

OCD Action Advocacy Service

National Service or Special Care Pathway Referral to a Centre of Excellence for OCD

What is this guide for?

This guide will give you the information that you need to know about securing a referral outside your area to a centre of excellence for OCD. It has some tips and ideas on how you can best present your case to your local Primary Care Trust (PCT) or Local Health Board (LHB) who will pay for your treatment. This guide can be used alongside the referral request template letter produced by OCD Action's Advocacy Service and available on the OCD Action website or via the OCD Action office. It can also be used for related conditions such as Body Dysmorphic Disorder or health anxiety.

Background information

The National Institute for Health and Clinical Excellence (NICE) has produced guidelines for NHS staff when working with and treating people with OCD. Treatment for OCD should be in line with their guidelines. See links at the bottom to download the guidelines.

NICE recommends a 'stepped care' approach. This means that an individual with OCD can access different levels of treatment depending on their needs. Treatments may range from help that your local GP can give to specialised and intensive treatment that is provided by a Centre of Excellence.

According to NICE, patients should have access to specialist services with expertise in OCD, when their OCD has made them severely impaired or when they have other significant health problems (co-morbidity). Specialist services are also recommended when a person with OCD has not responded to treatment, when they have only had a partial response or when their OCD has come back strongly.

NHS organisations and any organisations that provide care under the NHS must act according to The NHS Constitution. The constitution states that:

- **"You have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you."**
- **"You have the right to expect local decisions on funding of other drugs and treatments to be made rationally following a proper consideration of the evidence. If the local NHS decides not to fund a drug or treatment you and your doctor feel would be right for you, they will explain that decision to you."**

What is a Centre of Excellence for OCD?

Centres of Excellence bring together the leading healthcare professionals with experience in dealing with OCD. They have a wealth of experience in dealing with people who have OCD, often in very severe forms, and will be able to provide the best quality of treatment available to you under the NHS.

How do I get to attend a Centre of Excellence?

As there are very few centres of excellence for OCD it is likely that the centre that you want to go to is outside of your local Primary Care Trust (PCT) in England / or Local Health Board (LHB) in Wales and Scotland. This means that you need an out of area referral to the specialist centre who will decide if they can provide the care that you need and if this care is appropriate. As part of the referral process, your local PCT/ LHB will need to agree to fund your treatment. The request for funding is called an **"individual funding request"**.

Who can refer me?

Your psychiatrist or another senior member of your team such as your psychologist has to make the referral to the specialist centre. They will also need to get funding approved for the initial assessment, and ideally, for the whole treatment. In most cases they will need to make sure that funding is in place before speaking to the specialist centre. If funding is not in place, then the specialist centre will apply to the PCT on your behalf.

The individual funding requests

This is the request, with explicit support from a clinician, which seeks funding for your specific treatment. All applications are usually accompanied by written support and evidence provided by the clinical team. There will be a document that outlines the protocol which your referrer has to follow. You can ask your local NHS Trust for a copy of this.

The Individual funding panel of the Primary Care Trust (PCT) or Local Health Board (LHB) will meet to consider your clinician's application. In cases of urgent treatment, a decision can be made by one of the Executive Directors (Authorised Officer). The panel will consider such issues as:

- Do you meet the PCT's referral criteria?
- The nature of the proposed treatment or investigation and its clinical effectiveness
- An analysis of alternative treatment and its cost effectiveness
- The long term benefits
- Any exceptional circumstances
- The number of other people in the area that may be affected by the decision
- Whether their decision will set a precedent.

What can I do?

You are able to submit a statement to the panel outlining your case for funding and the exceptionality of your case. The referring clinician is expected to advise you that you can submit comments to the panel for consideration in the decision making process. Your statement should be forwarded with their completed application. You may need to find out the name of the commissioner who is responsible for mental health in your trust.

How do you get your clinician to agree to a referral?

As you can see, in order to get to a centre of excellence you need the full support of your psychiatrist or psychologist who will undertake the referral and funding request process.

Before any consultation with the clinician, it is helpful to write out the main points of your argument. In particular make sure you note down your views on why you think that previous treatment has not helped, how you have actively tried to engage with it and why you feel that you have not got any better.

Try and be as specific as you can about the treatment you have received and how OCD affects your life. Tell them about how long you spend on certain rituals or activities such as leaving the house or taking a shower or how often you experience intrusive thoughts. If you feel that you would rather write to your consultant, OCD Action has a letter template that you can use and adapt.

What if I cannot get a referral?

Some people have told us that they have found it difficult to get their clinician to agree to make a referral to a specialist centre. You could ask for a second opinion, for example you could try asking for an opinion from the Medical Director or Head of Psychology of the mental health trust.

However, often the best approach is to ask your clinician why they think a referral is not appropriate and to address their concerns in a calm and reasoned way. Always ask for the clinician's opinion in writing or alternatively write down what they tell you in front of them. Make sure that they give a clear explanation as to why they will not support an application to the PCT or LHB. It may be that they do not have the information that they need, that they are not aware that your case would meet referral under the NICE guidelines or simply do not appreciate the impact that your OCD is having on your life.

Some other things to think about...

