

# Accessing Treatment for OCD through the NHS

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## This Pack and Your Journey

Whether you are personally struggling with an obsessive-compulsive condition or supporting someone who does, this pack has been designed to support you to navigate the NHS mental health system and understand what should be happening at each step. Accessing treatment can be a challenge, especially if the professionals you are speaking to don't know what the best action to take is. Often, getting the right support can come down to knowing what someone is entitled to and how to ask for it.

You can use the chart on the next page to find where you or your loved one fit in the 'stepped care' system, and which of our factsheets might be most useful to read through. The table is a basic-language version of the one that can be found in the NICE 'quick-reference' version of the guidelines for OCD and BDD.

## The NICE guidelines for OCD and BDD

The National Institute for Health and Care Excellence (NICE) publishes guidelines for health and social care. Guidelines have been published for many conditions as well as particular practices and provide evidence-based recommendations and advice. These guidelines apply to England and Wales, but as Scotland and Northern Ireland don't have their own OCD/BDD treatment guidelines, these are considered best practice and should still be followed.

Although NICE guidelines are considered best practice, studies show that 25-30% of GPs don't consider them particularly relevant and go against them on a regular basis. The guidelines are not legally binding, but through case law it can be considered medically negligent to ignore them. The decision to act against the guidelines must be supported by a reasonable body of experts. This can either be an already existing clinical practice that the doctor can refer to, or can come from a specialist assessment.

Put simply, this means that if the guidelines are clear and explicit about what you should be offered or how you should be treated, a doctor or service cannot take a different action simply because they disagree. They must be able to give a medical reason, and their individual opinion is not considered enough, it has to be backed up by something official.

The guidelines for OCD and BDD are very in depth and clear, and we can help you to f ind yourself in them and put together information to show your doctor what should be happening. In most cases, this is all that is needed to move on to the appropriate next step in treatment.

If a doctor refuses to follow the guidelines, you can ask them to write that down in your medical record. You can specify that you want the note to reflect that you asked for the NICE-recommended treatment and were refused. You can also ask that your doctor provide you with a clear, written breakdown of their reasons for doing so.

If that still doesn't work, you now have a list of reasons that you can appeal against. We can support you to put together your arguments and give you contact details for who to contact about this in your area.

There are actually 4 versions of the guidelines for OCD/BDD!

The NICE Guideline is a list of all of the recommendations

The guide for the public is a simplified version written specifically for patients/carers

The quick-reference guide uses flowcharts and tables to help doctors figure out what should happen next in your care

The full guidelines include all the recommendations, outlines of all the research behind them, and accounts by people affected by OCD

Where?	For who?	What should happen?	
Specialist OCD/BDD services CAMHS Tier 4	Symptoms present risk of severe disability, neglect, or suicide	Reassessent of needs and options  > Medication, therapy, or both  > Medication combinations  > Consider hospital admission or suported living arangements	Step 6: Intensive needs or 'treatment resistance'  Page 22 for <u>Specialist</u> <u>Treatment for OCD and BDD</u>
Local or national specialist OCD/BDD services  CAMHS Tiers 3 and 4	or diagnosis	Reassessment of needs and options  Adults:  > Medication, therapy, or both  > Consider medication combinations  > Consider social care and care coordination	Step 5: Severe and hard to treat symptoms  The second montal health service has a
> No results, limited success, or quick relapse at previous levels  A service with a mix of Secondary	Children and young people: > Therapy, possibly with medication > Consider national specialist referral  Assessment of needs and options	If your local mental health service has a specialist OCD/anxiety disorders team  Page 13 for Secondary  Care for Adults	
professionals (i.e. not just therapists) CAMHS Tiers 2 or 3	condition or diagnosis > No results, limited succes, or quick relapse at previous level	Adults: >Medication, therapy, or both Children and young people: > Therapy > Consider medication	Step 4: Complex needs or further treatment  If your area has a primary care service that is part of a larger, 'multidisciplinary' team
GP Surgery  Primary Care mental health services	> Mild symptoms (management) > Moderate symptoms (initial	Adults: > Low-intensity therapy / guided self-he > Medication, therapy, or both > Consider involving family / carers Children and young people: > Guided self-help	Page 10 for <u>Primary</u> <u>Care for Adults</u>
CAMHS Tiers 1 and 2  GPs, nurses, and other frontline health professionals in various settings	Suspected / possible OCD or	> Therapy > consider involving family / school > Discussion of symptoms > Information, education, and contacts > Discussion of treatment options	Step 2: Recognition  Medication  Page 4 for Preparing  for a GP Appointment
CAMHS Tier 1  You, OCD Action, your loved ones, and the NHS	Suspected / possible OCD or BDD symptoms	> Referral to any of the appropriate step Information, education, and contac	Step 1: Awareness Contact our Helpline!

## Preparing for a GP Appointment

In most cases, the first step to treatment would be to speak to your GP to talk about what you've been experiencing and your options. This can be daunting if you are worried about your condition being misunderstood or you've had negative experiences in the past in which professionals haven't offered the right help. The information below can help by explaining what to expect, how to talk about your symptoms, and what information might be helpful to bring along.

## What to expect

Because of the nature of their role and training, a GP's areas of knowledge will vary depending on their experience. Whether or not a GP knows much about OCD, they will be aware of mental health conditions and have some training on how to support people with them. In fact, 1 in 4 GP appointments will be about mental health. Sometimes, though, a GP might know quite a lot about OCD and even be the person who recognises the symptoms in the first place.

A GP can prescribe medication and make a referral for therapy. They can also signpost you to relevant services and organisations, which offer information or non-treatment support like peer groups, befriending, or putting a personal plan together. Your GP should discuss all options with you, and then a decision about how to move forward should be made together. While this does happen in most cases, sometimes there are barriers in place like limits in timing or GP knowledge. On top of reading this factsheet, it can be helpful to read our guides about treatment and the NHS mental health system, in order to go into an appointment with an idea of your desired result.

On some rare occasions, a GP might be actively unhelpful, providing inaccurate information about OCD and what support is available. This can be very upsetting, especially if you are already feeling doubts about your condition or whether you will be able to recover. This might even cause someone to

get any support. It is important to remember that help is out there, and that these professionals are an exception, rather than the norm. You do not have to speak to your named GP if you are not comfortable doing so. Instead, you have a right to see any GP within the practice. Sometimes, a surgery will have a GP on staff who is particularly experienced around mental health, so it can be worth it to ask about this.

disengage with the mental health system and not

## Talking about OCD symptoms

One of the most common barriers to getting treatment for OCD is the embarrassment or fear that someone might feel at the thought of telling a professional about their symptoms. It is in the nature of OCD to bring on feelings of shame about not being able to stop the compulsions and worrying, so you might be concerned that your GP might dismiss your distressing experiences by saying things like "We all get these kinds of thoughts", "It's just anxiety", or "You've just got to try harder". Many people with OCD will have heard similar things in their lives. Depending on what your intrusive thoughts are about, you

might also be worried about a safeguarding report or risk assessment if the GP doesn't understand that these are unwanted.

Whatever the reason, the good news is that the GP doesn't need to know the details of what your worries are or what your compulsions look like, because these do not determine whether you are struggling with OCD.

It is recognised that intrusive thoughts are not indicators of risk. More information about OCD and risk can be found in the <u>Assessment and Diagnosis factsheet</u>.

Instead, what is important to make clear is that the OCD cycle is present, and how much of an impact it is having on your mental health and day to day life:

- Obsessive thoughts and worries that are automatic, unwanted, irrational, and very difficult to move on from.
- 2. Intense anxiety because of the doubt or sense of danger brought on by these thoughts
- Getting stuck in repetitive actions (physical and/or mental) in an attempt to cope with the anxiety and reduce doubt

As long as these three elements of your symptoms are covered, the GP doesn't need any more information to make a referral.

More information will be needed

for assessment and treatment, but this will be offered by the mental health team and should be with a professional who has specific training or experience in working with OCD.

Useful information and documents

If someone is asking for mental health support for the first time or hasn't had any treatment for a while, usually the GP will suggest treatment through the primary care mental health team. They might make the referral themselves or provide contact details to be used to self-refer. The NICE guidelines,

though, explain that you should be referred directly to the appropriate level of care, even if you haven't tried treatment at lower levels in the past.

NICE is the National Institute for Health and Care Excellence, and any GP will know that these are official guidelines. If a professional refuses to go along with what the guidelines say, this can be

appealed or a complaint can be put in. If asked to, the GP must provide a medical reason for refusing, and write this in your medical record.

OCD Action also provides information about treatment, referral pathways, and the mental health system.
Although they are not official documents in themselves, all the information within our factsheets

comes from the NICE guidelines and/or expert clinicians who run the NHS's specialist OCD treatment services. GP's and other professionals are also welcome to call our helpline if they are unsure of anything, although they should also be looking at the full NICE guidelines or speaking to colleagues with knowledge about OCD.

You can find our <u>GP Card</u> on the OCD Action website. This card summarises OCD related conditions, how to assess for them, and what treatments you should be offered.

