

obsessive-**compulsive**disorder *parents guide* **OCD?**



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.



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.



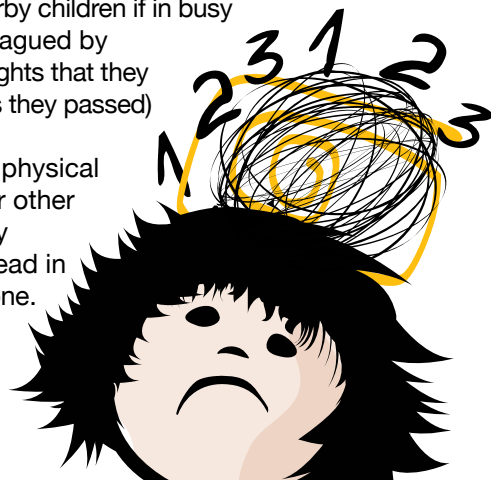
Which are the obsessions and which are compulsions?

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.



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?

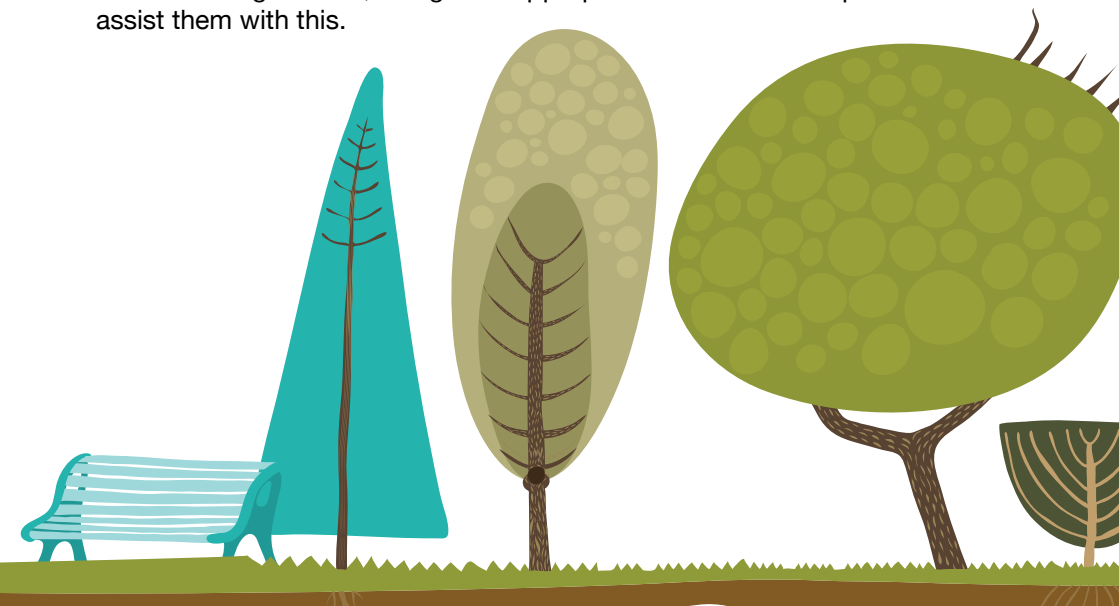
The treatment regarded as best for OCD is called CBT (Cognitive-Behavioural Therapy). This is a ‘talking’ therapy which aims to help the child challenge their unhelpful beliefs and to give them the tools necessary to combat their OCD. We know from previous research that CBT can help people who suffer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

