

understanding



obsessive-compulsive
disorder

Understanding obsessive-compulsive disorder (OCD)

This booklet is for anyone who has or thinks they may have OCD, and their friends, family or carers. It explains what OCD is and describes what treatment and help is available.

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What is obsessive-compulsive disorder (OCD)?

Obsessive-compulsive disorder (OCD) is described as an anxiety disorder. The condition has two main parts: obsessions and compulsions.

Obsessions

Obsessions are unwelcome thoughts, images, urges or doubts that repeatedly appear in your mind; for example, thinking that you have been contaminated by dirt and germs, or experiencing a sudden urge to hurt someone.

These obsessions are often frightening or seem so horrible that you can't share them with others. The obsession interrupts your other thoughts and makes you feel very anxious.

💡💡 *I get unwanted thoughts all through the day, which is very distressing and affects my ability to interact with others and concentrate on my studies and work.* 💡💡

Compulsions

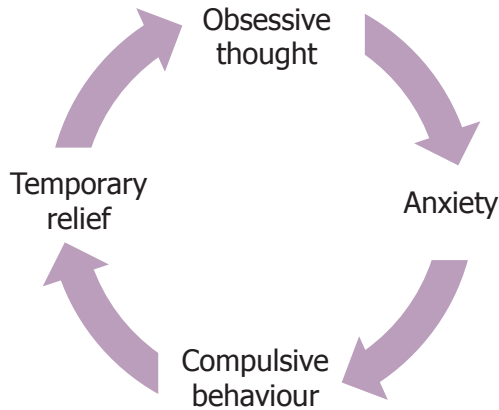
Compulsions are repetitive activities that you feel you have to do. This could be something like repeatedly checking a door to make sure it is locked or repeating a specific phrase in your head to prevent harm coming to a loved one.

The aim of a compulsion is to try and deal with the distress caused by the obsessive thoughts and relieve the anxiety you are feeling. However, the process of repeating these compulsions is often distressing and any relief you feel is often short-lived.

💡💡 *Getting ready for each day involves so much hand washing, mental rituals, and doing things in the same order everyday... Sometimes, I feel like staying in bed and avoiding the day.* 💡💡

The OCD cycle

The diagram below shows how obsessions and compulsions are connected in an OCD cycle.



Living with OCD

Although many people experience minor obsessions (e.g. worrying about leaving the gas on, or if the door is locked) and compulsions (e.g. rituals, like avoiding the cracks in the pavement), these don't significantly interfere with their daily lives, or are short-lived.

If you experience OCD, your obsessions and compulsions will cause you considerable fear and distress. They will also take up a significant amount of time, and disrupt your ability to carry on with your day-to-day life, including doing daily chores, going to work, or maintaining relationships with friends and family.

Many people with OCD experience feelings of shame and loneliness which often stop them from seeking help, particularly if they experience distressing thoughts about subjects such as religion, sex or violence. This means that many people try to cope with OCD alone, until the symptoms are so severe they can't hide them anymore.

OCD is also known to have a close association with depression, and some people find obsessions appear or get worse when they are depressed. (See Mind's booklet *Understanding depression*.)

What are the common signs of OCD?

Although everyone will have their own experiences, there are several common obsessions and compulsions that occur as part of OCD.

Common obsessions

The three most common themes are: unwanted thoughts about harm or aggression, unwanted sexual thoughts and unwanted blasphemous thoughts. Obsessions often appear closely linked to your individual situation. For example, if you are a loving parent, you may fear doing harm to a child and if you are religious, you may have blasphemous thoughts.

🍇🍇 *I have OCD harming thoughts and the compulsion to carry them out, which is absolutely terrifying to say the least.* 🍇🍇

Some examples of obsessions include:

- a fear of failing to prevent harm – e.g. worrying that you have left the cooker on and might cause a fire
- imagining doing harm – e.g. thinking that you are going to push someone in front of a train
- intrusive sexual thoughts – e.g. worrying about abusing a child
- religious or blasphemous thoughts – e.g. having thoughts that are against your religious beliefs
- fear of contamination – e.g. from dirt and germs in a toilet
- an excessive concern with order or symmetry – e.g. worrying if objects are not in order
- illness or physical symptoms – e.g. thinking that you have cancer when you have no symptoms.

