

Obsessive Compulsive Disorder

Understanding Treatment Options



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What is obsessive compulsive disorder?

Obsessive compulsive disorder (OCD) is a mental health condition involving obsessions, compulsions and anxiety.

Obsessions are thoughts, images or urges that you don't want, but can't stop thinking about. These are also called intrusive thoughts. When you experience these thoughts, you might feel very anxious, fearful, or sometimes disgusted.

Examples of obsessions include:

- imagining loved ones getting hurt
- being scared of getting sick from touching door handles
- feeling that something terrible will happen if something isn't in the right order

Compulsions are things you feel you must do often (but not always) in response to an obsession. Compulsions might also be referred to as 'rituals'. Sometimes you might not know why you feel and behave this way. Your compulsions might relieve your anxiety in the short term, but can lead to a cycle that keeps the OCD going, and in the longer term makes things worse.

Some examples of compulsions include:

- washing your hands repeatedly because you are worried about germs
- repeatedly checking things, such as if a door is locked
- a need to arrange things in a set way

All of us have intrusive thoughts from time to time. As children most of us go through a stage of being more obsessional, and this is a normal part of growing up. For example, you might want your bedtime routine to be exactly the same every night.

OCD is different to this, as your unwanted thoughts or compulsions last longer (usually more than 6 months), and cause you severe distress and/or interfere with your everyday life. OCD usually starts in the early teenage years, but is often not diagnosed until adulthood. This can sometimes happen if a young person is good at hiding that there is a problem.

Children and young people with OCD often also have phobias. Phobias are extreme fears which cause you a lot of distress and have a significant impact on your life.

We don't know exactly what causes OCD, but there are some evidence based treatment options to help with OCD symptoms.

Family involvement in OCD

Often, parents, carers or other family members can become involved in your OCD symptoms. For example, they might repeatedly reassure you that what you're worried about won't happen. Or they might get involved in particular rituals, or might help you to avoid things that you fear. They often do this because they think it will help with your distress, but while this might reduce your anxiety in the short term, it can actually make things worse in the longer term.

Other mental health conditions

It is common to have other mental health conditions alongside OCD, including:

- other anxiety disorders and phobias
- body dysmorphic disorder
- depression
- oppositional defiant disorder
- autism, where it can be hard to know whether the symptoms are part of OCD, or a core feature of autism
- tics
- Tourette's syndrome
- eating disorders, such as anorexia nervosa, bulimia nervosa and binge eating disorder

Paediatric Acute-onset Neuropsychiatric Syndrome (PANS)

Rarely, obsessive compulsive symptoms can be brought on or made worse by a common bacterial infection called Group A streptococcus (GAS). This infection can give you a sore throat or chest infection, before quickly causing you to develop tics and/or obsessive compulsive behaviour.

This is different to OCD, where the obsessive compulsive symptoms worsen more gradually. This condition is known as Paediatric Acute-onset Neuropsychiatric Syndrome (PANS), or by the older term Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS).

How can I get help?

If you are worried that you might have OCD then you should talk to a professional who could make a referral for you to Child and Adolescent Mental Health Services (CAMHS). You can do this by:

- seeing your GP
- (in some areas) asking for a referral from your school
- (in some areas) contacting the CAMHS teams directly

OCD Action is a UK based charity which is run for and by people with OCD. They provide information and advice on how to get help, and also run a helpline.

Planning treatment

Assessment

The first step in starting treatment is to have an assessment. Your assessment will include talking to a professional about how OCD affects you. They will also ask whether you have any other mental or physical health conditions, and think about whether your obsessive-compulsive symptoms are purely part of OCD, or whether they may be part of another problem (e.g. Tourette syndrome, or an eating disorder such as anorexia nervosa, bulimia nervosa or binge eating disorder).

As your family might have become involved in your obsessive-compulsive symptoms, it is also important to look at how the OCD is affecting them. It can be useful to look at how your family might be involved in treatment and how they might be able to help you.

If your OCD symptoms interfere with your education, your professional might also need to work with your school, college or university.

Psychoeducation

The first step in treatment for OCD is psychoeducation for you and your family. The professional treating you should talk to you about how they think your OCD is affecting you, and what can be done to help. There are also useful resources such as the OCD Action website.

Guided self-help or OCD specific group therapy

If your symptoms are very mild, you are highly motivated and well supported, and are able to participate independently, then you might be offered guided self-help or OCD specific group therapy.

If you are offered guided self-help or group therapy, it is important that a professional keeps track of whether your symptoms are improving. If they aren't then you should be offered cognitive behaviour therapy (CBT) which includes exposure and response prevention (CBT-ERP).