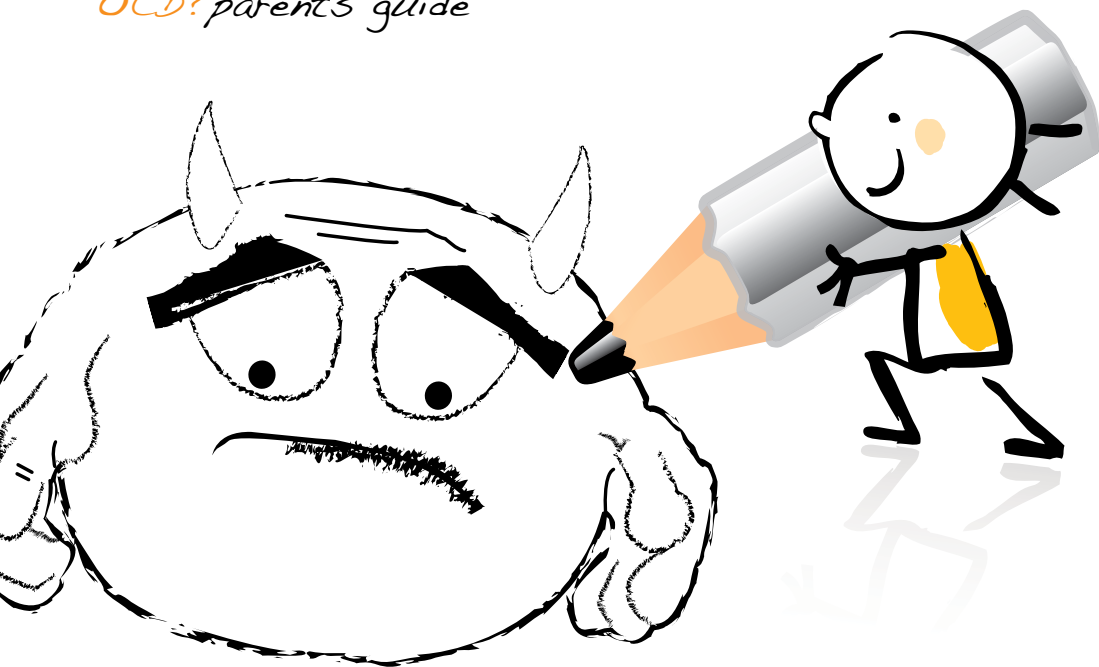
When people do CBT they learn how thoughts, feelings and what they do are connected. They also learn how to deal with upsetting thoughts and feelings. The CBT practitioner will spend time talking to your child about their OCD (and they may also ask to speak with you, particularly if it is a young child 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.

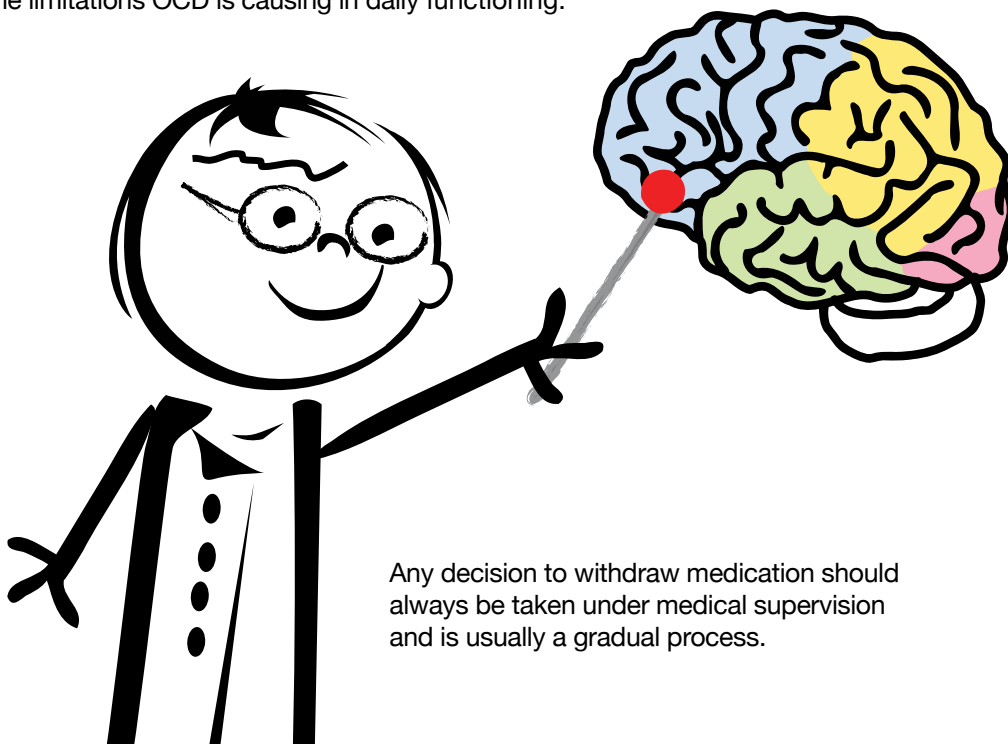
Facing up to OCD can be scary. Children and teens may naturally be apprehensive about resisting or not completing rituals. It may be helpful to remind the sufferer of what they are hoping to achieve out of CBT. Keeping the target in sight may help young people to remain focused on recovery. When learning 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 anti-depressant 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.



