of having further strokes. If this happens, the risk of developing dementia is higher (Passmore, Makin and Kehoe, 2014).

Single-infarct and multi-infarct dementia

These types of vascular dementia are caused by one or more smaller strokes. These happen when a large or medium-sized blood vessel is blocked by a clot. The stroke may be so small that the person doesn't notice any symptoms. Alternatively, the symptoms may only be temporary - lasting perhaps a few minutes - because the blockage clears itself. (If symptoms last for less than 24 hours this is known as a 'mini-stroke' or transient ischaemic attack (TIA). A TIA may mistakenly be dismissed as a 'funny turn'.)

If the blood supply is interrupted for more than a few minutes, the stroke will lead to the death of a small area of tissue in the brain. This area is known as an infarct. Sometimes just one infarct forms in an important part of the brain and this causes dementia (known as single-infarct dementia). Much more often, a series of small strokes over a period of weeks or months lead to a number of infarcts spread around the brain. Dementia in this case (known as multi-infarct dementia) is caused by the total damage from all the infarcts together (Passmore, Makin and Kehoe, 2014).

Subcortical dementia

Subcortical vascular dementia is caused by diseases of the very small blood vessels that lie deep in the brain. These small vessels develop thick walls and become stiff and twisted, meaning that blood flow through them is reduced.

Small vessel disease often damages the bundles of nerve fibres that carry signals around the brain, known as white matter. It can also cause small infarcts near the base of the brain.

Small vessel disease develops much deeper in the brain than the damage caused by many strokes. This means many of the symptoms of subcortical vascular dementia are different from those of stroke-related dementia.

Subcortical dementia is thought to be the most common type of vascular dementia (Passmore, Makin and Kehoe, 2014).

Mixed dementia (vascular dementia and Alzheimer's disease)

At least 10% of people with dementia are diagnosed with mixed dementia. This generally means that both Alzheimer's disease and vascular disease are thought to have caused the dementia. The symptoms of mixed dementia may be similar to those of either Alzheimer's disease or vascular dementia, or they may be a combination of the two (Passmore, Makin and Kehoe, 2014).

Symptoms of vascular dementia and its early warning signs

Early warning signs of vascular dementia can be hard to spot, but if they are identified early, treatment may help slow or halt the progression of the condition (NHS, 2015v).

Early signs

Possible early signs of vascular dementia can include slight -

- slowness of thought,
- difficulty with planning,

- trouble with language,
- problems with attention and concentration,
- mood or behavioural changes (NHS, 2015v).

This early stage is known as vascular cognitive impairment, and it may be barely noticeable or mistaken for something else, such as depression.

However, these symptoms can indicate that some brain damage has already occurred and treatment needs to be started immediately (NHS, 2015v).

The most common cognitive symptoms in the early stages of vascular dementia are -

- problems with planning or organising, making decisions or solving problems,
- difficulties following a series of steps (eg cooking a meal),
- slower speed of thought,
- problems concentrating, including short periods of sudden confusion (Passmore, Makin and Kehoe, 2014).

A person in the early stages of vascular dementia may also have difficulties with -

- memory - problems recalling recent events (often mild),
- language - e.g. speech may become less fluent,
- visuospatial skills - problems perceiving objects in three dimensions (Passmore, Makin and Kehoe, 2014).

As well as these cognitive symptoms, it is common for someone with early vascular dementia to experience mood changes, such as apathy, depression or anxiety. Depression is common, partly because people with vascular dementia may be aware of the difficulties the condition is causing. A person with vascular dementia may also become generally more emotional. They may be prone to rapid mood swings and being unusually tearful or happy (Passmore, Makin and Kehoe, 2014).

Other symptoms that someone with vascular dementia may experience vary between the different types. **Post-stroke dementia** will often be accompanied by the obvious physical symptoms of the stroke. Depending on which part of the brain is affected, someone might have paralysis or weakness of a limb. Or if a different part of the brain is damaged they may have problems with vision or speech. With rehabilitation, symptoms may get a little better or stabilise for a time, especially in the first six months after the stroke.

Symptoms of **subcortical vascular dementia** vary less. Early loss of bladder control is common. The person may also have mild weakness on one side of their body, or become less steady walking and more prone to falls. Other symptoms of subcortical vascular dementia may include clumsiness, lack of facial expression and problems pronouncing words (Passmore, Makin and Kehoe, 2014).

Disease progression

Vascular dementia will generally get worse, although the speed and pattern of this decline vary. Stroke-related dementia often progresses in a 'stepped' way, with long periods when symptoms are stable and periods when symptoms rapidly get worse. This is because each additional stroke causes further damage to the brain. Subcortical vascular dementia may occasionally follow this stepped progression, but more often symptoms get worse gradually, as the area of affected white matter slowly expands.

Over time a person with vascular dementia is likely to develop more severe confusion or disorientation, and further problems with reasoning and communication. Memory loss, for example for recent events or names, will also become worse. The person is likely to need more support with day-to-day activities such as cooking or cleaning.

As vascular dementia progresses, many people also develop behaviours that seem unusual or out of character. The most common include irritability, agitation, aggressive behaviour and a disturbed sleep pattern. Someone may also act in socially inappropriate ways.

Occasionally a person with vascular dementia will strongly believe things that are not true (delusions) or - less often - see things that are not really there (hallucinations). These behaviours can be distressing and a challenge for all involved (Passmore, Makin and Kehoe, 2014).

Advanced symptoms

If the damage to the brain continues, symptoms can quickly worsen, making daily activities increasingly difficult.

The symptoms will typically get worse in sudden steps, with stable periods lasting months or years in between. However, the rate of progression varies and it can be very difficult to predict when your symptoms may worsen (NHS, 2015v).

Symptoms of vascular dementia depend on which area of the brain has been damaged. Possible symptoms include -

- severe slowness of thought,
- feeling disorientated and confused,

- memory loss and difficulty concentrating,
- difficulty finding the right words,
- severe personality changes, such as becoming aggressive,
- depression, mood swings and apathy (unresponsiveness),
- finding it difficult to walk and keep balance, frequently falling,
- difficulty controlling urination (urinary incontinence),
- seeing things that aren't there (hallucinations) (NHS, 2015v).

Some people with vascular dementia will also have some symptoms of Alzheimer's disease, too (NHS, 2015v).

In the later stages of vascular dementia someone may become much less aware of what is happening around them. They may have difficulties walking or eating without help, and become increasingly frail. Eventually, the person will need help with all their daily activities (Passmore, Makin and Kehoe, 2014).

Seeking medical advice

If you think you may have early symptoms of vascular dementia, see your GP because the chances of slowing it down may be better if it's diagnosed early.

If you're worried about someone else, encourage them to make an appointment and perhaps suggest that you go along with them.

Symptoms of vascular dementia can have a number of different causes. Your GP can carry out some simple checks to find out what the cause may be, and refer you to a specialist if necessary (NHS, 2015v).

Diagnosis

Anyone who is concerned that they may have vascular dementia (or any other type of dementia) should seek help from their GP. If someone does have dementia, an early diagnosis has many benefits: it provides an explanation for the person's symptoms; it gives access to treatment, advice and support; and it allows them to prepare for the future and plan ahead. For vascular dementia, treatments and lifestyle changes may also slow down the progression of the underlying disease.

There is no single test for vascular dementia. The GP will first need to rule out conditions that can have similar symptoms, particularly depression. Symptoms could also be caused by infections, vitamin and thyroid deficiencies (diagnosed from a blood test) and side-effects of medication.

The doctor will also talk to the person about their medical history (e.g. high blood pressure or diabetes). This will include questions about dementia or cardiovascular disease in close family members. The doctor will probably do a physical examination and will ask about how the person's symptoms are currently affecting their life. The GP or a practice nurse may ask the person to do some tests of mental abilities. It is often helpful if a close friend or family member accompanies the person to medical appointments. They may be able to describe subtle changes that the person themselves has not noticed, such as starting to struggle with daily activities.

The GP may feel able to make a diagnosis of vascular dementia at this stage. If not, they will generally refer the person to a specialist. This might be an old-age psychiatrist (who specialises in the mental health of older people) based in a memory service, or a geriatrician (who specialises in the physical health of older people) in a hospital.

The specialist will assess the person's symptoms in more detail. The way that symptoms developed - in steps or more gradually - may suggest different underlying diseases. The person's thinking and other mental abilities will also be assessed further with a wider range of tests. In someone with vascular dementia, the test might show slowness of thought and difficulties thinking things through, which are often more common than memory loss.

A person suspected of having vascular dementia will generally have a brain scan to look for any changes that have taken place in the brain. A scan such as CT or MRI may rule out a tumour or build-up of fluid inside the brain. These can have symptoms similar to those of vascular dementia. A CT scan may also show a stroke or an MRI scan may show changes such as infarcts or damage to the white matter. If this is the case, the brain scan will be very helpful in diagnosing the dementia type, rather than simply ruling out other causes (Passmore, Makin and Kehoe, 2014).

Confirming a diagnosis of vascular dementia can be difficult, particularly when the condition is in its early stages. This is because many of the symptoms of dementia can also be caused by other conditions.

However, it's important to get a diagnosis as early as possible because treatment and lifestyle changes may slow down or stop the progression of the condition (NHS, 2015v).

For vascular dementia to be diagnosed correctly, you will have a number of tests and assessments, including -

- an assessment of your symptoms and mental abilities, including how quickly your symptoms have developed,
- a full medical history, including whether you have a history of conditions related to vascular dementia, such as strokes or high blood pressure,

- a physical examination,
- a review of the medication you are taking in relation to your symptoms,
- a range of tests, including blood tests, to rule out other possible causes of your symptoms, such as a vitamin B12 deficiency,
- brain scans, such as a CT scan, which can check for signs of a stroke or brain tumour, or a MRI scan, which can detect any shrinking of the brain,
- a heart rhythm test called an electrocardiogram (ECG) (NHS, 2015v).

Some of these tests can be carried out by your GP. Some will be carried out by other specialists, such as a neurologist (an expert in treating conditions that affect the brain and nervous system), an elderly care doctor, or a psychiatrist with experience of treating dementia (NHS, 2015v).

If the person has dementia, and the circumstances mean it is best explained by vascular disease in the brain, a diagnosis of vascular dementia will be made. For example, the dementia may have developed within a few months of a stroke, or a brain scan may show a pattern of disease that explains the dementia symptoms.

The diagnosis should be communicated clearly to the person and usually also those closest to them, along with a discussion about the next steps (Passmore, Makin and Kehoe, 2014).

Treatment

There is currently no cure for vascular dementia: the brain damage that causes it cannot be reversed. However, there is a lot that can be done to enable someone to live well with the condition. This will involve drug and non-drug treatment, support and activities (Passmore, Makin and Kehoe, 2014).

When you are diagnosed with dementia, your future health and social care needs will need to be assessed and a care plan drawn up (NHS, 2015v).

The person should have a chance to talk to a health or social care professional about their dementia diagnosis. This could be a psychiatrist or mental health nurse, a clinical psychologist, OT or GP. Information on what support is available and where to go for further advice is vital in helping someone to stay physically and mentally well (Passmore, Makin and Kehoe, 2014).

This is a way of ensuring you receive the right treatment for your needs. It involves identifying areas where you may need some assistance, such as -

- what support you or your carer need for you to remain as independent as possible,
- whether there are any changes that need to be made to your home to make it easier to live in,

- whether you need any financial assistance (NHS, 2015v).

Treating underlying conditions

The main aim of treatment for vascular dementia is to treat the underlying cause. This will usually involve making healthy lifestyle changes and taking medication.

Treating the underlying condition can help prevent further problems, such as strokes, and may help slow down or stop the progression of vascular dementia if it's diagnosed early (NHS, 2015v).

Control of cardiovascular disease

If the underlying cardiovascular diseases that have caused vascular dementia can be controlled, it may be possible to slow down the progression of the dementia. For example, after someone has had a stroke or TIA, treatment of high blood pressure can reduce the risk of further stroke and dementia. For stroke-related dementia in particular, with treatment there may be long periods when the symptoms don't get significantly worse.

In most cases, a person with vascular dementia will already be on medications to treat the underlying diseases. These include tablets to reduce blood pressure, prevent blood clots and lower cholesterol. If the person has a diagnosed heart condition or diabetes they will also be taking medicines for these. It is important that the person continues to take any medications and attends regular check-ups as recommended by a doctor (PASSMORE, MAKIN and KEHOE, 2014).

Lifestyle changes

Someone with vascular dementia will also be advised to adopt a healthy lifestyle, particularly to take regular physical exercise and, if they are a smoker, to quit. They should try to eat a diet with plenty of fruit, vegetables and oily fish but not too much fat or salt. Maintaining a healthy weight and keeping to recommended levels of alcohol will also help. The GP should be able to offer advice in all these areas (PASSMORE, MAKIN and KEHOE, 2014).

Adopting a healthier lifestyle should help reduce your risk of experiencing further damage to your brain. This may involve -

- eating healthily - for example, following a low-salt diet to manage high blood pressure,
- losing weight, if you are overweight,

- stopping smoking, if you smoke,
- getting fit,
- cutting down on alcohol (NHS, 2015v).

Medication

Any medication you're prescribed will depend on the underlying condition you have. You may be offered -

- antihypertensives, such as angiotensin-converting enzyme (ACE) inhibitors and beta-blockers, to treat high blood pressure,
- statins to treat high cholesterol,
- antiplatelets, such as aspirin or clopidogrel, to reduce your risk of blood clots and further strokes,
- anticoagulants, such as warfarin, which can also reduce your risk of blood clots and further strokes,
- diabetes medication, such as metformin,
- antidepressants to treat depression (NHS, 2015v).

Acetylcholinesterase inhibitors such as donepezil (Aricept), galantamine (Reminyl) or rivastigmine (Exelon), which are commonly used to treat Alzheimer's disease, aren't designed to treat vascular dementia specifically, but may sometimes be used.

They can be particularly helpful if you have a combination of vascular dementia and Alzheimer's disease (NHS, 2015v).

Other treatment and support

Supporting a person with vascular dementia to live well includes treatment for symptoms, support to cope with lost abilities, and help to keep up enjoyable activities. For someone who has had a stroke or has physical difficulties, treatment will also include rehabilitation.

The drugs that are routinely prescribed for Alzheimer's disease do not have benefits for vascular dementia, and are not recommended for it. These drugs may, however, be prescribed to treat mixed dementia (Alzheimer's disease and vascular dementia).

If someone is depressed or anxious, talking therapies (such as CBT) or drug treatments may also be tried. Counselling may also help the person adjust to the diagnosis.

There are many ways to help someone remain independent and cope with the cognitive symptoms of vascular dementia. For example, breaking complex tasks down into smaller steps will make them easier. An environment which is not too busy or noisy will make it easier to concentrate. For someone with memory loss, a regular routine and appropriate technology, such as pill boxes or electronic devices, can help (Passmore, Makin and Kehoe, 2014).

There are also a number of therapies that can help make everyday living easier if you have dementia. These include -

- occupational therapy to identify problem areas in everyday life, such as getting dressed, and help work out practical solutions,
- speech and language therapy to help improve any communication problems,
- physiotherapy to help with movement difficulties,
- psychological treatments, such as cognitive stimulation, to help improve memory, problem-solving skills, and language ability,
- relaxation therapies, such as aromatherapy, music or dance therapy, and massage (NHS, 2015v).

Keeping active

It is important that a person with any type of dementia stays active and continues to do things they enjoy. Keeping mentally active (cognitive stimulation) is known to help with memory and communication. Life story work, in which someone shares their life experiences and makes a personal record, may help with memory, mood and wellbeing. As the dementia worsens, many people enjoy more general reminiscence activities.

If the person has physical difficulties, for example after a stroke, they will usually benefit from rehabilitation. This could mean working with a physiotherapist (especially for help with weakness, coordination, movement and balance), occupational therapist (for everyday activities) or speech and language therapist (for all aspects of communication).

The details of the support that is available, and how people are generally referred, can vary around the country. The GP can give information about what is available in the local area (Passmore, Makin and Kehoe, 2014).

Behavioural changes

Over time, changes in the person's behaviour - such as agitation or aggression - become more likely. These are often a sign that the person is in distress. There are many potential causes. For example, the person might be in pain, they may have misunderstood something or someone, or they may be frustrated or understimulated. Individualised approaches should try to address the cause. General non-drug approaches (e.g. social interaction) often help. They should generally be tried before additional drugs are considered, particularly in the case of antipsychotics (Passmore, Makin and Kehoe, 2014).

Legal matters

If you've been diagnosed with dementia, you'll need to make arrangements for your care that take into account the possible decline in your mental abilities. This should include ensuring that your wishes are upheld if you're not able to make decisions for yourself.

You may wish to draw up an advance decision after first receiving a diagnosis of dementia. This makes your treatment preferences known now in case you are unable to do this in the future.

You may also want to consider giving a relative lasting power of attorney. This is the power to make decisions about you if you are unable to (NHS, 2015v).

Life expectancy

How long someone will live with vascular dementia varies greatly from person to person. On average it will be about five years after the symptoms started. The person is most likely to die from a stroke or heart attack (Passmore, Makin and Kehoe, 2014).

Dementia with Lewy bodies - DLB

Dementia with Lewy bodies (DLB) is a common form of dementia estimated to affect more than 100,000 people in the UK. Symptoms usually develop gradually and become more severe over the course of several years (NHS, 2015j).

DLB is a type of dementia that shares symptoms with both Alzheimer's disease and Parkinson's disease. It may account for around 10% of all cases of dementia. DLB tends to be mistakenly diagnosed as other conditions (that is, DLB is underdiagnosed).

DLB is sometimes referred to by other names, including Lewy body dementia, Lewy body variant of Alzheimer's disease, diffuse Lewy body disease, cortical

Lewy body disease, and senile dementia of Lewy body type. All these terms essentially refer to the same disorder (McKeith and Walker, 2013).

Lewy bodies

Lewy bodies, named after the doctor who first identified them, are tiny deposits of protein in nerve cells. Researchers don't have a full understanding of why Lewy bodies appear in the brain, or exactly how they contribute to dementia. However, their presence is linked to low levels of important chemical messengers (mainly acetylcholine and dopamine) and to a loss of connections between nerve cells. Over time, there is progressive death of nerve cells and loss of brain tissue.

Lewy bodies are the underlying cause of several progressive diseases affecting the brain and nervous system, notably DLB and Parkinson's disease. Together, these are sometimes called Lewy body disorders.

The symptoms a person experiences will depend partly on where the Lewy bodies are in the brain. Lewy bodies at the base of the brain are closely linked to problems with movement (motor symptoms). These are the main feature of Parkinson's disease. Lewy bodies in the outer layers of the brain are linked to problems with mental abilities (cognitive symptoms), which are characteristic of DLB.

Movement problems and changes in mental abilities can occur together. About one third of people diagnosed with Parkinson's disease eventually develop dementia (Parkinson's disease dementia). Similarly, at least two thirds of people with DLB develop movement problems at some point. The symptoms of DLB and Parkinson's disease dementia become more similar as the conditions progress. Together they are referred to as Lewy body dementias (McKeith and Walker, 2013).

Causes

Dementia with Lewy bodies is caused by deposits of an abnormal protein called Lewy bodies inside brain cells. These deposits, which are also found in people with Parkinson's disease, build up in areas of the brain responsible for things such as memory and muscle movement.

It's not clear why the deposits develop and how exactly they damage the brain, but it's thought they disrupt the brain's normal functions by interfering with chemical signals transmitted from one brain cell to another.

Dementia with Lewy bodies usually occurs in people with no family history of the condition, although there have been reports of rare cases that seem to run in families (NHS, 2015j).

Symptoms

The symptoms of dementia with Lewy bodies usually develop gradually and become more severe over the course of a few years (NHS, 2015j).

Like other forms of dementia, the condition causes problems with -

- thinking speed,
- language,
- understanding,
- judgement,
- memory (although significant memory loss may not occur until later on) (NHS, 2015j).

People with dementia with Lewy bodies may also have other symptoms that can help distinguish it from other types of dementia, such as -

- extreme swings between alertness and confusion or drowsiness, which may happen unexpectedly and change from hour to hour or day to day,
- slow movement, stiff limbs, and tremors (as seen in Parkinson's disease), which cause shuffling when walking,
- seeing or hearing things that aren't real (hallucinations), which can range from pleasant to distressing,
- fainting, unsteadiness, and falls,
- sleep disturbances, which can cause talking in your sleep or acting out dreams,
- loss of facial expression,
- difficulty swallowing (dysphagia),
- depression (NHS, 2015j).

These symptoms can make daily activities very difficult and can lead to further health problems, such as injuries from falls, and chest infections caused by accidentally inhaling food instead of swallowing it (NHS, 2015j).

Diagnosis

Confirming a diagnosis of dementia can be difficult, particularly when the condition is in its early stages. This is because many of the symptoms of dementia can also be caused by other conditions.

For dementia with Lewy bodies to be diagnosed correctly, you will have a number of tests and assessments, including -

- an assessment of your symptoms - for example, whether you have typical symptoms of dementia with Lewy bodies,
- a full assessment of your mental abilities,
- a physical examination,
- a review of the medication you are taking,
- a range of tests, including blood tests, to rule out other possible causes of your symptoms, such as a vitamin B12 deficiency,
- brain scans, such as a CT scan or a MRI scan, which can check for signs of a stroke, brain tumour or brain shrinkage - a SPECT scan, which looks at the dopamine system in the brain, can also sometimes help (NHS, 2015j).

Some of these tests can be carried out by your GP. Some will be carried out by other specialists, such as a neurologist (an expert in treating conditions that affect the brain and nervous system), an elderly care doctor, or a psychiatrist with experience of treating dementia (NHS, 2015j).

Treatment

There's currently no cure for dementia with Lewy bodies, but treatments can help manage the symptoms.

First of all, your future health and social care needs will need to be assessed and a care plan drawn up (NHS, 2015j).

This is a way of ensuring you receive the right treatment for your needs. It involves identifying areas where you may need some assistance, such as -

- what support you or your carer need for you to remain as independent as possible,
- whether there are any changes that need to be made to your home to make it easier to live in,
- whether you need any financial assistance (NHS, 2015j).

Medication

Medication cannot stop the progression of dementia with Lewy bodies, but it can sometimes help reduce the symptoms (NHS, 2015j).

Acetylcholinesterase inhibitors -

Acetylcholinesterase inhibitors, such as donepezil (Aricept), galantamine (Reminyl) or rivastigmine (Exelon), may help improve hallucinations, confusion, and drowsiness in some people.

These medicines work by increasing levels of the chemical acetylcholine in the brain, which improves the ability of the brain cells to send signals to each other.

Common side-effects of acetylcholinesterase inhibitors include feeling and being sick, diarrhoea, headaches, fatigue (extreme tiredness), and muscle cramps (NHS, 2015j).

Other medications -

Other medications that may help control some of the symptoms of dementia with Lewy bodies include -

- **levodopa** (a medication used to treat Parkinson's disease) can help reduce movement problems, although it can also worsen hallucinations and other psychotic symptoms, so it needs to be carefully monitored by your doctor,
- **antidepressants** may help you cope if you have depression,
- **clonazepam** can sometimes help improve your sleep if you experience sleep disturbances (NHS, 2015j).

Antipsychotics, such as haloperidol, should be avoided wherever possible, and should only be used to treat severely challenging behaviour that is putting you or others at risk of harm. This is because they can cause a range of serious side-effects, including rigidity and immobility.

If antipsychotics are needed, they will be prescribed at the lowest possible dose, for the shortest possible time, by a specialist experienced in treating dementia with Lewy bodies (NHS, 2015j).

Supportive measures and treatments

In addition to medication, there are a number of therapies and practical measures that can help make everyday living easier for someone with dementia. These include -

- occupational therapy to identify problem areas in everyday life, such as getting dressed, and help work out practical solutions,
- speech and language therapy to help improve any communication or swallowing problems,

- physiotherapy to help with movement difficulties,
- psychological treatments, such as cognitive stimulation, to help improve memory, problem-solving skills and language ability,
- relaxation techniques, such as massage, and music or dance therapy,
- home modifications, such as removing loose carpets and potential trip hazards, ensuring the home is well lit, and adding grab bars and handrails,
- checking for problems with vision and hearing that could be contributing to hallucinations (NHS, 2015j).

Legal matters

If you have been diagnosed with dementia, you will need to make arrangements for your care that take into account the gradual decline in your mental abilities. This should include ensuring that your wishes are upheld if you're not able to make decisions for yourself.

You may wish to draw up an advance decision after first receiving a diagnosis of dementia. This makes your treatment preferences known now, in case you are unable to do this in the future.

You may also want to consider giving a relative lasting power of attorney. This is the power to make decisions about you if you are unable to (NHS, 2015j).

Chapter 7

Rarer types of dementia

Contents

Corticobasal degeneration

Corticobasal degeneration (CBD) is a rare condition that can cause gradually worsening problems with movement, speech, memory and swallowing.

It's often also called corticobasal syndrome (CBS).

CBD is caused by increasing numbers of brain cells becoming damaged or dying over time.

Most cases of CBD develop in people who are between 50 and 70 years of age (NHS, 2015e).

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Symptoms

People with CBD develop a range of difficulties with movement, speech, memory and swallowing.

The condition tends to develop gradually, which means it can be mistaken for another condition at first - such as Parkinson's disease, dementia or a stroke.

The symptoms typically become more severe over several years, although the speed at which they worsen varies.

Some of the main symptoms of CBD are outlined below. Most people with the condition won't experience all of these (NHS, 2015e).

Early symptoms

CBD typically affects one of the limbs at first. This is usually a hand or arm, but sometimes a leg (NHS, 2015e).

Problems affecting the limb can include -

- a clumsy or "useless" hand,
- muscle stiffness,
- shaking (tremors) and spasms (dystonia [35]),
- loss of feeling,
- feeling like the limb doesn't belong to you (an "alien" limb) (NHS, 2015e).

Some people also develop problems with walking and co-ordination (NHS, 2015e).

Mid-stage symptoms

As CBD progresses, it may eventually start to cause problems in your other limbs.

Walking, balance and co-ordination may get worse. Many people have problems with their speech, which will become slow and slurred (NHS, 2015e).

Some people with CBD also have dementia, although this doesn't always occur, symptoms may include -

- problems recalling words, reading and using correct language (aphasia),
- short-term memory loss,
- problems carrying out tasks that require planning or thinking ahead,
- problems coping with sudden and unexpected situations,

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[35] a medical term for a range of movement disorders that cause muscle spasms and contractions

- difficulty with numbers and counting,
- difficulty seeing things, or knowing where they are located (such as furniture) (NHS, 2015e).

It's also common for someone with CBD to experience personality changes, such as becoming apathetic, irritable, agitated or anxious (NHS, 2015e).

Advanced stages

As CBD reaches an advanced stage, muscle stiffness will continue to get worse. People with the condition may lose the ability to move one or more limbs. Some people are unable to walk and need a wheelchair or assistance to transfer (such as help getting into and out of bed) (NHS, 2015e).

Other problems people with advanced CBD can experience include -

- worsening speech problems, which can make it hard for others to understand you,
- uncontrollable blinking,
- worsening dementia, meaning constant care may be needed,
- increasing difficulties swallowing, which may mean a feeding tube is required (NHS, 2015e).

As a result of swallowing problems, many people with CBD develop chest infections caused by fluid or small food particles falling down into their lungs (aspiration pneumonia [36]), which can be life-threatening (NHS, 2015e).

Diagnosis

It can be difficult to diagnose CBD, as there's no single test for it, and the condition can have similar symptoms to a number of others.

A diagnosis of CBD will be based on the pattern of your symptoms. Your doctor will also try to rule out conditions that can cause similar symptoms, such as Parkinson's disease, a stroke, motor neurone disease and Alzheimer's disease.

Your GP will need to carry out assessments of your symptoms, as well as other tests and scans. The diagnosis must be made or confirmed by a consultant with expertise in CBD. This will usually be a neurologist (specialist in conditions affecting the brain and nerves) (NHS, 2015e).

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[36] a chest infection caused by food particles falling into your lungs

Brain scans

If you have symptoms of CBD that suggest there's something wrong with your brain, it's likely you'll be referred for a brain scan (NHS, 2015e).

Types of scan that you may have include -

- MRI scan - where a strong magnetic field and radio waves are used to produce detailed images of the inside of the brain,
- PET scan - a scan that detects the activity of the brain,
- a DaTscan - to measure the amount of a chemical called dopamine that your brain is making (NHS, 2015e).

These scans can be useful in ruling out other possible conditions, such as brain tumours or strokes.

MRI scans can also detect abnormal changes to the brain that are consistent with a diagnosis of CBD, such as shrinkage of certain areas.

Scans that show the build-up of the tau protein in the brain that's associated with CBD are currently under development (NHS, 2015e).

Ruling out Parkinson's disease

A person's symptoms and signs usually help distinguish CBD from Parkinson's disease, but sometimes tests may be used to support the diagnosis and rule out other possible conditions.

You may be prescribed a short course of a medication called levodopa. This typically works very well in Parkinson's disease, but not so well in CBD.

If it doesn't lead to a significant improvement in your symptoms, it can help your doctor distinguish CBD from Parkinson's disease (NHS, 2015e).

Neuropsychological testing

It's also likely you'll be referred to a neurologist and possibly also a psychologist for neuropsychological testing.

This involves having a series of "memory tests" with words and pictures. They're designed to evaluate the full extent of your symptoms and their impact on your mental abilities (NHS, 2015e).

The tests will look at abilities such as -

- memory,
- concentration,

- understanding language,
- the processing of visual information, such as words and pictures,
- numbers and counting (NHS, 2015e).

Most people with CBD have a distinct pattern of difficulties on these tests.

The memory of previously learned facts and the person's own life story is generally maintained (NHS, 2015e).

Coping with a diagnosis

Being told that you have CBD can be devastating and difficult to take in.

You may feel numb, overwhelmed, angry, distressed, scared or in denial. Some people are relieved that a cause for their symptoms has finally been found. There's no right or wrong way to feel - everybody is different and copes in their own way.

Support from your family and care team can help you come to terms with the diagnosis.

The PSP Association can give you information and practical advice about living with CBD, as well as providing support to help you cope with the emotional impact of the condition.

You can get in touch with the PSP Association by calling their helpline on 0300 0110 122, or by emailing: helpline@pspassociation.org.uk.

You may find that many people - even the doctors you meet - have not heard of CBD. The PSP Association has online and printed information for patients, their families and professionals (NHS, 2015e).

Treatment

There's currently no cure for CBD and no treatment to slow it down, but there are lots of things that can be done to help manage the symptoms.

Care will be provided by a team of health and social care professionals working together. This is known as a multidisciplinary team (NHS, 2015e).

Members of your multidisciplinary team may include -

- **a neurologist** - a specialist in conditions that affect the brain and nerves,
- **a physiotherapist** - who can help with movement and balance difficulties,
- **a speech and language therapist** - who can help with speech or swallowing problems,

- **an occupational therapist** - who can help you improve the skills you need for daily activities at home, such as washing, dressing, or getting around,
- **a social worker** - who can advise you about the support available from social services,
- **a specialist neurology nurse** - who may act as your point of contact with the rest of the team,
- **special care advisors** from the PSP Association (NHS, 2015e).

A care plan will be drawn up in discussion with your team. This will outline the treatments you need to help with the symptoms of CBD, as well as the support and advice you require to make your life easier (NHS, 2015e).

Medication

There are currently no medications that treat CBD specifically. Depending on the person's symptoms or complications, the following may be used -

- Muscle stiffness of contractions - levodopa, amantadine, clonazepam, baclofen, gabapentin, or botulinum toxin injections to relax the muscles,
- Jerky movements - clonazepam or levetiracetam,
- Memory and related mental abilities - the medications used to treat Alzheimer's disease may also be used in CBD, such as donepezil or memantine,
- Irritability or depression - medicines such as citalopram or trazodone,
- Sleep problems - short term use of temazepam, zopiclone, melatonin or others medicines,
- Bladder problems and incontinence - medicines to relax the bladder, or help it empty more regularly may be needed, such as oxybutynin or miabegron,
- Pain and anxiety - simple painkillers like ibuprofen, and more specialist medicines like gabapentin,
- Bone strength - if people are prone to regular falling, osteoporosis (weak bones) and vitamin D problems should be ruled out or treated (NHS, 2015e).

In general, people with CBD are sensitive to medication side-effects. Doses may start low and be increased gradually.

Some medications should be avoided completely, such as haloperidol (a medicine used to treat some mental health problems) (NHS, 2015e).

Cognitive stimulation

Cognitive stimulation is a type of therapy used to treat dementia, and it may be helpful if a person with CBD has dementia symptoms.

It involves taking part in activities and exercises designed to improve your memory, problem-solving skills and language ability (NHS, 2015e).

Physiotherapy

A physiotherapist can give advice about how to remain safely mobile. Regular exercise can help strengthen your muscles, improve your posture and prevent stiffening of your joints.

They can teach you breathing exercises to use when you eat, to reduce your risk of developing aspiration pneumonia (NHS, 2015e).

Occupational therapy

An occupational therapist can give you advice about the best ways to increase your safety and prevent trips and falls during your day-to-day activities.

For example, a person with CBD may benefit from having bars placed along the sides of their bath to make it easier to get in and out.

The occupational therapist can also arrange access to mobility equipment such as walking frames, or wheelchairs, and to get equipment to help the person or their carer manage other everyday activities for washing, dressing, eating, and using the bathroom safely (NHS, 2015e).

Speech and language therapy

A speech and language therapist can help assess and treat speech and swallowing problems.

They can teach people a number of techniques to help make the voice as clear as possible and can advise you about suitable communication aids or devices that the person may need as CBD progresses.

A therapist can also advise you about different swallowing techniques and, working together with a dietitian (see below), they may suggest altering the consistency of your food to make swallowing easier (NHS, 2015e).

Diet and severe swallowing problems

You may be referred to a dietitian, who will advise you about making changes to your diet, such as including food and liquids that are easier to swallow, while ensuring that you have a healthy, balanced diet.

Feeding tubes may be recommended for severe swallowing problems, where the risk of malnutrition, weight loss, fatigue and dehydration is increased. You should discuss the pros and cons of feeding tubes with your family and care team.

The decision about whether and when to consider a feeding tube depends on the individual and should be discussed with a specialist (NHS, 2015e).

Palliative care

Palliative care [37] aims to relieve pain and other distressing symptoms while providing psychological, social and spiritual support. It can be offered at any stage of CBD, alongside other treatments (NHS, 2015e).

Palliative care can be received -

- in a hospice,
- at home or in a residential home,
- on a day-patient basis in a hospice,
- in a hospital (NHS, 2015e).

Advanced care planning

Many people with CBD make plans for the future that outline their wishes about medical care and other decisions. They share these plans with both their family and the health professionals involved in their care.

This can be useful in case you're unable to communicate your decisions later on because you're too ill. However, you don't have to do it if you don't want to (NHS, 2015e).

Issues that you may want to cover include -

- if you want to be treated at home, in a hospice or in a hospital when you reach the final stages of CBD,
- if you would be willing to use a feeding tube if you were no longer able to swallow food and liquid,

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[37] the treatment of incurable conditions

- if you'd be willing to be resuscitated if your heart were to stop (NHS, 2015e).

If you decide to discuss these issues, they can be written down in a number of ways -

- Advance decision to refuse treatment,
- Advance statement,
- Emergency healthcare plan,
- Preferred place of care,
- Enduring Power of Attorney (NHS, 2015e).

Your care team can provide you with more information and advice about these decisions and how best to record them (NHS, 2015e).

Care and support

If someone you know develops CBD, you may need information and advice about caring for them.

The NHS Choices Care and support section has a wide range of useful information about all aspects of caring for others, and advice for carers themselves.

You can also contact the PSP Association, who provide help and advice to people living with CBD. Their email address is: helpline@pspassociation.org.uk and you can call their helpline on 0300 0110 122.

The Parkinson's nurse within your local hospital may be able to provide you with useful information and support (NHS, 2015e).

Creutzfeldt-Jakob disease

Creutzfeldt-Jakob disease (CJD) is a rare and fatal condition that affects the brain. It causes brain damage that worsens rapidly over time (NHS, 2015g).

Types of CJD

There are four main types of CJD, which are described below (NHS, 2015g).

Sporadic CJD

Sporadic CJD is the most common type.

The precise cause of sporadic CJD is unclear, but it's been suggested that a normal brain protein changes abnormally ('misfolds') and turns into a prion. Most cases of sporadic CJD occur in adults aged between 45 and 75. On average, symptoms develop at age 60–65 years.

Despite being the most common type of CJD, sporadic CJD is still very rare, affecting only one or two people in every million each year in the UK. In the UK during 2014, there were 90 recorded deaths from sporadic CJD (NHS, 2015g).

Variant CJD

Variant CJD is likely to be caused by consuming meat from a cow that had bovine spongiform encephalopathy (BSE) or 'mad cow disease', a similar prion disease to CJD.

Since the link between variant CJD and BSE was discovered in 1996, strict controls have proved very effective in preventing meat from infected cattle from entering the food chain (see preventing Creutzfeldt-Jakob disease for more information).

However, the average time it takes for the symptoms of variant CJD to occur after initial infection (the incubation period) is still unclear. The incubation period could be very long (over 10 years) in some people, so those exposed to infected meat before the food controls were introduced can still develop variant CJD.

The prion that causes variant CJD can also be transmitted by blood transfusion, although this has only happened four times in the UK. There have been 177 recorded cases of variant CJD in the UK to date and there were no recorded deaths from the condition in the UK during 2014 (NHS, 2015g).

Familial or inherited CJD

Familial CJD is a very rare genetic condition where one of the genes a person inherits from their parent (the prion protein gene) carries a mutation that causes prions to form in their brain during adulthood, triggering the symptoms of CJD. It affects about 1 in every 9 million people in the UK.

The symptoms of familial CJD usually first develop in the early 50s.

In the UK during 2014, there were 10 deaths from familial CJD and similar inherited prion diseases (NHS, 2015g).

Iatrogenic CJD

Iatrogenic CJD is where the infection is accidentally spread from someone with CJD through medical or surgical treatment.

For example, a common cause of iatrogenic CJD in the past was growth hormone treatment using human pituitary growth hormones extracted from deceased individuals, some of whom were infected with CJD. Synthetic versions of human growth hormone have been used since 1985, so this is no longer a risk.

Iatrogenic CJD can also occur if instruments used during brain surgery on a person with CJD aren't properly cleaned between each surgical procedure and are re-used on another person. However, increased awareness of these risks means iatrogenic CJD is now very rare.

In the UK during 2014, there were just three deaths from iatrogenic CJD (caused by receiving human growth hormone before 1985) (NHS, 2015g).

Symptoms

The pattern of symptoms can vary depending on the type of CJD.

In sporadic CJD, the symptoms mainly affect the workings of the nervous system (neurological symptoms) and these symptoms rapidly worsen in the space of a few months.

In variant CJD, symptoms that affect a person's behaviour and emotions (psychological symptoms) will usually develop first. These are then followed by neurological symptoms around four months later, which get worse over the following few months.

Familial CJD has the same sort of pattern as sporadic CJD, but it often takes longer for the symptoms to progress, usually around two years rather than a few months.

The pattern of iatrogenic CJD is unpredictable, as it depends on how a person became exposed to the infectious protein (prion) that caused CJD (NHS, 2015g).

Initial neurological symptoms

Initial neurological symptoms of sporadic CJD can include -

- difficulty walking, caused by balance and co-ordination problems,
- slurred speech,
- numbness or pins and needles in different parts of the body,

- dizziness,
- vision problems, such as double vision and hallucinations (seeing or hearing things that aren't really there) (NHS, 2015g).

Initial psychological symptoms

Initial psychological symptoms of variant CJD can include -

- severe depression,
- intense feelings of despair,
- withdrawal from family, friends and the world around you,
- anxiety,
- irritability,
- difficulty sleeping (insomnia) (NHS, 2015g).

Advanced neurological symptoms

Advanced neurological symptoms of all forms of CJD can include -

- loss of physical co-ordination, which can affect a wide range of functions, such as walking, speaking and balance (ataxia [38]),
- muscle twitches and spasms,
- loss of bladder control and bowel control,
- blindness,
- swallowing difficulties (dysphagia),
- loss of speech,
- loss of voluntary movement (NHS, 2015g).

Advanced psychological symptoms

Advanced psychological symptoms of all forms of CJD include -

- loss of memory, which is often severe,
- problems concentrating,
- confusion,
- feeling agitated,
- aggressive behaviour,
- loss of appetite, which can lead to weight loss,
- paranoia,
- unusual and inappropriate emotional responses (NHS, 2015g).

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[38] the term for a group of disorders that affect co-ordination, balance and speech

Final stages

As the condition progresses to its final stages, people with all forms of CJD will become totally bedridden. They often become totally unaware of their surroundings and require around-the-clock care. They also often lose the ability to speak and can't communicate with their carers.

Death will inevitably follow, usually either as a result of an infection, such as pneumonia (a lung infection), or respiratory failure [39], where the lungs stop working and the person is unable to breathe. Nothing can be done to prevent death in these circumstances.

Advancements in palliative care mean that people with CJD often have a peaceful death (NHS, 2015g).

Causes

CJD is caused by an abnormal infectious protein in the brain called a prion.

Proteins are molecules, made up of amino acids, which help the cells in our body to function. They begin as a string of amino acids that then fold themselves into a three-dimensional shape. This 'protein folding' allows them to perform useful functions within our cells.

Normal (harmless) prion proteins are found in almost all body tissues, but at highest levels in brain and nerve cells.

The exact role of the normal prion proteins is unknown, but it's thought they may play a role in transporting messages between certain brain cells.

Mistakes sometimes occur during protein folding and the prion protein can't be used by the body. Normally, these misfolded prion proteins are recycled by the body, but if they're not they can build up in the brain (NHS, 2015g).

How prions cause CJD

Prions are misfolded prion proteins that build up in the brain and cause other prion proteins to misfold as well. This causes the brain cells to die, releasing more prions to infect other brain cells.

Eventually, clusters of brain cells are killed and deposits of misfolded prion protein, called plaques, may appear in the brain.

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[39] loss of lung function

Prion infections also cause small holes to develop in the brain, so it becomes sponge-like. The damage to the brain causes the mental and physical impairment associated with CJD and eventually leads to death.

Prions can survive in nerve tissue, such as the brain or spinal cord, for a very long time, even after death (NHS, 2015g).

Types of CJD

The different types of CJD are all caused by a build-up of prions in the brain. However, the reason why this happens is different for each type.

The causes of the main types of CJD are described below (NHS, 2015g).

Sporadic CJD

Even though sporadic CJD is very rare, it's the most common type of CJD, accounting for around 80% of all CJD cases.

It's not known what triggers sporadic CJD, but it may be that a normal prion protein spontaneously changes into a prion, or a normal gene spontaneously changes into a faulty gene that produces prions.

Sporadic CJD is more likely to occur in people who have specific versions of the prion protein gene. At present, nothing else has been identified that increases your risk of developing sporadic CJD (NHS, 2015g).

Variant CJD

There's clear evidence that variant Creutzfeldt-Jakob disease (vCJD) is caused by the same strain of prions that causes BSE or 'mad cow disease'.

In 2000, a government inquiry concluded that the prion was spread through cattle that were fed meat-and-bone mix containing traces of infected brains or spinal cords. The prion then ended up in processed meat products, such as beef burgers, and entered the human food chain.

Strict controls have been in place since 1996 to prevent BSE entering the human food chain and the use of meat-and-bone mix has since been outlawed.

It appears that not everyone who is exposed to BSE-infected meat will go on to develop vCJD.

All definite cases of vCJD occurred in people with a specific version (MM) of the prion protein gene, which affects how the body makes a number of amino acids. It's estimated that up to 40% of the UK population have this version of the gene.

Cases of vCJD peaked in the year 2000, in which there were 28 deaths from this type of CJD. There were no confirmed deaths in 2014. Some experts believe that the food controls have worked and that further cases of vCJD will continue to decline, but this doesn't rule out the possibility that other cases may be identified in future.

It's also possible for vCJD to be transmitted by blood transfusion, although this is very rare and measures have been put in place to reduce the risk of it happening.

We don't know how many people in the UK population could develop vCJD in the future and how long it will take for symptoms to appear, if they ever will.

A study published in October 2013 that involved testing random tissue samples suggested that around 1 in 2,000 people in the UK population may be infected with vCJD, but show no symptoms to date (NHS, 2015g).

Familial or inherited CJD

Familial or inherited CJD is a rare form of CJD caused by an inherited mutation (abnormality) in the gene that produces the prion protein. The altered gene seems to produce misfolded prions that cause CJD.

Everyone has two copies of the prion protein gene, but the mutated gene is dominant. This means you only need to inherit one mutated gene to develop the condition. Therefore, if one of the parents has the mutated gene, there's a 50% chance it will be passed on to their children.

As the symptoms of familial CJD don't usually begin until a person is in their 50s, many people with the condition are unaware that their children are also at risk of inheriting this condition when they decide to start a family (NHS, 2015g).

Iatrogenic CJD

Iatrogenic Creutzfeldt-Jakob disease (iCJD) is where the infection is spread from someone with CJD through medical or surgical treatment.

Most cases of iCJD have occurred through the use of human growth hormone, which is used to treat children with restricted growth. Between 1958 and 1985, thousands of children were treated with the hormone, which at the time was extracted from the pituitary glands (a gland at the base of the skull) of human corpses.

A minority of those children developed CJD, as the hormones they received were taken from glands infected with CJD. Since 1985, all human growth hormone in the UK has been artificially manufactured, so there's now no risk. However, a small number of patients exposed before 1985 are still developing iCJD.

A few other cases of iCJD have occurred after people received transplants of infected dura (tissue that covers the brain) or came into contact with surgical instruments that were contaminated with CJD. This happened because prions are tougher than viruses or bacteria, so the normal process of sterilising surgical instruments had no effect.

Once the risk was recognised, the Department of Health tightened the guidelines on organ donation and the reuse of surgical equipment. As a result, cases of iCJD are now very rare (NHS, 2015g).

BSE ('mad cow disease')

BSE, also known as 'mad cow disease', is a relatively new disease that first occurred in the UK during the 1980s.

One theory about why BSE developed is that an older prion disease that affects sheep, called scrapie, may have mutated. The mutated disease may have then spread to cows that were fed meat-and-bone mix from sheep, containing traces of this new mutated prion (NHS, 2015g).

Is CJD contagious?

In theory, CJD can be transmitted from an affected person to others, but only through an injection or consumption of infected brain or nervous tissue.

There's no evidence that sporadic CJD is spread through ordinary day-to-day contact with those affected or by airborne droplets, blood or sexual contact.

However, in the UK, variant CJD has been transmitted on four occasions by blood transfusion (NHS, 2015g).

Diagnosis

A diagnosis of CJD is usually based on medical history, symptoms and a series of tests.

A neurologist will carry out the tests to rule out other conditions with similar symptoms, such as Alzheimer's disease, Parkinson's disease or a brain tumour.

The only way to confirm a diagnosis of CJD is to examine the brain tissue by carrying out a brain biopsy, or more commonly (after death) by post-mortem examination of the brain.