It's important to know that it's your choice whether to use guided self-help or OCD specific group therapy instead of individual CBT-ERP. This decision shouldn't be made for you.

Cognitive behavioural therapy which includes exposure and response prevention (CBT-ERP)

Cognitive Behavioural Therapy (CBT) is a type of therapy where your professional helps you to learn about how your feelings, thoughts, and behaviours affect each other and keep you stuck in unnecessary, upsetting cycles. Your professional will also help you to find ways to change this.

When treating OCD, the therapy must include exposure and response prevention (ERP), which is an approach that works directly on the OCD cycle. CBT-ERP is the only evidence-based psychological therapy for OCD.

Although CBT-ERP is usually an individual therapy for children and young people, it can often be helpful to involve your parents or carers.

Multidisciplinary review

If CBT-ERP has not helped after 3 months it is important to check whether anything is getting in the way of your recovery. This is sometimes called a full multidisciplinary review, which means your professionals will meet with you and your parents or carers to talk through your recovery. After this you might be offered treatment with medication.

Medication

Your professional could suggest that you take medication called Fluvoxamine or Sertraline at the same time as continuing CBT-ERP. These medications are selective serotonin reuptake inhibitors (SSRIs), which are a type of anti-depressant that can help with OCD symptoms.

Your professional might recommend other SSRIs if they would suit your circumstances better.

You might also be prescribed medication if you do not want CBT with ERP. Occasionally, if your symptoms are very severe then your professional might prescribe you medication combined with CBT-ERP from the start of your treatment.

Referral to hospital

You might be referred to a specialist OCD service for children and young people at the Maudsley Hospital in London which is a national outpatient-based service.

Your professional might suggest that you have treatment in hospital if your OCD is very severe. For example if:

- it's having a big effect on your day-to-day life, and you are not able to do much else other than the compulsions/rituals
- you are not able to manage activities such as washing, dressing, and eating and drinking enough
- you are a risk to yourself or others

The hospital should be able to offer you intensive CBT-ERP.

What about my parents or carers?

Your professional should give your parents or carers information about OCD and your treatment options. If appropriate, your professional should work together with you and your parents or carers to make decisions about your care. Treatment for OCD is often more effective if parents or carers are involved so your professional will talk to you about how this might work.

OCD can also have an impact on your parents or carers, and your assessments might look at the effect of your compulsions on your family, including how much they are involved in supporting or carrying out your compulsions. Your parents or carers should be offered an assessment of their own needs, to look at any support that might help them.

Transitions between services

Transitioning from CAMHS to adult services can be a worrying time. To help it go smoothly, your professional should leave plenty of time to work with you to plan the change. You should get clear information about what to expect from adult services and it can be helpful to involve your parents or carers in the process.

You may also transition to another CAMHS service (e.g. if you move house). If this happens, your professional should work with you to make sure that your treatment can continue smoothly, and that your new service has all the information they need.

Cognitive behavioural therapy which includes exposure and response prevention

Strong evidence

Cognitive behavioural therapy (CBT) is a type of therapy where your therapist helps you to learn about how your feelings, thoughts, and behaviours affect each other and keep you stuck in unnecessary, upsetting, or harmful cycles. Your professional will also help you to find ways to change this.

CBT is used as a treatment for a range of problems, and a specific form of CBT is developed for each type of problem. When treating OCD, the therapy must include exposure and response prevention (ERP), which works directly on the OCD cycle. It's parts include:

- Exposure, where you do something that that will bring on the anxiety.
- Response prevention, where you are supported to make the active choice to stay anxious instead of doing a compulsion to reduce it. By doing this your anxiety will gradually reduce, which breaks the link between your intrusive thought and anxiety. This helps you to ignore the thoughts, and stops you from feeling the need to perform the compulsion.

ERP is based on the idea that the intrusive thoughts make you feel anxious, and so you use compulsions to get relief from the anxiety. This relief then supports your brain's belief that your intrusive thoughts must be right, and something bad will happen if you don't carry out the compulsion. This sets off a vicious cycle where you keep having the intrusive thoughts, and then need to carry out the compulsions.

You might start off with small things that only bring on a bearable amount of anxiety, and then build up from there. Or, you might only hold back compulsions for a few minutes at the beginning, and wait longer and longer each time.

Graded exposure

Eventually, ERP exercises will involve doing things that would have seemed quite scary at the start. This is called graded exposure. Your therapist will work out with you where to start, what kind of things to tackle, and help you to feel ready to tackle them. Your therapist will practice the exposure task with you in your sessions, and they will usually ask you to practice the tasks in between sessions on your own (often called 'homework').