Common compulsions

Common compulsions include physical compulsions, e.g. washing or checking, or mental compulsions, e.g. repeating a specific word or phrase.

💡💡 *I have to keep checking things three times and have to have certain items on me to help me feel safe.* 💡💡

Some examples might be:

- repeating actions – e.g. touching every light switch in the house every time you leave or enter the house
- touching – e.g. only buying things in the supermarket that you have touched with both hands
- focusing on a number – e.g. having to buy three of everything
- washing or cleaning – e.g. having to wash your hands very frequently in order to feel clean
- checking – e.g. reading through an email ten times before sending it
- ordering or arranging – e.g. keeping food organised by colour in the fridge
- repeating a specific word or phrase – e.g. repeating someone's name in order to prevent something bad happening to them
- praying – e.g. repeating a prayer again and again whenever you hear about an accident
- counteracting or neutralising a negative thought with a positive one – e.g. replacing a bad word with a good one.

Avoidance

You might find that some objects or experiences make your obsessions or compulsions worse, and you try to avoid them as a result. For example, if you fear contamination, you might avoid eating and drinking anywhere except in your own home. Avoiding things can have a major impact on your life.

💡💡 *OCD means that I miss out on things because I [stay in] to try to protect myself from the stress. It's sunny outside and I want to go out, but I know I probably won't.* 💡💡

What causes OCD?

There are different theories about why OCD develops, but none of these theories have been found to fully explain every person's experience.

'Dysfunctional' beliefs

One theory suggests that OCD develops because of 'dysfunctional' beliefs and interpretations.

If you experience OCD, you might believe that you have more responsibility for a situation than you actually do. Because of this, your reaction may be out of proportion. For example, many people experience sudden and intrusive thoughts, such as thinking that they might push someone in front of a train on a crowded platform. Most people dismiss it as a passing thought and do not believe they would actually do it. However, if you have OCD, you are more likely to believe that you might act on the thought. This makes you anxious or scared, and so you may then develop a compulsion to try and prevent it happening. This could start an OCD cycle (see p.5).

Personal experience

Some psychological theories suggest that OCD is caused by personal experience. It is thought that if you have had a painful childhood experience or suffered trauma or abuse, you might learn to use obsessions and compulsions to cope with anxiety. However, this theory does not explain why people who cannot point to any painful experiences might experience OCD.

It could also be that one or both of your parents may have had similar anxiety and shown similar kinds of behaviour (such as obsessional washing), and you learned to use this type of behaviour as a coping technique.

Biological factors

Some biological theories suggest that a lack of the brain chemical serotonin may have a role in OCD. However, experts disagree about what that role is, and it is unclear whether a lack of serotonin causes OCD or

is the effect of having the condition. Studies have also looked at genetic factors and how different parts of the brain might be involved in causing OCD, but have found nothing conclusive.

However, biological theories do not provide any explanation for how the condition develops differently in different people; for example, why one person might develop a contamination obsession while another develops an obsession about harming.

Some experts have noted that some children seem to develop OCD symptoms very suddenly after having a streptococcal (or strep) infection, such as strep throat or scarlet fever. However, it is currently not known why this might occur and no research has yet been able to identify a physical cause to explain the link.

How is OCD diagnosed?

If you are concerned that you have OCD, and you want to seek professional help, the first step would normally be to visit your GP. Your GP can provide an assessment and diagnosis, and help you access appropriate treatment.

If you visit a doctor to talk about OCD, they are likely to ask you direct questions about possible symptoms. For example:

- Do you wash or clean a lot?
- Do you check things a lot?
- Is there any thought that keeps bothering you that you'd like to get rid of but can't?
- Do your daily activities take a long time to finish?
- Are you concerned about putting things in a special order or do you find mess very upsetting?
- Do these issues trouble you?
- How are they affecting your everyday life?

