

Obsessive compulsive disorder (OCD)

Obsessive compulsive disorder (OCD) is an anxiety related disorder. Here there is information on the symptoms, causes and treatments for OCD. It is for people who are 18 or over and affected by mental illness in England. It is also for their loved ones, carers and anyone interested in this subject.

Key points:

- Obsessive compulsive disorder (OCD) is an anxiety disorder.
- If you have OCD, you will have obsessive thoughts and compulsive behaviours.
- OCD affects around 1 in 50 people in the UK.
- Other disorders, such as body dysmorphic disorder, can have similar symptoms to OCD.
- OCD can affect areas of your life, like work or relationships.
- To diagnose OCD, doctors will look at your symptoms and how long you have had them. They will also look at the effect OCD has on your life.
- The causes of OCD are unknown but may include family history, brain function, life events, or personality traits.
- The usual treatment options for OCD are cognitive behavioural therapy (CBT) alongside exposure and response prevention (ERP). You may also be offered medication.
- You can get help by talking to your GP or by self-referring to the NHS talking therapy service.
- Friends, relatives, and carers can help someone with OCD by getting to know their symptoms.

This factsheet covers:

1. What is obsessive compulsive disorder (OCD)?
2. What are the different symptoms of OCD?
3. What risks and complications can OCD cause?
4. How is OCD diagnosed?
5. What causes OCD?
6. How is OCD treated?
7. How can I get help and treatment?
8. What if I am not happy with my care or treatment?
9. Information for carers, friends and relatives

1. What is obsessive compulsive disorder?¹

Obsessive compulsive disorder (OCD) is an anxiety related disorder.

If you live with OCD, you will have obsessions. You will also have compulsions and possibly unhelpful beliefs too.

The obsessions and compulsions can be time-consuming, distressing, and have an impact on your day-to-day life.

What are obsessions?²

Obsessions are unwanted and intrusive thoughts, urges or images that come into your head. They happen often and again and again.

An intrusive thought means something that pops into your mind when you do not want it to. They can be scary or upsetting. Even if you try to ignore it, it keeps coming back.

Obsessions may be hard to ignore or control. They are likely to cause severe anxiety or distress.

If you live with OCD, you will try to deal with your obsession by carrying out a compulsion.

You can read more about obsessions from **OCD UK** here: www.ocduk.org/ocd/obsessions

What are compulsions?

In OCD, compulsions are mental or physical actions that aim to relieve anxiety from obsessions. You will do these often and again and again. They are also known as compulsive behaviours or rituals.³

The following is an example of an obsession and compulsion:

- **Obsession - the upsetting thought:** "What if I accidentally wrote something rude or offensive in my messages to friends, and upset someone?"
- **Compulsion - the action you do to feel better:** You do not think you wrote something rude or offensive. But to be sure, you read your messages to friends over and over to check.

You may realise that your thinking and behaviour is not logical, but you still find it difficult to stop.

When you carry out a compulsion, your relief usually does not last long. This can make your original obsession stronger. You may then feel you need to carry out your compulsion again to feel better. Over time these compulsions may happen more often or take longer to complete.⁴

Obsessions and compulsions can take up a lot of your time and energy and affect your day-to-day life. People may not be aware of the compulsions going on in your head. This may mean that they do not understand why you may be slow to complete a task.

You can read more about compulsions from **OCD UK** here:
www.ocduk.org/ocd/compulsions

What are unhelpful beliefs?

You may deal with unhelpful beliefs as part of your OCD. Such as:⁵

- Thinking something bad is more likely to happen than it really is.
- Feeling like everything must be perfect.
- Feeling like it's up to you to stop bad things from happening.
- Finding it hard to deal with uncertainty.
- Feeling like you must control your thoughts.
- Thinking your thoughts are just as bad as doing something.

These beliefs will vary among different people who live with OCD. They can also vary within the same person at different times. Most people will have some understanding of the accuracy of their beliefs.

How common is OCD?

