

Obsessive compulsive disorder (OCD)

Obsessive compulsive disorder (OCD) is an anxiety related disorder. This factsheet gives information on the symptoms, causes and treatments for OCD. It also has information for carers and family members.



- If you have obsessive compulsive disorder (OCD), you will usually have obsessive thoughts and compulsive behaviours.
- OCD affects around 1 in 50 people in the UK.
- The usual treatment options for OCD are cognitive behavioural therapy (CBT) and medication.
- If you have OCD, you may find that it affects areas of your life like work or relationships.

This factsheet covers:

- 1. What is obsessive compulsive disorder (OCD)?
- 2. What are the different symptoms of OCD?
- 3. How is OCD diagnosed?
- 4. What causes OCD?
- 5. How is OCD treated?
- 6. How can I get help and treatment?
- 7. What if I am not happy with my treatment?
- 8. What risks and complications can OCD cause?
- 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 are also likely to have compulsions and unhelpful beliefs too.

The obsessions and compulsions can be time-consuming, distressing and have a big impact on your day-to-day life. Such as with relationships or on your ability to work.

Obsessions

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

They may be hard to ignore or control. Obsessions are likely to cause you to have severe anxiety or distress.²

You are likely to try to deal with your obsession with another thought or action. For example, by carrying out a compulsion.

Compulsions

Compulsions are either mental or physical actions that you do often and repeatedly to relieve the anxiety from obsessions. You might also hear things that you do repeatedly being called compulsive behaviours or rituals.

For example, you might believe that you, or someone close to you, might come to harm if you don't carry out your compulsions. You may realise that your thinking and behaviour isn't logical but still find it difficult to stop.

When you carry out a compulsion, your relief usually doesn't last long. This makes 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.

Thoughts and rituals can take up a lot of your time and affect your day-to-day life. People may not be aware of the actions going on in your head. This may mean that they don't understand why you may be slow to complete a task.

Unhelpful beliefs

You may deal with unhelpful beliefs as part of your OCD. Such as:³

- Over estimating threat
- Perfectionism
- Enlarged sense of responsibility
- Being less able to deal with uncertainty

- Feeling a need to control thoughts
- Placing more importance on thoughts. Such as the belief that having a certain thought, is just as bad as acting on it.

These beliefs will vary among different people with OCD. And can also vary within the same person at different times. Most people will have either good or fair 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.⁴

Many people have obsessive compulsive traits. Having obsessive and compulsive traits doesn't necessarily mean that you have OCD. For example, you might worry if a window is closed, appliance is turned off or prefer things in a particularly neat or organised fashion. This is common. But you may decide to get support if your thoughts or actions are having a negative affect your day-to-day life.

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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:⁵

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

Contamination

Some people who live with OCD have a fear of contamination. Your obsessive thought is usually that any contamination will harm yourself or a loved one. You might fear:

- shaking someone's hand,
- using public toilets or shared toilets,
- touching door handles,
- using plates, glasses, or cutlery in a public place,
- using public telephones,
- visiting hospitals or GP surgeries.
- visiting someone else's house, and
- touching shared objects. Such as remote controls, computer keyboards or money.

This means you might constantly 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, or someone, might be harmed if you don't check something.

Common checking compulsions can include:

- that a light is switched off,
- that an appliance is turned off. Such as a cooker, an iron, a tap or a lamp,
- that a window is closed, or a door is locked,
- health conditions and symptoms online,
- that you have your wallet, purse, phone, or keys on you, 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 feed the need to do it, "just in case".

Symmetry, ordering and counting

You might worry that if everything isn't symmetrical or orderly, something bad will happen. This can grow into a need to have everything 'just right'.⁷

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.

Intrusive thoughts

An intrusive thought is an unwelcome thought, urge or image that enters your mind and is mostly out of your control. Most people with OCD will have some degree of intrusive thoughts, that are repetitive and can be disturbing in nature. For example:

- Sexually disturbing images or thoughts. Such as thoughts about members of your family.
- Violent images, thoughts or urges that are out of character. Such as an urge to stab someone or jump in front of a train. Or thoughts or images of being violent to a loved one or other people.

- Relationships. Such as constant thoughts about your relationship, your sexuality, if your partner is unfaithful, or that your relationship will end at any moment.
- Seeing a serious incident and thinking that something you did or didn't do might have caused it to happen.
- Religious thoughts. Such as a focus on the importance and significance of religion and religious matters. Or thoughts that are against your religious beliefs.

You may be concerned to tell a health professional about your obsessional thoughts. Especially if your thoughts are about harming others. You may be concerned that you will be labelled or think you are a risk to people around you.

But health professionals should be familiar with OCD and understand that your intrusive obsessional thoughts may be a symptom of OCD. They will use the information to think about the correct support and treatment for you.

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 won't sound as though others can hear it.

You can find more information about 'Hearing Voices' at www.rethink.org. Or call our General Enquires team on 0121 522 7007 and ask them to send you a copy of our factsheet.

