Obsessive-Compulsive Disorder

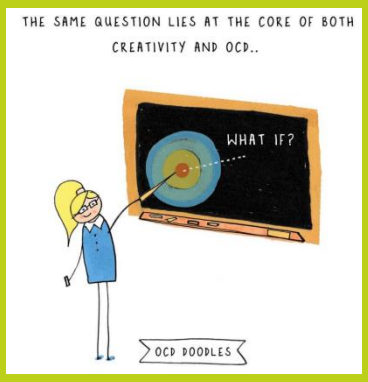
Obsessive-Compulsive Disorder (OCD) is the name given to a recognised condition that causes someone to become stuck in a cycle of distressing obsessions and compulsions. It is a very debilitating and often misunderstood condition, so much so that many hide it for years or decades. In fact, it's much more common than originally thought, and estimates are between 1-2% of the population. The good news is that OCD is a treatable condition, with both therapy and medication available that can help with management and recovery.

Obsessions

Obsessions happen when you become overly preoccupied with intrusive thoughts, misinterpreting them as indicators of risk and responsibility.

Intrusive thoughts are random and automatic worries, images, or sensations that everyone experiences as part of being human. They are the result of the brain constantly scanning for interest or danger, and hold no meaning in themselves. They are hypothetical in nature, so most people describe them with the words "What if…". For someone without OCD, most of them go by without notice, while others might catch someone's attention briefly because of the topic they are about.

If you have OCD, **obsessions** around one or more themes cause you to particularly notice those intrusive thoughts. Through the worry and attention, these random thoughts feel more and more meaningful. What defines an obsession is that you can't let go of your worry until you feel completely sure that it is dealt with. Any uncertainty or doubt around it feels unbearable. Obsessions are always about unwanted or feared things, and might cause you to feel that you are responsible for resolving the issue, preventing harm, or finding the answer.



Intrusive thoughts can be about things the person wants or agrees with (like daydreaming about a random and impossible situation) or against the person's values and desires (like randomly thinking back to an upsetting event).

Obsessions within OCD revolve around **unwanted thoughts**, causing them to become more **frequent** and **intense** through fear and anxiety.

Doubt

A key element of obsessions is that they are driven by doubt, not by lack of rational thinking. People with OCD tend to be aware of the irrationality of their concerns, which for many actually causes even more distress. Although you might know, logically, how unlikely the feared outcome is or that you are not responsible for avoiding it, the smallest possibility that this isn't the case becomes intolerable. When anxiety is triggered by a feared situation, it is so strong and loud that the logic is drowned out, and someone cannot help but carry out compulsions to get relief from it. The solutions then become part of the problem, as compulsions bring more attention to the topic of the obsession and the relief they bring reinforces the cycle.

Obsessions can be about any theme or topic, from something very specific to a general feeling of danger. Some common themes include contamination, violence, sexuality, religious beliefs, past or future events, abstract or existential questions, and relationships. The reality, though, is that every person struggling with OCD will have their own, individual, set of worries based on who they are and what matters to them. The OCD cycle will look the same no matter the theme, and the anxiety it brings will be just as intense and real to the person, because it is doubt rather than a rational fear that drives it all.

Intrusive sensations

While the majority of obsessions revolve around thoughts or worries, intrusive experiences also include images, sounds, and sensations.

Sensations can be particularly confusing or 'sticky' because the human brain is capable of making them feel very real. If you are worried about feeling excited or aroused, this can in itself cause the physical feeling you are looking out for. This doesn't happen because of desire or enjoyment, but can feel like it does because of the real feelings in the body combined with the doubt of OCD. For example, this might cause someone to feel like they want to smile at a 'bad' thought.

Many people who struggle with sexual obsessions find that these can bring intense physical sensations that feel like arousal, which are often referred to as 'groinal responses'. These are different from real arousal because they do not bring enjoyment and are instead a distressing and upsetting thing to experience.

Some people also refer to intrusive 'urges', though it's important to understand that this is different from actually having a desire to do something. It is the fear of that intention that brings on the sensation.

The cycle of obsessions, anxiety, and compulsions is what defines OCD and is shared by every person living with it. Some people, though, also use labels to describe what their OCD looks like. These are not officially different types of OCD, so you won't see them in our informational resources, but you might come across them in other OCD spaces or resources.