The most important thing to remember when preparing for any appointment is that there should always be support available.

The NICE Quick-Reference

**Guidelines** use tables and

professionals to work out

flowcharts to support

the ideal next steps in

your treatment.

Sometimes, if a professional doesn't know what the next step is or what options are available, they might say there aren't any. If you are told there is nothing available or that you've run out of options, ask them to write this down in your medical record for later reference, then contact our Helpline to find out what your options are from there.

## Assessment and Diagnosis

One of the biggest barriers people face with accessing treatment for their OCD is lack of recognition of their symptoms. Someone might not be completely open about them to professionals because they are embarrassed, or the assessor themselves might not be aware of the different ways OCD can manifest. Taking part in an assessment with a knowledgeable practitioner and with some preparation can help to open doors to the right support.

### What is an assessment?

The word assessment is used throughout the mental health system and can mean different things depending on what is being assessed and why. In general, the aim of a mental health assessment is to evaluate what symptoms you are struggling with, how much these are impacting on your life and wellbeing, and what your needs are.

There are two main reasons someone might be assessed for symptoms of OCD or related condition within the NHS.

#### Assessment for treatment

If you are referred for treatment, a mental health professional will make an assessment about whether you are in the right place and which of their services might be most appropriate. This might be done by a psychologist, therapist, or mental health nurse.

After the assessment, you should be told whether you have been put on a waiting list, what symptoms you described, and what treatment you will be offered. If you have described symptoms of OCD, you should be put on a waiting list for CBT with ERP, or you might be told it's for general 'psychological treatment'. This means you will be working with a psychologist who will adapt the therapy based on your symptoms. In this case it can help to remind the service that it should be someone with training in both OCD and ERP, as recommended by the guidelines. You can ask them to add this to your notes so that everyone is aware of it once you've made your way through the waiting list.

#### Assessment for medical diagnosis

If you need a medical diagnosis, you should be referred to a psychiatrist, who will do a more indepth assessment with the aim of defining what exactly you are struggling with and need. This is a separate and one-off appointment, so you won't necessarily be put on a waiting list for treatment as a result of it. At the end of it you should be given a report with a diagnosis and recommendations for treatment and support.

This is usually only necessary if there is a question about what condition/s you are struggling with. For example, if someone restricts what they eat, the treatment will be different depending on the reason why – it could be OCD ('The food is contaminated'), autism ('The texture is upsetting'), an eating disorder ('I will get fat if I eat'), or any number of other challenges. A diagnosis might be sought, in this case, so that the person receives the right treatment for their symptoms.

Another type of assessment is a 'care needs assessment', which is usually offered by social services. This looks at what support can help with daily life, rather than symptoms and treatment options. This is a legal right through the Care Act 2014.

## Do I need a diagnosis?

You don't need to be diagnosed by a psychiatrist in order to receive the appropriate treatments. Treatment will be offered based on what symptoms are describing, so you will be able to

access it as long as you speak to a professional who can recognise OCD. If the assessor doesn't have any expertise in OCD, you can ask to be seen by someone who does or provide information from our website.

In some situations it might be useful to have a diagnosis, even though it isn't necessary. For example, when asking for disability support at work or if your new GP doesn't know much about OCD. In these cases, you don't need a formal diagnosis from a psychiatrist, and instead can use notes from your medical record, which will have information about previous assessments and what treatment you've had . There is usually some mention of 'symptoms of OCD', either from an assessment or because you were offered treatment for them.

If seeing a professional privately, you don't need a diagnosis, but should instead focus on finding a therapist with the right training. A report of symptoms from a private psychologist or therapist might not be recognised formally, as these credentials don't qualify someone to provide a medical diagnosis. A diagnosis from a private psychiatrist, though, is considered reliable because of the level of training they have, so should be recognised by any other service or professional.

You have a right to privacy about your condition, so if you get a diagnosis or treatment you don't need to tell employers or educators about it, and they can't ask apart from to support you with it. More here on OCD and the Equality Act 2010

## What will an assessment look like?

As part of the assessment, you will be asked a number of questions. Some of these might not be about OCD specifically, but are still an important part of getting a clear picture of what you are experiencing and what can help.

At the start of an assessment, the professional should explain:

- What the assessment is for and what to expect
- What information they might share with others and under what circumstances
- That any decision about treatment will be made by you and healthcare professionals together
- That you can refuse permission for other members of staff to be present (for example, a student might be observing the session)

Going to an assessment can be challenging or tiring, as you will be asked to speak about some difficult things. You can think ahead about what might be helpful on the day.

You might want to bring some notes along, or ask a friend to come with you. The assessor should listen to how you are feeling in your life as well as in the assessment. If something is difficult to speak about, let them know.

During the assessment, you should be given enough time to talk about your symptoms and how you are affected by them. There should also be time at the end for you to ask any questions. If you are given a diagnosis or your symptoms match a certain condition this should be clearly explained, and you should be provided with some written information about it. The healthcare professional should discuss different treatments and give information about each.

The three key things that an assessor will be looking to understand are:

#### 1. What your symptoms are

It is common for people with OCD and related conditions to find it difficult to talk about their symptoms. You might feel embarrassed by them or be worried about being misunderstood. In order to make sure that the assessment is accurate and that you are offered the treatment you need, though, it's important to be honest and give a full account of what you are experiencing. This includes

other conditions, as the treatment could be adapted to be more appropriate to your individual needs.

OCD is not defined by what obsessions are about or what compulsions might look like. The elements of the cycle can have infinite manifestations, and it is the cycle in itself that the assessor should be looking for.

You can find some tips on

checking in with a mental

health professional about

their understanding of

OCD in our factsheet about

What to look for in a

therapist

#### 2. How those symptoms are affecting your mental health and quality of life

Most people experience occasional obsessions and compulsions that make them anxious or in response to anxiety, but in order to be diagnosed as OCD these must be having a noticeable impact on your life. People who live with

OCD find their symptoms intolerable and disabling. Common effects of OCD on mental health are high levels of anxiety, very low moods, fatigue, and feelings of shame, selfblame, or low confidence.

You might also be asked about suicidal thoughts or difficult childhood experiences to give more context on how the OCD symptoms are impacting you and what overall support to offer.

#### 3. How those symptoms are affecting your day to day functioning

OCD is often kept hidden, at least as much as possible, by people struggling with it, but this does not mean that it doesn't impact on the things they do. The assessor should ask about how much time and energy is taken up by your rituals and thoughts, because it is common for them to be happening in the background, taking up a big part of the day even though from the outside you seem to be getting on fine. You might avoid certain tasks, events, or situations in an attempt to manage your anxiety. You might find some tasks impossible, or harder than they should be because of all the rules you need to follow or how distracting your thoughts are.

## Will the assessor report me as a risk?

Intrusive thoughts can be about any topic, though most often they are in some way related to danger, including someone worrying about whether they might hurt themselves or others. OCD can cause you to worry excessively about these intrusive thoughts and become obsessed

> The obsession is a fear of these and experience with OCD will understand this and would not report these thoughts as a safeguarding concern.

In fact, the NICE Guidelines state:

with doubts about whether you might, for example, attack someone or be sexually attracted to children. things, and never a desire or sign of risk. A professional who has training

"If healthcare professionals are uncertain about the risks associated with intrusive sexual, aggressive or death-related thoughts reported by a person with OCD, they should consult mental health professionals with specific expertise in the assessment and management of OCD. These themes are common in people with OCD at any age, and are often misinterpreted as indicating risk." (Page 45)

## How do I get a second opinion?

Doctors and health professionals might have different opinions about what you are experiencing or what you need. This is especially true for mental health. If you disagree with a decision about your diagnosis or treatment, you can ask for a second opinion. While this isn't a legal right, it should be offered if you have a good reason for asking.

Before asking for a second opinion, it is important to make it clear to the doctor who made the first decision why you don't agree

You can find more information about second opinions in mental health on Rethink's informational page

with it. Giving more information, or clearing up any information that might have been misunderstood, can give the doctor the opportunity to change their mind.

If this doesn't work, you can ask to be assessed by another professional with as much or more expertise in the specific issue. There are a few specialist OCD services in the country, so if your OCD symptoms are quite complex or nuanced, you

might be able to be seen there for their second opinion. Funding for this would have to be approved by your local health board.

Under the GDPR, you have a right to see any information about you and get anything wrong changed. This includes if the assessor claims there is a risk when there isn't. The Information Commissioner's Office has more information about Your data rights

## Primary Care for Adults

Primary level healthcare involves all services that are available directly to you as a first point of contact. For OCD this includes your GP surgery and the primary care mental health team. The NICE guidelines recommend this step for support around management or initial treatment of OCD for individuals with mild to moderate symptoms.

#### At this level

A GP would usually be a first point of contact for someone looking for support for their OCD, although this isn't strictly necessary. Your GP should find and provide information about OCD and signpost to any relevant services or organisations, including the local primary care mental health team. Your GP should also discuss medication options and can prescribe an anti-obsessional tablet if you are interested in taking medication.

