OCD

Your questions answered

A guide for

Parents and Caregivers of children and young people suffering from **O**bsessive-**C**ompulsive **D**isorder

OCD UK

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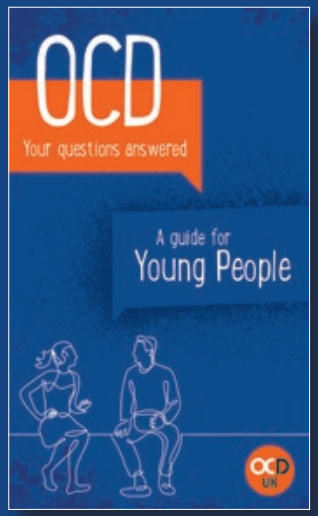
If you are reading this then you probably have concerns that your child may have **O**bsessive-**C**ompulsive **D**isorder, or they could have been diagnosed and you are searching for more information.

Whatever your reasons for reading this booklet, we hope that it gives you the information that you are looking for, and answers some of the questions that you may have. Nobody is to blame for OCD, and recovery is very much possible.

If you have any further questions after reading this booklet, please do not hesitate to get in touch **with our support team** by emailing **support@ocduk.org**.



Also available from OCD-UK

A guide for Young People

Please note that throughout this booklet, where we refer to parents, we are also referring to caregivers, and where we refer to children, this includes all young people and teens.

WHAT IS OCD?

Obsessive-Compulsive Disorder (OCD) is an anxiety-related condition where a person experiences frequent intrusive and unwelcome obsessional thoughts, which leads to the person carrying out repetitive behaviours.

OCD takes many different forms and disrupts normal, physical, and mental functions, interferes with daily life, and causes distress and anxiety.

LET'S BREAK IT DOWN.

It can be confusing to know the difference between **Obsessions** and **Compulsions**, so let's break it down.

OBSESSIONS

are unwanted and uncontrollable intrusive thoughts. These can also include images, impulses, feelings, worries and doubts.

COMPULSIONS

are any behaviours that are carried out with intent to stop the obsessions from becoming reality, to become completely certain about something, and reduce anxiety. Unfortunately, although the compulsions are carried out with these intentions, they actually cause the OCD to escalate, and the obsessions inevitably become more distressing.

Compulsions can also be mental rather than physical, which can make it harder for others to notice. For example, your child may repeatedly run through past events in their head in an attempt to check that they did not harm, upset, or offend anyone.

When children are troubled by their obsessions and compulsions, they can experience very high levels of anxiety.

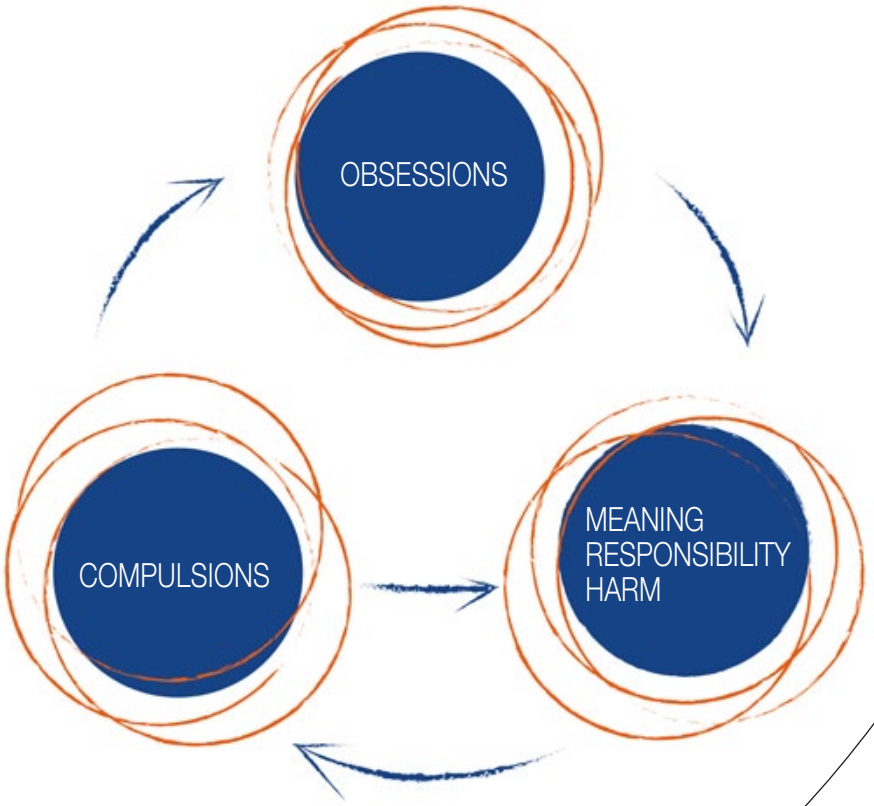
> Compulsions can be mental rather than physical, which can make it harder for others to notice.

