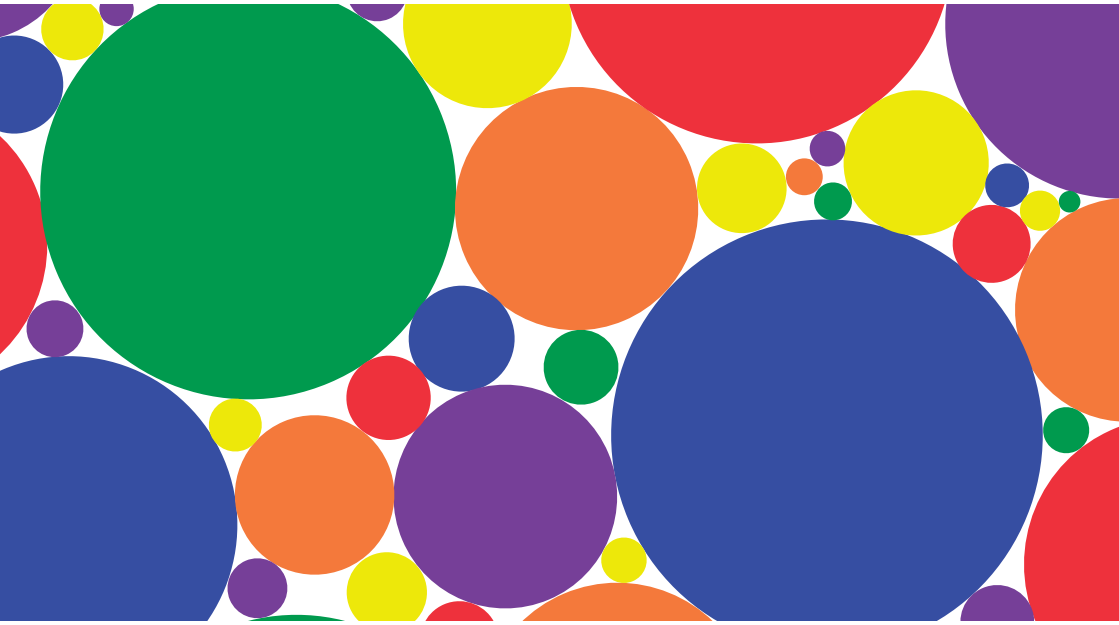
NHS funding processes and waiting times for adult service-users



Trans wellbeing and healthcare

Contents

1. About this publication

This publication will help you understand the processes involved in obtaining funding for treatment for gender variant conditions. It answers the questions that service-users typically ask, and it provides guidance on how to navigate this complex system with minimum delay. Your GP may also find this information helpful.

Many people who experience conditions of gender variance (sometimes known as 'gender dysphoria', and in its extreme form, 'transsexualism') still face great difficulty in getting their local primary care trusts (PCTs) to pay for their treatment promptly, or even at all. If you are experiencing gender discomfort to the point where you are likely to need medical intervention to help, it may assist you to know what treatments are likely to be covered, the factors that may delay the approval of your treatment and what you can do to speed the process.

You should also be aware that the system of funding is undergoing a major change as special commissioning groups (SCGs) play an expanding role.

This publication shows that:

- the NHS is legally required to fund treatment, but in accordance with reasonable local priorities, which permit wide differences in local funding policies;
- there are substantial local differences in the treatment that is covered and the speed at which funding is approved;
- the NHS is introducing a new structure, based on SCGs in each region. This should result in more consistent funding policies but should not be expected to increase the amount of money made available to pay for treatment;

- waiting times for psychiatric assessment and treatment have been very long in the past but will be reduced to 18 weeks, at least for new cases, from December 2007;
- currently, it is possible for service-users, sometimes with the help of their MPs and the trans support groups, to prevent unwarranted delays, to challenge refusals to fund certain treatments and even to shorten waiting times;
- GPs can play a highly important role in obtaining proper treatment and there is information available to them which would help them to take on this responsibility;
- there is no bar on mixing private and NHS treatment. However, service-users should be aware that there may be difficulties in doing so; and
- there are several avenues via which service-users can complain, if their treatment is denied or unduly delayed

2. What treatment will the NHS fund for me?

In England, the Department of Health (DH) allocates the money for funding the treatment of all conditions to the 152 PCTs. With regard to gender dysphoria, the decision in a North West Lancashire Health Authority court case established the right to treatment for transsexualism. Nonetheless, a PCT may decide that the treatment has low priority for funding, provided that it makes the decision on rational grounds.

