

## Getting a Referral to an Adult National & Specialist OCD Service

### 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 national & specialist OCD service. It has some tips and ideas on how you can best present your case to your Psychiatrist who will need to make the referral and who might need to make a request to your local funder<sup>1</sup> to 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 (BDD) or health anxiety.

### Background Information

The **NICE<sup>2</sup> Guidelines** (<http://www.nice.org.uk/CG31>) prescribe a stepped care model<sup>3</sup> for OCD treatment. Each step introduces additional interventions. The higher steps normally assume interventions in the previous step have been offered and/or attempted. There may however be situations where an individual may be referred to more specialist services from the outset.

This means that an individual with OCD can access different levels of treatment depending on their needs. The treatment recommended is always Cognitive Behavioural Therapy (CBT) with Exposure Response Prevention (ERP) usually in combination with medication but the intensity of that treatment and the expert OCD knowledge of the clinicians delivering the treatment will differ. Treatments may range from help that your local GP can give to specialised and intensive treatment that is provided by a national & specialised OCD service.

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-morbidities). National & specialist OCD services are also recommended when a person with OCD has not responded to combined treatment i.e. CBT with ERP + medication or when they have only had a partial response or when their OCD has come back strongly.

National & specialist OCD services bring together healthcare professionals with experience in dealing with OCD. They have a wealth of experience in working 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. However, there are also local specialist OCD services with expertise in treating people with OCD which, though they are not nationally funded, can sometimes provide intensive treatment.

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<sup>1</sup> This might be the local Clinical Commissioning Group (CCG) (England); Health Trust (Northern Ireland); local NHS Board (Scotland).

<sup>2</sup> NICE Guidelines apply to England & Wales but clinicians in Scotland & Northern Ireland should have regard to them when treating individuals with OCD/BDD. Although they are not legally enforceable, clinicians should put their reasons in writing to you if they are **not** following them.

<sup>3</sup> See Appendix 1: The Stepped Care Model

## How do I Get a Referral to a National & Specialist OCD Service?

If you think you might need treatment by a national & specialist OCD team your supervising clinician at your local Community Mental Health Team (CMHT), who may be a psychologist or psychiatrist, will need to make the referral on your behalf.

In England the local NHS funding body<sup>4</sup> usually pays for any assessment and treatment at a national & specialist OCD service out of their local NHS budget. There is small subgroup of the most severely affected cases of OCD that can be treated at the above hospitals at no cost to local health care services. This is for cases when a person with OCD has not responded to combined treatment with Cognitive Behavioural Therapy (CBT) & SSRI medication. (see National Funding p.3)

In most cases across the UK, in order for you supervising clinician to make a successful referral, they must also make a funding request<sup>5</sup> to their local or national funding body.<sup>6</sup>

Many funding requests are refused because the local funding body already pays the local CMHT to provide treatment for OCD<sup>7</sup>. Unless you have attempted at least one round of CBT available locally, your clinician or the funding panel will probably refuse your referral because you have not “exhausted local provision”. On some occasions appropriate CBT is simply not available locally & this would also be a reason to consider referral to a specialist service.

In addition to CBT for OCD, some people are prescribed a serotonin reuptake inhibiting drug (SSRI) which is a recognised treatment for OCD. Some evidence suggests that for more severe or complex illness, the treatments are more effective if combined together. It is important to note that “exhausting local provision” does not mean you must have tried a course of SSRI or CBT.

There are many reasons why local CBT might not have worked for you:

- the CBT was not good enough<sup>8</sup>
- your OCD is particularly severe
- the CBT worked for a while but the OCD has relapsed

None of these are your fault. It is more likely that your OCD is particularly severe and “treatment refractory”<sup>9</sup> and needs intervention from a specialist OCD service. If you have failed to engage, for example, you may require specialist advice and support that is not available locally.

You can request to see all the documentation to be put before the Funding Panel and you are able to submit a written statement to the panel. You should always be given a written explanation for any refusal to refer or fund.

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<sup>4</sup> Previously the Primary Care Trust (PCT) now the Clinical Commissioning Group (CCG)

<sup>5</sup> Individual Funding Request (IFR) England; Individual Patient Treatment Request (IPTR) Scotland; Individual Patient Funding Request (IPFR) Wales

<sup>6</sup> See Appendix 2 for details of the process in the different countries of the UK.