WHAT IS THE OCD CYCLE PROCESS?

OCD is not just the obsessions and compulsions, and it's important for us to understand the process and the other elements that are involved.

Although the obsessions and compulsions are two of the main ingredients in the recipe of OCD, there's much more involved in the OCD process that causes the condition to be so gripping.

Let's look at this illustration:



It's the **misinterpretation of an intrusive thought** that drives the OCD cycle process to begin, and this causes the thought to become more than just a thought. For example, if your child has an intrusive thought that they might give someone an illness and they will die, they might then misinterpret the thought to mean something significant; 'Does this mean this will happen', or 'If I don't do something to stop this from happening, I must be a bad person'.

The meaning that they apply to an intrusive thought generates feelings of guilt, shame, anxiety, and disgust. These emotions can then cause them to feel very **responsible for their intrusive thoughts**. This heightened sense of responsibility causes them to carry out compulsions, and they drive the OCD to become a vicious cycle.

The more they feel compelled to carry out a compulsion in response to the thoughts, the more this reinforces the need to continue doing so. The more they react to the thought, the stronger the obsession becomes, the more this reinforces the emotions, and the more responsible they feel.

This is the OCD cycle process.

PEOPLE WITHOUT OCD GET INTRUSIVE THOUGHTS TOO, HOWEVER THEY CAN QUICKLY LET IT GO AS JUST AN 'UNCOMFORTABLE THOUGHT'.

NORMALISING INTRUSIVE THOUGHTS

Intrusive thoughts are not unique to OCD. Anyone can get intrusive, unwanted, and uncomfortable thoughts. It's not the thought that's causing the problem, it's the meaning applied to the thought, and the reactions and behaviours.

It's important for children to understand that the aim of recovery isn't about stopping the thoughts, because it's very normal to have them, and impossible to stop them. The aim is to change the way they respond to the thoughts which will change the way they feel about them, so they no longer generate anxiety.

WHY DOES MY CHILD HAVE OCD?

There are a number of theories behind the cause of OCD, but there is not enough evidence to prove any of them to be conclusive. Something we do know though, is that it's nobody's fault. It's not the parent's fault, nor is it the child's fault. It does not mean that the sufferer has had a bad childhood, and it's not a reflection of parenting. The important thing to remember is that we do not need to know what caused OCD to be able to treat it.

ALTHOUGH THE OBSESSIONS AND COMPULSIONS ARE TWO OF THE MAIN INGREDIENTS IN THE RECIPE OF OCD, THERE'S MUCH MORE INVOLVED IN THE OCD PROCESS THAT CAUSES THE CONDITION TO BE SO GRIPPING.

WHAT SYMPTOMS SHOULD I BE LOOKING OUT FOR?

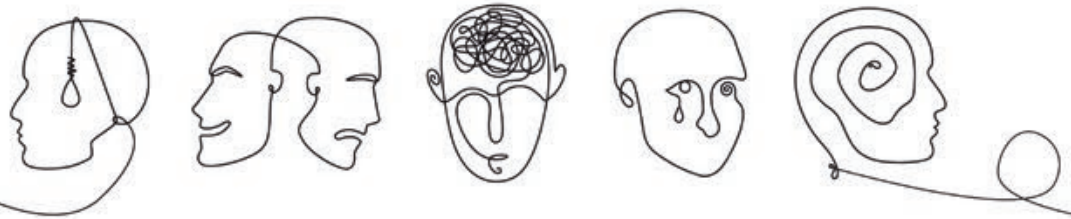
Only a suitably trained medical professional will be qualified to diagnose OCD, but there are some signs to look out for that may suggest your child might be suffering from OCD.