In Northern Ireland, Scotland, and Wales, many local areas have a primary care mental health team, which can offer you CBT with ERP. Your GP should be able to give information on the local team and how to access their services, which might require a referral.

In England, a service called Improving Access to Psychological Therapies (IAPT) has streamlined what is available in primary care for mental health. Every area should be offering the same support. IAPT services are often called 'Wellbeing' centres or 'Talking Therapies', but no matter the name each local area will have at least one IAPT service. Your GP can provide contact details for local options or you can find them yourself on the <a href="NHS IAPT search page">NHS IAPT search page</a>. You can either self-refer or ask your GP to refer you.

Advocacy tip: Services out of your area

If your GP is in England, you also have the right to be referred to services outside of your local area. This is through a referral type called Patient Choice.

### Recommended at this level

#### Low intensity

A brief course of CBT with ERP. Brief means up to ten hours of therapist time. This can be done using self-help resources, over the phone, online, or in a group. If in a group, therapist time is split evenly between members, so a 2 hour group session with 4 people will mean 30 minutes of therapist time per patient.

This is recommended for individuals with 'mild functional impairment', meaning people whose symptoms only partly get in the way of day to day life.

#### • High intensity

A more intensive course of CBT with ERP and/or a course of SSRI medication. More intensive means more than 10 hours of a therapist's time.

This is recommended for individuals with 'moderate functional impairment', meaning people whose symptoms noticeably get in the way of day to day life. It is also recommended for people who didn't improve with low intensity CBT.

#### Involving family/carers

No matter what level of 'functional impairment' you are experiencing, the service should also consider involving your carers or loved ones in your ERP plan, so that they can best support you with it at home. This should only happen if you are comfortable with it.

It can help to remember that whether to try medication, therapy, or a combination of both is always an individual decision. So even if a treatment is recommended and offered, you cannot be forced to start it.

## What to expect from an IAPT service (All areas in England)

Primary care mental health teams in other UK areas might have a similar process

#### Initial screening

This is often done over the phone and is an initial conversation with a professional in which they will ask you about what has brought you there. It might be quite brief. The aim of this conversation is to make sure that IAPT is an appropriate place for your treatment. The main things they will be screening for are low moods and high anxiety.

#### • Assessment for treatment

An assessment is a more formal appointment that is more often attended in person for a full session length, which is usually 50 minutes. The assessor will get a full picture of what you are experiencing and discuss treatment options. At this stage, if something different is offered, it can help to remember that CBT with ERP is the most effective treatment for OCD and what is recommended by the NICE guidelines.

IAPT centres do not typically offer a diagnosis, but they can recognise OCD symptoms and state that they have provided you with treatment for them.

#### Low intensity therapy with a Psychological Wellbeing Practitioner (PWP)

PWP's are trained practitioners who provide CBT-based support or guided self-help. A PWP can work through self-help books and worksheets with you individually or in a group. While a PWP can't take you through ERP or make an individual treatment plan, they can support and encourage you if you're able to do these for yourself.

#### • High intensity therapy

A high intensity therapist is a qualified CBT practitioner who can offer CBT themselves and guide you through your ERP work.

## After treatment through primary care

The primary care mental health team will provide a certain number of sessions with a therapist, after which you will usually be discharged from that service. Once these are finished, they should assess your mental health and discuss whether they feel that the treatment was successful. This doesn't always happen, though, so it can be helpful to know in advance what to do if the sessions offered weren't enough.

#### The NICE guidelines state:

"For those in whom there has been no response to treatment, care coordination (or other suitable processes) should be used at the end of any specific treatment programme to identify any need for continuing support and appropriate services to address it."

To put it simply, if you've had the recommended treatment and your OCD is still impacting on your quality of life, the situation should be reviewed so that the appropriate next step in support can be explored. The primary care mental health team can assess you and make a recommendation for next steps themselves, otherwise they should contact your GP when discharging to ask them to arrange this, ideally in writing.

For people who tried low intensity therapy, the next step would be high intensity therapy. If someone has not responded to either high intensity therapy or a round of an SSRI drug, the guidelines state that a multidisciplinary review should be carried out – this means getting a recommendation from a team of different professionals, usually in secondary care at the Community Mental Health Team (CMHT).

## Secondary Care for Adults

Secondary level healthcare is also sometimes referred to as 'hospital and community care' and involves more specialised services that offer emergency response and planned treatment for individuals with more severe or complex symptoms. You will need a referral from a primary care service (usually a GP) to access secondary care.

#### At this level

The secondary care mental health team is usually called the Community Mental Health Team (CMHT). This is a 'multidisciplinary' team, which simply means there are different types of professionals so that each patient can be offered the combination of services most appropriate for them.

The team often have a base, like a clinic, that they work out of, but might also work in local hospitals, GP

Advocacy tip: Services out of your area

If your GP is in England, you also have the right to be referred to services outside of your local area. For example, if a team nearby has an anxiety disorders unit that will be better equipped to treat OCD. This is through a referral type called Patient Choice.

surgeries, or community centres. Most of the time a referral is made by the GP, but in some cases the primary care mental health team can also make the referral. At the very least, the primary care mental health team can recommend or request that your GP refer you on to secondary care.

A CMHT might also include specialised teams within the larger service, which might be based in a separate building from the main team. These might cover specific conditions, like an eating disorder team, or specific groups of people, like those with learning disabilities. Some areas also have specific secondary care mental health services for young people ages 16-25.

#### Recommended at this level

The NICE guidelines recommend secondary care treatment for people living with OCD who meet at least one of these three criteria:

- Severe functioning impairment, meaning the symptoms of OCD impact very strongly on mental health, quality of life, and day to day activities like going to work and socialising.
- Comorbidity, meaning having more than one condition, which makes treating the OCD or engaging in the CBT more complex. If you don't not have a second diagnosis you can request a mental health assessment, explaining that you believe you are struggling with more than one issue and why.
- Poor or no response to initial treatment, meaning you've tried high-intensity CBT with ERP from a primary care service but this wasn't successful or enough.

The recommended treatment for OCD at this level of care is a combination of anti-obsessional medication and more intensive CBT with ERP. More intensive means more than 10 hours with a therapist.

It can help to remember that whether to try medication, therapy, or a combination of both is always an individual decision. So even if a treatment is recommended and offered, you cannot be forced to start it. You are entitled to choose to engage with just therapy or just medication if you prefer.

## Services at the Community Mental Health Team

#### Assessment for treatment

When you are referred for support or treatment through the CMHT, especially if referred for psychological treatment, you will be assessed by a mental health professional. The assessor will get a full picture of what you are experiencing and discuss treatment options. At this stage, if something different is offered, it can help to remember that CBT with ERP is the most effective treatment for OCD and what is recommended by the NICE guidelines.

These types of assessment do not typically result in an official diagnosis, but the service can recognise OCD symptoms and acknowledge them in your records. After the assessment, you would either be placed on a waiting list or referred to a more appropriate service if the assessor does not believe the CMHT is the best option.

Advocacy tip: Rejection after assessment

If the CMHT refers you down to primary level care after the assessment, you can ask to be given a reason in writing for this decision, which you can also dispute

#### • CBT with ERP with a Clinical psychologist

A clinical psychologist has years of training and experience working in the mental health system and offering psychological treatments to people with a range of needs. They will usually have a doctorate but are not medical doctors. They can offer more specialised CBT with ERP to you if you have severe symptoms or might be struggling with other challenges that make the OCD harder to treat.

Often, clinical psychologists will have training in a number of psychological treatments. This usually includes CBT but that might not be the main therapy they are experienced in. What is important is that they have training in OCD and ERP, as outlined in the treatment guidelines.

#### • Medication and Assessment for diagnosis with a Psychiatrist

A psychiatrist is a medical doctor who has specialised and trained in working with mental health conditions. The main services offered by psychiatry are assessment and medication. Your psychiatrist might also be the clinician overseeing your case, also known as your 'consultant'. If you haven't responded to initial medication recommendations and are exploring more complex options like combinations, this will most likely be done with a psychiatrist. They might also be asked to consult on your medication as a one-off, while your GP remains in charge of prescribing and monitoring symptoms.

An assessment with a psychiatrist is a one-off appointment which would result in a report of your symptoms, a diagnosis, and recommendations for your treatment. It is not necessary to attend a psychiatry assessment before having treatment.

Other services that might be available:

#### Mental health nursing and support

Community Psychiatric Nurses (CPN) and Mental Health Nurses (MHN) are trained in mental health and can offer you emotional and practical support, either at the CMHT or through home visits. Depending on their training and experience, this might include guiding you through CBT strategies or self-help resources for OCD. They can also give medication and monitor its effects.

#### • Occupational Therapy

An Occupational Therapist (OT) provides assessments, information, and practical support around self-care, everyday tasks, work, and leisure to help an individual live independently. For example, if you are getting extra support at work because of your OCD, or have had to reduce your workload because of it, your employer might request an OT assessment. Their report would focus on the

concrete <u>and</u> abstract obstacles brought on by your symptoms, as well as what adjustments would be appropriate.