Specialist services to advise local teams in diagnosis are available at the National CJD Research and Surveillance Unit in Edinburgh and the National Prion Clinic in London (NHS, 2015g).

Tests for CJD

A clinical neurologist will rule out other conditions with similar symptoms and check for some common signs of CJD by carrying out the tests below -

- **Magnetic resonance imaging (MRI) brain scan** - uses strong magnetic fields and radio waves to produce a detailed image of the brain and can show up abnormalities that are particular to CJD.
- **Electroencephalogram (EEG)** - records brain activity and may pick up abnormal electrical patterns seen in sporadic CJD.
- **Lumbar puncture** - a procedure where a needle is inserted into the lower part of the spine to draw out a sample of cerebrospinal fluid (which surrounds your brain and spinal cord) so it can be tested for a certain protein that indicates you may have CJD.
- **A prototype blood test** for variant CJD has also been developed by the prion unit at the Medical Research Council (MRC). It's available through the National Prion Clinic.
- **Tonsil biopsy** - a small piece of tissue can be taken from the tonsils and checked for the abnormal prions found in variant CJD (they're not present in other types of CJD).
- **Genetic test** - a simple blood test to find out whether you have a mutation (fault) in the gene that produces normal protein. A positive result may indicate familial (inherited) prion disease (NHS, 2015g).

Brain biopsy

During a brain biopsy, a surgeon drills a tiny hole into the skull and removes a small piece of brain tissue using a very thin needle. It's carried out under general anaesthetic, which means the person will be unconscious during the procedure.

As a brain biopsy carries the risk of causing brain damage or seizures (fits), it's only performed in a few cases where there's a concern that someone doesn't have CJD but some other treatable condition (NHS, 2015g).

Treatment

There's no proven cure for CJD, but clinical studies are under way at the National Prion Clinic to investigate possible treatments.

At present, treatment involves trying to keep the person as comfortable as possible and reducing symptoms through the use of medicines.

For example, psychological symptoms of CJD, such as anxiety and depression, can be treated with sedatives and antidepressants, and muscle jerks or tremors can be treated with medicines such as clonazepam and sodium valproate.

Any pain experienced can be relieved using powerful opiate-based painkillers (NHS, 2015g).

Advance directive

Many people with CJD draw up an advance directive (also known as an advance decision). An advance directive is where a person makes their treatment preferences known in advance, in case they can't communicate their decisions later because they're too ill (NHS, 2015g).

Issues that can be covered by an advance directive include -

- whether a person with CJD wants to be treated at home, in a hospice or in a hospital once they reach the final stages of the condition,
- what type of medications they would be willing to take in certain circumstances,
- whether they would be willing to use a feeding tube if they were no longer able to swallow food and liquid,
- whether they're willing to donate any of their organs for research after they die (the brains of people with CJD are particularly important for ongoing research),
- if they have respiratory failure (loss of lung function), whether they would be willing to be resuscitated by artificial means - for example, by having a breathing tube inserted into their neck (NHS, 2015g).

Your care team can provide more advice about making an advance directive. (NHS, 2015g).

Specialist team

If a person is thought to have CJD, they're referred to the National Care Team for CJD in the National CJD Research and Surveillance Unit in Edinburgh, or the National Prion Clinic in London, for diagnosis and care.

A doctor and nurse from these services will be assigned to liaise with local services, including the person's GP, social worker, physiotherapist and occupational therapist.

Specialist teams are available to diagnose and offer clinical and emotional support to patients and their families, and to work alongside the local care team. A local care team may include doctors and nurses, occupational therapists, dietitians, incontinence advisers and social workers (NHS, 2015g).

Treating symptoms of CJD

For more information about how some of the specific symptoms of CJD may be treated see -

- treating ataxia (loss of physical co-ordination),
- treating urinary incontinence (loss of bladder control),
- treating bowel incontinence (loss of bowel control),
- treating dysphagia (swallowing difficulties),
- treating dystonia (muscle spasms and stiffness),
- help and support for blindness or vision loss (NHS, 2015g).

Care and support in the advanced stages of CJD

As CJD progresses, people with the condition will need significant nursing care and practical support.

As well as help with feeding, washing and mobility, some people may also need help urinating. A catheter (a tube that's inserted into the bladder and used to drain urine) is often required.

Many people will also have problems swallowing, so they may have to be given nutrition and fluids through a feeding tube.

It may be possible to treat people with CJD at home, depending on the progression and severity of the condition.

Caring for someone with CJD can be distressing and difficult to cope with, so many carers prefer to use the specialist services of a hospital or hospice. (NHS, 2015g).

Prevention

Although CJD is very rare, the condition can be difficult to prevent.

This is because most cases occur spontaneously for an unknown reason (sporadic CJD) and some are caused by an inherited genetic fault (familial CJD).

Sterilisation methods used to help prevent bacteria and viruses spreading are also not completely effective against the infectious protein (prion) that causes CJD. However, tightened guidelines on the reuse of surgical equipment mean that cases of CJD spread through medical treatment (iCJD) are now very rare.

There are also measures in place to prevent variant CJD spreading through the food supply or via the supply of blood used for blood transfusions. These are described below (NHS, 2015g).

Protecting the food supply

Since the link between BSE or 'mad cow disease' and variant CJD was confirmed, strict controls have been in place to stop BSE entering the human food chain (NHS, 2015g).

These controls include -

- a ban on feeding meat-and-bone mix to farm animals,
- the removal and destruction of all parts of an animal's carcass that could be infected with BSE,
- a ban on mechanically recovered meat (meat residue left on the carcass that is pressure-blasted off the bones),
- testing on all cattle more than 30 months old (experience has shown that infection in cattle under 30 months of age is rare, and even cattle that are infected haven't yet developed dangerous levels of infection) (NHS, 2015g).

Blood transfusions

In the UK, there have been four cases where variant CJD has been transmitted by blood transfusion. In each case, the person received a blood transfusion from a donor who later developed variant CJD.

Three of the four recipients went on to develop variant CJD, while the fourth recipient died before developing variant CJD, but was found to be infected following a post-mortem examination.

It's not certain whether the blood transfusion was the cause of the infection, as those involved could have contracted variant CJD through dietary sources.

Nevertheless, steps were taken to minimise the risk of the blood supply becoming contaminated (NHS, 2015g).

These steps include -

- not allowing people potentially at risk from CJD to donate blood, tissue or organs (including eggs and sperm for fertility treatments),
- not accepting donations from people who've received a blood transfusion in the UK since 1980,
- removing white blood cells, which may carry the greatest risk of transmitting CJD, from all blood used for transfusions (NHS, 2015g).

Frontotemporal dementia

Frontotemporal dementia is an uncommon type of dementia estimated to affect around 16,000 people in the UK.

The term ”dementia” describes a loss of mental ability (cognitive impairment) that is more than would be expected with ageing. It's enough to affect day-to-day activities and gets progressively worse.

Frontotemporal dementia tends to affect the frontal and temporal lobes of the brain (the front and sides) in particular. These parts of the brain are largely responsible for language and the ability to plan and organise, and are important in controlling behaviour.

Frontotemporal dementia often starts at a younger age than usually seen in other types of dementia. Most cases are diagnosed in people aged 50–65, but it can also affect younger or older people (NHS, 2015l).

Causes

There are several different causes of frontotemporal dementia, but they all involve a build-up of abnormal proteins in the brain.

The abnormal proteins clump together and become toxic to the brain cells, which eventually kills them and causes the affected areas of the brain to shrink over time.

It's not fully understood why these abnormal proteins build up, but there is often a genetic link. Up to 40% of people with frontotemporal dementia have a family history of the condition (NHS, 2015l).

Symptoms

The symptoms of frontotemporal dementia usually develop gradually and get increasingly worse over a number of years.

The early symptoms can vary between different people with the condition, depending on which part of the brain is affected. Many people will initially have either behavioural or language problems.

As the condition progresses, most people experience problems in both of these areas, as well as additional physical problems and thinking difficulties. Eventually, the condition spreads to affect most brain functions.

These groups of symptoms are described below (NHS, 2015l).

Behavioural and mood changes

In most cases, people with frontotemporal dementia display a number of unusual behaviours that they are not aware they have developed.

These can vary widely from person to person - for example, some may be uninterested and seem to have no drive, while others may be impulsive and more outgoing, with no inhibitions (NHS, 2015l).

Typical signs are -

- inappropriate behaviour in public,
- impulsivity,
- loss of inhibitions,
- overeating, a change in food preferences (such as suddenly liking sweet foods), poor table manners,
- neglect of personal hygiene,
- repetitive or obsessional behaviours, such as humming, hand-rubbing and foot-tapping, or complex routines such as walking exactly the same route repetitively,
- seeming more selfish and unreasonable,
- inability to empathise with others, seeming cold and uncaring,
- irritability and aggression,
- being tactless or rude,
- being less or more outgoing than in the past,
- being lethargic, lacking enthusiasm (NHS, 2015l).

As the disease progresses, people with frontotemporal dementia may become socially isolated and withdrawn (NHS, 2015l).

Language problems

Many people with frontotemporal dementia experience problems with speech and language (NHS, 2015l).

Symptoms can include -

- using words incorrectly - for example, calling a sheep a dog,
- reduced vocabulary,
- repeating a limited number of phrases,
- more effortful or less articulate speech,
- automatically repeating things other people have said,
- reduced speech and conversation (NHS, 2015l).

Some people gradually lose the ability to speak, and can eventually become completely mute (NHS, 2015l).

Problems with thinking

Many people with frontotemporal dementia eventually lose the ability to think for themselves (NHS, 2015l).

Symptoms can include -

- needing to be told what to do,
- poor planning, judgement and organisation,
- becoming easily distracted,
- thinking in a rigid and inflexible way,
- losing the ability to understand abstract ideas,
- memory difficulties (although not common in the early stages) (NHS, 2015l).

Physical problems

In the later stages, many people with frontotemporal dementia may develop problems with movement. They may no longer initiate movements and may become rigid, similar to Parkinson's disease.

Some people may lose control of their bladder (urinary incontinence) and bowel (bowel incontinence) (NHS, 2015l).

In a few cases, frontotemporal dementia can occur with other neurological (nerve and brain) problems that cause additional physical symptoms, including -

- Motor neurone disease - which causes progressive weakness, usually with muscle wasting,
- Corticobasal degeneration - which can cause problems controlling certain limbs, loss of balance and co-ordination, slowness and reduced mobility,
- Progressive supranuclear palsy - which can cause problems with balance, movement, eye movements and swallowing (NHS, 2015l).

Seeking medical advice

If you think you may have early symptoms of dementia, it's a good idea to see your GP. If you're worried about someone else, encourage them to make an appointment and perhaps suggest that you go along with them.

Symptoms of dementia can have a number of different causes. Your GP can carry out some simple checks to try to find out what the cause may be, and they can refer you to a specialist for further tests if necessary (NHS, 2015l).

Diagnosis

Confirming a diagnosis of dementia can be difficult, particularly when the condition is in its early stages. This is because many of the symptoms of dementia can be caused by other conditions (NHS, 2015l).

For frontotemporal dementia to be diagnosed correctly, you will have a number of tests and assessments, including -

- an assessment of your symptoms - for example, whether you have experienced any behavioural changes or problems with speech and language,
- a full assessment of your mental abilities,
- a physical examination,
- a review of the medication you are taking,
- a range of tests, including blood tests, to rule out other possible causes of your symptoms, such as a vitamin B12 deficiency,
- brain scans, such as a MRI scan, which can show the loss of brain cells in the frontal and temporal regions of the brain (behind the forehead and near the ears) (NHS, 2015l).

Some of these tests can be carried out by your GP. Some will be carried out by specialists, such as a neurologist (an expert in treating conditions that affect the brain and nervous system), an elderly care doctor, or a psychiatrist with experience in treating dementia (NHS, 2015l).

Genetic testing

If frontotemporal dementia runs in your family, you may want to talk to your GP about being referred for a genetic test to find out if you carry one of the altered genes that causes the condition.

However, before having any tests, you should discuss the risks, benefits and limitations of genetic testing with a counsellor (NHS, 2015l).

Treatment

There is currently no cure for frontotemporal dementia, but treatment can help to manage some of the symptoms.

When you are diagnosed with dementia, your future health and social care needs will need to be assessed and a care plan drawn up (NHS, 2015l).

This is to ensure you receive the right treatment for your needs. It involves identifying areas where you may need some assistance, such as -

- what support you or your carer need for you to remain as independent as possible,
- whether there are any changes that need to be made to your home to make it easier to live in,
- whether you need any financial assistance (NHS, 2015l).

Medication

There is no medication specifically designed to treat frontotemporal dementia. Acetylcholinesterase inhibitors such as donepezil (Aricept), which are normally prescribed for Alzheimer's disease, are not effective.

However, there are medications that can help control some of the symptoms (NHS, 2015l).

Antidepressants

There is evidence to suggest that a type of antidepressant called SSRIs may help to control the loss of inhibitions, overeating and compulsive behaviour seen in some people with frontotemporal dementia.

There is also some evidence suggesting that a type of antidepressant called trazodone may help to control behavioural problems (NHS, 2015l).

Antipsychotics

Antipsychotics such as haloperidol are only really used for treating severely challenging behaviour that is putting you or others at risk of harm.

This is because these medications can cause a range of serious side-effects, including rigidity and immobility.

If antipsychotics are needed, they will be prescribed at the lowest possible dose and for the shortest possible time, and your health will be carefully monitored (NHS, 2015l).

Supportive measures and treatments

There are also a number of treatments and techniques that can help make everyday living easier if you have dementia, or are caring for someone who does. These include -

- occupational therapy to identify problem areas in everyday life, such as getting dressed, and help work out practical solutions,
- speech and language therapy to help improve any communication problems,
- physiotherapy to help with movement difficulties,
- psychological treatments, such as cognitive stimulation, to help improve memory, problem solving skills and language ability,
- relaxation therapies, such as aromatherapy, music or dance therapy, and massage,
- strategies for dealing with challenging behaviour, such as distraction techniques, having a structured daily routine, and encouraging activities to relieve boredom (such as doing puzzles or listening to music),
- offering food only at mealtimes and in suitable portions to help prevent overeating,
- incontinence products (NHS, 2015l).

Legal matters

If you've been diagnosed with dementia, you'll need to make arrangements for your care that take into account the possible decline in your mental abilities. This should include ensuring that your wishes are upheld if you're not able to make decisions for yourself.

You may wish to draw up an advance decision after first receiving a diagnosis of dementia. This makes your treatment preferences known now, in case you are unable to do this in the future.

You may also want to consider giving a relative or someone else "lasting power of attorney". This is the power to make decisions about you if you are unable to.

It's best to decide on these issues as early in the illness as possible, so that your competence to make decisions is not in question (NHS, 2015l).

Huntington's disease

Huntington's disease is a progressive brain disorder caused by a single defective gene on chromosome 4 (ALZ.ORG, 2016d).

Huntington's disease is an inherited condition that damages certain nerve cells in the brain.

This brain damage gets progressively worse over time and can affect movement, cognition (perception, awareness, thinking, judgement) and behaviour.

Early features can include personality changes, mood swings, fidgety movements, irritability and altered behaviour, although these are often overlooked and attributed to something else.

Huntington's disease was originally called Huntington's chorea ("chorea" [40] is the Greek word for dancing). This is because the involuntary movements associated with the condition can look like jerky dancing. However, "disease" is now the preferred term, because the condition involves a lot more than just abnormal movements.

Huntington's disease is caused by an inherited faulty gene. However, in around 3% of cases, there's no family history of the condition, normally because the parents died at a young age (NHS, 2014b).

Diagnosing Huntington's disease

If you have symptoms of Huntington's disease, your GP will refer you to a specialist clinician (usually a neurologist) if they feel your symptoms need further investigation.

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[40] fidgety or jerky movements

The specialist will ask about your symptoms to assess how likely it is that you have Huntington's disease and to rule out similar conditions.

They may also test a number of physical functions, such as your eye movements, balance, control, movement and walking. Your speech and cognition may also be tested. All of these can be affected by Huntington's disease (NHS, 2014b).

Treating Huntington's disease

There's no cure for Huntington's disease and its progress can't be reversed or slowed down.

As the condition progresses, it may put a strain on family and relationships. Treatments for Huntington's disease aim to improve any mood disturbance; this is done to maintain skills used in daily living that can deteriorate over time.

Medication can help manage some of the symptoms, such as irritability or excessive movement. Therapies such as speech and language therapy and occupational therapy can help with communication and day-to-day living.

Support is also available for the family of a person with Huntington's disease. This includes, for example, testing family members who don't have any of the condition's features (manifest) to see whether they carry the gene, or help with choosing a suitable care home in advanced cases.

Huntington's disease usually progresses and gets worse over a 10—25 year period from when it first appears, before the person eventually dies from it. During the condition's later stages, the person will be totally dependent and need full nursing care.

Death is usually from a secondary cause, such as heart failure, pneumonia or another infection (NHS, 2014b).

Who's affected by Huntington's disease?

Both men and women with a family history of Huntington's disease can inherit the condition. Symptoms usually start to appear during adulthood.

Juvenile (children's) Huntington's disease develops before the age of 20. Only 5–10% of people with Huntington's disease develop it at a very young age, and the pattern of features may be different.

It was previously thought that 4–6 people in a population of 100,000 were affected by Huntington's disease. However, UK research carried out in 2012 found the actual figure for those affected by the condition to be about 12 people per 100,000.

It’s thought that the number of people who have the Huntington’s gene and are not yet affected is about twice that of those who have symptoms (NHS, 2014b).

Current research

Research is underway to find disease-modifying medication and new treatments for the features of Huntington’s disease.

Exciting progress has been made in identifying potential ways of slowing down or halting the condition by ”switching off” the faulty gene that causes Huntington’s disease (NHS, 2014b).

Features of Huntington’s disease

The clinical features of Huntington’s disease can include psychiatric problems and difficulties with behaviour, feeding, communication and abnormal movements.

People can start to show the features of Huntington’s disease at almost any age, but most will develop problems between the ages of 35 and 55.

The condition usually progresses and gets worse for around 10–25 years, until the person eventually dies. Signs and symptoms may vary between individuals and there’s no typical pattern.

Early features, such as personality changes, mood swings and unusual behaviour, are often overlooked at first and attributed to something else.

Some people with Huntington’s disease may not recognise that they have any problems (NHS, 2014b).

Include abnormal involuntary movements, a severe decline in thinking and reasoning skills, and irritability, depression and other mood changes (ALZ.ORG, 2016d).

Behavioural changes

Behavioural changes are often the first features to appear in Huntington’s disease and can be the most distressing. These changes often include -

- a lack of emotions and not recognising the needs of others in the family,
- alternating periods of aggression, excitement, depression, apathy, antisocial behaviour and anger,

- difficulty concentrating on more than one task and handling complex situations,
- irritability and impulsiveness (NHS, 2014b).

A person with Huntington's disease may appear to have a lack of drive, initiative and concentration, making them seem lazy. However, this isn't the case - it's just the way the condition affects the brain. As part of this, they may also develop a lack of interest in hygiene and self care.

The Huntington's Disease Association has more information about the behavioural problems associated with the condition (NHS, 2014b).

Psychiatric problems

Many people with Huntington's disease have depression. This occurs as part of the condition, not just as a response to the diagnosis. Symptoms of depression include continuous low mood, low self-esteem, a lack of motivation or interest in things, and feelings of hopelessness.

A few people may also develop obsessive behaviours and schizophrenic-like problems, although this is relatively rare.

Studies have shown that people with Huntington's disease are more likely to consider suicide, particularly near the time of diagnosis when the condition is becoming apparent, and when they start to lose their independence (NHS, 2014b).

Movement problems

Huntington's disease affects movement. Early features include slight, uncontrollable movements of the face, and jerking, flicking or fidgety movements of the limbs and body. These move from one area of the body to another and can cause the person to lurch and stumble.

These features are often first seen when the person is walking or resting (sitting in a chair or lying in bed).

As the condition progresses, the uncontrollable movements will become more frequent and extreme. However, over time this may change and in the advanced stages of the condition a person's movements may become slow and their muscles more rigid (NHS, 2014b).

Feeding problems

People with Huntington's disease tend to lose weight, despite having a good appetite. They can find eating tiring, frustrating and messy because the mouth and throat muscles don't work properly, due to the loss of motor control. In some cases, this can lead to choking and recurrent chest infections.

Loss of coordination can lead to spilling or dropping food. Swallowing is a problem, so choking on food and drink, particularly thin drinks such as water, can be a common problem.

A referral to a dietitian or a speech and language therapist may be necessary if there are difficulties with swallowing. In some cases, a feeding tube can be inserted.

The Huntington's Disease Association has more information about the eating and swallowing difficulties associated with the condition (NHS, 2014b).

Communication problems

Communication and cognition (perception, awareness, thinking and judgement) are affected by Huntington's disease. People with the condition often have difficulty putting thoughts into words and slur their speech.

They can understand what's being said, but may not be able to respond or communicate that they understand. However, with time, a person with Huntington's disease will become less responsive, more withdrawn and communicate little (NHS, 2014b).

Sexual problems

People with Huntington's disease can have problems with sexual relationships, particularly during the early stages of the condition. This is usually a loss of interest in sex or, less commonly, making inappropriate sexual demands.

The Huntington's Disease Association has more information about sexual problems associated with the condition (NHS, 2014b).

End of life

In the later stages of Huntington's disease, the person will be totally dependent and need full nursing care.

Death is usually from a secondary cause, such as pneumonia or another infection.

You may find the end of life care guide useful if you’re caring for someone who’s dying, or if you want to plan your end of life care in advance (NHS, 2014b).

Causes

Huntington’s disease is caused by a faulty gene that runs in families (NHS, 2014b).

Genes and chromosomes

Genes are the instructions for making all parts of the human body and brain. They’re made up of DNA and packaged onto strands called chromosomes. We have two copies of all our genes, so our chromosomes are in pairs.

Humans have 46 chromosomes (23 pairs). The faulty gene that causes Huntington’s disease is found on chromosome number four.

The normal copy of the gene produces a protein called huntingtin, but the faulty gene contains an abnormal region of what are called CAG repeats. This area is larger than normal and produces a mutant form of huntingtin.

Cells in parts of the brain - specifically, the basal ganglia and parts of the cortex - are very sensitive to the effects of the abnormal huntingtin. This makes them function poorly and eventually die.

The brain normally sends messages through the basal ganglia and cortex to control movement and thinking, as well as motivation. If this part of the brain is damaged, it causes problems with control of movement, behaviour and thinking.

It’s still unclear exactly how abnormal huntingtin affects the brain cells and why some are more sensitive than others (NHS, 2014b).

Inheriting Huntington’s disease

A parent with the Huntington’s disease gene has one good copy of the gene and one faulty copy. Their child will inherit one of these genes. Therefore, there’s a 50:50 chance that the child will get the faulty gene and develop Huntington’s disease.

However, it’s very difficult to predict how old the child will be when they develop the condition if they inherit the abnormal gene, unless it contains a very long CAG repeat (>55).

There’s also a 50:50 chance that the child with Huntington’s disease will pass the faulty gene on to a child they may have in the future. This pattern of inheritance is called ”autosomal dominant”.

In around 3% of cases of Huntington’s disease, there’s no obvious family history of the condition. This could be due to adoption or because relatives with the condition died early from other causes. In rare cases, it’s due to a new expansion in the gene (NHS, 2014b).

Brain changes

The gene defect causes abnormalities in a brain protein that, over time, lead to worsening symptoms (ALZ.ORG, 2016d).

Diagnosis

If you have features of Huntington’s disease, your GP will refer you to a clinician with specialist expertise in the condition if they feel further investigation is needed.

Many areas have Huntington’s disease management clinics with a range of specialists, including a neurologist.

The specialist will ask about your symptoms, such as whether you’ve had recent emotional problems, to see if it’s likely you have Huntington’s disease and to rule out similar conditions.

They may also examine you and test your thinking, eye movements, balance, walking, and whether you have any involuntary movements, such as chorea (NHS, 2014b).

Confirming the diagnosis

People with Huntington’s disease often start to experience symptoms a number of years before the condition is actually diagnosed. This is particularly true in cases where someone is unaware that the condition runs in their family.

If you’re showing features of Huntington’s disease and it’s known to run in your family, or if your doctor strongly suspects that you have the condition, genetic testing can be carried out to confirm the diagnosis.

It’s important to realise that the diagnosis is based on the doctor recognising a combination of a number of factors - neurological examination, family history and genetic testing. It’s possible to have the gene change and still be healthy. This is known as ”premanifest Huntington’s disease” (NHS, 2014b).

Genetic test

The children of someone with Huntington’s disease can take a genetic test after the age of 18 to see whether they’ve inherited the faulty gene. If they’ve inherited the faulty gene, they’ll develop Huntington’s disease, but it’s not possible to work out at what age.

You can ask your GP or neurologist to arrange an appointment for you at a regional genetic clinic. You’ll receive some counselling and then blood samples will be taken. Your DNA will be extracted from the blood samples and analysed to see whether you have inherited the faulty gene.

You may have to wait two to four weeks for the test results (NHS, 2014b).

Brain scan

In the early stages of Huntington’s disease, there may not be any specific changes on the brain scan. A doctor may use a brain scan at any stage of the illness if they’re concerned there may be other problems in addition to Huntington’s disease.

A brain scan may involve having a CT scan or a MRI scan. An MRI scan is more detailed and is more sensitive at picking up changes in the brain. However, it’s a more claustrophobic procedure (NHS, 2014b).

Should I get tested?

Not everyone wants to know if they’ve inherited the faulty gene associated with Huntington’s disease. It’s a personal choice.

Some people say they would rather not know because they want to enjoy their life and they may die of other causes before the condition develops.

Most people have approximately 40 years of a normal healthy life before the condition develops.

Less than one in five people at risk of Huntington’s disease choose to have the genetic test.

If you’re considering genetic testing, it’s strongly recommended that you speak to a genetic counsellor first. Your GP can refer you.

The Huntington's Disease Association website has more information about predictive testing for Huntington's disease (NHS, 2014b).

Treatment

There's no cure for Huntington's disease. Its progress can't be reversed or slowed down, although this is the goal of many research projects.

Some of the features of Huntington's disease can be managed with medication and therapies, which may be coordinated by specialist teams.

Therapies, such as speech and language therapy and occupational therapy, can help with communication and day-to-day living.

Regular exercise is also very important. People who are active tend to feel much better physically and mentally than those who don't exercise. Someone with Huntington's disease may have poor coordination, but walking independently, with the use of walking aids if necessary, can make all the difference (NHS, 2014b).

Medication for Huntington's disease

Medicines for Huntington's disease, which can be taken in liquid form in many cases if needed, are described below.

Most of these medications have side-effects, such as extreme tiredness. However, it may sometimes be difficult to tell whether these are symptoms of the condition or a result of the medication (NHS, 2014b).

Antidepressants to treat depression

Antidepressants can help improve mood swings and treat depression. They include -

- SSRI antidepressants - such as fluoxetine, citalopram and paroxetine,
- tricyclic antidepressants - such as amitriptyline,
- other types of antidepressants - including mirtazapine, duloxetine and venlafaxine (NHS, 2014b).

Side-effects of antidepressants may include -

- constipation,
- sweating,
- shaking or trembling,

- difficulty sleeping (insomnia) (NHS, 2014b).

Mood stabilisers to treat irritability or mood swings

Mood stabilisers, particularly carbamazepine, may be considered as a treatment for irritability. Olanzapine can also help, along with sodium valproate and lamotrigine.

The dose of carbamazepine needs to be slowly increased and any side-effects monitored. Carbamazepine can't be used during pregnancy (NHS, 2014b).

Medication to suppress involuntary movements

The medications listed below suppress the involuntary movements - or chorea - seen in Huntington's disease. In the UK, antipsychotic medicines are usually preferred (NHS, 2014b).

- **anti-psychotic medication** - such as olanzapine, sulpiride, risperidone and quetiapine,
- **tetrabenazine** - reduces the amount of dopamine reaching some of the nerve cells in the brain,
- **benzodiazepines** - such as clonazepam and diazepam (NHS, 2014b).

Anti-psychotic medication may also help control delusions and violent outbursts. However, they may have severe side-effects, such as -

- stiffness and rigidity,
- sedation,
- tremor (shaking),
- moving slowly (NHS, 2014b).

Due to the possibility of experiencing these side- effects, the lowest possible dose of anti-psychotics are normally prescribed in the first instance (NHS, 2014b).

Living with Huntington's disease

Help is available to assist people with Huntington's disease in their day-to-day living. This might include physiotherapy, occupational therapy and speech therapy.

Huntington's disease puts a great deal of strain on relationships, and is very stressful and upsetting for the family. It's distressing to see a family member's state of mind deteriorate so much that they may not be like their former self at all.

Daily routines such as getting dressed and eating meals can be frustrating and exhausting. The types of help outlined below aim to ease the strain of the condition by improving skills that may deteriorate (NHS, 2014b).

Help with communication

Speech and language therapy can improve communication skills, memory and teach alternative ways of communicating. It can also help with swallowing problems. Communication aids can sometimes be helpful, as they allow communication without the need for talking. For example, you can point to symbols on a chart to indicate your mood or whether you're hungry.

The family of someone with Huntington's disease will need to be patient and supportive. They can try alternative ways of communicating if speech is a problem (NHS, 2014b).

Help with mealtimes

People with Huntington's disease need to have a high-calorie diet. A dietitian can help you work out an appropriate diet plan.

To help with eating and drinking, food should be easy to chew, swallow and digest. It can be cut into small pieces or puréed to prevent choking. Feeding equipment is also available, such as special straws and non-slip mats.

At some point, it may be necessary to use a feeding tube that goes directly into the stomach. If a person with Huntington's disease doesn't want to be artificially fed during the later stages of the condition, they should make their wishes known to their family and doctor. They may want to consider making an advance decision (a living will) or a statement of wishes and preferences.

The Huntington's Disease Association has more information about eating and swallowing. You can also email the Royal Hospital for Neuro-disability for further information and advice about swallowing difficulties and artificial nutrition. Their telephone number is 020 8780 4500, or you can email them on info@rhn.org.uk (NHS, 2014b).

Occupational therapy

An OT can help with day-to-day activities. Your home can be adapted by social services to make life easier for a person with Huntington's disease, as they may be at risk of injury from a fall or accidentally starting a fire.

Your shower, bath, chairs and bed may need to be adapted. You may also need to think about wheelchair access (NHS, 2014b).

Physiotherapy

A physiotherapist can help with mobility and balance by using a range of treatments, including manipulation, massage, exercise, electrotherapy and hydrotherapy. You may be referred to a physiotherapist through your GP or social services (NHS, 2014b).

Electronic assistive technology

The Royal Hospital for Neuro-disability provides an electronic assistive technology (EAT) service. It's made up of a team of healthcare professionals who provide EAT equipment for patients and residents within the hospital, as well as for people with disabilities living in the community or at other hospitals or units (NHS, 2014b).

Equipment includes -

- communication aids,
- computers and software,
- switches and other access devices,
- powered wheelchair controls,
- environmental controls (NHS, 2014b).

Information about Huntington's disease

The Huntington's Disease Association has a number of useful factsheets that provide advice about a range of topics, including -

- behavioural problems,
- communication skills,
- sexual problems,
- diet, eating and swallowing,
- Driving,
- seating, equipment and adaptations,
- information for teenagers (NHS, 2014b).

The charity can also help you explore the housing options available when full-time care is needed.

It's also worth finding out what benefits you may be entitled to if you have Huntington's disease, or if you're looking after someone with it.

You can do this through the Huntington's Disease Association or by contacting the Citizens Advice Bureau (CAB) (NHS, 2014b).

Driving

A person diagnosed with Huntington's disease who's started to experience clinical features should inform the Driver and Vehicle Licensing Agency (DVLA) because it will affect their ability to drive.

The DVLA will write to your doctor, with your permission, to ask for their opinion about your condition. Based on that information, a decision will be made about whether you can still drive and for how long before another assessment is needed.

There's no need to tell the DVLA if you're carrying the faulty gene but haven't yet developed the features of the condition (NHS, 2014b).

Korsakoff's syndrome

Korsakoff syndrome is a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). Korsakoff syndrome is most commonly caused by alcohol misuse, but certain other conditions also can cause the syndrome (ALZ.ORG, 2016a).

Korsakoff's Syndrome (KS) also known as Korsakoff's dementia, Korsakoff's psychosis or amnesic-confabulatory syndrome (HAILSHAMHOUSE, 2016).

Thiamine (vitamin B-1) helps brain cells produce energy from sugar. When levels fall too low, brain cells cannot generate enough energy to function properly. As a result, Korsakoff syndrome may develop (ALZ.ORG, 2016a). It is a neurological disorder caused by a lack of Thiamine (Vitamin B1) in the brain. The onset of this syndrome is linked to chronic alcohol abuse and/or severe malnutrition or secondary to an episode of Wernicke's encephalopathy (HAILSHAMHOUSE, 2016).

Korsakoff syndrome is most commonly caused by alcohol misuse, but can also be associated with AIDS, chronic infections, poor nutrition and certain other conditions.

Korsakoff syndrome is often, but not always, preceded by an episode of Wernicke encephalopathy, which is an acute brain reaction to severe lack of thiamine. Wernicke encephalopathy is a medical emergency that causes life-threatening brain disruption, confusion, staggering and stumbling, lack of coordination, and abnormal involuntary eye movements.

Because the chronic memory loss of Korsakoff syndrome often follows an episode of Wernicke encephalopathy, the chronic disorder is sometimes known as Wernicke-Korsakoff syndrome. But Korsakoff syndrome can also develop in individuals who have not had a prior episode of Wernicke encephalopathy (ALZ.ORG, 2016a).

The prevalence of Korsakoff's syndrome varies from country to country and can be affected by life choices, cultures, beliefs and social status and is expected to affect 1–3% of the population rising to 25–35% of those with an alcohol dependency (HAILSHAMHOUSE, 2016).

Symptoms

Korsakoff syndrome causes problems learning new information, inability to remember recent events and long-term memory gaps. Memory problems may be strikingly severe while other thinking and social skills are relatively unaffected. For example, individuals may seem able to carry on a coherent conversation, but moments later be unable to recall that the conversation took place or to whom they spoke.

Those with Korsakoff syndrome may "confabulate," or make up, information they can't remember. They are not "lying" but may actually believe their invented explanations. Scientists don't yet understand why Korsakoff syndrome may cause confabulation (ALZ.ORG, 2016a).

- Severe short-term memory loss resulting in a loss of life skills,
- Long-term memory loss of events prior to cerebral damage,
- Invented memories (confabulation) with a belief that they are accurate,
- Limited conversation,
- Lack of insight,
- Apathy,
- Low self-esteem (HAILSHAMHOUSE, 2016).

Diagnosis

Korsakoff syndrome is a clinical diagnosis representing a doctor's best judgment about the cause of a person's symptoms. There are no specific lab tests or brain scan procedures to confirm that a person has this disorder. The syndrome may sometimes be hard to identify because it may be masked by symptoms of other conditions common among those who misuse alcohol, including intoxication or withdrawal, infection or head injury.

Experts recommend that a medical workup for memory loss or other cognitive changes always include questions about an individual's alcohol use. Anyone admitted to the hospital for an alcohol-related condition should be professionally screened for memory loss and cognitive change (ALZ.ORG, 2016a).

Causes and risks

Scientists don't yet know exactly how Korsakoff syndrome damages the brain. Research has shown that severe thiamine deficiency disrupts several biochemicals that play key roles in carrying signals among brain cells and in storing and retrieving memories. These disruptions destroy brain cells and cause widespread microscopic bleeding and scar tissue.

Most cases of Korsakoff syndrome result from alcohol misuse. Scientists don't yet know why heavy drinking causes severe thiamine deficiency in some alcoholics, while others may be affected primarily by alcohol's effects on the liver, stomach, heart, intestines or other body systems.

Researchers have identified several genetic variations that may increase susceptibility to Korsakoff syndrome. Poor nutrition also may raise risk.

Korsakoff syndrome also can be caused by anorexia, overly-stringent dieting, fasting, starvation or weight-loss surgery; uncontrolled vomiting; AIDS; kidney dialysis; chronic infection; or cancer that has spread throughout the body (ALZ.ORG, 2016a).

Treatment

Some experts recommend that heavy drinkers and others at risk of thiamine deficiency take oral supplements of thiamine and other vitamins under their doctor's supervision.

Many experts also recommend that anyone with a history of heavy alcohol use who experiences symptoms associated with Wernicke encephalopathy be given injectable thiamine until the clinical picture grows clearer.

Once acute symptoms improve, individuals should be carefully evaluated to determine if their medical history, alcohol use and pattern of memory problems may be consistent with Korsakoff syndrome. For those who develop Korsakoff syndrome, extended treatment with oral thiamine, other vitamins and magnesium may increase chances of symptom improvement. Giving up alcohol is also an effective treatment.

In those who develop Korsakoff syndrome, with or without a preceding episode of Wernicke encephalopathy, there are few studies on long-term outcomes. Available data suggest that about 25% of those who develop Korsakoff syndrome eventually recover, about half improve but don't recover completely, and about 25% remain unchanged. Some research suggests that those who recover from an episode may have a normal life expectancy if they abstain from alcohol (ALZ.ORG, 2016a).

The main focus points of any rehabilitation programme are to improve skills and retrain in the following areas -

- importance of personal hygiene, sequence training on how to provide personal care and when it is required,
- awareness of good dietary and fluid intake (alcohol free), choosing of appropriate foods to avoid malnutrition,
- ability, sequencing and interest in purchasing, preparing, cooking and storing food,
- ability to manage financial matters,
- ability and sequencing to manage laundering clothing,
- ability to ensure personal space is kept clean and tidy,
- development of social skills, empowerment and improvement in self-esteem (HAILSHAMHOUSE, 2016).

Mild cognitive impairment

Causes

Mild cognitive impairment (MCI) can have a number of different possible causes. Some of these are treatable and some are not.

In some people, MCI is a 'pre-dementia' condition. This means that the brain diseases that cause dementia are already established. These diseases are not generally reversible and so, in time, these people's symptoms will worsen and their condition will progress from MCI to dementia.

For example, some people with MCI have mild memory loss that started gradually. These people are likely to develop Alzheimer's disease as their memory worsens (Rodda and Fryer, 2015).

Some people with MCI will turn out to have a different, often treatable, cause following assessment by a doctor. This could include -

- depression,
- anxiety or
- stress (Rodda and Fryer, 2015).

The same symptoms could also be caused by a physical illness (e.g. constipation, infection), poor eyesight or hearing, vitamin or thyroid deficiencies, or the side-effects of medication. Where this is the case, the person will be diagnosed with this condition - a thyroid deficiency or depression, for example - rather than MCI.

A doctor will not always be able to say what is causing MCI, even after a thorough assessment. It may be necessary to wait a few months or more, to see how the person's symptoms develop (Rodda and Fryer, 2015).

Symptoms

A person with MCI has mild problems with one or more of the following -

- **memory** - for example, forgetting recent events or repeating the same question,
- **reasoning, planning or problem-solving** - for example, struggling with thinking things through,
- **attention** - for example, being very easily distracted,
- **language** - for example, taking much longer than usual to find the right word for something,
- **visual depth perception** - for example, struggling to interpret an object in three dimensions, judge distances or navigate stairs (Rodda and Fryer, 2015).

These symptoms will have been noticed by the individual, or by those who know them. For a person with MCI, these changes may cause them to experience minor problems or need a little help with more demanding daily tasks (e.g. paying bills, managing medication, driving). However, MCI does not cause major problems with everyday living. If there is a significant impact on everyday activities, this may suggest dementia.

Most healthy people experience a gradual decline in mental abilities as part of ageing. In someone with MCI, however, the decline in mental abilities is greater than in normal ageing. For example, it's common in normal ageing to have to pause to remember directions or to forget words occasionally, but it's not normal to become lost in familiar places or to forget the names of close family members.

If the person with MCI has seen a doctor and taken tests of mental abilities, their problems will also be shown by a low test score or by falling test scores over time. This decline in mental abilities is often caused by an underlying illness (Rodda and Fryer, 2015).

Diagnosis

The assessment is the same as for suspected dementia. Your GP will talk to you about your symptoms, when they started and how they are affecting your daily life now. You will have your physical health and any medication that you are taking reviewed, and take tests to assess depression and your mental abilities (Rodda and Fryer, 2015).

A doctor will use their own judgement to make the diagnosis. Research guidelines state that MCI should be diagnosed if the person shows all of the following -

- symptoms (as listed above) are getting worse and cannot be otherwise explained,
- scores poorly for their age on a test of mental abilities,
- has minor or no problems with more complex daily activities (Rodda and Fryer, 2015).

Treatment

There are currently no drugs that have been approved for treating MCI, as opposed to dementia. It was initially hoped that the Alzheimer's drugs donepezil (e.g. Aricept), rivastigmine (e.g. Exelon) and galantamine (e.g. Reminyl) would help with symptoms of MCI, or slow its progression to dementia. However, a lot of trials of these drugs have been done and they have shown no clear benefit to patients.

Nevertheless, there is a lot someone with MCI can do to help lower their chances of developing dementia - see Tips for someone diagnosed with MCI. MCI is more likely to progress to dementia if the person has a poorly controlled heart condition or diabetes, or has strokes. Therefore, treatment for MCI will often include medication for any heart condition a person may have, or tablets to reduce high blood pressure, prevent clots or lower cholesterol. If depression is diagnosed this will also be treated, with medication, talking therapies or both.

A person with MCI will also be encouraged to lower their risk of developing dementia by adopting a healthy lifestyle. People who smoke should try to stop and people who drink alcohol should keep to recommended levels. Regular physical exercise also seems to reduce the risk of dementia. Eating a healthy diet and keeping to a healthy weight may also help. Ask your GP or primary care team for advice on all of these.

It is strongly recommended that someone with MCI keeps active, both mentally (e.g. doing puzzles, reading) and socially (e.g. seeing friends).

Recent evidence shows that a combined programme of approaches, rather than any one approach alone, can help to improve or maintain mental abilities in people with MCI. These approaches include medical treatment for vascular risk factors (a heart condition, diabetes or high blood pressure), physical activity, learning strategies to improve memory and thinking, and receiving and following advice on memory, health and diet.

In some areas, people with MCI are now routinely referred for regular sessions - sometimes called ’memory protection groups’ - to support them with these changes (Rodda and Fryer, 2015).

Tips for someone diagnosed with MCI

There is a lot you can do to help reduce your chances of MCI progressing to dementia. There are also many ways to deal with memory problems that will allow you to live well with MCI.

- Take medication (e.g. for blood pressure) as prescribed by the doctor, even if you feel fine. It will help keep underlying health conditions in check.
- If you do smoke, now is a good time to stop. If you drink, check you are well within the recommended limits. Ask your GP for advice on both of these.
- Try not to become stressed or anxious as this can make memory or thinking problems worse.
- Having a regular routine can help to minimise memory problems, though make sure to have some variety in your days or you may get bored. Similarly, try to always keep things in the same place as it will make them easier to find.
- Use calendars and diaries, or reminders on electronic devices, to help you remember appointments and important events.
- Get regular physical exercise - you could go for a brisk walk or a swim, or do some more energetic tasks in the garden or around the house. Try to do this for at least 30 minutes, five times a week.

- Try to break tasks down into small steps if you are struggling, then focus on just one step at a time. For example, while cooking focus on one step of the recipe in turn.
- Eat a healthy balanced diet with plenty of fruit and vegetables, lots of starchy foods (e.g. potatoes and rice), regular fish and some meat, but not too much saturated fat or dairy products (e.g. butter and cheese).
- Keep your brain active with puzzles, quizzes, reading or anything else you enjoy that stimulates your mind.
- Make time to relax - you might enjoying listening to music or sitting in the garden. You could also find out about how to practise breathing exercises by taking out a book about relaxation and breathing at your local library or looking online for tips.
- Try to sleep well - avoid stimulants like tea or coffee, or having alcohol, before bed.
- Stay socially active - make an effort to keep going out to see friends and family. If you attend a place of worship, continue to go regularly.
- Ask your GP about memory support groups for people with MCI in your area (Rodda and Fryer, 2015).

Prognosis

People who have MCI are at an increased risk of going on to develop dementia. In research studies carried out in memory clinics, 10%–15% of people who had MCI with gradual memory loss went on to develop dementia - usually Alzheimer's disease - each year.

In studies carried out in other settings, the rates of 'conversion' from MCI to dementia are about half this level (about 5% each year), but people with MCI still show a significantly increased risk of dementia.

Although MCI increases someone's risk of developing dementia, not everyone with MCI will get worse and develop dementia. Some people with MCI remain stable over time and some improve and no longer have any problems.

The outcome will generally depend on the cause of the MCI.

These different outcomes are one reason why some doctors find some aspects of MCI to be controversial (Rodda and Fryer, 2015).

Mixed dementia

In mixed dementia abnormalities linked to more than one cause of dementia occur simultaneously in the brain. Recent studies suggest that mixed dementia is more common than previously thought (ALZ.ORG, 2016d).

In the most common form of mixed dementia, the abnormal protein deposits associated with Alzheimer's disease coexist with blood vessel problems linked to vascular dementia. Alzheimer's brain changes also often coexist with Lewy bodies. In some cases, a person may have brain changes linked to all three conditions - Alzheimer's disease, vascular dementia and dementia with Lewy bodies.

Researchers don't know exactly how many older adults currently diagnosed with a specific type of dementia actually have mixed dementia, but autopsies show that the condition may be significantly more common than previously realised.

Autopsy studies play a key role in shedding light on mixed dementia because scientists can't yet measure most dementia-related brain changes in living individuals. In the most informative studies, researchers correlate each participant's cognitive health and any diagnosed problems during life with analysis of the brain after death (ALZ.ORG, 2016b).

Brain changes

Characterised by the hallmark abnormalities of more than one cause of dementia - most commonly, Alzheimer's and vascular dementia, but also other types, such as dementia with Lewy bodies (ALZ.ORG, 2016d).

Symptoms

Mixed dementia symptoms may vary, depending on the types of brain changes involved and the brain regions affected. In many cases, symptoms may be similar to or even indistinguishable from those of Alzheimer's or another type of dementia. In other cases, a person's symptoms may suggest that more than one type of dementia is present (ALZ.ORG, 2016b).

Diagnosis

A diagnosis of mixed dementia comes after a brain autopsy. Most individuals whose autopsies show they had mixed dementia were diagnosed with one specific type of dementia during life, most commonly with Alzheimer's disease. For example, in the Memory and Aging Project study involving long-term cognitive assessments followed by eventual brain autopsy -

- 94% of participants who were diagnosed with dementia were diagnosed with Alzheimer's. The autopsies of those diagnosed with Alzheimer's showed that 54% had coexisting pathology.
- The most common coexisting abnormality was previously undetected blood clots or other evidence of vascular disease.
- Lewy bodies were the second most common coexisting abnormality (ALZ.ORG, 2016b).

Causes and risks

Although mixed dementia is infrequently diagnosed during life, many researchers believe it deserves more attention because the combination of two or more types of dementia-related brain changes may have a greater impact on the brain than one type alone. Evidence suggests that the presence of more than one type of dementia-related change may increase the chances a person will develop symptoms (ALZ.ORG, 2016b).

