Your rights

Having a clear understanding of your rights and the help that is available to you means that you can be more in control of your treatment.

ACCESSING TREATMENT

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 unbearably and you think it is time you did something. Perhaps loved ones are getting concerned and are encouraging you to seek help. Whatever your position help is out there!

HOW TO ACCESS HELP

Your GP: A good place to start to find appropriate help would be to visit your local GP. Some people say they are very unsure of what to say on their first visit and are very nervous about disclosing obsessional thoughts and or compulsions. GPs will certainly know about OCD but their knowledge of it may vary. OCD Action have put together a card that you can give your GP at this initial consultation. The card can be downloaded from the Advocacy section of our website and explains the condition in full and the usual treatment options: http://www.ocdaction.org.uk/files/2010/03/GP-Card-v04.pdf

If you are very anxious about your visit to the GP, you could take a friend, 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 what treatment options are available to you. He or she should consider your views and wishes. Getting a correct diagnosis of your condition is important so that you can be treated appropriately. You can ask your GP to refer you for a general ‘Mental Health Assessment’ in order to get a correct diagnosis. This would usually be in the form of a referral to a local Community Mental Health Team (CMHT) or to a consultant or specialist in a hospital.

HANDY TIP:
If you find that your GP is not very helpful or knowledgeable remember you can see any GP in your practice - If necessary you could see all of them until you find one who can help & understands.

STEPPED CARE APPROACH

The National Institute for Health and Clinical Excellence (NICE) has produced Guidelines for NHS staff when working with and treating people with OCD. http://www.nice.org.uk/CG31

Treatment for your OCD should be in line with their recommended ‘stepped care’ approach where each step introduces additional interventions. The higher steps normally assume interventions in the previous step have been offered and/or attempted but there are situations where you may be referred to more specialist services from the outset; depending on your symptoms.

Guidelines apply in England & Wales but clinicians in Scotland & Northern Ireland should have regard to the NICE guideline when treating individuals with OCD/BDD.
This means that you can access different levels of treatment depending on your needs. The treatment provided is always Cognitive Behavioural Therapy (CBT) with Exposure Response Prevention (ERP) usually in combination with medication but the intensity of that treatment and the expert OCD knowledge of the clinicians delivering the treatment will differ. At the different steps treatments may range from help that your local GP can give to specialised and intensive treatment that is provided by a national & specialist OCD service.

The Stepped-care Model follows the following steps:

**Step 1** which involves the sort of awareness raising that OCD Action delivers.

**Steps 2-3**
If you have visited your GP, they should (depending on the severity of your condition) be initially managing and treating your OCD. Depending on the severity of your OCD treatments recommended for adults are:

- Up to ten hours of low intensity Cognitive Behavioural Therapy (CBT) which may include ‘Exposure Response Prevention’ (ERP).
- The use of self help materials.
- CBT by telephone or group CBT.

Patients are sometimes told that CBT is not available in their area or that waiting lists are long. For people in England CBT can be accessed through your local Improving Access to Psychological Therapies (IAPT) service:

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**Improving Access to Psychological Therapies (IAPT)** is an NHS service available across England offering interventions approved by the NICE for treating adults with depression and anxiety disorders.

IAPT services have a workforce made up of:

- **Psychological Wellbeing Practitioners** who provide CBT-based interventions to people with mild to moderate OCD. Although this has a poor evidence-base and is not generally recommended unless your symptoms are very mild and you are very self-motivated.

- **High Intensity Cognitive Behavioural Therapy Workers** trained in OCD-specific CBT and ERP who can treat people with moderate to severe OCD.

You may be able to self-refer or you might need to be referred by your GP. For more information on your local service see: [www.iapt.nhs.uk](http://www.iapt.nhs.uk)

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In January 2014, a new policy document called ‘**Closing the gap: priorities for essential change in mental health**’ was published by the Government. This document explains the Government’s strategy which aims to increase both accessibility and choice for mental health service users. It states that information about how effective services are, and about waiting time lengths, will be published; thus allowing mental health services users to make informed decisions when choosing a service.

Step 4
If you have not responded well to treatment, the next ‘step up’ is to be referred by your GP to the Community Mental Health Team (CMHT). This is likely to mean that you see a Psychiatrist or Psychologist (or both) who may be able to help you as well as a range of other people such as social workers, psychiatric nurses or occupational therapists.