#### Social services

Social workers bring a social perspective to the team's working. They help people to talk through their problems, give them practical advice and emotional support, and can provide some psychological support such as CBT strategies. They are often able to give expert practical help with money, benefits, and housing issues.

Being under the care of a CMHT does not mean you will necessarily interact with a social worker. You should never be referred to social services only because of the themes of your intrusive thoughts, because these are **not** signs of risk.

#### • Care coordination with any of the above

Also sometimes referred to as a key worker, a care coordinator is your main point of contact as a patient. They might speak to you regularly, monitor your mental health, offer information about the condition or services available, and, most importantly, coordinate your treatment plan and speak to professionals on your behalf.

#### • Crisis support with the Crisis team

The crisis team offers short-term support aimed at preventing someone who is having a mental health crisis from needing hospitalisation. They can offer medication, home visits, and coping strategies, and should also support you to be in touch with other services for treatment and more long-term support. If you feel at risk of seriously hurting yourself you can get crisis support through your GP, calling 111, or calling your <u>local urgent mental health helpline</u>.

## After treatment through secondary care

The NICE guidelines say that if you are 'in remission', which means your symptoms have improved and are not affecting your quality of life, you should be offered appointments over the next 12 months to monitor this. How often within these 12 months these will happen will depend on the individual case. If, after 12 months, you've has kept up your recovery, you will be discharged back to your GP.

The NICE guidelines also offer specific steps as to what treatments and care should be offered at each stage, if the previous treatments didn't work.

If the recommend treatment plan at this level (CBT with ERP combined with anti-obsessional medication) hasn't brought on any or enough of a positive change in symptoms, then a multidisciplinary review is needed to discuss the next steps in your treatment, including the possibility of a referral to a specialist service.

If you have tried a combination of CBT with ERP and anti-obsessional medication, and within that have tried both an SSRI drug and Clomipramine, then the next step should be a referral to a multidisciplinary team with expertise in OCD or BDD.

This expert team should assess you and recommend a treatment plan. This might include more therapy, using medication combinations that are known to help boost the positive effects, or treatment through a specialist OCD/BDD treatment service.

## Children and Adolescent Mental Health Services (CAMHS)

CAMHS offers mental health and psychological support to young people up to the ages of 16 or 18, depending on your local area.

The term Children and Adolescent Mental Health Services (CAMHS) has now been replaced throughout the NHS by Children and Young People's Mental Health Services (CYPMHS), but the acronym 'CAMHS' is still the most used term by professionals and is most likely what you will come across. Your local CYPMHS might be called something else, but as long as it is an NHS service for young people the same support should be available.

The CAMHS team often have a base, like a clinic, that they work out of, but might also work in local hospitals, GP surgeries, or community centres. Most of the time a referral is made by the GP or the school, but in many areas referrals are also accepted directly

from parents or older teenagers. If you or your child are being supported by other services, they might also be able to make the referral.

Your local CAMHS might also include specialised teams within the larger service, which might be based in a separate building. These might cover specific conditions, like an eating disorder team, or specific groups of people, like those with learning disabilities.

Levels within CAMHS

Unlike adult services, CAMHS have internal tiers, so that all young people have a single local service offering treatment and support at different levels of need.

Tier 1

At this level, professionals supporting the child or family should recognise symptoms and provide information or non-clinical support to you and your family. A referral should be made to the appropriate tier for treatment.

Tier 2

Young people with mild symptoms of OCD or BDD who have never accessed treatment should be offered CBT with ERP.

If you, or your child, have mild symptoms of OCD, are very motivated, and are able to engage independently, guided self-help or group therapy might be appropriate. Be aware, though, that the guidelines explicitly outline that it is the young person's choice whether to access these instead of individual CBT with ERP.

Family/carers should be involved in the treatment, and the school might also be.

• Tier 3

Young people who struggle with more severe symptoms of OCD, who have more than one diagnosis, or who have had previous treatment for OCD that wasn't successful should be supported at tier 3. The recommended therapy is always CBT with ERP, but at this level it will be delivered by more experienced professionals working in a varied team.



This factsheet covers treatment through local CAMHS teams. If your symptoms (or your child's) are so severe that local services aren't able to help, you can read our factsheet on Specialist Treatment.

Advocacy tip: Services out of your area

If your GP is in England, you/your child also have the right to be referred to services outside of your local area. For example, if a team nearby has an anxiety disorders unit that will be better equipped to treat OCD.

This is through a referral called Patient Choice.

Depending on your treatment history and the severity of your symptoms, anti-obsessional medication and a referral for specialist treatment should be considered at this stage.

#### Tier 4

At this level, children and young people receive treatment through specialist services, including inpatient or intensive options.

It can help to remember that whether to try medication, therapy, or a combination of both is always an individual decision. So even if a treatment is recommended and offered, you cannot be forced to start it. You/your child are entitled to choose to engage with just therapy or just medication.

If you are 16 or older, you are considered to be able to make your own choices about your health. If you are under 16, a professional will make a judgement about whether you understand enough about your options to make a decision on your own. Health services might want to involve your parents/carers in at least some parts of your treatment, but should also listen to what you want as part of making a decision.

#### Services at the Child and Adolescent Mental Health Services

#### Assessment for treatment

If you/your child are referred for support or treatment through CAMHS, especially if referred for psychological treatment, you will be assessed by a mental health professional. The assessor will get a full picture of what you are experiencing and discuss treatment options. At this stage, if something different is offered, it can help to remember that CBT with ERP is the most effective treatment for OCD and what is recommended by the NICE guidelines.

These types of assessment do not typically result in an official diagnosis, but the team can recognise OCD symptoms and acknowledge them in your records. After the assessment, you should be placed on a waiting list and given information about what treatment this is for.

#### • CBT with ERP with a CBT therapist or Clinical psychologist

A therapist or psychologist has years of training and experience working in the mental health system and offering psychological treatments to people with a range of needs. Psychologists will usually have a doctorate but are not medical doctors. They can offer more specialised CBT with ERP if you have severe symptoms or might be struggling with other obstacles that make the OCD harder to treat.

Often, practitioners will have training in a number of therapies. This usually includes CBT but that might not be the main therapy they are experienced in. What is important is that they have training in OCD and ERP, as outlined in the treatment guidelines.

#### Medication and Assessment for diagnosis with a Psychiatrist

A psychiatrist is a medical doctor who has specialised and trained in working with mental health conditions. The main services offered by psychiatry are assessment and medication. Your/your child's psychiatrist might also be the clinician overseeing your case, also known as your 'consultant'.

If you haven't responded to initial medication recommendations and are exploring more complex options like combinations, this will most likely be done with a psychiatrist. You might also be seen by a psychiatrist if you are younger than 16, because medication can carry certain risks for younger people. They might also be asked to consult on your medication as a one-off, while your GP remains in charge of prescribing and monitoring symptoms.

An assessment with a psychiatrist is a one-off appointment which would result in a report of your

symptoms, a diagnosis, and recommendations for your treatment. It is not necessary to attend a psychiatry assessment before having treatment.

Other services that might be available:

#### Psychological therapy

CAMHS offers a range of other psychological therapies for young people, such as play therapy or family therapy. These are sometimes offered as a first option to anyone referred to the service, regardless of what the young person is struggling with. They are not recommended for treating OCD.

Advocacy tip: Waiting times

Patients in England have a legal right, under the NHS

Patients in England have a legal right, under the NHS

constitution, to have their treatment start within 18 weeks.

There have been claims that this does not apply to children and young people, but this is not the case. This right still applies.

Many carers and family members find they become very involved in the young person's compulsions, and that reducing this as part of CBT with ERP can cause problems or tensions at home. In these cases, it might be helpful to attend some family therapy <u>alongside</u> CBT with ERP to support the young person's recovery.

#### Mental health nursing and support

Community Psychiatric Nurses (CPN) and Mental Health Nurses (MHN) are trained in mental health and can provide emotional and practical support to an individual, either at the CAMHS centre or through home visits. Depending on their training and experience, this might include guiding you/your child through CBT strategies or self-help resources for OCD. They can also give medication and monitor its effects.

#### Occupational Therapy

An Occupational Therapist (OT) provides assessments, information, and practical support around self-care, everyday tasks, education, and leisure to help an individual live independently. For example, if you/your child are getting extra support at school because of OCD, or have had to reduce their workload because of it, the process might involve an OT assessment. Their report would focus on the concrete <u>and</u> abstract obstacles brought on by your symptoms, as well as what adjustments would be appropriate.

#### Social services

Social workers bring a social perspective to the team's working. They help people to talk through their problems, give them practical advice and emotional support, and can provide some psychological support such as CBT strategies. They are often able to give expert practical help with money, benefits, and housing issues.

Being under the care of CAMHS does not mean someone will necessarily interact with a social worker. You/your child should never be referred to social services only because of the themes of intrusive thoughts, because these are **not** signs of risk.

