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Helping your Child with Obsessive Compulsive Disorder

A Parent / Carer Self Help Guide

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What is Obsessive Compulsive Disorder?

OCD is an anxiety (worry) disorder, which consists of obsessions and compulsions.

Obsessions are intrusive, repetitive and unwanted thoughts that your child may experience, usually accompanied by high levels of anxiety, guilt and a sense of responsibility.

Typical Obsessions may include:

- Fears about contamination / germs (e.g. fear of touching door handles)
- Fear that something bad may happen to themselves or their loved ones (e.g. fear that a parent may die or be attacked)
- Health related obsessions (e.g. fear of catching a sickness bug)
- Religious or moral obsessions (e.g. worrying that they might have offended God)
- Sexual obsessions (e.g. unwanted sexual images / thoughts)
- Magical obsessions (e.g. giving special meaning to certain words, or numbers, or thinking that thoughts can make or prevent things happening)

Compulsions, sometimes called rituals, are the things your child does to reduce the anxiety or guilt caused by the obsessional thoughts. Some compulsions will be obvious to you, others may not.

Typical Compulsions may include:

Things you might see:

- Washing and cleaning compulsions (e.g. hand washing, washing clothes that are not visibly dirty)
- Checking compulsions (e.g. checking the doors are locked or plug sockets are off)
- Repeating compulsions (e.g. re-writing work, going in and out of a doorway or tapping things a certain number of times)
- Needing to have things arranged, symmetrical or in a particular order.

Things you might not see:

- Counting compulsions (e.g. counting in head, counting steps)
- Repeating compulsions (e.g. repeating certain phrases in head, saying the same prayer repeatedly)

A word of caution...

Other conditions with similar symptoms

There are some other conditions that may have some similar symptoms to OCD. **It is important that your child has a diagnosis of OCD before following the advice in this booklet.** This is because the other conditions need to be treated in different ways.

It is also important to remember that some of these behaviours might be seen in younger children as a normal part of their development. All children at different stages worry about different things. It only becomes a problem when it lasts a long time and interferes with daily living.

How many People have OCD?

Research tells us that OCD occurs in about 1.9 - 3% of the teenage population, which works out as approximately one to three in every 100 adolescents.

What causes OCD?

At the moment, no one knows exactly what causes OCD, but there are some factors that research has shown can possibly make children more vulnerable to OCD. It is thought that some children are genetically more likely to be anxious, some children's temperament mean that they are more likely to develop anxiety related disorders, and OCD is sometimes triggered by an event that a child may perceive as frightening.

Developmental life events such as staying overnight away from home for the first time, exams, bullying, health problems, change in family circumstances and bereavement may also be linked to the onset or worsening of OCD symptoms.

The majority of children will have real, understandable anxiety in such circumstances, but if a child is vulnerable to developing OCD, these things can act as a trigger.

Effect of OCD on your child

OCD may affect your child in a number of ways. School work, home life, and friendships can often be affected. Some children are too young to realise that their thoughts and actions are unusual. Your child may not understand or be able to explain why they must go through their rituals. If your child is older they may feel embarrassed, they don't want to be 'different' from their peers and may worry that they are 'going crazy'. Children with OCD sometimes experience extreme anxiety, embarrassment, low self-esteem and sometimes even bullying.

For some children there is a real fear that their thoughts will come true if they do not do something to prevent it. This can leave them feeling overly responsible for themselves and other people.

They then become trapped in carrying out compulsions in order to prevent the predicted bad things from happening. This means your child does not have the opportunity to learn that if they do not complete the compulsion, the bad things they have been thinking about do not come true and keeps them trapped in this negative pattern of thoughts, feelings and behaviours.

It is important to remember that sometimes a young person knows that they do not need to complete a compulsion, but it is difficult to stop (like giving up a bad habit). They do not do these things deliberately.

Understanding the impact on you and your family

Caring for children with OCD can be an extremely hard, stressful and draining experience, which is difficult to share with others. Often a child's obsessions and compulsions dominate family life, which in turn can create tension between family members. You might find that you feel more angry with your child, which could lead to more arguments.