From April 2014 you have the right to choose who your GP refers you to for mental health treatment. You will be able to choose a provider and a consultant, or other mental health professional, who will be in charge of your care at your first outpatient appointment. Exceptions to this right to choice are where someone is detained under the Mental Health Act 1983 (as amended 2007) or where emergency/urgent treatment is required.

The 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. out-patient clinics, GP surgeries, day-centres, hostels and people’s own homes. The team can all offer psychological support, encouragement and practical help. In terms of treatments offered at this stage, NICE recommends the choice of either a course of a Selective Serotonin Reuptake Inhibitor (SSRI) (often commonly referred to as an anti-depressant), alternative SSRI or Clomipramine or more intensive CBT which would include ERP and more than 10 hours of therapist time, perhaps with a more experienced CBT therapist.

Step 5
If you have been seen by your CMHT and have still not made progress, you might (for example) have other mental health issues alongside your OCD or your OCD is affecting the quality of your life to a severe degree, then you may be able to be ‘stepped up’ again to more specialist services for OCD/BDD. These services may be out of your local area and your Community Mental Health Team may have to get funding for your assessment and subsequent treatment agreed by your local Clinical Commissioning Group (CCG) in England and local Health Board (LHB) in Wales & Scotland. For information on how to get a referral to a national & specialist centre please see our guidance: Getting a Referral to the Adult National & Specialist OCD Services

You will need to be referred by your lead clinician at your local CMHT who would need to remain involved in your care & treatment. Specialist units provide mainly outpatient treatment while some offer inpatient facilities.

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).

Step 6
If you have found no improvement in your symptoms after accessing national & specialist services you may need more intensive treatment at one of the specialist units (mentioned above) for an extended period of time. The category of people who access these services 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 monitoring the severity of your OCD using an outcome measure such as the Obsessive Compulsive Inventory (OCI). They should be:

- Clear about who they are and what they can do for you
- Explaining and seeking your informed consent for the proposed course of treatment with you (and explaining their reasoning if the treatment they are proposing differs from the evidence-based treatment recommended by NICE)
- Informing you about any medications and their possible side effects and
- Offering you follow up appointments and reviews.

You cannot be forced to undertake treatment of any kind e.g. you can’t be made to take medication before you will be considered for CBT, the only exception to this is if you are detained under the Mental Health Act 1983 (as amended 2007).

Your healthcare professionals should also put you in touch with any voluntary agencies who might be able to offer support if you ask for this, including mental health advocacy providers 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 already mentioned at the start of this information sheet 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 people with OCD and who you feel you could work with.

Useful Organisation:
- British Association for Behavioural & Cognitive Psychotherapies (BABCP) at www.babcp.com – lead organisation for CBT in the UK & Ireland.

Most of the consultants at the specialist units offer private appointments and there are other specialists practising privately in other areas of the UK. The BABCP website will offer guidance on how to access these specialists. Your GP or local hospital may also be able to give you information about specialists in your area.

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 and/or attend meetings and appointments with you.
Bullet points:

- 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.
- 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 CBT should involve, attend your local support groups & talk to other people with OCD etc.
- If you are about to start CBT and want to have some extra support while you are undergoing treatment call our Helpline and ask one of our volunteers about our Next Steps project as 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, find out what your options and choices about treatments are. If you’re 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 as 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 exercising your rights, bring a friend or professional 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 can’t be provided with recommended treatments. If you are having difficulty, please ring our Helpline or Advocacy Service or access help from other mental health charities.

Useful links:

- www.nice.org.uk/CG031 (NICE Guidelines)
- www.nhsdirect.nhs.uk
- www.nhschoices- (Constitution/Your rights)
- www.citizensadvice.org.uk
Complaints - If you need information and guidance about making a complaint about your treatment the following organisations can help:

**England**
NHS Complaints Advocacy Service: 0300 330 5454
www.nhscomplaintsadvocacy.org

**Wales**
Complaints advocacy service available through Community Health Councils: 0845 644 7814
http://www.wales.nhs.uk/sitesplus/899/home

**Scotland**
Patients Advice & Support Service (PASS) delivered by Citizen’s Advice: 0131 550 1000
www.cas.org.uk/patientadvice

**Northern Ireland**
Patient & Client Council: 0800 917 0222
http://www.patientclientcouncil.hscni.net/making-a-complaint

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

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

**Support:**
www.ocdaction.org.uk

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