#### Care coordination with any of the above

Also sometimes referred to as a key worker, a care coordinator is the main point of contact for you/your child. They might speak to you regularly, monitor your mental health, offer information about the condition or services available, and, most importantly, coordinate your treatment plan and speak to professionals on your behalf.

#### • Crisis support with the Crisis team

The crisis team offers short-term support aimed at preventing someone who is having a mental health crisis from needing hospitalisation. They can offer medication, home visits, and coping strategies, and should also support you/your child to be in touch with other services for treatment

and more long-term support. If you feel at risk of seriously hurting yourself, you can get crisis support through your GP, calling 111, or calling their <u>local urgent mental health helpline</u>.

## After treatment through CAMHS

The NICE guidelines say that if you/your child are 'in remission', which means your symptoms have improved and are not affecting your quality of life, you should be offered appointments over the next 12 months to monitor this. How often within these 12 months these will happen will depend on the individual case. If, after 12 months, you've has kept up your recovery, you will be discharged back to your GP.

The NICE guidelines also offer specific steps as to what treatments and care should be offered at each stage, if the previous treatments didn't work.

If you have engaged with a full round of CBT and haven't felt better after 12 weeks, you should be invited to a 'multidisciplinary review'. This means that a team of different professionals from the list above should discuss your case and make a recommendation for what should happen next.

## Ageing out of CAMHS

Depending on your local area, you will generally transfer to adult mental health services when you turn 16 or 18. Your CAMHS team should speak to you about this and start the referral process, around 6 months before you age out. If you don't already have a care coordinator, a member of the team should be assigned to manage your move to adult services. They should give you information about what will happen, listen to what you want, and prepare a plan with you.

If CAMHS have not spoken to you about the change to adult services, you can ask them about this any time. It might help you feel more supported if you know in advance when the planning and referral process might start.

CAMHS should only ever discharge you if you are recovered or feeling better enough to not have any further care. If you still have treatment or care needs, you should not be discharged and left to manage the adult referral process on your own.

## Support for Families and Carers

If someone you live with or are close to is struggling with OCD, this is likely to impact on you. As a carer, whether paid or unpaid, you are entitled to support, both as a carer and for your own wellbeing.

Watching a loved one struggle with something so distressing and debilitating is difficult in itself, and very often carers find themselves feeling powerless to help. On top of this, OCD is a condition that tends to become worse and more demanding over time if it goes untreated, meaning that the care needed from you might increase.

It's very common for family members to become involved in compulsions. This can feel like a double-edged sword because of the knowledge that helping with compulsions, providing reassurance, or doing things on the person's behalf are all unhelpful in the long run. While you might not think of yourself as a carer, you are entitled to support with your own needs around the unpaid work you do to support your loved one.

As a carer, you have a 'statutory' right to a carer's assessment. This means that your local authority legally must offer this. The assessment will look at your social, practical, and mental health needs, and at the end you and all professionals involved should receive a report about what support you should be offered. This could cover many areas of your life, including:

- Training and information around caring for your loved one
- Social support such as peer groups, befriending, or social prescribing
- Psychoeducation around taking care of yourself while caring for someone else
- Mental health support such as counselling or psychotherapy
- 'Replacement care' or other ways of supporting you to engage with work or education

The NICE guidelines for OCD and BDD include information about the impact on families and the support that should be offered to carers. Recently, NICE also published guidelines for supporting all adult carers, which give more information about how carer's assessments should be run and the level of knowledge that is expected of professionals supporting you. These guidelines emphasise the importance of identifying

carers, encouraging them to engage with their own support, and treating them like a valued member of the patient's care team:

"1.1.11 Health and social care organisations should promote ways of working with carers that acknowledge them as expert partners in care and value their skills and knowledge about the person they care for.

You can read the <u>guidelines for</u>
<u>supporting adult carers</u> directly on
the website of the National Institute
of Health and Care Excellence

These approaches should be incorporated into formal policies and processes."

## Specialist Treatment for OCD and BDD

Specialist treatment services are available for individuals who have the most severe or complex symptoms of OCD and need to work with expert professionals or in intensive settings. They bring together professionals with experience in treating anxiety disorders, including OCD, and often in very severe forms.

While the treatment they offer doesn't differ from other levels, these services specialise in working with people who have difficulty taking part in the treatments. There are a number of national services for adults and children, and a few different options around how to get a referral and secure funding for the treatment.

#### Offered at this level

Depending on your needs, treatment history, and what treatment centre you are receiving care from, there are a few different treatment options at this level. The appendix below has more detailed information about each of the centres and what they offer.

#### Assessment

This is usually done as a pre-curser to therapy, like with any other service. The assessor will get a full picture of what you are experiencing and discuss treatment options, then produce a report. The report will cover symptoms, diagnosis, and treatment recommendations. Sometimes, it can be easier for someone to get funding for just an assessment and use the report to get funding for the treatment.

#### Outpatient CBT with ERP

Outpatient means that you are living at home throughout your treatmen t, and travel into the centre for therapy on a regular basis, generally once a week. If necessary, the services can also offer options if you can't travel. They can work over video and sometimes offer home visits, until you are able to travel into the centre.

#### Inpatient and/or Intensive CBT with ERP

Inpatient means that you would be staying in the clinic for the duration of the treatment. Intensive means that you would be working with a professional multiple times a week, or even in a day.

This is only offered in the most severe cases, for example when there is a high level of risk or self-neglect, or if your symptoms make it impossible for you to attend regular outpatient treatment.

#### • Medication advice

Some of the services offer specialist medication advice for those who have struggled to find the right combination of medications so far. This is depending on the type of referral used.

While intensive and inpatient treatments are the highest level of treatment, that doesn't mean they are the best option for everyone. They are usually only offered when the person's living situation is a significant obstacle to treatment.

If you're able to attend outpatient therapy, the changes have a higher chance of 'sticking' or 'sinking in' because they are being included into day to day life in between sessions. Specialist teams will also be bale to work with your family members or carers so they can support your recovery at home, which can be a valuable part of treatment.

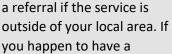
#### Neurosurgery

Currently, neurosurgery is not recommended by NICE because of the limited improvement it has been found to bring. For a few very extreme cases, though, that small improvement can be what allows the recommended treatments to work. Very few people are offered neurosurgery per year. The guidelines are currently under review and part of this will be considering new research on neurosurgery.

At the moment the only specialist centre that offers neurosurgery is the Advanced Interventions Service at Ninewells Hospital in Scotland. This is only available to people who have recently tried all of the recommended treatments at the highest level.

## How to get a referral

Each local area has a designated health board that makes decisions about what services to fund. When someone needs an assessment or treatment from a service outside their local area, the health board must approve it first. The idea behind this is that your local area won't pay extra for a service they can already offer you. There are a few different pathways that can be used to secure funding for specialist treatment, depending on where you live and what service you need.



This section covers how to get

you happen to have a specialist service in your area, the referral and funding might be secured in a different way. Check the appendix below

for more information.

#### National specialist funding

This is the 'traditional' referral pathway, usually led by your consultant at the Community Mental Health Team (CMHT).

If you are in Wales or Northern Ireland, this is the only pathway we are currently aware of. I you are in England or Scotland, this is most appropriate if you need local mental health support while you wait for specialist treatment or alongside it. Examples of cases that require this are young people, individuals who are at significant risk of self-harm, or patients who have additional conditions that also require care.

Through this pathway, the funding needs to be approved by the local health board before the person can go onto the waiting list for an assessment or treatment. In England, this is called the Clinical Commissioning Group (CCG). You can find information below on how to build a strong funding request with your consultant.

NHS England and NHS Scotland have multiple funding pathways available for different situations, and which can be much easier to secure than a more traditional funding request.

#### • Patient Choice (GPs in England only)

Currently the only service we know this can be used for is CADAT, at the Maudsley hospital in London. Other Oxford Specialist centre is considering whether to accept this type of referral. Patient Choice is a legal right under the NHS England constitution, which allows patients to choose where they want to receive treatment. This funding pathway can be used for any outpatient service that offers treatment for the condition the person is struggling with, at all levels in the stepped care system, including specialist.

This pathway is appropriate if you have severe symptoms but are not under the care of a local mental health team. If you are under the care of a mental health team, you would have to discharge yourself from it in order to use this option.

Through this pathway, a GP can refer you for specialist treatment, with a promise that your local area will pay for it. This means that you can be put on a waiting list and seen for treatment before the funding has been officially approved.

#### • NSD Funding (Scottish residents to the Advanced Interventions Service only)

The National Services Division of NHS Scotland funds the specialist OCD service in Scotland, at the Ninewells hospital in Dundee. This means that treatment at this service is already funded for Scottish residents. For more information on eligibility criteria for the Advanced Interventions Service, please see the appendix.

