

OCD & ACCESSING TREATMENT FOR ADULTS

It is important to understand your rights and the help that is available to you so that you can be more in control of your treatment.

TIME TO GET HELP

It can be a very isolating experience to have Obsessive Compulsive Disorder (OCD). You may feel you have OCD but you aren't sure, or your symptoms may be getting unbearable and you think it is time you did something. Perhaps friends and family are getting concerned and are encouraging you to seek help. Whatever your position there is help available.

'STEPPED CARE' APPROACH

An independent organisation known as NICE (The National Institute for Health and Clinical Excellence) produces guidelines for the NHS detailing how healthcare professionals should treat particular conditions. These Guidelines make recommendations of effective treatment based on the best evidence from medical research. In England & Wales NHS healthcare professionals must follow these guidelines; in Scotland and Northern Ireland they do not have to follow them but they should still take them into account.

This is how NICE state the importance of their guidance:

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The application of the recommendations in this guideline is not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

The NICE Guideline for OCD & BDD (<https://www.nice.org.uk/guidance/cg31>) recommends a particular type of Cognitive Behavioural Therapy (CBT) that includes Exposure Response Prevention (ERP) and/or medication as the most effective treatment for OCD. (Please see our information sheets: 'What is Cognitive Behavioural Therapy?' and 'Medication for OCD' available in the Downloadable Resources section of our website:

<http://www.ocdaction.org.uk/resource/what-cognitive-behavioural-therapy-cbt>

<http://www.ocdaction.org.uk/resource/medication-ocd>

NICE recommends that NHS health professionals should follow a 'stepped care' approach. **This means that you as a patient can access different levels of treatment depending on your needs.** Treatments can be 'stepped up' from the sort of help your local GP can give to specialised and intensive treatment that is provided by a National and Specialist OCD service.

Whatever the step, the treatment recommended is always CBT with ERP, or medication, or both. What changes with the different steps is the intensity of the treatment (the number of hours of treatment you receive) and the expert OCD knowledge of the health professional treating you. Normally you would be expected to try a lower step treatment first and this may reduce your symptoms without you needing more specialist treatment but you should start treatment at the step that is most appropriate for the severity of your OCD. If you have had unsuccessful OCD treatment in the past or your OCD is particularly severe then you should be offered more specialist treatment.

1st STEPS: Treatment throughyour GP

Your local GP is often a good place to start to find appropriate help. Some people are very nervous about what to say to a GP about their OCD and how much to disclose about their obsessional thoughts and/or compulsions. Some GPs will be very well informed about OCD but others may have less experience. OCD Action has produced an information card that you can give your GP at your first appointment. The GP card can be downloaded from the Downloadable Resources section of our website. It explains the condition in full and describes the usual treatment options: http://www.ocdaction.org.uk/sites/default/files/pdf-precompiled/ocdbdd_gp_card.pdf

If you are very anxious about your visit to the GP, you could take a friend or family member, or request support from your local Mental Health Advocacy Service. If you need help finding a service near you, please contact the OCD Action Helpline: 0845 390 6232.

Your GP should tell you about the treatment options available to you and should take into account your views and wishes. Getting a correct diagnosis is important so that you can be given the right treatment. You can ask your GP to refer you for a general 'Mental Health Assessment' so you can to get a correct diagnosis. This assessment may be carried out by a local Community Mental Health Team (CMHT), Improving Access to Psychological Therapies (IAPT) service or by a consultant psychiatrist or specialist in a hospital.

Advocacy Tip

If you find that your regular GP is not very helpful or knowledgeable about OCD remember you can see *any* GP in your practice. If necessary, you could see all of them until you find one who understands and can help.

In England, your GP may refer you onto an Improving Access to Psychological Therapies (IAPT) service although in many areas you can now self-refer directly to an IAPT service:

1st STEPS: Treatment through.....an Improving Access to Psychological Therapies (IAPT) service

These services offer treatments approved by NICE to adults with depression and anxiety disorders, including OCD. IAPT services offer a number of different talking therapies and you should be offered a choice of treatments. Remember that CBT with ERP is the therapy recommended as being the most effective for the treatment of OCD.

IAPT services should offer you an assessment (which may result in them giving you a diagnosis) and a recommended treatment plan. Currently IAPT services are aiming to ensure that 75% of people who are referred or who self-refer start treatment within 6 weeks and that 95% start within 18 weeks so you should not have to wait too long to begin CBT.