<sup>7</sup> Cognitive Behavioural Therapy (CBT) with Exposure Response Prevention (ERP).

<sup>8</sup> See OCD Action’s guide to good CBT: <http://www.ocdaction.org.uk/support-info/have-i-had-cbt-my-ocd>

<sup>9</sup> Treatment resistant

**Tip:** Don't assume your clinician knows how best to prove the case for you or how the national & specialist OCD service's intervention differs from locally provided CBT. It will really help your case if, when you ask for the referral, you take along the following:

- The NICE guidelines. The NICE guidance carries huge weight, so work out for yourself where you think you are on the stepped care model. Ask your Consultant to do the same and if there is a disparity ask them to put their reasons in writing.
- Your full case history, including a chronology of interventions and outcomes, and why you think previous/current treatment has failed.
- Any supporting documents to show that your OCD is entrenched/ treatment refractory.
- Efficacy of the particular service you're looking for a referral to.
- A personal statement detailing how your OCD/BDD is impacting on your daily life and on those around you i.e. employment, education, family, friendships, opportunity costs for more information on what to include see OCD Action's Template for Clinicians - <http://www.ocdaction.org.uk/sites/default/files/pdf-precompiled/template-for-consultants-0414.pdf>

This statement can accompany the funding request made by your clinician.

- Make sure you see the funding request and referral letter from your consultant before it is sent. These referrals are infrequent and many local consultants do not understand the process and feel that it is a reflection on the performance of their team to have to refer to a specialist centre. They are likely to say that the treatments available at the national & specialist OCD services are all available locally. You may have to negotiate the referral letter and funding request with them and emphasise the importance of the wording. It should clearly state that treatment has been undertaken and recurrence or no response has occurred and that treatment at the national & specialist centre is appropriate and essential.
- There will be a document that outlines the funding protocol which your referrer has to follow. You should ask your local Clinical Commissioning Group (CCG) or Local Health Board (LHB) for a copy of this as in England the criteria for granting a request seems to vary between CCGs.

**National Funding:** In England there is a "pot of money", which is nationally funded by *NHS England*, for the most serious cases, which does not require approval by your Clinical Commissioning Group (CCG). The criteria for NHS England funding are much stricter than those for CCG funded treatment. Adults eligible for the NHS England service must fulfil all the following treatment refractory criteria:

- a. Severe OCD/BDD i.e. greater than 30 on Y-BOCS<sup>10</sup> rating scale
- b. Failed 2 sets of CBT (including ERP) locally (of adequate quality & duration)
- c. Failed 3 trials of medication in adequate dose & duration i.e. 2 sets of SSRIs & 'augmentation' with a high dose of SSRI or an anti-psychotic drug.

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<sup>10</sup> Yale Brown Obsessive Compulsive Scale designed to rate the severity and type of symptoms in patients with OCD

If it is clear from the referral letter (that your clinician writes) that you meet the criteria then NHS England funding will cover the cost of the assessment. If it is not clear or you do not meet the criteria then local funding would need to be agreed before you can be assessed at a national and specialist OCD service.

### **If You Cannot Get a Referral**

- If your consultant will not agree to a referral then you might consider paying yourself for a private assessment at a national & specialist OCD service and asking your consultant to comply with its treatment recommendations.
- You could ask for a second opinion from the Medical Director or Head of Psychology at your local Foundation Trust. Although there is no legal right to this there is no harm in you asking. How you get an independent second opinion varies from area to area but for general guidance see: <http://www.rethink.org/living-with-mental-illness/rights-restrictions/second-opinions>
- Ask for a referral just for an assessment at a national & specialist OCD service.
- Ask your consultant to put in writing their reasons for refusing to refer you so that you can then think about to respond to their concerns. Make sure that they give a clear explanation as to why they will not support an application to the CCG 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 the NHS England funding criteria or simply do not appreciate the impact that your OCD is having on your life.
- Contact our Advocacy Service for support: 020 7253 5272 – we can help you write to your consultant or we may be able to attend a meeting with them.

