

OCD hos børn og unge, engelsk

For parents and young people

Information about

OCD IN CHILDREN AND YOUNG PEOPLE

The disorder, its treatment and prevention



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Approximately 100,000 people in Denmark are affected by OCD. Knowledge of OCD is important if you or a relative have the disorder. The more the person knows, the better he or she will be able to cope with it and avoid relapses.

This brochure describes OCD as well as the scope for its treatment. It is mainly intended for young people being treated by the psychiatric service in Region Midtjylland and for the parents of children and young people who have been diagnosed with OCD.

The psychiatric service in Region Midtjylland offers both outpatient and inpatient treatment.

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

Kind regards

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WHAT IS OCD?

OCD is an abbreviation for obsessive-compulsive disorder. It affects 1–2% of children and young people all over the world. OCD manifests itself in the same way in children, young people and adults, and the compulsive symptoms are more or less the same. OCD is characterised by recurring compulsive thoughts and/or 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 anxiety or a feeling of 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.

OCD is a mental disorder, as OCD sufferers are generally able to recognise the absurdity of their compulsive thoughts.

Nevertheless, they feel totally controlled by them, because the symptoms often have a disruptive effect on their everyday life and can lead to great anxiety.

Most children and young people as well as adults who suffer from OCD experience both compulsive thoughts and compulsive actions.

Compulsive thoughts, as already stated, are thoughts that constantly force their way into a person's awareness. These thoughts are very unpleasant and extremely troublesome. Most children and young people with OCD recognise that their compulsive thoughts and compulsive actions are

ABOUT OCD

- ❑ Approximately 50,000 children and young people have OCD.
- ❑ OCD affects equal numbers of boys and girls.
- ❑ OCD can be seen in children, young people and adults.
- ❑ 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.

“ The nasty thoughts were stuck there in my head. They felt like glue on my brain. ”

FREDERIK, AGE 9 – ABOUT HIS COMPULSIVE THOUGHTS



extreme or unreasonable, and they will try rationally to distance themselves from them.

Some, especially younger children, are not fully able to take a rational step back from these thoughts.

Compulsive actions, as already stated, are actions that have to be performed in a very particular way or according to a particular ritual pattern. Underlying these actions is often a compulsive thought that by per-

forming these actions, the person will be able to avert a disaster that he/she fears will happen otherwise. In some children with OCD – especially the younger ones – there are no compulsive thoughts behind the actions, but these children, too, experience extreme discomfort if they are unable to perform their compulsive actions.

The symptoms of OCD vary from person to person, and for most children and young people, the disorder has a major impact on their everyday life and quality of life.

WHY DO SOME CHILDREN AND YOUNG PEOPLE GET OCD?

There is no straightforward explanation of why some children and young people get OCD. Often, many different factors are involved – such as genes, inherent vulnerability and various types of stress and stressful events.

WHAT HAPPENS IN THE BRAIN OF SOMEONE WHO HAS OCD?

Today, OCD is regarded as a brain disorder where a disruption of one of the brain's neurotransmitters, mainly serotonin, plays an important part. When treatment is effective, it is possible to observe from brain scans that the neurotransmitter has changed from a state of disruption back to normal. As yet, however, little is known about how psychological and biological aspects in the brain interact with OCD.



HEREDITY

Many children and young people with OCD have a hereditary predisposition to develop the disorder. There is a higher risk of developing OCD if someone in the family has it. Often, one or more family members have similar compulsive symptoms or symptoms similar to these.

Some children and young people with OCD display particular personality traits such as a distinct sense of tidiness, accuracy or exaggerated caution, but a large proportion of children and young people with OCD do not have these traits.

SOCIAL AND PSYCHOLOGICAL FACTORS

Social and psychological factors have the unfortunate effect of sustaining compulsive symptoms or may even directly reinforce them. There might be stressful situations at school, e.g. bullying, traumatic experiences such as a death or serious accident, or a negative atmosphere in the family, such as arguments. 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.

OCD used to be considered a relatively rare condition. Many OCD sufferers regard their compulsive thoughts and compulsive actions as absurd and awkward, so they are often embarrassed about revealing

them to the people around them. This is why many have lived with their symptoms for a long time before they get treatment for the disorder.

Many children and young people with OCD perceive their compulsive thoughts as bizarre and perhaps incomprehensible to other people. This causes them to act very surreptitiously. Thus, it is quite typical for children and young people with OCD to keep their symptoms hidden. When they come for treatment, in many cases only they themselves and their immediate family (parents and possibly siblings) know about their symptoms and know how they have been affecting the OCD sufferer and his or her family's everyday life for a long time.