The process of allocating money that can be used to pay for treatment, and the relative amounts made available, vary. Consequently, some PCTs will fund many treatments readily, but others give all the treatments a

very low priority. So, to an extent, it is a 'postcode lottery'. This may change when the SCGs come into play, as these will develop consistent guidelines for funding treatment for gender variant conditions within the wide area that they each cover.

Generally, you will be able to obtain funding for specialist psychiatric assessment and for hormonal medication. In addition, a few PCTs will fund hair removal, especially on skin from a donor site that is to be used in later surgery. Speech therapy may also be included in the package of care provided by a gender identity clinic (GIC) or a private gender specialist, and some PCTs are willing to fund this treatment. However, when you are considering surgery, you may find that the PCT limits this, in line with the view that there are 'core procedures' – which would usually be funded – and 'non-core procedures' that may be deemed 'cosmetic' or 'aesthetic'. In the case of trans women, this is likely to mean that facial feminising surgery, for instance, will not be covered. Even breast augmentation may be deemed aesthetic, and therefore not funded, despite the fact that this surgery may be essential to the success of the transition to the new gender role. The exclusions of such types of surgery are in line with local policies, and apply to anyone, whether or not they are a transsexual person. Chest reconstruction for a trans man, however, is likely to be regarded as 'core' surgery.

In Appendix 3 you will find a list of treatments which the Parliamentary Forum on Transsexualism recommended should be available for trans people. In theory, these could all be funded; in practice, each PCT makes its own decisions. In any case, the amount spent on core procedures may be restricted by an annual spending limit. Rarely, a PCT will fund private or even overseas surgery, if the treatment matches its quality and cost standards.

3. How do the PCTs decide what to spend on treating gender dysphoria?

Each PCT has its own internal committee that sets priorities for spending the money that it receives from DH. Priorities are based on what the committee sees to be the most urgent needs of the local population and what is best for service-users. It will consider the cost of each type of treatment and examine the research evidence that demonstrates its benefits. It is unlikely that the PCT will set a fixed budget for treating gender dysphoria, because it is a relatively rare condition for which it is difficult to predict the annual number of new cases at a local level. The PCT will usually limit its spending by establishing a policy, which specifies the only types of treatment that it will fund. Where this is so, you, as a service-user, are entitled to see the document and challenge it.

4. How is treatment approved?

At the moment, PCTs still regard gender dysphoria as a condition which is likely to be treated according to a fixed sequence of stages. They have not yet adopted a more up-to-date understanding of differing degrees of gender variance, requiring a more flexible approach to treatment. Your PCT is, therefore, likely to fund your treatment according to a set pathway that includes: primary care provided by the GP (which is non-specialised);[1] secondary care provided by a local psychiatrist (which is a specialised mental health

1 Much of the treatment that trans people require is not specialised and can be undertaken at primary care level, sometimes in a shared-care arrangement with another specialist or clinic. Hormone administration and monitoring may be initiated locally by the GP where he or she has a 'special interest'. (Your GP may find it helpful to read our publication *Guidance for GPs and other clinicians on the treatment of gender variance*.)

service); and tertiary care (which is a highly specialised service for treating gender dysphoria).

Thus, the pathway typically takes in:

- contact with your GP (primary care);
- referral by the GP to a local psychiatrist (secondary care);
- referral by the local psychiatrist to a GIC; in some instances, the referral may be made to a private gender specialist approved by the PCT (tertiary care);
- referral by the GIC, or private gender specialist, to a surgical unit, which may occasionally be private and even overseas; for genital surgery, the surgical unit will usually require referrals from two experienced clinicians (tertiary care); and
- the GP will usually provide your ongoing hormone prescriptions and also tests to monitor your health, pre- and post-surgery; this will be based on the advice of the GIC or private gender specialist (primary care).

The GIC will not usually offer an appointment until the PCT has agreed to fund it. However, some PCTs may have a block contract with a GIC or private specialist that will automatically cover the payments for such appointments, provided that they have been made via the local psychiatrist.

