

# Treating Obsessive Compulsive Disorder (OCD)

**An information pack for parents &  
carers**

**Sussex CAMHS**



## WE ARE WITH YOU

We know that it is best to fight back against OCD as a team - family, young person and professionals together. As parents or carers, you are in a perfect position to support them to beat OCD. We know that OCD impacts not just the young person, but also you as a family, and OCD is very good at getting everyone involved!

This is why it is helpful for you to be like co-therapists, supporting your child to put into practice all they learn at therapy, and for you to also think about the ways that you may be unintentionally keeping the OCD cycle going. Don't underestimate your power and role in fighting against OCD. We hope the following information will help as you wait for treatment.

### Fighting OCD

1. We are with you
2. Top tips for parents
3. OCD and family accommodation
4. OCD and neurodivergence
5. What to expect from CBT for OCD
6. Support while you wait

***"It's been so empowering to properly realise I am not a really bad, dangerous person, which is how OCD has often made me feel. It's been hard work but am proud of the progress I have made, and who I really am."***

K, 15, Brighton

***"OCD has made our lives hell at home, but we now feel better equipped to support our daughter in her difficult battle."***

Parent, Brighton

## TOP TIPS FOR PARENTS

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Try and talk about the OCD being the problem, not your child or young person being the problem. Talk about it as "OCD", "brain bully" or whatever works for your family. Remind yourselves and your child that your child is separate from the OCD. We call this 'externalising' the OCD.

Remember that the OCD is to blame for the reassurance seeking, behaviours, and other rituals. It's not just your child trying to annoy you. This can be hard to keep coming back to.

Remember that it is okay to not tolerate unacceptable behaviours, and you can still put boundaries in firmly and kindly.

When you are supporting your child with their feelings, particularly anxiety, it can be helpful to think of this formula:

**Support = Acceptance + Confidence**

Accept and validate your child's emotions and provide confidence that they can manage these difficult feelings without compulsions. Support them by saying things like, "it's hard but you have the power to get through this".

Remember that doing compulsions helps in the short-term but keeps OCD going in the long term. It may be uncomfortable and distressing to go against OCD but this is what will help in the long-term.

Try to continue to talk about and do activities that are enjoyable and important to your child, as these values and interests can be a really good motivator for fighting back against OCD.

OCD can be powerful and takes over people's lives, but you can take the power back. OCD is the most treatable mental health diagnosis.

## OCD AND FAMILY ACCOMMODATION

Family accommodation is a term to describe the changes that families and parents make in their own behaviour to help their children avoid or lessen feelings of anxiety. OCD is very good at not just trapping young people, but also families, into doing what it wants. It is a really natural parental response to want to protect your child and to reduce their distress, therefore it is understandable to fall into patterns of accommodating anxiety and OCD. However, when a young person is struggling with OCD, this accommodation often works similarly to compulsions - helping to reduce distress in the short-term but keeping the OCD going in the long-term.

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Family accommodation includes participation in anxiety-driven behaviour and/or modifying family routines and schedules. Examples of participation in anxiety-driven behaviours include answering the same question over and over, buying large quantities of cleaning materials, turning light switches on and off several times etc. Active participation in these behaviours usually take up a lot of time and often causes parents frustration! Modification of family routines and schedules includes making changes to the patterns of daily life because of your child's OCD, such as no longer inviting guests over, going to work later than usual or arriving home early.

Remember - you are likely accommodating your child's OCD but that is a normal response, and you are not to blame. Be compassionate with yourself. However, you can play a role in overcoming OCD by becoming aware of your accommodations and making plans to change them.

## Things you could do around family accommodation while waiting for therapy:

Have a look through the Family Accommodation Scale to think about how you may be accommodating the OCD



Start to write down ways that you accommodate OCD and how often these happen



Try to make small changes to these accommodations and be consistent

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The book *Breaking Free of Child Anxiety and OCD* by Eli Lebowitz goes into a lot more detail about family accommodation and guides you through reducing this.

## OCD AND NEURODIVERGENCE

We know that there is a large crossover between OCD and neurodivergence, particularly Autism Spectrum Condition (ASC), and a lot of the young people that we work with do experience both. We have enclosed a leaflet regarding the common crossovers between the two diagnoses, however, we know that it is not easy to unpick.

Using the information in this leaflet, it may be helpful to start to work out which repetitive behaviours are linked to OCD and which may be due to an autistic/neurodivergent need. As a parent, you can still work at reducing the unhelpful accommodation for OCD whilst also working out the helpful accommodations for neurodivergence.

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## WHAT TO EXPECT FROM CBT FOR OCD

CBT with Exposure and Response Prevention (ERP) is the evidence-based recommended therapy for OCD and it has been shown to be highly effective. You can find out more about CBT with ERP here: <https://ocdaction.org.uk/resources/therapy/>

We offer up to around 20 sessions of CBT, however, the number of sessions that we offer here at CAMHS varies depending on the person and their situation and would include reviews to check in on your progress.

Sometimes a young person might struggle to respond to CBT with ERP. In these instances, a doctor may discuss the option of adding medication alongside CBT with ERP. The pros and cons of this decision will be discussed with you to help make an informed choice.

