

Information about

OCD IN ADULTS

The disorder, its treatment and prevention



CONTENTS

- 03** What is OCD?
- 05** Why do some people get OCD?
- 06** What are the symptoms of OCD?
- 09** How is OCD diagnosed?
- 09** What treatment is available for OCD?
- 12** What can you do yourself if you are suffering from OCD?
- 13** What can relatives do?
- 15** Where can you find more information?

Information about OCD in adults

The disorder, its treatment and prevention

OCD is a mental disorder with different degrees of severity. Despite being a nuisance, OCD can be a condition that people are able to live with while basically leading a normal life. OCD can also be an extremely disruptive condition where the symptoms rule out all possibility of a normal life.

When someone is suffering from OCD, knowledge of the disorder is important. The more the person knows, the better he/she will be able to cope with and prevent the disorder and its consequences.

This brochure describes the disorder as well as treatment options. It is mainly intended for individuals such as yourself being treated for OCD by the psychiatric service in Region Midtjylland, and their relatives.

We hope this brochure will help you and your relatives to learn more about OCD.

Kind regards

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WHAT IS OCD?

OCD is an abbreviation of obsessive-compulsive disorder. The disorder is characterised by recurring compulsive thoughts and/or compulsive actions. Most children and adults who suffer from OCD have both compulsive thoughts and compulsive actions.

Compulsive thoughts

- ❑ are unwanted thoughts, impulses or mental images.
- ❑ are often frightening and are about dreadful things that might happen.
- ❑ are unpleasant and experienced as intrusive. They often produce a feeling of anxiety or disgust.

Compulsive actions

- ❑ are repeated actions (e.g. hand-washing or checking-behaviour) or mental rituals (e.g. praying, counting or repeating words) that a person feels compelled to perform.
- ❑ are actions performed for the purpose of reducing discomfort or to avert some dreadful occurrence.

In some people with OCD there are no compulsive thoughts behind the actions, but they experience extreme discomfort if they are unable to perform their compulsive actions.

Most OCD sufferers know from common sense that their compulsive thoughts and compulsive actions are excessive or unreasonable – at least

some of the time. But when they are in the middle of a situation that triggers OCD, their compulsive thoughts often feel realistic and their compulsive actions often feel necessary. A minority of OCD sufferers are convinced that their thoughts are right and believe their compulsive actions are reasonable. They are unable to distance themselves rationally from their thoughts.

“ **I tried to control my compulsive thoughts, but the more I tried not to think of them, the more they filled my head. It was impossible to channel my thoughts, and I became more and more convinced that I was going mad.** ”

KATHRINE, AGE 24

OCD affects 2–3% of the population all over the world. The symptoms vary from person to person, and most find this condition has a major impact on their quality of life. Many OCD sufferers regard their compulsive thoughts and compulsive actions as absurd and embarrassing, so they are often embarrassed about revealing them to others. This is why some go around for years with compulsive symptoms that they keep hidden from other people. As a result, many OCD sufferers do not get the correct diagnosis and thus the right help.

OCD often begins in childhood or early adulthood. Approximately 80% develop OCD before the age of 25. Development of the symptoms is often gradual, with mild compulsive symptoms gradually increasing in their degree of severity. Other times, the symptoms occur suddenly, virtually overnight.

Many relatives and outsiders may find it difficult to understand that the OCD sufferer cannot just “pull himself or herself together” and stop performing the compulsive actions. But going against the compulsive symptoms often induces so much anxiety and discomfort that most people have given up the struggle by the time they come to be examined and treated.

ABOUT OCD

- 50,000 to 100,000 people in Denmark suffer from OCD.
- OCD affects just under 3% of all women and approximately 2% of all men. On average, symptoms in boys/men begin earlier than in girls/women.
- OCD is found in all age groups.
- The prevalence of OCD is more or less the same in all cultures and countries.
- OCD can be treated effectively with psychotherapy and medication.
- OCD becomes a chronic condition in some people.



WHY DO SOME PEOPLE GET OCD?

There is no straightforward explanation for why some people get OCD. The cause is often a complex interaction of different factors, including genes, innate susceptibility, and various types of stress and stressful events.

Factors in the brain

Today, OCD is regarded as a neuro-psychiatric disorder, in which a disruption of the brain's neurotransmitters, mainly serotonin, plays an important part.