Treatment

Because most people with mixed dementia are diagnosed with a single type of dementia, doctors often base their prescribing decisions on the type of dementia that's been diagnosed. No drugs are specifically approved by the U.S. Food and Drug Administration (FDA) to treat mixed dementia. Doctors who think that Alzheimer's disease is among the conditions contributing to a person's dementia may consider prescribing the drugs that are FDA-approved for Alzheimer's (ALZ.ORG, 2016b).

Research

Many researchers are convinced that growing understanding of mixed dementia, coupled with recognition that vascular changes are the most common coexisting brain change, may create an opportunity to reduce the number of people who develop dementia. Controlling overall risk factors for diseases of the heart and blood vessels may also protect the brain from vascular changes. (ALZ.ORG, 2016b).

Niemann-Pick disease type C

Overview

Niemann-Pick disease (NPD) refers to a group of inherited metabolic disorders in which sphingolipids [41] accumulate in cells throughout the body. NPD is part of a group of metabolic diseases classified as lysosomal storage disorders.

Classification is based on clinical and pathological features. NPD can also be classified into those with deficiency of acid sphingomyelinase activity (types A and B), and those with defective intracellular processing and transporting of LDL cholesterol (type C).

Acid sphingomyelinase (ASM) deficiency is a rare autosomal recessive [42] inborn error of metabolism that leads to the accumulation of sphingomyelin in cells and tissues. Historically, two distinct subtypes have been described on the basis of their phenotypes [43] (NP Types A and B).

Recent studies suggest that there is a disease spectrum related to the amount of enzyme activity, presenting as an intermediate phenotype characterised by different levels of neurological involvement.

Niemann-Pick disease type C (NP-C) is an extremely rare genetic disorder arising from neuronal accumulation of glycosphingolipids, due to abnormal lipid trafficking, causing structural and functional damage in cells and tissues. There are two subtypes, NP-C1 and NP-C2, which are phenotypically similar.

Fatal in many cases, NP-C1 has an extremely varied clinical presentation, but is characterised by a range of progressive neurological problems that become severe and limiting at late stages of the disease. It can present, either with or without associated hepatosplenomegaly [44] in infants, children or adults, and

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[41] a member of a class of lipids (fat-soluble constituents of living cells) containing the organic aliphatic amino alcohol sphingosine or a substance structurally similar to it

[42] A genetic condition that appears only in individuals who have received two copies of an autosomal gene, one copy from each parent. The gene is on an autosome, a nonsex chromosome. The parents are carriers who have only one copy of the gene and do not exhibit the trait because the gene is recessive to its normal counterpart gene

[43] the physical appearance resulting from the inherited information. e.g. someone with blue eyes has the phenotype blue eyes

[44] is enlargement of both the spleen and the liver

is characterised by eye movement abnormalities, dysphagia and dysarthria [45], ataxia and progressive cognitive dysfunction [46] leading to dementia.

NP-C2 is associated with a severe phenotype characterised by pulmonary infiltrates, respiratory failure and death in early childhood. However adult onset disease has been described in association with a number of identified mutations (NIEMANN-PICK, 2012a).

Niemann-Pick Type C Disease (NP-C) is a rare, genetically inherited and neurologically progressive, disease in which quantities of fatty substances accumulate in the brain and other major organs. The brain, central nervous system, liver and spleen are all affected (NIEMANN-PICK, 2012b).

Why is it is called Niemann-Pick? (Pronounced neeman-pick)

There is a group of Niemann-Pick diseases which, although quite separate in fundamental cause, have similar clinical presentations. They are named after two doctors who described the symptoms in the early part of the 20th century, and later classified as Types A, B and C in 1958. You may also read about Type D - this refers to a certain Niemann-Pick Type C mutation occurring only in Nova Scotia.

Over the last decade it has become apparent that Niemann-Pick Types A & B, rather than being two separate 'types' of the disease, actually represent the opposite ends of a spectrum of the same disease, both caused by a deficiency of the enzyme ASM (NIEMANN-PICK, 2012b).

How is Niemann-Pick Type C inherited?

The disease is inherited when two copies of a faulty gene (a mutation) are passed on to a child. In each pregnancy of a couple carrying the faulty gene, there is a 25% chance that they will both pass the mutated Niemann-Pick genes to their child, who would then be affected.

Niemann-Pick Type C is caused by an accumulation of cholesterol and other fatty acids in the brain and other major organs (NIEMANN-PICK, 2012b).

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[45] difficulty speaking caused by problems controlling the muscles used in speech

[46] Also known as **brain fog**. This disorder can affect a person's thoughts, memories, and reasoning capabilities, and can manifest itself as trouble with recalling words, with the ability to do math problems, and with one's mental focus

What is the disease incidence?

The incidence of disease is estimated as 1:120,000 (Vanier, 2010).

The number of UK patients, known to the Niemann-Pick Disease Group, is 86 (data correct January 2012) and range from children to adults with oldest adult being over 50 years of age.

It is estimated that there are approximately 1000 known suffers of NP-C worldwide but this figure is likely to be under-estimated due to the rarity of the disease and misdiagnosis (niemann-pick, 2012b).

Symptoms

The symptoms and severity of NP-C can vary greatly with age of onset and from patient to patient, they may include -

- jaundice at (or shortly after) birth,
- an enlarged spleen and/or liver (hepatosplenamegaly),
- difficulty with upward and downward eye movements (vertical supranuclear gaze palsy [47]),
- unsteadiness of gait, clumsiness, problems in walking (ataxia),
- difficulty in posturing of limbs (dystonia),
- slurred, irregular speech (dysarthria),
- learning difficulties and progressive intellectual decline (cognitive dysfunction - ”dementia”),
- sudden loss of muscle tone which may lead to falls (cataplexy),
- tremors accompanying movement and, in some cases, seizures,
- swallowing problems (dysphagia) (niemann-pick, 2012b).

The number of UK patients, known to the Niemann-Pick Disease Group is 85 (data correct January 2012) and range from children to adults with oldest adult being over 50 (niemann-pick, 2012b).

The symptoms and severity of NP-C can vary greatly between individuals, therefore clinical signs and symptoms of the disease are also extremely varied, but can be broadly grouped into categories based on the patient’s age at onset.

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[47] difficulty with upward and downward eye movement

Children (in rare cases these symptoms occur in late childhood and adults)

- vertical supranuclear gaze palsy (VSGP),
- progressive ataxia,
- dysarthria,
- dystonia,
- seizures,
- gelastic cataplexy [48],
- liver or spleen enlargement, particularly in early childhood,
- cognitive dysfunction (NIEMANN-PICK, 2012a).

Adolescents and adults

- psychiatric illness (depression- or schizophrenia-like),
- dementia,
- progressive neurologic deterioration,
- vertical supranuclear gaze palsy may be present (NIEMANN-PICK, 2012a).

NP-C2

- extensive pulmonary infiltration with foam cells [49],
- delayed psychomotor development,
- respiratory failure,
- death in early childhood (NIEMANN-PICK, 2012a).

Diagnosis

How is Niemann-Pick Type C diagnosed?

NP-C is an extremely rare disease that affects multiple body systems and has variable onset and progression over a course of years, making diagnosis challenging.

NP-C is initially diagnosed by taking a small piece of skin ("skin biopsy"), growing the cells ("fibroblasts") in the laboratory, and then studying their ability to

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[48] sudden loss of muscle tone or drop attacks

[49] having the appearance of foam in alveolar spaces

transport and store cholesterol. The transport of cholesterol in the cells is studied by measuring conversion of the cholesterol from one form to another ("esterification"). The storage of cholesterol is assessed by staining the cells with a compound ("filipin") which glows under ultraviolet light. It is important that both of these tests be performed, since reliance on one or the other may lead to the diagnosis being missed in some cases.

Diagnosis can also be made on DNA analysis if the mutations in the affected child are known. This can be done fairly simply on a blood test but is only carried out in a few specialist centres.

Based on molecular genetic testing, NP-C is now divided into two subtypes - NP-C1 and NP-C2 - as each is caused by a different gene mutation.

Approximately 95% of NP-C cases are caused by genetic mutations in the NP-C1 gene, with the other 5% caused by mutations in the NP-C2 gene.

The NP-C1 gene is located on chromosome 18. The gene provides instructions for producing a protein located mainly in the membranes of the lysosomes and endosomes. These are compartments in the cell that digest and recycle materials. While its exact function is not as yet completely understood, it is thought that this protein plays a role in the movement of cholesterol and other types of lipids (fats) across cell membranes.

The NP-C2 gene is located on chromosome 14. The gene provides instructions for producing a protein that is located mainly inside lysosomes, which are the compartments in the cell that digest and recycle materials. The NP-C2 protein binds to cholesterol, and researchers believe that it plays an important role in moving cholesterol and certain other lipids (fats) out of the lysosomes to other parts of the cell. At present the exact function of the NP-C2 protein is unknown.

In NP-C1, there is one common mutation; about 25% of those affected carry one copy of this. There are also over 250 other known mutations, often individual to families, and these may be difficult to find.

There are fewer NP-C2 mutations, therefore analysis is more straightforward. Once the mutations have been found in the affected individual, it is then possible to perform carrier testing on other members of the extended family using a simple blood test. At present this service is only carried out in a few specialist centres (NIEMANN-PICK, 2012b).

Niemann-Pick Disease Type C (NP-C) is diagnosed by measuring the level of the enzyme ASM in the white blood cells and is usually confirmed by DNA sequencing to identify mutations (NIEMANN-PICK, 2012a).

Pre-Natal testing

Pre-natal testing is available for NP-C. Cells can be grown from samples taken at around 11 weeks of pregnancy (chorionic villus sampling - CVS) or an amniotic fluid specimen can be analysed during the 15th to 20th weeks of pregnancy. However, it may take several weeks for the cells to grow. If the DNA mutations are known, this process is much quicker (NIEMANN-PICK, 2012b).

How is NP-C Inherited?

NP-C is inherited when two copies of a faulty gene (a mutation) are passed on to a child. In every pregnancy of a couple who each carry a copy of the faulty Niemann-Pick gene, there is a 1 in 4 chance (25%) that their child will have Niemann-Pick disease (NIEMANN-PICK, 2012b).

Niemann-Pick Disease Type C is inherited in an autosomal recessive manner. Based on molecular genetic testing, NP-C is now divided into two subtypes - NP-C1 and NP-C2 - as each is caused by a different gene mutation. Approximately 95% of Niemann-Pick type C cases are caused by genetic mutations in the NP-C1 gene, with the other 5% caused by mutations in the NP-C2 gene. The NP-C1 gene is located on chromosome 18 and the NP-C2 on chromosome 14 (NIEMANN-PICK, 2012a).

Incidence

NP-C arises sporadically across populations, regardless of race, although genetic isolates have been identified in Nova Scotia (sometimes referred to as Niemann-Pick type D), Colorado, and New Mexico.

The incidence of NP-C in the general population is estimated as 1:120,000. The number of UK patients, known to the Niemann-Pick Disease Group is 85 (data correct January 2012) and range from children to adults with oldest adult being over 50 (NIEMANN-PICK, 2012b).

Treatment

Is there any treatment for Niemann-Pick Type C?

There is no cure, for NP-C; although patients benefit from symptomatic treatments - individual medication to treat the symptoms. Occupational therapy can be used to help with posture, speech and movement.

In 2009, the European Medicines Agency approved the use of Zavesca(c) for the treatment of progressive neurological manifestations in adult and paediatric patients with Niemann-Pick Type C disease. Zavesca© has been shown to delay the progression and stabilise certain symptoms of the disease. However, this drug is not suitable for every affected individual and you are advised to discuss all medical issues with your doctor.

Research is taking place in many laboratories around the world, including Oxford University here in the UK, and the National Institutes of Health in Maryland, USA. Recent advances in characterisation and understanding of the disease has led to a number of possible therapeutic targets being identified, including Cyclodextrin and Histone Deacetylase Inhibitors (NIEMANN-PICK, 2012b).

What is Palliative Treatment?

Treatment & Therapies

The use of palliative treatments, or palliative care, is an approach designed to relieve symptoms and to improve the quality of life of patients who are experiencing symptoms or concerns associated with a life threatening, or long term, illness.

Palliative treatment will not cure your illness, it will however help to prevent or relieve troubling or painful symptoms.

Contrary to the commonly held view that palliative treatments are only used at end of life, these treatments can be used at any stage of an illness and can help someone to live longer, or more comfortably, even if they can't be cured (NIEMANN-PICK, 2012b).

Normal pressure hydrocephalus

Normal pressure hydrocephalus (NPH) is an abnormal buildup of cerebrospinal fluid (CSF) in the brain's ventricles, or cavities. It occurs if the normal flow of CSF throughout the brain and spinal cord is blocked in some way. This causes the ventricles to enlarge, putting pressure on the brain. Normal pressure hydrocephalus can occur in people of any age, but it is most common in the elderly. It may result from a subarachnoid haemorrhage, head trauma, infection, tumour, or complications of surgery. However, many people develop NPH even when none of these factors are present. In these cases the cause of the disorder is unknown (NINDS, 2016), hence its called idiopathic [50].

Symptoms

- difficulty walking,
- mild dementia,
- inability to control urination (ALZ.ORG, 2016d).

These include progressive mental impairment and dementia, problems with walking, and impaired bladder control. The person also may have a general slowing of movements or may complain that his or her feet feel ”stuck”. Because these symptoms are similar to those of other disorders such as Alzheimer’s disease, Parkinson’s disease, and Creutzfeldt-Jakob disease, the disorder is often misdiagnosed (NINDS, 2016).

Brain changes

Caused by the buildup of fluid in the brain. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid (ALZ.ORG, 2016d).

Diagnosis

Many cases go unrecognised and are never properly treated. Doctors may use a variety of tests, including brain scans (CT and/or MRI), a spinal tap or lumbar catheter, intracranial pressure monitoring, and neuropsychological tests, to help them diagnose NPH and rule out other conditions (NINDS, 2016).

Treatment

Treatment for NPH involves surgical placement of a shunt in the brain to drain excess CSF into the abdomen where it can be absorbed as part of the normal circulatory process. This allows the brain ventricles to return to their normal size. Regular follow-up care by a doctor is important in order to identify subtle changes that might indicate problems with the shunt (NINDS, 2016).

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[50] of unknown cause, or as one doctor friend of mine stated, ”We don’t know!”

Prognosis

The symptoms of NPH usually get worse over time if the condition is not treated, although some people may experience temporary improvements. While the success of treatment with shunts varies from person to person, some people recover almost completely after treatment and have a good quality of life. Early diagnosis and treatment improves the chance of a good recovery. Without treatment, symptoms may worsen and cause death (NINDS, 2016).

Parkinson's disease

Parkinson's disease is a condition in which parts of the brain become progressively damaged over many years.

Symptoms

The symptoms of Parkinson's disease usually develop gradually and are mild at first.

There are many different symptoms associated with Parkinson's disease. Some of the more common symptoms are described below.

However, the order in which these develop and their severity is different for each individual. It's unlikely that a person with Parkinson's disease would experience all or most of these (NHS, 2016c).

Main symptoms

The three main symptoms of Parkinson's disease affect physical movement -

- **tremor** - shaking, which usually begins in the hand or arm and is more likely to occur when the limb is relaxed and resting,
- **slowness of movement** (bradykinesia) - where physical movements are much slower than normal, which can make everyday tasks difficult and can result in a distinctive slow, shuffling walk with very small steps,
- **muscle stiffness** (rigidity) - stiffness and tension in the muscles, which can make it difficult to move around and make facial expressions, and can result in painful muscle cramps (dystonia) (NHS, 2016c).

These main symptoms are sometimes referred to by doctors as parkinsonism as there can be causes other than Parkinson's disease (NHS, 2016c).

Other symptoms

Parkinson's disease can also cause a range of other physical and mental symptoms (NHS, 2016c).

Physical symptoms

- **balance problems** - these can make someone with the condition more likely to have a fall and injure themselves,
- **loss of sense of smell** (anosmia) - sometimes occurs several years before other symptoms develop,
- **nerve pain** - can cause unpleasant sensations, such as burning, coldness or numbness,
- **problems with urination** - such as having to get up frequently during the night to urinate or unintentionally passing urine (urinary incontinence),
- **constipation**,
- **an inability to obtain or sustain an erection** (erectile dysfunction) in men,
- **difficulty becoming sexually aroused and achieving an orgasm** (sexual dysfunction) in women,
- **dizziness, blurred vision or fainting** when moving from a sitting or lying position to a standing one - caused by a sudden drop in blood pressure,
- **excessive sweating** (hyperhidrosis),
- **swallowing difficulties** (dysphagia) - this can lead to malnutrition and dehydration,
- **excessive production of saliva** (drooling),
- **problems sleeping** (insomnia) - this can result in excessive sleepiness during the day (NHS, 2016c).

Cognitive and psychiatric symptoms

- **Depression and Anxiety**,
- **Mild cognitive impairment** - slight memory problems and problems with activities that require planning and organisation,
- **Dementia** - a group of symptoms, including more severe memory problems, personality changes, seeing things that aren't there (visual hallucinations) and believing things that aren't true (delusions) (NHS, 2016c).

As Parkinson's disease progresses, it often results in a progressive dementia similar to dementia with Lewy bodies or Alzheimer's (ALZ.ORG, 2016d).

When to seek medical advice

See your GP if you're concerned you may have symptoms of Parkinson's disease.

Your GP will ask about your symptoms and your medical history to help them decide whether it's necessary to refer you to a specialist for further tests (NHS, 2016c).

Causes

Parkinson's disease is caused by a loss of nerve cells in the part of the brain called the substantia nigra.

Nerve cells in this part of the brain are responsible for producing a chemical called dopamine. Dopamine acts as a messenger between the parts of the brain and nervous system that help control and co-ordinate body movements.

If these nerve cells die or become damaged, the amount of dopamine in the brain is reduced. This means the part of the brain controlling movement can't work as well as normal, causing movements to become slow and abnormal.

The loss of nerve cells is a slow process. The symptoms of Parkinson's disease usually only start to develop when around 80% of the nerve cells in the substantia nigra have been lost (NHS, 2016c).

What causes the loss of nerve cells?

It's not known why the loss of nerve cells associated with Parkinson's disease occurs, although research is ongoing to identify potential causes.

Currently, it's believed a combination of genetic changes and environmental factors may be responsible for the condition (NHS, 2016c).

Genetics

A number of genetic factors have been shown to increase a person's risk of developing Parkinson's disease, although exactly how these make some people more susceptible to the condition is unclear.

Parkinson's disease can run in families as a result of faulty genes being passed to a child by their parents. However, it's rare for the disease to be inherited this way (NHS, 2016c).

Environmental factors

Some researchers also feel environmental factors may increase a person’s risk of developing Parkinson’s disease.

It’s been suggested that pesticides and herbicides used in farming and traffic or industrial pollution may contribute to the condition.

However, the evidence linking environmental factors to Parkinson’s disease is inconclusive (NHS, 2016c).

Other causes of parkinsonism

”Parkinsonism” is the umbrella term used to describe the symptoms of tremors, muscle rigidity and slowness of movement.

Parkinson’s disease is the most common type of parkinsonism, but there are also some rarer types where a specific cause can be identified (NHS, 2016c).

These include parkinsonism caused by -

- **medication (drug-induced parkinsonism)** - where symptoms develop after taking certain medications, such as some types of antipsychotic medication, and usually improve once the medication is stopped,
- **other progressive brain conditions** - such as progressive supranuclear palsy, multiple systems atrophy, and corticobasal degeneration,
- **cerebrovascular disease** - where a series of small strokes cause several parts of the brain to die (NHS, 2016c).

Types of parkinsonism

Idiopathic Parkinson’s disease

Idiopathic Parkinson’s disease - or Parkinson’s - is the most common type of parkinsonism. Unlike some other forms which have specific causes it is not known why idiopathic Parkinson’s occurs.

The main symptoms of idiopathic Parkinson’s are tremor, rigidity and slowness of movement.

Symptoms and the rate at which the condition progresses vary from person to person. This can make diagnosis difficult.

An early diagnosis means that treatment for Parkinson’s can begin sooner, which may be more effective.

Doctors may diagnose idiopathic Parkinson's by seeing if there is a response to Parkinson's medication. If symptoms improve, your specialist may confirm an idiopathic Parkinson's diagnosis (PARKINSONS, 2014).

Vascular parkinsonism

Vascular parkinsonism is one of the atypical forms of parkinsonism.

It affects people with restricted blood supply to the brain - usually older people who have problems with diabetes. People who have had a stroke may experience vascular parkinsonism.

Symptoms of vascular parkinsonism may include difficulty speaking, making facial expressions or swallowing.

Other signs can include problems with memory or confused thought, cognitive problems and incontinence.

Like Parkinson's, vascular parkinsonism is a progressive condition, with symptoms developing and changing over time (PARKINSONS, 2014).

Drug-induced parkinsonism

A small number (around 7%) of people diagnosed with parkinsonism have developed their symptoms following treatment with particular medication.

Drugs - known as neuroleptic drugs - used to treat schizophrenia and other psychotic disorders block dopamine. These drugs are thought to be the biggest cause of drug-induced parkinsonism.

The symptoms of drug-induced parkinsonism tend to be static. Only in rare cases do they change in the manner that the symptoms of Parkinson's do.

Most people will recover within months, and often within hours or days, of stopping the drug that is the cause (PARKINSONS, 2014).

What drugs cause drug-induced parkinsonism?

Any drug that blocks the action of dopamine (referred to as a dopamine antagonist) is likely to cause parkinsonism. Drugs used to treat schizophrenia and other psychotic disorders such as behaviour disturbances in people with dementia (known as neuroleptic drugs) are possibly the major cause of drug-induced parkinsonism worldwide. Parkinsonism can occur from the use of any of the various classes of neuroleptics (PARKINSONS, 2008).

The atypical neuroleptics - clozapine (Clozaril) and quetiapine (Seroquel), and to a lesser extent olanzapine (Zyprexa) and risperidone (Risperdal) - appear to have a lower incidence of extrapyramidal side-effects [51], including parkinsonism. These drugs are generally best avoided by people with Parkinson's, although some may be used by specialists to treat symptoms such as hallucinations occurring with Parkinson's. Risperidone and olanzapine should be used with caution to treat dementia in people at risk of stroke (the risk increases with age, hypertension, diabetes, atrial fibrillation, smoking and high cholesterol), because of an increased risk of stroke and other cerebrovascular problems. It is unclear whether there is an increased risk of stroke with quetiapine and clozapine.

While these drugs are used primarily as antipsychotic agents, it is important to note that they can be used for other non-psychiatric uses, such as control of nausea and vomiting. For people with Parkinson's, other anti-sickness drugs such as domperidone (Motilium) or ondansetron (Zofran) would be preferable.

As well as neuroleptics, some other drugs can cause drug-induced parkinsonism. These include some older drugs used to treat high blood pressure such as methyldopa (Aldomet); medications for dizziness and nausea such as prochlorperazine (Stemetil); and metoclopromide (Maxolon), which is used to stop sickness and in the treatment of indigestion.

Calcium channel blocking drugs used to treat high blood pressure, abnormal heart rhythm, angina pectoris, panic attacks, manic depression and migraine may occasionally cause drug-induced parkinsonism. The most well-documented are cinnarizine (Stugeron) and flunarizine (Sibelium). Calcium channel blocking drugs are, however, widely used to treat angina and high blood pressure, and it is important to note that most common agents in clinical use probably do not have this side-effect. These drugs should never be stopped abruptly without discussion with your doctor.

A number of other agents have been reported to cause drug-induced parkinsonism, but clear proof of cause and effect is often lacking. Amiodarone, used to treat heart problems, causes tremor and some people have been reported to develop Parkinson's-like symptoms. Sodium valproate, used to treat epilepsy, and lithium, used in depression, both commonly cause tremor which may be mistaken for Parkinson's. Some reports have linked SSRI antidepressant drugs such as fluoxetine (Prozac) to drug-induced parkinsonism but hard evidence of cause

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[51] term used to describe the development of a variety of movement disorders as a result of taking certain medications such as neuroleptic drugs. These side effects may include akathisia (restlessness), dystonias (involuntary, sustained muscle spasms), parkinsonism and tardive dyskinesias (abnormal, involuntary muscle movements)

and effect is unsubstantiated. This type of drug is increasingly used to treat depression in Parkinson's (PARKINSONS, 2008).

Generic name	Trade name
Amisulpride	Solian
Chlorpromazine hydrocloride	Chloractil/Largactil
Clozapine	Clozaril, Denzapine
Flupenthixol	Depixol
Fluphenazine hydrochloride	Modecate/Moditen/Motival (includes nortriptyline)
Haloperidol	Dozic/Haldol/Serenace
Methotrimeprazine/Levomepromazine	Nozinan
Olanzapine	Zyprexa
Oxypertine	Oxypertine
Pericyazine	Neulactil
Perphenazine	Fentazin, Triptafen (Perphenazine+amitriptyline)
Pimozide	Orap
Pipotiazine	Piportil
Prochlorperazine	Stemetil
Promazine hydrochloride	Promazine
Quetiapine	Seroquel
Risperidone	Risperdal
Sulpiride	Domatil/Sulpitil/Sulpor (Sulparex is discontinued)
Thioridazine	Melleril
Trifluoperazine	Stelazine
Zuclopenthixol acetate	Clopixol
Zotepine	Zoleptil

Table 7.1: List of neuroleptic drugs available in the UK

Generic name	Trade name	Used to treat
Amiodarone	Cordarone X	Heart problems
Cinnarizine	Stugeron	Nausea and vomiting, motion sickness, vertigo, dizziness, tinnitus, vascular disease and Raynaud's syndrome, high blood pressure, abnormal heart rhythm, angina pectoris, panic attacks, manic depression and migraine
Fluphenazine	Motival, Motipress	A combination of antidepressant and with nortriptyline antipsychotic drug
Lithium	Camcolit, Li-Liquid, Liskonum, Priadel	Depression
Methyldopa	Aldomet	High blood pressure
Metoclopramide	Maxolon	For sickness and indigestion. Also included in some medicines used migraine such as Paramax (with paracetamol) and Migramax (with aspirin)
Prochlorperazine	Stemetil	Dizziness and nausea
Tranylcypromine	Parnate	Depression

Table 7.2: Other drugs that can cause drug-induced parkinsonism

What are the characteristics of drug-induced parkinsonism and how does it differ from idiopathic Parkinson's?

Drug-induced parkinsonism is more likely to be symmetrical (on both sides of the body) and less likely to be associated with tremor, although it can sometimes present asymmetrically and with a tremor. **Akinesia** [52] with loss of arm swing can be the earliest feature. **Bradykinesia** [53] can be an early common symptom, causing expressionless face, slow initiation of movement and speech difficulties (PARKINSONS, 2008).

Other drug-induced movement disorders

Tardive dyskinesia is another drug-induced movement disorder that can occur in people who are on neuroleptic drugs. This refers to excessive movement of the lips, tongue and jaw (known as oro-facial dyskinesias). The term 'tardive' means delayed or late appearing and this refers to the fact that the person may have been treated with the neuroleptic for some time before the dyskinesia be-

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[52] poverty of movement

[53] slowness of movement

comes apparent. Tardive dyskinesia can be difficult to treat and may, sadly, be permanent in some people (PARKINSONS, 2008).

Are there any other risk factors for drug-induced parkinsonism?

The incidence of drug-induced parkinsonism increases with age. Drug-induced parkinsonism is more prevalent in older people and is twice as common in women than men. Other risk factors include a family history of Parkinson's and affective disorders [54]. There may be a genetic predisposition to drug-induced parkinsonism. Younger people may develop sudden onset of dystonia (abnormal muscle postures) and abnormalities of eye movements if treated with drugs that cause drug-induced parkinsonism (PARKINSONS, 2008).

How quickly will the symptoms of drug-induced parkinsonism appear after someone starts taking a drug that may cause it?

It depends on the properties of the drug. In 50% of cases, the symptoms generally occur within one month of starting neuroleptics. In some older people, features can be identified as early as the fourth day of treatment, and sometimes after one dose. However, there can occasionally be a delayed development of parkinsonism (PARKINSONS, 2008).

How does drug-induced parkinsonism progress?

Drug-induced parkinsonism tends to remain static and does not progress like idiopathic Parkinson's but this is not usually all that helpful in making the diagnosis (PARKINSONS, 2008).

If the offending drug is stopped, will the drug-induced parkinsonism improve and if so, how long will this take?

Generally, 60% of people will recover within two months, and often within hours or days, of stopping the offending drug. However, some people may take as long as two years. One study reported that 16% of cases went on to be confirmed to have idiopathic Parkinson's. These people were probably going to develop Parkinson's at some stage in the future in any event, but the offending drug

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[54] mental illnesses characterized predominantly by marked changes in mood, including manic depression

'unmasked' an underlying dopamine deficiency. This theory is supported by research studies with specialist PET scans [55] (PARKINSONS, 2008).

What other treatment is available?

In many cases, the first approach to treatment will be to try stopping the offending drug for a sufficient length of time, reducing it, or changing it to another drug that may be less likely to cause drug-induced parkinsonism. Please note: you should not stop taking any drug because you think it is causing drug-induced parkinsonism, or worsening existing Parkinson's without first discussing the situation with your doctor. Some drugs need to be withdrawn slowly, particularly if the person has been taking the drug for a considerable time, and problems can arise if they are withdrawn abruptly.

Sometimes, for medical reasons, the person cannot stop taking the drug that causes drug-induced parkinsonism. Where this is the case, the benefits of the drug need to be weighed against the side-effects of parkinsonism. Sometimes, adjusting the dose of the neuroleptic drug downwards to a level that does not cause parkinsonism may help. However, this is not always possible, without taking the dose to a sub-therapeutic level (i.e. a level where it is not as effective at treating the psychotic illness for which it is prescribed). Usually, changing the medication to an atypical neuroleptic is the best approach.

If it is not possible to stop taking the offending drug, then anticholinergic drugs may be used. However, these are best avoided in older people, because they may cause confusion, as well as worsening tardive dyskinesia.

Amantadine (Symmetrel), another drug used to treat Parkinson's, can also be used to treat drug-induced parkinsonism if the person cannot stop taking the offending drug. However, like anticholinergic drugs, amantadine may also cause confusion, and sometimes psychosis in older people, and therefore is more suitable for younger people with drug-induced parkinsonism (PARKINSONS, 2008).

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[55] the PET (Positron Emission Tomography) scan provides anatomical information about the brain. This means that PET scans can assess the functioning of different parts of the brain while the individual is carrying out a particular movement or engaging in a specific mental activity. With PET it is also possible to examine the state of particular neurotransmitter receptor sites in the brain. PET scans require the use of radioactive material in very small quantities, usually the equivalent to the radioactive exposure during a transatlantic flight. The dopamine systems in the brain, which are affected in Parkinson's, can be assessed with PET scanning

Can these drugs aggravate existing idiopathic Parkinson’s disease?

Yes. Stopping the medication (where possible) may be enough to relieve the drug-induced parkinsonism, although improvements can take several months (PARKINSONS, 2008).

Can illegal drugs such as heroin cause drug-induced parkinsonism?

In the late 1970s, a group of drug users in California took synthetic drugs, manufactured illegally, as a cheap alternative to heroin. One of these addicts, aged 23 years, became ill and over several days developed symptoms of parkinsonism, such as tremor, rigidity and akinesia. When he was treated with anti-Parkinson’s drugs, he improved dramatically. When he died from an overdose of other drugs, a postmortem examination was carried out and it was found that severe damage had been done to the dopamine containing cells in the basal ganglia, similar to that seen in Parkinson’s. He was uncharacteristically young to have developed Parkinson’s, so doctors suspected that the illegal drugs he was taking had caused his condition. They analysed the material that he had used in the manufacture of the drugs and they found it contained a chemical called MPTP. Further research showed that a breakdown product of MPTP was capable of producing severe damage to the dopamine-containing cells in the basal ganglia.

Since this first case, other drug addicts have developed a similar syndrome after injecting themselves with drugs contaminated by MPTP. Although rigorous research into other illegal drugs is limited to date, theoretically, cocaine, ecstasy and other illegal drugs may also be possible causes of drug-induced parkinsonism. More research in this area is needed (PARKINSONS, 2008).

I have read that some illegal drugs may actually improve the symptoms of Parkinson’s. Is this true?

A BBC TV *Horizon* programme, broadcast in the UK in February 2001, featured a person with Parkinson’s who found that some of his Parkinson’s symptoms were improved temporarily when he took ecstasy. Ecstasy is known to affect a neurotransmitter [56] called serotonin. The levels of serotonin are abnormal in brains of

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[56] chemical messengers produced by the nerve cells in the brain. Their purpose is to pass messages from the brain to other parts of the body. There are a number of different neurotransmitters which each with a particular function. For instance dopamine, which is in short supply in the brains of people with Parkinson’s, is involved in processes that involve the co-ordination of movement. Serotonin has a variety of functions, including being involved in controlling states of consciousness and mood

people with Parkinson's and the findings of the BBC *Horizon* programme have suggested that further research into the relationship between serotonin and Parkinson's is needed and may lead in the future to new non-dopaminergic treatments for the condition. These treatments will not, however, use ecstasy, which remains an illegal drug and is known to have long-term adverse effects associated with its use. Also, although ecstasy gave temporary relief to the person in the programme, there is no evidence to suggest that anyone else with Parkinson's would benefit in the same way from the drug.

Media attention in recent years has also focused on the role that cannabis may play in the management of pain in neurological conditions like multiple sclerosis. This is now being researched.

At present, there is little information available on research into cannabis and Parkinson's (PARKINSONS, 2008).

Dementia with Lewy bodies

Dementia with Lewy bodies is similar, in some ways, to Parkinson's and Alzheimer's.

Symptoms differ slightly from Parkinson's and include problems with memory and concentration, attention, language and the ability to carry out simple actions.

People who have dementia with Lewy bodies commonly experience visual hallucinations and some Parkinson's-type symptoms, such as slowness of movement, stiffness and tremor.

Dementia with Lewy bodies is also a progressive condition, which means that the symptoms can become worse over time. Currently, there is no cure or treatment for the condition (PARKINSONS, 2014).

Inherited Parkinson's

There is no conclusive evidence that Parkinson's is a hereditary condition that can be passed on within families, apart from in exceptionally rare cases.

It is thought that although it is not directly inherited, some people may have genes that increase the possibility of developing Parkinson's.

People who have genes that are prone to Parkinson's may be more likely to develop the condition when combined with other factors, such as environmental toxins or viruses.

At present, it is estimated that up to 5% of people with Parkinson's may have a genetic cause.

The role genetics may play in the development of Parkinson's is currently the subject of much research (PARKINSONS, 2014).

Juvenile Parkinson's

The term early onset Parkinson's is used when people are diagnosed under the age of 40.

Juvenile Parkinson's is a term used when the condition affects people under the age of 20 (PARKINSONS, 2014).

Other types of atypical parkinsonism

A diagnosis indicating that someone doesn't have Parkinson's but does have another unknown condition can be unsettling.

In some cases the symptoms that allow doctors to make a specific diagnosis appear slowly, over a longer period of time, as the condition develops.

If tremor is the only symptom and it seems different from the tremor found in Parkinson's, then a person may be diagnosed with essential tremor, dystonic tremor, indeterminate tremor or atypical tremor.

Some symptoms may lead to a diagnosis of Multiple System Atrophy (MSA), Normal Pressure Hydrocephalus or Progressive Supranuclear Palsy (PSP) (PARKINSONS, 2014).

Symptoms

Problems with movement are common symptoms of the disease. If dementia develops, symptoms are often similar to dementia with Lewy bodies (ALZ.ORG, 2016d).

Brain changes

Alpha-synuclein clumps are likely to begin in an area deep in the brain called the substantia nigra. These clumps are thought to cause degeneration of the nerve cells that produce dopamine (ALZ.ORG, 2016d).

Diagnosis

No tests can conclusively show that you have Parkinson's disease. Your doctor will base a diagnosis on your symptoms, medical history and a detailed physical examination.

Your GP will talk to you about the problems you're experiencing and may ask you to perform some simple mental or physical tasks, such as moving or walking around, to help with the diagnosis.

In the early stages, your GP may find it difficult to say whether you definitely have the condition because symptoms are usually mild (NHS, 2016c).

Referral to a specialist

If your GP suspects Parkinson's disease, you'll be referred to a specialist. This will usually be -

- **a neurologist** - a specialist in conditions affecting the brain and nervous system,
- **a geriatrician** - a specialist in problems affecting elderly people (NHS, 2016c).

If your GP thinks you may be in the early stages of Parkinson's disease, you should see a specialist within six weeks. If they think you may be in the later stages, you should see a specialist within two weeks.

The specialist will most likely ask you to perform a number of physical exercises so they can assess whether you have any problems with movement (NHS, 2016c).

A diagnosis of Parkinson's disease is likely if you have at least two of the three following symptoms -

- shaking or tremor in a part of your body that usually only occurs at rest,
- slowness of movement (bradykinesia),
- muscle stiffness (rigidity) (NHS, 2016c).

If your symptoms improve after taking a medication called levodopa, it's more likely you have Parkinson's disease.

Special brain scans, such as a single photon emission computed tomography (SPECT) scan, may also be carried out in some cases to try to rule out other causes of your symptoms (NHS, 2016c).

Receiving the diagnosis

Being told you have Parkinson’s disease can be emotionally distressing, and the news can often be difficult to take in.

This means it’s important that you have the support of your family and a care team who will be able to help you come to terms with the diagnosis.

You may find it useful to contact Parkinson’s UK, the Parkinson’s support and research charity.

They can be contacted by -

- free helpline on 0808 800 0303 (Monday to Friday, 9am to 7pm, and 10am to 2pm on Saturdays)
- email: hello@parkinsons.org.uk

Parkinson’s UK brings people with Parkinson’s, their carers and families together through a network of local groups, as well as online resources and a confidential helpline.

The Parkinson’s UK website provides information and support on every aspect of living with Parkinson’s (NHS, 2016c).

Treatment

There’s currently no cure for Parkinson’s disease, but treatments are available to help relieve the symptoms and maintain your quality of life (NHS, 2016c).

These treatments include -

- supportive therapies - such as physiotherapy,
- medication,
- surgery (for some people) (NHS, 2016c).

You may not need any treatment during the early stages of Parkinson’s disease as symptoms are usually mild. However, you may need regular appointments with your specialist so your condition can be monitored.

A care plan should be agreed with your healthcare team and your family or carers. This will outline the treatments and help you need now and what you are likely to need in the future, and should be reviewed regularly.

Read the National Institute for Health and Care Excellence (NICE) guidelines on Parkinson’s disease.

The various treatments for Parkinson’s disease are outlined below (NHS, 2016c).

Supportive therapies

There are several therapies that can make living with Parkinson's disease easier and help you deal with your symptoms on a day-to-day basis.

There are efforts underway to try to increase the availability of these supportive therapies for Parkinson's patients on the NHS.

Your local authority may be able to advise and help you. Ask your local authority for a care and support needs assessment (NHS, 2016c).

Physiotherapy

A physiotherapist can work with you to relieve muscle stiffness and joint pain through movement (manipulation) and exercise.

The physiotherapist aims to make moving easier, and improve your walking and flexibility. They also try to improve your fitness levels and ability to manage things for yourself (NHS, 2016c).

Occupational therapy

An occupational therapist can identify areas of difficulty in your everyday life - for example, dressing yourself or getting to the local shops.

They can help you work out practical solutions, and ensure your home is safe and properly set up for you. This will help you maintain your independence for as long as possible (NHS, 2016c).

Speech and language therapy

Many people with Parkinson's disease have swallowing difficulties (dysphagia) and problems with their speech.

A speech and language therapist can often help you improve these problems by teaching speaking and swallowing exercises, or by providing assistive technology (NHS, 2016c).

Diet advice

For some people with Parkinson's disease, making dietary changes can help improve some symptoms.

These changes can include -

- increasing the amount of fibre in your diet and making sure you're drinking enough fluid to reduce constipation,
- increasing the amount of salt in your diet and eating small, frequent meals to avoid problems with low blood pressure, such as dizziness when you stand up quickly,
- making changes to your diet to avoid unintentional weight loss (NHS, 2016c).

You may see a dietitian, a healthcare professional trained to give diet advice, if your care team thinks you may benefit from changing your diet (NHS, 2016c).

Medication

Medication can be used to improve the main symptoms of Parkinson's disease, such as shaking (tremors) and movement problems.

However, not all the medications available are useful for everyone, and the short- and long-term effects of each are different (NHS, 2016c).

Three main types of medication are commonly used -

- Levodopa
- Dopamine agonists,
- Monoamine oxidase-B inhibitors (NHS, 2016c).

Your specialist can explain your medication options, including the risks associated with each medication, and discuss which may be best for you. Regular reviews will be required as the condition progresses and your needs change.

Read on to learn about the treatments you may be offered (NHS, 2016c).

Levodopa

Most people with Parkinson's disease eventually need a medication called levodopa.

Levodopa is absorbed by the nerve cells in your brain and turned into the chemical dopamine, which is used to transmit messages between the parts of the brain and nerves that control movement.

Increasing the levels of dopamine using levodopa usually improves movement problems.

It is usually taken as a tablet or liquid, and is often combined with other medication, such as benserazide or carbidopa.

These medications stop the levodopa being broken down in the bloodstream before it has a chance to get to the brain (NHS, 2016c).

They also reduce the side-effects of levodopa, which include -

- feeling sick (nausea) or vomiting,
- tiredness,
- dizziness (NHS, 2016c).

If you're prescribed levodopa, the initial dose is usually very small and will be gradually increased until it takes effect.

At first, levodopa can cause a dramatic improvement in the symptoms.

However, its effects can be less long-lasting over the following years - as more nerve cells in the brain are lost, there are fewer of them to absorb the medicine. This means the dose may need to be increased from time to time.

Long-term use of levodopa is also linked to problems such as uncontrollable, jerky muscle movements (dyskinesias) and "on-off" effects, where the person rapidly switches between being able to move (on) and being immobile (off) (NHS, 2016c).

Dopamine agonists

Dopamine agonists act as a substitute for dopamine in the brain and have a similar but milder effect compared with levodopa. They can often be given less frequently than levodopa.

They are often taken as a tablet, but are also available as a skin patch (rotigotine).

Sometimes dopamine agonists are taken at the same time as levodopa, as this allows lower doses of levodopa to be used.

Possible side-effects of dopamine agonists include -

- nausea or vomiting,
- tiredness and sleepiness,
- dizziness (NHS, 2016c).

Dopamine agonists can also cause hallucinations and increased confusion, so they need to be used with caution, particularly in elderly patients, who are more susceptible.

For some people, dopamine agonists have been linked to the development of compulsive behaviours, especially at high doses, including addictive gambling and an excessively increased libido.

Talk to your healthcare specialist if you think you may be experiencing these problems.

As the person themselves may not realise the problem, it's key that carers and family members also note any abnormal behaviour and discuss it with an appropriate professional at the earliest opportunity.

If you're prescribed a course of dopamine agonists, the initial dose is usually very small to prevent nausea and other side-effects.

The dosage is gradually increased over a few weeks. If nausea becomes a problem, your GP may prescribe anti-sickness medication.

A potentially serious, but uncommon, complication of dopamine agonist therapy is sudden onset of sleep.

This generally happens as the dose is being increased and tends to settle once the dose is stable.

People are usually advised to avoid driving while the dose is being increased in case this complication occurs (NHS, 2016c).

Monoamine oxidase-B inhibitors

Monoamine oxidase-B (MAO-B) inhibitors, including selegiline and rasagiline, are another alternative to levodopa for treating early Parkinson's disease.

They block the effects of an enzyme or brain substance that breaks down dopamine (monoamine oxidase-B), increasing dopamine levels.

Both selegiline and rasagiline can improve the symptoms of Parkinson's disease, although their effects are small compared with levodopa. They can be used alongside levodopa or dopamine agonists (NHS, 2016c).

MAO-B inhibitors are generally very well tolerated, but can occasionally cause side-effects, including -

- nausea,
- headache,
- abdominal pain,
- high blood pressure (NHS, 2016c).

Catechol-O-methyltransferase inhibitors

Catechol-O-methyltransferase (COMT) inhibitors are prescribed for people in later stages of Parkinson's disease. They prevent levodopa from being broken down by the enzyme COMT (NHS, 2016c).

Side-effects of COMT inhibitors include -

- nausea or vomiting,
- diarrhoea,
- abdominal pain (NHS, 2016c).

Non-oral therapies

When Parkinson's symptoms become difficult to control with tablets alone, a number of other treatments can be considered (NHS, 2016c).

Apomorphine

A dopamine agonist called apomorphine can be injected under the skin (subcutaneously) either by -

- a single injection, when required
- a continuous infusion using a small pump carried around on your belt, under your clothing, or in a bag (NHS, 2016c).

Duodopa

If you have severe on-off fluctuations, a type of levodopa called duodopa may be used.

This medication comes as a gel that's continuously pumped into your gut through a tube inserted through your abdominal wall.

There's an external pump attached to the end of the tube, which you carry around with you.

About 25 specialist neuroscience centres in the UK offer this treatment. This treatment is only available if you have very severe on-off fluctuations or involuntary movements (NHS, 2016c).

Surgery

Most people with Parkinson's disease are treated with medication, although a type of surgery called deep brain stimulation is used in some cases.

This surgery is also available in specialist neuroscience centres around the UK, but it's not suitable for everyone.

If surgery is being considered, your specialist will discuss the possible risks and benefits with you (NHS, 2016c).

Deep brain stimulation

Deep brain stimulation involves surgically implanting a pulse generator similar to a heart pacemaker into your chest wall.

This is connected to one or two fine wires placed under the skin, and is inserted precisely into specific areas in your brain.

A tiny electric current is produced by the pulse generator, which runs through the wire and stimulates the part of your brain affected by Parkinson's disease.

Although surgery doesn't cure Parkinson's disease, it can ease the symptoms for some people (NHS, 2016c).

Treating additional symptoms

As well as the main symptoms of movement problems, people with Parkinson's disease can experience a wide range of additional symptoms that may need to be treated separately (NHS, 2016c).

These include -

- **depression and anxiety** - this can be treated with self care measures such as exercise, psychological therapy or medication,
- **problems sleeping** (insomnia) - this can be improved by making changes to your normal bedtime routine,
- **erectile dysfunction** - this can be treated with medication,
- **excessive sweating** (hyperhidrosis) - this can be reduced using a prescription antiperspirant, or surgery in severe cases,
- **swallowing difficulties** (dysphagia) - this can be improved by eating softened food, or by using a feeding tube in more severe cases,
- **excessive drooling** - this can be improved with swallowing exercises, or surgery or medication in severe cases,
- **urinary incontinence** - this can be treated with exercises to strengthen the pelvic floor muscles, medication, or surgery in severe cases,
- **dementia** - this can be treated with cognitive therapies and medication in some cases (NHS, 2016c).

Clinical trials

Much progress has been made in the treatment of Parkinson's disease as the result of clinical trials, where new treatments and treatment combinations are compared with standard ones.

All clinical trials in the UK are carefully overseen to ensure they are worthwhile and safely conducted. Participants in clinical trials sometimes do better overall than those in routine care.