IAPT services have a workforce made up of:

- **Psychological Wellbeing Practitioners (PWPs)** who provide CBT-based support; often called guided self-help. This is likely to be supporting people to carry out CBT with self-help books and materials or through self-help groups. This approach is recommended if your symptoms are mild and you are very self-motivated. Although IAPT guidelines say that PWPs can treat people with mild to moderate OCD, in many cases PWPs do not actually provide the individual **CBT with ERP** that NICE recommends. If you do start out seeing a PWP and your symptoms do not improve you should be 'stepped up' or referred onto:
- **High Intensity Cognitive Behavioural Therapy Workers** who are trained in OCD-specific CBT and ERP. NICE Guidelines recommend CBT with ERP even for people with mild to moderate OCD so ideally you should be receiving treatment from a High Intensity CBT worker.

For more information on your local IAPT services: put IAPT or psychological therapies into the search box on the NHS Choices website - <http://www.nhs.uk/pages/home.aspx> you should then be asked to put in your postcode.

INITIAL TREATMENT RECOMMENDED BY NICE

Initial treatments for adults include:

- A brief course (up to ten hours of a therapist's time) of individual or group low Cognitive Behavioural Therapy (CBT) including Exposure Response Prevention (ERP). In group therapy an hour of a therapist's time is divided by the number of participants so an hour of group CBT for 4 people would be counted as 15 minutes per individual. For more information on what this sort of CBT should be like, please see our fact sheet: 'CBT Checklist' available in the Downloadable Resources section of our website: <http://www.ocdaction.org.uk/support-info/have-i-had-cbt-my-ocd>
- A course of medication known as a Selective Serotonin Reuptake Inhibitor (SSRI) (often called an anti-depressant) OR CBT with ERP for more than 10 hours of a therapist's time.
- Combined treatment of an SSRI and CBT with ERP.

CHOICE: Choosing your mental health service provider in England.

In England, since 2014, adults with mental health problems have had the legal right to choose who their GP refers them to for out-patient mental health treatment. This means that, providing you are over 16 and not under the care of a Community Mental Health Team (CMHT), you can choose any out-patient mental health service in England to be referred to. The out-patient service could be a Community Mental Health Team (CMHT), and Improving Access to Psychological Therapies (IAPT) service or a National & Specialist OCD Service.

For more information please see: [NHS Improvements Leaflet: 'Choice in Mental Health: How It Can Work For You'](#) available in the Downloadable Resources section of our website:

Stepped up to a Community Mental Health Team (CMHT)

If you have not responded well to initial treatment, the next 'step up' is to be referred, by your GP or IAPT service, to the Community Mental Health Team (CMHT). This is likely to mean that you see a Psychiatrist or Clinical Psychologist (or both) who may be able to help you, as well as a range of other people such as social workers, psychiatric or mental health nurses or occupational therapists. The team can all offer psychological support, encouragement and practical help.

The Community Mental Health Team may have a base, like a clinic, where they can see you. They may also work in a range of other places e.g. hospital out-patient clinics, GP surgeries, day-centres, hostels and people's own homes. For more information please see: ['What is a CMHT?'](#) available in the Downloadable Resources section of our website:

At this stage NICE recommends that you be offered a combination of a Selective Serotonin Reuptake Inhibitor (SSRI) with more intensive CBT with ERP (more than 10 hours of a therapist's time). If this is unsuccessful you may be offered a course of another drug called Clomipramine.

Stepped up again to a National & Specialist OCD Service

It is possible that you will have had treatment through your Community Mental Health Team (CMHT) and still have not made progress. It could be that your OCD is affecting the quality of your life to a severe degree or that you have other mental health issues alongside your OCD. In this situation, you may be able to be 'stepped up' to more specialist services for OCD/BDD called National and Specialist services. These specialise in the treatment of OCD and have experienced CBT Therapists providing CBT with ERP and/or medication. They mainly provide outpatient treatment although two offer inpatient treatment.

They may be out of your local area and your Community Mental Health Team (CMHT) may have to get your local Clinical Commissioning Group (CCG) in England and Local Health Board (LHB) in Wales & Scotland to agree the funding for your assessment and subsequent treatment. Your psychiatrist or Clinical Psychologist at your local CMHT needs to make a referral to the National & Specialist service and your Community Mental Health Team would need to remain involved in your care while you are receiving specialist treatment.

For more information, please see our Advocacy resource: Getting a Referral to an Adult National & Specialist OCD Service available in the Downloadable Resources section of our website: [http://www.ocdaction.org.uk/sites/default/files/pdf-precompiled/leaflet -
referral to ns adult ocd services 0514.pdf](http://www.ocdaction.org.uk/sites/default/files/pdf-precompiled/leaflet-_referral_to_ns_adult OCD_services_0514.pdf)

At this stage in your treatment, NICE recommends an SSRI or Clomipramine, CBT (including ERP), or a combination of SSRI or Clomipramine and CBT (including ERP).

Stepped up again to more intensive and extended treatment at a National & Specialist OCD Service

If you have no improvement in your symptoms after a course of treatment with National & Specialist services, you may need more intensive treatment at one of these services for an extended period of time. People who access these services at this level have OCD or BDD which carries a risk to their life. They may be severely self-neglecting and be severely distressed or disabled by their condition.