Effective treatment shows a normalisation of this disruption. Brain scans show that certain areas and structures of the brain are frequently affected. In rare cases, OCD may be due to brain infections.

Genetic factors

Many OCD sufferers have a genetic predisposition to develop the disorder. There is a higher risk of developing OCD if someone in the family has it – especially if the disorder begins early. Some OCD sufferers have particular personality traits in the form of a strong sense of tidiness, accuracy or excessive caution. However, a lot of OCD sufferers do not have these personality traits.

Other factors

Although all the evidence points to OCD being predominantly a genetic, biological and neurological disorder, social and psychological factors are also involved. External stress factors, both positive and negative, can contribute to the development of the disorder, or to aggravating existing symptoms. For example, inappropriate patterns of communication or a negative atmosphere in the family may have the unfortunate effect of sustaining or directly reinforcing the compulsive symptoms. This is why it is often important to also involve social and psychological aspects in the treatment, and to involve the family and other key people.

“ If you give **OCD** an inch, it **will take a mile**. It was as if it was never satisfied, **and the compulsive actions** became more and more extensive and **prevented me**, ultimately, from doing **my work**. ”

ERIK, AGE 47

WHAT ARE THE SYMPTOMS OF OCD?

People with OCD exhibit many different compulsive thoughts and actions. Some OCD sufferers have one type of symptoms, but most have several different types, and the substance and nature of the compulsive symptoms can change over time. For this to be classed as OCD, the symptoms must involve suffering or affect everyday functions. Compulsive thoughts may have many different themes, and compulsive actions take many different forms. Here are some of the most frequent forms:

Compulsive thoughts about dirt and infection and compulsive actions in the form of hygiene and cleaning. There is usually an excessive fear of getting dirty, of becoming sick, or of accidentally spreading dirt or bacteria to other people. This often results in compulsive actions in the form of excessive hygiene or cleaning.

Habitually checking things is a type of compulsive action that may occur in virtually all types of compulsive thoughts. An OCD sufferer exhibiting checking-behaviour habitually checks specific things over and over again, e.g. door locks, electrical appliances, whether he/she has forgotten something,

whether any harm has come to other people, etc. For some OCD sufferers, this makes it almost impossible to leave the flat or house because they are unable to finish their checking rituals.

Compulsive thoughts of an aggressive or sexual nature. Many OCD sufferers are anxious about doing harm to other people or to themselves, either intentionally or negligently. Others are tormented by compulsive thoughts about committing sexual assaults. OCD sufferers who are tormented by these compulsive thoughts often try to avoid situations that trigger these thoughts. The vast majority have mental rituals, e.g. in the form of trying to control their thoughts, trying to force these thoughts out of their head, or other things. Many are afraid that they will act on their thoughts and many keep them secret because they are ashamed of thinking these thoughts.

Compulsive thoughts of a religious or moral nature. Here, the OCD sufferer is controlled by excessive, strict and rigid rules about what is right from a religious or ethical point of view. Often, the OCD sufferer tries to avoid even the tiniest deviation from these rules.

Hoarding or collecting-mania is characterised by the OCD sufferer's excessive collecting of things, or having difficulty throwing things out. For example, these could be things of sentimental value, or things they think they might need one day.

“ **The more I checked the stove, the more I doubted my senses. In the end, I could stand in front of the stove staring for a long time and still be in doubt about whether or not it was turned off.** ”

MARTIN, AGE 35

Compulsive thoughts about symmetry or accuracy are characterised by an excessive compulsion to arrange things symmetrically or in a particular order. Some people feel extremely uncomfortable if things are not arranged correctly. Others have compulsive thoughts about something bad happening to them personally or to their loved ones if things are not arranged correctly.

Annoying involuntary imaginings. Many OCD sufferers are tormented by intrusive unpleasant mental images or “inner films” with unpleasant image sequences.

Compulsive thoughts of a superstitious nature could be excessive avoidance behaviour or rituals associated with contact with superstitious phenomena, e.g. black cats, graveyards, particular dates, numbers, etc.

Somatic compulsive thoughts are excessive thoughts about physical illness that often result in the OCD sufferers excessively going to the doctor, checking their body for signs of illness or excessively seeking information online about the illness in question.