If you are asked if you want to take part in a trial, you will be given an information sheet about the trial.

If you want to take part, you will be asked to sign a consent form. You can refuse to take part or withdraw from a clinical trial without it affecting your care (NHS, 2016c).

Complementary and alternative therapies

Some people with Parkinson's disease find complementary therapies help them feel better. Many complementary treatments and therapies claim to ease the symptoms of Parkinson's disease.

However, there's no clinical evidence they're effective in controlling the symptoms of Parkinson's disease.

Most people think complementary treatments have no harmful effects. However, some can be harmful and they shouldn't be used instead of the medicines prescribed by your doctor.

Some types of herbal remedies, such as St John's wort, can interact unpredictably if taken with some types of medication used to treat Parkinson's disease.

If you're considering using an alternative treatment along with your prescribed medicines, check with your care team first (NHS, 2016c).

Living with Parkinson's

A diagnosis of Parkinson's disease is life changing. You'll need long-term treatment to control your symptoms, and you may eventually have to adapt the way you do simple everyday tasks.

Everyone's experience of living with Parkinson's is different, but there are lots of issues and challenges shared by many people living with the condition.

You may find some of the advice below helpful if you've been diagnosed with Parkinson's disease (NHS, 2016c).

Keeping well

It’s important to do what you can to stay physically and mentally healthy if you have Parkinson’s disease (NHS, 2016c).

Exercise and healthy eating

Regular exercise is particularly important in helping relieve muscle stiffness, improving your mood, and relieving stress.

There are many activities you can do to help keep yourself fit, ranging from more active sports like tennis and cycling, to less strenuous activities such as walking, gardening and yoga.

You should also try to eat a balanced diet containing all the food groups to give your body the nutrition it needs to stay healthy (NHS, 2016c).

Vaccinations

Everyone with a long-term condition is encouraged to get a yearly flu jab each autumn.

The pneumococcal vaccination is also usually recommended, which is a one-off injection that protects against a serious chest infection called pneumococcal pneumonia (NHS, 2016c).

Relationships and support

Being diagnosed with a long-term condition like Parkinson’s disease can put a strain on you, your family and friends. It can be difficult to talk to people about your condition, even if they’re close to you.

Dealing with the deterioration of symptoms, such as increasing difficulty with movement, may make you feel frustrated and depressed. Spouses, partners or carers will inevitably feel anxious or frustrated as well.

Be open about how you feel, and let your family and friends know what they can do to help. Don’t feel shy about telling them you need some time to yourself, if that’s what you want (NHS, 2016c).

Support

If you have any questions about your condition, your GP or Parkinson’s disease specialist nurse may be able to help.

You may also find it helpful to talk to a trained counsellor or psychologist, or someone at a specialist helpline. Your GP surgery will have details of these.

Some people find it helpful to talk to others with Parkinson's disease, either at a local support group or in an internet chat room (NHS, 2016c).

Care and support services

It's worth taking time to think about your specific needs and what would help you achieve the best quality of life.

For example, you may wish to consider equipment, help in your home, and home adaptations (NHS, 2016c).

Parkinson's UK

Parkinson's UK is the main Parkinson's support and research charity in the UK.

They can offer the support and advice you may need if you're living with Parkinson's disease, and can let you know about support groups in your local area (NHS, 2016c).

They can be contacted by -

- free confidential helpline on 0808 800 0303 (Monday to Friday, 9am to 7pm, and 10am to 2pm on Saturdays),
- email: hello@parkinsons.org.uk (NHS, 2016c).

The Parkinson's UK website also features all the latest news, publications and research updates, as well as an online community where you can share your experiences of living with Parkinson's (NHS, 2016c).

Work and finances

Being diagnosed with Parkinson's doesn't mean you have to stop working. Many people with the condition keep working for years after their diagnosis.

You may find it hard to cope financially if you do have to stop work or work part-time because of your condition (NHS, 2016c).

However, you may be entitled to one or more of the following types of financial support -

- You are entitled to Statutory Sick Pay from your employer if you have a job but can't work because of your illness.

- You may be entitled to Employment and Support Allowance (ESA) if you don't have a job and can't work because of your illness.
- You may be eligible for Personal Independence Payment (PIP), which replaced the Disability Living Allowance (DLA), if you're aged 64 and under and need help with personal care or have walking difficulties.
- You may be able to get Attendance Allowance if you're aged 65 or over.
- You may be entitled to Carer's Allowance if you're caring for someone with Parkinson's disease.
- You may be eligible for other benefits if you have children living at home or if you have a low household income (NHS, 2016c).

Driving

If you've been diagnosed with Parkinson's disease, you must inform the DVLA and your insurance company.

You won't necessarily have to stop driving. You'll be asked to complete a form providing more information about your condition, as well as details of your doctors and specialists. The DVLA will use this to decide whether you're fit to drive (NHS, 2016c).

Complex Parkinson's disease and palliative care

Complex Parkinson's disease is defined as the stage when treatment is unable to consistently control symptoms, or the person has developed uncontrollable jerky movements (disabling dyskinesia).

These problems can still be helped by adjustment or addition of some of the medications used to treat Parkinson's disease, under the supervision of a doctor with a specialist interest in Parkinson's disease.

As Parkinson's disease progresses, you'll be invited to discuss the care you want with your healthcare team as you near the end of your life. This is known as palliative care.

When there's no cure for an illness, palliative care tries to alleviate symptoms, and is also aimed at making the end of a person's life as comfortable as possible.

This is done by attempting to relieve pain and other distressing symptoms, while providing psychological, social and spiritual support for you and your family.

Palliative care can be provided at home or in a hospice, residential home or hospital. You may want to consider talking to your family and care team in advance about where you'd like to be treated and what care you wish to receive (NHS, 2016c).

Posterior cortical atrophy

posterior cortical atrophy (PCA) refers to gradual and progressive degeneration of the outer layer of the brain (the cortex) in the part of the brain located in the back of the head (posterior). It is not known whether PCA is a unique disease or a possible variant form of Alzheimer's disease. In many people with PCA, the affected part of the brain shows amyloid plaques and neurofibrillary tangles, similar to the changes that occur in Alzheimer's disease but in a different part of the brain. In other people with PCA, however, the brain changes resemble other diseases such as Lewy body dementia or a form of Creutzfeld-Jacob disease. Most cases of Alzheimer's disease occur in people age 65 or older, whereas the onset of PCA commonly occurs between ages 50 and 65 (ALZ.ORG, 2016c).

Prevalence

There is no standard definition of PCA and no established diagnostic criteria, so it is not possible to know how many people have the condition. Some studies have found that about 5% of people diagnosed with Alzheimer's disease have PCA. However, because PCA often goes unrecognised, the true percentage may be as high as 15% (ALZ.ORG, 2016c).

Symptoms

The most common problem first noticed by individuals with PCA is with vision. Quite understandably, this leads many people to consult their optician, but in fact the visual problems experienced are not related to the eye. Rather, the problems stem from the difficulty the affected brain has with interpreting the information sent to it by the healthy eyes. The precise nature of the visual problems experienced may vary widely but often include difficulty with some or all of the following -

- recognising objects in pictures (for example household items in a catalogue, especially if the pictures were taken from obscure angles or the picture is incomplete),
- recognising faces (for example TV characters, friends, relatives),

- appreciating the spatial location of objects around them (for example missing when reaching out to pick something up, finding it hard to press the correct numbers on a telephone, not seeing something you are looking for when it is right in front of you),
- judging distances (for example when driving, when descending stairs),
- judging the speed of moving traffic,
- perceiving movement among things which are stationary,
- following the text when trying to read a book or newspaper, causing one to miss some lines of text or to read others twice,
- reading particular words, finding that letters appear to move around or become superimposed over one another,
- reading certain types of text (for example large print such as newspaper headlines, handwritten notes),
- experiencing objects as having an unusual colour,
- experiencing increased sensitivity to bright light or shiny surfaces,
- seeing clearly, experiencing double vision,
- seeing clearly, feeling that one eyes are jerking around or not completely under one's control (PCASUPPORT, 2016).

However, vision is not the primary or only area of difficulty for everyone with posterior cortical atrophy. Skills such as literacy, numeracy, and the ability to make skilled movements may also be affected. Such difficulties may be experienced in the following ways -

- problems recalling the exact spelling of words,
- difficulties with handwriting,
- difficulties with remembering the shape or name of particular letters or numbers,
- slowness and difficulty with mental arithmetic,
- problems dealing with money and small change,
- awkwardness making gestures (e.g. waving, thumbs up),
- difficulties with using particular tools, kitchenware or implements (e.g. cutlery, scissors, glasses),
- problems with dressing and clothing (partly related to difficulties with visual perception) (PCASUPPORT, 2016).

PCA can affect people in different ways initially. In some instances, the disease affects both sides of the brain equally, leading to a combination of many of the symptoms described above. For other people, the disease affects one particular brain area earlier or more significantly; as a result, problems with spelling and writing for example might be the first sign of the condition with vision relatively unaffected, whereas for others, difficulties in seeing where objects are might be the initial symptom (pcasupport, 2016).

Diagnosis

PCA tends to affect people at an earlier age than typical Alzheimer's disease, with individuals often being in their mid-fifties or early sixties at the time of their first symptoms. However, it can also affect older people. The first signs are often subtle symptoms which may be difficult for the person experiencing them to explain. Individuals with early visual complaints are typically referred to opticians and eye specialists before referral to a neurologist. However, as mentioned earlier, other selective problems with spelling, numeracy and learned motor skills have also been reported. Even once an appropriate referral has been made, it may take some time before the diagnosis is made formally. Understandably, patients may feel frustrated by the time of diagnosis, typically one to three years from the onset of symptoms (pcasupport, 2016).

The underlying cause of PCA in the majority of cases is abnormal alterations to brain cells similar to that which is seen under the microscope in Alzheimer's disease. However, a small number of other conditions can result in similar symptoms, at least initially. These include -

- **Dementia with Lewy bodies** - where individuals may also experience visual hallucinations and may become stiff and slow down in their movements, in a similar manner to people with Parkinson's disease.
- **Corticobasal degeneration** - where individuals may have difficulty using one side of their body. Sometimes they have difficulty controlling the movement of one arm, which seems to move on its own as if it had a 'mind of its own'.
- Prion diseases such as **Creutzfeldt-Jakob disease**, very rare conditions in which individuals may rapidly decline in their cognition and develop other problems such as jerking movements of their limbs (myoclonus), stiffness, loss of balance control, and develop seizures (pcasupport, 2016).

There is no diagnostic test for PCA. However, tests such as specialised visual tests (organised by eye-specialists), neuropsychological tests of cognitive skills (for example memory, perception, literacy), blood tests, brain scans (MRI or CT), lumbar puncture (examination of the fluid circulating around the brain and spinal cord) and electroencephalogram (EEG) may help to exclude potentially treatable causes such as infection, inflammation or brain tumours. The shrinkage of the back part of the brain as a result of brain cell loss may be visible on the brain scan. It may be difficult to come up with one diagnosis in life and a definitive diagnosis can only be made once the brain tissue is examined by a pathologist. PCA is a rare condition but its exact prevalence in the normal population is currently unknown (PCASUPPORT, 2016).

Proposed diagnostic features

Suggested core features include: -

- insidious onset and gradual progression,
- presentation with visual complaints in the absence of ocular disease,
- relatively preserved episodic memory, verbal fluency and personal insight,
- presence of symptoms including visual agnosia [57], simultanagnosia [58], optic ataxia [59], ocular apraxia [60], dyspraxia [61] and environmental disorientation,
- absence of stroke or tumour (MENDEZ, GHAJARANIA and PERRYMAN, 2002), (TANG-WAI, GRAFF-RADFORD, BOEVE et al., 2004).

Treatment

Although there is no medication available to treat PCA specifically, patients may find some of the medications available to treat patients with typical Alzheimer's disease helpful. The medications are called acetyl cholinesterase inhibitors and include donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl). However, these medications are only designed to treat the symptoms of the disease and are not a cure.

Although individuals with PCA often show relatively preserved insight, they are frequently very disabled by the decline in their ability to interact successfully with the visual world around them. In particular, the cognitive problems associated with the condition often lead to a loss of independence, cause activities of daily living to be compromised, and inhibit the enjoyment of previous hobbies, especially reading. Such problems can lead to depression, irritability, frustration

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[57] the loss of the ability to recognise objects, people, or shapes

[58] a rare neurological disorder characterised by the inability of an individual to perceive more than a single object at a time

[59] the condition in which some, or all, aspects of visual guidance over reaching with the hand and arm are lost

[60] difficulty moving the eyes on command

[61] a complex neurological condition, which affects muscle co-ordination and perception

and a loss of self-confidence. Individuals with PCA who are experiencing low mood may benefit from a trial of antidepressant medication (PCASUPPORT, 2016).

Disease progression

As the disease progresses, word finding, day-to-day memory and general cognitive functions may become affected. In the later stages of the disease, people with PCA may develop jerking movements of their limbs and occasionally seizures. Unfortunately as with typical Alzheimer's disease, the condition is progressive with a gradual deterioration of skills and abilities over the years following diagnosis. The duration of the PCA condition is poorly understood, with some people living approximately the same length of time as individuals with typical Alzheimer's disease (on average 10–12 years following the onset of symptoms) and others living with the condition for longer (PCASUPPORT, 2016).

Progressive supranuclear palsy

progressive supranuclear palsy (PSP) is a rare and progressive condition that can cause problems with balance, movement, vision, speech and swallowing.

It's caused by increasing numbers of brain cells becoming damaged over time.

The PSP Association estimates there are around 4,000 people with PSP living in the UK. However, it's thought that the true figure could be much higher, because many cases may be misdiagnosed.

Most cases of PSP develop in people who are over 60 years of age (NHS, 2015q).

Causes

PSP occurs when brain cells in certain parts of the brain are damaged as a result of a build-up of a protein called tau.

Tau occurs naturally in the brain and is usually broken down before it reaches high levels. In people with PSP, it isn't broken down properly and forms harmful clumps in brain cells. Where these clumps form and the amount of abnormal tau in the brain can vary in people with PSP, which means the condition can have a wide range of symptoms.

The condition has been linked to changes in certain genes, but these genetic faults are not inherited and the risk to other family members, including children or siblings of someone with PSP, is very low (NHS, 2015q).

Symptoms

People with PSP develop a range of difficulties with balance, movement, vision, speech and swallowing.

The condition tends to develop gradually, which means it can be mistaken for another, more common, condition at first. The symptoms typically become more severe over several years, although the speed at which they worsen varies.

Some of the main symptoms of PSP are outlined below. Most people with the condition won't experience all of these (NHS, 2015q).

Early symptoms

The initial symptoms of PSP can include -

- sudden loss of balance when walking, that usually results in repeated falls, often backwards,
- muscle stiffness, particularly in the neck,
- extreme tiredness,
- changes in personality, such as irritability, apathy (lack of interest) and mood swings,
- changes in behaviour, such as recklessness and poor judgement,
- a dislike of bright lights (photophobia),
- difficulty controlling the eye muscles, particularly problems with looking up and down,
- blurred or double vision (NHS, 2015q).

Some people have early symptoms that are very similar to those of Parkinson's disease, such as tremors and slow movement (NHS, 2015q).

Mid-stage symptoms

Over time, the initial symptoms of PSP will become more severe.

Worsening balance and mobility problems may mean that walking becomes impossible and a wheelchair is needed. Controlling the eye muscles will become more difficult, increasing the risk of falls and making everyday tasks, such as reading and eating, more problematic (NHS, 2015q).

New symptoms can also develop at this stage, such as -

- slow, quiet or slurred speech,
- problems swallowing (dysphagia),
- reduced blinking reflex, which can cause the eyes to dry out and become irritated,
- involuntary closing of the eyes (blepharospasm), which can last from several seconds to hours,
- disturbed sleep,
- slowness of thought and some memory problems,
- neck or back pain, joint pain and headaches (NHS, 2015q).

Advanced stages

As PSP progresses to an advanced stage, people with the condition normally begin to experience increasing difficulties controlling the muscles of their mouth, throat and tongue.

Speech may become increasingly slow and slurred, making it harder to understand. There may also be some problems with thinking, concentration and memory (dementia), although these are generally mild and the person will normally retain an awareness of themselves.

The loss of control of the throat muscles can lead to severe swallowing problems, which may mean a feeding tube is required at some point to prevent choking or chest infections caused by fluid or small food particles passing into the lungs.

Many people with PSP also develop problems with their bowels and bladder functions. Constipation and difficulty passing urine are common, as is the need to pass urine several times during the night. Some people may lose control over their bladder or bowel movements (incontinence) (NHS, 2015q).

Diagnosis

It can be difficult to diagnose PSP, as there's no single test for it, and the condition can have similar symptoms to a number of others.

There are also many possible symptoms of PSP and several different sub-types that vary slightly, making it hard to make a definitive diagnosis in the early stages of the condition.

A diagnosis of PSP will be based on the pattern of your symptoms and by ruling out conditions that can cause similar symptoms, such as Parkinson's disease or a stroke.

Your doctor will need to carry out assessments of your symptoms, plus other tests and scans.

The diagnosis must be made or confirmed by a consultant with expertise in PSP. This will usually be a neurologist (NHS, 2015q).

Brain scans

If you have symptoms of PSP that suggest there's something wrong with your brain, it's likely you'll be referred for a brain scan.

Types of scan that you may have include -

- MRI scan - where a strong magnetic field and radio waves are used to produce detailed images of the inside of the brain,
- PET scan - a scan that detects the radiation given off by a substance injected beforehand,
- a DaTscan - where you're given an injection containing a small amount of a radioactive material and pictures of your brain are taken with a gamma camera (NHS, 2015q).

These scans can be useful in ruling out other possible conditions, such as brain tumours or strokes.

MRI scans can also detect abnormal changes to the brain that are consistent with a diagnosis of PSP, such as shrinkage of certain areas. Scans that show the build-up of the tau protein in the brain that's associated with PSP are currently under development (NHS, 2015q).

Ruling out Parkinson's disease

You may be prescribed a short course of a medication called levodopa to determine whether your symptoms are caused by PSP or Parkinson's disease.

People with Parkinson's disease usually experience a significant improvement in their symptoms after taking levodopa, whereas the medication only has a limited beneficial effect for some people with PSP (NHS, 2015q).

Neuropsychological testing

It's also likely you'll be referred to a neurologist and possibly also a psychologist for neuropsychological testing.

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This involves having a series of tests that are designed to evaluate the full extent of your symptoms and their impact on your mental abilities.

The tests will look at abilities such as -

- memory,
- concentration,
- understanding language,
- the processing of visual information, such as words and pictures (NHS, 2015q).

Most people with PSP have a distinct pattern in terms of their mental abilities, including poor concentration, a low attention span and problems with spoken language and processing visual information. Their memory of previously learned facts isn't usually significantly affected (NHS, 2015q).

Coping with a diagnosis

Being told that you have PSP can be devastating and difficult to take in.

You may feel numb, overwhelmed, angry, distressed, scared or in denial. Some people are relieved that a cause for their symptoms has finally been found. There's no right or wrong way to feel - everybody is different and copes in their own way.

Support from your family and care team can help you come to terms with the diagnosis.

The PSP Association can give you information and practical advice about living with PSP, as well as providing support to help you cope with the emotional impact of the condition.

You can get in touch with the PSP Association by calling their helpline on 0300 0110 122, or by emailing: helpline@pspassociation.org.uk (NHS, 2015q).

Treatment

There's currently no cure for PSP and no treatment to slow it down, but there are lots of things that can be done to help manage the symptoms.

As PSP can affect many different areas of your health, you'll be cared for by a team of health and social care professionals working together and this is known as a multidisciplinary team (MDT) (NHS, 2015q).

Members of your MDT may include -

- **a neurologist** - a specialist in conditions that affect the brain and nerves,
- **a physiotherapist** - who can help with movement and balance difficulties,
- **a speech and language therapist** - who can help with speech or swallowing problems,
- **an occupational therapist** - who can help you improve the skills you need for daily activities, such as washing or dressing,
- **a social worker** - who can advise you about the support available from social services,
- **an ophthalmologist or orthoptist** - specialists in treating eye conditions,
- **a specialist neurology nurse** - who may act as your point of contact with the rest of the team (NHS, 2015q).

Some of the main treatments that may be recommended are outlined below.

Medication

There are currently no medications that treat PSP specifically, but some people in the early stages of the condition may benefit from taking levodopa, amantadine or other medications used to treat Parkinson's disease.

These medications can improve balance and stiffness for some people with PSP, although the effect is often limited and only lasts for up to a few years.

Antidepressants can help with the depression that's often associated with PSP, and some may also help with balance, stiffness, pain and sleep problems.

It's important to tell your doctor about the symptoms you're experiencing, so they can consider which of these treatments is best for you (NHS, 2015q).

Physiotherapy

A physiotherapist can give you advice about making the most of your remaining mobility using exercise, while making sure you don't overexert yourself. Regular exercise may help strengthen your muscles, improve your posture and prevent stiffening of your joints.

Your physiotherapist can advise about equipment that could benefit you, such as a walking frame or specially designed shoes to reduce the risk of slipping and falling.

They can teach you breathing exercises to use when you eat, to reduce your risk of developing aspiration pneumonia (NHS, 2015q).

Speech and language therapy

A speech and language therapist (SLT) can help you improve your speech and swallowing problems (dysphagia).

They can teach you a number of techniques to help make your voice as clear as possible and can advise you about suitable communication aids or devices that you may need as PSP progresses.

Your therapist can also advise you about different swallowing techniques and, working together with a dietitian (see below), they may suggest altering the consistency of your food to make swallowing easier.

As your swallowing problems become more severe, you'll need additional treatment to compensate for your swallowing difficulties (NHS, 2015q).

Diet and severe swallowing problems

You may be referred to a dietitian, who will advise you about making changes to your diet, such as including food and liquids that are easier to swallow, while ensuring that you have a healthy, balanced diet.

For example, mashed potatoes are a good source of carbohydrates, while scrambled eggs and cheese are high in protein and calcium.

Feeding tubes may be recommended for severe swallowing problems, where the risk of malnutrition and dehydration is increased. You should discuss the pros and cons of feeding tubes with your family and care team, preferably when your symptoms of dysphagia are at an early stage.

The main type of feeding tube used is called a percutaneous endoscopic gastrostomy (PEG) tube. This tube is placed into your stomach through your abdomen (tummy) during an operation (NHS, 2015q).

Occupational therapy

An OT can advise you about how you can increase your safety, and prevent trips and falls during your day-to-day activities.

For example, many people with PSP benefit from having bars placed along the sides of their bath to make it easier for them to get in and out.

The OT will also be able to spot potential hazards in your home that could lead to a fall, such as poor lighting, badly secured rugs and crowded walkways and corridors (NHS, 2015q).

Treating eye problems

If you're having problems controlling your eyelids, injections of botulinum toxin can be used to help relax the muscles of your eyelids. It works by blocking the signals from the brain to the affected muscles. The effects of the injections usually last for up to three months.

If you're experiencing dry eyes because of reduced blinking, eyedrops and artificial tears can be used to lubricate them and reduce irritation.

Glasses with specially designed lenses can help some people with PSP who have difficulty looking down. Wearing wraparound, dark glasses can help those who are sensitive to bright light (photophobia) (NHS, 2015q).

Palliative care

Palliative care can be offered at any stage of PSP, alongside other treatments. It aims to relieve pain and other distressing symptoms while providing psychological, social and spiritual support (NHS, 2015q).

Palliative care can be received -

- in a hospice,
- at home or in a residential home,
- on a day patient basis in a hospice,
- in a hospital (NHS, 2015q).

Advanced care planning

Many people with PSP consider making plans for the future that outline their wishes (both medical and other decisions) and make them known to both their family and the health professionals involved in their care.

This can be useful in case you're unable to communicate your decisions later on because you're too ill, although it's voluntary and you don't have to do it if you don't want to.

Issues that you may want to cover might include -

- if you want to be treated at home, in a hospice or in a hospital when you reach the final stages of PSP,
- the type of painkillers you would be willing to take,
- if you would be willing to use a feeding tube if you were no longer able to swallow food and liquid,
- if you're willing to donate any of your organs after you die,

- if you'd be willing to be resuscitated by artificial means if you experienced respiratory failure (NHS, 2015q).

If you decide to discuss these issues, they can be written down in a number of ways -

- Advance decision to refuse treatment,
- Advance statement,
- Emergency healthcare plan
- Lasting Power of Attorney (NHS, 2015q).

Your care team can provide you with more information and advice about these decisions and how best to record them (NHS, 2015q).

Chapter 8

Tests

Contents

A range of tests and diagnostic procedures is needed to diagnose dementia, but there are several that are fairly commonly used to diagnose dementia.

These tests for dementia are mainly tests of mental abilities, blood tests and brain scans (NHS, 2015i).

Mental abilities

Mini Mental State Examination

People with symptoms of dementia are often given questionnaires to help test their mental abilities, to see how severe any memory problems may be. One widely used test is the MMSE.

The MMSE assesses a number of different mental abilities, including -

- short- and long-term memory,
- attention span,
- concentration,
- language and communication skills,
- ability to plan,
- ability to understand instructions (NHS, 2015i).

The MMSE is a series of exercises, each carrying a score with a maximum of 30 points. These exercises include -

- memorising a short list of objects and then repeating the list,
- writing a short sentence that is grammatically correct, such as ”the dog sat on the floor”,
- correctly answering time-orientation questions, such as identifying the day of the week, the date or the year (NHS, 2015i).

The MMSE is not a test to diagnose dementia. However, it is useful for assessing the level of mental impairment that a person with dementia may have.

Test scores may be influenced by a person’s level of education. For example, someone who cannot read or write very well may have a lower score, but they may not have dementia. Similarly, someone with a higher level of education may achieve a higher score, but still have dementia (NHS, 2015i).

Generalised anxiety disorder scale (2 items) questionnaire

The GAD-2 short screening tool consists of the first two questions of the GAD-7 scale.

Over the last 2 weeks, how often have you been bothered by the following problems	Not at all	Several Days	More than half the days	Nearly every day
1. - Feeling nervous, anxious or on edge	0	1	2	3
2. - Not being able to stop or control worrying	0	1	2	3
3. - Worrying too much about different things	0	1	2	3
4. - Trouble relaxing	0	1	2	3
5. - Being so restless that it is hard to sit still	0	1	2	3
6. - Becoming easily annoyed or irritable	0	1	2	3
7. - Feeling afraid as if something awful might happen	0	1	2	3

Table 8.1: The GAD-7 and GAD-2 screening tool

Blood tests

A person with suspected dementia may have blood tests to check their overall level of health. These blood tests can also rule out other conditions that may be responsible for their symptoms, such as thyroid hormones and vitamin B12 levels (NHS, 2015i).

Brain scans

CT scan

A CT scan uses X-rays and a computer to create detailed images of the inside of the body.

CT scans are sometimes referred to as CAT scan or computed tomography scans.

They're carried out in hospital by specially trained operators called radiographers and can be done while you're staying in hospital or during a short visit (NHS, 2015h).

When CT scans are used

CT scans can produce detailed images of many structures inside the body, including the internal organs, blood vessels and bones (NHS, 2015h).

They can be used to -

- **diagnose conditions** - including damage to bones, injuries to internal organs, problems with blood flow, strokes and cancer,
- **guide further tests or treatments** - for example, CT scans can help to determine the location, size and shape of a tumour before having radiotherapy, or allow a doctor to take a needle biopsy (where a small tissue sample is removed using a needle) or drain an abscess,
- **monitor conditions** - including checking the size of tumours during and after cancer treatment (NHS, 2015h).

CT scans wouldn't normally be used to check for problems if you don't have any symptoms (known as screening). This is because the benefits of screening may not outweigh the risks, particularly if it leads to unnecessary testing and anxiety (NHS, 2015h).

Preparing for a CT scan

Your appointment letter will mention anything you need to do to prepare for your scan.

You may be advised to avoid eating anything for several hours before your appointment, to help ensure that clear images are taken.

You should contact the hospital after receiving your appointment letter if you have any allergies or kidney problems, or if you're taking medication for diabetes, because special arrangements may need to be made.

You should also let the hospital know if you're pregnant. CT scans aren't usually recommended for pregnant women unless it's an emergency, as there's a small chance the X-rays could harm your baby.

It's a good idea to wear loose comfortable clothes, as you may be able to wear these during the scan. Try to avoid wearing jewellery and clothes containing metal (such as zips), as these will need to be removed (NHS, 2015h).

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Before having a CT scan

Before having the scan, you may be given a special dye called a contrast to help improve the quality of the images. This may be swallowed in the form of a drink, passed into your bottom (enema), or injected into a blood vessel.

Tell the radiographer if you feel anxious or claustrophobic about having the scan. They can give you advice to help you feel calm and can arrange for you to have a sedative (medication to help you relax) if necessary.

Before the scan starts, you may be asked to remove your clothing and put on a gown. You'll also be asked to remove anything metal, such as jewellery, as metal interferes with the scanning equipment (NHS, 2015h).

What happens during a CT scan

During the scan, you'll usually lie on your back on a flat bed that passes into the CT scanner.

The scanner consists of a ring that rotates around a small section of your body as you pass through it. Unlike a MRI scan, the scanner doesn't surround your whole body at once, so you shouldn't feel claustrophobic.

The radiographer will operate the scanner from the next room. While the scan is taking place, you'll be able to hear and speak to them through an intercom.

While each scan is taken, you'll need to lie very still and breathe normally. This ensures that the scan images aren't blurred. You may be asked to breathe in, breathe out, or hold your breath at certain points.

The scan will usually take around 10–20 minutes (NHS, 2015h).

What happens afterwards

You shouldn't experience any after effects from a CT scan and can usually go home soon afterwards. You can eat and drink, go to work and drive as normal.

If a contrast was used, you may be advised to wait in the hospital for up to an hour to make sure you don't have a reaction to it (see below). The contrast is normally completely harmless and will pass out of your body in your urine.

Your scan results won't usually be available immediately. A computer will need to process the information from your scan, which will then be analysed by a radiologist (a specialist in interpreting images of the body).

After analysing the images, the radiologist will write a report and send it to the doctor who referred you for the scan, so they can discuss the results with you. This normally takes a few days or weeks (NHS, 2015h).

Are CT scans safe?

CT scans are quick, painless and generally safe. However, there's a small risk you could have an allergic reaction to the contrast dye used and you will be exposed to X-ray radiation.

The amount of radiation you're exposed to during a CT scan varies, depending on how much of your body is scanned. CT scanners are designed to make sure you're not exposed to unnecessarily high levels.

Generally, the amount of radiation you're exposed to during each scan is the equivalent to between a few months and a few years of exposure to natural radiation from the environment.

It's thought exposure to radiation during CT scans could slightly increase your chances of developing cancer many years later, although this risk is thought to be very small (less than 1 in 2,000).

The benefits and risks of having a CT scan will always be weighed up before it's recommended. Talk to your doctor or radiographer about the potential risks beforehand, if you have any concerns (NHS, 2015h).

MRI scan

MRI is a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body. An MRI scanner is a large tube that contains powerful magnets. You lie inside the tube during the scan (NHS, 2015o).

An MRI scan can be used to examine almost any part of the body, including the -

- brain and spinal cord,
- bones and joints,
- breasts,
- heart and blood vessels,
- internal organs, such as the liver, womb or prostate gland (NHS, 2015o).

The results of an MRI scan can be used to help diagnose conditions, plan treatments and assess how effective previous treatment has been (NHS, 2015o).

What happens during an MRI scan?

During an MRI scan, you lie on a flat bed that's moved into the scanner. Depending on the part of your body being scanned, you'll be moved into the scanner either head first or feet first.

The MRI scanner is operated by a radiographer, who is trained in carrying out imaging investigations. They control the scanner using a computer, which is in a different room, to keep it away from the magnetic field generated by the scanner.

You'll be able to talk to the radiographer through an intercom and they'll be able to see you on a television monitor throughout the scan.

At certain times during the scan, the scanner will make loud tapping noises. This is the electric current in the scanner coils being turned on and off. You'll be given earplugs or headphones to wear.

It's very important to keep as still as possible during your MRI scan. The scan lasts 15 to 90 minutes, depending on the size of the area being scanned and how many images are taken (NHS, 2015o).

How does an MRI scan work?

Most of the human body is made up of water molecules, which consist of hydrogen and oxygen atoms. At the centre of each hydrogen atom is an even smaller particle, called a proton. Protons are like tiny magnets and are very sensitive to magnetic fields.

When you lie under the powerful scanner magnets, the protons in your body line up in the same direction, in the same way that a magnet can pull the needle of a compass.

Short bursts of radio waves are then sent to certain areas of the body, knocking the protons out of alignment. When the radio waves are turned off, the protons realign. This sends out radio signals, which are picked up by receivers.

These signals provide information about the exact location of the protons in the body. They also help to distinguish between the various types of tissue in the body, because the protons in different types of tissue realign at different speeds and produce distinct signals.

In the same way that millions of pixels on a computer screen can create complex pictures, the signals from the millions of protons in the body are combined to create a detailed image of the inside of the body (NHS, 2015o).

Safety

An MRI scan is a painless and safe procedure. You may find it uncomfortable if you have claustrophobia, but most people find this manageable with support from the radiographer. Going into the scanner feet first may be easier, although this is not always possible.

MRI scans don't involve exposing the body to X-ray radiation. This means people who may be particularly vulnerable to the effects of radiation, such as pregnant women and babies, can use them if necessary.

However, not everyone can have an MRI scan. For example, they're not always possible for people who have certain types of implants fitted, such as a pacemaker (a battery-operated device that helps to control an irregular heartbeat).

Extensive research has been carried out into whether the magnetic fields and radio waves used during MRI scans could pose a risk to the human body. No evidence has been found to suggest there's a risk, which means MRI scans are one of the safest medical procedures currently available (NHS, 2015o).

PET scan

PET scans are used to produce detailed three-dimensional images of the inside of the body.

The images can clearly show the part of the body being investigated, including any abnormal areas, and can highlight how well certain functions of the body are working (NHS, 2015p).

PET scans are often combined with CT scans to produce even more detailed images. This is known as a PET-CT scan.

They may also occasionally be combined with a MRI scan. This is known as a PET-MRI scan (NHS, 2015p).

Why PET scans are used

An advantage of a PET scan is that it can show how well certain parts of your body are working, rather that showing what it looks like.

They're particularly helpful for investigating confirmed cases of cancer, to determine how far the cancer has spread and how well it's responding to treatment.

Sometimes PET scans are used to help plan operations, such as a coronary artery bypass graft or brain surgery for epilepsy. They can also help diagnose some conditions that affect the normal workings of the brain, such as dementia (NHS, 2015p).

How PET scans work

PET scanners work by detecting the radiation given off by a substance called a radiotracer as it collects in different parts of your body.

In most PET scans a radiotracer called fluorodeoxyglucose (FDG) is used, which is similar to naturally occurring glucose (a type of sugar) so your body treats it in a similar way.

By analysing the areas where the radiotracer does and doesn't build up, it's possible to work out how well certain body functions are working and identify any abnormalities.

For example, a concentration of FDG in the body's tissues can help identify cancerous cells because cancer cells use glucose at a much faster rate than normal cells (NHS, 2015p).

What happens during a PET scan

PET scans are usually carried out on an outpatient basis. This means you won't need to stay in hospital overnight.

It's important to arrive on time for your scan, as the radiotracer used has a short shelf-life and your scan may be cancelled if you're late (NHS, 2015p).

Preparation -

Your appointment letter will mention anything you need to do to prepare for your scan.

You will usually be advised not to eat anything for six hours beforehand. Drinking is allowed, but you should ideally just drink water. You should also avoid strenuous exercise for 24 hours before your appointment.

It's a good idea to wear loose comfortable clothes, as you may be able to wear these during the scan (although sometimes you may be asked to change into a hospital gown).

Try to avoid wearing jewellery and clothes containing metal (such as zips), as these will need to be removed (NHS, 2015p).

Radiotracer injection -

Before the scan, the radiotracer is injected into a vein in your arm or hand. You will need to wait quietly for about an hour, to give it time to be absorbed by the cells in your body.

It's important to relax, keep as still as possible, and avoid talking while you wait, as moving and speaking can affect where the radiotracer goes in your body. You can go to the toilet if you need to at any point (NHS, 2015p).

The scan -

For the scan, you lie on a flat bed that will be moved into the centre of the large, circular scanner.

You should stay still and not talk while the scanner takes pictures of your body, which usually takes up to 30 minutes.

The scan is completely painless, but you may feel uncomfortable lying still for this long. If you feel unwell at any point there is a buzzer you can press to alert the medical team. The medical team will be able to see you throughout the scan.

For some people, being inside the scanner can be an unpleasant experience. Inform the hospital before the day of the scan if you think this may be a problem for you. They may be able to arrange for you to have a sedative to help you relax during the scan (NHS, 2015p).

Afterwards -

You should not experience any side-effects after a PET scan and should usually be able to go home soon afterwards.

The results of your scan will not usually be available on the same day. They will be sent to your specialist to be discussed at your next appointment (NHS, 2015p).

Are there any risks?

Any exposure to radiation carries a very small risk of potential tissue damage that could lead to cancer at a later date.

However, in a standard PET scan the amount of radiation you're exposed to is small - about the same as the amount you get from natural sources, such as the sun, over three years.

The radiotracer becomes quickly less radioactive over time and will usually be passed out of your body naturally within a few hours. Drinking plenty of fluid after the scan can help flush it from your body.

As a precaution, you may be advised to avoid prolonged close contact with pregnant women, babies or young children for a few hours after a PET scan, as you will be slightly radioactive during this time.

The CT component of a PET-CT scan also involves exposure to a small amount of additional radiation, but the risk of this causing any problems in the future is still very small (NHS, 2015p).

Other scans and procedures to diagnose dementia

Other types of scan, such as a SPECT scan or a PET scan, may be recommended if the result of your CT or MRI scan is uncertain. These scans look at how the brain functions and can pick up abnormalities with the blood flow in the brain.

In some cases, an EEG may be taken to record the brain's electrical signals (brain activity).

Electroencephalogram

An EEG is a recording of brain activity.

During the test, small sensors are attached to the scalp to pick up the electrical signals produced when brain cells send messages to each other.

These signals are recorded by a machine and are looked at by a doctor later to see if they're unusual.

The EEG procedure is usually carried out by a highly trained specialist called a clinical neurophysiologist during a short visit to hospital (NHS, 2015k).

When an EEG is used

An EEG can be used to help diagnose and monitor a number of conditions affecting the brain.

It may help identify the cause of certain symptoms - such as seizures (fits) or memory problems - or find out more about a condition you've already been diagnosed with (NHS, 2015k).

Preparing for an EEG

Your appointment letter will mention anything you need to do to prepare for the test.

Unless told otherwise, you can usually eat and drink beforehand and continue to take all your normal medication.

To help the sensors stick to your scalp more easily, you should make sure your hair is clean and dry before arriving for your appointment and avoid using products such as hair gel and wax.

You might want to bring a hairbrush or comb with you as your hair may be a bit messy when the test is finished. Some people bring a hat to cover their hair until they can wash it at home afterwards (NHS, 2015k).

How an EEG is carried out

There are several different ways an EEG recording can be taken. The clinical neurophysiologist will explain the procedure to you and can answer any questions you have. You'll also be asked whether you give permission (consent) for the various parts of the test to be carried out.

Before the test starts, your scalp will be cleaned and about 20 small sensors called electrodes will be attached using a special glue or paste. These are connected by wires to an EEG recording machine.

Routine EEG recordings usually take 20 to 40 minutes, although a typical appointment will last about an hour, including some preparation time at the beginning and some time at the end. Other types of EEG recording may take longer (NHS, 2015k).

Types of EEG

The main types of EEG are explained below.

Routine EEG -

A routine EEG recording lasts for about 20 to 40 minutes.

During the test, you'll be asked to rest quietly and open or close your eyes from time to time. In most cases, you'll also be asked to breathe in and out deeply (known as hyperventilation) for a few minutes.

At the end of the procedure a flashing light may be placed nearby to see if this affects your brain activity (NHS, 2015k).

Ambulatory EEG -

An ambulatory EEG is where brain activity is recorded throughout the day and night over a period of one or more days. The electrodes will be attached to a small portable EEG recorder that can be clipped on to your clothing.

You can continue with most of your normal daily activities while the recording is being taken, although you'll need to avoid getting the equipment wet (NHS, 2015k).

Video telemetry -

Video telemetry, also known as video EEG, is a special type of EEG where you're filmed while a recording is taken. This can help provide more information about your brain activity.

The test is usually carried out over a few days while staying in a purpose-built hospital suite.

The EEG signals are transmitted wirelessly to a computer. The video is also recorded by the computer and kept under regular surveillance by trained staff (NHS, 2015k).

What happens after an EEG

When the test is finished, the electrodes will be removed and your scalp will be cleaned. Your hair will probably still be a bit sticky and messy afterwards, so you may want to wash it when you get home.

You can usually go home soon after the test is finished and can return to your normal activities. You might feel tired after the test, particularly if you had a sleep or sleep-deprived EEG, so you may want someone to pick you up from hospital.

You won't normally get your results on the same day. The recordings will need to be analysed first and will be sent to the doctor who requested the test. They can discuss the results with you a few days or weeks later (NHS, 2015k).

Are there any risks or side-effects?

The EEG procedure is painless, comfortable and generally very safe. No electricity is put into your body while it's carried out. Apart from having messy hair and possibly feeling a bit tired, you won't normally experience any after-effects.

However, you may feel lightheaded and notice a tingling in your lips and fingers for a few minutes during the hyperventilation part of the test. Some people develop a mild rash where the electrodes were attached.

There's a very small risk you could have a seizure while the test is carried out, but you'll be closely monitored and help will be on hand in case this happens (NHS, 2015k).

Chapter 9

Conditions

Contents

Delirium

Delirium is also known as 'acute confusion'.

What is acute confusion in the elderly?

Acute confusion in the elderly is sudden and occurs in the space of hours to days. It is sometimes referred to as secondary dementia or delirium. It usually has a specific cause which has to be searched for and ruled out because once corrected, the patient tends to return to their normal self.

In medicine delirium is usually a symptom of acute illness but it has a definition of its own and its core features are -

- A disturbance of consciousness,
- A change in cognition,

- Rapid onset of hours to days,
- Tendency to fluctuate,
- Abnormalities of awareness and affect (e.g hallucinations or emotional lability) (Barros, 2016).

Acute confusion is not associated with degenerative brain changes, which can be found on CT of the brain, and it is not chronic confusion, which tends to be due to old age dementia and in that spectrum the most common is Alzheimer's disease.

Note that patients can have acute or chronic confusion, where their confusion state differs from their usual baseline level of confusion. Thus it is crucial to obtain a good collateral history from someone who knows the patient well (Barros, 2016).

Signs and Symptoms

This is variable and sometimes person specific but anything out of the ordinary in someone's personality should raise suspicion. Things to look out for are -

- agitation (Hyperactive),
- drowsiness (Hypoactive),
- hallucinations (usually visual in delirium),
- nonsensical speech,
- altered sleep pattern (Barros, 2016).

Please take into consideration and rule out sensory impairment, language barrier and ethnical differences when considering confusion states (Barros, 2016).

There are 2 main types of delirium -

- Hyperactive
- Hypoactive

Note that fluctuation between the two is common (Birtles, 2016).

Hyperactive delirium

This is the typical delirium picture -

- agitation,
- delusions,
- hallucinations,
- wandering,
- aggression (Birtles, 2016).

Hypoactive delirium

Hypoactive delirium is much easier to miss. Often this type of delirium can be confused with depression.

- lethargy,
- slowness with everyday tasks,
- excessive sleeping,
- inattention (Birtles, 2016).

Causes

Sudden confusion in the elderly has many causes.

Using the mnemonic VITAMIN C,D,E,F

- **V** - Vascular - CVA, TIA, Vascular dementia,
- **I** - Infective/Inflammatory - Local or systemic infection e.g UTI, Chest infection, Infected ulcer, Sepsis,
- **T** - Trauma - Head injury, Intracranial haemorrhage,
- **A** - Auto-immune - Thyroid dysfunction,
- **M** - Metabolic - Electrolyte disturbances, SIADH,
- **I** - Idiopathic/Iatrogenic - Medication e.g Opiates and Sedatives, Alcohol, recreational drugs,
- **N** - Neoplastic - SOL in the brain, Cancer,
- **C** - Congenital - Severe Cardiac myopathy, Hypertensive encephalopathy, Seizures,
- **D** - Degenerative/Developmental - Dementia, Learning disabilities, Depression,
- **E** - Endocrine/Environmental - Diabetes, Dehydration, Constipation, Nutritional deficits e.g. Vitamin deficiencies, change of environment, sleep apnoea, hypo/hyperthermia,
- **F** - Functional - Sensory deficiencies e.g hearing problems, visual problems, language (Barros, 2016).

A change in environment coupled with sensory impairment (common in the elderly) increases the risk of developing delirium. These factors alone can cause delirium without any deeper organic cause, but this should only be considered as a diagnosis of exclusion. Things that can cause or lead to delirium include pretty much anything (Birtles, 2016).

Using the mnemonic CHIMPS PHONED

- **C** - constipation,

- **H** - hypoxia,
- **I** - infection,
- **M** - metabolic disturbance,
- **P** - pain,
- **S** - sleeplessness,
- **P** - prescriptions,
- **H** - hypothermia/pyrexia,
- **O** - organ dysfunction (hepatic or renal impairment),
- **N** - nutrition,
- **E** - environmental changes,
- **D** - drugs (over-the-counter, illicit, recreational, their partner/neighbour/pets, alcohol and smoking) (Birtles, 2016).

Diagnosis

History

Taking a good history is essential, if not from the patient, then from a carer or family member (Barros, 2016).

- Previous cognitive function and health status,
- Baseline functional ability (mobility, aids),
- Onset and course of confusion,
- Previous episodes,
- Signs/Symptoms of an underlying cause,
- Social history,
- Full drug history including non-prescribed drugs and alcohol intake (Barros, 2016).

Clues from the medical notes -

- Current diagnoses - consider dementia and depression as standalone causes or in conjunction with delirium,
- Medications - perform a medication review - opiates / calcium supplements etc,
- Vascular problems - previous Strokes / MI / ischaemic limbs ↑ likelihood of vascular dementia,
- Other presenting complaints,
- History of recurrent admissions (Birtles, 2016).

Abbreviated mental test score -

- Useful, quick method to gain an objective assessment of cognition,

- Can be repeated to allow ongoing recognition of improvement / deterioration,
- Also consider use of a more formal screening tool (MMSE/ACE-III/frontal lobe tests) (Birtles, 2016).

Examination

- Full neurological exam (however this can be difficult in terms of compliance),
- Determine the consciousness level (AVPU, Glasgow Coma Scale),
- Full set of observations (Don't forget temperature and blood sugar),
- Abbreviated Mental Test (AMT) and/or Mini Mental State Examination (MMSE),
- Use a confusion scale for example the Confusion Assessment Method (CAM) (see below for how to use this) (Barros, 2016).

