



## OCD? parents guide

#### What is OCD and whom does it affect?

OCD (obsessive-compulsive disorder) is an anxiety disorder characterised by unwanted and repetitive thoughts (obsessions), and actions carried out by the sufferer in an attempt to rid themselves of the anxiety caused by those thoughts (compulsions). It can range from mild to severe, and takes many different forms.

When children are troubled by their obsessional problems they can experience very high levels of anxiety and distress, and they can find the problem takes up a lot of their time and attention.

Research studies have estimated that between 1.9% and 3% of children suffer from OCD, so if you think of a typical secondary school with 1,000 pupils, between 19 and 30 of them may have OCD. The illness will affect children from all types of social and ethnic background, with no one social group more or less vulnerable to it.





## Why have we produced this guide?

OCD can be a terrifying illness, even for adults, and young sufferers may feel that they are going mad or that they are the only one who feels this way. It can certainly be overcome, but sufferers often need a great deal of support, both from friends / family and health professionals.

Many parents of OCD sufferers are often unaware of how best to help their child. The illness can be very confusing for all involved and can put a strain on family relationships.

Teachers at school or college might notice that something is not quite right but may be unsure of how to approach the subject.

Sometimes OCD behaviours might be minimal and considered to be childhood habits that your child may eventually grow out of.

Our intention is that this guide will help to clarify information about OCD symptoms and treatments, as well as offering hope and encouragement for those affected by this very treatable disorder.



## OCD? parents quide

#### What symptoms should I be looking out for?

Only a medical professional will be qualified to diagnose your child as suffering from OCD. But there are signs to look out for that might give you an indication that they may be suffering from OCD, such as:

- a desire to have their room tidied in a particular way, with everything perfectly aligned
- repetitive hand-washing or prolonged, repeated showering / bathing
- worrying excessively about their handwriting and neatness of their schoolwork
- worrying about harm coming to loved ones, such as parents, siblings, friends or pets
- going to extreme lengths to protect the family home by repeatedly checking locks and taps
- feeling the need to count whilst they perform certain tasks, sometimes in multiples of a particular number
- refusing to let go of or discard seemingly useless or old items
- worrying excessively about becoming ill or catching specific diseases

There is an almost infinite number of OCD 'themes'; those listed above are just some of the most common.







#### Which are the obsessions and which are compulsions?

Obsessions are the initial thoughts that cause anxiety, and compulsions are the actions or rituals (which can be mental or physical) carried out by the sufferer to try to alleviate the anxiety and discomfort.

The list below offers some examples of commonly-occurring obsessions, with possible compulsions in brackets:

- my hands are dirty and covered with germs that will make me or other people ill (repetitive, often ritualistic, hand-washing)
- I might push my little sister off the swing in the playground (avoidance of being alone with the sister; repeated questioning of her and others to ensure that she is safe and well)
- if I don't have a perfectly-ordered bedroom then something bad will happen (excessive tidying / cleaning of their room)
- I might have forgotten to switch the lights off when I left a room and they
  could spark and cause a fire, which might kill my family and it would all be
  my fault (repetitive checking of light-switches to ensure that they are
  switched off; asking other people to check because the sufferer does not
  trust their own judgment)
- I might have offended somebody today or done something wrong ('confessing' perceived wrong doings; requesting reassurance that nothing is wrong)
- someone may break in and steal my mum and dad's possessions or attack them (constant checking that doors and windows are locked and asking for reassurance that other people check the doors and windows are secure)

I feel I may have touched a younger child inappropriately (avoidance of being around very young children; seeking reassurance that the sufferer did not brush past or touch nearby children if in busy shopping centre; the sufferer will be plagued by unwanted and repulsive obsessive thoughts that they had inappropriately touched the child as they passed)

Compulsions can also be mental rather than physical which can make them much more difficult for other people to notice. For example, a sufferer may repeatedly run through past events in their head in an effort to check that they did not harm anyone. They might also count to a certain number in their head because it makes them feel safe.

## OCD? parents guide

## What should I do if I think my child has OCD?

If you think your child may have OCD then the first thing to do is to speak with their GP (if they are a young child). With older children / teenagers, they might wish to speak with their GP alone, but you should encourage them to seek help. Whilst awareness of OCD is gradually increasing, there are unfortunately still some GPs who have a very limited knowledge of the illness.

OCD-UK have created a GP 'Ice Breaker' which you may wish to print off our website and pass to the GP, it explains what OCD is, and that you know your child needs to be diagnosed and offered treatment of Cognitive Behavioural Therapy (CBT).

