OCD

Your questions answered

A guide for Young People

OCD UK

If you're reading this, you're probably having some worries – we are too!

Welcome to our guide for young people with OCD, by young people with OCD. We hope you find the information helpful and find the answers to any questions you may have about Obsessive-Compulsive Disorder.

OCD affects people in many different ways. You can't help having OCD but you can seek help for it – there is always hope of recovery for everyone!

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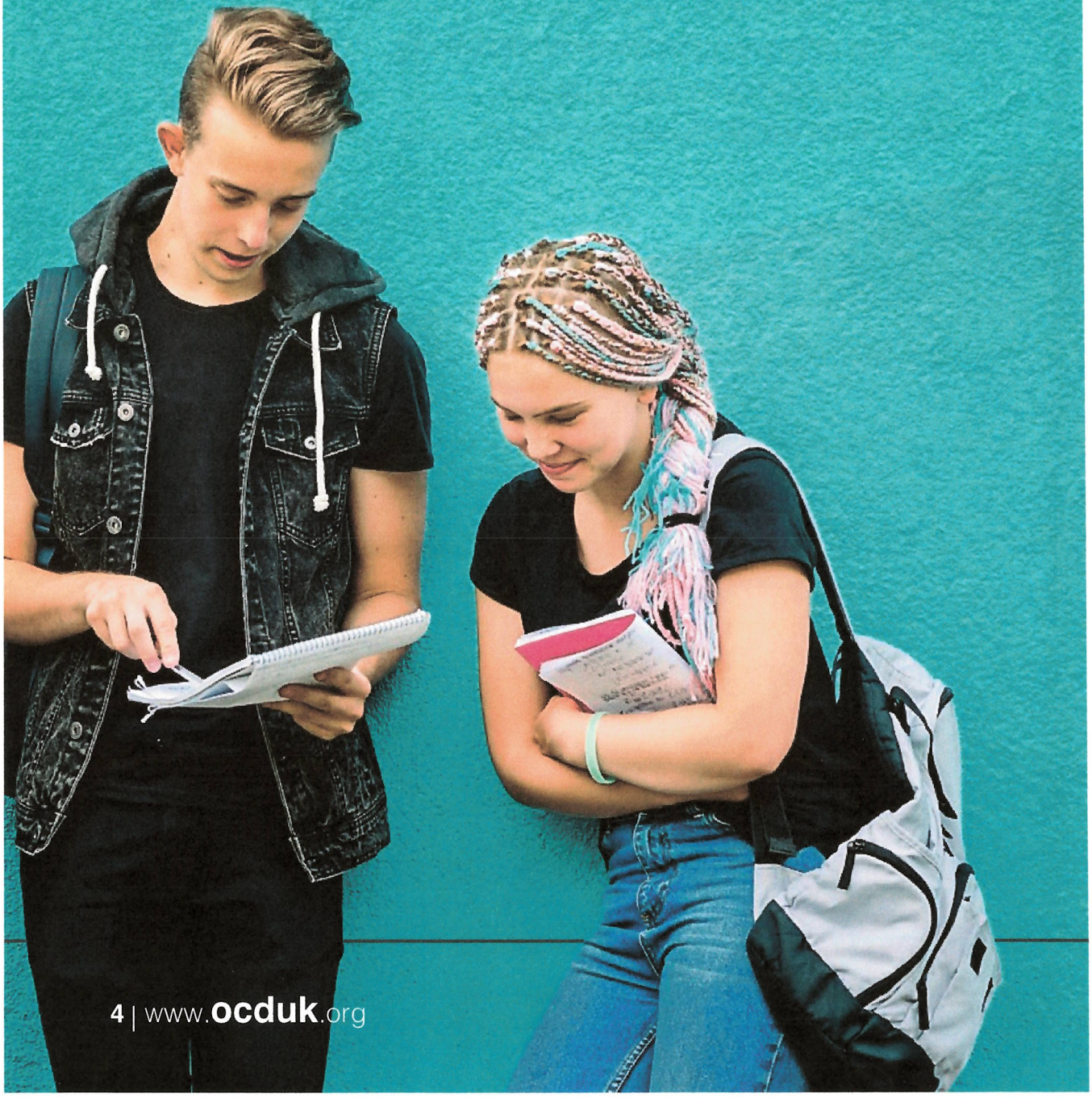
THIS GUIDE WAS
WRITTEN BY OCD-UK YOUNG AMBASSADORS
#OCDUKYA

WHAT IS OCD?