Any decision to withdraw medication should always be taken under medical supervision and is usually a gradual process.

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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.



why?

Why does my child have OCD?

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.

Should I tell my child's school about the OCD?

The decision about whether or not to inform your child's school will depend on your own and your child's preferences, as well as the severity of the OCD. With very young sufferers there is often little attempt to hide the OCD symptoms and, as a result, teaching staff may already be aware of them. Older children and adolescents may be better able and feel under more pressure to hide the disorder from friends and teachers. However, your son or daughter may be under tremendous stress because of the OCD and exams, and informing the school could be a beneficial and supportive move. As a result of OCD your child may be having difficulties completing homework and / or problems with developing / maintaining social relationships.

It is also important, however, that the child feels involved in making the decision whether or not to tell the school.

Regardless of the age of your child, it might be useful to provide the school with some information about OCD. We have included a section for teachers and other school staff at the back of this book. We have also created two guides, one for younger children and one for teens which may help you explain OCD to your child and/or their siblings and friends. Please feel free to request copies of these.



Symptoms in school

The following list shows some of the various symptoms that school staff may observe or become aware of:

- poor attention (student may be obsessing or performing mental rituals)
- reduction in grades
- frequent or prolonged toilet visits
- inability to touch objects, materials or other people
- excessive questioning and need for reassurance
- avoidance of participating in school activities around other children
- late arriving for school
- late handing in work
- frequent erasing and dissatisfaction with work completed
- repetitive behaviours
- difficulties making decisions

What can school staff do to help?

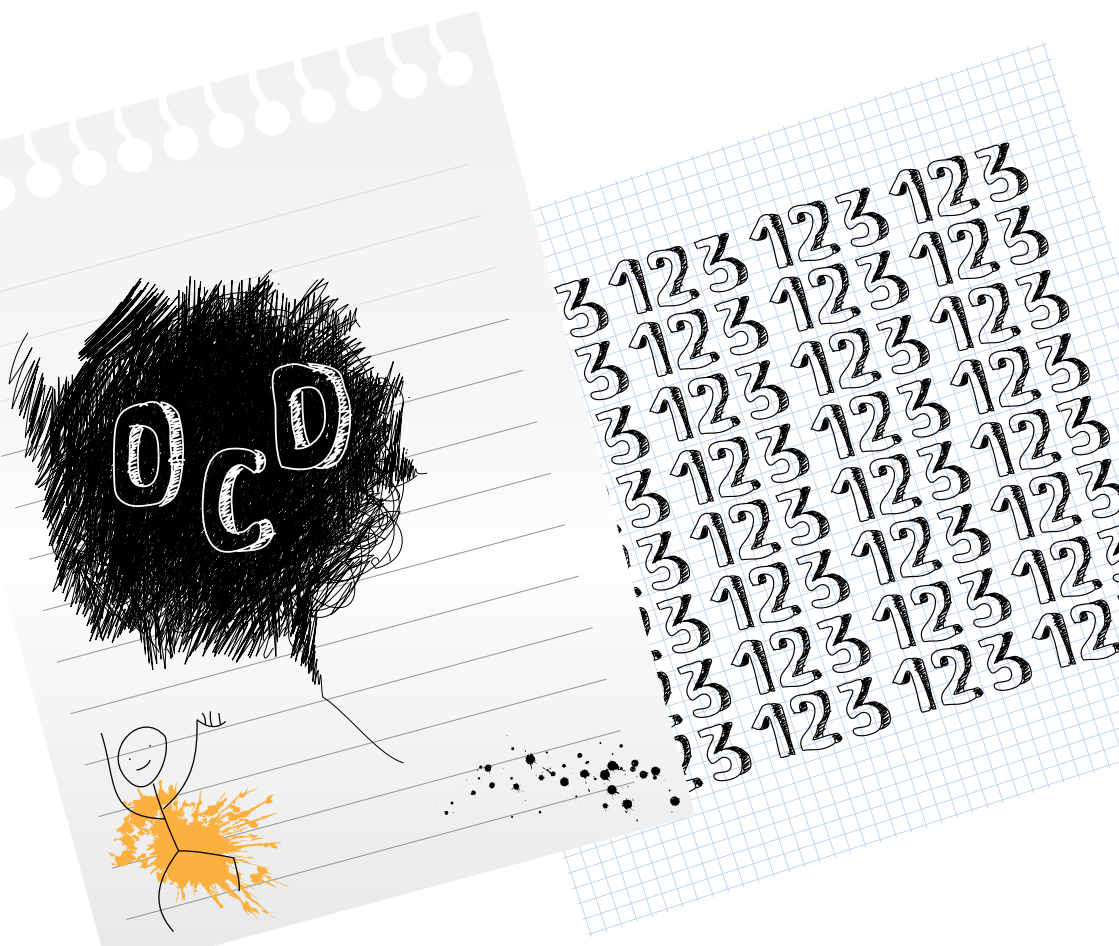
When schools become aware of the existence of OCD in students it may be helpful to implement strategies, depending on the severity of symptoms. An important primary task for teaching staff is effective communication between the affected student, parents and occasionally other agencies who may be involved with treating the OCD symptoms. Working towards similar targets using the same methods of tackling the OCD symptoms will be more effective for the student both in school and at home.