- Referring you to an outside care team may be seen as a 'failure' by your local team.

Make sure that you acknowledge the help that you have received from them to date and recognise the limitations that they have to work under.

- You may not actually often see your Consultant Psychiatrist as your care on a daily or weekly basis will most likely be given by your Community Mental Health Team, so approaching your psychiatrist directly can be daunting.

Remember that they are there to help you and that the more prepared you are for a discussion with them; the more confident you should feel. Remember also that you can always write to them using the OCD Action Advocacy Service's template.

- Potential referrers may argue that you have "disengaged" with treatment available to you locally. And so ineligible for referral as local treatments options must be tried first.

Make sure you are clear that you have tried the best that you can and if you have not been able to attend treatment, explain what the barriers have been. For example it may be that your OCD has prevented you from attending regularly as an outpatient and you need a more intensive programme.

What if the PCT refuses to fund my treatment?

PCTs are unlikely to fund your treatment at a centre of excellence if they feel you have not tried all the treatments that they are able to provide locally, the term often used for this is "not exhausted local services".

You can always argue that because of the severity of your condition, you need to jump a few steps in the NICE Guideline stepped care process, so you don't have to have done everything on offer.

Furthermore, there is now an emphasis on patient choice, so that if you do not now wish to take recommended medication, then you do not have to. Although the guidelines are not legally enforceable, teams would have to give a pretty good reason not to follow them.

Don't accept the argument "You've tried CBT" and "they are not going to do anything different at the specialist centre". Always refer to the best practice NICE guidelines for OCD that say when patients should be referred to more specialist centres for OCD.

Appeals

You have the right to appeal the decision of the Individual Funding Panel within a time period set out by them. Any appeal will be heard by the Appeals Panel. The role of the Appeals Panel is to see if the Individual Funding Panel has followed its own procedures correctly, considered all the evidence and come to a reasonable decision based on the evidence. The Appeal Panel has a different membership from the standard Individual Funding panel.

The Appeals Panel can uphold your appeal and refer the case for reconsideration to the IFR panel. The Appeals Panel will do this if they believe that the Individual Funding Panel has:

- Failed in a material way to follow its own procedures
- Failed in material way to consider the evidence presented to it
- Come to a decision that no reasonable IFR panel could have reached on the evidence before it

The appeals panel do not have authority to grant funding; they can only make recommendations to the IFR panel.

What you will need.

In order to make sure that your appeal is as effective as it can be you will need as much information as possible as to why your request for funding was turn down. You should ensure that you have:

- A complete copy of the Minutes of the original application hearing.
- A confirmation of the job titles and medical, clinical, and/or other qualifications of panel members of both the original panel and the appeals panel.
- A confirmation of whether a Consultant Psychiatrist was present at the original meeting to provide an expert opinion.
- Copies of the PCT/LHB policies governing the exceptional treatment process including any policy guidance relating to the appeal process.
- Copies of the original application sent to them from your consultant.
- Terms of reference for the appeal panel.
- Copies of the refusal letter.

Stress that time is of the essence and until you receive this information you will not be able to prepare your appeal. Please also ask for an acknowledgement that this request for information has been received.

Your clinician should be part of the appeals process. Where the request for funding is declined, your health professional can ask for the decision to be reconsidered if supported by additional and new information. If your clinician feels that the process had not been handled appropriately, he or she may appeal against the decision by writing to the Individual Funding Request Appeal Panel, asking for the case to be reconsidered.

What else can you do?

The appeals process is the first step but you also have the right to make a complaint under the NHS and Social Care Complaints Regulations. You should be aware however that any investigation under these regulations will examine whether the correct policies and procedures have been followed when considering a funding request and will not make a comment on the decision made.

Sources of Help & Information

OCD Action's Advocacy Service:	0845 390 6234
OCD Action's website:	www.ocdaction.org.uk (for advocacy documents)
NICE Guidelines on OCD & BDD	www.nice.org.uk/CG31
OCD Action's Helpline: 0845 390 6232	(for OCD information and emotional support).

Specialist Centres for the treatment of OCD/ BDD

Centre for Anxiety Disorders and Trauma

Maudsley Hospital

Denmark Hill
London SE5 8AZ
Tel: 020 3228 2101

Behavioural Cognitive Psychotherapy Unit

Springfield University Hospital

Teak Tower and Heather Ward
61 Glenburnie Road
Tooting
London SW17 7DJ
Tel: 020 8682 6000

Anxiety Disorders Residential Unit

Royal Hospital Beckenham,

The Bethlem Royal Anxiety Disorders Residential Unit
Alexandra House
Monks Orchard Road
Beckenham
Kent BR3 3BX
Tel : 020 3228 4146

OCD Specialist Service

Queen Elizabeth II Hospital

Howlands
Welwyn Garden City
Hertfordshire AL7 4HQ
Tel : 01438 314333

The Priory Hospital North London

Grovelands House
The Bourne
Southgate
London N14 6RA
Tel: 020 8882 8191

Sheffield Health and Social Care

NHS Foundation Trust,

OCD and BDD Specialist Team
Brunswick House
299 Glossop Road
Sheffield
S10 2HL
Tel 0114 271 6901