Some parents feel guilty if the disorder has run in the family or feel maybe it is caused by their parenting. It is important to remember that OCD is not caused by bad parenting.

Siblings of children with OCD may also experience significant stress because of the OCD behaviours. Sometimes they are teased by their peers because of their sibling's 'bizarre' behaviour. They may even be reluctant to invite friends home, and may feel that you have more time for their sibling than for them.

You are not on your own

Given the strain that OCD can have on your family, you may find it helpful to share your worries and experiences with other parents who have children with OCD. The OCD-UK online Bulletin Board forums have a section specifically for family and friends, and are free to use at www.ocdforums.org. The resources section of this booklet highlights sources of further support.

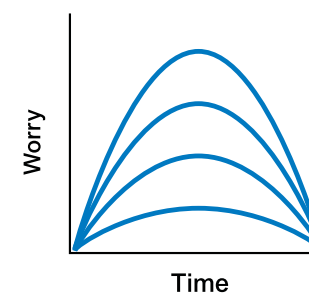
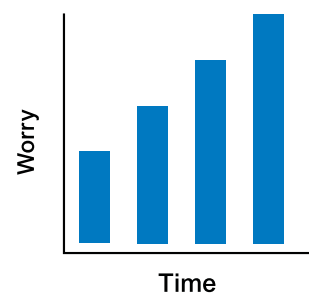
What can be done to help?

It is understandable, and even instinctual, to get drawn into helping your child with their rituals and giving them reassurance to reduce their anxiety and distress. However, this is what OCD needs to survive. Whilst your reassurance relieves anxiety in the immediate moment, it does not permanently reduce anxiety. For your child to beat OCD, they need to face their anxiety and not complete their compulsions or rituals. This will allow them to see that over time, their anxiety will come down by itself as the perceived danger does not come true. This can take time and planning, but is very effective in reducing OCD.

For illustration of the above, we've included two graphs.

The graph on the left shows what happens to your child's anxiety each time they get reassurance. It initially goes down, but then rises again, and they need more reassurance.

The graph on the right shows what happens if you do not give reassurance. The worry may initially go higher, but over time it reduces on its own. The next time they don't get reassurance, their anxiety does not go up so high, and reduces more quickly.



Role of parents

- Try to understand exactly what obsessions and compulsions your child is having. Often children and teens are horrified by their obsessive thoughts and compulsive behaviours, thinking they are bad, or even 'evil'. They try to keep them a secret, even from their parents and therapists. If your child is able to tell you their thoughts, try not to express distress, as this can contribute to the negative feelings that they may already have. Although the thoughts may be shocking, it is important to remember that such thoughts are very common in most people, even people who do not have OCD, and the reason why people do not usually talk about them is because they are not viewed as socially acceptable. It is also important to remember that just because they may have a thought, does not mean they would act on it. In order for things to change and to prevent OCD from being able to hide, it is important that your child feels supported and not judged because of the thoughts they are having.
- Sometimes when you feel angry with your child because of the OCD, it may be helpful to remember that your child cannot control what the OCD is doing to them and it is not their fault. OCD is an illness. It sometimes helps to view the OCD as something that is separate to your child. One way to do this is to call OCD a name of someone or something they don't like for example, Worry Wart, Fred etc. Teens may find this too childish and favour calling OCD by its medical term.

- Withdrawing all reassurance and not participating in any rituals may cause great distress to your child. It is therefore important to sit down with your child and discuss which rituals you could stop participating in, starting with the least distressing and gradually working up to the more distressing rituals.