Investigations

- Bloods -
  - FBC - white cells for signs of infection, anaemia, increased MCV (macrocytic anaemia can be caused by B12 or folate deficiency which can have a variety of origins: leukemias, alcohol use, lack of intake, lack of absorption (i.e. post-gastrectomy), pernicious anaemia; hypothyroidism, liver disease.),
  - U&E - deranged electrolytes can cause confusion (consider sodium, but relative to what is normal for the patient),
  - LFTs - confusion can be caused by liver failure, malnutrition or be based on the background of alcohol abuse,
  - INR - can be useful to know if the patient is on Warfarin and you are concerned about intracranial bleeding,
  - TFTs - confusion is more common in hypothyroid states,
  - Calcium - Hypercalcaemia often causes confusion/delirium - Bones, moans, psychotic groans ring a bell?
  - B12 + folate/haemotinics - macrocytic anaemias, and B12/folate deficiency can compound confusion,
  - Glucose - hypoglycaemia is a common cause of confusion - it's also potentially life threatening, so don't miss it! (Birtles, 2016)
- Blood cultures if appropriate - as part of sepsis screen (Birtles, 2016).
- Urine dipstick/culture - UTI is a very common cause of delirium in the elderly, however a positive dipstick result alone in an elderly patient is not a significant finding or enough to warrant commencement of antibiotic

therapy. A positive dipstick without clinical signs is not satisfactory to diagnose urinary sepsis as a cause of delirium.
  - Look for other evidence supporting the diagnosis (WCC↑ / Suprapubic tenderness / Dysuria / Frequency / Offensive urine / Positive urine culture). In the meantime ensure you are considering other differential diagnoses (Birtles, 2016).
- Chest X-ray - As part of a sepsis screen to identify infection source - ?Pneumonia (Birtles, 2016).
- ECG,
- CT head, looking for -
  - Ischaemic stroke,
  - Intracranial bleeds (from trauma or spontaneous),
  - Space occupying lesions (Birtles, 2016).
- Others - arterial blood gases if appropriate, Haematinics if anaemia is found, Lumbar puncture (LP) if meningism is present (Barros, 2016).
- Observations
  - Early Warning Scores can be incredibly useful and also incredibly deceptive,
  - BP / Pulse - ↓BP ↑Pulse may indicate sepsis / dehydration / Idiopathic (antihypertensives overdose),
  - Temperature, respiratory rate and oxygen sats are all important diagnostic clues,
  - Tachycardia may be masked if the patient is on medications to alter heart rate (beta blockers / Digoxin) (Birtles, 2016).

Management

Find the underlying cause and treat it - delirium is a symptom, not a full diagnosis (Birtles, 2016).

Supportive management

Try to keep a consistent nursing and medical team, gentle re-orientation, calm and consistent care, regular introductions of yourself and your role, clear and concise communication. Ensure the patient has access to aids such as glasses, hearing aids and walking sticks where appropriate. Enable the patient to do what they can for themselves - independent washing, dressing, eating, toileting and other activities may still be possible with varying levels of encouragement (Birtles, 2016).

Environmental adaptation

Ensure there is access to a clock (and other orientation reminders for day, date, time etc), familiarity of objects where possible - having photographs available, using the patient's own clothes/washcloths. Involving the family, friends and/or carers in the care of the patient. Control level of noise and where possible aim for a side-room. Ensure lighting is adequate and temperature is ambient (Birtles, 2016).

Medication

Avoid where possible. Persistent wandering, and delirium as a diagnosis alone are not cause for sedation. Aim to keep the patient safe by the least restrictive method. Use of drugs can worsen delirium and come with their own adverse effects. Haloperidol (oral, IV or IM) is usually the first-line medical option, starting with a low dose in the elderly (0.5mg), which can be repeated after 30 minutes if no response is seen. If benzodiazepines are to be used, lorazepam is first-line (0.5mg starting dose) due to its rapid onset and short half-life (Birtles, 2016).

Post-discharge

Families/carers need to be aware that delirium can continue for a period of time after the cause has been treated. Information should be given to those surrounding the patient on management of any residual disorientation or inattention. Follow-up is advisable (Birtles, 2016).

Prevention is better than cure

Avoid drugs known to precipitate delirium - benzodiazepines etc

Highlighting patients more 'at risk' and observing them closely for signs of delirium.

Assessment of other factors which may induce or exacerbate delirium - pain control, drugs etc.

Employing supportive/environmental management approaches for all patients, regardless of delirium risk.

Increased awareness! (Birtles, 2016)

Motor neurone disease

Motor neurone disease is a rare condition that progressively damages parts of the nervous system. This leads to muscle weakness, often with visible wasting.

Motor neurone disease, also known as amyotrophic lateral sclerosis (ALS), occurs when specialist nerve cells in the brain and spinal cord called motor neurones stop working properly. This is known as neurodegeneration (NHS, 2015n).

Corticobasal degeneration

CBD is a rare condition that can cause gradually worsening problems with movement, speech, memory and swallowing.

It's often also called corticobasal syndrome (CBS).

CBD is caused by increasing numbers of brain cells becoming damaged or dying over time (NHS, 2015f).

Progressive supranuclear palsy

Progressive supranuclear palsy (PSP) is a rare and progressive condition that can cause problems with balance, movement, vision, speech and swallowing.

It's caused by increasing numbers of brain cells becoming damaged over time (NHS, 2015r).

Chapter 10

Menopause

Post-menopause positives

Your memory will improve

Many of us see forgetfulness as an inevitable part of ageing - but there's strong evidence to suggest our memories actually improve after the menopause.

Around 60% of women suffer a temporary decline in memory during the menopause, according to a study from the University of California. But note the word 'temporary'. Researchers found that learning capacity had returned to pre-menopausal levels after the menopause (MURPHY, 2015).

You'll sleep better

If night sweats have been wreaking havoc with your sleep patterns, you'll already be looking forward to a good night's slumber when they finally subside.

In fact, aside from a brief blip in middle-age, our all-round sleep quality actually appears to improve as we grow older. A University of Pennsylvania study of 150,000 US adults found the fewest sleep complaints among the over-70s (MURPHY, 2015).

You'll be much happier

Feeling down and disheartened during the menopause? Don't worry: you're set to cheer up very soon.

Our satisfaction levels reach their lowest point during our mid-50s, but start to rise again soon after - peaking at the age of 69, according to a study at the London School of Economics (Murphy, 2015).

You'll be less disappointed

Here's another cheering statistic from that London School of Economics study: at 68, people underestimate their future happiness by 4.5%.

Or to put it another way: we think our future is going to be slightly worse than it actually turns out to be.

That may not sound hugely positive - but compare this to the great expectations you had in your 20s, and the disappointment you felt when all your dreams didn't come true after all. Age teaches you acceptance and appreciation, and to be satisfied with your lot (Murphy, 2015).

You'll feel much calmer

An end to the menopause means an end to the often debilitating mood swings that are triggered by hormonal changes. And if you'd spent the previous 40 years suffering from PMS every month, you'll be even more relieved to finally see the back of your periods (Murphy, 2015).

You'll suffer fewer headaches

Headaches - and migraines in particular - can often be triggered by hormone fluctuations and stress, both of which are prevalent throughout the menopause.

The good news? Around 67% of women find their migraines go away entirely or improve significantly after the menopause, according to Migraine Action (Murphy, 2015).

You could have the best sex ever

Think your most satisfying times between the sheets are over? Not necessarily so! More than 60% of over-65s enjoy a fulfilling sex life, according to an Age UK survey. And a recent study at the University of San Diego found that 67% of sexually active older women achieve an orgasm 'most of the time' or 'always'.

Co-author Dr Susan Trompeter commented: '*Not only were the oldest women in this study the most satisfied overall, those who were recently sexually active ex-*

perienced orgasm satisfcation rates similar to the youngest participants' (Murphy, 2015).

You'll feel more confident

Coping with menopausal symptoms such as hot flushes, mood swings and disturbed sleep, can knock your body confidence for six. But once things settle down again, there's a good chance you'll feel a lot better about your appearance. After all, experience has told you how to look your best.

In fact, women feel most confident in their beachwear after the age of 55, according to a survey of 2,000 people for TK Maxx (Murphy, 2015).

You'll have fewer colds

As we age, we spend less time fighting off the sniffles - simply because our immune systems learn to deal with familiar viruses. The average 50-something catches half the amount of colds as a teenager, for example.

And while we're on the topic of sniffles, you may be pleased to hear you're less likely to suffer hay fever as you grow older, too (Murphy, 2015).

You'll have more freedom

Reaching retirement age means you have more time to do the things you enjoy doing - unencumbered by menopause symptoms, of course.

Now's the time to see more of your friends, travel the world, take up new hobbies and generally just enjoy yourself (Murphy, 2015).

Chapter 11

Stress

Contents

Stress: what it does to your health

Stress is bad for you. We know it and tell ourselves that we'll deal with it, later. But we've got some very good reasons for dealing with it now (apart from improving your health and reducing your risk of a range of diseases including high blood pressure, heart disease and diabetes). Stress makes you fat, flatulent and flattens your sex drive. Still want to deal with it later?

We just weren't designed to cope with stress long-term. The human body's response to danger works well when we spot something big and scary coming our way. The alarm bells go off and the 'fight or flight' system kicks in, releasing stress hormones, among them adrenaline and cortisol. Between them they increase the heart rate, raise the blood pressure, boost energy supplies to our bloodstream and increase the substances that repair tissues (Dobson, 2015).

Cortisol

Cortisol has some other interesting effects on the human body. It reduces the functions not necessary in that situation, changes our immune system responses and dampens down the systems we don't need when we're running for our lives - our immune, digestive and reproductive systems and growth processes.

Once the danger has passed, the stress hormone levels decrease, and everything gets back to normal. Which is fine, as long as the danger passes.

When we're under pressure all the time - at work, at home, financially and in our relationships - those stress hormones stay raised, causing long-term damage to our health, and some unpleasant symptoms.

'*You can see that the body's behaving logically,*' explains nutritionist Dr Marilyn Glenville. '*In a stressful situation, it's doing everything it can to save our lives. In a real life or death situation it's a brilliant mechanism. But these hormones are only supposed to be used for a few minutes. If we're living like that day in and day out, it's not healthy. And we live with the consequences.*' One of which, is getting fatter without eating more (Dobson, 2015).

The problem - Fat

'*The stress hormone cortisol layers fat around your middle of your body. It's almost like a protective cushion. The body stores fat here because it's near the liver and the major arteries, and close at hand if you need that extra energy supply quickly. It's your safety net*' says Dr Glenville. '*But if you're constantly stressed this goes on and on, with your body getting the message to store fat because there's a crisis. So you can be eating the same amount, but putting on weight. Stress also affects your thyroid function, and slows your metabolism down, adding to your weight problem.*'

Unfortunately, if you respond to stress in this way, you'll be putting on weight where you least want it. Weight stored around your middle puts you at increased risk of breast cancer, diabetes and heart disease.

(Not everyone reacts like this. Some people lose their appetite and lose weight, even becoming underweight, which also has consequences for your long-term health) (Dobson, 2015).

The problem - Wind

'*Stress hormones can create an inflammatory response, that can affect anywhere in the body, from pains in your joints or muscles, to your gut itself, causing Irritable Bowel Syndrome*,' says Dr Glenville. '*The irritation can make it feel as though you want to go to the toilet, especially if you're nervous before an event. It's why, when people are really scared, they open their bowels.*'

Add to that the body's instant reaction to stress, which is to shut down the digestive system. The result is that your food isn't digested properly. And the result of that can be bloating, flatulence and IBS. Less obvious, but every bit as important, are the effects on our health from not absorbing nutrients properly.

'*Sitting calmly and eating slowly, even if it's only for ten minutes in the middle of the day, is really important*,' says Marilyn Glenville. '*Rushing around, fast food and eating on the go isn't good for your digestion or for your health. If you aren't getting the goodness from your food that you need, it has a knock-on effect on your health*' (Dobson, 2015).

The problem - Low sex drive

To add insult to injury, high levels of stress knock your sex drive for six, in the process probably adding to your reasons for feeling stressed. '*Stress affects your hormones, reducing your levels of testosterone, and your sex drive*,' explains Marilyn Glenville. '*It even affects the quantity and quality of your sperm. This happens anyway as we get older, but stress compounds the effect.*'

Men aren't the only ones affected. Women produce testosterone too, from the ovaries, and also male hormones from the adrenal glands. And just like men, women lose their sexual get up and go when the pressure is on.

These aren't the only obvious signs that your body is reacting to an overload of pressure. Strange aches and pains, trouble sleeping, a daisy-chain of infections one after the other, hair loss and rashes are all signs that it's time to face up to your stress (Dobson, 2015).

Take control - be less stressed

'*When you have too many balls in the air at one time, stress is the outcome,*' says Ann McCracken, Vice Chair of the International Stress Management Association. '*It often shows in a change of behaviour, someone who is normally outgoing becoming withdrawn, for instance, or an easy-going person becoming irritable.*'

'*It's often the things you have no control over that can make you stressed. When a family member has to go into hospital, for instance. Control is a big issue.*' And if stress is long-running, it can take its toll.

'*The important thing is to recognise your own symptoms,*' says Ann McCracken. '*Self-awareness is important. Some people know that if they come out in a rash, or their psoriasis flares up, it's because they're stressed. Too often we ignore the symptoms, and work through them. You need to step back, take stock of your lifestyle, and the number of balls you have up in the air. 'What's happening in my life?' is the question you need to ask yourself, rather than 'Why is my body out of balance?'*'

Regaining some control of your situation goes a long way towards reducing your stress levels. If you've got too much on your plate, don't let embarrassment stop you asking for help. Talk to your family and friends and see if anyone can take on some of your load. Say no, nicely, to people who ask you to take on more tasks. And see your GP, sooner rather than later (Dobson, 2015).

Self-help tips for stress

- Eat well, and make sure you have a healthy, balanced diet with at least five portions of fruit and vegetables a day, wholegrains, low-fat protein, and not too much salt, sugar and stimulants such as caffeine and alcohol.
- Get enough sleep. Most of us need about seven hours a night. Make your bedroom a restful place (no work or TV), and keep to the same bedtime and waking hours, seven days a week.
- Exercise every day. It's important for your physical health, and exercise is also recognised as being good for relieving stress and depression. Aim for at least 30 minutes moderate exercise on at least five days a week. You can break this up into two lots of 15 minutes or three lots of 10 minutes. Go with a friend and build in some social life too.
- Relax. Yoga, pilates, meditation and deep-breathing exercises all help to relieve stress and help you feel relaxed and peaceful. Find a relaxation technique that works for you and do it regularly.
- Smile. When you smile you release feelgood hormones that make you feel happier. Laughing works too.

- See your friends, and talk to them about how you're feeling. Just having a sympathetic ear can make a huge difference to how you feel (Dobson, 2015).

Stress

What is stress?

Stress is the feeling of being under too much mental or emotional pressure.

Pressure turns into stress when you feel unable to cope. People have different ways of reacting to stress, so a situation that feels stressful to one person may be motivating to someone else.

Many of life's demands can cause stress, particularly work, relationships and money problems. And, when you feel stressed, it can get in the way of sorting out these demands, or can even affect everything you do.

Stress can affect how you feel, think, behave and how your body works. In fact, common signs of stress include sleeping problems, sweating, loss of appetite and difficulty concentrating.

You may feel anxious, irritable or low in self-esteem, and you may have racing thoughts, worry constantly or go over things in your head. You may notice that you lose your temper more easily, drink more or act unreasonably.

You may also experience headaches, muscle tension or pain, or dizziness.

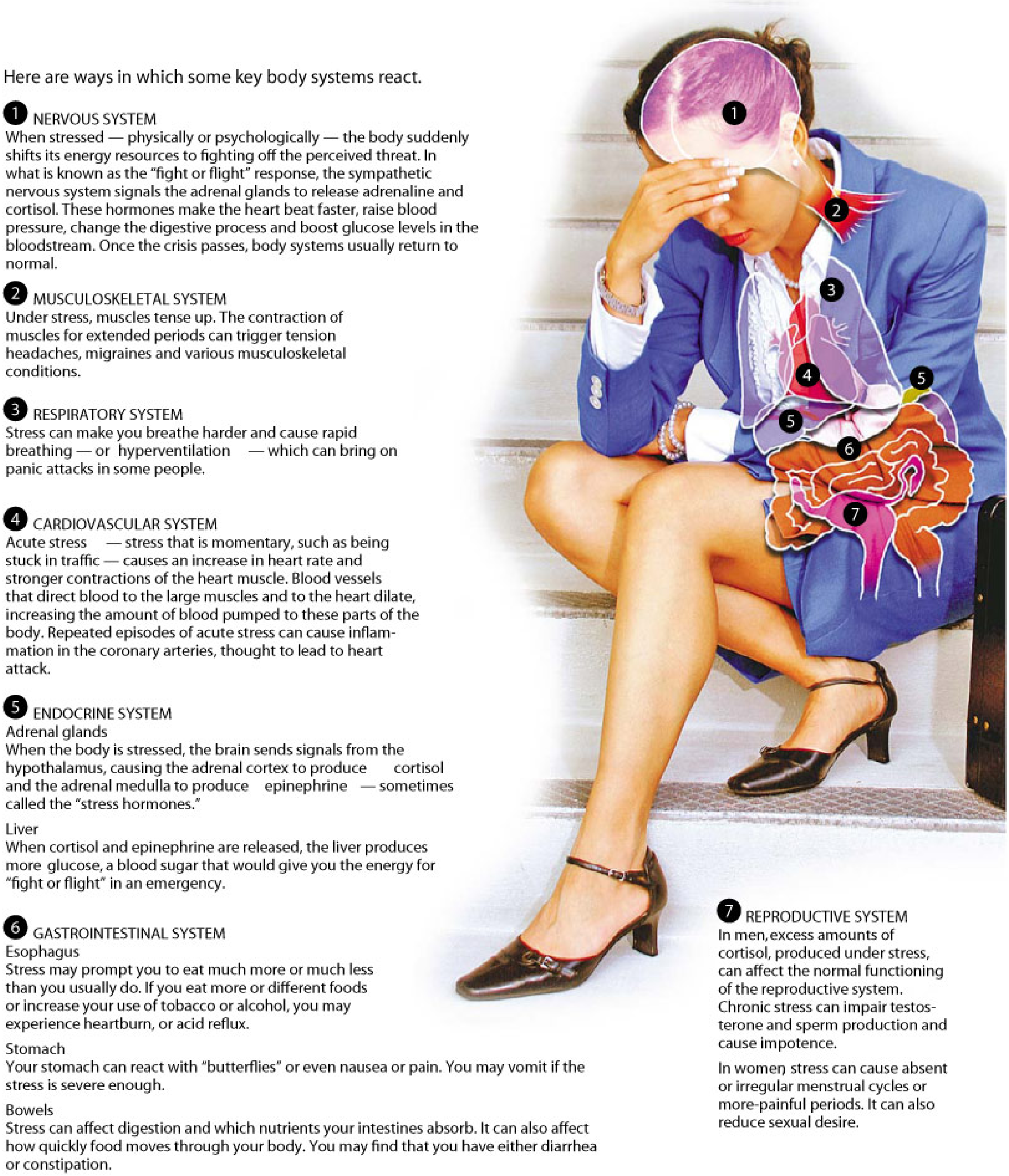
Stress causes a surge of hormones in your body. These stress hormones are released to enable you to deal with pressures or threats - the so-called ”fight or flight” response.

Once the pressure or threat has passed, your stress hormone levels will usually return to normal. However, if you're constantly under stress, these hormones will remain in your body, leading to the symptoms of stress (NHS, 2014c).

Symptoms

There are numerous emotional and physical disorders that have been linked to stress including depression, anxiety, heart attacks, stroke, hypertension, immune system disturbances that increase susceptibility to infections, a host of viral linked disorders ranging from the common cold and herpes to AIDS and certain cancers, as well as autoimmune diseases like rheumatoid arthritis and multiple sclerosis. In addition stress can have direct effects on the skin (rashes, hives, atopic dermatitis, the gastrointestinal system (GERD, peptic ulcer, irritable bowel syndrome, ulcerative colitis) and can contribute to insomnia and degenerative neurological disorders like Parkinson's disease. In fact, it's hard to think of any disease in which stress cannot play an aggravating role or any part of the body that is not affected.

This list will undoubtedly grow as the extensive ramifications of stress are increasingly being appreciated (STRESS.ORG, 2016a).



Here are ways in which some key body systems react.

① NERVOUS SYSTEM
When stressed — physically or psychologically — the body suddenly shifts its energy resources to fighting off the perceived threat. In what is known as the "fight or flight" response, the sympathetic nervous system signals the adrenal glands to release adrenaline and cortisol. These hormones make the heart beat faster, raise blood pressure, change the digestive process and boost glucose levels in the bloodstream. Once the crisis passes, body systems usually return to normal.

② MUSCULOSKELETAL SYSTEM
Under stress, muscles tense up. The contraction of muscles for extended periods can trigger tension headaches, migraines and various musculoskeletal conditions.

③ RESPIRATORY SYSTEM
Stress can make you breathe harder and cause rapid breathing — or hyperventilation — which can bring on panic attacks in some people.

④ CARDIOVASCULAR SYSTEM
Acute stress — stress that is momentary, such as being stuck in traffic — causes an increase in heart rate and stronger contractions of the heart muscle. Blood vessels that direct blood to the large muscles and to the heart dilate, increasing the amount of blood pumped to these parts of the body. Repeated episodes of acute stress can cause inflammation in the coronary arteries, thought to lead to heart attack.

⑤ ENDOCRINE SYSTEM
Adrenal glands
When the body is stressed, the brain sends signals from the hypothalamus, causing the adrenal cortex to produce cortisol and the adrenal medulla to produce epinephrine — sometimes called the "stress hormones."

Liver
When cortisol and epinephrine are released, the liver produces more glucose, a blood sugar that would give you the energy for "fight or flight" in an emergency.

⑥ GASTROINTESTINAL SYSTEM
Esophagus
Stress may prompt you to eat much more or much less than you usually do. If you eat more or different foods or increase your use of tobacco or alcohol, you may experience heartburn, or acid reflux.

Stomach
Your stomach can react with "butterflies" or even nausea or pain. You may vomit if the stress is severe enough.

Bowels
Stress can affect digestion and which nutrients your intestines absorb. It can also affect how quickly food moves through your body. You may find that you have either diarrhea or constipation.

⑦ REPRODUCTIVE SYSTEM
In men, excess amounts of cortisol, produced under stress, can affect the normal functioning of the reproductive system. Chronic stress can impair testosterone and sperm production and cause impotence.

In women stress can cause absent or irregular menstrual cycles or more-painful periods. It can also reduce sexual desire.

Figure 11.1: Stress

Common signs and symptoms of stress

- Frequent headaches, jaw clenching or pain,
- Gritting, grinding teeth,
- Stuttering or stammering,
- Tremors, trembling of lips, hands,
- Neck ache, back pain, muscle spasms,
- Light headedness, faintness, dizziness,
- Ringing, buzzing or ”popping sounds”,
- Frequent blushing, sweating,
- Cold or sweaty hands, feet,
- Dry mouth, problems swallowing,
- Frequent colds, infections, herpes sores,
- Rashes, itching, hives, ”goose bumps”,
- Unexplained or frequent ”allergy” attacks,
- Heartburn, stomach pain, nausea,
- Excess belching, flatulence,
- Constipation, diarrhoea, loss of control,
- Difficulty breathing, frequent sighing,
- Sudden attacks of life threatening panic,
- Chest pain, palpitations, rapid pulse,
- Frequent urination,
- Diminished sexual desire or performance,
- Excess anxiety, worry, guilt, nervousness,
- Increased anger, frustration, hostility,
- Depression, frequent or wild mood swings,
- Increased or decreased appetite,
- Insomnia, nightmares, disturbing dreams,
- Difficulty concentrating, racing thoughts,
- Trouble learning new information,
- Forgetfulness, disorganisation, confusion,
- Difficulty in making decisions,
- Feeling overloaded or overwhelmed,
- Frequent crying spells or suicidal thoughts,
- Feelings of loneliness or worthlessness,
- Little interest in appearance, punctuality,
- Nervous habits, fidgeting, feet tapping,
- Increased frustration, irritability, edginess,
- Overreaction to petty annoyances,
- Increased number of minor accidents,
- Obsessive or compulsive behaviour,

- Reduced work efficiency or productivity,
- Lies or excuses to cover up poor work,
- Rapid or mumbled speech,
- Excessive defensiveness or suspiciousness,
- Problems in communication, sharing,
- Social withdrawal and isolation,
- Constant tiredness, weakness, fatigue,
- Frequent use of over-the-counter drugs,
- Weight gain or loss without diet,
- Increased smoking, alcohol or drug use,
- Excessive gambling or impulse buying (STRESS.ORG, 2016a).

Managing stress in daily life

Stress is not an illness itself, but it can cause serious illness if it isn't addressed. It's important to recognise the symptoms of stress early. Recognising the signs and symptoms of stress will help you figure out ways of coping and save you from adopting unhealthy coping methods, such as drinking or smoking.

There is little you can do to prevent stress, but there are many things you can do to manage stress more effectively, such as learning how to relax, taking regular exercise and adopting good time-management techniques.

Studies have found that mindfulness courses, where participants are taught simple meditations across a series of weeks, can also help to reduce stress and improve mood (NHS, 2014c).

When to see your GP about your stress levels

If you've tried self-help techniques and they aren't working, you should go to see your GP. They may suggest other coping techniques for you to try or recommend some form of counselling or cognitive behavioural therapy.

If your stress is causing serious health problems, such as high blood pressure, you may need to take medication or further tests.

Mental health issues, including stress, anxiety and depression, are the reason for one-in-five visits to a GP (NHS, 2014c).

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Recognising your stress triggers

If you're not sure what's causing your stress, keep a diary and make a note of stressful episodes for two-to-four weeks. Then review it to spot the triggers.

Things you might want to write down include -

- the date, time and place of a stressful episode,
- what you were doing,
- who you were with,
- how you felt emotionally,
- what you were thinking,
- what you started doing,
- how you felt physically,
- a stress rating (0–10 where 10 is the most stressed you could ever feel) (NHS, 2014c).

You can use the diary to -

- work out what triggers your stress,
- work out how you operate under pressure,
- develop better coping mechanisms (NHS, 2014c).

Doctors sometimes recommend keeping a stress diary to help them diagnose stress (NHS, 2014c).

Take action to tackle stress

There's no quick-fix cure for stress, and no single method will work for everyone. However, there are simple things you can do to change the common life problems that can cause stress or make stress a problem. These include relaxation techniques, exercise and talking the issues through (NHS, 2014c).

Get stress support

Because talking through the issues is one of the key ways to tackle stress, you may find it useful to attend a stress management group or class. These are sometimes run in doctors' surgeries or community centres. The classes help people identify the cause of their stress and develop effective coping techniques.

Ask your GP for more information if you're interested in attending a stress support group (NHS, 2014c).

Breathing exercise for stress

This calming breathing technique for stress, anxiety and panic takes just a few minutes and can be done anywhere.

You will get the most benefit if you do it regularly, as part of your daily routine.

You can do it standing up, sitting in a chair that supports your back, or lying on a bed or yoga mat on the floor.

Make yourself as comfortable as you can. If you can, loosen any clothes that restrict your breathing.

If you're lying down, place your arms a little bit away from your sides, with the palms up. Let your legs be straight, or bend your knees so your feet are flat on the floor.

If you're sitting, place your arms on the chair arms.

If you're sitting or standing, place both feet flat on the ground. Whatever position you're in, place your feet roughly hip-width apart (NHS, 2016b).

- Let your breath flow as deep down into your belly as is comfortable, without forcing it.
- Try breathing in through your nose and out through your mouth.
- Breathe in gently and regularly. Some people find it helpful to count steadily from one to five. You may not be able to reach five at first.
- Then, without pausing or holding your breath, let it flow out gently, counting from one to five again, if you find this helpful.
- Keep doing this for three to five minutes (NHS, 2016b).

Chapter 12

Diet and mental health

Contents

A healthy diet

Recent evidence suggests that good nutrition is essential for our mental health and that a number of mental health conditions may be influenced by dietary factors.

One of the most obvious, yet under-recognised factors in the development of major trends in mental health is the role of nutrition. The body of evidence linking diet and mental health is growing at a rapid pace. As well as its impact on short and long-term mental health, the evidence indicates that food plays an important contributing role in the development, management and prevention of specific mental health problems such as depression, schizophrenia, attention deficit hyperactivity disorder, and Alzheimer's disease.

Nearly two thirds of those who do not report daily mental health problems eat fresh fruit or fruit juice every day, compared with less than half of those who do report daily mental health problems. This pattern is similar for fresh vegetables and salad. Those who report some level of mental health problem also eat fewer healthy foods (fresh fruit and vegetables, organic foods and meals made from scratch) and more unhealthy foods (chips and crisps, chocolate, ready meals and takeaways).

A balanced mood and feelings of wellbeing can be protected by ensuring that our diet provides adequate amounts of complex carbohydrates, essential fats, amino acids, vitamins and minerals and water.

While a healthy diet can help recovery, it should sit alongside other treatments recommended by your doctor (MENTALHEALTH, 2016b).

Food consumption

Food production and manufacturing techniques, coupled with changing lifestyles and increasing access to processed foods, mean that our intake of fresh, nutritious, local produce is much lower, at the same time as our intake of fat, sugar, alcohol and additives is much higher. It has been estimated that the average person in the UK and other industrialised countries will eat more than 4 kilogrammes of additives every year.

Over the last 60 years there has been a 34% decline in UK vegetable consumption with currently only 13% of men and 15% of women now eating at least five portions of fruit and vegetables per day. People in the UK eat 59% less fish than they did 60 years ago - decreasing the consumption of essential omega-3 fatty acids (MENTALHEALTH, 2016b).

What should I eat?

Eat fewer high sugar foods and more wholegrain cereals, nuts, beans, lentils, fruit and vegetables.

Sugary foods are absorbed quickly into the bloodstream. This may cause an initial 'high' or surge of energy that soon wears off as the body increases its insulin production, leaving you feeling tired and low.

Wholegrain cereals, pulses, fruit and vegetables are more filling and, because the sugar in these foods is absorbed more slowly, don't cause mood swings. These foods are more nutritious as they contain thiamin (B1), a vitamin that has been associated with control of mood, and folate and zinc (supplements of these nutrients have been shown to improve the mood of people with depression in a small number of studies) (MENTALHEALTH, 2016b).

Nutrition

Healthy body, healthy mind

Feeling good is about looking after our minds and our bodies. With depression we can feel overwhelmed by our emotions and struggle to get motivated, and our physical health can suffer as a result. The worthlessness and exhaustion that comes with depression often makes it harder for us to take good care of our bodies, and over time this can do even more damage to our confidence and self-esteem. There is growing evidence linking poor physical health and poor mental health, and recent studies suggest that if you have a long-term condition such as heart disease or diabetes you're twice as likely to become depressed (DEPRESSIONALLIANCE, 2016b).

Eating well

An emotional relationship with food can make it hard to eat as healthily as we'd like. It's common to use food to soothe and comfort ourselves, so try keeping a mood and food diary. This can help you to recognise triggers for emotional eating and to understand how certain foods affect the way you feel. You might notice that small changes to your diet can make a big difference to your energy levels. Eating five portions of fruit or vegetables a day is a simple way to start, and fresh vegetable soups and stir fry's can help us to get a number of portions in one go. Some studies suggest that people with depression may be low in certain essential fatty acids (Omega 3) found in fish oils, so keeping a stack of tinned mackerel or sardines in the cupboard is a cheap and easy way to top up (DEPRESSIONALLIANCE, 2016b).

Keeping active

Exercise boosts the feel-good hormones in our brains, helping to lift our mood. A refreshing walk in the park or 10 minutes of gardening can add a purpose to our day, and you might find the extra activity helps you sleep better. Keeping active also reduces stress, and we often gain a sense of achievement by meeting goals we've set for ourselves. Ask your GP if an 'Exercise on Prescription' scheme is available in your area, and try linking up with others to keep things fun and sociable. Studies show that exercising outdoors is especially good for boosting mood, so Green gyms, Walking for health and Fitness meet ups are great ways to get outside and meet new people (DEPRESSIONALLIANCE, 2016b).

- Take small steps. A short, daily walk is a huge achievement if you're unwell with depression.
- Depression often comes with low self-esteem and poor body image, but focusing on nutrition rather than losing/gaining weight can help to keep things more positive.
- Avoid putting pressure on yourself. Depression can make even simple activities feel overwhelming, so know your limits and rest when you need to.
- Treat yourself occasionally. Depression can make us feel guilty and undeserving of even small pleasures.
- Drink plenty of water and try keeping alcohol and caffeine in moderation (DEPRESSIONALLIANCE, 2016b).

Even mild dehydration can alter mood

Most people only think about drinking water when they are thirsty; but by then it may already be too late.

Even mild dehydration can alter a person's mood, energy level, and ability to think clearly, according to two studies recently conducted at the University of Connecticut's Human Performance Laboratory.

The tests showed that it didn't matter if a person had just walked for 40 minutes on a treadmill or was sitting at rest - the adverse effects from mild dehydration were the same. Mild dehydration is defined as an approximately 1.5% loss in normal water volume in the body.

The test results affirm the importance of staying properly hydrated at all times and not just during exercise, extreme heat, or exertion, says Lawrence E. Armstrong, one of the studies' lead scientists and a professor of physiology in UConn's Department of Kinesiology in the Neag School of Education.

"*Our thirst sensation doesn't really appear until we are 1% or 2% dehydrated. By then dehydration is already setting in and starting to impact how our mind and body perform,*" says Armstrong, an international expert on hydration who has conducted research in the field for more than 20 years. "*Dehydration affects all people, and staying properly hydrated is just as important for those who work all day at a computer as it is for marathon runners, who can lose up to 8% of their body weight as water when they compete.*"

Separate groups of young women and men were tested. Twenty-five women took part in one study. Their average age was 23. The men's group consisted of 26 men with an average age of 20. All of the participants were healthy, active individuals, who were neither high-performance athletes nor sedentary - typically exercising for 30 to 60 minutes per day.

Each participant took part in three evaluations that were separated by 28 days. All of the participants walked on a treadmill to induce dehydration, and all of the subjects were hydrated the evening before the evaluations commenced. As part of the evaluation, the subjects were put through a battery of cognitive tests that measured vigilance, concentration, reaction time, learning, memory, and reasoning. The results were compared against a separate series of tests when the individuals were not dehydrated.

In the test involving the young women, mild dehydration caused headaches, fatigue, and difficulty concentrating, according to one of the studies, which appears in the February issue of The Journal of Nutrition (Armstrong et al., 2011). The female subjects also perceived tasks as more difficult when slightly dehydrated, although there was no substantive reduction in their cognitive abilities.

In the test involving the young men, mild dehydration caused some difficulty with mental tasks, particularly in the areas of vigilance and working memory, according to the results of the second UConn study. While the young men also experienced fatigue, tension, and anxiety when mildly dehydrated, adverse changes in mood and symptoms were "*substantially greater in females than in males, both at rest and during exercise*," according to the study. The men's study was published in the British Journal of Nutrition in November 2011 (Ganio et al., 2011).

"*Even mild dehydration that can occur during the course of our ordinary daily activities can degrade how we are feeling - especially for women, who appear to be more susceptible to the adverse effects of low levels of dehydration than men*," says Harris Lieberman, one of the studies' co-authors and a research psychologist with the Military Nutrition Division, U.S. Army Research Institute of Environmental Medicine in Natick, Mass. "*In both sexes these adverse mood changes may limit the motivation required to engage in even moderate aerobic exercise. Mild dehydration may also interfere with other daily activities, even when there is no physical demand component present.*"

Why women and men are so adversely affected by mild dehydration is unclear, and more research is necessary. But other research has shown that neurons in the brain detect dehydration and may signal other parts of the brain regulating mood when dehydration occurs. This process could be part of an ancient warning system protecting humans from more dire consequences, and alerting them to the need for water to survive.

In order to stay properly hydrated, experts like Armstrong recommend that individuals drink eight, 8-ounce glasses of water a day, which is approximately equivalent to about 2 litres of water. People can check their hydration status by monitoring the colour of their urine. Urine should be a very pale yellow in individuals who are properly hydrated. Urine that is dark yellow or tan in color indicates greater dehydration. Proper hydration is particularly important for high-risk groups, such as the elderly, people with diabetes, and children.

The dehydration studies were supported by Danone Research of France and were conducted in partnership with the U.S. Army Research Institute of Environmental Medicine, University of Arkansas, and Texas Health Presbyterian Hospital''s Institute for Exercise and Environmental Medicine in Dallas, Texas. UConn professor Douglas Casa, adjunct assistant professor Elaine Lee, and members of the graduate student team at UConn's Korey Stringer Institute for the prevention of sudden death in sport helped gather data for the two studies (Poitras, 2012).

Chapter 13

Looking after ...

Contents

Benefits of early dementia diagnosis

Dementia is one of the health conditions that people are most frightened of.

You may find it hard to accept that memory problems are affecting your life. If you're concerned about memory or other problems associated with dementia, it's normal to be reluctant to seek help and face such a diagnosis. However, there are potential benefits to getting medical advice.

Being diagnosed early can help you get the right treatments and find the best sources of support, as well as making decisions about the future (NHS, 2015c).

A dementia diagnosis can help uncertainty

It may not be clear why you have problems with your memory or why your behaviour has changed. These problems may be because of dementia, or down to other reasons such as poor sleep, low mood, medications or other medical conditions. This uncertainty can be distressing for both you and your family and friends.

While a diagnosis of dementia can be devastating news, an explanation of what the problem is and what can be done about it may help you feel empowered and reduce some of the worry caused by uncertainty.

Some people find it helpful to discuss with doctors and nurses how the dementia may affect them or their loved one in the future, and there is advice available on how to stay independent with dementia and live well with dementia (NHS, 2015c).

Getting treatments for dementia

Dementia is not a single condition - it refers to difficulties with thinking and memory that may be caused by several different underlying diseases. This is one reason why not everyone with dementia experiences the same problems.

Recognising that there is a problem, and discovering the underlying cause of the dementia, is important. This is because it will help guide your choice of treatments and services.

An early diagnosis of dementia may also be beneficial because some causes of dementia are treatable and fully or partially reversible, depending on the nature of the problem. Conditions such as some vitamin deficiencies, side-effects of medications and certain brain tumours may fall into this category.

Alzheimer's disease and dementia with Lewy bodies gradually damage the brain. Acetylcholinesterase inhibitor medicines have been shown to benefit in Alzheimer's disease and dementia with Lewy bodies. These treatments, such as donepezil (Aricept), rivastigmine (Exelon) and galantamine (various brand names), improve symptoms by making the remaining brain cells work a bit harder. Memantine is another medication that can help in Alzheimer's disease.

Although they will not cure your dementia, these medications can make a significant difference to your day-to-day living and functioning.

Treating high blood pressure, high cholesterol and poorly controlled diabetes is also important, as is stopping smoking and keeping to a healthy weight. These factors (known as risk factors) all contribute strongly to vascular dementia, and may make Alzheimer's disease worse. Your GP can assess your risk factors, advise if treatment is needed and monitor you.

Medications for other conditions can be reviewed, in case they are having a negative effect on how well your mind is working (NHS, 2015c).

Other support if you have dementia

Whether or not there are specific treatments for the cause of the dementia affecting you, having the right diagnosis is important for getting the right advice and support. There is a wide variety of help and information available both for people with dementia and their friends, relatives and carers (NHS, 2015c).

This dementia support includes -

- Information on help available at home or in the community, such as from social services, day centres and respite care, community mental health teams, speech and language therapists, dietitians and occupational therapists.
- Advice regarding financial affairs and planning for the future.
- Financial benefits and support (such as Attendance Allowance).
- Advice about driving (see Staying independent with dementia).

- Advance care planning and help with setting up a Lasting Power of Attorney if the dementia is progressive. This allows a person to be involved in discussions about their future while they are still able to do so effectively.
- Information and support groups. There are numerous sources of information and advice that are easier to find if you have a diagnosis (for example, the Alzheimer's Society and FTD support group). Access to a support group is easier if a diagnosis is clear, because support groups can provide specialist information and links to others in similar situations (NHS, 2015c).

Advice and support for other medical conditions

If doctors and nurses are aware that a person has a condition causing dementia, this is also helpful when treating other medical problems. This includes taking extra time to explain things to patients in a way they can understand, setting up safer ways of taking medication (for example, pill organiser boxes that help you remember when to take tablets), and understanding and offering extra support if someone has to come into hospital as an inpatient for another reason (NHS, 2015c).

Dementia research and planning of dementia services

Getting the right diagnosis is also important for research and understanding more about the causes of dementia. Better recognition of how important and common the causes of dementia are is vital for planning services to provide the help and support people need, both locally and nationally (NHS, 2015c).

Looking after someone with dementia

If you have dementia, or you are looking after someone who has dementia, you are likely to face many practical issues in your daily life.

People with dementia can feel vulnerable as their condition progresses and they increasingly rely on other people to do things for them. It is important that people who have dementia feel reassured and supported, while retaining some level of independence.

Although some symptoms are common to many people with dementia, each person's experience of the disease and how they cope with it will be different (NHS, 2015m).

Helping someone with dementia with everyday tasks

When a person with dementia finds that their mental abilities are declining, they're likely to feel anxious, stressed and scared. They may be aware of their increasing clumsiness and inability to remember things, and this can be very frustrating and upsetting for them.

If you are looking after someone with dementia, you can help them feel more secure by creating a regular daily routine in a relaxed environment, where they're encouraged and not criticised.

Involving the person you look after in everyday tasks may make them feel useful and improve their sense of self-worth. They could help with the shopping, laying the table or sweeping leaves in the garden, for example.

As the illness progresses, these tasks may become harder for them to manage independently, and you may need to give them more support (NHS, 2015m).

How you can help

The main way you can help someone with dementia is by offering support sensitively and try not to be critical of what they do. It can be very important for the person with dementia to feel that they're still useful.

In the early stages, memory aids can be used around the home to help the person remember where things are.

For example, you could put pictures on cupboard doors of what's inside, such as cups and saucers.

This may help to trigger their memory and enable them to retain their independence a little longer (NHS, 2015m).

Keeping up hobbies and interests when someone has dementia

Many people with dementia will still enjoy their hobbies or interests. For example, if they like cooking, they may be able to help make a meal. Going for a walk or gardening is a simple way to get some exercise and a sense of achievement. Or they may prefer listening to music or playing a board game. Caring for a pet cat or dog can bring a lot of pleasure to some people.

If the person you care for was very sociable and outgoing, or if they have a large family, they may really enjoy visits from one or two family members or friends.

However, they may struggle to keep up with conversations if they have a lot of visitors at the same time.

You can find tips and ideas for people with dementia in this activities guide from Care UK (NHS, 2015m).

Maintaining good health and nutrition in someone with dementia

It's important that the person you care for has a healthy, balanced diet and gets some exercise. The longer they stay fit and healthy, the better their quality of life will be. If you want some easy exercises, try these sitting exercises.

If the person you care for doesn't eat enough or eats unhealthy food, they can become susceptible to other illnesses. People with dementia can become more confused if they get ill (NHS, 2015m).

Common food-related problems for people with dementia include -

- not recognising foods,
- forgetting what food they like,
- refusing or spitting out food,
- resisting being fed,
- asking for strange food combinations (NHS, 2015m).

This behaviour is usually due to confusion, or irritation in the mouth caused by dental problems, rather than wanting to be awkward. If you're concerned about the person's eating behaviour, speak to your GP (NHS, 2015m).

How you can help

Involve the person you care for. For example, if they cannot feed themselves, you could put the cutlery in their hand and help guide it to their mouth. You could also involve them in preparing food, if they are able to.

Try to stay calm. If you feel stressed at mealtimes, the person you care for will probably be stressed too. Make sure you have plenty of time for meals, so you can deal with any problems that arise.

Try to accommodate behaviour changes. It's likely that the person you care for will change their eating patterns and habits over time. Being aware of this and trying to be flexible will make mealtimes less stressful for both of you.

If you think the person you care for may have health or dental problems, get help from your GP or dentist. You could also contact a local carers' group to speak to other people who may have experienced similar difficulties.

If the person with dementia smokes, replace matches with disposable lighters to lower the risk of them accidentally causing a fire.

If the person you care for drinks alcohol, check if this is recommended alongside any medication they make take. If in doubt, ask your GP (NHS, 2015m).

Dealing with incontinence in someone with dementia

Incontinence can be difficult to deal with and can be very upsetting for the person you care for. It's common for people with dementia to experience incontinence. This can be due to urinary tract infections, constipation causing added pressure on the bladder, or medication.

A person with dementia may also simply forget to go to the toilet, or may forget where the toilet is. They may also have lost the ability to tell when they need the toilet (NHS, 2015m).

How you can help

It's important to be understanding, retain a sense of humour and remember that it's not their fault. You may also want to try the following -

- Put a sign on the toilet door, such as a photo of the toilet.
- Keep the toilet door open and make sure that the person you care for can access it easily.
- Make sure they can remove their clothes - some people with dementia can struggle with buttons and zips.
- Look out for signs that they may need to go to the toilet, such as fidgeting and standing up and down.
- Get adaptations to the toilet if necessary - you may be able to get these through a care and support needs assessment (NHS, 2015m).

If you're still having problems with incontinence, ask your GP to refer you to a continence advisor, who can advise on things like waterproof bedding or incontinence pads (NHS, 2015m).

Helping someone with dementia with their personal hygiene

People with dementia can become anxious about certain aspects of personal hygiene and may need help with washing. For example, they may be scared of falling when getting out of the bath, or they may become disorientated in the shower.

The person you care for may not want to be left alone or they may resist washing, because they find the lack of privacy undignified and embarrassing. Try to do what's best for them (NHS, 2015m).

Helping someone with dementia sleep well

People with dementia often experience disturbed sleep. They may wake up during the night or be restless. These problems may get worse as the illness progresses. People with dementia may also have painful illnesses such as arthritis that cause, or contribute to, sleep problems.

Some medication can cause sleepiness during the day and interfere with sleep at night. Sleeping pills can be used with care in people with dementia.

However, ”sleep hygiene” measures are best for people with dementia - for example, no naps during the day, regular bedtimes, and avoiding alcohol or caffeine at night (NHS, 2015m).

Taking care of your own wellbeing

If you or a family member has dementia, you may find it difficult to stay positive. Remember that you are not alone, and that help and support is available. Talk to someone about your worries. This could be a family member or friend, a member of your local dementia support group, or your GP can refer you to a counsellor in your area.

It is important for a carer's physical health and psychological wellbeing that they are able to take a break (respite) from care. Carers may also need respite care if they have to go into hospital or meet other important commitments.

Friends, relatives and neighbours can provide respite care at home. You can also arrange home respite care through home care agencies or, in some areas, your local authority. Care away from home can confuse some people with dementia, both while they are away and when they come back. If you decide on respite care away from the person's home, it is a good idea to visit beforehand to check that it meets the needs of the person with dementia.

Caring for someone with dementia can be frustrating and stressful at times, but there are many organisations that can help. For more details, call the Carers Direct helpline on 0300 123 1053. Lines are open 9am–8pm Monday to Friday and 11am–4pm on weekends.