EXAMPLES OF OBSESSIONS:

- Excessive worrying that harm may come to loved ones
- Excessive worrying that they may have harmed someone they love
- Feeling responsible to keep others safe
- Excessive worrying about becoming unwell, or catching illnesses
- Excessive worrying (or abnormal disgust) towards bodily fluids
- Fears that they are disgusting
- Excessive worrying about something 'bad' happening
- Excessive worrying that they are a 'bad' person
- Having a 'feeling' that something isn't right
- Excessive worrying about their sexual orientation

EXAMPLES OF COMPULSIONS:

- Going to extreme lengths to protect loved ones
- Checking doors, switches, plugs and appliances repeatedly
- Checking use by dates on food packets
- Avoiding certain foods and repeatedly asking for reassurance that it's cooked properly
- Constant reassurance seeking
- Feeling the need to count as they perform certain tasks, sometimes in multiples of a particular number
- Performing certain behaviours until it feels 'just right'
- Refusing to throw away seemingly useless items in the fear that 'something bad' may happen or because they have 'a feeling' they need to keep the items
- Finding the need to order particular items
- Avoiding public toilets
- Avoiding certain people, places or objects that trigger their obsessions (fears/worries)
- Repeatedly telling someone what they are worried about
- Confessing (for example, if they have had a violent intrusive thought and they feel they need to confess this to someone).



There are many different themes and symptoms, and the ones listed above are only the **most common**. The list is by no means the limit of the different symptoms within OCD, and if your child is experiencing symptoms which are not listed above, it doesn't mean that it isn't OCD. If you're unsure, **write down any concerns you have and discuss them with a medical professional** i.e. GP or Child and Adolescent Mental Health Services (CAMHS).

TREATMENT

WHAT SHOULD I DO IF I THINK MY CHILD HAS OCD?

There are two options at this point, either visit the GP for a referral to your local Child and Adolescent Mental Health Services, commonly referred to as CAMHS (pronounced CAMS), or you can self-refer online (depending on if your local CAMHS service offer this option).

If you decide to visit the GP and your child is young, you can either go alone, or go together. It depends on what is best for you and your child. With older children, they may wish to speak to their GP alone, but you should encourage them to seek help.

If you decide to visit the GP instead of self-referring online, OCD-UK have created a **GP 'Ice Breaker'**, which you may wish to print out from our website and pass to their GP. The Ice Breaker explains what OCD is, and that you are aware that your child needs to be diagnosed and offered treatment.

WHAT NEXT?

Once you have been referred to CAMHS, your child should be put on a waiting list for an assessment. The word assessment can sound quite scary, but don't worry, this is just an appointment to discuss your child's symptoms with a health professional in your area, who knows how to diagnose or treat OCD.

Your child should be asked questions about the symptoms they are experiencing, including how long they have been experiencing them and how much they interfere with their life. Some parents encounter barriers to accessing treatment for their child, should that happen feel free to contact us and we can advise you where necessary.

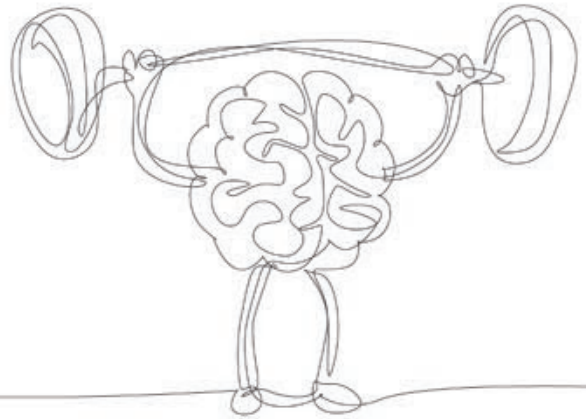
WHAT DOES TREATMENT FOR OCD INVOLVE?

The NICE guidelines (which are a set of guidelines that the NHS are recommended to follow for diagnosis and treatment) suggest that if your child's symptoms are mild, they should first be offered guided self-help. This is usually in the form of a book to help your child with their thoughts and actions.

If that doesn't help, or you don't want to try the exercises, your child should be offered **Cognitive Behavioural Therapy (CBT)** with **Exposure and Response Prevention (ERP)**. This is the current recommended, evidence-based treatment for OCD, and we will talk about what CBT and ERP are in the next couple of questions.

If your child's symptoms are more severe, your child should be offered CBT with ERP, and if it hasn't helped after 12 weeks, the NICE guidelines recommend that your healthcare professional should suggest that you see a range of other healthcare professionals who are experts in OCD, who will look at all the treatment your child has had so far.