A doctor will then consider your answers against a list of medical criteria in order to make a diagnosis. If you receive a diagnosis of OCD, it should

also say how severe your OCD is; for example, if you have mild, moderate or severe OCD.

It can be extremely difficult to discuss your experiences with a doctor, particularly if you experience distressing thoughts about issues such as religion, sex or violence. However, it is important to try and talk as honestly as you can, so your GP can suggest the right type of help for you.

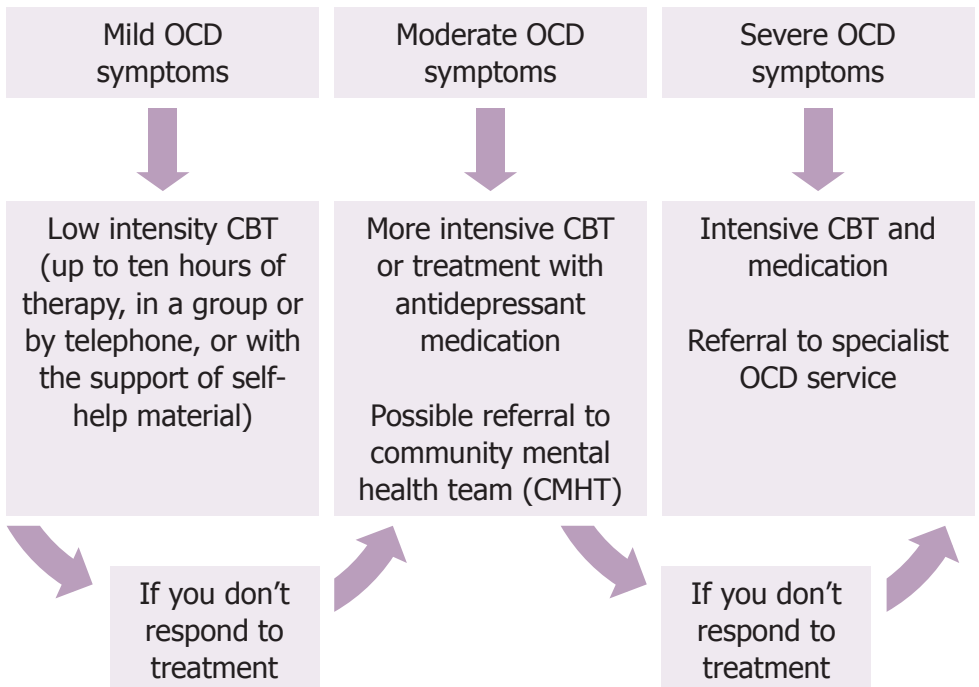
If you find it difficult talking about your OCD, you may find it useful to prepare beforehand. You could think about how you would answer the questions on p.9 and write down the answers to take with you. Then if you start to feel embarrassed or overwhelmed when you are with your GP, you can refer to your notes – or even hand them to the doctor.

What treatments are available?

Before you have any treatment, your doctor should discuss all your treatment options with you, and your views and wishes should be taken into account.

NICE's 'stepped' model

If you access help on the NHS, your treatment should be in line with NICE (National Institute for Health and Care Excellence) guidelines. NICE recommends 'stepped' treatment for OCD. This means that you should receive different types of treatment depending on how severe your symptoms are and how you responded to any previous treatment. The diagram below is adapted from NICE's guidelines (see NICE in 'Useful contacts' on p.20).



However, the treatments recommended in the NICE guidelines are not appropriate for everyone. There are a number of options available to treat OCD and different things work for different people. You may find that a combination of approaches is most helpful for you, and different approaches may help you at different times.

Cognitive behaviour therapy (CBT)

●● *CBT techniques helped me to see the intrusive thoughts for what they are, and put them in their place.* ●●

Cognitive behaviour therapy (CBT) is a talking treatment which aims to identify connections between your thoughts, feelings and behaviour. It aims to help you develop practical skills to manage any negative patterns of thinking or behaviour that may be causing you difficulties. It can be done one-to-one, or in a group. There is considerable evidence to suggest that this therapy is especially effective in dealing with OCD.