Here are some examples of labels based on the theme of the obsessions:

Contamination OCD
HOCD (Homo/Heterosexual or Harm)
Sensorimotor OCD
Existential OCD
POCD (Paedophilia)
ROCD (Relationship or Religious)
False memory OCD
Real-life OCD

Compulsions

Compulsions are purposeful actions that a person with OCD takes part in to get some relief from the anxiety and obsessions they experience.

Like obsessions, these can take any form, and the OCD cycle will be the same no matter what they look like. The actions or rituals most associated with OCD are visible ones, such as checking, cleaning,

hoarding, or arranging things. Most people with OCD, though, also experience mental or invisible compulsions such as:

- Rumination, which is going over and over thoughts, possibly to try to rationalise
- Checking thoughts or memories
- Asking for reassurance from others
- Avoiding situations or people that bring on the intrusive thoughts
- Neutralising, or thinking a good thought to cancel out the bad one
- Avoiding anxiety or compulsions by trying to accept that the thoughts are true

Here are a few examples of labels based on compulsions:

Pure O (mental/invisible compulsions only)
Checking OCD
Staring OCD
Rumination OCD

Compulsions can have a seemingly logical connection to the topic of someone's obsessions, like hiding knives due to a fear of stabbing a loved one. They can also be completely unrelated, though, like wearing matching socks to reduce the likelihood of one's house burning down. It can help to remember that it is doubt and a feeling of responsibility that drives compulsions, not logic. In fact, even if the compulsion seems logical, the person will not stop until they've fulfilled a certain requirement or until it feels 'just right'. This might be several hours into the ritual. No matter how rational or irrational a person's worries or safety behaviours seem, using logic is not going to be a successful way of breaking the cycle.

Previous definitions of OCD included that some people might experience only obsessions or only compulsions. It is now better understood that all people living with OCD experience both, but sometimes in less obvious ways. Someone might perform compulsions that are not directly triggered by intrusive thoughts or obsessions, but this is because of the cycle becoming more automatic in the brain. In these cases, the obsession is no longer a fear of harm, for example, but a fear of the harm-based intrusive thoughts in themselves. Some describe this as 'obsessing about obsessing'. The goal of the compulsions in this case is not to relieve anxiety, but to avoid it coming up at all.

Myth: poor parenting or difficult childhood experiences such as a divorce or bullying cause OCD/anxiety

People with OCD, their families, and their loved ones do no cause OCD. A specific event or set of events might have contributed to how and when the OCD symptoms started, but not to the fact that they did.

The most important thing loved ones can do isn't to worry about whether they're to blame, but rather to support the person with where they are in their journey to better understanding and recovery.

Causes

There has been a lot of research into possible causes of OCD, but there is no definite answer, as it can be different from person to person. Like many mental health conditions, it seems to be a mix of genetic tendency, psychological factors, and experiences.

Genetic – OCD and related symptoms tend to run in families. Family members of people with OCD might have the condition itself, other anxiety-based struggles, or involuntary jerky movements (tics)

Psychological – Individual tendencies like being vulnerable to stress and anxiety, feeling overly responsible, or a sense of perfectionism could be tied into why a person gets so 'stuck' in the OCD cycle

Environmental – The experiences and societal values someone is exposed to in their life can inform assumptions or pressures that become a part of the person's OCD cycle

Triggers

A trigger is the event or experience that brings on the symptoms, rather than the reason

When OCD symptoms arise because of becoming a parent or obsessions revolve around parenthood, this is often called Perinatal, Maternal, or Parental OCD.

OCD Action has an over-the-phone support group open to anyone experiencing Perinatal OCD. See a full list of our groups here.

The charity Maternal OCD offers resources to people struggling with this.

CADAT-PAX (Centre for Anxiety Disorders and Trauma – Parents with AnXiety) is a unit for new parents within the larger CADAT specialist OCD treatment service.

for them. This can be a single traumatic event or, in most cases, the build-up of life stressors eventually 'spilling over'.