OCD affects around 1 in 50 people in the UK. It affects both men and women equally.⁶

Many people have obsessive compulsive traits. This does not always mean that you live with OCD. For example, you might worry if a window is closed, an appliance is turned off or prefer things to be very neat or organised. This is common.

But you may decide to get support if your thoughts or actions are having a negative effect on your day-to-day life.⁷

Are there other conditions with similar symptoms?⁸

Other conditions can have similar symptoms to OCD such as:

- Body dysmorphic disorder
- Body-focused repetitive behaviours (BFRBs), like skin picking and hair pulling
- Health anxiety
- Hoarding

You can find more information about **Anxiety disorders** at www.rethink.org. Or call us on 0121 522 7007 and ask us to send you a copy.

You can find more information about **Body-focused repetitive behaviours (BFRBs)** at www.rethink.org.

You can find more information about **Hoarding** from Mind at: www.mind.org.uk/information-support/types-of-mental-health-problems/hoarding

2. What are the different symptoms of OCD?

There are many different symptoms of OCD. Your experience of OCD will be unique to you. But it is thought that OCD symptoms will generally fall into common categories such as:⁹

- Contamination.
- Checking.
- Symmetry, ordering and counting.
- Hoarding.
- Intrusive thoughts .

Contamination

Some people who live with OCD have a fear of contamination.¹⁰

Your obsessive thought is usually that contamination will harm you or a loved one. You might fear things like:

- shaking someone's hand,
- using public toilets or shared toilets, or
- touching door handles.

You might feel the need to make sure that something is clean and free from germs or dirt. Even if it is considered by others as very clean.

The act of over cleaning is a compulsion.

Checking

You might worry that something bad will happen if you do not check things.¹¹

Common checking compulsions can include:

- that a light is switched off,
- that an appliance is turned off, such as a cooker or an iron,
- that a window is closed, or a door is locked,
- health conditions and symptoms online,
- that you have items on you such as your phone or keys, and
- re-reading something to check you have taken in all the information.

This means you might feel the need to check something often and repeatedly to make sure nothing bad happens. Even if you know this is illogical, you will feel the need to do it, "just in case".¹²

Symmetry, ordering, and counting¹³

You might worry that if everything is not symmetrical or orderly, something bad will happen. This can grow into a need to have everything 'just right'.

Common compulsions can include:

- Aligning clothes in your wardrobe.
- Ensuring tin cans are facing the same way on the shelf. Or there are an even number of items in a cupboard
- Counting to a particular number, or going through a standard sequence of numbers, repeatedly.
- Repeating certain words silently.

Hoarding

Depending on symptoms, hoarding can sometimes be diagnosed as OCD. This is likely to happen if your hoarding is obsessive. But hoarding for some people will be diagnosed as a separate condition on its own.¹⁴

Hoarding is where you find it difficult to get rid of items, even when space is becoming limited. Or when most people would see the items as not being useful.¹⁵

You may find that you buy, collect, and store items even when you do not need them. You may hoard things because of:

- fear that you, or someone else, will be harmed if you throw something away,
- feeling an object may come in useful at a later point, or
- an emotional attachment to the item.

You can find more information about **Hoarding** from Mind at:

www.mind.org.uk/information-support/types-of-mental-health-problems/hoarding

Intrusive thoughts

An intrusive thought is an unwelcome thought, urge or image that enters your mind. They are mostly out of your control.

Most people who live with OCD will have some degree of intrusive thoughts, that repeat themselves and can be disturbing.

You may worry about telling a health professional about your intrusive thoughts. Especially if they are about harming others. You might worry that they will judge you or think you are a risk to others.

Health professionals can diagnose OCD without knowing details about your intrusive thoughts. It helps if you share them, but it's not essential.

What matters is describing your symptoms clearly. Tell them how these symptoms affect your daily life and mental health. This helps them understand what support you need.¹⁶

They can only take action without you agreeing if they think you are a serious risk to yourself or other people.

Is hearing voices the same as intrusive thoughts?

No. But both can be upsetting and difficult to ignore.

If you hear voices, you will hear a sound. It will sound as though other people can hear it. But you will be the only one who can hear it.