Reading Well Books on Prescription for dementia offers support for people diagnosed with dementia and their relatives and carers. GPs and other health professionals can recommend titles from a list of 25 books on dementia. The books are available for anyone to borrow for free from their local library.

Find out about the Reading Well Books on Prescription for dementia titles (NHS, 2015m).

Staying independent with dementia

Being diagnosed with dementia will have a big impact on your life. You and your family may worry about how long you can care for yourself, particularly if you live alone. People with dementia can remain independent for some time, but will need support from family and friends (NHS, 2015t).

Living at home when you have dementia

In the early stages of dementia, many people are able to look after their homes in the same way as before their diagnosis. However, as the illness gets worse, it is likely that someone who has dementia will find it difficult to look after their home and they may need help with daily activities, such as housework and shopping. The home of a person with dementia may also need to be adapted to enable them to stay safe, mobile and independent (NHS, 2015t).

Living alone with dementia

It's good to stay independent for as long as possible. Many people with dementia continue to live successfully on their own for some time. However, be aware that, as your condition progresses, you will need extra support to help you cope, and it's better to get this in place early.

Talk to family, friends and health professionals about how they can help you to stay independent. They can advise on how to cope with practical tasks, such as shopping. Find out about the local support services that can help you manage in your home - for example, by doing laundry and supervising meals (NHS, 2015t).

Working when you have dementia

Coping at work can be worrying for people with dementia. You should speak to your employer as soon as you feel ready. You can also get advice from the disability employment adviser at your local job centre, your trade union or your local Citizens Advice Bureau. If you decide to leave work, seek advice about your pensions and benefits.

You could continue to work or return to work by asking your employer if you can change your workload. Your local disability employment adviser can help and advise you (NHS, 2015t).

Driving

Some people with dementia prefer to give up driving because they find it stressful, but others continue driving for some time. To continue driving, you must inform the Driver and Vehicle Licensing Agency that you have dementia.

The DVLA will ask for medical reports and possibly a special driving assessment to decide whether you can continue driving.

Read more about driving and dementia on the Alzheimer's Society website.

People with dementia must give up driving when their symptoms become bad enough to make them unsafe on the road. This is to protect themselves, their passengers and other road users (NHS, 2015t).

Assistive technology for people with dementia

Assistive technology is available for people with dementia or other conditions that affect memory. AT Dementia is an organisation that provides access to technology aimed specifically at people with dementia, including -

- daily living aids - special utensils to help people eat and drink,
- stand-alone devices - aids that can be used without being linked to a monitoring centre or carer,
- telecare - sensors or detectors that automatically send a signal to a carer or monitoring centre by telephone; you can read more about telecare on the Carers Direct website (NHS, 2015t).

Chapter 14

Abuse and neglect

Contents

Everyone has the right to live in safety, free from abuse and neglect.

Abuse and neglect can occur anywhere: in your own home or a public place, while you are in hospital or attending a day centre, or in a college or care home.

You may be living alone or with others. The person causing the harm may be a stranger to you, but more often than not the person is known, and it can be the case that you usually feel safe with them. They are usually in a position of trust and power, such as a health and care professional, relative or neighbour (NHS, 2015b).

In 1993 'Action on Elder Abuse' established this definition of elder abuse -

> "A single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person"

This has been subsequently adopted by the World Health Organisation, is promoted by the International Network for the Prevention of Elder Abuse, and has been variously adopted by countries throughout the World, including the Republic of Ireland (with a slight addition).

Different forms of abuse and neglect

There are many forms of abuse and neglect, including -

Sexual abuse

One of the challenges of elder sexual abuse is that, because it is often denied, the opportunity to protect forensic evidence can be lost by the kindness of others who desire to make the older person comfortable instead of calling the police. It is important to establish the basic principle that sexual abuse is a crime, regardless of the age of a victim.

Very often the behaviour of an older person, even if they have confusion, will tell you that something is wrong. Having dementia does not always mean that someone cannot communicate, and it is possible that they can make their feelings known to you if you take the time to listen, observe and take notice. It is the capacity to believe that elder sexual abuse is possible, without seeing it everywhere, which will increase the potential to detect and respond to it when it happens (ELDERABUSE, 2015f).

This includes indecent exposure, sexual harassment, inappropriate looking or touching, as well as rape. Sexual teasing or innuendo, sexual photography, subjection to pornography, witnessing sexual acts, and sexual acts that you didn't agree to or were pressured into consenting to all count as sexual abuse (NHS, 2015b).

Some of the physical signs to watch for are -

- Bruises around the breasts or genital area,
- Unexplained venereal disease or genital infections,
- Unexplained vaginal or anal bleeding,
- Difficulty in walking or standing,
- Marked changes in behaviour,
- Torn, stained, or bloody underclothing,
- An older person telling you they have been sexually assaulted or raped (ELDERABUSE, 2015f).

Physical abuse

This can include being assaulted, hit, slapped, pushed, restrained, being denied food or water, or not being helped to go to the bathroom when you need to go. It can also include misuse of your medication (NHS, 2015b).

The signs of physical abuse are often evident but can also be hidden by the abuser or the victim. Any unexplained injuries should always be fully investigated. Evidence to look out for include -

- Cuts, lacerations, puncture wounds, open wounds, bruises, welts, discolouration, black eyes,
- burns, bone fractures, broken bones, and skull fractures,
- Untreated injuries in various stages of healing or not properly treated,
- Poor skin condition or poor skin hygiene,
- Dehydration and/or malnourished without illness-related cause,
- Loss of weight,
- Soiled clothing or bed,
- Broken eyeglasses/frames, physical signs of being subjected to punishment, or signs of being restrained,
- Inappropriate use of medication, overdosing or under-dosing,
- An older person telling you they have been hit, slapped, kicked, or mistreated (ELDERABUSE, 2015d).

Psychological abuse

This includes someone emotionally abusing you or threatening to hurt or abandon you, stopping you from seeing people, and humiliating, blaming, controlling, intimidating or harassing you. It also includes verbal abuse, cyber bullying and isolation, or an unreasonable and unjustified withdrawal of services or support networks (NHS, 2015b).

Psychological abuse can have a profound impact on someone's mental health; they can feel trapped, threatened, humiliated, used, or a combination of all these. Most signs therefore relate to someone's mental state, and changes in behaviour (ELDERABUSE, 2015e).

- Helplessness,
- Hesitation to talk openly,
- Implausible stories,
- Confusion or disorientation,
- Anger without apparent cause,
- Sudden change in behaviour,
- Emotionally upset or agitated,
- Unusual behaviour (sucking, biting, or rocking),
- Unexplained fear,
- Denial of a situation,
- Extremely withdrawn and non communicative or non responsive,
- An older person telling you they are being verbally or emotionally abused (ELDERABUSE, 2015e).

Domestic abuse

This is typically an incident or pattern of incidents of controlling, coercive or threatening behaviour, violence or abuse by someone who is, or has been, an intimate partner or family member (NHS, 2015b).

Discriminatory abuse

This includes some forms of harassment, slurs or similar unfair treatment relating to race, gender and gender identity, age, disability, sexual orientation, or religion (NHS, 2015b).

Financial abuse

This could be someone stealing money or other valuables from you, or it might be someone who is appointed to look after your money on your behalf using the money inappropriately or coercing you into spending it in a way you are not happy with. Internet scams and doorstep crime are also common forms of financial abuse (NHS, 2015b).

- Signatures on cheques etc., that do not resemble the older person's signature, or signed when the older person cannot write,
- Sudden changes in bank accounts, including unexplained withdrawals of large sums of money by a person accompanying the older person,
- The inclusion of additional unknown names on an older person's bank account,
- Abrupt changes to, or the sudden establishment of, wills,
- The sudden appearance of previously uninvolved relatives claiming their rights to an older person's affairs or possessions,
- The unexplained sudden transfer of assets to a family member or someone outside the family,
- Numerous unpaid bills, or overdue rent, when someone else is supposed to be paying the bills,
- Unusual concern by someone that an excessive amount of money is being expended on the care of the older person,
- Lack of amenities, such as TV, personal grooming items, appropriate clothing, that the older person should be able to afford,
- The unexplained disappearance of funds or valuable possessions such as art, silverware, or jewellery,
- Deliberate isolation of an older person from friends and family, resulting in the caregiver alone having total control (ELDERABUSE, 2015b).

Why does it happen?

Powers of Attorney -

On occasions banks and solicitors can unintentionally assist in the misuse of Enduring Powers of Attorney. Only a Lasting Power of Attorney needs to be registered with the Court of Protection before it is used and even then there is little to prevent a determined attorney from financially abusing an incapacitated donor. A useful first step if abuse is suspected is to contact by letter the bank of the donor and any estate agent involved - they will be able to let the solicitor know that someone is keeping a watching brief (ELDERABUSE, 2015b).

Neglect

Neglect is also a form of abuse. Neglect includes not being provided with enough food or the right kind of food, or not being taken proper care of. Leaving you without help to wash or change dirty or wet clothes, not getting you to a doctor when you need one, or not making sure you have the right medicines all count as neglect (NHS, 2015b).

Neglect will often manifest in the physical, social or health circumstances of the older person (ELDERABUSE, 2015c).

- Dirt, faecal or urine smell, or other health and safety hazards in older person's living environment,
- Rashes, sores, or lice on him/her,
- The Older person is inadequately clothed,
- The Older person is malnourished or dehydrated,
- The Older person has an untreated medical condition,
- The Older person has poor personal hygiene,
- There is evidence of the withholding of medication or over-medication of the Older Person,
- There is evidence of a lack of assistance with eating and drinking,
- There are unsanitary and unclean conditions (ELDERABUSE, 2015c).

Family abuse

It is important to consider family abuse from two perspectives: abuse that is perpetrated deliberately, and abuse that is not. This is particularly true when we consider neglect because one form of neglect can be intentional and one passive i.e. the 'perpetrator' is doing his or her best but cannot provide the level of care and support that is needed, sometimes because they don't know what care support is available and sometimes because the local authority does not provide the support that is needed. From the perspective of the older 'victim' of course the impact is the same, and they experience abuse.

Although we recognise the intense stress that can be involved in providing personal care to a family member, very often this will have a detrimental impact on the carer themselves rather than necessarily manifest as elder abuse (ELDERABUSE, 2015a).

Where abuse is intentional it is likely that the following signs will be apparent -

- The older person may not be allowed to speak for themselves, or see others, without the presence of the family member (suspected abuser) being present,
- They may display attitudes of indifference or anger toward the older person, or the obvious absence of assistance,
- a Family member may blame the elder person (e.g. accusation that incontinence is a deliberate act),
- They may display aggressive behaviour (threats, insults, harassment) toward the older person,
- They may have a previous history of abuse of others,
- They may display inappropriate affection toward the older person,
- They may display flirtatious behaviour, or coyness, etc that might be possible indicators of inappropriate sexual relationships,
- They may create social isolation of the family, or isolation or restriction of activity of the older person,
- There may be conflicting accounts of incidents by family, supporters, or the older person,
- They may display inappropriate or unwarranted defensiveness,
- There may be indications of unusual confinement (closed off in a room; tied to furniture; change in routine activity),
- There may be the obvious absence of assistance, or attendance (ELDERABUSE, 2015a).

A point to remember

A major point to remember - whether you are personally coping with abuse or whether you are concerned about the abuse of another - is that you are not alone. Abusers very often exploit the fact that someone may be (or feel) isolated. They can encourage, emphasise or create dependency in someone in order to exploit that feeling to their own advantage. And, very often, they will rely on someone not disclosing, or the natural disbelief that many people hold when considering elder abuse.

It is important therefore to protect yourself if you are an older person, and sometimes that can be very simple. It is also important that neighbours, friends, families and doctors are alert to the possibility of abuse - and are therefore ready to act on concerns or suspicions. Too often abuse has continued because people spotted something that felt wrong, but took no action as they doubted their own concerns. And sometimes the abuse has then continued for years longer. Being alert to the possibility of abuse is sensible, without needlessly seeing it everywhere. Being prepared to act is prudent (ELDERABUSE, 2015g).

Concerned for yourself

It is not easy sometimes to accept that you are being abused, and it can be even more difficult to tell someone else. Sometimes this is because the person who is doing it is a close family member or a friend, and sometimes it is because you think people will laugh at you or ridicule you or it will affect how your community or friends think about you. It is often for these sorts of reasons that abuse goes unchallenged.

A good place to start therefore is to ring the helpline if you can. Our number (080 8808 8141) will not appear on your telephone bill, and our staff and volunteers understand the difficulties you might face and the options you may be able to consider. They will work things out with you, and you will never be asked to do anything that you feel unable to do. We will always seek to respect your confidentiality, but there may be rare occasions when this is not possible (for example, if the abuse you are experiencing might affect other people too) (ELDERABUSE, 2015g).

Things to think about.

If you feel that you might be at risk of abuse you should consider the following actions, which might help to reduce that risk. Often abusers are only successful because they keep you quiet or stop others from finding out what is happening to you. It is therefore wise to -

- Maintain contact with any friends or neighbours that you have known for a long time and who you are confident can be trusted,
- Keep in contact with those friends and neighbours if you move to a new address. If you cannot go to see them, try to write letters regularly telling them about your new life and what is happening to you,
- Encourage friends to visit you at home and try to join a local group or club. The more interaction you have with other people the less chance there will be for you to become isolated,
- Have regular medical or dental appointments. Dentists and GP's are people who should be able to talk to you, or spot signs that you are being abused,
- Make sure that people are aware that you know where you have put important documents or property, and always open and post your own mail. If you have to rely on others to post your own mail then try to use more

than one person. Don't leave cash, jewellery, or valuable possessions lying about,
- Talk to a lawyer about arrangements that you can make for any future possible disabilities or problems, and always get legal advice before making arrangements for someone to take care of you in exchange for your property, possessions, or money. Don't allow anyone to keep from you the details of your finances or property management,
- Don't sign anything unless it has been checked by someone not involved and independent of the issue.
- If someone asks you to sign a Power of Attorney, always get independent advice to make sure you understand what it means (ELDERABUSE, 2015g).

Concerned for someone else?

Try to speak to the older person about what you have noticed, being as open and honest as possible. Give the older person the opportunity to talk and listen carefully to what they tell you, offering to seek help if that is appropriate. Some people may want to talk but may be worried about how you might react so it is important to stay calm if they begin telling you that they have been abused. Some people may ask you to promise not to tell anyone else about the abuse. Whether you are a doctor, friend or relative, you should always be honest and never make false promises - sometimes the abuse might affect more than one person and you will have a responsibility to other people too.

You must remember that an older person is an adult, and should never be treated like a child, even if they appear confused and disoriented (he or she can still react to what you are saying and how you say it). Try not to take over or be over-protective, and remember that you should not lead someone into saying something. Try to balance the need of the older person to be heard with the need to ensure you do not prejudice future action, such as a police or disciplinary investigation.

If it is appropriate, try to explain simply the sort of people who might be able to help e.g. Health or social care professionals (such as a GP), police, home carers, care-home employees, volunteers and advocates. Perhaps offer to approach one of these on the person's behalf. Ask what they want you to do.

Remember that in some minority communities there is great stigma associated with abuse by family members and it is not always true that the older person would prefer to talk to someone from their own community. This may in fact be the last thing that they want, so never seek to use a family friend, neighbour or similar as an interpreter. Seek such services from an organisation unknown to the older person.

If you were correct in your concerns or still have strong suspicions, you can talk to the Action on Elders Abuse helpline on 080 8808 8141 and seek advice. If you work in health or social care you should speak to your line manager immediately - and remember that you have a professional relationship with the older person. This means that matters of this nature are disclosed to you as a representative of your organisation. If you suspect your line manager is the abuser then speak to someone in Human Resources or to another more senior manager. Do not keep it to yourself (ELDERABUSE, 2015g).

Abuse in your home

Risk

You're more at risk of abuse at home if -

- you are isolated and don't have much contact with friends, family or neighbours,
- you have memory problems or have difficulty communicating,
- you become dependent on someone as a carer,
- you don't get on with your main carer,
- your carer is addicted to drugs or alcohol,
- your carer relies on you for a home, or financial and emotional support (NHS, 2015b).

There are many reasons why elder abuse occurs and these may vary with each incident. In some circumstances it is an spontaneous act, perpetrated by someone who takes advantage of an opportunity that arises. In other cases it is premeditated and calculated. In still other situations it is caused by prejudices or by the environment that creates institutional attitudes and approaches. In all cases there is an element of power and control exercised by the perpetrator over the abuser.

Some abuse however is caused by ignorance, lack of skills or lack of external support. This is particularly the cases with passive neglect, where there is no intent to harm but is caused by unintentional failures. The impact on the older person however is always significant and is always defined by Action on Elder Abuse (AEA) as abuse, regardless of the motivation or intent of the perpetrator (ELDERABUSE, 2015h).

Causes

- poor quality long term relationships,
- a carer's inability to provide the level of care required,
- a pattern of family violence exists or has existed in the past,
- a carer has mental or physical health problems,
- the social isolation of a family member (ELDERABUSE, 2015h).

Abuse within a family situation can be the most challenging to address and needs a mixture of tact, sensitivity, understanding and robustness. It is often difficult for an older person to believe, or to admit, that they are being abused by a member of their own family (ELDERABUSE, 2015h).

I think I am being abused or neglected: what can I do?

Who to talk to if you feel you are being abused or neglected -

- Don't worry about making a fuss - tell someone you trust as soon as possible.
- Speak to friends or careworkers, who may have an understanding of the situation and be able to take steps quickly to improve the situation.
- You can also talk to professionals such as your GP or social worker about your concerns, or you could ask to speak to your local council's Adult Safeguarding team or co-ordinator.
- Call Action on Elder Abuse 0808 808 8141 for advice.
- If you believe a crime is being, or has been, committed - whether it's physical abuse or financial - talk to the police or ask someone you trust to do so on your behalf. (NHS, 2015b).

Spotting signs of elder abuse: advice for carers

It's not always easy to spot the symptoms of abuse. Someone being abused may make excuses for why they're bruised, they don't want to go out or talk to people, or they're short of money.

It's important to know the signs of abuse and, where they are identified, gently share your concerns with the person being abused. If you wait, hoping the person will tell you what's been happening to them, you could delay matters and allow the abuse to continue.

It's not always easy to spot the symptoms of abuse. Someone being abused may make excuses for why they're bruised, they don't want to go out or talk to people, or they're short of money.

It's important to know the signs of abuse and, where they are identified, gently share your concerns with the person being abused. If you wait, hoping the person will tell you what's been happening to them, you could delay matters and allow the abuse to continue. (NHS, 2015b).

Behavioural signs of abuse in an older person include them -

- becoming quiet and withdrawn,
- being aggressive or angry for no obvious reason,
- looking unkempt, dirty or thinner than usual,
- sudden changes in their normal character, such as appearing helpless, depressed or tearful,
- physical signs of abuse, such as bruises, wounds, fractures and other untreated injuries,
- the same injuries happening more than once,
- not wanting to be left on their own or alone with particular people,
- being unusually lighthearted and insisting there's nothing wrong (NHS, 2015b).

Additionally, their home may lack heat, be unusually dirty or untidy, or you might notice things missing.

Other signs to watch out for include a sudden change in their finances, not having as much money as usual to pay for shopping or regular outings, or getting into debt. Watch out for any official or financial documents that seem unusual, and for documents relating to their finances that suddenly go missing.

If you feel someone you know is showing signs of abuse, talk to them to see if there's anything you can do to help. If they're being abused, they may not want to talk about it straight away, especially if they've become used to making excuses for their injuries or change in personality.

Don't ignore your concerns, though. That could allow any abuse to carry on or escalate (NHS, 2015b).

I'm worried about someone who may be experiencing abuse or neglect. What should I do?

Start by talking to the person in private if you feel able to do so. Mention some of the things that concern you – for instance, that they've become depressed and withdrawn, have been losing weight, or seem to be short of money.

Let them talk as much as they want to, but be mindful that if they've been abused, they may be reluctant to talk about it because they're afraid of making the situation worse, because they don't want to cause trouble or they might be experiencing coercion by someone or being threatened in some way.

It's best not to promise the person you won't tell anyone what you've heard. If an adult is being abused or neglected, it's important to find help for them and stop the harm. Stay calm while the person is talking, even if you're upset by what you hear, otherwise they may become more upset themselves and stop telling you what's been going on.

It can be very difficult for an abused or neglected person to talk about what's been happening to them. Unless you're concerned for their immediate health and safety and feel it's vital to act straight away, give them time to think about what they'd like to do.

If you're right and the person has been abused or neglected, ask them what they'd like you to do. Let them know who can help them. Say you can seek some help on their behalf if they want or if it's difficult for them to do so themselves. It's important to listen to what they say and not to charge into action if this isn't what they want (NHS, 2015b).

Who to contact about elder abuse

If an adult has told you about their situation, you might want to talk to other people who know the person you're worried about to find out if they have similar concerns.

There are also professionals you can contact. You can pass on your concerns to the person's GP and social worker. Local authorities have social workers who deal specifically with cases of abuse and neglect. Call the person's local council and ask for the adult safeguarding co-ordinator.

You can also speak to the police about the situation. Some forms of abuse are crimes, so the police will be interested. If the person is in danger or needs medical attention, call their GP if known or emergency services if immediate assistance is required.

You can also call the Action on Elder Abuse helpline, free and in confidence, on 0808 808 8141 (NHS, 2015b).

Chapter 15

Other conditions

Contents

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Complementary and alternative therapy

What are they?

A complementary therapy is one that can be used in addition to, or instead of, conventional western medicine.

An alternative therapy often claims to be a complete system, which can be used instead of conventional western medicine.

Complementary and alternative approaches share a belief in the body's ability to heal itself. Some of them use an understanding of the working of the body which is not studied by practitioners of conventional medicine, based on Eastern understandings of energy meridians and fields.

Usually such treatments are tailored to the individual, and do not use a 'one size fits all' approach. This means that they are rarely tested by conventional randomised controlled trials, and therefore are not regarded as ’evidence-based’, and so few of them are recommended by the National Institute of Health and Care Excellence (NICE) or available on the NHS.

However, many people choose to use them and find them helpful. Most treatments are non-invasive and they rarely cause the unpleasant or long-lasting side-effects that can be associated with medication. The practitioner commits more time to the client than a GP is usually able to do.

I cannot endorse any of these therapies, but I know that many people who have mental health problems consider trying them and would like to know more about them. Here I shall include information about some of the therapies that are available; there are many others.

I suggest that you seek the advice of a professional trained in the therapy you are considering, and a person involved in your care if you are thinking about changing or starting a treatment (MIND, 2016a).

Different therapies

Acupuncture

The underlying principle of treatment is that illness and pain occur when the body’s qi, or vital energy, cannot flow freely. There can be many reasons for this; emotional and physical stress, poor nutrition, infection or injury are among the most common. Mental ill-health is equally viewed as one way in which imbalance can exist within the body. By inserting ultra-fine sterile needles into specific acupuncture points, a traditional acupuncturist seeks to re-establish the free flow of qi to restore balance and trigger the body’s natural healing response. Acupuncture is approved by NICE (the National Institute for Health and Care Excellence) as a treatment for lower back pain (MIND, 2016a).

- British Medical Acupuncture Society
  01606 786782 or 020 7713 9437
  medical-acupuncture.co.uk
  Encourages the use and scientific understanding of acupuncture. List of practitioners.
- British Acupuncture Council
  020 8735 0400
  acupuncture.org.uk
  Largest body of professional acupuncturists. List of practitioners.
- National Acupunture Detoxification Association
  nadauk.com

Focus on ear acupuncture for drug and alcohol addiction and trauma (MIND, 2016a).

Aromatherapy

Aromatherapy is the systematic use of essential oils to improve physical and emotional well-being. Essential oils, extracted from plants, are thought to possess distinctive therapeutic properties.

The oils can be applied through creams, inhalation, massage or by adding drops to a warm bath. Aromatherapy massage involves a gentle massage, using essential oils diluted with a nut or vegetable oil, such as almond.

- Aromatherapy Council
  aromatherapycouncil.co.uk
  List of practitioners (MIND, 2016a).

Bowen technique

Bowen is a contact therapy, but is not massage, nor manipulation. It uses a very light touch at certain points on the skin, and can be done through light clothing. It can help both physical and emotional problems.

- The Bowen Association UK
  bowen-technique.co.uk
  List of practitioners (MIND, 2016a).

Herbal remedies

Herbal medicine uses plants, in many forms, to promote good health and to treat ill health. The main types of herbal medicine are Western, Chinese, and Ayurvedic.

Some people turn to herbal medicines because they feel plants are more natural than medication and believe herbs are likely to have fewer side-effects. Many medications are derived from plants, and it is important to remember that some herbs can be very poisonous, including some that are the basis of medicines (MIND, 2016a).

Herbal medicine (western)

Western herbal medicines can be used to treat health problems in a similar manner to conventional medicine, but the herbal practitioner will usually take a holistic, rather than an illness-focused, approach. While many herbal medicines are commercially available and registered by the Medicines and Healthcare products Regulatory Agency, many practitioners will make their own preparations from fresh or dried plants (MIND, 2016a).

- British Herbal Medicine Association
  0845 680 1134
  bhma.info
  Information about herbal medicine (MIND, 2016a).
- National Institute of Medical Herbalists
  01392 426022
  nimh.org.uk
  Register of herbalists (MIND, 2016a).

Ayurvedic

Ayurvedic medicine is based on ancient Indian theory and uses medicines made from plants and minerals aiming to restore balance in the body (MIND, 2016a).

- Ayurvedic Practitioners Association
  apa.uk.com
  Information and list of practitioners (MIND, 2016a).

Chinese herbal medicine

See Traditional Chinese medicine (TCM) (MIND, 2016a).

Massage

Massage uses touch in a sensitive and respectful way, taking account of physical symptoms, mental, emotional and spiritual well-being, and your lifestyle. Understanding the context in which problems develop is as important as looking for the symptoms (MIND, 2016a).

- Massage Therapy UK
  massagetherapy.co.uk
  Information on the main types of massage available and UK directory of practitioners (MIND, 2016a).

Reflexology

Reflexology is based on the principles of 'zone therapy' (similar to the meridians or energy pathways) and the theory that the body's energy field is a hologram, and every organ and system of the body has a counterpart in reflex points in the feet, hands and ears. Practitioners mainly work on the feet (MIND, 2016a).

- Association of Reflexologists
  aor.org.uk
  Information and list of practitioners (MIND, 2016a).
- British Reflexology Association
  britreflex.co.uk
  Information and list of practitioners (MIND, 2016a).

Shiatsu

Traditional Japanese massage which, like acupuncture, works by stimulating and balancing the body's energy flow along 'meridians' or energy pathways. The practitioner uses techniques such as holding, pressing, and stretching, to balance Ki or Qi (energy) in the body (MIND, 2016a).

- Shiatsu Society
  0845 130 4560
  shiatsu.org
  Information and list of practitioners (MIND, 2016a).

Nutritional therapy

Nutritional therapy uses the science of nutrition and diet to promote good health. It may help alleviate a wide range of conditions and assist in recovery. Each person's needs may be dependent on a number of factors, from inherited weaknesses to the influence of lifestyle and environment.

In addition to dietary and nutritional advice, recommendations may include guidance on natural detoxification, methods to support digestion and absorption, and procedures to promote colon health (MIND, 2016a).

- British Association for Applied Nutrition and Nutritional Therapy (BANT)
  bant.org.uk
  List of practitioners (MIND, 2016a).
- Nutritional Therapy Council
  nutritionaltherapycouncil.org.uk (MIND, 2016a).

- Food for the Brain
  foodforthebrain.org
  Charity promoting research and information on diet in relation to mental health (MIND, 2016a).

Traditional Chinese medicine (TCM)

Traditional Chinese medicine (TCM) has been the main medical system used in China for more than 2,000 years. It is based on a different understanding of the body from conventional western medicine, and aims to rebalance the body's energy systems.

In Chinese herbal medicine, treatments are prepared from fresh and dried materials and minerals.

TCM also includes acupunture and tuina, a form of massage (MIND, 2016a).

- Association of Traditional Chinese Medicine
  atcm.co.uk
  Information and list of practitioners (MIND, 2016a).

Yoga and meditation

Yoga and Meditation practices may include: posture work, breath work, reflection, use of sound and short supportive phrases, and visualisation.

Yoga, in its most general sense, it is a spiritual practice designed to increase awareness and self-knowledge, so that you can be freed from old behaviour patterns. The exercises can lead to greater physical and mental freedom, and to greater control over the body and thought processes (MIND, 2016a).

- British Wheel of Yoga
  01529 306851
  bwy.org.uk (MIND, 2016a).
- Iyengar Yoga Institute
  iyi.org.uk (MIND, 2016a).
- Laughter Yoga
  laughteryoga.org (MIND, 2016a).

Meditation

Meditation encourages you to be still and at rest. There are various different techniques and schools of mediation, based in different philosophies, but all aim to quieten your mind and put you into a state of calm and stillness.

- School of Meditation
  020 7603 6116
  schoolofmeditation.org (MIND, 2016a).

Regulation

- Complementary and Natural Healthcare Council
  Albert Buildings
  49 Queen Victoria Street
  London
  EC4N 4SA
  020 7653 1971
  cnhc.org.uk (MIND, 2016a).

The Complementary and Natural Healthcare Council (CNHC) was set up with government support as the voluntary regulator for complementary healthcare. Practitioners register with the CNHC and go onto a public register.

The government has recommended that GPs recommend CNHC registered practitioners to patients who wish to use these approaches. The CNHC has a list of the therapies that are registered with them (MIND, 2016a).

- The Health and Care Professions Council (HCPC)
  Park House
  184 Kennington Park Road
  London
  SE11 4BU
  0845 300 6184
  hcpc-UK.org (MIND, 2016a).

Keep a register of health professionals who meet their standards for their training, professional skills, behaviour and health. Regulate 15 health professions including arts therapists (MIND, 2016a).

Other forms of regulation

Some therapies have professional associations which are membership organisations. They provide a range of benefits and services for practitioners and act in the interests of the profession. Most have their own codes of practice and registers of professionals who work to those.

If you are thinking about going to a complementary or alternative practitioner, it is always a good idea to ask about their qualifications, professional registration and code of practice before starting a course of treatment (MIND, 2016a).

Confusion

Confusion has a very specific meaning in medical terminology, read on to learn more.

Being in a state of confusion means not being able to think clearly or quickly, feeling disorientated, and struggling to pay attention, make decisions, or remember things.

However, the medical terminology is 'having disturbed orientation in regard to time, place, or person.' A simple test for confusion is to ask the person their name, age and today's date, and see if they seem unsure or answer incorrectly. People do not generally see the distinction between a definition of 'muddled thinking' and the medical definition.

It's understandable to fear the worst and assume it's a sign of dementia - but if the confusion came on over a short period of time (acute confusion), dementia is unlikely to be the sole cause (NHS, 2015d).

What to do if someone is showing signs of confusion

If the confusion has come on suddenly, take them to your nearest hospital or call 999 for an ambulance, especially if they're showing other signs of illness such as a fever, or their skin or lips are turning blue (NHS, 2015d).

If the person is diabetic...

If the person is diabetic, check their blood sugar level. You can check this if they have a testing device with them. You'll need to prick their finger with the device and place the droplet of blood on the testing strip. Compare the reading with these target blood sugar levels (NHS, 2015d).

- **If the reading is high**, take them to hospital or call 999.
- **If the reading is low**, give them a sugary snack or drink. Wait 10 minutes to see if they recover. If they don't, take them to hospital or call 999 (NHS, 2015d).

While you wait for the ambulance

- **Stay with them**. Introduce yourself if you need to, reassure them, and remind them where they are at regular intervals.
- **Check the person's medication cupboard** - if in their home - and make a note of what drugs they're taking.
- **Ask if any other family members have been unwell**, to check whether carbon monoxide poisoning could be a possible cause of the confusion (NHS, 2015d).

Common causes of sudden confusion

The most common causes of sudden confusion are -

- **a lack of oxygen in the blood (hypoxia)** - the cause could be anything from a severe asthma attack to a problem with the lungs or heart,
- **an infection** anywhere in the body, especially in elderly people,
- **a stroke or TIA ("mini stroke")**,
- **a low blood sugar level (hypoglycaemia)**,
- **diabetic ketoacidosis**, a serious complication of diabetes caused by a lack of insulin in the body,
- **certain medications**, including digoxin, diuretics, steroids, and opiates,
- **alcohol poisoning** or alcohol withdrawal,
- **drug misuse** (NHS, 2015d).

This information should give you a better idea of the cause of someone's confusion, but shouldn't be used as a diagnostic tool. Always see your doctor for a proper diagnosis (NHS, 2015d).

More unusual causes of sudden confusion

Less common causes of sudden confusion are -

- an infection of the brain or its lining (encephalitis or meningitis),

- an imbalance of salts and minerals in the blood,
- a severely underactive thyroid gland,
- thiamine (vitamin B1) deficiency,
- a brain tumour,
- hypoparathyroidism or hyperparathyroidism (rare hormone disorders),
- Cushing's disease (a tumour of the pituitary gland),
- an epileptic seizure,
- carbon monoxide poisoning (NHS, 2015d).

How to stay safe online

Overview

Explains how to keep yourself safe and look after your wellbeing when you use the internet for information or support for your mental health. It covers protecting your privacy, how to take relationships offline safely and how to address online bullying and abuse (MIND, 2015).

How can online resources help?

Using online resources can be a great way to support your mental health. For example, you might want to -

- find information about mental health topics,
- research different options for treatment and support,
- learn about other people's experiences of mental health problems, and share your own,
- connect with new people and build your support network of friends (MIND, 2015).

While the internet can be useful, it also has its dangers. Whatever you're using the internet for, it's important to think about how best to look after your mental health online, and how to keep yourself safe (MIND, 2015).

What information can I trust?

How do I find reliable health information online?

Not everything you read about mental health on the internet will be reliable. Anyone can post content online, so it's important to think about where it's coming from. Some useful questions to ask yourself when you read online content are -

- Is this factual information or is it someone's personal experience or opinion?
- Who has written it? Are they a reliable source?
- Is it up to date? When was it written?
- Is it relevant to my situation? (MIND, 2015)

If you're looking for information about mental health online, it's a good idea to use well-known sources like Mind or NHS Choices, which are certified by the Information Standard [62] (MIND, 2015).

How do I find reliable health care online?

You might want to use the internet to search for professional treatment and support, such as talking treatments or psychiatric medication. It's your choice how you seek treatment, but when searching for professional help online it's important to bear the following points in mind.

- **GP appointments** - if you want professional treatment for a mental health problem, the best place to start is usually by talking to your GP. The NHS provides an online tool for finding NHS GP practices near you, which you can access through their website here.
- **Talking treatments** - there are some people online who call themselves therapists, but who do not have any qualifications or training. If you're looking for a therapist online it's a good idea to -
  - search through a professional website such as the BACP, rather than through a general search engine such as Google.
  - ask them about their professional qualifications and training before receiving any treatment; you can check these with their professional body.
- **Medication** - you should only ever buy medication online from a registered pharmacy; do not trust any website that sells prescription drugs without a legitimate prescription (MIND, 2015).

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[62] an independent quality mark of good practice in health information

Can I trust other people's advice?

You might find it useful to use the internet to learn about other people's experiences of something you're also going through, or to seek advice from peers. It can help you -

- discover coping strategies,
- become part of a community,
- feel comforted or less alone (MIND, 2015).

However, when making decisions about what's right for you, it's important to keep the following in mind -

- **What's true for someone else might not be true for you**. For example, you might read that someone else found a particular talking treatment or medication helpful in managing their mental health condition, or that they experienced a particular side-effect. But everyone is different; the same treatment might not work the same way for you, or at all - even if you have the same diagnosis.
- **When someone states something as a fact, it might just be their opinion**. It's up to you to judge how reliable their opinion is, and how relevant it is to your situation.
- **Reading other people's comments might sometimes make you feel worse**. For example, you might come across blogs expressing opinions which you find upsetting or with content that you find triggering, or you might be given advice which isn't actually suitable for you (MIND, 2015).

How can I find support online?

There are lot of ways to get support for your mental health online. Here we consider some things to be aware of when you use -

- Social media,
- Blogs and vlogs,
- Online community forums,
- Chat rooms,
- Private messaging (MIND, 2015).

Even if you don't go online to actively get support for your mental health problem, you might find that you get more support than you realise from the social interactions and friendships you build. If you find that a particular online community or group isn't helpful for you at all, that doesn't necessarily mean that you can't find support anywhere online - you might just need to try a few different things (MIND, 2015).

Social media

Social media sites can be quite different from each other - they might attract different groups of people and can feel like very different online environments. Sites include -

- Facebook,
- Twitter,
- Tumblr,
- Instagram (MIND, 2015).

Pros

- Lots of people use this type of community so it might be a good place to stay in touch with friends and family.
- Social networks let you set your own privacy settings, so you have more control over who you interact with.
- There are often ways of meeting or interacting with new people (e.g. hashtags or groups) (MIND, 2015).

Cons

- They have a low level of moderation, and the people who run the site might not be easy to get in touch with if you have a question or problem.
- You might sometimes find seeing so many people's updates overwhelming or upsetting, especially if you're not feeling very well (MIND, 2015).

Blogs and vlogs

Blogs and vlogs (video blogs) are channels which individuals, groups and organisations use to publish articles they've written or videos they've created. They're usually centred around a particular topic or theme. Sites include -

- Youtube,
- Wordpress,
- Blogspot (MIND, 2015).

Pros

- Communities can develop around a particular person or organisation's blog - for example, in the comments section.
- Talking to people you meet in this way can mean you share an interest (MIND, 2015).

Cons

- Comments sections might sometimes be unmoderated so may be less safe to use.
- All your posts will be public so you may need to be careful about what you post.
- It's possible that an individual could decide to stop blogging (MIND, 2015).

Online community forums

There are lots of different forms online that can be general or based around a specific topic, for example a band or local area. There are also mental health specific forums and communities like -

- Elefriends
- Big White Wall
- Black Dog Tribe (MIND, 2015).

This is sometimes called online peer support (MIND, 2015).

Pros

- Mental health specific forums might have a higher level of moderation when it comes to triggering content or disagreements, which means you might feel safer.
- Members of these communities will usually have experience of mental health problems, so you can to talk to people who might be more likely to understand what you're going through.
- Posts are normally saved, so you can look at previous posts if you want to.
- Your posts can be any length you like (MIND, 2015).

Cons

- There is usually a sign up process, so you will need an email address.

- Your comments or posts might be removed by the moderators if they're deemed inappropriate or potentially triggering to other people.
- Conversations often happen over days or weeks as people return to a topic.
- People using these kinds of forums will often be struggling with their mental health themselves. This means updates and conversations can be around difficult issues which you might find upsetting or triggering (MIND, 2015).

Chat rooms

There are lots of different chat rooms available online, hosted by lots of different organisations (MIND, 2015).

Pros

- There is usually not a sign up process and it is therefore quick and easy to use.
- They're usually completely anonymous, which you might find makes it easier for you to talk to people (MIND, 2015).

Cons

- They're not usually moderated.
- There's a high risk of some people posting irresponsible or inappropriate content in chat rooms, because they're anonymous and unmoderated.
- Posts are not usually saved so you can't look back at previous conversations. Interactions move very quickly, so they may not be suitable if you want to build lasting friendships or have a conversation over time (MIND, 2015).

Private messaging

Private messaging can feel similar to text messaging someone or calling them up on your phone, but it's usually conducted online using apps, such as -

- Whatsapp
- Facebook messenger
- Skype (MIND, 2015).

Pros

- You can stay in contact with people you know without the costs associated with texts or phone calls.
- Some apps let you communicate in fun or innovative ways (MIND, 2015).

Cons

- With some apps, you can only communicate with someone if you have their phone number. If you don't know the other person well, you might not feel comfortable with this.
- You might feel like you should always be available via private messaging, or that you always have to respond to messages right away, which can feel overwhelming (MIND, 2015).

Staying well online

We all need to look after our mental wellbeing, and this is true online too. This section provides guidance on -

- Dealing with upsetting content,
- Managing online relationships,
- Noticing when your online activity isn't helpful,
- Maintaining your online-offline balance
- Getting further support (MIND, 2015).

Dealing with upsetting content

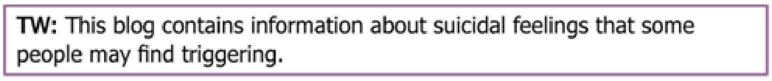
It's possible that you might come across some articles, videos or images online that you could find distressing, or that might trigger negative feelings or behaviour - even if you're on a site you usually find helpful. For example, a blog that talks explicitly about self-harm may make you feel the urge to harm yourself, or a post on a social network about someone else's experience of depression may make you feel low yourself. Remember -

- **Avoid sites and feeds you know you might find triggering**.
- **Try to be aware of how you're feeling** when you're online. For example, if you're not feeling well, you might be more vulnerable to things you'd normally be able to deal with.

- **If you do see something that upsets you, close the window** or scroll quickly past it. You might even want to turn off your computer and take a break.
- **Consider whether your posts could be triggering for other people**, and think about using trigger warnings so that they can decide whether or not they want to view them. Try and be specific about why the content might be triggering, so that they have all the information they need to make a decision. If it's very likely to be triggering, you may want to consider not posting it at all (MIND, 2015).

What's a trigger warning?

You might come across trigger warnings online (sometimes shortened to 'TW' or 'tw'). This is a way of warning others that a post or page is going to contain some content that could be upsetting or triggering. The purpose of using trigger warnings is to help everyone keep themselves safe online. For example -



TW: This blog contains information about suicidal feelings that some people may find triggering.

Figure 15.1: Trigger warning

If you see a trigger warning, think carefully about whether you still want to read the content (MIND, 2015).

Managing online relationships

Sometimes when we're online, we can forget we're actually talking to real people. Although it's possible to make great friendships online, not every person you meet will be someone you get on with - just like in offline life. Remember -

- **Don't say anything online that you wouldn't say to someone face-to-face**. It might feel easy to say whatever you want from behind a screen but try to think about how your words could affect people, as you'd want them to do for you.
- **Try not to read too much into things**. Misunderstandings can happen easily online because the signs we use during face-to-face conversation, such as tone of voice or body language, aren't available online. It's easy for someone to hit 'send' before thinking how what they've written may come across to you.

- **Try to give other people the benefit of the doubt**. If you're not sure about what someone means by what they've written, ask them to clarify.
- **Be respectful of other people's views and opinions** - even if you don't share them.
- **You can't always expect an immediate response**. People may not be online all the time, so they may not be able to respond straight away.
- **Be careful about how much you share with people** you don't know well.
- **Don't tolerate online abuse or bullying** Bullying and abuse (MIND, 2015).

Noticing when your online activity isn't helpful

While it can be a huge comfort to talk to people experiencing the same sorts of issues as you, sometimes this kind of interaction can stop being helpful for you (MIND, 2015).

Take a moment to ask yourself -

- **Do the people you connect with online share the same motivation as you**, or do they have different goals? For example, if you have an eating problem and are looking online for positive ways to challenge those thoughts and feelings, connecting with people who aren't ready to seek support for their own problems might not help.
- **How much time are you spending giving support to other people online**, and how is this impacting your own wellbeing? Being a friend to other people can feel great, but caring for someone who's going through a difficult time can also be very stressful, and could affect your own wellbeing.
- **How long have you been using a particular kind of online support**, and has it made you feel better or worse overall? (MIND, 2015)

It's important to put your own safety and wellbeing first. If you notice that a certain online environment has stopped being a positive thing in your life, you might want to think about taking a break from it (MIND, 2015).

Maintaining your online-offline balance

Sometimes getting support online isn't always the best way to look after yourself, especially if the amount of time you're spending online is starting to have a negative impact on your offline relationships and responsibilities. It's important to try to find a balance (MIND, 2015).

Try using these tips -

- **Try switching off your phone, computer and any other mobile devices**, so you aren't tempted to check in online. You could start by giving yourself short, timed breaks, such as 10 minutes at a time, and build up to taking longer breaks away from your screen.
- **Set aside some time each day to do something else**, like reading a book, doing some physical exercise or trying out a relaxation technique.
- **Protect time in your day to eat healthily and get good sleep**.
- **Think about taking a longer break from online activity**, especially if you're going through a difficult time with your mental health (MIND, 2015).

Getting further support

Sometimes online support can't realistically give us all the help we want. If you find that things are becoming too much for you to cope with, or are worried about the way you are feeling or behaving, you may want to get additional support offline. You can -

- **Talk to a close friend or family member** in person about how you're feeling.
- **Make an appointment to talk to your GP** about your mental health.
- Contact your local Mind to see what support they might be able to offer.
- Make sure you know how to get help in a crisis (MIND, 2015).

How can I protect my privacy?

As we share more and more of our lives online, it's important to make sure we protect our privacy and prevent people from accessing private information about ourselves. You can -

- Check your privacy settings,
- Use secure passwords,
- Protect your personal details,
- Think about who will see your post,
- Be extra careful with sexually explicit content,
- Don't break the law (MIND, 2015).

What is private information?

Private information is anything you might not want other people to see. That might include -

- **Personal details** like where you live, work or study.
- **Financial details**, like your bank account or credit card details.
- **Personal photos**, including pictures of your friends, family, or sexually explicit photos.
- **Sensitive information**, for example about your health, sexual orientation or religious beliefs.
- **Confidential information**, for example information from your workplace.
- **Your personal opinion**, which could be anything from political comments to jokes or complaints (MIND, 2015).

Check your privacy settings

Make sure you are aware of how private a site or community is. Just because a site requires you to log in, this doesn't necessarily mean that your profile is entirely private – some parts might still be shown publicly. You can -

- **Read the website's privacy policy** to know how your information will and won't be used.
- **Control the level of privacy** you have on some sites, so you can decide who can see what you post (DEPRESSIONALLIANCE, 2016c).

Use secure passwords

It's important to have a secure password whatever kind of site you're using. It's a good idea to -

- change your password regularly,
- always log out when you're away from your computer, tablet or phone,
- change your password immediately if you think someone has accessed your account without your permission (MIND, 2015).

Websites like Get Safe Online and Know the Net can tell you more about how to choose a secure password (MIND, 2015).

Protect your personal details

What you share online can affect both your privacy and the privacy of others, so it's important to think carefully about what you post (MIND, 2015).

- **Don't post personal details anywhere public**, for example on Facebook or Twitter. (This includes details such as your phone number, address or bank details.)
- **Be careful when sending someone your bank details, using online banking or online shopping**. If you think someone has used information you have shared to do things like open bank accounts or obtain documents you should report it as soon as you can to Action Fraud (MIND, 2015).

Think about who will see your post

Sharing things like jokey photos or personal opinions can seem harmless at the time, but sometimes we end up regretting it in the future. You might want to think about -

- **Would you want your friends, family, or employer seeing it?** Very few sites are 100% private, and information is often shared online.
- **Can you see yourself regretting it in future?** Will you still want people to see it in 5, 10 or 20 years' time? It's very difficult to remove something from the internet permanently (MIND, 2015).