HOW DO COMPULSIVE SYMPTOMS START?

Symptoms can start suddenly, often between the ages of 8–10 or 14–15, or in early adulthood. In some people, the symptoms can be more insidious, beginning with just a few daily rituals and gradually developing into more and more compulsive actions.

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 many children and young people have given up the struggle by the time they come to be examined and treated.

WHAT ARE THE SYMPTOMS OF OCD?

Many children and young people with OCD 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 picking up an infection, doing things they are afraid of, or because they are afraid of revealing some of the compulsive symptoms they otherwise try to keep hidden.

Children and young people with OCD exhibit many different compulsive thoughts and compulsive actions. Most of them have several different

“ **The OCD tells me that the bad bacteria will spread – both on my body and to everything I touch – if I don’t wash thoroughly and more or less constantly ...** ”

DAVID, AGE 15

compulsive thoughts, and the content and nature of these compulsive symptoms can change over time.

Anxiety about illness and death

The most common compulsive symptoms are anxiety about dirt and infection and rituals that involve excessive hand-washing or showering. Here, the OCD sufferer’s thoughts constantly revolve

around the danger of falling ill with cancer or AIDS, for example. Another frequent compulsive symptom is checking rituals in the form of checking-behaviour. A child or young person suffering from OCD with checking rituals has to keep checking particular things over and over again, e.g. whether there is water running in the bathroom, whether the light in the basement is switched off, or whether the oven has been left on. Checking rituals make it almost impossible for some children and young people to leave the house because they are unable to end their checking rituals.

Some OCD sufferers have compulsive thoughts about death or anxiety about harming other people or themselves. Some are bothered by compulsive thoughts and mental images of attacking or killing somebody close to them.

“ Although, deep down, I knew my family would not really become ill and perhaps die if I didn't perform my rituals, I felt compelled to perform them – just to be on the safe side. ”

ISABELLA, AGE 13

Mental rituals

Some OCD sufferers perform mental rituals. Mental rituals are compulsive actions performed in the person's mind, and thus are not visible to other people. Mental rituals may take the form of counting mania, where certain things around the person have to be counted, or having to recite particular words or rhymes to oneself. Mental rituals can be just as disruptive as visible compulsive actions.

They are often more difficult for relatives to spot, as the visible signs of mental rituals may simply be impaired ability to concentrate, irritability, tiredness or the person feeling down. Symptoms of mental rituals in children and adolescents may manifest themselves in difficulty in dealing with their schoolwork – because they may feel compelled to read things over and over again, and because they have to perform various rituals before they can proceed with their homework.

THE MOST COMMON COMPULSIVE ACTIONS

- ❑ Washing rituals
- ❑ Checking-behaviour
- ❑ Repetitive rituals
- ❑ Compulsion to organise and arrange things.

MOST FREQUENTLY OCCURRING COMPULSIVE THOUGHTS

- ❑ Dirt and infection
- ❑ Anxiety that something dreadful will happen
- ❑ Fear of illness
- ❑ Fear of death
- ❑ Compulsion for symmetry
- ❑ Fear of sex
- ❑ Religious thoughts
- ❑ Fear of harming oneself or others.

Compulsive actions involving symmetry or accuracy

The compulsive actions of some OCD sufferers relate to symmetry. They want things around them to be arranged in a very specific way, or they have to do things a specific number of times.

As previously mentioned, children and young people may keep their OCD symptoms hidden from the people around them to a certain extent, and “save the symptoms up for later”. This phenomenon can be seen, for example, during hospitalisation, or when an OCD sufferer has to go away on a camping trip or on holiday. In everyday life, the OCD sufferer often does not exhibit distinct symptoms of OCD during school hours. Back home, on the other hand, the symptoms flare up tremendously. Often, children and young people say they have kept a careful internal record of the compulsive actions they still have “on account” when they get home from school or their studies.

What symptoms are usually evident at home?