Obsessive-Compulsive Disorder (OCD) is an anxiety related condition that has two main elements – **obsessions** and **compulsions.**



OBSESSIONS

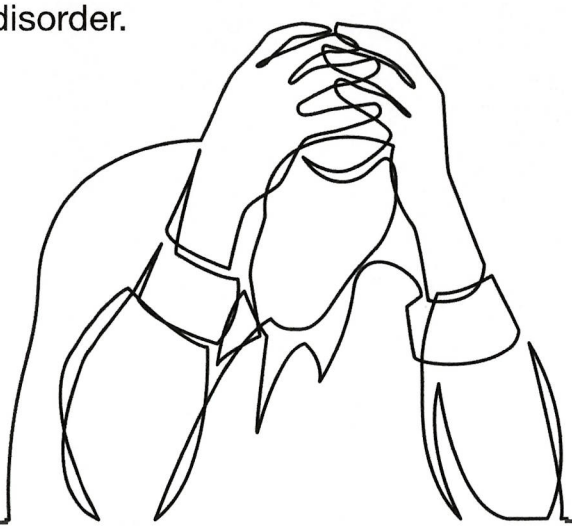
Unwelcome thoughts that pop into your mind. They can be thoughts in words or they can be images, urges or feelings of doubt. The thoughts can be around themes of violence, sexuality, disease or germs (contamination), harm to self or others, child abuse, illness, order and symmetry as well as other things.

COMPULSIONS

Repetitive behaviours that are carried out in response to the distress brought on by obsessions. They can be actions such as checking, cleaning, washing, checking the internet or asking others for reassurance or they can be rituals that happen in your head – some examples are counting, repeating certain words, reviewing memories or information.

DISORDER

An illness that disrupts normal physical or mental functions. This means that OCD is more than just liking things neat and tidy or liking clean hands or a clean house. Obsessions and compulsions that combine to have an impact on someone's daily life are classified as a disorder.

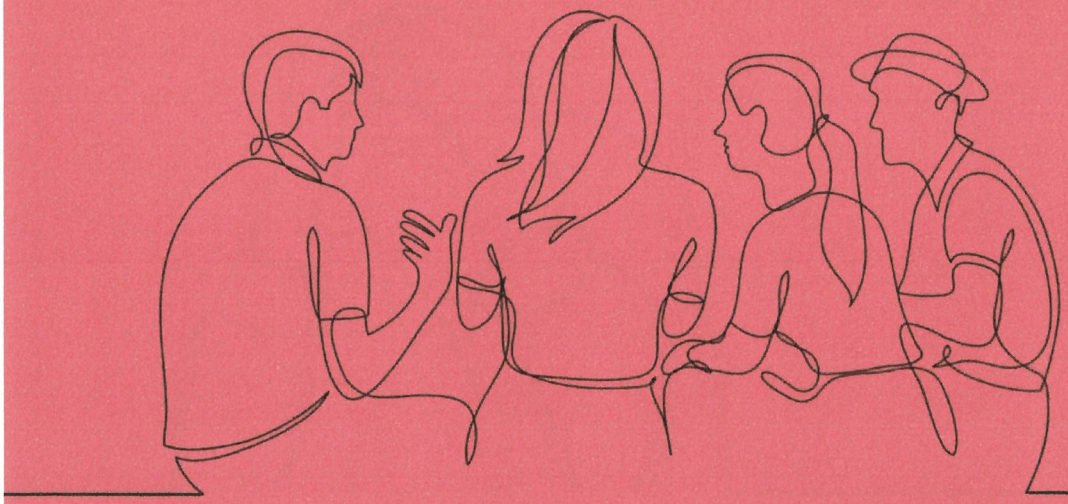


ARE THERE DIFFERENT TYPES OF OCD?