The GP can then arrange a referral to your local Child and Adolescent Mental Health Services (CAMHS). Here you and/or your child will be able to discuss their symptoms with a health professional in your area, who knows how to diagnose and treat OCD.

Early intervention is vital; there is considerable proof that the sooner OCD is identified and treated, the more chance there is of a better recovery.





#### What are the recommended treatments for OCD?

The treatment regarded as best for OCD is called CBT (Cognitive-Behavioural Therapy). This is a 'talking' therapy which aims to help the child challenge their unhelpful beliefs and to give them the tools necessary to combat their OCD. We know from previous research that CBT can help people who suffer from OCD.

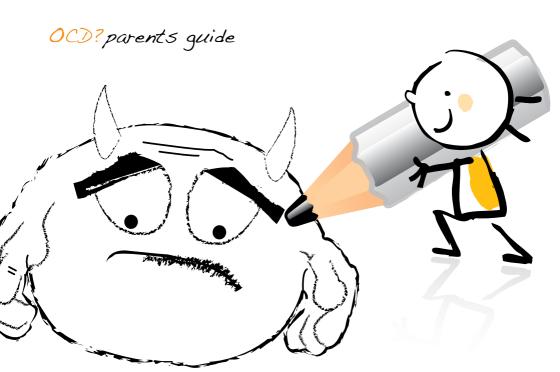
When people do CBT they learn how thoughts, feelings and what they do are connected. They also learn how to deal with upsetting thoughts and feelings. The CBT practitioner will spend time talking to your child about their OCD (and they may also ask to speak with you, particularly if it is a young child involved or the child is reluctant to talk openly about it). They may then, with the sufferer's help, create a hierarchy of OCD fears – this involves putting the OCD fears into order according to how much anxiety and distress they cause. The therapist should help your child to face the least distressing fears first, gradually working up to the more challenging ones.

Exposure and Response Prevention (ERP) should also form part of CBT treatment. This involves your child being exposed in a very structured way to what makes them feel anxious, and not carrying out their compulsive rituals after exposure.

Whilst the therapist will guide and challenge the child, they should never force them to do anything they feel unable to.

Your child may also be set homework in between sessions, such as keeping a diary of their anxiety levels or trying to cut down on particular compulsions, e.g. if they usually wash their hands three times before eating then they might be asked to reduce that to two times. Depending upon the child's age and understanding of OCD, it might be appropriate for one or both parents to assist them with this





Very young children may be told to imagine their OCD to be a bit like a bully, trying to get them to do things they don't want to and part of their homework may be to draw a picture of what they think their OCD bully looks like. It can be helpful to refer to the OCD as the bully, so your child does not feel they are to blame for their OCD. Please do send us a copy of your child's OCD bully drawing for publication in our children's OCD magazine.

It may also help to prepare yourself for the possibility of your child disclosing symptoms of which you were unaware. It may be helpful to remember that OCD can have many symptoms. When children and young people first feel able to describe symptoms, remember that these are OCD. Intrusive thoughts often contain the sufferer's most feared and dreaded thoughts and as a result their very nature may involve fears connected with crime, violence or sexual content. Remaining calm and accepting will help encourage your child to talk openly.

Facing up to OCD can be scary. Children and teens may naturally be apprehensive about resisting or not completing rituals. It may be helpful to remind the sufferer of what they are hoping to achieve out of CBT. Keeping the target in sight may help young people to remain focused on recovery. When learning any new skill, practice and persistence are key ingredients. CBT requires dedication from the sufferer and support from the family. Very young children may need CBT techniques adapted into more child-friendly activities.

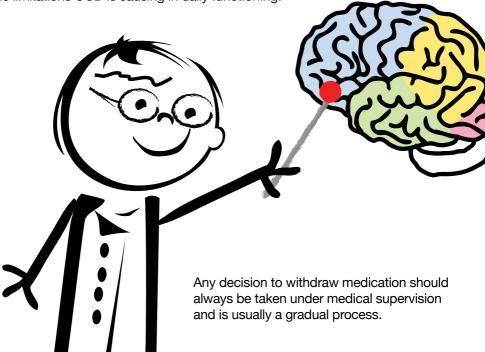


#### Medication

Medication may also be offered, usually in the form of an SSRI (Selective Serotonin Reuptake Inhibitors) anti-depressant medications; which can help to reduce the sufferer's anxiety, this may then help them feel more able to engage with CBT. As with CBT, medication takes time to have an effect and results may not be immediate. Depending upon the individual, alternative medication from within the SSRI group may be needed if benefits are not seen within certain time limits. It is not unusual to try more than one drug to find the most suitable for the individual.