They may offer your child medicine in addition to further therapy if their OCD is severe. If your child doesn't want further therapy, they may consider offering just **medication**.

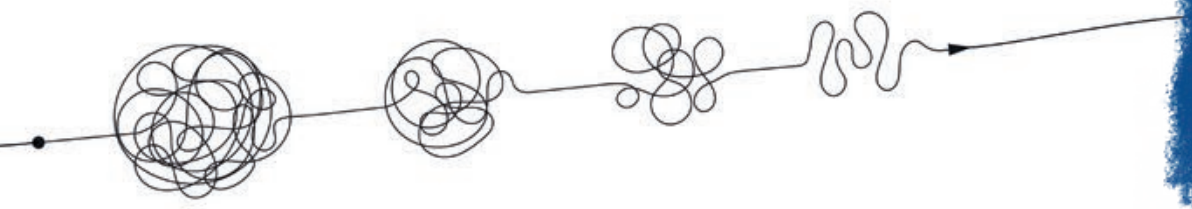


WHAT IS COGNITIVE BEHAVIOURAL THERAPY?

Cognitive Behavioural Therapy, otherwise known as CBT, is a form of talking therapy that concentrates on current problems and is unlikely to focus on past events.

CBT looks at our cognition, which is how we think (C), affects our behaviours (B), and how we feel both emotionally and physically.

CBT is based on the concept that thoughts, feelings, and actions are interconnected, and that negative thoughts and feelings can trap you in a vicious cycle. The aim of CBT is to learn ways to change our relationship with intrusive thoughts and challenge the meaning we place on them. Unlike other talking therapies, CBT is a doing therapy, and should include behavioural experiments to guide us in understanding why we behave the way we do in response to intrusive thoughts, and to learn what happens if we change these responses.



> The aim of CBT is to learn ways to change our relationship with intrusive thoughts and challenge the meaning we place on them.

WHAT IS EXPOSURE AND RESPONSE PREVENTION?

Exposure and Response Prevention, otherwise known as ERP, is a type of therapy that involves letting obsessions (intrusive thoughts) be present, without performing compulsions (behaviours) to neutralise them.

ERP encourages a person to learn that **uncomfortable feelings will eventually fade** and reduce if they don't respond to intrusive thoughts with a compulsion. Because of the nature of ERP, and how just the thought of doing it is often scary, especially for children, exposure exercises should begin with feared situations that cause anxiety they will be able to tolerate. They will then begin working up to more difficult exposures.

EXAMPLE

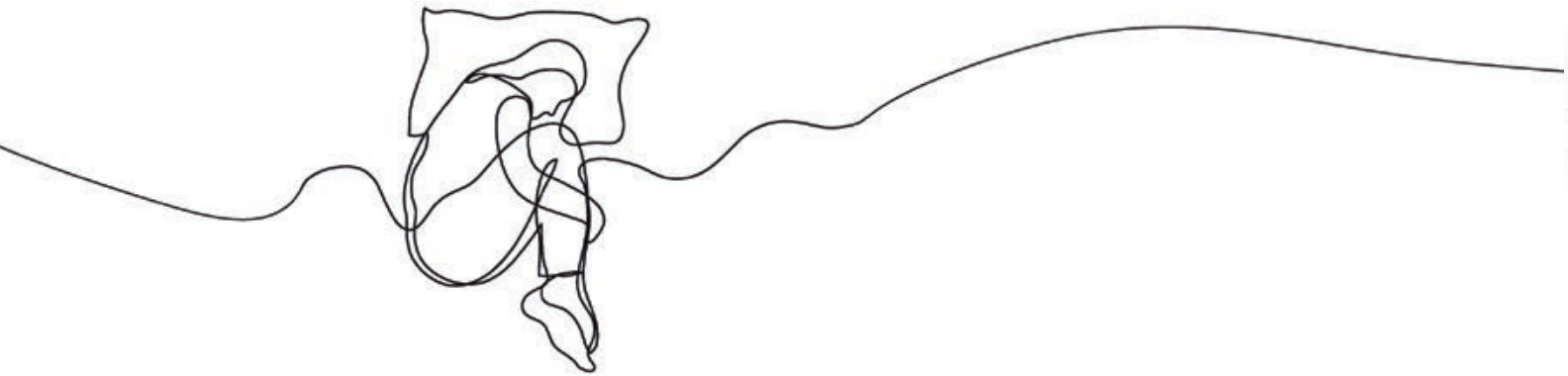
For example, for a child who is experiencing contamination related obsessions around bodily fluids, using any toilet other than their own might be something that OCD prevents them from doing. Although using a public toilet might be a step too far, they may find that starting with using their grandparent's toilet isn't as anxiety inducing. They will then begin by exposing themselves to their obsession (what if this toilet is contaminated?) and allow that thought to be present without performing a compulsion (compulsively washing, checking, reassurance reeking).