Before the PCT will agree to fund hormone treatment, it has to be recommended by a psychiatrist working in one of the GICs, or an approved private gender specialist. The GIC or the private gender specialist will arrange for you to be seen by an endocrinologist, if that is necessary. An endocrinologist is a doctor who specialises in

hormone treatments. The prescription would then usually be issued by your GP in accordance with the advice from the GIC or gender specialist. Your GP would also arrange health monitoring tests for you, which would be carried out locally. The PCT's agreement to surgery must also be obtained, before the surgical unit will offer an appointment.

The PCT's decision-making process may include consideration of each individual funding application by a committee. This process may result in a delay of several months before the GIC, or the surgical unit, will be able to offer an appointment.

5. Is there any flexibility in the way that I can obtain treatment?

Although the treatment pathway described above is what typically happens, it is not obligatory. Your treatments may be:

- organised by your GP;
- provided locally;
- inclusive of all elements of the care package; and
- still funded by your PCT.

This localised approach might be economical because it limits the need for costly appointments at the GIC. If you live a long way from a GIC, another benefit would be that you would avoid a time-consuming and expensive journey. It might also offer you more scope for greater flexibility and choice among the different elements of the treatment package.

However, this localised approach might not be suitable for all service-users, especially those with complex medical needs. Also, many GPs do

not feel sufficiently experienced in gender variant conditions to take on the responsibility for this treatment. A second referral from another doctor is still necessary for gender confirmation surgery (gender reassignment surgery).

If your GP wishes to consider playing an active role in providing medical care for trans people, please recommend our publication *Guidance for GPs and other clinicians on the treatment of gender variance* (http://www.pfc.org.uk/files/EngenderedPenalties.pdf).

6. Are the strategic health authorities involved in funding?

The strategic health authorities (SHAs), of which there are 10 in England, are responsible for high-level policies in the regions that they cover. They do not control the PCTs' decisions regarding the treatment of any condition, including gender dysphoria. The SHAs may have a view, which might be highly influential, but it is not binding on the PCTs. So, even if they say that you may have a particular treatment, your PCT could still decide not to fund you.

7. What is the intended role of specialist commissioning groups?

Gradually, the funding of a number of specialised conditions, including gender dysphoria, is being allocated via 10 SCGs. One SCG is located within each SHA. Their intended role is to develop common policies on behalf of the PCTs within the boundary of each SHA. The SCGs will then enter into contracts with the providers of specialist health services. In respect of gender dysphoria, these include the GICs, which provide psychiatric and other non-surgical treatment, as well as the units that provide surgery.

It is possible that some of these providers may be in the private sector or overseas, where these are found to meet the standards required. Both of these options may, in fact, cost less than a GIC. This could be advantageous to trans people in that access to treatment will be more uniform across the country. However, a disadvantage could be that there will be no flexibility in what is regarded as 'core' versus 'non-core' treatments. Some PCTs may stop offering treatments which they are currently funding.

8. How is treatment paid for?

The amount of money that each PCT makes available for treating gender dysphoria will be notified to whichever SCG covers its area. The role of the SCG is to enter into contracts with a particular GIC, or private gender specialist, and one or more designated surgical units. This may involve these service providers in submitting tenders for the work. The contract would state the specifications for the treatment to be provided. After the contract is awarded, the designated providers will apply for funding in respect of each referral, unless a blanket funding scheme covering all referred service-users has been agreed. As yet, it is not clear whether or not any services will actually be sought from private providers in the UK or overseas, even though the SCGs are permitted to enter into contracts with them.

See Appendix 1 for a flowchart that summarises the intended process for approving, funding and providing treatment. However, until this system is fully in place, you should look to your local PCTs for information on policies and funding processes.

9. How long will I have to wait for treatment?

> *All commissioning bodies and health care practitioners, whether in private practice or the NHS, should also be aware that unnecessary, non-clinical delay in administering hormones or moving to the surgical stage of treatment could result in legal challenge.*[2]

The 18 week NHS target, from when you see your GP to when you receive specialist treatment at a GIC, applies to gender dysphoria from December 2007. Previously, as for other conditions that are categorised as mental illnesses and subject to tertiary referrals, there was no waiting time target. In fact, the wait was typically at least six months for the first appointment and then for each follow-up appointment at a GIC. A large part of the wait for a first appointment was usually accounted for by the time it took for the GIC to obtain confirmation that the PCT would fund it.