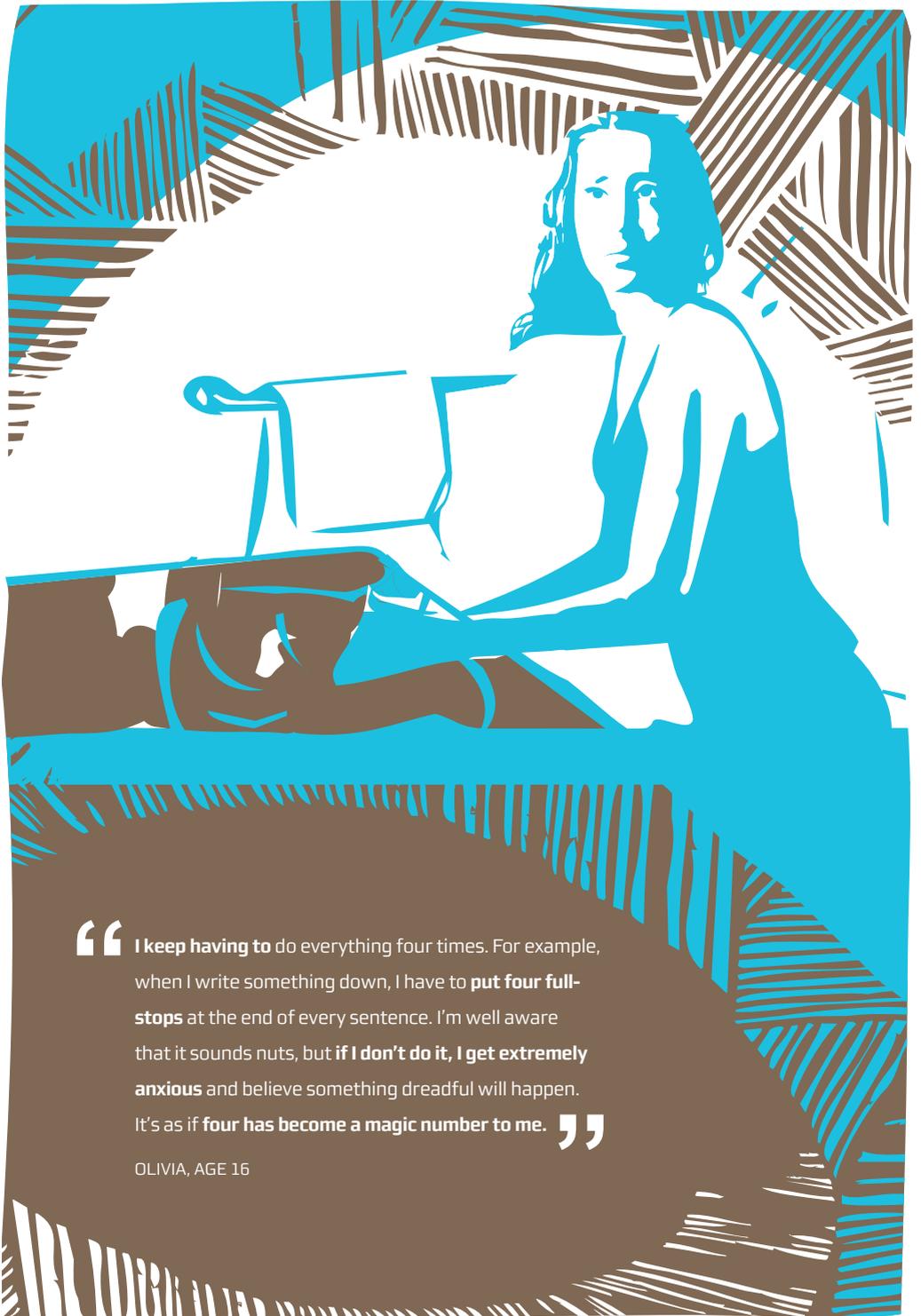
- ❑ The child performs lengthy rituals (e.g. hand-washing or showering).
- ❑ The child exhibits avoidance behaviour, i.e. avoids certain places in the house and avoids touching certain things.
- ❑ The child seeks isolation.
- ❑ The parents are repeatedly asked by the child whether he/she has done things correctly.
- ❑ The child is afraid and sad.

- ❑ The child goes into a rage and becomes desperate and anxious if prevented from performing his/her compulsive actions.
- ❑ The child often involves his/her parents in the rituals.
- ❑ The child is unable to concentrate on homework, books or films.

What symptoms are usually evident at school?

- ❑ Possibly no symptoms, as many children with OCD are able to conceal the symptoms and are embarrassed to reveal them.
- ❑ The child may need to leave lessons more frequently because of the hand-washing compulsion.
- ❑ The child may have difficulty concentrating in class because of compulsive thoughts.
- ❑ The child avoids touching others or things belonging to others.
- ❑ The child seems tense and sad.
- ❑ The child reacts violently if anyone gets in the way of his/her need for tidiness.