If the therapy is delivered correctly, you should see results and your child should begin to experience the uncomfortable feelings reducing and fading. There is no age limit with treatment for OCD, however treatment must be delivered at an age-appropriate level of understanding.

OCD-UK believe that the **gold standard treatment approach** for OCD should always include both components of the treatment, CBT and ERP together, rather than separately.

WHAT IF MY CHILD DOESN'T ENGAGE IN TREATMENT?

There are a number of factors why your child may be reluctant to engage in treatment. The fear of the unknown, difficulties talking about OCD, and the fear that it 'wont work' are just a few examples of these barriers. Listening to other young people's success stories from treatment could be a good way to break the fear of the unknown. You can find different stories on our young ambassador's pages on our website.



Another common barrier is embarrassment. For some older children, shame is often a barrier when talking about OCD, especially if the nature of their obsessions are violent or sexual. Barriers are very common, and a good therapist will discuss ways to break these barriers with your child (and family if required). A competent therapist will:

- Explain therapy so your child is able to understand the aim of treatment
- Create goals with your child, so they can begin to recognise and believe in recovery
- Build trust with your child
- Help your child to choose to change, and choose to engage in therapy (instead of doing it to please therapist/family)
- Begin with behavioural exercises that may cause some anxiety, but at a level they are able to tolerate, before gradually working up the ladder to more difficult exposures.

MEDICATION

If therapy does not prove to be initially successful, medication may also be offered, usually in the form of an SSRI (Selective Serotonin Reuptake Inhibitor) which is a group of anti-depressant medication.

SSRIs can help some people feel better, for others it can reduce anxiety, which may lead to your child feeling more able to engage in therapy. Just like with CBT, medication does not have an immediate effect, and may take time for results to be noticeable. We are often asked which is the best SSRI medication for children, but at this time there is not one medication that works for everyone.

It's important that your child is comfortable with any choices made around treatment and medication.

HOW DO I KNOW IF MY CHILD SHOULD TAKE MEDICATION?

This conversation should be carried out with your child and a psychiatrist, or prescribing doctor. Side effects are possible, although most are mild and short-lived. Most doctors will discuss side effects when they prescribe medication, and if they don't, ask the doctor to explain the side effects and what to do if they should occur. Voice any concerns and ask any questions you have, and make sure that whatever decision is made, that your child is comfortable and it's their choice.

WHAT IF MY CHILD NO LONGER WANTS TO TAKE MEDICATION?

It's important that your child is comfortable with any choices made around treatment and medication. If the decision has been made to withdraw medication, this process should be taken under medical supervision and is usually a gradual process. Seek advice from a medical professional.

COMMON QUESTIONS

WILL OCD AFFECT MY CHILD'S FUTURE RELATIONSHIPS AND WORK?

The short answer? No! If your child has been diagnosed with OCD, this is quite clearly a negative thing to happen. However, being diagnosed and seeking treatment at a younger age means that there is **more chance to reach recovery** without OCD affecting their future relationships and work life.

IS RECOVERY FROM OCD POSSIBLE?

Absolutely! The definition of recovery is to return to a normal state of health, mind, or strength. And this is absolutely possible with OCD. It doesn't always feel easy, and treatment is a process which does take time; however, it's important to focus on **recovery being possible**, rather than it being easy and quick.

MY CHILD'S OCD IS NOT CONSTANT, SHOULD WE STILL SEEK TREATMENT?

OCD symptoms can wax and wane. Change can cause OCD to flare up, for example changing schools, moving to a new house or even small amounts of change like new friendships. It's also common for symptoms to change, for example, a child who has been experiencing contamination related obsessions may begin to experience harm related obsessions. Regardless of the symptoms, the cause is always the same – OCD. Regardless of the particular themes or symptoms, treatment for OCD is the same.