### **If Funding is Refused**

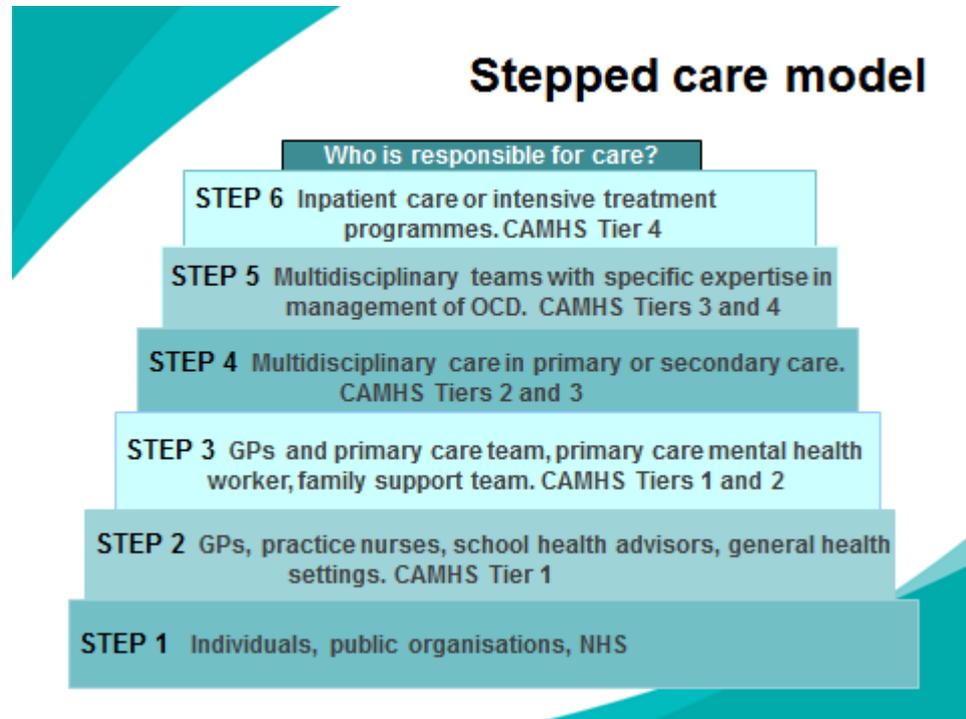
- Ask again. Your consultant can apply more than once providing there has been a 'material change in circumstances' e.g. new clinical evidence.
- You have a right of appeal to the Independent Funding Appeal Panel if funding is refused and you believe that the CCG/Health Trust/NHS Board did not follow their own procedure – see your local CCG/HT/NHS Board's policy.
- Find out why – don't be afraid to write or phone the decision makers directly e.g. the IFR Team Manager or Co-ordinator.
- Consider involving your Assembly Member or MP.
- Contact OCD Action's Advocacy Service for support.

If you fail to get a referral or the funding is declined because you think the case was not presented adequately, you can make a complaint either directly or through your local PALS (Patient Advisory and Liaison Service) who will mediate with your health professional.

**Remember:** Most people have to push hard for this treatment, so expect to be knocked back at first. **SO DON'T GIVE UP!**

- Be persistent
- Keep pointing out the NICE guidance & evidence
- Don't be afraid to write to or phone the decision makers directly e.g. the IFR Team Manager or Co-ordinator
- Consider involving your Assembly Member or MP.

## Appendix 1: NICE Guidelines – stepped care model for OCD



## Appendix 2

### Funding Processes Across the UK

#### IFR Process - England

##### Screening

All requests made are screened by a designated officer of the CCG/LHB such as the IPFR Senior Officer (Manager) in Wales who decides whether the request is appropriate for consideration by the Individual (Patient) Funding Request Panel. There can be many reasons why a request is screened out including:

- Insufficient clinical & other information
- The request represents a service development i.e. there is a 'cohort of similar patients.'

It may be possible to request a review of the screening decision you should check your CCG/LHB's policy.

##### Individual (Patient) Funding Request Panel

If the application is not screened out then it is passed to the Individual (Patient) Funding Request Panel. In Wales cases of urgent treatment can be decided by the Chair of the IPFR Panel while in England practice varies. 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
- Clinical Exceptionality i.e. that the patient is significantly different to the general population of patients with the condition in question & that the patient is likely to gain significantly more benefit from the intervention than the average patient with the condition, at the same stage of progression.
- The number of other people in the area that may be affected by the decision
- Whether the decision will set a precedent.

For procedures in **Northern Ireland** please see: HSCB Arrangements for the Consideration of Requests for Care and/or Treatment on Behalf of Individual Patients and your Health Trust's policy on Individual Funding Requests/Extra Contractual Referral (Non Acute ECR). The request would need to be endorsed by the Health Trust and is then passed to the HSCB for consideration.