Treatment length

CBT-ERP for OCD typically involves between 12 and 20 sessions. These should last about 45 minutes to 1 hour and should generally be at least once a week.

CBT-ERP usually works better if your parents or carers are involved.

Multi-disciplinary review

If CBT-ERP has not helped after 3 months it is important to check what might be getting in the way of recovery, for example:

- are you following the treatment plan?
- is there another problem, such as depression?
- are there problems in your social or family life which are making things worse?

This is sometimes called a full multi-disciplinary review, which means your professionals meet with you and your parents or carers to talk through these questions. After this, you might be offered treatment with medication.

Medication



Strong evidence

Selective serotonin reuptake inhibitors (SSRI medication)

Selective serotonin reuptake inhibitors (SSRIs) are a group of medications used to treat depression, which can also be helpful for OCD. This medication could be offered to you if:

- after 12 weeks of CBT-ERP your symptoms have not improved
- from the start you do not want CBT-ERP
- from the start your symptoms are very severe, when you might be prescribed medication combined with CBT-ERP

Fluvoxamine or Sertraline will usually be the first SSRI medications recommended to you by your professional.

Your professional might also recommend other SSRIs if they would suit you better, for example if you take other medications. If you also have depression, your professional might suggest Fluoxetine instead.

Medication combined with CBT-ERP

Unless you do not want CBT-ERP, you should continue with CBT-ERP while taking medication as this is usually more helpful. However this does mean it can be difficult to know which part of your treatment was the most helpful, which your professional might talk to you about when you come to stopping the medication.

Sometimes if the medication reduces your anxiety a lot early on in your treatment, it can make it harder to do the CBT-ERP as this relies on your experiencing anxiety and learning to manage it.

Reviewing medication

SSRIs take several weeks to work to improve your OCD symptoms, and the dose usually needs to be increased gradually to reach an effective level.

If after 3 months at an appropriate dose the first-choice medication has not worked for you, then your professional might suggest a multidisciplinary review.

After this review, your professional might offer you different SSRI medication. Alternatively, you might switch to an older medication called clomipramine. Clomipramine has been found to be more helpful than the other SSRIs but also has more side-effects.

There is less research evidence on treatment when SSRIs and clomipramine haven't worked in combination with CBT-ERP. If this is the case for you then your professional might seek advice from a specialist OCD service, where they are likely to see more people who have not responded to usual treatments. They might suggest combining different SSRI medications, or adding a low dose of an antipsychotic medication such as risperidone or aripiprazole.

Relapse

Although medication for OCD can be effective, it is common to relapse once you stop taking the medication. This means your OCD symptoms could return. It is important to know that medication is more effective if combined with CBT-ERP.

Guided self-help

 Some evidence

If you have mild OCD symptoms and are highly motivated and well supported, then your professional might suggest guided self-help. This involves following the

principles of cognitive behaviour therapy (CBT) which includes exposure and response prevention (CBT-ERP), but without the one-to-one involvement of a therapist.

If you have mild OCD your professional might also recommend a group for CBT with ERP. This is different to a support group, where the emphasis would be on people supporting each other with the help of a facilitator but does not involve active treatment. However, group CBT for OCD is not often offered for children and young people as it can be difficult to find enough people of roughly the same age with mild OCD who all need treatment at the same time.

If your professional suggests guided self-help or group CBT, then you should be given the choice of whether to have one of these options or individual CBT-ERP.

If you start guided self-help or group therapy, it is important that your professional keeps track of whether your symptoms are improving. If they aren't, then you should be offered individual CBT-ERP.

Your parents or carers would usually be involved in your treatment. It might also be helpful to involve your school or college, to make sure they know the best way to support you.

Treatments which should not be recommended

Insufficient evidence

- **Psychodynamic psychotherapy and counselling** are not recommended as treatment for OCD as they are unlikely to be effective.
- **Transcranial magnetic stimulation** involves using pulsing magnetic fields to activate or suppress the brain. It is non-invasive as the machine is held close to your head and doesn't involve any surgery. It has been tried as a treatment for OCD in adults where other treatments have not worked. There is virtually no research on its use for children and young people.
- **Deep brain stimulation** involves implanting electrodes in certain areas of the brain. These electrodes produce electrical impulses that regulate certain cells and chemicals within the brain. It has been tried as a treatment for OCD in adults, but there are concerns about the risks and uncertain benefits. There is no research involving children and young people.