Children and young people often have a great need to involve their parents in their rituals. To some extent, this may be because the child needs parental assurance that he/she is good enough or has done things well enough during the day. Often, though, the parents are more directly involved in the child's rituals. For example, the parents have to say yes or no in a very specific way when the child asks numerous questions in the evening. The mother has to open and shut doors before and after the child has washed his/her hands, bring a towel, etc.



“ I keep **having to** do everything four times. For example, when I write something down, I have to **put four full-stops** at the end of every sentence. I’m well aware that it sounds nuts, but if I **don’t do it, I get extremely anxious** and believe something dreadful will happen. It’s as if **four has become a magic number to me.** ”

OLIVIA, AGE 16

HOW IS OCD DIAGNOSED?

In children and young people with typical OCD symptoms, diagnosis is generally not too difficult. Both examination and the initial treatment are usually handled by a specialist in child and youth psychiatry or by a psychologist with expertise in OCD. The diagnosis is made against the backdrop of the severity of the compulsive symptoms, based on an in-depth

interview. Often, both the child and the family are given specific questionnaires to fill in. These are designed to assist with the diagnosis of OCD and shed light on the particular compulsive symptoms the child/young person has, how much strain they impose on the person's everyday life, and the degree of anxiety associated with the symptoms.

WHAT TREATMENT IS AVAILABLE FOR OCD?

Psychotherapy in the form of cognitive behavioural therapy and medication.

Psychoeducation

Psychoeducation, including stress relief, etc., is particularly useful for children and young people with OCD. At the start of a course of treatment, it is important to provide information about OCD and to offer training in all matters relevant to OCD, both to the OCD sufferer and to close relatives. This step of the treatment is called psychoeducation and enables the OCD sufferer and his/her family to find better ways of tackling the disorder in daily life. During this part of the treatment, a decision will also be made as to whether the OCD sufferer needs to be relieved of some of the things that can cause stress (schoolwork, weekend job, etc.) for a while. It also provides

an opportunity to discuss the important matter of which individuals in the network of the child or young person need to be informed about the OCD symptoms.

Apart from this, the treatment will usually comprise the following elements:

- ❑ Cognitive behavioural therapy
- ❑ Possibly medication
- ❑ Possibly a follow-up appointment.

Cognitive behavioural therapy

The key treatment for OCD in children and young people is cognitive behavioural therapy.

Cognitive behavioural therapy is the psychotherapeutic treatment for which there is the best documentation, and which is recommended for children, young people and adults with OCD.

The same treatment principles are used for children and young people as for adults. The treatment is a combination of cognitive therapy and exposure with response prevention. Obviously, the course of therapy is tailored to the age and level of cognitive functioning of the child. Like adult OCD patients, children and young people with OCD can learn to recognise their automatic thoughts and develop more constructive cognitive strategies. Accordingly, the child's age, maturity, resources and cognitive skills will be decisive when it comes to the choice of therapeutic approach.

Cognitive therapy works with the child's thoughts, emotions, behaviour and his/her bodily sensations, as OCD sufferers tend to think about impending disaster. During the sessions, the OCD sufferer works with the therapist to try out different ways of thinking and acting, supported by small tasks to perform at home.

In giving behavioural therapy treatment, the therapist uses exposure techniques. This means the OCD sufferer is exposed to situations that will give rise to compulsive thoughts, and the urge to perform compulsive actions will increase. In these situations, attempts are made to change the OCD sufferer's behaviour by actually exposing the person to what he/she is afraid of – gradually, cautiously and in small doses. Next, response prevention is applied, in order to practise not performing the compulsive action. Based on the OCD sufferer's symptoms, the child and the therapist will usually establish a hierarchy and jointly produce a programme specifying which symptoms to tackle first.

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. Generally speaking, therefore, it is important to involve the whole family, or other people close to the sufferer, in the treatment.

The basic principle in tackling the rituals is to challenge and confront the anxiety in bite-sized pieces – from the least to the most anxiety-inducing situations. This could, for example, be a reduction in hand-washing in terms of number of times or duration.

Treatment with medication

For milder cases of OCD, cognitive behavioural therapy may typically be used on its own, but for more severe cases of OCD, medication may often be necessary as a supplement to the behavioural therapy. Medication can never be used as a stand-alone treatment but should always be combined with behavioural therapy.