Be extra careful with sexually explicit content

If you send someone a sexually explicit image, it's possible that they could use it to try to harm you in the future, such as by sharing it with someone else, or threatening to post it publicly. Your photo or video could also be accidentally shared beyond you and the person you sent it to. Although this does not happen often, it is something to keep in mind before you share sexually explicit content with anyone - even privately (MIND, 2015).

Remember -

- Even if the other person is someone you feel you know and trust, relationships can change.
- No one has the right to share your personal information without your consent, including images.
- Even if you consented to having the picture taken, or took it yourself, if you have not consented to it being shared you can report it to the police (MIND, 2015).

The Get Safe Online website provides more information on how you can manage this sort of situation (MIND, 2015).

Don't break the law

Sharing content or information you don't own, or that is either confidential or untrue, can have serious consequences in some circumstances (MIND, 2015).

You must not -

- **upload any content you don't own the copyright for**, such as films, music or books. This is illegal unless you have permission from the copyright holder.
- **publicly post other people's personal information - including pictures - without their permission.** This could be upsetting for them, and in some circumstances might be a criminal offence.
- **publicly post false or confidential information about organisations**. In serious cases this might result in you being sued for libel (damaging an organisation's reputation in print), or disciplined for misconduct if you are an employee of the organisation - you could lose your job (MIND, 2015).

Bullying and abuse

Just like in offline life, you might encounter people who upset you or behave in ways that cause you serious problems. This might be by -

- behaving in a threatening way,
- emotional abuse or manipulation,
- verbal harassment or intimidation,
- sexual harassment (MIND, 2015).

Unfortunately, the internet provides an opportunity for people to carry out bullying and abuse in extra ways too, such as -

- posting private pictures or information about you,
- hacking your account (accessing it without your permission),
- using your identity without your permission (identity fraud) (MIND, 2015).

It can be horrible to experience bullying or abuse online, but remember: **you don't have to put up with it** (MIND, 2015).

What can I do about bullying and abuse?

If you experience bullying or abuse, there are some things you can do immediately -

- Don't respond - it can encourage further unwanted communication.
- Block or delete the person - this means they won't be able to contact you and you can't see what they write (MIND, 2015).

If you're worried for your safety or the safety of others, you might need to take more serious steps -

- **Keep a record of any posts or messages that you've received**, for example, take a screenshot or save messages to an offline file. This can help if you need to provide evidence to the site moderators or the police.
- **Report it to the site moderators**. Most websites will have a policy for reporting bad behaviour, so make sure you read this before you start. The Know the Net website has information on exactly how to report people on some of the most well-known websites.
- **Talk to a trusted friend or family member** - they may be able to offer help and support.
- **Contact the police** if you are being threatened or abused online and you feel in danger (MIND, 2015).

It's important to remember to take care of yourself when you're handling a difficult situation like this (MIND, 2015).

Taking relationships offline

The internet can be a great place to make connections with new people. If you have made a good online friendship with someone, you may decide to take it offline. This might mean talking over the phone or arranging to meet face-to-face.

Many people have established long-lasting and supportive friendships this way, but it's also important to keep yourself safe (MIND, 2015).

What should I consider before meeting up offline?

You might want to ask yourself these questions -

- **How much do I know about this person?** Try and think about what they've told you about themselves. How long have you been talking to them? Do you have any mutual friends?

- **Are they definitely who they say they are?** While most people are honest, not everyone represents themselves accurately online.
- **Do I feel pressured into meeting up?** You don't have to do anything you don't feel comfortable with. It's ok to tell someone you're not ready to meet offline just yet, or that you'd rather keep your relationship online-only.
- **Do we want the same thing from an offline relationship?** It's important to be clear beforehand about why you want to meet, to make sure that your motivations and expectations are the same. For example, you might just want to continue an existing friendship, but the other person might assume that you want to develop your relationship further (MIND, 2015).

What can I do to keep myself safe?

When meeting up with someone for the first time, it's a good idea to be keep these suggestions in mind -

- **Don't give out your phone number or address** until you're confident that you know who you are talking to.
- **Always make sure you meet in a public place**, during the daytime, when other people will be around.
- **Let a friend or family member know where you are**, who you are with and when you expect to be back.
- **Keep in touch with your friend or family member while you're out** - you might want to make sure you've charged your phone fully before leaving the house.
- **Ask someone else to come with you**. If you're both part of an online community, perhaps ask other people in the group to come too (MIND, 2015).

Self-harm

Self-harm is when you hurt yourself as a way of dealing with very difficult feelings, old memories, or overwhelming situations and experiences. The ways you hurt yourself can be physical, such as cutting yourself. They can also be less obvious, such as putting yourself in risky situations, or not looking after your own physical or emotional needs (MIND, 2016c).

Self-harm is when somebody intentionally damages or injures their body. It's usually a way of coping with or expressing overwhelming emotional distress.

Sometimes when people self-harm, they feel on some level that they intend to die. Over half of people who die by suicide have a history of self-harm.

However, the intention is more often to punish themselves, express their distress or relieve unbearable tension. Sometimes the reason is a mixture of both.

Self-harm can also be a cry for help (NHS, 2015s).

Types of self-harm

Ways of self-harming can include -

- cutting yourself,
- poisoning yourself,
- over-eating or under-eating,
- burning your skin,
- inserting objects into your body,
- hitting yourself or walls,
- overdosing,
- exercising excessively,
- scratching and hair pulling (MIND, 2016c).
- poisoning themselves with tablets or toxic chemicals,
- misusing alcohol or drugs,
- deliberately starving themselves (anorexia nervosa) or binge eating (bulimia nervosa) (NHS, 2015s).

After self-harming, you might feel better and more able to cope for a while. However, self-harm can bring up very difficult feelings and could make you feel worse.

If you self-harm, you may feel embarrassed or ashamed about it. You might be worried that other people will judge you or pressurise you to stop if you tell them about it. This may mean that you keep your selfharming a secret. This is a very common reaction, although not everyone does this (MIND, 2016c).

People often try to keep self-harm a secret because of shame or fear of discovery. For example, if they're cutting themselves, they may cover up their skin and avoid discussing the problem. It's often up to close family and friends to notice when somebody is self-harming, and to approach the subject with care and understanding (NHS, 2015s).

Signs of self-harm

If you think a friend or relative is self-harming, look out for any of the following signs -

- unexplained cuts, bruises or cigarette burns, usually on their wrists, arms, thighs and chest,
- keeping themselves fully covered at all times, even in hot weather,
- signs of depression, such as low mood, tearfulness or a lack of motivation or interest in anything,
- self-loathing and expressing a wish to punish themselves,
- not wanting to go on and wishing to end it all,
- becoming very withdrawn and not speaking to others,
- changes in eating habits or being secretive about eating, and any unusual weight loss or weight gain,
- signs of low self-esteem, such as blaming themselves for any problems or thinking they're not good enough for something,
- signs they have been pulling out their hair,
- signs of alcohol or drugs misuse (NHS, 2015s).

People who self-harm can seriously hurt themselves, so it's important that they speak to a GP about the underlying issue and request treatment or therapy that could help them (NHS, 2015s).

Why do people harm themselves?

There are no fixed rules about why people self-harm. For some people, it can be linked to specific experiences, and be a way of dealing with something that is happening now, or that happened in the past. For others, it is less clear. If you don't understand the reasons for your self-harm, it's important to remind yourself that this is OK, and you don't need to know this in order to ask for help (MIND, 2016c).

Self-harm is more common than many people realise, especially among younger people. It's estimated around 10% of young people self-harm at some point, but people of all ages do. This figure is also likely to be an underestimate, as not everyone seeks help (NHS, 2015s).

Any difficult experience can cause someone to self-harm. Common causes include -

- pressures at school or work,
- bullying,

- money worries,
- sexual, physical or emotional abuse,
- bereavement,
- confusion about your sexuality,
- breakdown of relationships,
- an illness or health problem,
- difficult feelings, such as depression, anxiety, anger or numbness, experienced as part of a mental health problem (MIND, 2016c).

In most cases, people who self-harm do it to help them cope with overwhelming emotional issues, which may be caused by -

- **social problems** - such as being bullied, having difficulties at work or school, having difficult relationships with friends or family, coming to terms with their sexuality if they think they might be gay or bisexual, or coping with cultural expectations, such as an arranged marriage,
- **trauma** - such as Abuse and neglect, the death of a close family member or friend, or having a miscarriage,
- **psychological causes** - such as having repeated thoughts or voices telling them to self-harm, disassociating (losing touch with who they are and with their surroundings), or borderline personality disorder (NHS, 2015s).

These issues can lead to a build-up of intense feelings of anger, guilt, hopelessness and self-hatred. The person may not know who to turn to for help and self-harming may become a way to release these pent-up feelings.

Self-harm is linked to anxiety and depression. These mental health conditions can affect people of any age. Self-harm can also occur alongside antisocial behaviour, such as misbehaving at school or getting into trouble with the police.

Although some people who self-harm are at a high risk of suicide, many people who self-harm don't want to end their lives. In fact, the self-harm may help them cope with emotional distress, so they don't feel the need to kill themselves (NHS, 2015s).

Some people have also described self-harm as a way to -

- express something that is hard to put into words,
- make experiences, thoughts or feelings that feel invisible into something visible,
- change emotional pain into physical pain,
- reduce overwhelming emotional feelings or thoughts,
- have a sense of being in control,
- escape traumatic memories,
- stop feeling numb, disconnected or dissociated,

- create a reason to physically care for yourself,
- express suicidal feelings and thoughts without taking your own life,
- communicate to other people that you are experiencing severe distress (MIND, 2016c).

Sometimes people talk about self-harm as attention-seeking. If people make comments like this, it can leave you feeling judged and alienated. In reality, most people keep their self-harm private, and it can feel very painful to have your behaviour misunderstood in this way.

If you do self-harm as a way of bringing attention to yourself, remember that you deserve a respectful response from those around you, including from nurses and/or doctors (MIND, 2016c).

Getting help

If you're self-harming, you should see your GP for help. They can refer you to healthcare professionals at a local community mental health service for further assessment. This assessment will result in your care team working out a treatment plan with you to help with your distress.

Treatment for people who self-harm usually involves seeing a therapist to discuss your thoughts and feelings, and how these affect your behaviour and wellbeing. They can also teach you coping strategies to help prevent further episodes of self-harm. If you're badly depressed, it could also involve taking antidepressants or other medication (NHS, 2015s).

If you are thinking about stopping or reducing your self-harm, finding ways of helping yourself can feel very empowering.

This section gives some ideas for things you can do to support yourself better. Some can be done when you feel like self-harming. Others can be done at any time. You may need to try a few to find out what works for you. These techniques may be helpful on their own, or alongside professional help (MIND, 2016c).

There is no magic solution or quick fix for self-harm, and making changes can take time and involve periods of difficulty. It is common to make some progress and then get back into old behaviours again. If this happens to you, remind yourself that it's not failing - it is simply part of the process (MIND, 2016c).

If you do not feel able to stop self-harming completely, it is important to be honest with yourself and consider what else you can do that would feel helpful. For example, you may be able to work towards reducing or stopping your self-harm in the future, even if you find it too difficult to stop self-harming immediately (MIND, 2016c).

Work out your patterns of self-harm

It may be that things happen so fast, it feels impossible to realise you have an urge to self-harm before you find that you are hurting yourself.

Keeping a diary of what happens before, during and after each time you self-harm, can help you work out what gives you the urge to self-harm, and recognise when the urge is coming on. It is helpful to do this over a period of time - maybe a month - so that you start to see patterns (MIND, 2016c).

Learn to recognise triggers

Your triggers are the things that give you the urge to hurt yourself. This could be anything from people, situations, anniversaries, certain times of the day, physical sensations or particular thoughts or feelings.

In your diary, note down what was happening before you last self-harmed. Did you have a particular thought? Did you have an argument? Did you have to see someone you don't like? Did a situation or object remind you of something difficult?

This can be quite an intense experience and bring up difficult feelings and emotions. If you feel confident to try this on your own, make sure you do something relaxing or enjoyable afterwards. If you find doing this distressing, you may want to ask for support from a trusted friend, family member, or nurse or doctor (MIND, 2016c).

Learn to recognise urges

The next step is to identify how you experience the urge to self-harm. Urges come in lots of different ways and may be different for you at different times (MIND, 2016c).

Urges can include -

- physical sensations, such as a racing heart, nausea, or very shallow breath,
- feelings of heaviness, fogginess or blackness,
- disconnecting with yourself, such as feeling like you are outside of your own body or losing all feelings of sensation,
- strong emotions, like sadness, fear, despair or rage,
- specific thoughts, such as 'hurt' or 'I'm going to cut',

- making decisions that you know aren't good for you, for example by excessive working or exercising rather than experiencing your feelings (MIND, 2016c).

If you are able to recognise your urges, this can help you take positive steps towards reducing or stopping your self-harm. You might also find it helpful to think about how your urges relate to your triggers.

Even at times when you are unable to resist the urge to self-harm, it is still helpful to think about what happened, so you understand this better next time (MIND, 2016c).

Distract from the urge to self-harm

Distracting yourself is a way of changing the cycle of self-harm by choosing to do something else. A distraction, like hitting a cushion or writing a list, provides something else to focus on and another way of expressing your feelings. This can help reduce the intensity of your urge to self-harm. Distracting can be done when you feel an urge to harm yourself, or as you become aware you are hurting yourself.

Once you know the different feelings and situations that cause you to want to self-harm (your triggers and urges), you can create a personal list of distractions. It is important to notice when a distraction works in one situation or with a certain feeling, but not in another. Then you can consider what you may need to do in different situations or for different urges (MIND, 2016c).

Delay self-harm

Another technique is to wait ten minutes before you self-harm. If you still have the urge, then let yourself. If not, increase the time you wait to half an hour, a morning, a day, a week etc. By doing this, you slowly build up the gaps between each time you self-harm, and reduce how often you feel the need to do it. Even if you start self-harming again, you will now know that you can go for periods of time without doing so (MIND, 2016c).

Other ways of making long term changes

It is also helpful to think about steps you can take to understand your self-harm and to find other ways of supporting yourself (MIND, 2016c).

Build your self-esteem

Practising positive and encouraging self-talk can help make a difference to how you feel. As you experience urges to self-harm, try reminding yourself why you are having certain thoughts or feelings. For example: '*I feel like I want to cut because I don''t think that person likes me*'. Then replace it with another thought, like: '*Even though I feel like cutting, I am going to find another way to express how upset I feel*'.

It can also help to explore personal beliefs about yourself and others by writing them down in a diary. For example, you may believe you will never be able to stop hurting yourself or that no one will be able to help you. Ask yourself if you can be absolutely sure that these beliefs are true and how it would feel for you to let them go or change them. If you find this difficult, you may want to ask for support from a trusted friend, family member, or professional.

It might also be helpful to write down all the things you like about yourself, no matter how small. Try to do this on a regular basis, perhaps every week. This will help shift your attention from negative feelings to more positive ones, and help you build your self-esteem over time (MIND, 2016c).

Look after your general wellbeing

Looking after yourself can help you feel more positive. For example -

- Doing regular physical activity can boost your mood and reduce stress.
- Eating regular meals with plenty of fresh fruit and vegetables can also help.
- Making sure you get enough sleep helps you feel better and more able to cope.
- Doing something creative can help you express your feelings. For example, write a song, story or blog, paint, draw or use clay.
- Spending time every week doing things that you enjoy, such as seeing friends or going for a walk, is also important. Try to make time to do this, no matter what else is going on (MIND, 2016c).

Reach out for support

Reaching out can feel hard, especially if you worry that people will judge you or if you believe that other people might not want to help you. Try to remind yourself that everyone needs support at different times, and that it is OK to ask for help.

When you are ready to reach out, choose someone that you trust to talk to about how you are feeling. This could be a friend, a family member, a counsellor, health professional or psychologist.

You may also find it helpful to write a list of all the people, organisations and websites that you can go to for help when you are finding things difficult. This will remind you that you are not alone, and where you can get help (MIND, 2016c).

What support and treatment is available?

You might believe that it is impossible to stop self-harming if you have been doing it for a while. This isn't true. It can take time, effort and determination to stop, but lots of people have managed to do it.

Sometimes, you may need to get outside support to help you make positive changes. You may find that you need to try a few different things to find what works for you, and combine self-help techniques with professional support. (See 'How can I help myself?')

It takes courage to ask for support. It is understandable that you may have concerns that you won't be understood or that you will be pressured to make changes faster than you want to. However, it's important to remember you have the right to receive support that is both empowering and respectful. Any health professional, such as your GP or psychiatrist, should discuss all your options with you, and your views and preferences should be taken into account when making decisions about your treatment.

If you receive treatment on the NHS, it should be in line with National Institute for Health and Care Excellence (NICE) guidelines (MIND, 2016c).

These say that -

- any health professionals should treat you in a way that is sensitive and non-judgemental,
- ideally, health professionals should be trained in communicating sensitively with people who self-harm and be aware of potential stigma,
- any treatment you are given should be tailored to your individual needs,
- treatments offered may include structured sessions of talking treatments, such as CBT, psychodynamic therapy or problem-solving approaches (MIND, 2016c).

If you are concerned about your treatment or care, or find it hard to access the support you need, it may be helpful to get an advocate to support you. This could be a friend, family member or professional (MIND, 2016c).

Your GP

If you want to seek professional help, the first step would usually be to visit your GP. Your GP can discuss your self-harm with you in confidence. They may assess you and let you know about available treatment options, or they may refer you to a specialist.

If your GP is concerned that your self-harm is a threat to your life, or if you need medical treatment for injuries resulting from your self-harm, they may suggest that you spend some time in hospital for treatment and care (MIND, 2016c).

Talking treatments

Talking treatments can be short- or long-term and involve talking with someone who is trained to listen with empathy and acceptance - usually a counsellor or therapist. They do not aim to give advice, but offer you the chance to explore your feelings and find your own solutions to any difficulties you are having. Talking things through with another person can help you understand your feelings and behaviour, and start to make positive changes. It can also help you feel supported to have someone else accept and understand your experiences.

Talking treatments are free on the NHS, and some local organisations, including some local Minds, provide therapy and counselling free of charge or at low cost. To find out what support you can get in your area, ask your GP or contact Mind Infoline. If you can afford it, you could also consider seeing a private therapist. Check that they are appropriately trained and accredited before you start. (See BABCP, BACP and UKCP) (MIND, 2016c).

Talking treatments that might be useful include -

- **Psychodynamic therapy** - This focuses on how past experiences contribute to current experiences and feelings. It can be short- or long-term. It can be more intensive than some other therapies, because it involves talking about your childhood, your relationships, and how these things might relate to your self-harm.
- **Cognitive behavioural therapy** - CBT aims to identify connections between thoughts, feelings and behaviour, and to help develop practical skills to manage them. A CBT therapist may support you to look at what happens just before you self-harm, to keep a diary of self-harming episodes and find other channels for your feelings. CBT does not usually explore the underlying causes of self-harming.
- **see dialectical behaviour therapy (DBT)** - This therapy was designed for people with borderline personality disorder. It combines techniques

from CBT that help to change thoughts and feelings, along with techniques that strengthen self-acceptance. If you have been diagnosed with borderline personality disorder and your self-harm is part of this condition, DBT might be something that would help you (MIND, 2016c).

Your relationship with your therapist

One of the most important things about talking treatments is the relationship you have with your therapist. You may not always agree with each other, but you must both be committed to working together in spite of any difficulties.

Sometimes a counsellor may ask you to commit to not self-harming during a course of counselling. It's important that you don't feel pressured into making decisions about this, and that anything you decide is realistic for you at the time. If your counsellor is not specifically trained in self-harm, it might be useful to ask them to find out more, for example by reading information, or by talking to organisations for people that self-harm (MIND, 2016c).

Support groups

In a support group, people with similar experiences meet to discuss their feelings and experiences, and share tips for coping. Support groups can be run by a group leader or by group members. They may focus on specific issues, such as self-harm, or be more general. You can find out about support groups in your area by contacting Mind Infoline, or a self-harm organisation such as Self-injury Support (MIND, 2016c).

Online support

If you do not feel ready to talk face-to-face with someone, you might find online support useful. Several self-harm services offer confidential email or text support, and there are also forums where people who self-harm share their experiences and offer support to each other. Mind's online community Elefriends may also be a good source of support, to help you discuss the difficult feelings and emotions that cause you to self-harm in a way that is safe and supportive for others.

It's important to use caution when using online support, as the content on some sites can be overwhelming and may trigger your urges. Make sure that the websites you use are moderated, and that you know how to protect yourself and other people online. When talking about self-harm online, it's important to think sensitively about how what you write can affect your own, and other people's, feelings. Some people find that talking about feelings, rather than behaviours, is the best way to express yourself safely (MIND, 2016c).

What can friends and family do to help?

This section is for friends and family who want to support someone they know who self-harms (MIND, 2016c).

Be supportive

There are lots of things that you can do to make a difference to someone you know who self-harms. Your attitude and how you relate to them is one of the key things that can help them feel supported (MIND, 2016c).

Things that you can do to help include -

- Let your friend or family member know that you are there, if and when they are ready to talk. It is common for people to worry that they will be judged for their self-harm or that they will be a burden on others, so it's important to let them know you are there for them if they want.
- Show concern for their injuries, but at the same time, relate to them as a whole person rather than just someone who self-harms.
- Offer them a chance to talk about how they are feeling. Try to understand and empathise with what they are saying even when it is hard to hear.
- Try to understand that they may be scared of stopping self-harm if they use it as a way of coping. If they are finding it hard to stop, try to help them find other ways of coping and to seek help if they need it.
- Let them be in control of decisions about support and any plans to reduce or stop their self-harm.
- Emphasise other parts of their life where they are doing well, and the good qualities that they have (MIND, 2016c).

Have an honest conversation about staying safe

It is common to feel scared about the possibility of someone you care about seriously hurting themselves or even committing suicide. While it is understandable to have these fears, it is useful to remember that self-harm doesn't necessarily mean that someone wants to end their life.

There are, however, a small number of people who do go on to take their own lives, either intentionally or accidently. It's therefore important to have an honest conversation with your friend or family member about staying safe - for example, being aware when things are getting too much and knowing when to seek help (MIND, 2016c).

Take care of yourself

Finding out that someone you love and care about is self-harming can be a very shocking and upsetting experience. And supporting someone who is self-harming can be a long process with many ups and downs. It's important to take care of yourself - this will help you to be able to stay involved for longer and avoid becoming unwell yourself (MIND, 2016c).

You might find these suggestions could help -

- Try to have clear boundaries about how much and what sort of support you can offer.
- Find out what other support is available so you are not the only source of support.
- Get support for your own feelings. Lots of organisations offer information and support to people who are concerned about someone else's self-harm, or you may find it helpful to try a talking treatment if you are finding things difficult (MIND, 2016c).

Useful organisations

There are organisations that offer support and advice for people who self-harm, as well as their friends and families. These include-

- Samaritans - call 116 123 (open 24 hours a day), email: jo@samaritans.org or visit your local Samaritans branch,
- Mind - call 0300 123 3393 or text 86463 (9am-6pm on weekdays),
- Harmless - email info@harmless.org.uk,
- National Self Harm Network forums,
- YoungMinds Parents Helpline - call 0808 802 5544 (9.30-4pm on weekdays) (NHS, 2015s).

Suicide

Suicide is the act of intentionally ending your life.

If you're reading this because you have, or have had, thoughts about taking your own life, it's important you ask someone for help. It's probably difficult for you to see at this time, but you're not alone and not beyond help.

Many people who have had suicidal thoughts say they were so overwhelmed by negative feelings they felt they had no other option. However, with support and treatment they were able to allow the negative feelings to pass (NHS, 2015u).

Causes

Despite being a leading cause of death, both in the UK and worldwide, there is little hard evidence to explain why some people attempt suicide.

Most people who choose to end their lives do so for complex reasons. In the UK, research has shown many people who die by suicide have a mental illness, most commonly depression or an alcohol problem.

In many cases, suicide is also linked to feelings of hopelessness and worthlessness (NHS, 2015u).

Vulnerability to suicide

Many experts believe a number of things determine how vulnerable a person is to suicidal thinking and behaviour. These include -

- life history - for example, having a traumatic experience during childhood, a history of sexual or physical abuse, or a history of parental neglect,
- mental health - for example, developing a serious mental health condition, such as schizophrenia,
- lifestyle - for example, if you misuse drugs or misuse alcohol,
- employment - such as poor job security, low levels of job satisfaction or being unemployed,
- relationships - being socially isolated, being a victim of bullying or having few close relationships,
- genetics and family history (NHS, 2015u).

In addition, a stressful event may push a person ”over the edge”, leading to suicidal thinking and behaviour.

It may only take a minor event, such as having an argument with a partner. Or it may take one or more stressful or upsetting events before a person feels suicidal, such as the break-up of a significant relationship, a partner dying or being diagnosed with a terminal illness (NHS, 2015u).

Mental health conditions

It's estimated 90% of people who attempt or die by suicide have one or more mental health conditions. However, in some cases, the condition may not have been formally diagnosed by a clinician. Conditions leading to the biggest risk of suicide are described below (NHS, 2015u).

Severe depression

Severe Depression causes symptoms of low mood, tiredness, loss of interest, despair and hopelessness that interfere with a person's life. People with severe depression are much more likely to attempt suicide than the general population (NHS, 2015u).

Bipolar disorder

Bipolar disorder causes a person's mood to swing from feeling very high and happy to feeling very low and depressed. About one in three people with bipolar disorder will attempt suicide at least once. People with bipolar disorder are 20 times more likely to attempt suicide than the general population (NHS, 2015u).

Schizophrenia

Schizophrenia is a long-term mental health condition that typically causes hallucinations (seeing or hearing things that are not real), delusions (believing in things that are not true) and changes in behaviour. It's estimated that one in 20 people with schizophrenia will take their own life.

People with schizophrenia are most at risk of suicide when their symptoms first begin. This is because they frequently suffer loss at this time - for example, loss of employment and relationships. It's also increased when people with schizophrenia experience depression. The risk tends to reduce over time.

People with schizophrenia are also at increased risk of Self-harm (NHS, 2015u).

Borderline personality disorder

Borderline personality disorder is characterised by unstable emotions, disturbed thinking patterns, impulsive behaviour and intense but unstable relationships with other people. People with a borderline personality disorder often have a history of childhood sexual abuse. They have a particularly high risk of suicide.

Self-harm is often a key symptom of this condition.

It's estimated just over half of people with borderline personality disorder will make at least one suicide attempt (NHS, 2015u).

Anorexia nervosa

Anorexia nervosa is an eating disorder. People with anorexia feel fat and try to keep their weight as low as possible. They do this by strictly controlling and limiting what they eat, as well as sometimes inducing vomiting. It's estimated around one in five people with anorexia will make at least one suicide attempt. Anorexia is associated with a high risk of suicide (NHS, 2015u).

Other risk factors for suicide

Other things that can make a person more vulnerable to suicidal thoughts include -

- being gay, lesbian or transgender, arising from the prejudice these groups often face,
- being in debt,
- being homeless,
- being a war veteran,
- being in prison or recently released from prison,
- working in an occupation that provides access to potential ways of dying by suicide, such as working as a doctor, nurse, pharmacist, farmer or as a member of the armed forces,
- exposure to other people with suicidal behaviour, especially close friends or family members (NHS, 2015u).

Antidepressants and suicide risk

Some people experience suicidal thoughts when they first take antidepressants. Young people under 25 seem particularly at risk.

Contact your GP immediately or go to your local hospital if you have thoughts of killing or harming yourself at any time while taking antidepressants.

It may be useful to tell a relative or close friend if you have started taking antidepressants. Ask them to read the leaflet that comes with your medication. Also ask them to tell you if they think your symptoms are getting worse or if they are worried about changes in your behaviour (NHS, 2015u).

Genetics and suicide

Suicide and some mental health problems can run in families. This has led to speculation that certain genes may be associated with suicide.

However, it would be too simple to claim there's a ”suicide gene” as the factors leading to suicide are complex and wide ranging. Genetics may influence personality factors (such as acting impulsively or aggressively) that may increase the risk of suicidal behaviour, especially when a person is depressed (NHS, 2015u).

Other theories

An American psychologist called Thomas Joiner developed a theory known as the 'interpersonal theory of suicide'. The theory states three main factors which can cause someone to turn to suicide. They are -

- a perception (usually mistaken) they are alone in the world and no one really cares about them,
- a feeling (again, usually mistaken) they are a burden on others and people would be better off if they were dead,
- fearlessness towards pain and death (NHS, 2015u).

The theory argues fearlessness towards pain and self-harm may be learnt over time, which could explain the strong association between self-harming behaviour and suicide.

People who are regularly exposed to the suffering and pain of others may develop this fearlessness over time. This could help explain why suicide rates are higher in occupations linked to such exposure, such as soldiers, nurses and doctors (NHS, 2015u).

How common is suicide?

During 2012 there were 5,981 suicides in the UK but the number of attempted suicides is much higher.

Suicide occurs in people of all ages, including children, but adults in middle- and late-middle age have the highest suicide rate (NHS, 2015u).

Warning signs of suicide

Sometimes there may be obvious signs that someone is at risk of attempting suicide. However, this is often not the case (NHS, 2015u).

High-risk warning signs

A person may be at high risk of attempting suicide if they -

- threaten to hurt or kill themselves,
- talk or write about death, dying or suicide,
- actively look for ways to kill themselves, such as stockpiling tablets (NHS, 2015u).

If the person has previously been diagnosed with a mental health condition, contact a member of their care team or the centre or clinic where they were being treated.

If you don't have these details, contact your nearest accident and emergency (A&E) department and ask for the contact details of the nearest crisis resolution team (CRT). CRTs are teams of mental healthcare professionals, such as psychiatrists and psychiatric nurses, who work with people experiencing severe psychological and emotional distress.

While waiting for help to arrive, remove any possible means of suicide from the person's immediate environment, such as medication, knives or other sharp objects, household chemicals, such as bleach and ropes or belts (NHS, 2015u).

For more information about CRTs, the charity Rethink Mental Illness has a crisis teams factsheet you can download (NHS, 2015u).

Other warning signs

A person may also be at risk of attempting suicide if they -

- complain of feelings of hopelessness,
- have episodes of sudden rage and anger,
- act recklessly and engage in risky activities with an apparent lack of concern about the consequences,
- talk about feeling trapped, such as saying they can't see any way out of their current situation,
- self-harm - including misusing drugs or alcohol, or using more than they usually do,
- noticeably gain or lose weight due to a change in their appetite,
- become increasingly withdrawn from friends, family and society in general,
- appear anxious and agitated,
- are unable to sleep or they sleep all the time,

- have sudden mood swings - a sudden lift in mood after a period of depression could indicate they have made the decision to attempt suicide,
- talk and act in a way that suggests their life has no sense of purpose,
- lose interest in most things, including their appearance,
- put their affairs in order, such as sorting out possessions or making a will (NHS, 2015u).

If you notice any of these warning signs in a friend, relative or loved one, encourage them to talk about how they are feeling.

Also share your concerns with your GP or a member of their care team, if they are being treated for a mental health condition (NHS, 2015u).

Getting help

If you're reading this because you're having suicidal thoughts, try to ask someone for help. It may be difficult at this time, but it's important to know you're not beyond help and you're not alone.

Talking to someone can help you see beyond feelings of loneliness or despair and help you realise there are options.

There are people who want to talk to you and help. Try talking to a family member or friend about how you're feeling.

There are several telephone helplines you can call at any time of the day or night. You can speak to someone who understands how you're feeling and can help you through the immediate crisis (NHS, 2015u).

Helplines and support groups

We know it can be difficult to pick up the phone, but reach out to somebody and let them know how you are feeling.

- Samaritans (116 123) operates a 24-hour service available every day of the year. If you prefer to write down how you're feeling, or if you're worried about being overheard on the phone, you can email Samaritans at jo@samaritans.org.
- Childline (0800 1111) runs a helpline for children and young people in the UK. Calls are free and the number won't show up on your phone bill.
- PAPYRUS (0800 068 41 41) is a voluntary organisation supporting teenagers and young adults who are feeling suicidal.

- Depression Alliance is a charity for people with depression. It doesn't have a helpline, but offers a wide range of useful resources and links to other relevant information.
- Students Against Depression is a website for students who are depressed, have a low mood or are having suicidal thoughts.
- Bullying UK is a website for both children and adults affected by bullying (NHS, 2015u).

Help for young men

Men may be more likely to avoid or ignore problems and many are reluctant to talk about their feelings or seek help when they need it.

A support group called the Campaign Against Living Miserably (CALM) is an excellent resource for young men who are feeling unhappy. As well as their website, CALM also has a helpline (0800 58 58 58) (NHS, 2015u).

Talking to someone you trust

If you don't want to speak to someone on a helpline, you could talk to -

- a member of your family, a friend or someone you trust, such as a teacher,
- your GP, a mental healthcare professional or another healthcare professional,
- a minister, priest or other type of faith leader (NHS, 2015u).

Seeing your GP

It would also help to see your GP. They can advise you about appropriate treatment if they think you have a mental health condition, such as Depression or Anxiety.

Your GP may be able to help you with access to talking therapies. Talking therapies, such as counselling and CBT, are often used to help people who have suicidal thoughts and usually involve talking about your feelings with a professional (NHS, 2015u).

Offering support to someone who's feeling suicidal

One of the best things you can do if you think someone may be feeling suicidal is to encourage them to talk about their feelings and to listen to what they say.

Talking about someone's problems is not always easy and it may be tempting to try to provide a solution. But often the most important thing you can do to help is listen to what they have to say.

If there is an immediate danger, make sure they are not left on their own (NHS, 2015u).

Do not judge

It's also important not to make judgements about how a person is thinking and behaving. You may feel that certain aspects of their thinking and behaviour are making their problems worse. For example, they may be drinking too much alcohol.

However, pointing this out will not be particularly helpful to them. Reassurance, respect and support can help someone during these difficult periods (NHS, 2015u).

Asking questions

Asking questions can be a useful way of letting a person remain in control while allowing them to talk about how they're feeling. Try not to influence what the person says, but give them the opportunity to talk honestly and openly.

Open ended questions such as "*Where did that happen?*" and "*How did that feel?*" will encourage them to talk. It's best to avoid statements that could possibly end the conversation, such as "*I know how you feel*" and "*Try not to worry about it*" (NHS, 2015u).

Getting professional help

Although talking to someone about their feelings can help them feel safe and secure, these feelings may not last. It will probably require long-term support to help someone overcome their suicidal thoughts.

This will most likely be easier with professional help. Not only can a professional help deal with the underlying issues behind someone's suicidal thoughts, they can also offer advice and support for yourself (NHS, 2015u).

More information

For more detailed information about helping someone with suicidal thoughts, the charity Rethink Mental Illness has a factsheet available about supporting someone with suicidal thoughts (NHS, 2015u).

Help for someone with a mental illness

If someone who has previously been diagnosed with a mental illness has suicidal thoughts, contact a member of their care team or the centre or clinic where they were being treated.

If you don't have these details, contact your nearest accident and emergency (A&E) department and ask for the contact details of the nearest CRT.

CRTs are teams of mental healthcare professionals, such as psychiatrists and psychiatric nurses, who work with people experiencing severe psychological and emotional distress.

For more information about CRTs, the charity Rethink Mental Illness has a crisis teams factsheet you can download (NHS, 2015u).

Prevention

Improving your mental health

It's impossible to guarantee you will never get a mental health condition, but you can take steps to improve your mental health.

If you're stronger emotionally, you may find it easier to cope with stressful or upsetting incidents, reducing your risk of developing a mental health condition, such as depression, and the risk of suicidal thoughts (NHS, 2015u).

Exercise and diet

Research shows that for some people with mild depression, exercise can be as effective as antidepressant medication in reducing depressive symptoms (NHS, 2015u). Being physically active helps to -

- lift your mood,
- reduce stress and anxiety,
- encourage the release of ”feel-good” chemicals, called endorphins,
- improve self-esteem (NHS, 2015u).

The National Institute for Health and Care Excellence (NICE) recommends exercise should be used to treat depression in people of all ages.

It's also important to eat a healthy diet. Eating healthily may be as important for maintaining mental health as it is for protecting against physical health problems (NHS, 2015u).

Alcohol

Drinking alcohol can be tempting as a way of trying to cope with problems or unpleasant emotions. But alcohol is a depressant, which means it can make unpleasant emotions worse, such as sadness and hopelessness.

To avoid common mental health problems associated with alcohol misuse, don't drink more than the recommended daily limits of alcohol (NHS, 2015u). These are -

- two to three units a day for men,
- two to three units a day for women (NHS, 2015u).

A unit of alcohol is approximately half a pint of normal-strength lager or a single measure (25ml) of spirits. A small glass of wine (125ml) is 1.5 units.

See your GP if you have difficulty moderating your alcohol consumption (NHS, 2015u).

Drugs

People who have problems or unpleasant emotions also commonly use drugs as a way of coping. However, as with alcohol, persistent drug misuse can increase your risk of developing a serious mental health condition, such as depression.

If you find it difficult to stop taking drugs, you may require counselling or medication (NHS, 2015u).

Avoid isolation

Becoming socially isolated is a significant risk factor for suicide. Try to remain engaged as much as possible with the world around you. Talk to someone you trust about how you feel and maintain your friendships and interests, even if you don't feel like it at times.

If you find it difficult to make friends, you may benefit from joining a local activity group, such as a book group or walking group. Your local library, community centre or local council should be able to provide you with details of the various groups and clubs in your community.

Networks of local support groups are run throughout the country by many larger mental health charities, including -

- Depression Alliance,
- Depression UK (NHS, 2015u).

Research has shown that people who regularly spend time helping others through charitable activities or other voluntary work are typically more mentally healthy than the general population. You may benefit from volunteering with a local charity or voluntary organisation.

All charities and most voluntary organisations are grateful for any help. Simply choose an issue you feel strongly about and contact a relevant organisation. The most effective way of finding and contacting an organisation is on the internet (NHS, 2015u).

Staying positive

Staying positive may sound like a meaningless phrase, particularly to someone with severe depression, but it's important to try to remain as positive as possible.

Persistent negative thinking can mean you risk withdrawing from the world and becoming more isolated.

Breaking this pattern usually requires a conscious effort, such as ”stepping back” when an event upsets you and considering how you can respond in a more positive way.

If you can't change negative patterns of thinking, you may benefit from a type of talking treatment called CBT. CBT can help you manage your problems by changing how you think and act (NHS, 2015u).

Self-help

When you are diagnosed with generalised anxiety disorder (GAD) or depression, your GP may recommend trying self-help treatments before having more intensive psychological therapy or medication.

This will usually involve working from a book or computer programme for around six weeks or longer. In some cases, you may be closely supported by a trained therapist who you will speak to every week or two, although some treatments only involve minimal or occasional contact with a therapist who will monitor your progress.

There are a number of different books and courses available that can help you learn to cope with your anxiety, but the National Institute for Health and Care Excellence (NICE) only recommends trying treatments based on the principles of CBT.

CBT is a type of psychological treatment that can help you understand your condition better and how your problems, thoughts, feelings and behaviour affect each other. The aim of CBT-based treatments is to help you learn ways to manage your anxiety by modifying negative or unhelpful behaviour and thoughts (NHS, 2015u).

Talking treatments

What are talking treatments?

Talking treatments are a type of treatment that involve talking to a therapist about your thoughts and feelings. A therapist is a person trained in one or more types of talking treatment. Talking treatments can help you manage and cope with -

- mental health problems,
- physical health problems,
- difficult emotions,
- difficult experiences (MIND, 2016d).

The purpose of talking treatments is to help you understand your feelings and behaviour better and, if you want, to change your behaviour or the way you think about things. You may talk about things which are troubling you, and it can be a time to explore your feelings.

There are lots of different types of talking treatments, which use different styles and techniques to help you, but they all have the same goal: helping you feel better able to cope with your emotions and the things that happen in your life (MIND, 2016d).

Different terms for talking treatments

There are several different terms people use to refer to talking treatments, and this can feel a bit confusing sometimes. You may hear the following words used -

- counselling,
- therapy,
- talking therapy,
- psychological therapy,
- psychotherapy (MIND, 2016d).

These terms can often be used interchangeably, but sometimes they can refer to a specific type of talking treatment (MIND, 2016d).

Is there evidence that talking treatments work?

It is difficult to assess exactly how effective talking treatments are compared with other services, as there has been relatively little research into talking treatments until recently. Some talking treatments have been researched more than others and have received more funding.

Some therapies have been developed for certain mental health problems, and they can be more effective for some problems than others (MIND, 2016d).

What can talking treatments help with?

Talking treatments can help with -

- **Coping with difficult life events**, such as losing your job or a bereavement.
- **Coping with upsetting or traumatic experiences**, whether it's something recent or in your past.
- **Coping with difficult emotions**, for example if you struggle with low self-esteem or anger.
- **Coping with long-term physical health conditions**, by helping you learn how to cope with the symptoms and their impact on your mental wellbeing.
- **Depression and anxiety**. Talking treatments have been shown to be particularly useful for some people in treating and preventing common mental health problems like depression and anxiety.

- **Other mental health problems**. Talking treatments can help with a range of diagnoses, and specific talking treatments have been developed for some mental health problems. See our information about Dialectical Behaviour Therapy DBT as a treatment for Borderline Personality disorder (BPD) and Cognitive Behavioural Therapy CBT for Phobias (MIND, 2016d).

Some talking therapies are particularly helpful for certain types of problems and have been recommended specifically by the National Institute for Health and Care Excellence (NICE). See our A-Z of mental health for more information about NICE-recommended treatments for specific mental health problems (MIND, 2016d).

What alternatives are there?

If talking treatments are not right for you, there are alternatives. Some people find the following helpful -

- **Medication** - there are drugs which can be prescribed to treat different types of mental health problems, or to reduce the symptoms. See our pages on medication for more information.
- **Arts therapies** are a way of using the arts - such as, music, art, dance or drama – in a therapeutic environment. See our pages on arts therapies for more information.
- **Complementary and alternative therapy** share a belief in the body's ability to heal itself. See Complementary and alternative therapy.
- **Ecotherapy** is the name given to a wide range of programmes that aim to promote good mental and physical wellbeing through outdoor activity in a green environment. See ecotherapy for more information.
- **Electric Convulsive Therapy** can be an effective treatment if you are seriously depressed and no other treatment has worked for you. See Electric shock treatment (MIND, 2016d).

Talking treatments or medication?

You might be offered both talking treatments and medication as part of your treatment, and many people find that taking medication helps them feel stable enough to get the most out of a talking treatment. However, other people find medication or talking treatments alone are more helpful.

Whether you find talking treatments or medication more effective depends on you, because different people will find different things helpful. It's important to remember that you don't have to choose between either talking treatments or medication - it's your choice what treatment you want to try, and this could be both together (MIND, 2016d).

How do talking treatments work?

Talking treatments work by giving you space to talk about your thoughts, feelings and behaviour with someone who is professionally trained to help you understand these things better, and help you find ways to change the things you want to (MIND, 2016d).

Here you can find information about -

- What's the theory behind talking treatments?,
- What might I learn in therapy?,
- How long until I feel better?,
- how therapy might make you feel (MIND, 2016d).

What's the theory behind talking treatments?

Each type of talking treatment has its own theory about why we think and feel the way we do, and how it's best to help you. Broadly speaking, there are two main theory traditions that started in America and Europe.

In America, therapists focused on how behaviour and thought patterns affect how we feel, and so developed therapies to help us change our behaviour and thoughts to help us improve how we feel. This includes talking treatments like CBT.

In Europe, therapists were interested in the reasons why we think and feel things, and developed therapies to help us understand our thoughts and feelings, and so be better able to cope with them. This includes talking treatments like psychodynamic therapy (MIND, 2016d).

What might I learn in therapy?

What you learn in therapy can be very individual. Some people may find they learn a lot, while others may find therapy less useful. You may learn about -

- **ways of coping** - you may learn ways to understand and cope with traumatic memories, upsetting life events, difficult feelings, thoughts or behaviours,
- **your thoughts** - you may learn to become more aware of your thoughts and how they affect you,

- **your feelings** - you may feel more able to talk about and understand your feelings,
- **relationship difficulties** - you may learn to understand difficulties you are having in relationships and ways to make sense of them (MIND, 2016d).

How long until I feel better?

The time it takes for you to feel better can be individual to you, and may vary from person to person. You may feel an immediate sense of relief when you begin therapy. This might be because you are being listened to for the first time, or because you have been struggling for a long time.

You may also feel anxious or distressed at first. This may be because you have to focus on difficult feelings that you might prefer to ignore. You may find it helpful to discuss any concerns you have about how you are reacting to the therapy - at any stage (MIND, 2016d).

Can therapy make me feel worse?

Therapy can be challenging and upsetting. It can involve talking about difficult situations and painful feelings, which might make you feel worse in the short term. You may find this process can also be physically tiring.

If you do start to feel worse, you might find this frustrating and disappointing if you're not reacting to your treatment as you'd hoped. If you do feel worse you can -

- **Talk to your therapist openly about how you are feeling or how you work together**. This could help you get the most from your therapy and get extra support if you need it.
- **Contact your therapist for emergency support** out of appointments, if this is something your therapist offers. Remember to check with them in advance if this is okay.
- **Call a listening service**, like the Samaritans. They can listen to anything that is upsetting you.
- **Try online peer support** for extra support in between sessions. Mind runs its own online support community, Elefriends. If you're using the internet for support for your mental health, take a look at our pages on how to keep yourself safe online.
- **Contact a crisis service** if you feel you need urgent help. See our pages on crisis services for more information on what options there are and when to use them (MIND, 2016d).

What should I know before starting a talking treatment?

Here you can find information about -

- Being ready for therapy?,
- What can I ask them?,
- What should the therapist tell me about?,
- talking treatments and confidentiality (MIND, 2016d).

Being ready for therapy?

Although many people can benefit from talking treatments, not everyone finds it helpful. You might find that it just doesn't suit you, or doesn't meet your needs at the current time. Before deciding to have therapy, it might be helpful to think about the following -

- **Do I want to talk to a therapist about something that is troubling me or would like professional help with?** Therapy can involve talking to a therapist about anything that is confusing, painful or uncomfortable that you would like help with.
- **Am I comfortable talking about my feelings?** Therapy can involve becoming aware of your anxieties and emotions. Initially, you may find this process uncomfortable or distressing.
- **Is there anything I need help with before starting therapy?** You may find there are situations or problems you want help with before you feel able to consider therapy (MIND, 2016d).

What can I ask them?

You can ask your therapist questions about your treatment or their approach at any point before you start therapy, during it, or when you end. When starting a talking treatment, you may want to ask about -

- your therapist's qualifications [63],
- the type of therapy they practice or the treatment they have offered you,
- how long the therapy will last and its structure,
- if there is any cost involved

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[63] It's good practice for a therapist to be a member of a professional body, such as the BACP, BABCP, the UKCP or the British Psychological Society (BPS). You can ask them about their professional qualifications and training. You can also check these with their professional body, whose websites have details of what membership means and any ethical guidelines their members must adhere to.

- their policy on confidentiality (MIND, 2016d).

If you are thinking of seeing a therapist privately, see our page on private treatment for more information about questions you may want to ask (MIND, 2016d).

What should the therapist tell me about?