It is important to be aware that symptoms may vary considerably between individuals. For some students it is possible to 'mask' symptoms in school giving the appearance of 'functioning normally'. However, it is helpful for schools to be aware of the pressures the young person is experiencing and possible limitations in school performance even though no intervention techniques may be necessary in school at this time.

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The following list provides some guidelines for helping students with OCD:

- ensure effective communication between home and school – in the case of a young child with OCD it may be helpful to use a diary which can be passed from parents to teachers and vice versa
- if there is difficulty with handwriting (because of the need for 'perfection') consider allowing the use of computers to enable task completion. This may reduce the need to obsess over handwriting
- in Maths be aware of any problems when using numbers. Some students with OCD may think of certain numbers as 'unlucky' or 'bad' and go to great lengths to avoid them
- consider the implications of open-ended tasks for those students who become distressed at the prospect of reaching decisions. Help the student by providing precise and clear instructions. Self-doubt is often a major part of OCD



- consider allowing the student to choose a desk and location they are comfortable with
- consider the impact of exams on students with OCD and discuss with them how they can be supported
- be aware that the student may request many visits to the bathroom. Preventing this activity may increase anxiety
- provide the student with a list of the day's activities and remind them a few minutes prior to changing activities if required. This may help avoid the stress of feeling rushed and under pressure. Notify the student of anything unusual which will occur, e.g. a fire drill
- support the student in maintaining peer relationships with team-building activities. Social relationships may worsen due to the OCD
- understand that stressful situations often increase OCD symptoms
- be aware of clothing obsessions. Some OCD sufferers have great difficulty wearing clothing that is felt to be uncomfortable or contaminated. Wherever possible be relaxed about school uniforms. It will be far more productive for the student to feel comfortable than to be obsessing about clothing
- OCD can damage confidence and self-esteem. Help individuals to focus on their strengths and areas where they are confident
- OCD sufferers may be targets for bullying because of compulsive behaviours or lack of self-esteem. Your alertness and timely intervention will help ensure that the student is spared further distress and torment
- some students may find adapting to new situations difficult. New terms, teachers and environments may feel overwhelming. Provide extra support in this period of adjustment. Make sure that the student has a clear timetable for their day (in the case of older sufferers) or consider appointing someone to be with them until they are confident with new routines and environments (in the case of younger sufferers)
- remember that OCD is variable in symptoms and severity
- never punish a student for OCD behaviours – he / she finds his / her behaviour incredibly stressful and frustrating
- provide assistance according to the individual's needs. Support can be reduced over time as the student recovers but may need to be re-established in times of relapse