Your Child and OCD in the School Context

Ways that OCD can present at school

We have found that children who have OCD sometimes experience the following problems at school:

- Extreme tiredness (as they may have been up at night doing rituals, or exhausted by the constant battle with the obsessions and compulsions, and resultant negative emotions)
- Refusal to attend school
- Repeated lateness
- Poor concentration (may be distracted by thoughts/rituals)
- Completing work very slowly if rituals involve repeating, checking, re-doing work and asking questions repeatedly
- Continually asking to leave the room (e.g. if they need to carry out washing rituals)
- Low self-esteem and difficulty with peer relationships
- Separation anxiety from family, particularly if their obsessions are related to harm coming to their loved ones

Ways of reducing the impact of OCD in school

We would recommend talking to relevant staff at school to make them aware of your child's difficulties. It would be helpful to talk about what your child might do in school and the strategies you are using to tackle OCD, so that teachers do not unwittingly support OCD rather than your child. It may also be useful to identify a teacher or learning mentor that your child can go to when things get particularly difficult at school.

It may be helpful to remember that there is a range in the severity level of OCD symptoms. For example, some children have very mild OCD, and may not have any obsessions and compulsions in school or vice versa, may not have any obsessions or compulsions at home.

This situation may create conflict between home and school. In these circumstances, communication with your child's teachers is key.

Treatment for OCD

The most important thing about treatment is to start it as soon as possible after diagnosis, because delaying this makes OCD more difficult to treat.

National Institute for Health and Clinical Excellence (NICE)

NICE guidelines are recommendations on the appropriate treatment and care of people with specific diseases and conditions within the NHS in England and Wales. Recommendations are based on the most up to date research available.

The guidelines recommend psychological treatment such as Cognitive Behavioural Therapy (CBT) as the first line of treatment for OCD in young people. Medication should be a secondary option and given alongside CBT. These treatments should be available at your local Child and Adolescent Mental Health Service (CAMHS). We understand that taking your child to a mental health service may be anxiety provoking, but these are the people who can help your child make the quickest recovery.

What is Cognitive Behavioural Therapy (CBT)?

CBT aims to identify connections between thoughts, feelings and behaviour, and through various tasks, challenge unhelpful thoughts so that behaviours and feelings can change. There is considerable evidence to suggest that this therapy is especially effective in treating OCD.

CBT will help your child:

- Find their negative or unhelpful ways of thinking
- Check and test the evidence for their negative and unhelpful thoughts
- Develop more helpful ways of thinking
- Learn to stop completing compulsions
- Decrease anxiety to a manageable level
- Learn to tolerate low levels of anxiety
- Find new ways to cope with their other unpleasant feelings
- Overcome their problems to help improve their quality of life

Medication

In some circumstances when your child's condition is dramatically impacting on their daily functioning, medication may be considered. This may be prescribed by your child's General Practitioner (GP) or your child may be offered the opportunity to see a Psychiatrist at your local CAMHS.

The medication helps to decrease anxiety so that your child feels more able to start making the changes recommended in this booklet. If medication is offered, you and your child will always have a choice about whether to start taking it. This will not affect any other treatment you will be offered. If prescribed medication, your GP or Psychiatrist will review your child's progress at regular intervals.

Helpful Resources

Useful books

[Obsessive-compulsive disorder: the facts](#)

S. Rachman, P. de Silva. Oxford University Press, 2001.
ISBN 019956177X

[Overcoming Obsessive Compulsive Disorder](#)

David Veale (2005) Constable and Robinson,
ISBN 1841199362

Useful organisations

[Carers UK](#)

20-25 Glasshouse Yard, London EC1A 4JT
Helpline: 0808 808 7777 Tel: 020 7490 8818
email: info@ukcarers.org Website: www.carersonline.org.uk

[Coventry Carers](#)

3 City Arcade, Coventry, CV1 3HX
Tel: 024 7663 2972
Website: www.coventrycarers.org.uk

[OCD Youth](#)

Young People's OCD Clinic, Michael Rutter Centre
Maudsley Hospital, Denmark Hill, London SE5 8AZ
Website: www.ocdyouth.iop.kcl.ac.uk

[OCD-UK](#)

PO Box 8955, Nottingham, NG10 9AU, United Kingdom
Website: www.ocduk.org