If your child's OCD does wax and wane, it's still **important to seek help**. If OCD is left to fester, it often becomes more anxiety inducing, debilitating and time consuming.

CHANGE CAN CAUSE OCD TO FLARE UP, FOR EXAMPLE CHANGING SCHOOLS, MOVING TO A NEW HOUSE OR EVEN SMALL AMOUNTS OF CHANGE LIKE NEW FRIENDSHIPS.

I HAVE HEARD THAT REASSURANCE IS UNHELPFUL IN FIGHTING OCD. IS THIS TRUE?

Reassurance seeking is a compulsion, so when we give someone with OCD reassurance, we are accommodating OCD in the same way we would be if we were helping them with their compulsions. Just like any other compulsion, reassurance can give temporary relief for a short time, but unfortunately has a detrimental effect in the long term.

For parents, it's extremely difficult to know how to support their child whilst at the same time not accommodating the OCD. When a child is plagued by their OCD, it's a natural reaction for a parent to want to stop that pain. When you love someone, you will do anything to help them to feel better. Therefore, **we never judge or blame parents** for times they have had to give reassurance to their children. OCD is not your fault, and this is hard for you too. **Be kind to yourself**, you are doing your best and that's enough.

I HAVE GIVEN MY CHILD LOTS OF REASSURANCE, IS IT MY FAULT THAT THEY ARE SUFFERING?

Absolutely not. Nobody is to blame here apart from OCD itself. It's natural to reassure someone you love when they are distressed. In reality, there will be times where you may have had no option but to reassure your child.

For example, perhaps it has been a bad day for your child and it's late at night where sleep is needed. In those circumstances, offering reassurance may have been the only option you had. It's extremely important that you don't beat yourself up if this happens, OCD is a complex disorder, and it isn't easy to support someone who is suffering from it. If it happens, remind yourself you are doing your best, keep in mind that the long-term goal is to overcome this, but go easy on yourself for not being at that goal just yet.

There will be bad days, so speak to your child's therapist to discuss alternative techniques for dealing with that situation in the future. If you are currently waiting to receive therapy for your child, make a note so when that time comes you can have this conversation.

Although giving reassurance reinforces the OCD, sudden termination of it can cause high levels of distress and anxiety, so it's advised to gradually reduce reassurance giving, especially if there is currently a lot of reassurance seeking at home.

Please be aware that even gradual reduction may not be possible until your child starts working with a health professional. Remember, your job is to support and love your child through their struggles, it isn't your responsibility to fix this and make OCD go away, don't be too hard on yourself.

HOW CAN I SUPPORT MY CHILD WITHOUT GIVING REASSURANCE?

It can be difficult to know how to support your child who is suffering because of OCD, without accommodating the OCD monster. When it comes to reassurance seeking, it's important that your child knows they are heard, even if that means not giving the OCD the reassurance it's asking for.

Remember, it's not your child asking for reassurance, it's the OCD asking. By saying it's the 'OCD asking', we are shifting the blame onto the disorder, and not the individual. Nobody is to blame for OCD other than OCD itself.

NOBODY IS TO BLAME HERE APART FROM OCD ITSELF.

Here are some ways you can respond to your child without giving in to the OCD;

- "I hear you, but I think this might be OCD asking, and I can't give OCD what it wants because I am on your side"
- "I know this is hard for you, but I think this might be the OCD bully asking, and we know what the bully is trying to do here. Let's go for a walk instead"
- "I hear you, but this sounds like OCD asking. I know this is difficult, I am here for you. Shall we go and do some drawing?"

In these examples, we are ignoring the challenging behaviour that OCD is inflicting, without ignoring the individual. We are then refocusing with something active (drawing and walking were just examples, it helps to use activities that your child finds enjoyable and distracting).

We know that you may have already tried responding this way, and it may not have given you the results you hoped for. What doesn't work today might work another day, **recovery takes time**. It might also be because your child needs therapeutic intervention to be able to feel confident enough to challenge the OCD.

SHOULD I TELL MY CHILD'S SCHOOL ABOUT THE OCD?

This decision is a personal choice, and it will depend on you and your child's preferences. For younger children, there is often very little attempt to hide their symptoms, which could mean teaching staff may already be aware of certain behaviours.

Older children and adolescents, however, may be able to hide their symptoms from their friends and teachers more easily. Regardless of age and circumstances, your child may be under tremendous stress because of the OCD and school work and informing the school could be a beneficial and supportive move.