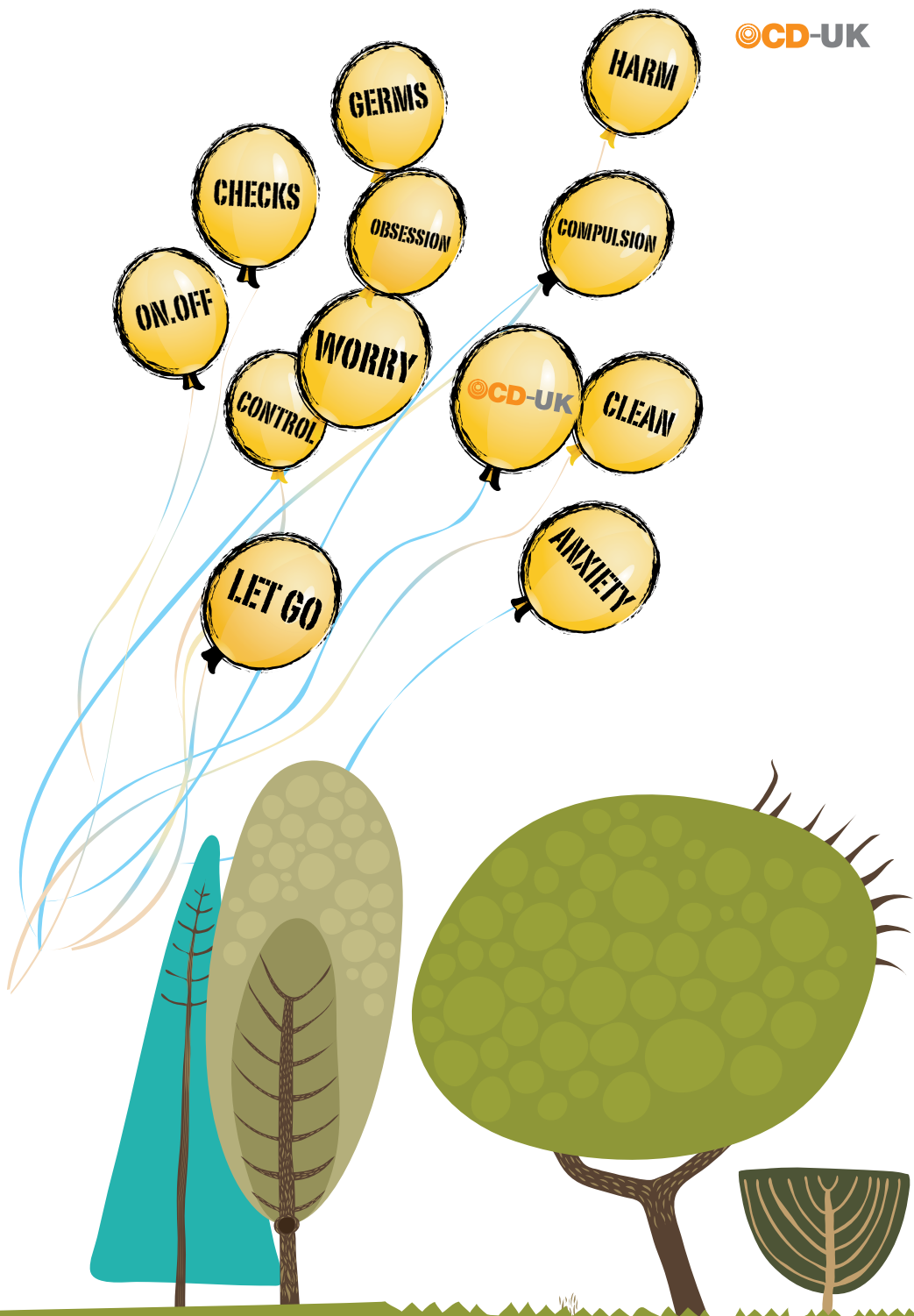
Remember to consider yourselves

Seeing your child suffering from OCD can be extremely upsetting and sometimes distressing, so it is important that you consider your own wellbeing and health whilst supporting your child.