Repetitive rituals involve repetitions of ordinary, everyday actions, such as switching lights on and off, opening and shutting the door or going back and forth across the doorstep. Some repeat their actions a specific number of times; others repeat the actions until it feels right.

Mental compulsive actions are compulsive actions carried out in the OCD sufferer’s head, and which are not visible to the people around them. This could be saying prayers, reciting rhymes, trying to

suppress or change unwanted thoughts or counting-rituals.

Seeking affirmation is often used by OCD sufferers to obtain reinforcement from others that the things they fear will not happen, or that what they have done is good enough. They often ask the same questions over and over again, and this kind of compulsive action can be quite a burden on the relatives of the OCD sufferer.

Compulsive thoughts can also be about other subjects, and the compulsive behaviour can assume other forms than those referred to here. Almost any kind of thought or behaviour can develop into a compulsive symptom. Within the different types of symptoms, the disorder manifests itself in widely divergent ways in the individual.

Some OCD sufferers become socially isolated because it is difficult for them to be around other people. They might have to wash their hands many times a day and they are always unsure whether they have washed them thoroughly enough. Others have difficulty leaving the house because they are worried about doing things they are afraid of, or because they are afraid of revealing some of the compulsive symptoms they otherwise try to keep hidden.

“ **I was afraid** that if I told anyone about my thoughts of intentionally **harming other people**, they would distance themselves from me. **And I was afraid, too**, about whether I really was a violent person **when my thoughts were centred so much on violence** and rape. ”

RASMUS, AGE 42



“ I was very scared about starting medication, but a good chat with a doctor put to rest some of my preconceived ideas and fears. It helped a lot to know that the medication wouldn't change my underlying personality, that the medication would not lead to physical dependency and that any side-effects would cease when I tapered off the medicine. ”

CAMILLA, AGE 29

HOW IS OCD DIAGNOSED?

An OCD diagnosis is made based on in-depth discussions with a doctor or psychologist and examination of the person involved. Special questionnaires, prepared with a view to diagnosing OCD, are often used. In some cases, the person's GP can make the diagnosis. In other cases, it may be a difficult case that needs referral to a specialist in adult psychiatry, or to an outpatient psychiatric department with specialised knowledge of this field. The difficulties can be because the OCD sufferer finds it hard to talk about his/her symptoms, or because symptoms can vary so greatly

and may resemble symptoms of other mental disorders.

“ I went around believing I was a danger to those around me because of the content of **my thoughts**. So being diagnosed with OCD was a big relief. I discovered, first, that the compulsive thoughts were not **a sign I was going mad** or was dangerous, and secondly, that I was not the only one thinking thoughts like these. ”

OLIVER, AGE 18

WHAT TREATMENT IS AVAILABLE FOR OCD?

There are two types of documented, effective treatment for OCD: Psychotherapy in the form of cognitive behavioural therapy, and medication.

Doctors, psychologists and others with experience of treating OCD can decide what type of treatment is most appropriate. Before dismissing any option, it is important to get sufficient information about medication and cognitive behavioural therapy in order to be able to make an informed decision. In addition, it is important to remember that there is always a choice.

The person is never forced to go on medication or to undertake a course of therapy, and it is always possible to taper off the treatment.

Psychotherapy/counselling

Psychotherapy often takes the form of cognitive behavioural therapy. Cognitive behavioural therapy is the psychotherapy treatment for which there is the best documentation, and which is recommended for children, young people and adults with OCD. Some people will need supplementary medicine, while many OCD sufferers get good results from cognitive behavioural therapy.

The treatment usually starts with information about OCD. This part of the treatment is called psychoeducation and leads to a common understanding of obsessive compulsive disorder and the mechanisms that maintain it in an individual. It also introduces the thinking underlying the methods used in the treatment. It is important for the OCD sufferer to have some understanding of why the treatment is designed as it is, because effort is required to get the best out of the treatment.

At the start of the treatment, a list of problems and goals is prepared jointly with the therapist to establish a clear agreement about what to work towards.

In the treatment, the therapist works with a number of cognitive methods with a view to challenging the OCD sufferer's disaster mindset. During the sessions, the OCD sufferer works with the therapist to try out different ways of thinking, supported by small tasks to perform at home.