However, from December 2007, the 18 week target will apply to tertiary referrals for psychiatric and hormonal treatment. That will be a major improvement. The GICs will be under great pressure to meet the target. At least one of the major GICs has already begun to increase staffing in order to reduce its waiting times.

At present, the GICs have too few psychiatrists or psychologists to be able to offer more frequent appointments for assessment which would be necessary if waiting times are to be reduced. They may also be unable to offer additional appointments for psychotherapy. According to the international standards of care, these would help to confirm the service-user's readiness to start hormonal medication

2 Parliamentary Forum on Transsexualism, *Guidance for Health Organisations Commissioning Treatment for Gender Dysphoria and Transsexualism*, 2005, www.gires.org.uk.

before embarking on the Real Life Experience (RLE), which means living and working full time in the new gender role.

Instead, it is still the policy in some GICs to require service-users to start living full-time in the opposite role, without the benefit of substantial psychotherapy or any feminising or masculinising hormones. It is only when the change of role is deemed 'successful', that treatment with hormones is initiated. This is likely to cause a delay of several months in accessing medication. This could be regarded as non-clinical delay and, therefore, may be open to legal challenge.

If you have already started to self-medicate with hormones, the GIC or private gender specialist will need to ensure that the products are genuine and the dosages safe; they will also need to assess your health and monitor the effects of the medication. They may allow it to continue, perhaps in a modified form, especially if you can demonstrate that a substantial period of time has already been spent in the new gender role.

Unlike psychiatry and hormonal medication, surgery is already covered by the NHS waiting time target. You should expect any surgery within 18 weeks from the date that the GIC or private gender specialist refers you to the surgical unit.

10. What can I do to speed up the process and get approval to fund my treatment?

It is advisable for all trans people who intend to obtain treatment within the NHS to find out as soon as possible about the policy adopted by their local PCT and who will be involved in making decisions. Contact details for each PCT can be obtained via the

postcode search facility provided by the NHS:
www.nhs.uk/ServiceDirectories/Pages/PrimaryCareTrustListing.aspx

It is then often necessary for you to contact via telephone and/or in writing the people within the PCT who are involved in the process of approving treatment. This may give you early warning of funding difficulties or other reasons for delay. Following notification of an appointment date at the GIC, making direct contact with the staff who arrange appointments may be worthwhile. This may, for instance, enable you to obtain earlier treatment by taking up an appointment that another service-user has cancelled.

If you have to change an appointment, good reason should be given in writing to avoid any subsequent misunderstanding, which might jeopardise your entitlement to treatment. An **unexplained** change might be taken as a sign that you are uncertain about whether to continue treatment or not. Consequently, you should, in addition to any rearrangement made via telephone, send a letter that gives the reasons for changing the appointment and keep a copy of it in case it is needed during the next visit to the GIC. For example, the letter might state:

Further to my conversation with Ms Jolly on June 3rd 2007, regarding my next appointment at the GIC, which was for September 6th 2007, I am writing to confirm that the original date conflicted with an important training course that my employer wishes me to attend. As this is vital to my career, I was obliged to cancel my appointment. It is now rescheduled for October 1st 2007.

If you change an appointment for surgery, it is not necessary for you to wait for a further 18 weeks. The time already spent waiting must be taken into account.

11. What can my GP do to help?

The GP's support in obtaining funding is vital. It is likely that your GP will be unfamiliar with gender dysphoria and the way that funding is provided for treating the condition. You may find it helpful to tell your GP about this publication and others in the series. You might provide copies of the most relevant items. These include an introductory leaflet and a comprehensive guide to treatment specifically for GPs (see *Guidance for GPs and other clinicians on the treatment of gender variance* http://www.pfc.org.uk/files/EngenderedPenalties.pdf). Even if you have a supportive and knowledgeable GP, you may still wish to find out for yourself how the system works within your particular PCT.

If the GP is unsupportive, he or she should refer you to another doctor and the PCT should ensure that a replacement GP is provided.

12. What happens if I want to get some of my treatment from a private doctor?

The British Medical Association has issued clear guidance on switching between the NHS and private sector: www.bma.org.uk/ap.nsf/Content/NHSprivate

- Patients who are entitled to NHS-funded treatment may opt into or out of NHS care at any stage.
- Patients who have had a private consultation for investigations and diagnosis may transfer to the NHS for any subsequent treatment.
- They should be placed directly onto the NHS waiting list at the same position as if their original consultation had been within the NHS.

