ocdaction
it's time to act

# Accessing Treatment for OCD through the NHS

# 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.

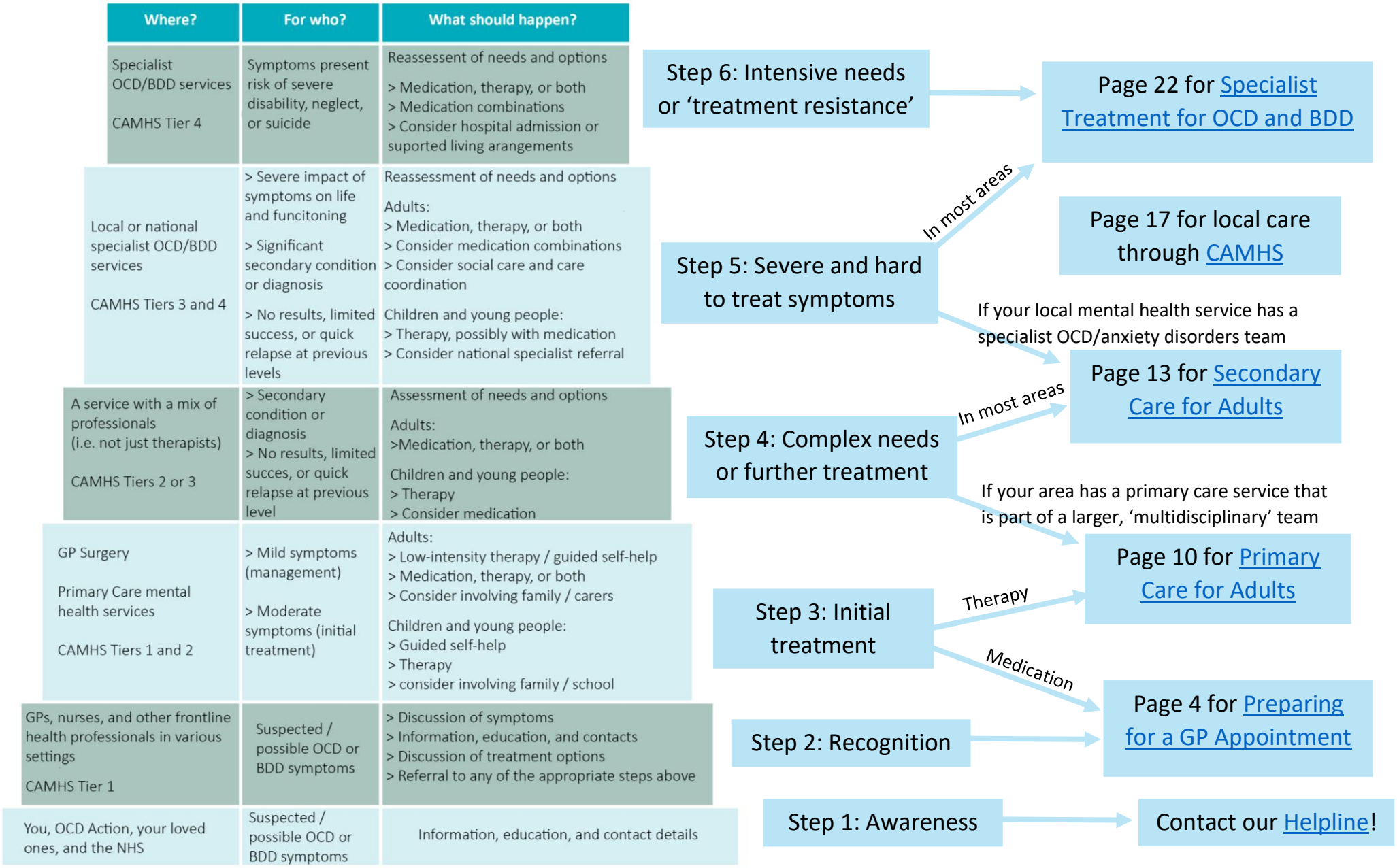
There are actually 4 versions of the guidelines for OCD/BDD!