Your therapist should tell you about the talking treatment they are offering you - this is called informed consent [64]. You should expect to be told about -

- what the treatment involves,
- the benefits and risks involved,
- any alternatives,
- what will happen if the treatment doesn't go ahead (MIND, 2016d).

Your therapist should also work with you to develop an agreement or 'contract' of how you would both like the sessions to work. This may include agreeing about -

- **Frequency of sessions** - when they will take place and for how long. See About sessions? for more information about how sessions can be structured, how long they last and where they might take place.
- **Payment** - if you're paying for therapy, you may agree how you can pay, how much and when.
- **Confidentiality and consent** - what rules they have about consent and confidentiality, and when the therapist may need to break confidentiality (MIND, 2016d).

Having your say in your treatment

Making decisions about your treatment should be a conversation, involving both you and your health care professionals. This is sometimes called shared decision making. You should expect to have a say in what treatments you receive. See seeking help for a mental health problem for more information about how to have your say in treatment and make yourself heard (MIND, 2016d).

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[64] 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

Is it confidential?

Therapy is always confidential, and this is an important part of the working relationship between you and the therapist, making it safe for you. However, there are some exceptions, which allow the therapist to work responsibly. For example -

- **Supervisions** - therapists always discuss clients regularly with a supervisor (an experienced therapist who is qualified to provide supervision) who also has to maintain confidentiality. Supervision is an essential part of the work and it's seen as unethical for a therapist to work without it because -
  - it helps your therapist look after their own mental health, so they're better able to support you,
  - it means there is an impartial third party who is aware of how your therapist is treating you, and can make sure that your treatment is effective and appropriate,
- **Safety** - if, under any circumstances, the therapist is concerned that you are at serious risk of harming yourself or someone else, they may need to inform your GP, health care professional or someone else.
- **Organisational confidentiality** - if your therapist is working as part of a GP practice, confidentiality may apply to the practice as a whole rather than to the individual therapist. This may mean that information is available to your GP. If this is the case, the therapist should make it clear to you at the start (MIND, 2016d).

About sessions?

Here you can find information about -

- How are sessions delivered?,
- how sessions are structured
- what to do if you're not happy with your treatment (MIND, 2016d).

How are sessions delivered?

Talking treatment sessions can take a number of different forms, depending on your individual needs, your choice and the type of therapy you're offered or which is available (MIND, 2016d).

Your treatment might be delivered -

- individually, with just you and the therapist,
- in a group,
- with your family members, partner, friend or colleague (see Types of talking therapies for more information about relationship therapy and family therapy) (MIND, 2016d).

You might get treatment at -

- an NHS clinic,
- a hospital,
- school,
- university,
- work,
- your therapist's office or home,
- a charity's therapy rooms,
- over the phone,
- through a computer programme or book (MIND, 2016d).

You might be treated by a -

- counsellor,
- psychotherapist,
- psychologist,
- psychiatrist (MIND, 2016d).

How are sessions structured?

The structure of the therapy sessions may vary, depending on -

- the type of therapy you have,
- how the therapy is delivered - for example, one-to-one or in a group,
- the problem you want help with - for example, your therapist may go through specific exercises designed to help you with the problem you're experiencing; or you might have a more general discussion about how you're feeling (MIND, 2016d).

What will they ask me?

What a therapist asks you may vary depending on the problem you want help with and the type of therapy you are getting. Therapists may ask you about -

- your relationships,
- your childhood,
- your emotions,

- your thoughts,
- your behaviour,
- situations or events you find difficult (MIND, 2016d).

How long is each session?

Sessions can last between 30 minutes to an hour and a half, but most commonly sessions last for 50 minutes.

The length of sessions may vary depending on the type of therapy you have, the problem you want help with and how well you're feeling. The way in which therapy is delivered may also affect the length of sessions - for example, group sessions may last a little longer (MIND, 2016d).

How often will I have sessions?

How often you have sessions may also vary. You may see a therapist once a week, or two–three times a week.This may depend on -

- the type of therapy you have,
- where you access therapy from,
- how well you're feeling - when you're unwell, you may see a therapist more frequently (MIND, 2016d).

How long will I stay in therapy?

How long you have therapy for may depend on where you go and who you see. Therapy can be -

- time-limited, meaning it may last a set number of sessions. Most therapists through the NHS offer time-limited sessions,
- open-ended, meaning it can continue for as long as you need it. Most private therapists will take clients on for open-ended work (MIND, 2016d).

How will I feel when it ends?

You may find when therapy comes to an end, you can feel a mixture of feelings. You may feel -

- sad that therapy and the relationship with your therapist has ended,
- positive to move on (MIND, 2016d).

This may depend on the experience you've had of therapy and the therapeutic relationship you've formed with your therapist. If you are concerned about how you will feel when therapy ends, you can talk to your therapist about this at any time during treatment (MIND, 2016d).

What should I do if I'm not happy with the therapy?

It's important to remember that therapy can be challenging, and hard work. Therapeutic relationships can be challenging because they often involve talking about difficult feelings, thoughts and situations. It can also take time to build trust and feel comfortable (MIND, 2016d).

However, you may not be happy with the therapy you are getting for a number of reasons. For example, you may be unhappy with -

- the type of therapy you are getting,
- the relationship with the therapist (MIND, 2016d).

If you are not happy with any aspect of your therapy, you may want to consider -

- asking your therapist whether they can offer a different type of therapy,
- talking to your therapist about the difficulties you are having in the therapeutic relationship,
- seeking another therapist, if accessing therapy privately,
- asking your GP or the NHS service if there is another therapist you can work with (MIND, 2016d).

If you are very unhappy with the treatment you have received, you can make a complaint or seek further support -

- The Clinic for Boundary Studies provides support services for people who feel they have been harmed from someone in a position of trust.
- The British Association for Counselling and Psychotherapy (BACP) has a service called 'Ask Kathleen' where you can ask questions about any concerns you have about good practice in therapy.
- Your therapist should also tell you their complaints procedure if you ask (MIND, 2016d).

Types of talking therapies

Which talking treatment is right for me?

It can feel daunting trying to work out which talking treatment is right for you, especially if there are several options available. How effective any treatment is differs from person to person, and you might need to try different things before you find out what works for you. You might want to think about -

- **What you want the therapist to help you with**. For example, is it a diagnosed mental health problem, an upsetting event, or your feelings more generally?
- **How much time you want to spend in therapy**. Some types of therapy have a fixed number of sessions, while others can continue until you feel ready to stop.
- **What sort of work are you okay with trying**. For example, some types of therapy might set you homework or tasks between sessions, while others might involve trying out exercises like visualisations (MIND, 2016d).

Do therapists just use one type of talking treatment?

Some therapists prefer to use one type of therapy over another, while other therapists are trained in many types and may choose an approach they think will work best for you. You may hear them use words like 'eclectic' or 'integrative' when they describe how they work (MIND, 2016d).

Cognitive Analytic Therapy (CAT)

Focus

Cognitive Analytic Therapy (CAT) combines Cognitive Behavioural Therapy's focus on your current thoughts and feelings, with psychodynamic therapy's focus on your past experiences. This can help you understand why you think and feel the way you do, and learn how to change the things you want to (MIND, 2016d).

Good for

CAT can treat a range of mental health problems, emotional and relationship difficulties.

There is some evidence to show it is particularly helpful in treating Borderline Personality Disorder (BPD) and eating disorders (MIND, 2016d).

Duration

Sessions usually last 50 minutes. You might be offered between four to 24 sessions, though 16 sessions are most common. You are likely to be asked to do some 'homework' between sessions, which could be filling in a diary or other worksheets (MIND, 2016d).

Who's involved

You and your therapist (MIND, 2016d).

Availability

Some availability on the NHS, depending on your area. Check with your GP. You can also find a private CAT therapist through the UK Council for Psychotherapy or the Association for Cognitive Analytic Therapy (MIND, 2016d).

Cognitive Behavioural Therapy (CBT)

Focus

CBT looks at how your feelings, thoughts and behaviour influence each other and how you can change these patterns (MIND, 2016d).

Good for

- There's evidence that CBT is particularly effective in treating depression and anxiety, but it can also help most mental health problems.
- There are specially tailored versions of CBT designed to treat obsessive compulsive disorder (OCD), phobias and trauma.
- CBT can also help you cope with some chronic health problems (MIND, 2016d).

Duration

- Sessions often last between 30 to 60 minutes.
- You'll usually be offered between four to 16 CBT sessions.
- You are likely to be asked to do some 'homework' between sessions (MIND, 2016d).

Who's involved

You and your therapist (MIND, 2016d).

Availability

Available through the NHS, often delivered through your local IAPT service. May be long waiting lists. You can find a private therapist through the British Association for Behavioural and Cognitive Psychotherapies (MIND, 2016d).

Variants

- CBT with exposure response prevention for OCD,
- CBT with exposure therapy for OCD or phobias,
- Trauma focused CBT for PTSD,
- Mindfulness Based Cognitive Therapy (MBCT),
- Rational Emotive Behaviour Therapy,
- Dialectical Behaviour Therapy DBT,
- Cognitive Therapy,
- Behaviour Therapy (MIND, 2016d).

Counselling

Focus

Counselling aims to give you a safe, confidential space to talk about your thoughts and feelings with someone who'll listen to you. Counselling is often a shorter, more focused treatment than psychotherapy. You are likely to focus on one or two particular issues you want to work on, and you might not go into too much depth about your past or difficult thoughts and feelings (MIND, 2016d).

Good for

- Counselling can help you cope with mild versions of common mental health problems, like depression and anxiety.
- Counselling is also often offered to help you handle a specific issue, like bereavement or stress at work (MIND, 2016d).

Duration

- Counselling sessions usually last 30 to 60 minutes.

- Counselling can last anywhere from one session to several months' treatment.
- How long you continue to see your counsellor depends on the issue you're seeking help with and how you access counselling (MIND, 2016d).

Who's involved

You and your counsellor (MIND, 2016d).

Availability

Available through the NHS, often through your local IAPT service. You can find a private counsellor through the British Association of Counselling and Psychotherapy's website It's Good To Talk.

You can also access counselling through charities like Cruse Bereavement Care, Rape Crisis and Relate if you want help with the issue each charity deals with (MIND, 2016d).

Couples and relationship therapy

Focus

Relationship therapy can use techniques from a range of therapeutic styles, with the aim of helping you both better understand your relationship and reflect on how to change and problems you would like to tackle (MIND, 2016d).

Good for

Any issues that you want to address as part of a relationship. This might include -

- mental health problems as they impact family relationships,
- physical health problems as they impact family relationships,
- other relationship issues like breakdown in your relationship, divorce, becoming parents, bereavement, and other conflict (MIND, 2016d).

Duration

- Sessions may last 50 to 90 minutes.
- If you are offered relationship therapy through the NHS, this is likely to be for a fixed number of sessions.

- If you seek relationship therapy privately, you are more likely to be able to carry on seeing your therapist indefinitely (MIND, 2016d).

Who's involved

- you,
- your therapist,
- another person. Often this is your partner, but it can be a family member or colleague, depending on the relationship you want help with (MIND, 2016d).

Availability

Some availability on the NHS. You can find relationship therapy through the British Association of Counselling and Psychotherapy's website It's Good To Talk (MIND, 2016d).

Dialectical Behaviour Therapy (DBT)

Focus

DBT was developed from CBT specifically to help people experiencing borderline personality disorder (MIND, 2016d).

Good for

DBT was specifically developed to treat borderline personality disorder, but it can also be successful for people experiencing eating disorders and self-harming behaviour (MIND, 2016d).

Duration

A course of DBT usually lasts for about a year. This consists of -

- Weekly one-to-one therapy sessions lasting 50 to 60 minutes.
- Group skills training, which can be as often as once a week.
- Homework between sessions.
- Crisis counselling by telephone when you need it (MIND, 2016d).

Who's involved

- you,
- a group of people also on the same course of DBT,
- a team of therapists (MIND, 2016d).

Availability

DBT is available on the NHS in some areas, though waiting lists can be long. There is also some limited availability of DBT privately (MIND, 2016d).

Family therapy (or Systemic Therapy)

Focus

Family therapy can use techniques from various therapeutic styles, with the aim of helping you to understand as a family any difficulties you're going through, particularly in your relationships to each other. The therapist can then help you reflect and identify how you can change any problems you might want to (MIND, 2016d).

Good for

Any issues that you want to address as part of a whole family. This might include -

- mental health problems as they impact family relationships,
- physical health problems as they impact family relationships,
- other family issues like bereavement, adoption, divorce, abuse and other conflict (MIND, 2016d).

Duration

- Sessions may last 50 to 90 minutes.
- If you are offered family therapy through the NHS this is likely to be for a fixed number of sessions.
- If you seek family therapy privately, you are more likely to be able to carry on seeing your therapist indefinitely (MIND, 2016d).

Who's involved

- you,

- your therapist,
- any members of your family who feel they would benefit from talking through problems with a trained professional (MIND, 2016d).

Availability

Available on the NHS in some areas. You can find a family therapist through the British Association of Counselling and Psychotherapy's website It's Good To Talk (MIND, 2016d).

Interpersonal therapy (IPT)

Focus

IPT focuses on your relationships with other people and how your thoughts, feelings and behaviour are affected by your relationships, and how they affect your relationships in turn (MIND, 2016d).

Good for

- IPT has been shown to be particularly effective in treating depression,
- IPT has specifically adapted versions to treat -
  - eating disorders,
  - mild depression and depression during and after pregnancy,
  - bipolar disorder,
  - borderline personality disorder (BPD),
- IPT has not been shown to work as well in treating anxiety (MIND, 2016d).

Duration

- Sessions usually last 50 minutes.
- You're likely to be offered a set number of sessions, usually 16, through the NHS.
- IPT for BPD lasts 24 sessions (MIND, 2016d).

Who's involved

You and your therapist (MIND, 2016d).

Availability

Most IPT therapists work in the NHS, often in your local IAPT service. However, you can find private dynamic interpersonal therapy (DIT) through the British Psychoanalytic Council (MIND, 2016d).

Psychodynamic therapy

Focus

In psychodynamic therapy you'll talk to your therapist about what's going on in your life now, what's happened to you in the past, and how your past experiences can affect how you think, feel and behave in the present.

Your therapist will help you make the connections between the past and the present. They will also help you reflect on how you can start to make decisions and behave based on how you are feeling now instead of what has happened in the past (MIND, 2016d).

Good for

- Psychodynamic therapy can be most beneficial to people experiencing depression, anxiety, personality or eating disorders, or other personal difficulties - although it can be useful for a wide range of mental health problems.
- You're likely to get the most out of psychodynamic therapy, whatever reason you're seeking therapy, if you're willing to and interested in exploring your past and your subconscious motivations. This can be a difficult and upsetting process.
- There is a version specifically useful for people experiencing eating disorders called focul psychodynamic therapy (MIND, 2016d).

Duration

- Sessions usually last 50 minutes,
- Therapy delivered through the NHS is often for a limited number of sessions of about six to 18 months,
- Private therapists will often continue treatment until you both decide you're ready to end therapy (MIND, 2016d).

Who's involved

You and your therapist (MIND, 2016d).

Availability

Some availability on the NHS, often through your local IAPT service. You can find a private therapist through BACP (MIND, 2016d).

How can I access a talking treatment?

Through the NHS

You can access free talking treatments through the NHS, although this may depend on what's available in your local area and the nature of the problem you want help with.

You can get talking treatments on the NHS through -

- **self-referral** - some services offer self-referral options, where you can contact the service directly to refer yourself for a talking treatment. This is more common for IAPT services. See the NHS service finder page to search for services near you and find out if you can self-refer.
- **your GP** - (MIND, 2016d).

What is IAPT?

Improving Access to Psychological Therapies (IAPT) is a programme offering talking treatments for common mental health problems, such as anxiety and depression. This programme is also called 'psychological services (IAPT)' in some places, as the government is in the process of changing its name.

Most areas have an IAPT service, however, some talking treatments are not available in all areas and the waiting times can be long. See the NHS Choices website to find your local IAPT service. Also see our pages on seeking help for a mental health problem for more information about having your say in your treatment.

If you are finding it very difficult to access the service you want on the NHS, you could think about exploring options through the private sector. See What if I want to go private? for more information (MIND, 2016d).

Through a charity or organisation

Some voluntary, community and charity sector organisations can offer you more affordable access to talking treatments, for example -

- Your Local Mind may be able to offer you talking treatments.
- Organisations, such as Cruse Bereavement Care, offer free counselling services if you have experienced the death of someone close to you.
- Mental Health Matters (MHM) also offers a telephone counselling service and talking therapies in some areas.
- If you are a student, your university or educational institution may have counselling services they can offer you.
- Your workplace might offer an Employee Assistance Programme that could help you access a limited number of free therapy sessions (MIND, 2016d).

You may also find websites offering free talking treatments online, but be aware that these sites might not offer professionally-trained therapists or adhere to an ethics policy. See What should I know before starting a talking treatment? our page on what to find out before starting therapy for more information on making sure you're confident in the therapy you choose.

See also How to stay safe online for more information about how to safely find information and support for your mental health online (MIND, 2016d).

What if I want to go private?

Private therapists usually charge for appointments and can be expensive, although some therapists may offer reduced rates for people on low incomes. You may consider seeing a therapist privately for a number of reasons, for example -

- the variety of talking treatments available to you may be greater,
- you may be able to access treatment more quickly,
- you may want to continue therapy over a longer period of time than you can on the NHS (MIND, 2016d).

How can I find a therapist?

You can find a therapist through the British Association for Counselling and Psychotherapy (BACP). Any therapist you find through this website will have signed up to the BACP's ethical framework, which means they must -

- behave in a professional and safe way towards you,
- explain their responsibilities regarding confidentiality,

- tell you their complaints procedure if you ask for it (MIND, 2016d).

What should I ask when arranging an appointment?

Before you decide whether you want to book an appointment, you may want to ask about the following -

- How much do they charge per session? Do they offer reduced rates for people on low incomes?
- Do they still charge for missed appointments?
- Do they offer a free introductory session to allow you to decide whether you can work together?
- When and where would the sessions take place?
- You can also ask them for details of their qualifications and to explain what the qualifications mean (MIND, 2016d).

Glossary

A

advance decision An advance decision is a statement of instructions about what medical treatment you want to refuse in case you lose the capacity to make these decisions in the future. It is legally binding 51, 52, 134, 139, 150, 159, 168

advocate An advocate is another person that helps you express your views and wishes, and helps make sure your voice is heard 47, 49, 334

affective disorders mental illnesses characterized predominantly by marked changes in mood, including manic depression 206

akinesia poverty of movement 205

alcoholic dementia a form of dementia caused by long-term, excessive consumption of alcoholic beverages, resulting in neurological damage and impaired cognitive function 86

anxiety anxiety is a feeling of unease, such as worry or fear, that can be mild or severe 116

aphasia aphasia is a condition that affects the brain and leads to problems using language correctly. People with aphasia make mistakes in the words they use, sometimes using the wrong sounds in a word, choosing the wrong word, or putting words together incorrectly. Aphasia also affects speaking and writing in the same way. Many people with the condition find it difficult to understand words and sentences they hear or read 17, 115, 143

aspiration pneumonia a chest infection caused by food particles falling into your lungs 144, 148, 232

ataxia the term for a group of disorders that affect co-ordination, balance and speech 153, 160, 191–193

attorney An attorney is a person over the age of 18 whom you have appointed to make decisions on your behalf about your welfare and/or your property and financial affairs. You need an attorney if you are unable to make such decisions yourself. If you do not have the capacity to appoint an attorney,

the Court of Protection may appoint a deputy to perform this role.
- A health and welfare attorney makes decisions about things like your daily routine, your medical care, where you live and, if you specially request this, whether you should have life-sustaining treatment.
- A property and financial affairs attorney makes decisions about things like paying bills, collecting benefits and selling your home 51, 52

autosomal recessive A genetic condition that appears only in individuals who have received two copies of an autosomal gene, one copy from each parent. The gene is on an autosome, a nonsex chromosome. The parents are carriers who have only one copy of the gene and do not exhibit the trait because the gene is recessive to its normal counterpart gene 190, 195

B

BMI body mass index - a measure that uses your height and weight to work out if your weight is healthy. The BMI calculation divides an adult's weight in kilograms by their height in metres squared. For example, A BMI of 25 means 25kg/m2 71

bowel incontinence an inability to control bowel movements, resulting in involuntary soiling. It's also sometimes known as faecal incontinence . 116, 160, 164

bradykinesia slowness of movement 205

C

catatonic staying frozen in one position for a long time; or repeating the same movement for no obvious reason; or being extremely restless, unrelated to medication 46

chorea fidgety or jerky movements 168, 174, 177

chronic A health condition or disease that is persistent or otherwise long-lasting in its effects or a disease that comes with time 29, 30, 85, 87, 180–182, 251

cognition a generic term embracing the mental activities associated with thinking, learning, and memory 121, 168, 169, 172, 250

cognitive dysfunction Also known as **brain fog**. This disorder can affect a person's thoughts, memories, and reasoning capabilities, and can manifest itself as trouble with recalling words, with the ability to do math problems, and with one's mental focus 191–193

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 46, 48–52, 94, 219, 247, 290

Court of Protection The Court of Protection makes decisions and appoints deputies to act on your behalf if you are unable to make decisions about your personal health, finance or welfare 51

D

delirium an acute, transient and reversible state of confusion, usually the result of other organic processes (infection, drugs, dehydration etc.), the onset is acute and the cognition of the patient can be highly fluctuant over a short period of time 74, 114, 250–256

depression Depression affects people in different ways and can cause a wide variety of symptoms. They range from lasting feelings of sadness and hopelessness, to losing interest in the things you used to enjoy and feeling very tearful. Many people with depression also have symptoms of anxiety. There can be physical symptoms too, such as feeling constantly tired, sleeping badly, having no appetite or sex drive, and complaining of various aches and pains. The severity of the symptoms can vary. At its mildest, you may simply feel persistently low in spirit, while at its most severe depression can make you feel suicidal and that life is no longer worth living 13, 18, 21, 28–45, 57–62, 64–66, 73, 74, 82, 85, 90, 91, 95, 100, 109, 114–116, 122, 126, 128, 132, 136, 138, 147, 153, 159, 170, 171, 176, 184, 185, 226, 232, 252, 253, 264, 265, 268, 269, 272–275, 328, 329, 339, 340, 344, 345, 347–349

deputy A deputy is a person the Court of Protection appoints to make decisions for you once you have lost capacity to make them yourself. A deputy usually makes decisions about finances and property. The court can appoint a deputy to take healthcare and personal care decisions, though this is relatively rare 51, 52

diagnosis the process of determining by examination the nature and circumstances of a diseased condition 9, 22, 24, 31, 38, 39, 61, 69, 91–100, 109, 110, 116–119, 128–130, 132, 134, 136, 139, 144–146, 157, 158, 160, 165, 168, 171, 174, 181, 185, 188, 193, 194, 198, 225, 227, 229–231, 252, 255, 256, 279–281, 286

dialectical behaviour therapy This is a type of talking therapy which was originally developed by an American psychologist named Marsha Linehan. It is based on cognitive behavioural therapy, but has been adapted to meet the particular needs of people who experience emotions very intensely 335, 379

dysarthria difficulty speaking caused by problems controlling the muscles used in speech 191–193

dysphagia dysphagia is the medical term for swallowing difficulties. Some people with dysphagia have problems swallowing certain foods or liquids, while others can't swallow at all 116, 136, 153, 160, 191, 192, 213, 229, 233

dyspraxia a complex neurological condition, which affects muscle co-ordination and perception 226

dystonia a medical term for a range of movement disorders that cause muscle spasms and contractions 143, 160, 192, 193

E

electroencephalogram it is a recording of brain activity 225, 379

extrapyramidal side-effects term used to describe the development of a variety of movement disorders as a result of taking certain medications such as neuroleptic drugs. These side effects may include akathisia (restlessness), dystonias (involuntary, sustained muscle spasms), parkinsonism and tardive dyskinesias (abnormal, involuntary muscle movements) 203

F

foam cells having the appearance of foam in alveolar spaces 193

G

gelastic cataplexy sudden loss of muscle tone or drop attacks 193

general anaesthetic a state of controlled unconsciousness caused by medications sending you to sleep in a controlled way 45, 48, 53, 55–57, 158

H

hallucinations where someone sees, hears, smells, tastes or feels things that don't exist outside their mind . 16, 81, 99, 115, 127, 128, 136, 138, 139, 153, 225, 251, 340

hepatosplenomegaly is enlargement of both the spleen and the liver 190

I

idiopathic of unknown cause, or as one doctor friend of mine stated, ”We don't know!” 197, 201, 202, 252, 255

Information Standard an independent quality mark of good practice in health information 313

informed 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 356

K

Korsakoff's syndrome a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1) . . . 86

M

mania feeling very high and overactive (less severe mania is known as hypomania) . . . 34

N

neurologist a doctor who specialises in conditions of the nervous system, in conditions that affect the brain and spinal cord 94, 130, 137, 144, 145, 157, 158, 165, 168, 174, 175, 225, 230

neurotransmitter chemical messengers produced by the nerve cells in the brain. Their purpose is to pass messages from the brain to other parts of the body. There are a number of different neurotransmitters which each with a particular function. For instance dopamine, which is in short supply in the brains of people with Parkinson's, is involved in processes that involve the co-ordination of movement. Serotonin has a variety of functions, including being involved in controlling states of consciousness and mood 208

NHS The 'National Health Service' is the publicly funded national healthcare system in the UK. The organisation, funded primarily by taxation, provides free or low-cost healthcare to all legal residents of the UK. Medications are subsidised as well and prescriptions may be free when situations warrant 38, 41, 42, 57, 63, 66, 86, 88–90, 105, 109, 110, 150, 213, 304, 313, 334, 335, 358–360, 362–369

O

occupational therapist they help people of all ages to carry out everyday activities which are essential for their own health and wellbeing . . . 41, 102, 105

ocular apraxia difficulty moving the eyes on command . . . 226

optic ataxia the condition in which some, or all, aspects of visual guidance over reaching with the hand and arm are lost . . . 226

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 . . . 149, 154, 196, 222, 234

PET scans the PET (Positron Emission Tomography) scan provides anatomical information about the brain. This means that PET scans can assess the functioning of different parts of the brain while the individual is carrying out a particular movement or engaging in a specific mental activity. With PET it is also possible to examine the state of particular neurotransmitter receptor sites in the brain. PET scans require the use of radioactive material in very small quantities, usually the equivalent to the radioactive exposure during a transatlantic flight. The dopamine systems in the brain, which are affected in Parkinson's, can be assessed with PET scanning 207

phenotype the physical appearance resulting from the inherited information. e.g. someone with blue eyes has the phenotype blue eyes 190, 191

prognosis a forecasting of the probable course and outcome of a disease, especially of the chances of recovery 9

Q

qualifications It's good practice for a therapist to be a member of a professional body, such as the BACP, BABCP, the UKCP or the British Psychological Society (BPS). You can ask them about their professional qualifications and training. You can also check these with their professional body, whose websites have details of what membership means and any ethical guidelines their members must adhere to 355

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 . 100, 196, 198, 212, 221, 283

R

respiratory failure loss of lung function 154, 159, 191, 193, 235

S

self-harm this is when somebody intentionally damages or injures their body. It's usually a way of coping with or expressing overwhelming emotional distress 37, 43, 62, 318, 326–338, 342, 343

simultanagnosia a rare neurological disorder characterised by the inability of an individual to perceive more than a single object at a time 226

sphingolipids a member of a class of lipids (fat-soluble constituents of living cells) containing the organic aliphatic amino alcohol sphingosine or a substance structurally similar to it 190

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suicide the act of intentionally ending your life 37, 61, 62, 171, 327, 329, 337–344, 348

T

toxic Capable of causing injury or death, especially by chemical means; poisonous 58, 162, 327

tremor a type of uncontrollable shake or tremble of part of the body 76, 136, 143, 159, 177, 192, 198, 201, 203, 205, 208–211, 214, 228, 268

V

vertical supranuclear gaze palsy difficulty with upward and downward eye movement 192, 193

visual agnosia the loss of the ability to recognise objects, people, or shapes 226

X

X-ray a quick and painless procedure commonly used to produce images of the inside of the body 118, 238, 239, 241, 243, 255

Acronyms

A

AEA Action on Elder Abuse 297

ASM Acid sphingomyelinase 190, 191, 194

B

BSE bovine spongiform encephalopathy 151, 155, 157, 161

C

CAT Cognitive Analytic Therapy 361, 362

CAT scan computerised axial tomography scan 95, 238

CBD corticobasal degeneration 142–150, 257

CBT cognitive behavioural therapy . . 27, 39–41, 74, 132, 334–336, 345, 349, 350, 352, 353, 362, 363, 365

CJD Creutzfeldt-Jakob disease 150–162

CRT crisis resolution team 343, 347

CSF cerebrospinal fluid 196, 197

CT computerised tomography . . . 95, 129, 130, 137, 175, 197, 225, 238–241, 243, 246, 251, 255

D

DBT see dialectical behaviour therapy 335, 336, 352, 363, 365, 366

DLB Dementia with Lewy bodies 134, 135

DVLA Driving and Vehicle Licensing Agency 104, 180, 222, 287

DVLNI Driving and Vehicle Licensing Northern Ireland 104

E

ECT electroconvulsive therapy 45–57

EEG electroencephalogram 225, 246–249

F

FDA Food and Drug Administration 189

G

GP General Practitioner, a community-based doctor 29, 30, 34, 37–43, 58, 60, 62, 63, 66, 69, 74, 76, 77, 80, 81, 88–90, 92–94, 96–103, 105, 106, 108–110, 116, 117, 128–131, 133, 137, 144, 160, 165, 166, 168, 174, 175, 179, 185–187, 200, 211, 220, 221, 264, 269, 270, 274, 280, 283–286, 295, 296, 298, 300, 301, 304, 309, 313, 321, 328, 330, 334, 335, 341, 344, 345, 348, 349, 357, 360, 362

I

iCJD Iatrogenic Creutzfeldt-Jakob disease 156, 157, 161

IPT interpersonal therapy 41, 367, 368

L

LPA lasting power of attorney 102, 103

M

MCI Mild cognitive impairment 183–187

MDT multidisciplinary team 231

MMSE mini mental state examination 118, 237, 254

MRI magnetic resonance imaging 95, 129, 130, 137, 145, 165, 175, 197, 225, 230, 240–243, 246

N

NPD Niemann-Pick disease 190

NPH Normal pressure hydrocephalus 196–198

O

OCD obsessive compulsive disorder 362, 363

OT occupational therapist 102, 130, 178, 233

P

PCA posterior cortical atrophy 223–227

PET positron emission tomography 95, 145, 230, 243–246

PSP progressive supranuclear palsy 227–234

S

SLT speech and language therapist 233

SNRI serotonin-noradrenaline reuptake inhibitor 44

SPECT single photon emission computerised tomography 95, 137, 246

SSRI selective serotonin reuptake inhibitor 43, 44, 166, 176, 203

T

TCAS Tricyclic antidepressants 43, 44

TIA transient ischaemic attack 124, 131, 252

TMS Transcranial magnetic stimulation 57

U		
UTI	Urinary Tract Infection	74, 75, 252, 254
V		
vCJD	variant Creutzfeldt-Jakob disease	155, 156

Bibliography

ageuk (2015) *Depression* url: http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/depression/what-is-depression/ (cit. on pp. 17, 29–32, 38–39, 63–64)

— (2016) *Dementia* url: http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/dementia/what-is-dementia/ (cit. on pp. 107–111)

alz.org (2016a) *Korsakoff's Syndrome* url: http://www.alz.org/dementia/wernicke-korsakoff-syndrome-symptoms.asp#about (cit. on pp. 180–183)

— (2016b) *Mixed dementia* url: http://www.alz.org/dementia/mixed-dementia-symptoms.asp (cit. on pp. 188–189)

— (2016c) *Posterior cortical atrophy* url: http://www.alz.org/dementia/posterior-cortical-atrophy.asp (cit. on p. 223)

— (2016d) *Types of dementia* url: http://www.alz.org/dementia/types-of-dementia.asp# (cit. on pp. 12–13, 15–20, 22, 111, 114, 168, 170, 174, 188, 197, 199, 210)

Armstrong, L. E. et al. (2011) "Mild Dehydration Affects Mood in Healthy Young Women" in: *The Journal of Nutrition* 111, p. 142000 doi: 10.3945/jn.111.142000 url: http://jn.nutrition.org/content/early/2011/12/20/jn.111.142000.abstract (cit. on p. 276)

Barros, S. (2016) *Acute Confusion* url: http://www.fastbleep.com/medical-notes/other/28/84/558 (cit. on pp. 251–255)

Birtles, A. (2016) *Delirium, confusion and assessing a confused patient* url: http://geekymedics.com/delirium-acute-confusional-states/ (cit. on pp. 251–256)

Chekea, L. G., J. S. Simonsa and N. S. Claytona (2015) "Higher body mass index is associated with episodic memory deficits in young adults" in: *The Quarterly Journal of Experimental Psychology* doi: 10.1080/17470218.2015.1099163 url: http://www.tandfonline.com/doi/full/10.1080/17470218.2015.1099163 (cit. on p. 71)

Crane, M. (2016) *Long-term stress erodes memory* Ohio State University url: https://news.osu.edu/news/2016/03/02/long-term-stress-erodes-memory/ (cit. on p. 70)

DEPRESSIONALLIANCE (2016a) *Five ways to wellbeing* URL: http://www.depressionalliance.org/information/five-ways-wellbeing (cit. on pp. 67–68)

— (2016b) *Nutrition* URL: http://www.depressionalliance.org/information/nutrition (cit. on pp. 274–275)

— (2016c) *What is depression?* URL: http://www.depressionalliance.org/information/what-depression (cit. on pp. 29, 34–35, 39, 58, 322)

DEVORE, E. E. et al. (2014) "Sleep Duration in Midlife and Later Life in Relation to Cognition" in: *Journal of the American Geriatrics Society* 62.6, pp. 1073–1081 DOI: 10.1111/jgs.12790 URL: http://onlinelibrary.wiley.com/doi/10.1111/jgs.12790/abstract (cit. on p. 71)

DOBSON, L. (2015) "Stress: what it does to your health" in: *Saga Magazine* URL: http://www.saga.co.uk/magazine/health-wellbeing/mind/stress-what-it-does-to-your-health (cit. on pp. 262–265)

ELDERABUSE (2015a) *Family abuse* Action on Elder Abuse URL: http://elderabuse.org.uk/familyabuse (cit. on pp. 293–294)

— (2015b) *Financial abuse* Action on Elder Abuse URL: http://elderabuse.org.uk/financialabuse (cit. on p. 292)

— (2015c) *Neglect* Action on Elder Abuse URL: http://elderabuse.org.uk/neglect (cit. on p. 293)

— (2015d) *Physical abuse* Action on Elder Abuse URL: http://elderabuse.org.uk/physicalabuse (cit. on p. 290)

— (2015e) *Psychological abuse* Action on Elder Abuse URL: http://elderabuse.org.uk/psychologicalabuse (cit. on p. 291)

— (2015f) *Sexual abuse* Action on Elder Abuse URL: http://elderabuse.org.uk/sexualabuse (cit. on p. 290)

— (2015g) *Useful contacts* Action on Elder Abuse URL: http://elderabuse.org.uk/usefulcontacts (cit. on pp. 295–297)

— (2015h) *What is elder abuse: Why does it happen?* Action on Elder Abuse URL: http://elderabuse.org.uk/why-does-it-happen (cit. on pp. 297–298)

FENN, K. et al. (2014) *Missing sleep may hurt your memory* URL: http://msutoday.msu.edu/news/2014/missing-sleep-may-hurt-your-memory/ (cit. on p. 71)

GANIO, M. S. et al. (2011) "Mild dehydration impairs cognitive performance and mood of men" in: *British Journal of Nutrition* 106.10, pp. 1535–1543 DOI: http://dx.doi.org/10.1017/S0007114511002005 URL: http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8425835 (cit. on p. 276)

GÓMEZ-PINILLA, F. (2008) "Brain foods: the effects of nutrients on brain function" in: *Nature Reviews Neuroscience* 9.7, pp. 568–578 DOI: 10.1038/nrn2421 URL: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2805706/ (cit. on p. 72)

Green, S. (2015) *Spot the subtle signs of dementia* Saga.co.UK url: http://www.saga.co.uk/magazine/health-wellbeing/mind/dementia-signs (cit. on pp. 80–81)

Greendale, G. A. et al. (2009) "Effects of the menopause transition and hormone use on cognitive performance in midlife women" in: *Neurology* 72.21, pp. 1850–1857 doi: 10.1212/WNL.0b013e3181a71193 url: http://www.ncbi.nlm.nih.gov/pubmed/19470968 (cit. on p. 70)

hailshamhouse (2016) *Korsakoff's Syndrome* url: http://hailshamhouse.co.uk/services/korsakoffs-syndrome/ (cit. on pp. 180–181, 183)

Llewellyn, D. and A. Bayer (2016) *Risk factors for dementia* Alzheimers Org UK url: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=102 (cit. on pp. 82–90)

McKeith, I. and Z. Walker (2013) *What is dementia with Lewy bodies (DLB)?* Alzheimers.Org.UK url: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=113 (cit. on p. 135)

Mendez, M. F., M. Ghajarania and K. M. Perryman (2002) "Posterior cortical atrophy: Clinical characteristics and differences compared to Alzheimer's disease" in: *Dementia and Geriatric Cognitive Disorders* 14.1, pp. 33–40 (cit. on p. 226)

mentalhealth (2016a) *Anxiety* Mental Health Foundation url: https://www.mentalhealth.org.uk/a-to-z/a/anxiety (cit. on pp. 13–14, 24–28)

— (2016b) *Diet and mental health* Mental Health Foundation url: https://www.mentalhealth.org.uk/a-to-z/d/diet-and-mental-health (cit. on p. 273)

mind (2015) *How to stay safe online* url: http://www.mind.org.uk/information-support/tips-for-everyday-living/online-safety-and-support/overview/?o=6863 (cit. on pp. 312–326)

— (2016a) *Complementary and alternative therapy* url: http://www.mind.org.uk/information-support/drugs-and-treatments/complementary-and-alternative-therapy/ (cit. on pp. 304–310)

— (2016b) *Electroconvulsive therapy (ECT)* url: http://www.mind.org.uk/information-support/drugs-and-treatments/electroconvulsive-therapy-ect/ (cit. on pp. 45–57)

— (2016c) *Self-harm* url: http://www.mind.org.uk/information-support/types-of-mental-health-problems/self-harm/ (cit. on pp. 326–338)

— (2016d) *Talking treatments* url: http://www.mind.org.uk/information-support/drugs-and-treatments/talking-treatments/ (cit. on pp. 350–371)

Murphy, J. (2015) *10 post-menopause positives* Saga Co UK url: http://www.saga.co.uk/magazine/health-wellbeing/wellbeing/10-post-menopause-positives (cit. on pp. 258–260)

Murphy, J. (2016) *What's messing with your memory?* Saga.co.UK url: http://www.saga.co.uk/magazine/health-wellbeing/mind/what-causing-memory-problems (cit. on pp. 69–72)

NHS (2014a) *Depression* url: http://www.nhs.uk/conditions/depression/Pages/Introduction.aspx (cit. on pp. 29, 32–37, 40–46, 57–62)

— (2014b) *Huntington's disease* url: http://www.nhs.uk/Conditions/Huntingtons-disease/Pages/Introduction.aspx (cit. on pp. 168–180)

— (2014c) *Understanding stress* url: http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/understanding-stress.aspx (cit. on pp. 265, 269–270)

— (2015a) *About dementia* url: http://www.nhs.uk/conditions/dementia-guide/pages/about-dementia.aspx (cit. on pp. 80–82)

— (2015b) *Abuse and neglect of vulnerable adults* url: http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/vulnerable-people-abuse-safeguarding.aspx (cit. on pp. 289–293, 297–301)

— (2015c) *Benefits of early dementia diagnosis* url: http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-early-diagnosis-benefits.aspx (cit. on pp. 279–281)

— (2015d) *Confusion* url: http://www.nhs.uk/conditions/confusion/Pages/Introduction.aspx (cit. on pp. 310–312)

— (2015e) *Corticobasal degeneration* url: http://www.nhs.uk/conditions/Corticobasal-degeneration/Pages/Introduction.aspx (cit. on pp. 14, 142–150)

— (2015f) *Corticobasal degeneration* url: http://www.nhs.uk/Conditions/Corticobasal-degeneration/ (cit. on p. 257)

— (2015g) *Creutzfeldt-Jakob disease* url: http://www.nhs.uk/Conditions/Creutzfeldt-Jakob-disease/Pages/Introduction.aspx (cit. on pp. 15, 150–162)

— (2015h) *CT scan* url: http://www.nhs.uk/conditions/CT-scan/Pages/Introduction.aspx (cit. on pp. 238–241)

— (2015i) *Dementia diagnosis tests* url: http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-diagnosis-tests.aspx (cit. on pp. 236–238)

— (2015j) *Dementia with Lewy bodies* url: http://www.nhs.uk/conditions/dementia-with-lewy-bodies (cit. on pp. 134, 136–139)

— (2015k) *EEG* url: http://www.nhs.uk/conditions/eeg/pages/introduction.aspx (cit. on pp. 246–249)

— (2015l) *Frontotemporal dementia* url: http://www.nhs.uk/Conditions/frontotemporal-dementia/Pages/Introduction.aspx (cit. on pp. 162–168)

— (2015m) *Looking after someone with dementia* url: http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-carers.aspx (cit. on pp. 281–286)

— (2015n) *Motor neurone disease* url: http://www.nhs.uk/conditions/motor-neurone-disease (cit. on p. 257)

NHS (2015o) *MRI scan* URL: http://www.nhs.uk/conditions/MRI-scan/Pages/Introduction.aspx (cit. on pp. 241–243)

— (2015p) *PET scan* URL: http://www.nhs.uk/Conditions/PET-scan/Pages/Introduction.aspx (cit. on pp. 243–246)

— (2015q) *Progressive supranuclear palsy* URL: http://www.nhs.uk/conditions/Progressive-supranuclear-palsy/Pages/Introduction.aspx (cit. on pp. 227–235)

— (2015r) *Progressive supranuclear palsy* URL: http://www.nhs.uk/conditions/Progressive-supranuclear-palsy (cit. on p. 257)

— (2015s) *Self-harm* URL: http://www.nhs.uk/conditions/Self-injury/Pages/Introduction.aspx (cit. on pp. 327–330, 338)

— (2015t) *Staying independent with dementia* URL: http://www.nhs.uk/Conditions/dementia-guide/Pages/staying-independent-with-dementia.aspx (cit. on pp. 286–287)

— (2015u) *Suicide* URL: http://www.nhs.uk/conditions/Suicide/Pages/Introduction.aspx (cit. on pp. 339–350)

— (2015v) *Vascular dementia* URL: http://www.nhs.uk/Conditions/vascular-dementia/ (cit. on pp. 121–123, 125–134)

— (2016a) *Alzheimers disease* URL: http://www.nhs.uk/conditions/Alzheimers-disease/ (cit. on pp. 111–119)

— (2016b) *Breathing exercise for stress* URL: http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/ways-relieve-stress.aspx (cit. on p. 271)

— (2016c) *Parkinson's disease* URL: http://www.nhs.uk/Conditions/Parkinsons-disease/Pages/Introduction.aspx (cit. on pp. 198–201, 211–223)

— (2016d) *Preventing Alzheimer's disease* URL: http://www.nhs.uk/Conditions/Alzheimers-disease/Pages/Prevention.aspx (cit. on pp. 116, 119–120)

— (2016e) *Tips for coping with depression* URL: http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/dealing-with-depression.aspx (cit. on pp. 65–66)

NIEMANN-PICK (2012a) *Niemann-pick disease* URL: http://www.niemann-pick.org.uk/health-professionals/niemann-pick-disease/niemann-pick-disease-type-c (cit. on pp. 191, 193–195)

— (2012b) *Niemann-Pick Type C* URL: http://www.niemann-pick.org.uk/niemann-pick-disease/niemann-pick-type-c (cit. on pp. 191–192, 194–196)

NINDS (2016) *Normal pressure hydrocephalus* URL: http://www.ninds.nih.gov/disorders/normal_pressure_hydrocephalus/normal_pressure_hydrocephalus.htm (cit. on pp. 197–198)

PARKINSONS (2008) *Drug-induced Parkinsonism* URL: http://www.parkinsons.org.uk/sites/default/files/publications/download/english/fs38_druginducedparkinsonism.pdf (cit. on pp. 202, 204–209)

PARKINSONS (2014) *Types of Parkinson's and parkinsonism* URL: http://www.parkinsons.org.uk/content/types-parkinsons-and-parkinsonism (cit. on pp. 202, 209–210)

PASSMORE, P., S. MAKIN and P. KEHOE (2014) *Vascular dementia* Alzheimers.Org.UK URL: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=161 (cit. on pp. 121–131, 133–134)

PCASUPPORT (2016) *Posterior cortical atrophy* URL: https://www.ucl.ac.uk/drc/pcasupport/information_about_pca (cit. on pp. 224–227)

POITRAS, C. (2012) "Even Mild Dehydration Can Alter Mood" in: *UConn Today* URL: http://today.uconn.edu/2012/02/even-mild-dehydration-can-alter-mood/ (cit. on pp. 72, 277)

RODDA, J. and T. FRYER (2015) *Mild cognitive impairment* Alzheiemers.Org.UK URL: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=120 (cit. on pp. 183–187)

SOLOMONS, L. and J. WALTON (2014) *After a diagnosis* Alzheimers.Org.UK URL: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=122 (cit. on pp. 98–106)

STRESS.ORG (2016a) *Stress* URL: http://www.stress.org/stress-effects/ (cit. on pp. 21, 266, 269)

— (2016b) *Stress - management tips* URL: http://www.stress.org/management-tips/ (cit. on p. 21)

TANG-WAI, D. F., N. R. GRAFF-RADFORD, B. F. BOEVE et al. (2004) "Clinical, genetic, and neuropathologic characteristics of posterior cortical atrophy" in: *Neurology* 63.7, pp. 1168–1174 (cit. on p. 226)

TAYLOR, J. and S. LLIFE (2014) *Assessment and diagnosis* Alzheimers.Org.UK URL: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=260 (cit. on pp. 91–98)

THOMPSON, S. et al. (2008) *Five Ways to Wellbeing: The Evidence* New Economics Foundation URL: http://www.neweconomics.org/publications/entry/five-ways-to-well-being-the-evidence (cit. on p. 68)

VANIER, M. T. (2010) "Niemann-Pick disease type C" in: *Orphanet Journal of Rare Disease* 5.16 DOI: 10.1186/1750-1172-5-16 (cit. on p. 192)

WEBER, M., M. RUBIN and P. MAKI (2013) *Researchers Zero In on Cognitive Difficulties Associated with Menopause* URMC URL: https://www.urmc.rochester.edu/news/story/3714/researchers-zero-in-on-cognitive-difficulties-associated-with-menopause.aspx (cit. on p. 70)

WESTCOTT, P. (2015) "Six common causes of forgetfulness" in: *Saga Magazine* (cit. on pp. 72–77)

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