Ensure that you speak to your GP or other health professional about your own feelings and needs; information or advice about what support is available to you should be discussed and/or made available.

Don't be afraid to enjoy the occasional 'OCD free' days when they come along, and they will. Just occasionally your child may have a good day where the OCD seems less severe. When those days come along, enjoy them, have fun, lots of laughter, and worry about OCD later. Some days we all need a day off from fighting, and that is ok provided you have a long-term treatment strategy in place.





Pam's story

Mother of two Pam started to notice OCD behaviours in her son David when he was a young child. "He was a real worrier. He had rituals where he would have to tap the window a certain number of times and wash his hands obsessively," remembers Pam.

When David hit puberty he had a breakdown. Horrified by the disturbing thoughts that filled his head, he would scream to try to make them go away. Pam didn't know where to turn.

After being referred to a child psychologist, Pam's son David was put on medication and a course of CBT. "It was a difficult time for the whole family," remembers Pam. "But it really helped that we worked closely with the CBT therapist and specialists at the Maudsley Hospital. The more we found out about OCD, the less afraid we felt and we began to realise we could cope."

Pam and her husband used distraction techniques and tried to keep David busy by taking him for long walks, drives or to arcades. "One of our favourite distraction methods was a rhyming slang game. We bought David a book of rhyming slang, which he memorised. We'd say the slang and he'd have to guess what it meant. It helped occupy his mind and made us all laugh!"

Sleep was a problem for David, and also affected his parents. "Sometimes David was too frightened to sleep so we would make up stories to try to relax his nerves, creating a scenario that was as safe as possible," says Pam.

Pam is aware that her son's OCD put a strain on the whole family. "My daughter watched her brother and parents falling apart and tried to hold everyone together. We were so embroiled in what was going on with David that we had little time to consider the impact on our daughter. She held in all her emotions, even though we always tried to be open about it. I think she was trying to be strong for us."

It was determination, patience and understanding that helped Pam get through this emotionally exhausting time. "The more we learnt about OCD the less worried we became. We also found that separating the OCD behaviour from our son and becoming more emotionally detached helped us to cope; otherwise the more upset we got the more it affected him.

"There were times when we didn't know where to turn. Then we discovered the OCD-UK discussion forums. Being able to talk online to people in similar situations lifted a huge weight off our shoulders – we discovered there was

support out there and that we weren't alone. I eventually became a moderator on the website."

"Don't put off getting help. Don't feel like it's your fault or a problem with your parenting. Communicate and talk openly about the condition," advises Pam. "We coped day by day and tried to stay positive. It's important to appreciate the good days and, on the bad ones, believe it can only get better tomorrow."

Despite the OCD, David, now aged 19, passed 7 GCSE's and has been offered a degree place following a 2 year BTEC course at art college. David is currently enjoying a gap year - working in a cafe and training to be a tennis coach. Pam said of her son "his obsessive nature is being directed in a positive way - recognising and accepting that OCD is part of who he is."

This story has been reproduced with kind permission from Children First for Health (www.childrenfirst.nhs.uk) - Great Ormond Street Hospital's leading health information website for young people of all ages and parents.

OCD Glossary

Acronyms are common place within the OCD treatment environment; these are some of the more common ones that you may come across.

BDD Body Dysmorphic Disorder (BDD) is an anxiety disorder, part of the OCD spectrum of disorders whereby a person is abnormally preoccupied with an imagined or slight defect in their physical appearance.

CAMHS Child and Adolescent Mental Health Services (CAMHS) are NHS-provided services to support young people with emotional, behavioural, psychological and mental health problems.

CBT Cognitive Behavioural Therapy (CBT) is a psychological treatment that looks at how we think (Cognitive), and how this affects what we do (Behaviour). In treatment other ways of thinking are considered, and how this would affect the way you behave.

ERP Exposure and Response Prevention (ERP) should also form part of the CBT treatment which involves being exposed in a very structured way, with the support of your therapist, to what makes you feel anxious, and not carrying out compulsive rituals after exposure.