## SUPPORT WHILE YOU WAIT

We know that it is incredibly difficult waiting for therapy to start, with mixed emotions whilst you wait. You may be feeling relieved at knowing that there is an evidence-based treatment for OCD, which has been shown to be really effective, and also frustrated that you are having to wait for this.

There are a number of different places that can offer some support whilst you wait, and there are places that you can go to learn more about OCD and start the process of fighting back against it, both as a young person with OCD and a parent. Some of these support services and resources are outlined below.

Please note that none of these support services are a replacement for treatment, but they can be a good way to connect with others with common experiences and continue working towards your goals. They are also not there to provide urgent help.

If there is a change in your mental health presentation, or an increase in risk, please contact our CAMHS Duty Team **on 0300 304 0061**.

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## OCD Action

Help and Information Line: 08453906232 (UK)

-Advice and information about OCD:

<http://www.ocdaction.org.uk/>

-Information and resources for young people with OCD and their families: <http://www.ocdyouth.org/>

## OCD Action Support Groups

OCD Action offer a range of support groups providing a safe and welcoming environment where you can connect with others with similar experiences and offer mutual support without judgement. All support groups are peer led and facilitated by a dedicated team of trained volunteers.

**For young people aged 16-20, with OCD/BDD/Trich & Derm:** First and third Thursday of the month, 7pm via Zoom

**For parents/guardians of people of any age with OCD -** Third Wednesday of the month, 7pm via phone

**For parents/guardians of people of any age with BDD -** First Tuesday of the month, 7pm via Zoom

**For parents/guardians of children (aged 17 and under) with OCD -** First Thursday of the month, 7pm via Zoom

To join a support group, go to <https://ocdaction.org.uk/online-support-groups/>

For anyone who would like more information before they sign up please email [sign-up@ebtsupportgroups.co.uk](mailto:sign-up@ebtsupportgroups.co.uk) or call **020 7253 5272**.

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## OCD Action Youth e-helpline (ages 14-25)

Complete form on <https://ocdaction.org.uk/ocd-youth/>

The Youth e-Helpline is for anyone between the ages of 14 and 25 who is affected by OCD or a related condition (such as BDD or a Body-focused Repetitive Behaviour). Whether you live with OCD yourself, or are concerned about a friend or family member, Youth e-Helpline volunteers are here to support you!

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You don't need to have a diagnosis of OCD to get in touch. In fact, about half of the young people who email are unsure about whether they have OCD or not. The Youth e-Helpline team is made up of volunteers who are mostly young people with OCD themselves, so they really understand the challenges of living with OCD when you're young. They can chat to you about how you're feeling and offer you support and information about OCD and how to access the recommended treatments. OCD can be exhausting and isolating, but it really can get better!

## OCD UK

This website supports young people and adults affected by OCD: <http://www.ocduk.org/> and has a Parents Project offering support, guidance and information to parents who have children with OCD between the ages of 5-18.

### OCD UK Support Groups

OCD UK also provide a range of online support groups. Whilst these are primarily for those aged 18+, they do offer 'themed' support groups, often including one for young people aged 12-17 and one for families and friends. These are held via Zoom.

You can check upcoming groups and their dates, and sign up, on their website - <https://www.ocduk.org/support-groups/online/>

### OCD UK Parent Project

OCD UK has been granted some funding from the National Lottery Community Fund to design and deliver online and in-person educational workshops for parents who have children with OCD. The project is specifically designed for parents who have children between the ages of 5-18 which is the CAMHS age bracket. Workshops cover an introduction to OCD, symptoms, evidence-based treatment, how to help at home, parent interaction and lived experience.

Book a place here - <https://www.ocduk.org/parents/>

For any questions about the project, email [parents@ocduk.org](mailto:parents@ocduk.org)

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## Books

### **Stand Up to OCD! A CBT Self-Help Guide and Workbook for Teens** by Kelly Wood and Douglas Fletcher.

Written by a clinician from the National Specialist OCD Service.

We recommend chapters 2-7 of this book

### **Breaking Free From OCD: A CBT Guide for Young People and Their Families** by Jo Derisley and Isobel Heyman, Sarah Robinson and Cynthia Turner

We recommend reading chapters 1-4 of this book.

### **Can I Tell You About OCD?** By Amita Jassi

Written by a clinician from the National Specialist OCD Service. With illustrations throughout, this is an ideal introduction to OCD and also a good resource to share with younger siblings.

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## Other Support

### **OCD Is Not Me**

A short video to give hope to young people with OCD and their families:

<http://www.ocdisnotme.com/>

### **Young Minds**

A UK national charity for young people and parents of children with mental health problems: [www.youngminds.org.uk](http://www.youngminds.org.uk)

### **No Panic**

This website provides support and information to people affected by OCD, panic attacks, phobias and more:

<http://www.nopanic.org.uk/>

### **In Conversation... OCD**

A 30-minute podcast our team conducted with ACAMH covering a range of topics, including what OCD is, its symptoms and its treatment: <https://www.acamh.org/blog/ocd-conversation/>

### **OCD and the Brain**

Website about OCD and the brain developed by researchers, charities and people living with OCD.

[www.OCDandthebrain.com](http://www.OCDandthebrain.com)

*Please note: This is a collection of resources that parents often find helpful, and they are not authored by or owned by Sussex Partnership NHS Foundation Trust. We will attempt to keep these resources as up to date as possible, but you may find changes with the links and information given.*

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