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.
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 suffers 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
**OCD? parents guide**

**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.
worry
compulsion
obsession
GERMS
ON.OFF
CHECKS
OBSESSION
CONTROL
WORRY
COMPULSION
HARM
CLEAN
ANXIETY
LET GO
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 begun 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.

**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 obsessive 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.

**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.

**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

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

OCD-UK would like to acknowledge the kind support of Dr Victoria Bream-Oldfield, Leigh Jackson, Jo Sharman, Catherine, Jayne and Pari. Also the dedication and commitment of all volunteers who contributed to the completion of this booklet. Some of the images used in this leaflet are stock model images used for illustration purposes.

This booklet is published by
OCD-UK, © OCD-UK 2009 PO Box 8955, Nottingham NG10 9AU www.ocduk.org
Charity Registration Number: 1103210