You are entitled to come back to the NHS. There is no firm policy bar on mixing NHS and private care. Nonetheless, there may be funding and treatment difficulties if you wish to mix NHS and private services. For example, you could, in the treatment of many conditions, pay for a private outpatient appointment for the sake of speed but then opt for an NHS procedure.

However, in the case of complex care packages, as in the treatment of gender variance, it can get more complicated. Some GICs say that they are happy for service-users to obtain, say, surgery privately, so long as the clinic doctors agree that you are ready for this stage, and they approve of your choice of surgeon. The tertiary-level psychiatrist may disapprove if you obtain some of your treatments elsewhere, without obtaining prior approval.

Moreover, the PCT may be reluctant to provide funding if they think you are jumping the queue. If you have obtained hormonal medication privately, but wish the NHS to provide surgery, this is unlikely to be approved until the PCT's 'patient suitability criteria', agreed in the service specification with the surgical unit, have been met. The PCT would not fund a combination of NHS and private surgery in a single

episode. For instance, if it had been persuaded to fund an operation on the Adam's apple (thyroid chondroplasty), that operation could not be combined with privately funded reshaping of the nose.

Even if you are considered to be suitable for surgery by a private consultant (whether or not he or she is employed in a unit that is under contract to an SCG), you may not meet the PCT's criteria. In that case, you may be asked to undergo the usual NHS process to demonstrate suitability. If you do not wish to do that, then, of course, you may ask for your individual circumstances to be considered by the PCT.

If you have had surgery overseas, without the approval of a psychiatrist at a GIC, then you may have difficulty in obtaining, within the NHS, any corrective procedure that may be necessary (unless it is a medical emergency). In such cases, the NHS surgeon would probably require a referral from an NHS psychiatrist and confirmation that the PCT will pay for the treatment. The psychiatrist may be reluctant to give that referral without an extended period of assessment. In any case, the PCT may not necessarily fund all the reconstructive surgery. For example, in a case where breast implants have become infected, there is no doubt that the NHS would remove the implants and treat the infection but it might not fund replacements. However, to prevent an asymmetric appearance, it would be unlikely to refuse to fund replacement if only one implant had become infected.

Therefore, if you think you might want to use private services and also some NHS treatment for gender dysphoria, you should investigate this matter carefully with your local PCT. You should also make an appointment to discuss the matter with the NHS clinicians whose services you may need to use after private treatment.

13. What should I do if I am denied funding for treatment?

If you are not considered to be eligible for funding (through the designated service provider and according to the agreed service specification), you may ask your local PCT to consider your individual case. Cases are usually prepared by your own GP and/or your psychiatrist. The decision may be made by a case review panel.

Additional information, which supports you, is also considered. For instance, you can write directly to the PCT about the impact that non-treatment is having on your life and the resultant stress you are experiencing (see sample letter in Appendix 2). Further support may be obtained from the support groups (see our publication *Transgender experiences*). The PCT will require the arguments for funding treatment to be supported, as far as possible, by 'evidence-based medicine'.