#### • Highly Specialised Service (HSS) (England and Scotland)

NHS England has a designated 'pot of money' that it sometimes uses to fund the treatment of the most serious and hard to treat cases. Certain specialist services are approved for HSS funding (see appendix). This pathway has much stricter requirements than others, but if the referral written by your consultant shows that the patient meets them the funding will be approved. To meet the criteria for this funding, you must meet all three of the following:

#### 1. A high score on an OCD or BDD scale

30 or above on Y-BOCS (for adults with OCD) and CY-BOCS (for children with OCD) 36 or above on the BDD-YBOCS (for people with BDD)

**OR** Your consultant can also provide a statement about how severe your symptoms are instead of a score

#### 2. Unsuccessful treatment through therapy

2 rounds of 'adequate' CBT with EPR for adults

1 round of 'adequate' CBT with ERP for children

#### 3. Unsuccessful treatment through medication

1 round of an SSRI for children

2 rounds of SSRIs, plus a round of augmentation, for adults with OCD

2 rounds of SSRIs for adults with BDD

**OR** if you are unable to take a full round of medication (3 months) because of your condition or because of the side effects you experience, the medication requirement can be dropped on a case by case basis

## Putting together a strong referral

No matter what pathway you chooses to use, a referral will be sent out to the service by a medical professional, outlining why they believe specialist treatment is necessary. If the specialist service agrees based on the information in the referral, they will see you for an assessment, through which they'll make their final decision.

For both National Specialist and HSS funding, your consultant or the service must also put this argument forward to the funding board. For HSS funding, the criteria above are quite specific, so the funding request just needs to clearly show that you meet those. Local health boards, on the other hand, will make the decision on a case by case basis. The most common reason given for refusing local funding is if you haven't 'exhausted local provision'. What this means is that you haven't tried everything available locally yet. This does not mean having to try medication. In most cases, you will have to have CBT through your local CMHT before being considered for specialist treatment through the National Specialist funding pathway.

These types of referrals are infrequent, so your consultant or GP might not know how to best put one together. You can see the referral and funding request documentation before they are sent off, if you ask, so that anything that doesn't represent the situation can be changed.

Professionals might also be reluctant to make a referral because they worry it reflects badly on their team that they were not able to help. It can be helpful to bring along some information to back up why you think you need this referral:

- The NICE guidelines hold a lot of weight, because they are nationally recognised and professionals must be able to give a reason for going against them. The guidelines outline the stepped care model that specialist treatment is at the top of, so it can help to explain where on the steps you should be 'slotted in'. If the clinician disagrees with where you believe you are on the scale, they have to be able to explain why in writing.
- Your full case history, including previous treatment, why
  previous treatment might have failed, and any documents
  that show your symptoms are entrenched or resistant to
  treatment so far (also called 'treatment refractory').
- A personal statement from you and/or your carer/s about how your symptoms impact your daily life (self care, activities, employment, education, relationships...) and mental health. OCD Action have <u>a template letter</u> than can be used for this and/or to request the referral.
- Information about the service you want a referral to and why
  this is different from local options. This can be their
  specialisation, which the NICE guidelines can provide some
  helpful quotes for, or data on how often the service is
  successful, which you can find on their website.

## Trying again

Most people do have to push hard for this treatment, so it's to be expected to get some knock-back or to have to fight for it. It is important not to give up, and there are a number of things you can try if you haven't been successful.

## If the clinician is refusing to make the referral

It can be helpful to ask them to explain, in writing, their reasons for refusing. This gives you the chance to respond to their concerns or provide more information towards why it is necessary. It also means that they won't be able to claim to have different reasons if challenged.

Another option is to get assessed by an OCD/BDD specialist, and then use the assessment report to further back up the need for specialist treatment. This can be paid for privately, or you can ask to be referred for just the assessment – this is already included in the

## Parent tips:

Mental health services sometimes talk about a young person's 'engagement' in therapy. What this really means is that they need some extra help in order to understand and commit to the treatment. This isn't your child's fault, and it might be that their needs can be met through a reasonable adjustment. It's also possible that a specialist team would be better able to help.

In your statement, you can include the impact of OCD at home or school, possible upcoming stressors (e.g. exams, puberty), and data (or usually lack thereof) showing poor outcomes from your local CAMHS for moderate/severe OCD.

You can download the <u>CY-BOCS scale</u> online and fill it out with your child or ask the

template letter linked above. A second opinion can also be requested, either from the specialist service (which funding would still need to be approved for) or from the local area. The Medical Director and Head of Psychology at the local Foundation Trust are two locally available roles that can provide a strong second opinion.

## If the funding request is unsuccessful

The health board should always give a written explanation for this, which can then be used to make any changes or additions to the referral. The referral can be sent through again as long as there has been a 'material change in circumstances', which includes adding more clinical evidence to it.

There are also a number of people or organisations that can support you through this process or if you come across any obstacles that shouldn't be there:

- If the health board's decision or actions seem to be against their funding protocol or criteria (which can be requested online), the rejection can be appealed to the Independent Funding Appeal Panel. Different local areas each have their own set of protocols.
- Although the reason for the decision should be sent through in writing, if you or your consultant
  have any other questions or want more detail, you can call or write to the decision makers directly
  to find out more about why.
- If the rejection seems to be because the information was not presented to the board well enough, a complaint can be made directly or through the Patient Advice and Liaison Service (PALS, might go by a different name in your area), which can offer mediation with the health professional.
- In some cases, when things just don't seem to be moving along as they should, contacting the local Assembly Member or Member of Parliament can be helpful.

## After specialist treatment

The NICE guidelines say that if you are 'in remission', which means your symptoms have improved and are not affecting your quality of life, you should be offered appointments over the next 12 months to monitor this. How often within these 12 months these will happen will depend on the individual case. If, after 12 months, you've has kept up your recovery, you will be discharged back to your GP.

Once the specialist treatment has been completed, you would usually be discharged back to your local services for monitoring of recovery. If you used Patient Choice to access the specialist treatment, your GP will need to refer you to the Community Mental Health Team (CMHT) for this. The specialist service should provide a plan or recommendations for your local team to follow.

The NICE guidelines also state that people who struggle with chronic or 'treatment refractory' OCD/BDD and haven't improved through specialist treatment, "should have continuing access to specialist treatment services staffed by multidisciplinary teams of healthcare professionals with expertise in the management of the disorders". This means that they should always be under the care of a secondary or higher-level mental health team for ongoing support and treatment.

## Appendix: Specialist Centres

Name of service and main services offered-

<u>Centre for Anxiety Disorders and Trauma (CADAT) at the Maudsley hospital</u>
Outpatient treatment for adults

Oxford Health Specialist Psychological Intervention Centre (OHSPIC)
Outpatient treatment for OCD

<u>Anxiety Disorders Residential unit (ADRU) at the Bethlem hospital</u>
Residential treatment for adults

National OCD/BDD Service at the Springfield hospital

Inpatient treatment and outreach for adults

<u>Highly Specialised Services for Obsessive Compulsive Disorders (OCDs) and Applied Neuroscience through the Hertfordshire Partnership University NHS Foundation Trust Personalised treatment for adults</u>

<u>Specialist service for OCD and BDD treatment at the Priory Hospital North London</u> Inpatient treatment for adolescents and adults (12+)

Advanced Interventions Service at the Ninewells hospital Intensive and inpatient treatment for adults

Obsessive Compulsive Disorder Service at the Michael Rutter centre (Maudsley hospital)
Outpatient treatment for young people (up to 18 years old)

## Centre for Anxiety Disorders and Trauma (CADAT) at the Maudsley hospital

Including 'CADAT-PAX' (Parents with AnXiety) unit

Postal address:

Centre for Anxiety Disorders and Trauma, The Maudsley Hospital, South London & Maudsley Trust, 99 Denmark Hill, London, SE5 8AZ

Telephone: 020 3228 2101

Email addresses:

<u>CADAT@slam.nhs.uk</u> (general queries) <u>cadatreferrals@slam.nhs.uk</u> (for referrals)

More details about the information below: <a href="https://www.slam.nhs.uk/national-services/adult-services/centre-for-anxiety-disorders-and-trauma/">https://www.slam.nhs.uk/national-services/adult-services/centre-for-anxiety-disorders-and-trauma/</a>

#### Care options-

(Based on treatment needs, referral type, and location)

- Outpatient CBT for OCD, BDD, and Hoarding Disorder (12-20 sessions)
- Home-based CBT for OCD and BDD (12-20 sessions)
  - o For Hoarding Disorder specifically in Lambeth, Southwark, and Lewisham
- Intensive CBT for OCD, BDD, and Hoarding Disorder (1 week of treatment)
- Medication advice for individuals funded by HSS
- 'Team assessment' Treatment recommendations to the local mental health team

#### Who the service is for-

- Adults whose main psychological concern is an anxiety or trauma condition (or both)
  - OCD, BDD, HD, PTSD, Depersonalisation, Mysophonia, other panic/anxiety/phobic conditions
- If taking medication, must be a 'stable dose' meaning you aren't currently testing out different tablets and dosages
- If you are pregnant or a parent of a child under 4yo you will be seen through CADAT-PAX, which has a shorter waiting list and specialises in this period of life

#### How to get a referral-

You can download the referral form by clicking <a href="here">here</a>

Lambeth, Southwark, and Lewisham residents:

 Do not use the form. Referrals can be made directly to your local mental health teams, because CADAT is included within your local services.