The behavioural element (also known as Exposure Response Prevention – ERP) is strongly recommended for treating OCD. ERP works by helping you to confront your obsessions and resist the urge to carry out compulsions. The aim is to help you feel less anxious about obsessive thoughts over time, and make you less likely to engage in compulsive behaviour. For example, if you fear that you will harm someone and avoid sharp objects as a result, you might build up to a therapy session where you hold a knife while sitting in a room with other people.

This technique needs to be carefully managed to avoid causing distress and anxiety, so it is important that you understand the treatment fully and feel comfortable with your therapist.

●● *It's hugely frustrating and exhausting trying to break out of patterns that you know aren't helpful or healthy. It can feel hopeless. But by challenging the behaviours, thoughts or compulsion you can eventually achieve fresh change that seemed impossible.* ●●

You are entitled to receive free CBT on the NHS, and your GP should be able to refer you to a local practitioner. However, waiting times for talking

treatments on the NHS can be long. If you feel that you don't want to wait or that you would like more support than is being offered, you may choose to see a therapist privately. The British Association for Behavioural and Cognitive Psychotherapies maintains a register of accredited CBT therapists. (See 'Useful contacts' on p.20 and Mind's booklet *Making sense of cognitive behaviour therapy*.)

Medication

Some people find drug treatment helpful for OCD, either alone or combined with talking treatments, such as cognitive behaviour therapy (CBT).

👤👤 *I've been on meds for the last three years and my OCD is so much more controllable.* 👤👤

Before taking any medication, it is important to read the patient information leaflet (that comes with the medicine) and discuss possible benefits and side effects with your doctor.

Antidepressants

The drugs prescribed most commonly are SSRI antidepressants, such as fluoxetine (Prozac), fluvoxamine (Faverin), paroxetine (Seroxat), citalopram (Cipramil) and sertraline (Lustral). These drugs are all recommended by NICE for the treatment of OCD. These drugs may have side effects, including nausea, headache, sleep disturbance, gastric upsets and increased anxiety. They may also cause sexual problems.

The tricyclic antidepressant clomipramine (Anafranil) is also licensed for the treatment of obsessional states in adults. This should normally only be prescribed if an SSRI antidepressant has already been tried and not been effective. The side effects of clomipramine can include a dry mouth, blurred vision, constipation, drowsiness and dizziness. (For more information, see Mind's booklet *Making sense of antidepressants*.)

Tranquilisers

If you are experiencing very severe anxiety as a result of OCD, you may be offered tranquillising drugs, such as diazepam (Valium). This type of

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medication should only be used for short periods of treatment because of the risk of addiction. The side effects of tranquilisers can include drowsiness, confusion, unsteadiness and nausea. (For more information, see Mind's booklet *Making sense of sleeping pills and minor tranquillisers*).

Beta-blockers

Beta-blockers are occasionally given to people to treat the immediate symptoms of severe anxiety. They don't treat the anxiety itself, but act on the heart and blood pressure to reduce physical symptoms, such as palpitations. The beta-blocker most commonly used for anxiety is propranolol (Inderal). The main side effects include a slow heartbeat, diarrhoea and nausea, cold fingers, tiredness and sleep problems.

Neurosurgery for mental disorder

Neurosurgery (previously known as psychosurgery) is surgery on the brain. It is not recommended for treating OCD, but is very occasionally offered in severe cases, when other treatments have been unsuccessful. Neurosurgery is strictly regulated under the Mental Health Act, and can't be given without consent. (See Mind's online booklet *Making sense of neurosurgery for mental disorder* for more information.)