An intrusive thought will not sound as though others can hear it.

You can find more information about **Hearing voices** at www.rethink.org. Or call us on 0121 522 7007 and ask us to send you a copy.

Ben's story

I realised at a young age that I had rituals that I felt I needed to carry out. When I started university, they became worse.

I would not be able to leave our shared flat unless I had opened and closed the bedroom door several times. I would repeat this endlessly until I felt comfortable and that it was "enough."

I told a couple of friends, but I felt stupid and embarrassed. It caused problems with my studies and social life.

The rituals got worse over time. I noticed that I was spending longer and longer before I could stop.

It was only after I asked for help that I managed to get the correct support and treatment.

3. What risks and complications can OCD cause?

Compulsions can take up a lot of your time. They can affect things like work, personal relationships and home life.¹⁷

If you have a fear of contamination, you may feel the need to clean or wash things multiple times.¹⁸ This could affect your day-to-day life. Washing yourself repeatedly could have physical effects, or you may be spending a lot of money on cleaning products.

Hoarding can make it difficult to live in your own home comfortably. You may experience problems with hygiene. For example, mounting clutter can lead to rodents living in your house. In extreme cases, hoarding items may become a safety risk due to fire or injury.¹⁹

You might find it difficult to leave your house because of your symptoms. A therapist may be able to visit you at home. Or offer you talking therapy over the phone, or by video call.²⁰ If you need this sort of help, speak to your doctor or therapist.

4. How is OCD diagnosed?

The 2 main manuals used by medical professionals to diagnose mental health conditions are called:

- **International Classification of Diseases 11 (ICD-11)** which is produced by the World Health Organisation (WHO), and
- **Diagnostic and Statistical Manual (DSM 5)** which is produced by the American Psychiatric Association (APA).

The manuals explain which symptoms you should have, and for how long, for you to receive a certain diagnosis.

For example, according to DSM 5 to get a diagnosis of OCD:²¹

- you have obsessions which are intrusive and unwanted,
- you are also likely to have compulsions which are not pleasurable, which aim to reduce your anxiety, and
- your obsessions and compulsions must:
 - last more than 1 hour each day, or
 - causes you significant issues in your daily life.

It's very common for people without OCD to sometimes have an intrusive thought or repetitive behaviour. Such as double checking that an appliance is switched off.²²

5. What causes OCD?²³

The exact cause of OCD is unknown. But the NHS say different things may play a part, including:

- **Family history.** You are more likely to develop OCD if a family member lives with it. It might be learned behaviour. But it could be because of your genes.
- **Differences in your brain activity.** Some people with OCD have areas of very high activity in their brain. Or low levels of a chemical called serotonin.
- **Life events.** OCD may be more common in people who have experienced a traumatic or upsetting event or events.
- **Personality.** You might develop OCD if you are:
 - very careful and precise, with high personal standards, or

- usually quite anxious or
- have a very strong sense of responsibility for yourself or others

Although it is not known exactly why OCD develops, it can be treated successfully.

6. How is OCD treated?

OCD is usually treated with the following evidenced based treatments:²⁴

- cognitive behavioural therapy (CBT)
- exposure and response prevention (ERP), and
- medication.

Cognitive behavioural therapy (CBT)²⁵

CBT is a talking therapy that looks at the link between how you think, feel and behave. CBT focuses on problems and difficulties in the present rather than your past or childhood.

CBT helps you understand how:

- you think about yourself and the world around you, and
- your thoughts affect your reactions to situations.

Exposure and response prevention (ERP)²⁶

ERP helps people deal with situations or things that make them anxious or frightened. With the support of your therapist, you are 'exposed' to whatever makes you frightened or anxious. For example, leaving the house without checking locks multiple times.

You learn other ways of coping with your fear or anxiety instead of avoiding the situation or repeating a compulsion. You repeat this until your anxiety or fear is more manageable.