Consistency is key when it comes down to fighting OCD, and if your child is receiving therapeutic help, which involves certain approaches and techniques at home, it would be extremely beneficial for your child's teachers to be on the same page to avoid any unravelling of progress.

That being said, we know that some children and young people are reluctant to tell the school about their experiences with OCD for many reasons such as shame, guilt, embarrassment, or fear of judgement. You might feel as though you are stuck between a rock and a hard place. ▸

You don't want to tell the school without your child's permission, but equally you know that the school knowing will help them in their recovery. In these circumstances, we would recommend talking through the positives that telling the school would bring and try to guide them in to making their own decision of telling the school about OCD.

Don't forget – you matter too

Supporting and caring for someone with OCD is difficult. It's often time consuming, extremely upsetting and exhausting. It's important to remember that your mental health matters too, and your happiness is just as important as your child's.

Don't be afraid to enjoy the occasional 'OCD free' days when they come along, and they will. Occasionally, your child may have a good day where OCD feels less severe. When those days come, enjoy them, have fun and laughter, and worry about OCD later. Some days we all need a day off from fighting, and that's ok provided you have a long-term treatment strategy in place. Don't feel guilty for enjoying yourself on the good days.

Make sure you reach out to others if you are struggling. Ensure to speak to your GP or other health professional about your own feelings and needs and reach out to your loved ones and let them know how they can support you too. It's important to show yourself compassion, supporting someone suffering because of this disorder is both emotionally and physically draining for everyone involved. Remember, you are doing a fantastic job, and together you will get through this.

You may also wish to reach out to other parents in our support groups and on our website discussion forums. Sometimes speaking to others who know how you feel and what you are going through can be comforting and reassuring.

There are online presentations, webinars, and self-help books which we recommend, and you may find helpful. Links to these can be found at the back of this booklet.

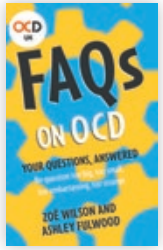
OCD and Autism

Some parents contact us for advice on co-morbid OCD and Autism. We have resources about that on our website.

ACRONYMS

OCD	Obsessive-Compulsive Disorder
CAMHS	Child and Adolescent Mental Health Services
NICE	National Institute for Health and Care Excellence
CBT	Cognitive Behavioural Therapy
ERP	Exposure and Response Prevention
SSRI	Selective Serotonin Reuptake Inhibitor

FURTHER READING - BOOKS

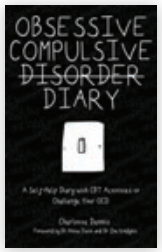


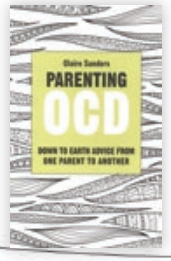
FAQs on OCD
by Zoë Wilson & Ashley Fulwood

Break Free from OCD
by Dr Fiona Challacombe, Dr Victoria Bream Oldfield & Professor Paul Salkovskis

Stand up to OCD
by Kelly Wood & Douglas Flecther

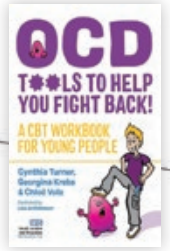
OCD Diary
by Charlotte Dennis

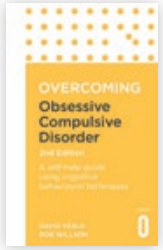




Parenting OCD
by Claire Sanders

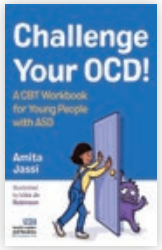
Tools to help you fight back
by Cynthia Turner, Georgina Krebs & Chloë Volz





Overcoming OCD
by David Veale and Rob Willson

CBT workbook for young people with ASD
by Amita Jassi



Books available from *www.ocduk.org/shop*

IT'S IMPORTANT TO SHOW YOURSELF COMPASSION, SUPPORTING SOMEONE SUFFERING BECAUSE OF THIS DISORDER IS BOTH EMOTIONALLY AND PHYSICALLY DRAINING FOR EVERYONE INVOLVED. REMEMBER, YOU ARE DOING A FANTASTIC JOB, AND TOGETHER YOU WILL GET THROUGH THIS.

THANK YOU

This guide was designed by Elli Loose.
elli.ellixir dr-elisabeth-loose

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- ocdforums.org

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