Bexley, Bromley, and Greenwich residents:

Funding only available through your local CCG. See 'National Specialist' option below

#### Other England residents:

- Patient Choice (for people not under the care of a mental health team)
   GP fills out the form, including 'Patient Choice only' section at the top of page 3, confirming you meet the criteria listed in that section.
  - CADAT receives the referral form, and can immediately add you to their waiting list.
- 2. National Specialist (for people under the care of a Community Mental Health Team <u>OR</u> who cannot use the other options)

Consultant (usually psychologist/psychiatrist) fills out the form, including 'National Specialist' section on page 3, confirming you meet the criteria listed in that section.

If you aren't under a Community Mental health Team, your GP can do the referral but must confirm that you don't need local support for complex needs.

CADAT receives the referral form, and will contact your local CCG to request the funding. \*In some areas\* the CCG will require that your doctor does the funding request instead. If this is the case, CADAT will let them know.

3. Highly Specialised Service (HSS, for people who have had lots of good quality but unsuccessful treatment)

Consultant (usually psychologist/psychiatrist) fills out the form, including 'Treatment Resistant Obsessive Compulsive Disorder / Body Dysmorphic Disorder Service' Section on pages 3 and 4, confirming you meet the criteria for that section.

CADAT receives the referral form, and may assess you. If they agree that you meet the criteria for HSS (national funding from NHS England) they will apply to the funding for you.

#### Wales and Northern Ireland residents:

Funding only available through your local health health board
 Consultant (usually psychologist/psychiatrist) fills out the form, including 'National Specialist'
 section on page 3, confirming you meet the criteria listed in that section.
 If you aren't under a Community Mental health Team, your GP can do the referral but must
 confirm that you don't need local support for complex needs.

CADAT receives the referral form, and will contact your local health funding board to request the funding.

\*In some areas\* the health funding board will require that your doctor does the funding request instead. If this is the case, CADAT will let them know.

#### Scotland residents:

1. National Specialist

Your consultant (usually psychologist/psychiatrist) fills out the form, including 'National Specialist' section on page 3, confirming you meet the criteria listed in that section.

If you aren't under a Community Mental health Team, your GP can do the referral but must confirm that you don't need local support for complex needs.

CADAT receives the referral form, and will contact your local health board to request the funding.

\*In some areas\* the health board will require that your doctor does the funding request instead. If this is the case, CADAT will let them know.

2. Highly Specialised Service (HSS, for people who have had lots of good quality but unsuccessful treatment)

Your consultant (usually psychologist/psychiatrist) fills out the form, including 'Treatment Resistant Obsessive Compulsive Disorder / Body Dysmorphic Disorder Service' Section on pages 3 and 4, confirming you meet the criteria for that section.

CADAT receives the referral form, and may assess you. If they agree that you meet the criteria for HSS (national funding from NHS England, which Scotland contributes to) they will apply to the funding for you.

## Oxford Health Specialist Psychological Intervention Centre (OHSPIC)

Postal address: Oxford Health Specialist Psychological Intervention Centre

Warneford Hospital

Oxford

OX3 7JX

ohspic@oxfordhealth.nhs.uk Headington

More details about the information below:

https://ohspic.web.ox.ac.uk/

Telephone: 01865 226361

Email address:

#### Care options-

(Based on treatment needs, referral type, and location)

- Outpatient CBT for OCD and Hoarding Disorder
- Home-based or 'outreach' CBT for OCD and Hoarding
- Intensive CBT for OCD and Hoarding Disorder
- Medication advice
- 'Team assessment' Treatment recommendations to the local mental health team

#### Who the service is for-

Adults and children whose main psychological concern is an anxiety or trauma condition (or both)

- OCD, Hoarding Disorder, PTSD, other panic/anxiety/phobic conditions
- If there is also a secondary condition outside of these (like BDD or ASD), care for this will be considered as well

#### How to get a referral-

Whole of UK. You can read about this in more detail here

- 1. An NHS healthcare professional who knows your case well fills out the referral form and adds a referral letter outlining any further information and treatment documentation
- 2. The clinic lets the referrer know whether the referral is appropriate and how much an assessment will cost. They will provide a 'Funding Approval Form' (FAF)
- 3. The referrer makes a request for funding from your local health board. If approved, the health board will confirm this by filling out the FAF
- 4. You will be assessed through a single, 2-3 hour appointment. Within 3 weeks, the clinic will send a report to the referrer, outlining their treatment recommendations and the cost of this. They will again provide a FAF for this
- 5. The referrer makes a second request to the health board, this time for the treatment funding. Again, your local health board will fill out the FAF if they approve it
- 6. You will be put on a waiting list for treatment, which will start within 18 weeks

The centre is currently considering whether to accept Patient Choice referrals.

## Anxiety Disorders Residential Unit (ADRU) at the Bethlem hospital

Postal address:
Dower House
Bethlem Royal Hospital
Monks Orchard Road
Beckenham
Kent
BR3 3BX

Telephone: 01865 226361

Email address:

Anxiety.DisordersResidentialUnit@slam.nhs.uk

More details about the information below:

https://www.slam.nhs.uk/nationalservices/adult-services/anxiety-disordersresidential-unit/

#### Care options-

(Based on treatment needs, referral type, and location)

- Residential treatment for OCD and BDD (average 12-16 weeks)
  - Not 'inpatient' as unstaffed evenings and nights
  - o CBT, occupational therapy, regular reviews, group work
  - o Relapse prevention plan as part of discharge
- Second opinion assessment for complex cases

#### Who the service is for-

- Adults whose main psychological concern is an anxiety or trauma condition (or both)
  - o OCD, BDD, PTSD, other panic/anxiety/phobic conditions
- You must be able to travel home on weekends meaning having a place you can stay and an ability to travel (independently or with your own support)
- You must be able to perform basic self-care and self-medicate
- Cannot be struggling with current issues of psychosis, addiction, or high risk behaviour that need their own care or treatment

#### ADRU Operational Policy (June 2020) also says:

Examples of suitability of our service are:

- There has been no response to adequate trials of treatments in other settings, or
- a person has additional diagnoses, such as depression, that make outpatient treatment more complex, or
- the compulsions and avoidance behaviours are so severe or habitual that they cannot undertake normal activities of daily living or prevent the person attending an outpatient setting, or
- if it is helpful to separate the person with an anxiety disorder from their family members if there is excessive accommodation or aggression by either party or to enable them to practice independent living.

#### How to get a referral-

You can download the referral form by clicking <a href="here">here</a>

#### Whole of UK

- 1. National Specialist
  - Your consultant (usually psychiatrist, but other referrals will be considered) would send a completed referral form for assessment and/or treatment to the unit, outlining your symptoms and treatment history.
  - Your consultant also needs make a funding request to the local health board. This can be done beforehand or alongside, but you cannot be placed on a waiting list until the funding is approved.
- 2. Highly Specialised Service (HSS, for people in England or Scotland who have had lots of good quality but unsuccessful treatment)
  - Your consultant (usually psychiatrist, but other referrals will be considered) would send a completed referral form for assessment and/or treatment to the unit, outlining your symptoms and treatment history.
  - They would also make a funding request to NHS England, outlining how you meet the HSS criteria. This can be done beforehand or alongside, but you cannot be placed on a waiting list until the funding is approved.

## National OCD/BDD Service at the Springfield hospital

Postal address:
National OCD/BDD Service
Springfield University Hospital
61 Glenburnie Road
Tooting
London
SW17 7DJ

Telephone: 020 3513 6961

Email address:

ocdbdd@swlstg.nhs.uk

More details about the information below:

https://www.swlstg.nhs.uk/our-

services/specialist-services/ocd-bdd-service

#### Who the service is for-

Adults whose main psychological concern is OCD, BDD, or Hoarding Disorder.

#### Care options-

Read more on all of these here

#### Trustwide Service (OCD/BDD)

Read more here

Your GP or consultant (psychiatrist/psychologist) can ask for support from one of the therapists in the service. This can be:

- Support and guidance for the mental health professionals who work with you
- Joint working with your team and delivering therapy as part of your care plan
- Treatment for you directly from the service in your home or as an outpatient

The usual criteria for this service is to have tried 1 round of CBT and 2 rounds of medication unsuccessfully, but if your case is clearly quite severe or complex, they might consider you without these having been met.

#### National Service (OCD/BDD/HD)

(Based on treatment needs, referral type, and location)

- Outpatient/community CBT
- Home-based CBT
- Inpatient treatment
  - o Appropriate for people who are not able to self-care independently

#### How to get a referral-

You can find the referral forms for the different services <u>here</u>

#### Whole of UK

1. National Specialist

Your consultant (usually psychiatrist, but other referrals will be considered) would send a completed referral form for assessment and/or treatment to the unit, outlining your symptoms and treatment history.