Medication alone does not usually lead to the compulsive symptoms stopping, but the symptoms will usually be reduced by around 25–45%. Approximately three-quarters of children and young people with OCD experience some degree of improvement via medication. For the majority of OCD patients, the effect only kicks in a number of weeks following medication. This is why treatment efforts will mostly continue for at least 12 weeks to make sure the dose is sufficient.

Some people experience side-effects, especially at the start of the treatment.

Most side-effects disappear after a few weeks on medication. The ideal dose of the medication differs from person to person. Many side-effects are most pronounced at the start, and often disappear once the body has become accustomed to the substance. Any persistent and unacceptable side-effects will always disappear when the person stops taking the substance.

In connection with medication, it is important to have check-ups with your GP or a psychiatrist. If the effect is insufficient or if there are a lot of side-effects, it will often be possible to find a different drug that is more effective and has fewer side-effects.

The psychiatrist or GP will usually recommend continuing with the medication for at least six to twelve months after there has been an improvement, after which the medication can be gradually tapered off as agreed with your doctor. It is important to taper off the medication as agreed with a doctor and over a period in which the child/young person is doing well and is not exposed to external stresses.

What can you do yourself if you are a young person with OCD?

- ❑ You should know that you are not alone. At any given school, there will generally be a number of people with OCD.
- ❑ There is no shame in having OCD – not even when OCD takes control of your actions.
- ❑ It is completely natural to feel embarrassed about your OCD symptoms, and to find it difficult to talk about them initially, perhaps.

- ❑ Talk to your parents or a close friend about the thoughts that are oppressing you, and seek help.
- ❑ Be open and honest with your therapist. In order for your therapist to give you the very best help, it is important for you to tell him/her as much as you can about your compulsive symptoms.
- ❑ Follow the course of treatment. Although it may be difficult at times, it is important, as far as you possibly can, to participate in the treatment and to keep to the agreements your therapist makes with you and your parents. You also need to accept that, in order for your parents to give you the best possible help, they must try to avoid helping you with your rituals; instead, they need to support your OCD-free, healthy side.
- ❑ Try to be active and, as far as possible, participate in activities with other people. The more you do the things you enjoy doing in the company of others, the more you will overcome your compulsive symptoms in everyday life.

MOST FREQUENT SIDE-EFFECTS

- ❑ Headaches
- ❑ Nausea
- ❑ Insomnia
- ❑ Tiredness
- ❑ Sexual side-effects in the form of reduced libido.

WHAT CAN YOU, AS PARENTS, DO?

Being the parent of a child who suffers from OCD can be a challenging experience. It is important to remember that compulsive symptoms have nothing to do with a lack of willpower. As parents, you can support your child by encouraging him/her to seek treatment. It is important for you not to become involved in your child's compulsive thoughts or compulsive actions, as that would only reinforce the symptoms. Instead, try to focus on normal things in the time you spend with your child in order to reduce the impact of the compulsive symptoms. For boyfriends/girlfriends, siblings and other people close to the sufferer, it can be very difficult to discern

when to offer support and when to resist, when to help and what the OCD sufferer is able to cope with alone.

When you have a vulnerable child, there may be a tendency to think the best way of offering support is to "remove all the obstacles from the child's path". However, in doing this, you risk robbing the child of the possibility of tackling his/her own problems and developing good personal problem-solving strategies. It is not uncommon for two parents to react differently to the pressure exerted by OCD. This can create additional family problems in the form of arguments and relationship problems for the couple.



ADVICE FOR PARENTS

- ❑ Try to find out what your child is thinking. Your child will probably keep some thoughts secret in order to protect you or because your child thinks they are too embarrassing.
- ❑ Try to gain an impression of the extent to which compulsive thoughts take up your child's day.
- ❑ Find out whether your child is able to resist the symptoms. Does your child have any strategies for combating OCD?
- ❑ Help your child to try to resist the symptoms by gradually reducing the extent of them, e.g. with fewer

hand-washings, and by trying to distract your child by doing enjoyable, entertaining things together.

- ❑ If you have become involved in your child's rituals, you must slowly and cautiously try to extricate yourself. Avoid getting caught up in your child's rituals; instead, try to explain to him/her that the best way to regain control over his/her thoughts is to resist the rituals.
- ❑ Talk to your child every day and agree fixed times for talking about how things are going with the disorder, so that OCD does not completely dominate your time together.

KEY FACTS

- ❑ OCD is a disorder with compulsive thoughts and compulsive actions.
- ❑ Most children and young people with OCD have many 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.

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

📄 ocd-foreningen.dk

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