OCD is a cycle of obsessions and compulsions driven by anxiety and distress. What a person worries about or fears is described as their 'theme' or 'type', but since all types follow the same cycle, in a way all OCD is the same.

You might notice that some people add extra letters to the OCD abbreviation to represent different types of OCD, such as HOCD (Homosexual OCD), ROCD (Relationship OCD) or POCD (Paedophile OCD). Adding extra letters to the OCD abbreviation can also be confusing – for example, HOCD typically refers to a straight person with a fear of being gay, however a gay person may have the same fear of being straight. HOCD can also be confused with other themes like harm or hoarding (the inability to discard useless or worn out possessions).

These are not medically recognised terms and can lead to people searching for a specialist in a particular type of OCD, when they need a specialist in the condition of OCD.



'Pure O (Purely Obsessional)' is a name sometimes used when a person experiences recurring, distressing and intrusive thoughts and they don't believe that they have any external (physical) compulsions.

Pure O is not a medically recognised term and can be unhelpful, as a person with 'Pure O' does have compulsions like anyone experiencing OCD. Some of these compulsions will be in the mind, such as checking memory and thinking things over, often to make sure of something. However, there are nearly always physical compulsions too, like asking loved ones for reassurance, checking the body for signs of illness or sexual arousal, searching the internet for further reassurance.

All types of OCD, including 'Pure O' can involve physical avoidance compulsions.

Often, people experience more than one type of OCD. Some people start with one obsession and it changes to another, based on what's happening in their life at the time. Some people experience various obsessions and compulsions at the same time.

WHAT ARE TRIGGERS, AVOIDANCE AND REASSURANCE?

Regardless of the type of OCD a person may be experiencing, the following are usually involved:

TRIGGERS

The places, people, objects, thoughts or anything that provokes an obsession.

AVOIDANCE

The compulsive behaviour of avoiding places, people, objects, thoughts or anything that triggers OCD.

REASSURANCE

The compulsive behaviour of seeking reassurance from family, friends or other people, the internet or even your own bodily reactions.

An example of all three in action: Seeing a knife could be a **trigger** for someone who has an obsession that they might stab someone they love. They may **avoid** seeing and using knives by not cooking or by locking knives away. If they come into contact with a knife, they may seek **reassurance** from their partner that they haven't harmed anyone with a knife.

Like all compulsions, avoidance and reassurance seeking relieve anxiety in the short term, but in the long term they strengthen OCD and prevent recovery.

What starts as a solution, becomes part of the problem.

DO I HAVE OCD AND CAN I GET HELP?

If you have searched for OCD on the internet, you probably found a number of online OCD tests that you can complete yourself; however, these are not reliable, even as a guide.

If you think you might have OCD then it could be helpful to speak to someone you trust. This could be a family member, school nurse, SENCO (Special Educational Needs Coordinator), school counsellor, teacher or lecturer.

They should be able to help you get an appointment with your doctor (sometimes called a GP – General Practitioner), who can then advise you on the best way forward and maybe talk with you more about why you think you have OCD. OCD-UK has created a simple 'ice breaker' handout for you to give to a doctor or parent that explains you may have OCD. You can download this from the OCD-UK website at **www.ocduk.org**.

Obsessive-Compulsive Disorder is not like some other illnesses that can be diagnosed with a blood test or scan. There is no medical test that can say for certain whether or not you have OCD.

Depending on your age, your doctor might refer you to CAMHS (Child and Adolescent Mental Health Services) for assessment, further support and treatment, which should include therapy. Some schools can refer directly to CAMHS.

CAMHS teams work with children up to 18 years of age. Depending on where you live, you may be asked to self-refer to adult services because some adult services start working with people from 16 years of age. You may start with CAMHS then transition to adult services.

WHAT IS CBT?