HOCD Some sufferers use acronyms to refer to their type of OCD. HOCD is mainly used to refer to fears associated with Homosexuality OCD, an unwarranted obsessional fear of being gay. The acronym is often used as an avoidance from using the word Homosexual. The term HOCD can also lead to confusion over the type of OCD being referred to because some use it to describe other forms of OCD. For these reasons and the fact that HOCD does not have any official medical meaning, OCD-UK do not recommend using this acronym.

Magical Thinking is a form of OCD which involves linking actions or events that could not possibly be related to each other. For instance, you may believe that simply imagining a horrific car crash will increase the likelihood of such a crash taking place.

OCPD Obsessive-Compulsive Personality Disorder (OCPD) is a personality disorder which involves a preoccupation with details, rules, lists, order, organisation, and schedules; being very rigid and

inflexible in their beliefs; showing perfectionism that interferes with completing a task and having inflexible morality, ethics, or values. OCPD is often confused with OCD but despite the similar names, they are two very distinct disorders. People experiencing OCPD do not generally feel the need to repeatedly perform ritualistic actions.

POCD Some sufferers use acronyms to refer to their type of OCD. POCD is widely used to refer to fears associated with Paedophilia OCD, an unwarranted obsessional fear of being a paedophile. The acronym is often used as an avoidance from using the word Paedophilia. The term POCD can also lead to confusion over the type of OCD being referred to because some use it to describe other forms of OCD. For these reasons and the fact that POCD does not have any official medical meaning, OCD-UK do not recommend using this acronym.

Pure O Pure Obsessional OCD, commonly referred to as 'Pure O' by sufferers, is a form of OCD that is distinct from traditional OCD in that it features no outward manifestations; instead, both the anxiety-inducing obsessions and the relief-seeking compulsions of OCD take place only in the mind. With 'Pure O', the compulsions manifest as unseen mental rituals, but they are compulsions nonetheless, which is why the term 'Pure O' is somewhat imprecise.

ROCD Some sufferers use acronyms to refer to their type of OCD. ROCD is commonly used to refer to fears associated with Relationship OCD, where sufferers obsessively question whether their current partner is really the right person for them, and whether they actually love their partner or not, even in the most loving of relationships. The term ROCD can also lead to confusion over the type of OCD being referred to, religious OCD another such example. For these reasons and the fact that ROCD does not have any official medical meaning, OCD-UK do not recommend using this acronym.

SSRI Selective Serotonin Re-uptake Inhibitors (SSRIs) is the name given to a group of anti-depressant medicines that are often prescribed to patients with OCD.

Further help for parents and teachers

Further information, including interactive internet discussion forums, can be found at www.ocdforums.org or you can email admin@ocduk.org

Where else can I find information?

There are lots of organisations which provide information about OCD and other anxiety problems. Here are a few of the organisations you could get in touch with:

OCD-UK: The leading UK charity for young people and adults with OCD (www.ocduk.org).

A nice, informal way of talking with other parents is on the OCD-UK discussion forums at www.ocdforums.org,

OCD-UK have created a special 'Children's OCD-UK Membership' package which may benefit your child, this includes three special OCD magazines for children each year, at least three social events for children to come together and meet with children affected by OCD each year and a special fully moderated children's OCD website. Visit the OCD-UK website for more information.

Getting involved with OCD-UK

If you would like to help other parents, then get involved with OCD-UK who are always recruiting volunteers. It may be that you want to share your story for inclusion on the OCD-UK website or in the OCD-UK members magazine, **Compulsive Reading**.

©CD-UK We are the leading national charity, independently working with and for people with Obsessive-Compulsive Disorder (OCD). We aim to bring the facts about OCD to the public and to support those who suffer from this often debilitating anxiety disorder.

Our objective is to make a positive and meaningful difference in the everyday lives of people affected by Obsessive-Compulsive Disorder, by providing accessible and effective support services and by campaigning for improved access and quality treatment and care for people with OCD. We believe it is vital that every person affected by OCD receives the highest quality of treatment and care that they are entitled to and deserve.

Other booklets available from OCD-UK 'Jolly and Grump Children's Guide to OCD' and 'A Parent's Guide to OCD' – Please send an A4 sized large letter SAE to receive your copies – be sure to state which booklet you require.

Find out about more:

You can find out more about OCD-UK and details of how you can get involved and help at www.ocduk.org



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