Certain life events are known for being common triggers for anxiety-based conditions such as OCD. Becoming a new parent, including the family planning period, usually brings up feelings of responsibility, and is one of the most common triggers for symptoms of OCD starting or getting worse. A new parent might be particularly vulnerable to becoming anxious in response to intrusive thoughts about their parenting or the wellbeing of their child. There might be a hormonal element to this, but it can happen to fathers and adoptive parents, as well. Some people know at least in part what brought on their symptoms, while for others it was mainly a case of bad luck. The good news is that the treatment for OCD is not based on the cause or trigger, so there's no need to know. Rather, it looks at getting you 'unstuck' from the OCD cycle you are currently in through changing your relationship to the thoughts and practicing new reactions to them.

Severity and impact

OCD is a condition that varies greatly from person to person, not only around themes and compulsion styles but also in levels of severity and constancy.

While the impact of OCD ranges from mild to very severe, each person's distress is very real. Everyone experiences obsessions and compulsions on occasion, but for the experience to be labelled 'disorder' (the D in OCD) they have to cause distress and impact noticeably on the person's quality of life.

When someone lives with OCD, they don't experience their worries and rituals as quirks or annoyances, as they might look from the outside. The intensity of the anxiety and doubt that is felt on the inside is debilitating, exhausting, and often constant. The irrationality of the cycle can be scary or confusing. On top of this, it can bring to feeling ashamed and alone, or like you are losing touch with reality when you are not.

It is very common for people living with OCD to keep their symptoms hidden. This can be because of the embarrassment someone feels about their irrational worries and behaviours, and often because of a fear of their intrusive thoughts being misunderstood as desires. Being aware of what is rational and what isn't doesn't help reduce the anxiety or 'stickiness' of the OCD cycle, but it can

allow the person to choose what they show to others. You might stick to invisible compulsions when around other people as much as possible, or have an easier time holding back while you're out, and then get overwhelmed by anxiety and the need for compulsions when you get home. OCD is often referred to as the 'hidden' or 'secret' disorder, and people who struggle with it might wait years, even decades, before seeking any support. This is also in part because of misinformation and misunderstanding about the condition. Someone might be told that there is no help available or that they just need to learn to live with it. In reality, there are reliable and proven treatments available for OCD and recovery is possible.

Whether you think of your OCD as a disability or not, you have legal rights and protections under the Equality Act 2010.

In it, disability is defined as a condition that impacts your ability to carry out day to day tasks for a year or more of your life.

> In 1990, the World Health Organisation listed 'Obsessive-Compulsive Disorders' within the top ten most debilitating health conditions, based on its effect on daily activities, social life, work, and education
>
> In 2008, it was ranked 5th in most disabling mental health conditions

Common myths

Knowledge and understanding about OCD has greatly improved compared with even a few years ago. It is more common for non-specialist professionals to be able to recognise OCD for what it is and offer the right support. Still, it can be helpful to be aware of myths surrounding the condition.

Myth: OCD is rare in children and therefore won't be diagnosed

Fact: OCD can affect children, adolescents, and adults. The NICE guidelines state that the earliest age it can be reliably diagnosed is 4-5 years.

At least half of adults who get help for OCD report having it as children. In most of these cases, they did not tell anyone because they were embarrassed, or they did ask for help but didn't receive it.

You can find more information about assessment of young people on page 31 of the NICE guidelines

Myth: People with OCD just want control

Fact: People with OCD are often deeply distressed by how little they can control what is happening in their mind. Compulsions and rituals do not help them feel more in control, but often less, because they can't stop themselves from taking part in them. They happen because the person feels an overwhelming sense of danger and compulsions give some temporary relief from this.

Myth: People with OCD enjoy their rules and compulsions

Fact: Obsessions revolve around unwanted intrusive thoughts that go against their values, desires, and beliefs. The psychological term for this is 'ego-dystonic'.

The OCD cycle is driven by anxiety and doubt, and could not work as it does if the intrusive thoughts were wanted.

The biggest myth: there is no help for OCD

Fact: There are well-researched treatments available, both privately and through the NHS, which can help you recover from OCD.

There are many misconceptions around OCD and recovery. Some people are told they just have to learn to live with it, others are offered the wrong support. Through our services, OCD Action can support you to access treatment at the right level for you.

You can read more about the recommended treatments – Cognitive Behavioural Therapy with Exposure and Response Prevention, and Anti-Obsessional Medication – in our Treatments for OCD pack.

You can read about how to navigate the NHS system and access support in our Accessing Treatment for OCD pack.

You can also contact our helpline to speak to a volunteer about how to access treatment – on support@ocdaction.org.uk or 0300 636 5478.