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 Specialist Treatment for OCD and BDD
Local or national specialist OCD/BDD services
CAMHS Tiers 3 and 4
> Severe impact of symptoms on life and funcitoning
> Significant secondary condition or diagnosis
> No results, limited success, or quick relapse at previous levels
Reassessment of needs and options
Adults:
> Medication, therapy, or both
> Consider medication combinations
> Consider social care and care coordination
Children and young people:
> Therapy, possibly with medication
> Consider national specialist referral
Step 5: Severe and hard to treat symptoms
In most areas
Page 17 for local care through CAMHS
If your local mental health service has a specialist OCD/anxiety disorders team
Page 13 for Secondary Care for Adults
A service with a mix of professionals (i.e. not just therapists)
CAMHS Tiers 2 or 3
> Secondary condition or diagnosis
> No results, limited succes, or quick relapse at previous level
Assessment of needs and options
Adults:
>Medication, therapy, or both
Children and young people:
> Therapy
> Consider medication
Step 4: Complex needs or further treatment
In most areas
If your area has a primary care service that is part of a larger, 'multidisciplinary' team
Page 10 for Primary Care for Adults
GP Surgery
Primary Care mental health services
CAMHS Tiers 1 and 2
> Mild symptoms (management)
> Moderate symptoms (initial treatment)
Adults:
> Low-intensity therapy / guided self-help
> Medication, therapy, or both
> Consider involving family / carers
Children and young people:
> Guided self-help
> Therapy
> consider involving family / school
Step 3: Initial treatment
Therapy
Medication
Page 4 for Preparing for a GP Appointment
GPs, nurses, and other frontline health professionals in various settings
CAMHS Tier 1
Suspected / possible OCD or BDD symptoms
> Discussion of symptoms
> Information, education, and contacts
> Discussion of treatment options
> Referral to any of the appropriate steps above
Step 2: Recognition
You, OCD Action, your loved ones, and the NHS
Suspected / possible OCD or BDD symptoms
Information, education, and contact details
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 disengage with the mental health system and not 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.

## 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.

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

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.

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:

1. 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
3. 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.

The NICE Quick-Reference Guidelines use tables and flowcharts to support professionals to work out the ideal next steps in your treatment.

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 GP Card 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.

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.

# 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.

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.

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.

**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.

## 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.

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.

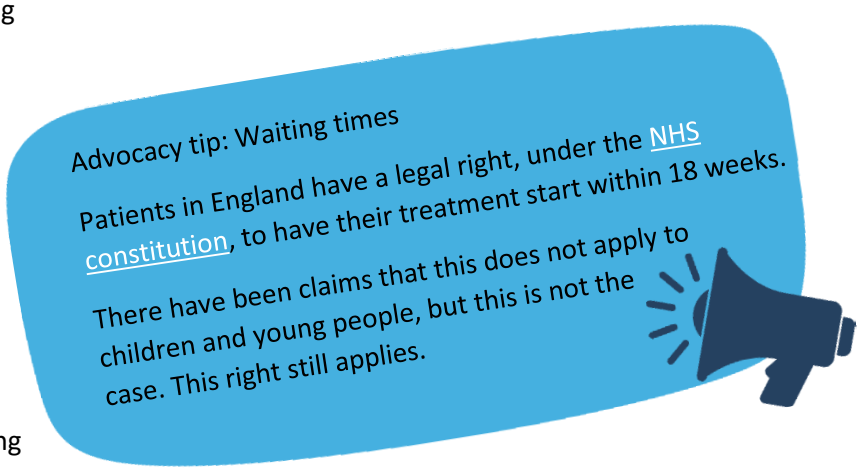
If you are 16 or older, you are considered to be able to make your own choices about your health. If you are under 16, a professional will make a judgement about whether you understand enough about your options to make a decision on your own. Health services might want to involve your parents/carers 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.
  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 alongside 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 and 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 local urgent mental health helpline.

## 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.