How should your Healthcare Professional be helping you?

Whatever your level of care, your mental health care professionals should be offering you support and a point of contact in case of crisis. They should be keeping track of whether your OCD is getting better or worse using a questionnaire or checklist such as the Obsessive Compulsive Inventory (OCI). They should:

- Be clear about who they are and what they can do for you.
- Fully explain any proposed treatment, allow you the opportunity to ask questions, give you time to think about it and seek your informed consent. In addition, if the treatment they are offering is different from the evidence-based treatment recommended by NICE, they should explain why.
- Inform you about any medications and their possible side effects.
- Offer you follow up appointments and reviews.

Advocacy Tip

You cannot be forced to accept treatment of any kind. For example, you cannot be made to take medication before you would be considered for CBT. The only exception is if you are detained (or 'sectioned') under certain sections of the Mental Health Act 1983 (as amended 2007) when you may be treated without your consent.

Your healthcare professionals should also put you in touch with any voluntary agencies able to offer support if you ask for this, including mental health advocacy such as OCD Action's Advocacy Service who could liaise with your GP and other agencies on your behalf.

Accessing CBT Privately

Although you are entitled to receive free CBT on the NHS (and in England the IAPT scheme mentioned above is a good way of accessing this), if you cannot access appropriate support or the waiting times seem too long you may consider paying to see a therapist privately. It is worth taking the time to find someone with experience and knowledge in the treatment of OCD, and with whom you feel you could work.

The British Association for Behavioural & Cognitive Psychotherapies (BABCP) website will offer guidance on how to access these specialists: www.babcp.com. Many of the therapists at the National and Specialist services offer private appointments and there are other specialists practising privately in other areas of the UK. Your GP may also be able to give you information about specialists in your area.

Advocacy Tips: accessing services

- Take a look at the OCD Action website information pages. The better informed you are about your condition, the more confident you will feel about asking for help.
- Access our Helpline or Advocacy Service for further information and support. Our Advocates can help you draft letters, make phone calls, plan strategies for meetings and appointments, or attend them with you.
- Take a look at the Forum and post questions - there will be many people going through the same thing.
- Download our **GP card** - this may help with your first consultation and it's handy to bring along to further meetings:
http://www.ocdaction.org.uk/sites/default/files/pdf-precompiled/ocdbdd_gp_card.pdf
- Prepare for meetings with your GP or other professionals – be clear about how your OCD is affecting your life, work and relationships and the lives of those around you; refer to the NICE Guidelines when asking for treatment and be clear what treatment you are asking for.
- If you are having to wait to start CBT (with ERP), use the time to prepare for what the treatment will entail – read some self-help books, download our **CBT checklist** so that you have a clear idea what good CBT looks like, attend your local support groups & talk to other people with OCD.
<http://www.ocdaction.org.uk/support-info/have-i-had-cbt-my-ocd>
- If you are about to start CBT and want to have some extra support while you are undergoing treatment call our Helpline and ask about our Next Steps project. We can provide you with regular phone calls with a single volunteer throughout your course of treatment to help keep you motivated.
- Be aware of your rights as a patient - ask for information, and find out what your options and choices about treatments are. If you are being refused treatment, ask for reasons in writing and complain if you are not happy with your care.
- Make a note of the name and role of the professional you are seeing along with the service or team that they are from. Many times, people contact us and they are not sure who they are going to an appointment with or who has spoken to them on the phone.
- If you don't feel confident about standing up for your rights, bring a friend or an Advocate to meetings.
- Don't be swayed by issues over resources and funding. Look at the NICE Guidelines and what they say. Your clinician should give you very good reasons if you cannot be provided with recommended treatments. If you are having difficulty, please ring our Helpline to see if we can offer advocacy support or access help from other mental health charities.

COMPLAINTS

If you need help with making a complaint about your treatment the following organisations can provide information and/or support:

England

Information on how to make a complaint is available from NHS England:
<https://www.england.nhs.uk/contact-us/complaint/>

Wales

Complaints Advocacy Service available through Community Health Councils: 02920 235 558
<http://www.wales.nhs.uk/sitesplus/899/page/71619>

Scotland

Patients Advice & Support Service (PASS) delivered by Citizen's Advice.
www.cas.org.uk/patientadvice

Northern Ireland

Patient & Client Council: 0800 917 0222
<http://www.patientclientcouncil.hscni.net/making-a-complaint>

Action Against Medical Accidents (AvMA): An independent charity that supports people affected by medical accidents or clinical negligence. Helpline: 0845 123 2352 (Mon - Fri 10am – 3.30pm)
<https://www.avma.org.uk/>

Patients Association: provides information and support about any aspect of the healthcare system. Helpline: 020 8423 8999 www.patients-association.com

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