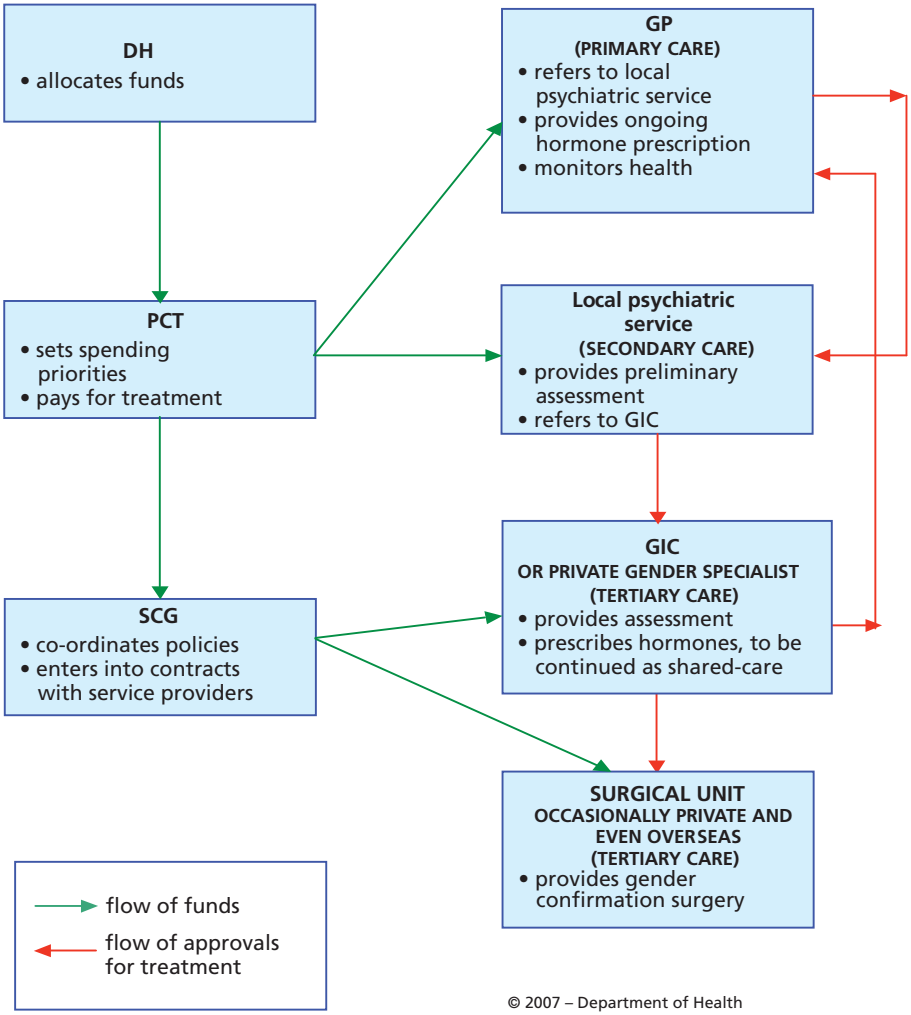
Many trans people have found it helpful to involve their local Member of Parliament (MP), in order to add weight to their arguments with the PCT. The MP may be willing to write a supportive letter to the chair of the PCT on your behalf. The MP may also write to the chair of the SHA, which may be able to influence the PCT's decision. Parliament publishes information on each MP at: www.parliament.uk/directories/hciolists/alcm.cfm

The MP may wish to have a copy of *Transsexualism – the inside story: information for MPs* (October 2007), the document prepared by the Gender Identity Research and Education Society (GIRES) on behalf of the Parliamentary Forum on Transsexualism specifically for MPs: www.gires.org.uk/Text_Assets/Parliament_forum.pdf

If you are denied treatment – despite your best efforts and those of your GP, your MP and the support groups – you would have to resort

to the complaints process that is described in *Pursuing your complaints* that DH has published for transgender users of health services. Some service-users who are denied treatment resort to legal action. If you do choose to go down this path, having exhausted all other possibilities, you need to be aware that it is likely to be a lengthy, expensive and uncertain process, although it is possible that the PCT may decide that funding the treatment is a better use of public money than engaging in costly litigation.

Appendix 1
Approving, funding and providing treatment for gender dysphoria



Appendix 2
Example of a letter to a PCT about funding surgery

I am a trans women. I have been living as a woman continuously for 18 months, and I have been on hormones for two and a half years, so my appearance is considerably feminised. Up to recently, I have had good relationships with my family and my employers. I intend living as a woman for the rest of my life.

My mental health specialist and my GP have both referred me for gender confirmation surgery to make my genital appearance that of a woman. I have no health problems that could make surgery risky.

Despite all these factors, I understand that the PCT Panel has made a decision that my surgery cannot be funded at this time. I have not been told why this decision has been taken, or how long I will have to wait before it is reviewed. Without this surgery I am living in limbo as I cannot achieve a sense of personal wholeness while I still have male genitalia. This has a huge impact on my daily life. I continue to feel great stress about the 'wrongness' of my body, and I am always fearful that someone will find out that I am not as I appear on the outside.