Community mental health and social care

If your OCD is severe or complex, your GP may refer you to a community mental health team (CMHT). A CMHT is usually made up of range of professionals, such as psychiatrists, psychologists, social workers and occupational therapists. The team can offer medication, basic counselling or other mental health treatments like cognitive behaviour therapy (CBT). They should also be able to help with you with wider issues you have as a result of your OCD, such as difficulties around housing, benefits or everyday living.

Even if you are not referred to a CMHT, or if you feel you are not receiving the support you need, you may be entitled to have a social care assessment to see if you are eligible for social care support. For more information, see Mind's online booklet *The Mind guide to community-based mental health and social care*.

Specialist OCD services

If you require more intensive support, it is recommended that you are referred to a specialist OCD service in your area. However, in reality, access to specialist services across the country is patchy and you may need to travel outside your local area.

If you feel you are not getting access to the treatment you require, you may find it useful to have an advocate. This is someone who can support you and speak up for you, so you can get the help you need. You can find an advocate by contacting your local Patient Advice and Liaison Service (PALS) via NHS Choices. Some local Minds also run advocacy services. (See 'Useful contacts' on p.20)

How can I help myself?

Treatment of OCD often includes a combination of strategies, including self-help. The following suggestions are some ideas you could try to help you manage your OCD.

Self-help materials

Some people use self-help books, computer programmes or websites to help manage their OCD. Many self-help materials are based on cognitive behaviour therapy (CBT) principles (see p.12), which have been shown to be particularly effective in treating OCD.

OCD UK (see 'Useful contacts' on p.20.) has a list of popular self-help books on their website, and there are several computerised CBT programmes available for free or via prescription from your GP.

There are many self-help resources available, and you may have to try a few before finding one that is right for you. You may decide to use materials alongside professional help, or you may use them to develop your own coping strategies.

Peer support groups

A self-help, or peer support group, offers an opportunity to meet up with people who have gone through the same sort of experiences as you. It can help you feel less isolated and give you and other group members a chance to share how you cope with your feelings and experiences.

You can also access peer support groups online, through forums, social media sites or online communities. While online peer support can be extremely helpful, it's important to remember that you don't always know who you're talking to, so you should think carefully about what information you want to share. See Mind's online booklet *How to stay safe online* for tips.

You can find details of support groups and online peer support on the OCD UK and OCD Action websites (see 'Useful contacts' on p.20).

Relaxation and mindfulness techniques

Learning a relaxation technique won't help you resolve obsessive thoughts or compulsions, but it may help you deal with anxiety that you experience as a result of your OCD. Relaxation techniques can teach you:

- how to improve your breathing to reduce tension
- physical exercises that relax your muscles
- action plans to help you progress from coping with non-stressful situations to those that you find difficult.

For local relaxation classes, search the internet, or contact your local library or GP. Also see Mind's booklet *How to manage stress* and leaflet *Mind tips for better mental health: relaxation*.

Some people may also find mindfulness techniques helpful to manage unwanted or intrusive thoughts and reduce anxiety. Mindfulness is a way of paying attention to the present moment, using techniques like meditation, breathing exercises and yoga. Be Mindful has details of local mindfulness classes around the UK. (See 'Useful contacts' on p.20.)

Physical activity

Doing some regular physical activity, whether it is going for a short walk or playing a team sport, can help improve your mental wellbeing – particularly if you do it outside. Exercise releases feel-good hormones and doing something active can distract you from unwanted thoughts. See Mind's booklet *How to improve and maintain your mental wellbeing* and the leaflet *Mind tips for better mental health: physical activity*.

Talk to someone you trust

●● Trying to hide my OCD led to stress, which made my condition worse. I'm more open about it now and my friends and colleagues are also more aware. ●●

Talking about OCD isn't easy. But if you can manage to talk to someone you trust about your condition, it could help you feel it is less frightening, and make you feel less isolated. It may also help other people understand your OCD behaviour and how they can help you.

Plan for a crisis

You may want to make a crisis plan, or advance statement, to tell people what you want to happen if you are in crisis. This can help reduce stress and address any worries about what will happen to you or your family if you become ill. (See Mind's booklet *The Mind guide to crisis services* for more information on how to plan for a crisis.)