Medication

Your doctor may offer you a type of antidepressant called a selective serotonin reuptake inhibitor (SSRI). The main types of SSRIs doctors offer for OCD are fluoxetine, fluvoxamine, paroxetine, sertraline, and citalopram.²⁷

If your doctor offers you medication, they should tell you how it might help and what side effects to expect.

The **National Institute for Health and Care Excellence (NICE)** produces guidance on OCD treatment. You can find the guidance at: www.nice.org.uk/guidance/cg31.

What if these treatments do not work?

Additional treatment options are further talking therapy or medication.²⁸ For example, your doctor may offer you a different type of SSRI or an antidepressant called clomipramine.²⁹

If these treatments still do not work, then you should be referred to a specialist OCD team. They should offer you additional treatments, which might include:³⁰

- having additional CBT with ERP or cognitive therapy,
- taking an antipsychotic drug in addition to an SSRI or clomipramine,
- taking clomipramine and a drug called citalopram at the same time.

The following webpage from **OCD UK** gives details about specialist NHS OCD services:

www.ocduk.org/overcoming-ocd/accessing-ocd-treatment/accessing-ocd-treatment-through-the-nhs/specialist-ocd-treatment-services

Cultural or religious guidance³¹

OCD symptoms may sometimes involve religion. Such as obsessions with religious or cultural practices.

The boundary between religious or cultural practice and OCD symptoms might sometimes be unclear to healthcare professionals.

The NICE guidelines say professionals can seek the advice and support of an appropriate religious or community leader, if appropriate. But they should only do this with your consent.

You can find more information about:

- Talking therapies
- Antidepressants
- Antipsychotics
- Spirituality, religion, and mental illness

at www.rethink.org. Or call us on 0121 522 7007 and ask us to send you a copy.

7. How can I get help and treatment?

You might be worried about your symptoms, or they are causing problems in your day-to-day life. You can talk with your GP.

Your GP may:³²

- offer you medication,
- refer you to a service for talking therapy, or
- refer you to a NHS specialist mental health service.

Your GP will look at different areas when considering treatment options for you. Such as the following:

- Your goals and preferences.
- Your diagnosis and symptoms.
- What options you have already tried.
- Any other conditions you have.
- Guidance from the **National Institute for Health and Care Excellence (NICE)**.

You can find more information about:

- GPs and your mental health

at www.rethink.org. Or call us on 0121 522 7007 and ask us to send you a copy.

How do I get talking treatment?³³

Talking treatment is often provided by a service called the NHS talking therapy service. They deal with mild to moderate mental health symptoms.

You can self-refer to your local service. But you can ask your GP to refer you if you prefer.

You can also get talking treatment through a specialist mental health service if you live with more severe OCD.

You can find more information about **Talking therapies** at www.rethink.org. Or call our us on 0121 522 7007 and ask us to send you a copy.

How do I get referred to a specialist mental health service?

Usually, a GP will refer you to a NHS specialist mental health service if they think your symptoms are more severe.

A specialist doctor, called a psychiatrist, may then see you for an assessment.

Healthcare professionals may ask you questions to find out how you are affected by your symptoms, like.³⁴

- 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 cannot?
- Do your activities take a long time to finish?
- Are you concerned about putting things in a special order or are you very upset by mess?
- Do these problems trouble you?

You can find more information about:

- NHS mental health teams
- Recovery and mental illness

at www.rethink.org. Or call our us on 0121 522 7007 and ask us to send you a copy.

8. What if I am not happy with my care or treatment?

If you are not happy with your care or treatment you can:

- talk to your doctor about your care and treatment,
- ask for a second opinion,
- get an advocate to help you speak to your doctor,
- make a complaint or,
- contact Patient Advice and Liaison Service (PALS)

Find your local PALS here: www.nhs.uk/service-search/other-health-services/patient-advice-and-liaison-services-pals

You can find more information about:

- Second opinions – About your mental health diagnosis or treatment
- Advocacy for mental health – Making your voice heard
- Complaining about the NHS or social services

at www.rethink.org. Or call us on 0121 522 7007 and ask us to send you a copy.