The first kind of help offered should be a talking therapy called CBT (Cognitive Behavioural Therapy).

The 'cognitive' part of CBT helps us to understand our thoughts and how we respond to them. The 'behavioural' part of CBT is where your therapist helps you to face your fears. This can include something called ERP (Exposure and Response Prevention) which is gradually being exposed to an OCD trigger and supported to resist compulsive behaviours and rituals. This therapy technique helps you to learn that the anxiety will reduce and eventually disappear.

Each appointment should last up to one and a half hours and appointments will take place over a number of weeks. You will probably be asked to complete 'homework' in-between sessions. This will be explained to you and reviewed the following session. Your therapist may also ask to meet with your family to help them better understand you and your OCD and learn how best to help you with your therapy.

Therapy can be hard, but you will never be forced to do something if you're not ready. Your therapist is there to guide you through the process.

WHAT ABOUT MEDICATION?

Sometimes there are long waiting lists for therapy via CAMHS and adult services so your doctor may recommend that you try medication while you wait.

Some people take medication while having therapy because they find that medication reduces their anxiety enough for them to fully engage with CBT. The group of medications often prescribed for OCD are called SSRIs (Selective Serotonin Reuptake Inhibitors).

Medication can take a while to work and some people have to try a few different types to find one that works for them.

SSRIs are also prescribed for depression, which sometimes occurs alongside OCD. SSRIs are usually the first choice of medication because they have fewer side effects than most other types of antidepressant. It's important to remember that effective medication for one person may not work so well for another. Your doctor may need to change the dosage or type of medication using 'trial and improvement'.

If medication is no longer needed or a person no longer wants to take it, they can reduce their medication slowly, carefully and under medical supervision.

Taking medication is not a failing, many people take medication until they feel confident enough to tackle OCD without it. You don't have to take medication, you may decide not to and that is ok too.

IT'S YOUR CHOICE!

DO I HAVE TO TELL MY PARENTS?

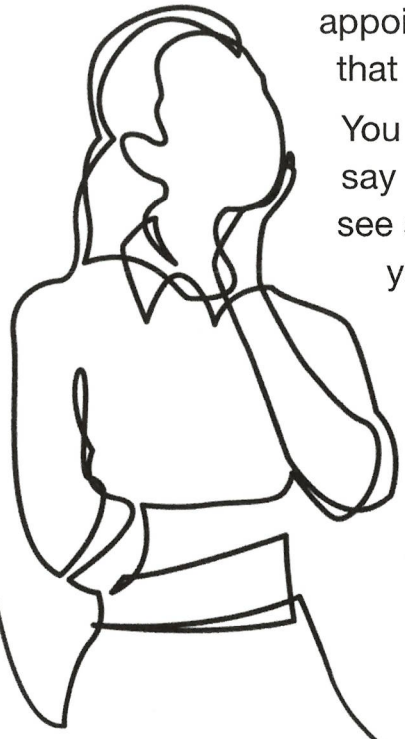
Fighting OCD alone can be tough, so it can be helpful to have the support of your family.

If you prefer, your doctor can see you without your parents or carers present. They can also refer you for therapy without telling your parents. Some young people with OCD prefer not to tell their parents, others find that it's helpful to have their support. It's a personal choice only you can make.

Anything you tell your doctor is confidential and will not be passed on to your parents, but there are exceptions to this e.g. if a doctor is worried that you or someone else is at risk of harm.

You can make an appointment with your doctor by phoning the surgery and speaking to the receptionist or going there in person. The receptionist may ask who the appointment is for and the reason, to make sure that you see the right person at the right time.

You don't have to tell them why, you can just say it's for something personal. You can ask to see a male or female doctor if this would make you feel more comfortable.



Some surgeries have online booking. You may have to register first, so call or visit the practice to find out how to do this.

If you're over 16, you can register with a doctor by yourself. You can find a list of local surgeries in your area on the NHS website. If they are accepting new patients, they will ask you to fill in a registration form.

Some young people with OCD prefer not to tell their parents, others find that it's helpful to have their support.