[http://www.hscbusiness.hscni.net/pdf/Protocol\\_ECR\\_and\\_IFR\\_arrangements.pdf](http://www.hscbusiness.hscni.net/pdf/Protocol_ECR_and_IFR_arrangements.pdf)

In **Wales**, since December 2012, funding for all referrals to national & specialist services in England is controlled by the Welsh Health Specialist Services Committee (WHSSC). See the All Wales Policy Making Decisions on Individual Patient Funding Requests (IPFR) <http://www.wales.nhs.uk/sites3/Documents/898/All%20Wales%20IPFR%20Policy%20-%20%20pdf.pdf>

**Scotland** has its own national OCD service, the Advanced Interventions Service at Ninewells Hospital in Dundee which offers intensive/ inpatient treatment programmes for Scottish patients with OCD. Referrals (and some treatments, such as neurosurgery or intensive exposure and response prevention) are cost-free to NHS Boards in Scotland. Referrals should come from a consultant psychiatrist working in the NHS who will need to retain responsibility for the individual's care.

To meet the criteria for treatment resistance, the person should have had two attempts at psychological therapy from an accredited and suitably experienced Cognitive Behavioural Therapist. Each of the attempts should have included at least twenty hours of Exposure and Response Prevention. If, at the end of this treatment, the person continues to have significant symptoms which are impairing their ability to function then they may be considered to be resistant to standard psychological treatment.

<http://www.advancedinterventions.org.uk/index.htm>

**Complaints - If you need information and guidance about making a complaint about your treatment the following organisations can help:**

**England**

NHS Complaints Advocacy Service: 0300 330 5454

[www.nhscomplaintsadvocacy.org](http://www.nhscomplaintsadvocacy.org)

**Wales**

Complaints advocacy service available through Community Health Councils: 0845 644 7814

<http://www.wales.nhs.uk/sitesplus/899/home>

**Scotland**

Patients Advice & Support Service (PASS) delivered by Citizen's Advice: 0131 550 1000

[www.cas.org.uk/patientadvice](http://www.cas.org.uk/patientadvice)

**Northern Ireland**

Patient & Client Council: 0800 917 0222

<http://www.patientclientcouncil.hscni.net/making-a-complaint>

**Action Against Medical Accidents (AvMA):** An independent charity that supports people affected by medical accidents or clinical negligence. Helpline: 0845 123 2352 (Mon - Fri 10am - 5pm)

[www.avma.org.uk](http://www.avma.org.uk)

**Patients Association:** provides information and support about any aspect of the healthcare system. Helpline: 0845 608 4455 [www.patients-association.com](http://www.patients-association.com)

**Sources of Help & Information**

OCD Action's Advocacy Service:

020 7253 5272

OCD Action's website:

[www.ocdaction.org.uk](http://www.ocdaction.org.uk) (for advocacy documents)

NICE Guidelines on OCD & BDD

[www.nice.org.uk/CG31](http://www.nice.org.uk/CG31)

OCD Action's Helpline: 0845 390 6232

(for OCD information and emotional support).

## **Nationally Funded Specialist Centres for the Treatment of OCD/ BDD**

### **England & Wales**

#### **Centre for Anxiety Disorders and Trauma (CADAT)**

##### **Maudsley Hospital**

Denmark Hill  
London SE5 8AZ  
020 3228 2101

- Out-patient service

#### **National OCD/BDD Service**

##### **Springfield University Hospital**

61 Glenburnie Road  
Tooting  
London SW17 7DJ  
020 8682 6000

- 24hr nursing care

#### **Anxiety Disorders Residential Unit (ADRU)**

##### **Royal Bethlem Hospital Beckenham,**

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

- Hostel-like residential unit

#### **Highly Specialised OCD/BDD Service**

##### **Hertfordshire Partnership NHS University Foundation Trust**

##### **Queen Elizabeth II Hospital**

Howlands  
Welwyn Garden City  
Hertfordshire AL7 4HQ  
01707 224409

- Out-patient service

#### **The Priory Hospital North London**

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

- In-patient service

### **Scotland**

#### **Advanced Interventions Service**

Ninewells Hospital & Medical School  
Dundee DD1 9SY  
01382 496233

- Out-patient & in-patient service