Side effects are also a possibility which some patients experience, although most are mild and short-lived. It is impossible to predict how the individual will react and this should be discussed with the prescribing doctor.

Many parents may feel apprehensive about allowing their youngster to take antidepressant medication. It is important to remember that this drug group is used because of the beneficial effects on serotonin levels in the brain, rather than to 'drug' the child. This medication can be invaluable where the sufferer also shows symptoms of depression as is sometimes the case with OCD sufferers. Talk over your fears with the prescribing doctor. Your concerns should be treated with respect and understanding. It can often help to weigh up the benefits or negative aspects of any medications in comparison to the limitations OCD is causing in daily functioning.



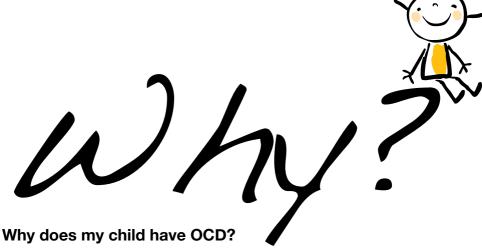
# OCD? parents guide

In practice, your child may be offered drug treatment straightaway because of a waiting list for CBT in some parts of the country.

The National Institute for Health and Clinical Excellence (NICE) and the National Collaborating Centre for Mental Health launched their set of clinical guidelines for the identification, treatment and management of Obsessive Compulsive Disorder for children and adults on 23rd November 2005. NICE is the independent organisation responsible for providing national guidance in England and Wales on the promotion of good health and the prevention and treatment of ill health. Clinical guidelines are recommendations on the appropriate treatment and care of people with specific diseases and conditions within the NHS in England and Wales. They are based on the best available evidence. Guidelines are produced to try to help healthcare professionals in their work.

The NICE guidelines are important and useful tools for parents whose children have OCD because they provide a standard which every NHS trust must implement in the treatment of OCD, and helps you gain a clearer understand of what treatment your child should be receiving.

If you would like a copy of the NICE guidelines you can view them online, or order a copy by calling the NHS Response Line or contacting OCD-UK and asking for: N0920 Information for the Public.



OCD is neither a character flaw nor a sign of weakness. It also does not mean that the sufferer had a bad childhood or that you are poor parents. Scientists believe that a combination of physiological and environmental factors lies behind OCD, but there is no cast-iron answer as to why some people develop OCD whilst others do not; it is certainly nobody's fault.



#### My child's OCD is not constant - what should I do?

OCD symptoms can wax and wane, usually in conjunction with stress at home / school or other traumatic life events. It is also common for symptoms to change; for example, a child who previously obsessed over cleanliness might start worrying obsessively about symmetry.

It is important to remember, though, that regardless of the actual obsessions and compulsions, the cause is the same – OCD. Essentially it does not really matter what the actual symptoms are, as the treatment should focus on challenging the obsessional thoughts and on how the child should deal with them.

# I have heard that 'reassurance' is unhelpful in fighting OCD; what is it and why should I avoid it?

'Reassurance' is a term often used which means 'accommodating' the OCD, i.e. giving in to it, going along with it and following its demands. For parents it is often so difficult to decide how to support the sufferer whilst at the same time not supporting the OCD.

When a sufferer is really struggling with their OCD and is distressed, it is a natural reaction for a parent to want to stop that pain. It is easy to say, "no, your hands are clean and do not need washing again," but the danger is that the next time an obsession comes the sufferer will look to the parent for reassurance, rather than trusting their own instincts and standing up to the OCD. It would be better for the parent to ask the child to think themselves about what it is that is making them want to wash again.

Reassurance does reduce the sufferer's anxiety for a short time but unfortunately has a detrimental effect in the long term. If the child allows the anxiety to rise then they will gradually learn that the anxiety disappears on its own, given time. If, however, they use reassurance to reduce the anxiety then the next time the obsession and resulting anxiety will be just as strong, if not stronger.

However, in reality there will be occasions where offering your child reassurance is just completely unavoidable, perhaps it's been a bad day for your child and it's late at night for example, where sleep is needed. In these circumstances offering reassurance on rare and extreme occasions may not necessarily be the wrong thing to do. It is important that you don't beat yourself up if that happens, but instead get a good night's sleep yourself and the following day speak with your child's therapist about alternative techniques for dealing with that situation in the future.