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 its own disorder.⁸

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

You may find that you buy, collect and store items even when you don't 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 emotionally attached to the item.

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 a number of 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 study and social life.

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

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

What other disorders have symptoms of OCD?

Other disorders can have similar symptoms to OCD such as:

- Body dysmorphic disorder
- Skin picking
- Hair pulling
- Health anxiety
- Hoarding
- Obsessive compulsive personality disorder

You can find more information about:

- Anxiety disorders
- Personality disorders

at www.rethink.org. Or call our General Enquires team on 0121 522 7007 and ask them to send you a copy of our factsheet.

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3. How is OCD diagnosed?

The 2 main manuals used by medical professionals to diagnose a mental illness are called:

- International Classification of Diseases (ICD) 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 should be present, and for how long, for you to receive a diagnosis.

For example, according to the DSM 5 to get a diagnosis of OCD:9

- you have obsessions which are intrusive and unwanted,
- you are also likely to have compulsions which are not pleasurable, although your compulsion may help to relieve anxiety or distress caused by the obsession, and
- your obsession and compulsions must either be time consuming, lasting more than 1 hour each day. Or
- causes you significant distress.

The time-consuming criteria is particularly important. This is because it helps to work out the difference between someone with OCD and the general population.

It's very common for people without OCD to have the occasional intrusive thought or repetitive behaviour. Such as double checking that an appliance is switched off or increasing hand washing and home cleaning in response to the covid 19 outbreak.¹⁰

As part of the diagnosis process, health professionals are likely to ask you about your beliefs around your experiences. This is because many people with OCD will have unhelpful beliefs.

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4. What causes OCD?

We don't know exactly why someone may develop OCD.

The following things could all play a part on why a person develops OCD:

- personal experience. Such as trauma
- biological and genetic factors, and
- personality.

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

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5. How is OCD treated?

OCD is usually treated with the following evidenced based treatments:11

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

Cognitive behavioural therapy (CBT)

CBT 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 can help you to understand how you think about yourself, the things around you, and how that affects your reaction to situations.¹²

Exposure and response prevention (ERP)

NICE guidelines say that you should only be offered ERP alongside CBT.¹³ You can read more about the NICE guidelines below.

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, dirt or germs.

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 managable.

Medication

Your doctor may offer you a type of antidepressant called a selective serotonin reuptake inhibitor (SSRI) to help with your OCD. The main types of SSRIs doctors use for OCD are fluoxetine, fluvoxamine, paroxetine, sertraline, and citalopram.¹⁴

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

NICE guidelines

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

If you have OCD and your symptoms are mild, your doctor should offer you low intensity psychological treatments of up to 10 hours. Low intensity treatments include:¹⁵

- brief CBT, including ERP, using self-help materials,
- brief individual CBT, including ERP, by telephone, and
- group CBT, including ERP.

If you have moderate OCD, your doctor should offer you the choice of either:¹⁶

- a course of SSRIs, or
- arrange more intensive CBT, including ERP. The therapy should be one-to-one with a therapist.

You might have severe symptoms. Your doctor should offer you CBT including ERP, together with an SSRI.¹⁷

What if these treatments don't work?

If these have not helped, your doctor or therapist may suggest further assessment and treatment. This might be given further psychological therapy or medication.¹⁸ For example, your doctor may offer you a different type of SSRI or an antidepressant called clomipramine.¹⁹

If these treatments still don't work, then you will be referred to a specialist OCD team. They should give you additional treatments, which might include:²⁰

- 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.

National specialist OCD services

If you have severe, long-term OCD you may be referred to a specialist national OCD service. Especially if you have not responded well to the treatments available from local or regional services.

The following webpage from the NHS Choices website gives details of some specialist OCD services: www.nhs.uk/conditions/obsessive-compulsive-disorder-ocd/treatment/.

Cultural or religious guidance²¹

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 our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet

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6. How can I get help and treatment?

You should make an appointment to talk with your GP if you are worried about your symptoms. Or they are causing problems in your day-to-day life.

Your GP may:

- Offer you medication,
- refer you to a service for talking treatment or
- refer you to a 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 tried already.
- Any other conditions you have.
- Guidance from the National Institute for Health and Care Excellence (NICE).

How do I get talking treatment?

Talking treatment is often provided by a service called an IAPT service. This stands for Improving Access to Psychological Therapies. They deal with mild to moderate mental health symptoms.

You can self-refer to IAPT services in most areas. But you can ask your GP to refer you if you prefer. Professionals in an IAPT service are not medically trained. But they are trained to give therapy and identify OCD symptoms. They will assess if they think you will benefit from having treatment with them.

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

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

Usually, a GP will refer you to a 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 questions to find out how you are affected by your symptoms.²²

- 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 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:

- GPs what to expect from your doctor
- NHS Mental Health Teams (MHTs)
- Talking therapies
- Recovery

at <u>www.rethink.org</u>. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

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7. What if I am not happy with my treatment?

If you are not happy with your treatment you can:

- talk to your doctor about your treatment options,
- ask for a second opinion,
- get an advocate to help you speak to your doctor,
- contact Patient Advice and Liaison Service (PALS) and see whether they can help, or
- · make a complaint.