Other behavioural therapy methods are also employed for the purpose of challenging the inappropriate compulsive behaviour (compulsive actions, avoidance behaviour, etc.) that the OCD sufferer often becomes trapped in. Many find that their compulsive actions and avoidance behaviour are necessary in order to control the unpleasant compulsive thoughts and disaster mindset, to prevent dreadful things from happening or to reduce the unpleasantness. In fact, though, the compulsive behaviour contributes to reinforcing the compulsive thoughts and the unpleasantness, and thus maintains the symptoms.

The most important behavioural therapy methods for OCD are exposure and response prevention. During exposure, the OCD sufferer is exposed, gradually, cautiously and in small doses, to the things and situations that trigger compulsive symptoms. This is done in combination with response prevention, which means the person refrains from carrying out the compulsive actions. So the OCD sufferer learns that the anxiety or unpleasantness will fade away on its own without the need to engage in compulsive behaviour, and he/she gains personal experience of how excessive and unrealistic the disaster mindset really is.

Cognitive behavioural therapy is arranged jointly with you

Some OCD sufferers are afraid to seek cognitive behavioural therapy because they know it means exposure and response prevention. It is important to know that the therapy is always arranged collaboratively between the OCD sufferer and the therapist; that exposure is never forced; and that the therapist will never prevent the sufferer from engaging in compulsive behaviour.

Home assignments are a very important part of the treatment, as this is where the person transfers what has been learnt in therapy to his/her everyday life. This is why, from the very outset, the person needs to be prepared to set aside plenty of time for home assignments between sessions. Home assignments may include exposure and response prevention assignments or use of other methods.

The OCD sufferer's symptoms may have a major impact on other people, and

often the family or other people close to the sufferer become actively involved in the compulsive actions. Often, therefore, it is important to involve the whole family, spouse or other people close to the sufferer in the treatment.



I was afraid of cognitive behavioural therapy because I had seen on TV that it involves exposure and response prevention. But I discovered it was 100% up to me how far I wanted to go and at what pace.



KIM, AGE 20

Treatment with medication

Cognitive behavioural therapy is usually recommended as the first choice in the treatment of OCD. However, in more severe cases of OCD, or where cognitive behavioural therapy has not been effective enough, it may be necessary to combine counselling with medication.

In the main, antidepressants are used and are effective in the treatment of OCD. This medicine was originally developed to treat depression. The most commonly used types are selective serotonin reuptake inhibitor (SSRI) drugs. The name is derived from the chemical effect of the substance. There are several different types of SSRI drugs, and if one drug is not sufficiently effective, or has unacceptable side-effects, there may be good reason to try a different drug. In addition to SSRI drugs, an older type of antidepressant, chlomipramine, is also used in the treatment of OCD. Sometimes, the addition of a small dose of anti-psychotic medicine can be effective when combined with an anti-depressant.

Unfortunately, it can take a long time for the medication to work. It requires patience to wait for the effect of the treatment, but it is important to try one drug thoroughly before possibly switching to a different one. It is also important to take a sufficiently high dose.

Medication rarely results in the OCD symptoms disappearing altogether, but many report that their compulsive thoughts become less intrusive, and the urge to engage in the compulsive behaviour is reduced.

Some, but by no means all, experience side-effects from the medicine. Many side-effects disappear after a few weeks of treatment, and the remaining side-effects are usually mild.

However, some people do experience persistent side-effects, and in these cases, switching to a different drug may be necessary. Any side-effects disappear when the person comes off the medication, and none of the SSRI drugs, antidepressants or anti-psychotic drugs lead to physical dependency.

MOST FREQUENT SIDE-EFFECTS

- Headaches
- Nausea
- Insomnia
- Tiredness
- Reduced libido
- Weight gain

If the medication is effective, it is advisable to continue with it for at least six to twelve months after there has been an improvement, after which the medication can be gradually tapered off under the supervision of the doctor. It is important to taper off the medication under the supervision of a doctor and over a period in which the person is doing well and is not exposed to external stresses.

Some people experience a relapse when tapering off the medication, and at that point it can be an advantage to be familiar with the cognitive behavioural therapy methods and tools so that these can be used if there are signs of a relapse. Some people may need life-long medication.

WHAT CAN YOU DO YOURSELF IF YOU ARE SUFFERING FROM OCD?