I travel as part of my job. Recently, I was searched by a security guard at an airport. She didn't notice anything, but she might have done, and this possibility makes me extremely stressed. Searches happen frequently now, so travel is a constant problem and I live in fear of being discovered. Using toilet facilities is a nightmare. I am scared to use facilities in shops, theatres, cinemas, leisure or sports centres in case I am challenged. Of course, any venue which involves communal changing is just impossible. Even if I had a gender recognition certificate, I would still feel that fear.

The legal obligation to treat this medical condition comes from the case of North West Lancashire Health Authority v A, D, & G, QBC 1999/0226/4; 0228/4; 0230/4. Lord Justice Auld, in that decision, made it clear that commissioning authorities may not use their prioritisation policies to effect a 'blanket ban'. Yet it appears that this is what has happened to me.

Please can you take account of the fact that cost of treatment of trans people is a fraction of the overall PCT budget. Moreover, you have received a letter from the XXXXXXX Support Group, which provides evidence about the efficacy of the treatment I am seeking.

With proper treatment, I know I can continue to live as a stable, fully-functioning person, making a meaningful contribution to society. Deprived of treatment, I am becoming more and more stressed. My mental health is already deteriorating and this is affecting my relationships with my family; I am functioning less well at work and I dread losing my job and becoming a burden on everyone. I have fought so hard to achieve my transition this far, and have complied with everything that has been required of me. I have to admit that this denial of funding for my surgery has made me have suicidal thoughts. I do not want to become an ongoing liability to NHS mental health services.

It would help me if I could understand what criteria are being used to judge whether or not funding for surgery will be approved promptly; I request that the PCT provides me with detailed reasons for refusing to fund surgery, and that its Panel reviews my situation urgently.

Regards

Anon

Copies to: A N Other MP; XXXXXXX Support Group

Appendix 3
List of possible treatments

Extract from *Guidelines For Health Organisations Commissioning Treatment Services for Individuals Experiencing Gender Dysphoria and Transsexualism* (2005), prepared by the Parliamentary Forum on Transsexualism, available at: www.gires.org.uk

The list of treatments to which trans people should have access, is not intended to be prescriptive, but should be used flexibly in response to the various needs and circumstances of the individual service-users. The list is not exhaustive and may be extended in line with advances in treatment, e.g. crico-thyroid approximation.

In cases of adult gender dysphoria/transsexualism health commissioners are expected to be responsible for funding:

- *Support from the GP throughout the process*
- *Referral to a psychiatrist with specialist experience in gender dysphoria*
- *Ongoing assessment and psychological support when necessary. This should be provided by a clinician with relevant specialist experience, e.g. a psychiatrist, psychologist or psychotherapist or specialist nurse*
- *Within a gender identity clinic, the package offered should include an image consultant, and facilities for peer support groups (facilitated or self led) & relatives' support groups*
- *Hormone treatment including a referral to a specialist endocrinologist, or other relevant specialist*

- *Referral to specialist in reproductive medicine for advice and information about reproductive options such as cryogenic gamete storage and mechanical sperm retrieval and egg retrieval. Provision of storage of gametes and assisted fertility services should be offered in accordance with existing local policy*
- *Providers of removal of facial hair for trans women*
- *Referral for mastectomy for trans men*
- *Speech and language therapy*
- *Thyroid chondroplasty for trans women*
- *Breast augmentation in trans women*
- *Specific gender confirmation surgery when appropriate. This would include:*
  - *referral for hair removal from donor site*
  - *orchidectomy & penectomy, vaginoplasty & clitoroplasty for trans women*
  - *hysterectomy, salpingo-oophorectomy, vaginectomy, metoidioplasty, scrotoplasty, urethroplasty & phalloplasty for trans men*
- *Appropriate district nurse pre-operative and post-operative advice and support*
- *Post-operative referral to endocrinologist or other relevant specialist*
- *Ongoing monitoring of hormone regime (usually by GP or, where appropriate, an endocrinologist)*
- *Follow-up review by gender specialist (at 12 months)*

In cases of young people experiencing gender dysphoria, their treatment services should be well integrated with adult services. Few gender dysphoric prepubertal children become gender dysphoric adults, whereas those experiencing the condition as adolescents, almost invariably do require access to adult services (Wren, 2000). Commissioners are responsible for funding:

- *GP support & liaison*
- *referral to specialist child/adolescent gender identity unit*
- *referral to endocrinologist for hormone blocking during puberty*
- *psychological support services.*

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