Your consultant also needs make a funding request to the local health board. This can be done beforehand or alongside, but you cannot be placed on a waiting list until the funding is approved.

2. Highly Specialised Service (HSS, for people in England or Scotland who have had lots of good quality but unsuccessful treatment)

Your consultant (usually psychiatrist, but other referrals will be considered) would send a completed referral form for assessment and/or treatment to the unit, outlining your symptoms and treatment history.

They would also make a funding request to NHS England, outlining how you meet the HSS criteria. This can be done beforehand or alongside, but you cannot be placed on a waiting list until the funding is approved.

# Highly Specialised Services for Obsessive Compulsive Disorders (OCDs) and Applied Neuroscience through the Hertfordshire Partnership University NHS Foundation Trust

Postal address:
Prof NA Fineberg
Consultant Psychiatrist
Rosanne House
Parkway
Welwyn Garden City
AL8 6HG

More details about the information below: https://www.hpft.nhs.uk/services/communityservices/highly-specialised-services-forobsessive-compulsive-disorders-ocds-andapplied-neuroscience/

#### Care options-

- Outpatient CBT for OCD, BDD, Hoarding Disorder, and BFRB
- Inpatient CBT for OCD, BDD, Hoarding Disorder, and BFRB
- Medication treatment for OCD, BDD, Hoarding, and BFRB
- Inreach for people admitted onto wards at Hertfordshire Partnership University NHS
   Foundation Trust and inpatient units elsewhere in England, including for people receiving
   treatment under the mental health act
- Assessment for neurosurgery

#### Who the service is for-

- Adults whose <u>main</u> psychological concern is OCD or a related condition (including Hoarding Disorder and BFRB) at levels 4-6 on the <u>stepped care chart</u>
- Needs, criteria, and cost of treatment will be discussed individually

#### Hertfordshire Partnership University NHS Foundation Trust website (February 2021) says:

We provide person-centred treatment/care, both in the outpatient clinic and/or in an inpatient care setting, delivered to the highest standard. We use research-enhanced treatment, including off-label and approved pharmacological agents. Psychological interventions include Cognitive Behaviour Therapy (CBT) with Exposure and Response Prevention (ERP). Various other psychological interventions are utilised to help enhance treatment response. Given the cognitive inflexibility and rigidity often experienced by our service-user group, which at times impacts treatment progress, we are constantly exploring new pharmacological and psychological approaches to improve flexibility and outcomes on an individualized basis.

A very small group of patients who further fail to respond to our treatment are offered the opportunity for assessment for suitability for somatic treatment e.g. neuromodulation or neurosurgery.

#### How to get a referral-

Whole of UK

- 1. National Specialist
  - Your consultant (usually psychiatrist, but other referrals will be considered) would send a completed referral form for assessment and/or treatment to the unit, outlining your symptoms and treatment history.
  - Your consultant also needs make a funding request to the local health board. This can be done beforehand or alongside, but you cannot be placed on a waiting list until the funding is approved.
- 2. Highly Specialised Service (HSS, for people in England or Scotland who have had lots of good quality but unsuccessful treatment)
  - Your consultant (usually psychiatrist, but other referrals will be considered) would send a completed referral form for assessment and/or treatment to the unit, outlining your symptoms and treatment history.
  - They would also make a funding request to NHS England, outlining how you meet the HSS criteria. This can be done beforehand or alongside, but you cannot be placed on a waiting list until the funding is approved.

## Specialist service for OCD and BDD treatment at the Priory Hospital North London

Postal address:
National OCD/BDD Service
Springfield University Hospital
61 Glenburnie Road
Tooting
London
SW17 7DJ

Telephone: 0808 159 8296 020 8023 6799

Email address: Priory.Referral@nhs.net

More details about the information below: https://www.priorygroup.com/nhs/locations/priory-hospital-north-london-nhs-services

#### Care options-

- Inpatient treatment for OCD and BDD
  - One to one, group, and general psychology groups

#### Who the service is for-

 Adults and adolescents (12-17) whose <u>main</u> psychological concern is OCD or BDD The NHS service also includes a CAMHS inpatient unit for adolescents with any psychological conditions. If another condition is present that makes treatment more complex, they might be transferred to this unit. It has a total of 21 beds.

#### How to get a referral-

Whole of UK

1. National Specialist

Your consultant (usually psychiatrist, but other referrals will be considered) would send a completed referral form for assessment and/or treatment to the unit, outlining your symptoms and treatment history.

Your consultant also needs make a funding request to the local health board. This can be done beforehand or alongside, but you cannot be placed on a waiting list until the funding is approved.

2. Highly Specialised Service (HSS, for people in England or Scotland who have had lots of good quality but unsuccessful treatment)

Your consultant (usually psychiatrist, but other referrals will be considered) would send a completed referral form for assessment and/or treatment to the unit, outlining your symptoms and treatment history.

They would also make a funding request to NHS England, outlining how you meet the HSS criteria. This can be done beforehand or alongside, but you cannot be placed on a waiting list until the funding is approved.

## Advanced Interventions Service at the Ninewells hospital

Advanced Interventions Service Area 7, Level 6 South Block Ninewells Hospital and Medical School Dundee DD1 9SY Telephone: 01382 496233

Email address:

enquiries@advancedinterventions.org.uk

More details about the information below: <a href="https://www.advancedinterventions.org.uk/">https://www.advancedinterventions.org.uk/</a>

#### Care options-

- Assessment with treatment advice for your local team
- Intensive inpatient or home-based CBT with ERP for OCD
- Neurosurgery (Anterior Cingulotomy)
- <u>Inference-Based Therapy</u> (OCD Action does not have any further information on this treatment)

#### Who the service is for-

- Adults whose main psychological concern is OCD at levels 5 or 6 on the stepped care chart
  - Usually expected to have tried multiple rounds of CBT and medication

#### Advanced Intervention Service's website (February 2021) says:

We recognise that it can often be difficult to access the kind of psychological therapy that is often recommended by guidelines. In people with more severe and more chronic OCD, they will often need longer sessions, for more time, and usually at home. Most services struggle to deliver treatment outside of an office-based environment.

We would advise getting in touch to discuss things with us. We can often liaise with local services to help support delivery of treatment, and look at options for ensuring that people don't get caught in a catch-22 where they need more treatment, but can't get that treatment locally.

#### How to get a referral-

Read more about the referral process, guidelines, and criteria here

For Scottish residents, the local clinician (usually psychiatrist) just needs to write to the service with information about your condition and treatment history. The funding for this service is provided by the National Services Division.

#### Rest of UK

- 1. National Specialist
  - Your consultant (usually psychiatrist, but other referrals will be considered) would send a completed referral form for assessment and/or treatment to the unit, outlining your symptoms and treatment history.
  - Your consultant also needs make a funding request to the local health board. This can be done beforehand or alongside, but you cannot be placed on a waiting list until the funding is approved.
- 2. Highly Specialised Service (HSS, for people in England or Scotland who have had lots of good quality but unsuccessful treatment)
  - Your consultant (usually psychiatrist, but other referrals will be considered) would send a completed referral form for assessment and/or treatment to the unit, outlining your symptoms and treatment history.
  - They would also make a funding request to NHS England, outlining how you meet the HSS criteria. This can be done beforehand or alongside, but you cannot be placed on a waiting list until the funding is approved.

## Obsessive Compulsive Disorder Service at the Michael Rutter centre (Maudsley hospital)

Postal address: Michael Rutter Centre De Crespigny Park London SE5 8AZ

Telephone: 020 3228 5222

Email address:

ocdbdd.camhs@slam.nhs.uk

"Families, GPs, and referrers are welcome to contact us for information."

More details about the information below:

Watch a short video about the assessment process

OCD Service
BDD Service

#### Care options-

- Outpatient CBT for OCD (14-20 sessions avg.), BFRB, and BDD (20 sessions avg.). Also ASD, tic conditions, and other anxiety disorders
  - Where appropriate, will include and work with parents/carers
  - o Remote options like telephone and video available
- Some inpatient and outreach treatment
- Medication treatment
- 'Team assessment' Treatment recommendations to the local mental health team
- Follow-up appointments for a year after

#### Who the service is for-

- Young people (up to 18) with a suspected diagnosis of OCD, BFRB, BDD
- Must be under the care of a local mental health team

#### How to get a referral-

Read more about what goes into a referral here

Whole of UK

1. National Specialist

Your consultant (usually psychiatrist, but

other referrals will be considered) would send a completed referral form for assessment and/or treatment to the service, outlining your symptoms and treatment history. When the service receives the referral form, they will contact your local health board to request the funding.

Password: assessment

\*In some areas\* the health board will require that your doctor does the funding request instead. If this is the case, the service will let them know.

2. Highly Specialised Service (HSS, for people in England or Scotland who have had lots of good quality but unsuccessful treatment)

Your consultant (usually psychiatrist, but other referrals will be considered) would send a completed referral form for assessment and/or treatment to the service, outlining your symptoms and treatment history.

When the service receives the referral form, they may assess you. If they agree that you meet the criteria for HSS they will apply to the funding for you.