

Accessing Treatment – your rights

It can be a very isolating experience to have Obsessive Compulsive Disorder (OCD). Statistically it takes the average person with the condition 12 years before they will seek help. 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 loved ones are getting concerned and are encouraging you to seek help. Whatever your position help is out there!

How to access help

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 has 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. 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 or to a Consultant or Specialist in a hospital. You have the right to make some choices about your care and treatment provided under the NHS Constitution which upholds a number of patient rights.

Although the Constitution generally covers all patients accessing NHS Services there are areas such as the choice of referral to specific hospitals/consultants that currently *do not apply to mental health service users*. If however you are a mental health service user with a physical condition (for example a heart condition) your right to choice of hospital or consultant is not affected.

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. Treatment for your OCD should be in line with their recommended 'stepped care' approach. You can be referred to any level of 'Stepped Care' depending on your symptoms.

If you have visited your GP, they should (depending on the severity of your condition) be initially managing and treating your OCD. For adults, according to their impairment, recommended treatments are:

- Cognitive Behavioural Therapy (CBT) up to ten hours of therapy which can include 'Exposure Response Prevention'
- The use of self help materials.
- CBT by phone or group CBT.

Patients are sometimes told that CBT is not available in their area or that waiting lists are long. The department of health has introduced a scheme to make psychological therapies more widely available and this includes CBT. This programme is called 'Improving access to psychological therapies' (IAPT). To see if the scheme is active in your area, please access www.iapt.nhs.uk. You can ask your GP to refer you to your local IAPT service and you can self refer to an IAPT centre and only need to go through your GP if medication is being considered for you.

If you have not responded well to treatments, 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. The team may have a base, like a clinic, where they can see you. They will also work in a whole range of other places – outpatient 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 an SSRI, 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 OCD therapist.

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 Primary Health Care Trust (PCT) in England and Local Health Board (LHB) in Wales and Scotland. For information on how to get a referral to a 'Specialist Centre' please see details of our guide National Service or Special Care Pathway Referral to a Centre of Excellence for OCD which can be found on our website. You will need to be referred by your CMHT. Units will provide outpatient treatment and some will offer inpatient facilities.

Centres of Excellence

Trustwide OCD/BDD Service,
The Springfield Hospital,
London

Centre for Trauma and Anxiety
at the Maudsley Hospital,
London

Anxiety Disorders Residential
Unit at the Bethlem Royal Hospital
Beckenham, Kent

The Queen Elizabeth II Hospital,
Welwyn, Hertfordshire

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

If you have found no improvement in your symptoms after accessing 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.

The Department of Health provides an extra centrally funded (as opposed to locally funded) service for people with this form of OCD. This resource is called the National Commissioning Group Service (NCG). To be referred via this route you will have accessed your local Community Mental Health Team (CMHT) and they will have to make your referral. Very specific criteria have to be met before you can access this referral route.

Accessing treatments via NCG, means you are likely to be treated for longer and by more highly experienced therapists. To obtain more details please see www.iop.kcl.ac.uk/ncg.

How should your Health care professional be helping you?

Whatever your level of care, your mental health care professionals should be offering you support, monitoring and a point of contact in case of crisis. They should be explaining and agreeing the proposed course of treatment with you and should be informing you about any medications and their possible side effects and offering follow up appointments and reviews. You cannot be forced to undertake treatments of any kind. The only exception to this is if you are detained under the Mental Health Act 1983. 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. They should be liaising with your GP and other agencies if required.

Accessing CBT Privately

You are entitled to receive free CBT on the NHS, (and 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 you can always choose to pay to see a therapist privately. Care should be taken to find out who is appropriately qualified to offer CBT for OCD. You can access more information by visiting the Register of Cognitive Behavioural Therapists www.cbtregisteruk.com. Most of the Consultants at the specialist units offer private appointments and there are other specialists practising privately in other areas of the UK. 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 Advocate can help you draft letters or plan strategies for meetings and appointments.
- 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.
- Be aware of your rights as a patient to ask for information, options and choices about treatments and complain if you are not happy with your care.
- 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. There should be 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 refer to our website guide *'Being Referred to a centre of excellence'*

USEFUL links

www.nice.org.uk/CG031 (NICE Guidelines)

www.nhsdirect.nhs.uk

www.nhschoices.nhs.uk (Information of the NHS Constitution)

www.citizensadvice.org.uk

Complaints

www.nhs.uk (How to complain about the NHS)

www.pals.nhs.uk (Sets out complaints pathway. PALs can put you in touch with the Independent Complaints Advocacy Service (ICAS))

www.carersfederation.co.uk

www.ombudsman.org.uk If you are not satisfied with the outcome of your complaint then you can contact the Parliamentary and Health Ombudsman Complaints Helpline 0345 015 4033

www.cqc.org.uk (Independent regulator of health and social care in England)

www.hiw.org.uk (Independent watchdog for health services in Wales)

www.apil.org.uk Lists of Solicitors who specialise in medical negligence cases can be obtained from 'The Association of Person Injury Lawyers' (APIL)

This leaflet is part of a series that includes;

1. What is OCD?
2. Assessment and Diagnosis
3. **Accessing Treatment – your rights**
4. What is Cognitive Behavioural Therapy?
5. Medication for OCD
6. Young people and OCD
7. Supporting a person with OCD
8. Habit Disorders
9. BDD

For support, information and advocacy please call **0845 390 6232**

Or visit www.ocdaction.org.uk
to join our online community

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