9. Information for carers, friends and relatives

Below are some things that you can do to support someone who lives with OCD:

- Discuss their symptoms with them, and what effect they have.
- Ask the person about their self-management techniques.
- Go at their pace.
- Be patient. As frustrating as it is for you, it is even more frustrating for them.
- Keep an open mind and try to understand why they are doing things.
- Encourage them to see a GP if you are worried about their mental health.
- Ask to see a copy of their care plan if they have one.
- Challenge stigma.

For more information, follow this link to **Mind's** webpage on **Supporting someone with OCD**: www.mind.org.uk/information-support/types-of-mental-health-problems/obsessive-compulsive-disorder-ocd/for-friends-family

You can also find out more about:

- Supporting someone with a mental illness
- Getting help for someone in a mental health crisis
- Carer's assessments – Under the Care Act 2014
- Confidentiality, information and your loved one - For loved ones of people living with mental illness
- Worried about someone's mental health
- Stress – How to cope

at www.rethink.org. Or call us on 0121 522 7007 and ask us to send you a copy..

Further reading

Brain Lock: Free yourself from obsessive-compulsive disorder – By Dr Jeffrey Schwartz

In Brain Lock, covers a simple four-step method for overcoming OCD using principles of cognitive-behavioural therapy. Real-life stories are used to explain the method.

You can find out more about the book and access a brief handout outlining the principles of the method, by following the links below.

Website: www.hope4ocd.com/foursteps.php and www.ocduk.org/shop/brain-lock

Useful Contacts

OCD-UK

OCD-UK has been working for children and adults affected by OCD since 2004. They provide advice, information, and support services for those affected by OCD.

Phone helpline: 01332 588112

Address: Suite 8, Riverside Business Centre, Foundry Lane, Milford, Derbyshire DE56 0RN

Online contact form: www.ocduk.org/ocduk-contact

Website: www.ocduk.org

OCD Action

National charity focusing on OCD.

Helpline phone: 0300 636 5478

Helpline email: support@ocdaction.org.uk

Office phone: 020 7254 5272

Office email: info@ocdaction.org.uk

Address: Suite 506-507 Davina House, 137-149 Goswell Road, London EC1V 7ET

Website: www.ocdaction.org.uk

Maternal OCD

Maternal OCD is a charity co-founded by two mothers who have lived experience of perinatal OCD. It aims to raise awareness, provide information and support to mums and their families, and encourage and support perinatal OCD research.

Email: info@maternalocd.org

Website: <https://maternalocd.org>

Triumph Over Phobia (TOP UK)

A UK registered charity which aims to help people who experience phobias, obsessive compulsive disorder and other related anxiety. They do this by running a network of self-help therapy groups.

Phone: 01225 571740

Address: Triumph Over Phobia, Suite 206, 3 Edgar Buildings, George Street, Bath, BA1 2FJ

Email: info@topuk.org

Website: www.topuk.org

Hoarders UK

The UK national charity for people impacted by hoarding behaviours.

Phone: 020 3239 1600

Address: Suite 107/108 Davina House, 137-149 Goswell Road, London, EC1V 7ET

Email: info@hoardinguk.org

Website: <https://hoardinguk.org>

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Or write to us at:

Rethink Mental Illness Advice and Information Service,
28 Albert Embankment, London, SE1 7GR.



We are the charity for people severely affected by mental illness, no matter what they're going through.

For further information on Rethink Mental Illness
Phone: **0121 522 7007**
Email: info@rethink.org



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Go to www.rethink.org for information on Mental health conditions and symptoms, treatment and support, physical health and wellbeing, ethnic minorities and mental health, LGBT+ mental health, mental health laws and rights, work, studying, and mental health, police, courts, and prison, and advice for carers.

Do not have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, excluding bank holidays, and we will send you the information you need in the post.

Do you have accessibility tools for this information?

You can find this information on our website at www.rethink.org. There is an accessibility function on this webpage called **Recite**. On the desktop site, click on the icon in the top right-hand corner next to **Donate**. On the mobile site, scroll right and click on the '**Turn on accessibility**' icon.

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