- Realise that you are not alone. Approximately one person in 50 suffers from OCD worldwide. You can meet other people who have OCD through the Danish OCD Association, for example.
- You are not going mad, and there is nothing shameful about having OCD. Unfortunately, many people are embarrassed about their symptoms and try to conceal them from those around them; that is a pity, because OCD is treatable.
- Learn to recognise your illness. Many have a false impression of the causes and maintenance mechanisms of the disorder. This can lead to attempts to combat the compulsive symptoms instead serving only to aggravate them.
- Seek treatment. There are effective forms of treatment available today, so do not live with untreated OCD. Remember: you will never be forced to start taking medication or to undergo exposure and response prevention. Before ruling anything out, make sure you have been given sufficient information about both medication and therapy so you can make an informed choice.
- Be open and honest with your therapist. It is important that you speak completely frankly and openly about your symptoms to your GP/psychologist in order to secure the best treatment.
- Follow the treatment – even if, especially at the start, the side-effects of the medication can be bothersome, and even if cognitive behavioural therapy may be unpleasant for a while.
- Try to be active and participate in activities with other people. The more you confront your own anxieties and try to prevent yourself from carrying out compulsive actions, the more control you will gain over your symptoms.

WHAT CAN RELATIVES DO?

It can be useful for relatives to learn about OCD because this helps explode any myths and avoid a feeling of guilt, self-reproach, and reproach from the OCD sufferer. It is important to remember that compulsive symptoms have nothing to do with a lack of willpower. It can be a great relief to think of OCD as an uninvited guest that no one, not even the OCD sufferer, has invited in.

It is important for you, as a relative, not to become involved in the OCD sufferer's compulsive thoughts and compulsive actions and not to adapt your own behaviour to the disorder. Accommodating behaviour by relatives, like the OCD sufferer's own compulsive actions, helps to maintain and reinforce the disorder. Instead, try to focus on normal things in the time you spend with the OCD sufferer in order to reduce the impact of the compulsive symptoms.

As a relative, you can support the OCD sufferer by encouraging him/her to seek treatment. Some OCD sufferers do not want to recognise that they have a problem or refuse to get treatment. In that case, you have to accept that that is their own choice, and that you yourself must try to lead as normal a life as possible. You cannot force someone to go for treatment, but as a relative, you can stop your own accommodating behaviour so that you are not unwittingly a part of the maintenance mechanisms of the disorder.

If the OCD sufferer has children who are affected in one way or another by the parent's OCD, give the child as much help as possible so that he/she is affected as little as possible. Perhaps involve a professional such as a doctor or psychologist who might be able to support the child.

It is important to look after yourself and take care of your own needs. It can be a challenging experience being close to someone who suffers from OCD. Compulsive symptoms often directly or indirectly affect friends and family, and it can be unpleasant and frustrating to witness someone you care about suffering. Maintain as normal a routine as possible, and continue to lead your

KEY FACTS

- OCD is a disorder with compulsive thoughts and/or compulsive actions.
- Most OCD sufferers have several different compulsive symptoms.
- OCD often begins in childhood or adolescence.
- Cognitive behavioural therapy is the first choice of treatment.
- The effectiveness of medication (SSRI drugs) is well documented.

own life, with normal activities and social relationships. If you, as a relative, do not look after yourself, there is a danger that you will develop a stress reaction or depression requiring treatment. If this is the case, seek professional help.

Some people may benefit from talking to other relatives. This can be arranged through the Danish OCD Association and other patient associations that provide networking groups for OCD sufferers and relatives alike.



“ Ultimately, my son’s OCD governed everyday life for the whole family. Everyone was forced to comply with the OCD’s rules of excessive hygiene, which resulted in a lot of arguments. But we didn’t feel like we had any choice, as my son felt so awful if the rules were not followed. ”

JANNI, AGE 48 – PARENT OF A SON WITH OCD

About the quotations

All quotations are fictitious.

About the fact box

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Where can you find **MORE INFORMATION** ?

📄 psykinfomidt.dk

Here you will also be able to find articles on psychiatric diagnoses in various languages

📄 ocd-foreningen.dk

📄 psykiatrifonden.dk

Scan the QR code to access more facts about OCD in adults, useful links, videos, books, etc.