What can friends and family do to help?

This section is for friends and family who want to support someone they know with OCD.

Listen and try to understand

Friends or family can help a lot by accepting the feelings of the person with OCD and knowing that they find it difficult to cope with them. Finding out about the condition and showing you understand what they are going through can be a very important source of support.

It is helpful if you can understand that it can be particularly difficult for someone experiencing the symptoms of OCD to acknowledge their thoughts, especially if they are shameful or embarrassing.

Support them in getting help

👩👧 *Living with my daughter who has OCD is an emotional roller coaster... but having found the right medication and therapist, she is coming on in leaps and bounds.* 👩👧

If the person you know with OCD is working to a self-help programme, either on their own or with a therapist of some kind, you might be able to support them with this, or go to treatment sessions with them.

Directing your friend or family member to information materials or personal stories about other people's experiences can also help them understand their condition and make them feel less alone.

Work out how to deal with compulsions

It can be distressing to watch someone you love carrying out compulsive behaviour. However, trying to prevent your friend or family member from carrying out compulsive behaviour is often counter-productive and tends to increase their anxiety. Your friend or relative might ask you to go along with their compulsions; for example, not going into the bathroom until

it has been cleaned. This can be disruptive and does not always help to relieve their anxiety.

There is no right or wrong answer about how you to deal with this, but talking about it together might help. If your friend or family member is getting professional help, the professional responsible for their care may be able to advise you how best to deal with this in your individual situation.

Get support for yourself

It can be distressing to be close to someone experiencing OCD, particularly if you are caring for them. You might find it useful to talk to other people in the same situation as you, and to find out more about these complex problems. You can find details of support groups and organisations that provide information on OCD, including information for carers, in 'Useful contacts' on p.20.

Useful contacts

Mind

Mind infoline: 0300 123 3393
(Monday to Friday 9am to 5pm)
email: info@mind.org.uk
web: mind.org.uk
Details of local Minds and other local services, and Mind's Legal Advice Line. Language Line is available for talking in a language other than English.

Anxiety UK

tel: 08444 775 774
web: anxietyuk.org.uk
Support, help and information for those with anxiety disorders.

Beating the blues

web: beatingtheblues.co.uk
Provides free computerised CBT with a referral from a GP.

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

tel: 0161 705 4304
web: babcp.com
Can provide details of accredited CBT therapists.

Carers UK

advice line: 0808 808 7777
web: carersuk.org
Independent Information and support for carers.

MoodGYM

web: moodgym.anu.edu.au
Provides free computerised CBT.

NHS choices

web: nhs.uk
Information about OCD and where to find a Patient Advice Liaison Service (PALS) office in your area.

NICE (The National Institute for Health and Care Excellence)

web: nice.org.uk
Provides guidance on health and social care.

OCD Action

tel: 0845 390 6232
web: ocdaction.org.uk
Information and support for people with experience of OCD, and their friends, family and carers.

OCD-UK

tel: 0845 120 3778

web: ocduk.org

Information and advice for people with OCD and their friends, family and carers.

Samaritans

Freepost RSRB-KKBY-CYJK

Chris, PO Box 90 90

Stirling FK8 2SA

helpline: 08457 90 90 90

email: jo@samaritans.org

web: samaritans.org

24-hour support for anyone experiencing distress, despair or suicidal thoughts.

[illegible]

Further information

Mind offers a range of mental health information on:

- diagnoses
- treatments
- practical help for wellbeing
- mental health legislation
- where to get help

To read or print Mind's information booklets for free, visit mind.org.uk or contact Mind infoline on 0300 123 3393 or at info@mind.org.uk

To buy copies of Mind's information booklets, visit mind.org.uk/shop or phone 0844 448 4448 or email publications@mind.org.uk

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Mind
(National Association for Mental Health)
15-19 Broadway
London E15 4BQ
tel: 020 8519 2122
fax: 020 8522 1725
web: mind.org.uk

Mind

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