There is more information about these options below.

Treatment options

You should first speak to your doctor about your treatment. Explain why you are not happy with it. You could ask what other treatments you could try.

Tell your doctor if there is a type of treatment that you would like to try. Doctors should listen to your preference. If you are not given this treatment, ask your doctor to explain why it is not suitable for you.

Second opinion

A second opinion means that you would like a different doctor to give their opinion about what treatment you should have. You can also ask for a second opinion if you disagree with your diagnosis.

You don't have a right to a second opinion. But your doctor should listen to your reason for wanting a second opinion.²³

Advocacy

An advocate is independent from the NHS. They are free to use. They can be useful if you find it difficult to get your views heard. There are different types of advocates available.

Community advocates may be able to support you to get a health professional to listen to your concerns. And help you to get the treatment that you would like.

You can get an NHS Complaints advocate to help you make a complaint about an NHS service.

You can search online to search for a local advocacy service.

The Patient Advice and Liaison Service (PALS)

PALS is part of the NHS. They give information and support to patients.

You can find your local PALS' details through this website link: www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363.

Making a complaint

It is often quicker to try to solve your issue informally by first talking to the service or professional directly. Explain:

- What you are not happy with
- The impact this has had on you, and
- What you would like to happen

If an informal discussion doesn't help you can make a formal complaint.

You can get an NHS Complaints advocate to help you make a complaint about an NHS service.

You can find out more about:

- Medication. Choice and managing problems
- Second opinions
- Advocacy
- Complaining about the NHS or social services

at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

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8. 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. For example, checking something repeatedly can take up hours of your day.

If you have a fear of contamination, you may feel the need to clean or wash things multiple times. 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 rodent infestations. In extreme cases, hoarding items may become a safety risk due to fire or injury.

You might find it difficult to leave your house or to be in a clinic because of your OCD. A therapist may be able to visit you at home. Or offer you CBT over the phone. You should speak to your doctor or therapist if you need this sort of help.

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9. Information for carers, friends and relatives

How can I get support?

You can speak to your GP. You should be given your own assessment through the community mental health team to work out what effect your caring role is having on your health. And what support you need.²⁴

You can get peer support through carer support services or carers groups. You can search for local carers' groups and services on the Carers Trust website here: https://carers.org/search/network-partners.

You can ask your local authority for a carer's assessment if you need more practical and financial support to help care for someone.

As a carer you should be involved in decisions about care planning. But you don't have a legal right to this.²⁵

Supporting the person you care for

You might find it easier to support someone with OCD if you understand their symptoms, treatment plan and self-management techniques. You could ask them to share this information with you.

The person that you care for may also have a care plan. This outlines the care that they will get and who is responsible for it. A care plan should always have a crisis plan. A crisis plan will have information about who to contact if they become unwell.

You can use this information to support and encourage them to stay well and get help if needed.

You can find out more information about:

- Supporting someone with a mental illness
- Getting help in a crisis
- Suicidal thoughts. How to support someone
- Responding to unusual thoughts and behaviours
- Carers' assessment and support planning
- Confidentiality and information sharing. For carers, friends and family

Supporting someone with a mental illness

at <u>www.rethink.org</u>. Or call our General Enquires team on 0121 522 7007 and ask them to send you a copy of our factsheet.

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Further Information

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

In Brain Lock, a simple four-step method for overcoming OCD using principles of cognitive-behavioural therapy is presented. 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 link below.

Website: www.hope4ocd.com/foursteps.php



OCD-UK

Supporting children and adults with OCD. Their phone line is staffed by volunteers and may not always be answered. They advise you to email if you can't get through.

Phone helpline: 01332 588112

Address: OCD-UK, Harvest Barn, Chevin Green Farm, Chevin Road

Belper, Derbyshire, DE56 2UN

Email via website: www.ocduk.org/contact-us

Website: www.ocduk.org

OCD Action

National charity focusing on OCD.

Phone: 0300 636 5478

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

EC1V 7ET

Email: support@ocdaction.org.uk
Website: www.ocdaction.org.uk

Maternal OCD

Maternal OCD is a charity co-founded by two mothers who have lived experience of perinatal OCD which 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: PO Box 3760 Bath BA2 3WY

Email: info@topuk.org
Website: www.topuk.org

Hoarding UK

The UK national charity for people impacted by hoarding behaviours.

Phone: 020 3239 1600

Address: Suite 103 Davina House, 137-149 Goswell Road, London,

EC1V 7ET

Email: info@hoardinguk.org
Website: https://hoardinguk.org/

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Rethink Mental Illness Advice Service

Phone 0808 801 0525 Monday to Friday, 9:30am to 4pm (excluding bank holidays)

Email advice@rethink.org

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or write to us at Rethink Mental Illness: RAIS

PO Box 17106 Birmingham B9 9LL

or call us on 0808 801 0525

We're open 9:30am to 4pm Monday to Friday (excluding bank holidays)



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