If you're under the age of 16, your parents or carers have probably registered you at a doctor's surgery. You can choose to see a doctor there but you don't have to. You can still register by yourself at another surgery, but you might be asked some questions to understand your reasons for changing surgery and to make sure you're safe.

If you choose a surgery that differs from the one that you were registered at by your parents or carers, then you may be de-registered at your current surgery.

WHAT ABOUT FRIENDS & SCHOOL/COLLEGE?

Deciding whether or not to tell your friends about your OCD can be tricky. There is no right or wrong answer to this question, as each person is different. Most people know which of their friends they feel that they can trust and those who may not be so ready to listen. Some people confide in a friend and find out they have different problems which helps them understand.

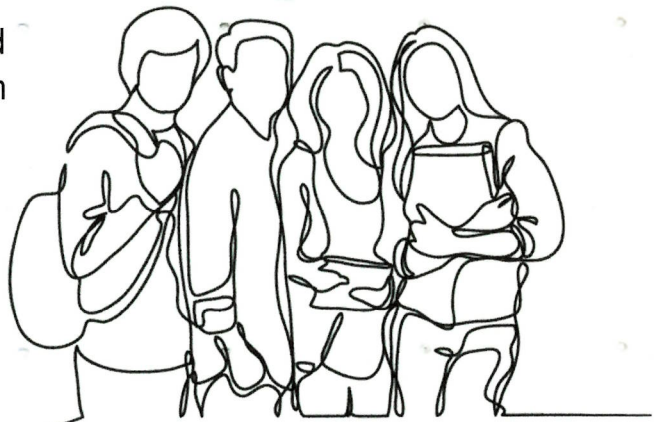
Some people find that their OCD affects their schoolwork/coursework and so choose to inform school/college via a teacher, lecturer, school nurse, SENCO or counsellor.

It might be helpful for you to talk this decision over with your parents and/or therapist to help you decide what is best for you. Your parents could also accompany you to meetings when informing the school if you think this would help. Many therapists are more than happy to write a letter to the school to explain about your OCD and how it affects you.

It can be useful to have someone such as a school nurse or counsellor to talk to when you're struggling with OCD. It may also help you if your teachers/tutors are aware of how OCD affects you. Struggling with OCD while trying to study can be very difficult, especially in situations which may already be stressful e.g. exams, new terms, changing school etc.

Information and awareness of OCD is increasing all of the time so it is likely that your teachers will be able to offer you support and assistance should you need it. Educational settings are required to identify and address the special educational needs of students.

If you find that your OCD is having a negative effect on your revision/build-up to exams then you may be eligible for 'special consideration' from the examination boards at GCSE and A-level. This requires a letter from your doctor or mental health professional, which is then sent together with a form filled in by your examinations officer. If you would like more information, speak to your tutor or examinations officer.



HOW DO I TELL PEOPLE AND WHAT IF THEY DON'T LISTEN?

Explaining OCD can be difficult. Sometimes friends think they have OCD because they like their belongings to be tidy or because they like to be clean, but they don't really understand what OCD actually is. Sometimes, there are cultural barriers around mental health and some people think that being ill is a sign of weakness.

If you are trying to explain to your friends, parents, teachers, tutors or a health professional that you think you have OCD and they don't seem to be listening or taking you seriously, don't give up!

Here are some ideas you could try:

- Share this guide to help explain the reality of OCD.
- Show the OCD-UK logo that represents how obsessions and compulsions are linked. It also highlights the fact that the D in OCD, means disorder.
- Use our 'ice breaker' handout that explains you may have OCD. You can download this from the OCD-UK website at **www.ocduk.org**.
- Use everyday situations to try and help people to relate. For example, if you had checking OCD you could say "do you ever wonder if your friend has made it home ok and for a second you panic that something may have happened to them? It's like that for me but x100! I worry about people staying safe and for some reason my brain tells me it's my responsibility. I need to check everyone is ok."
- Choose another time and talk about it again. Use examples of your OCD and ask if they have noticed any of your compulsive behaviours.

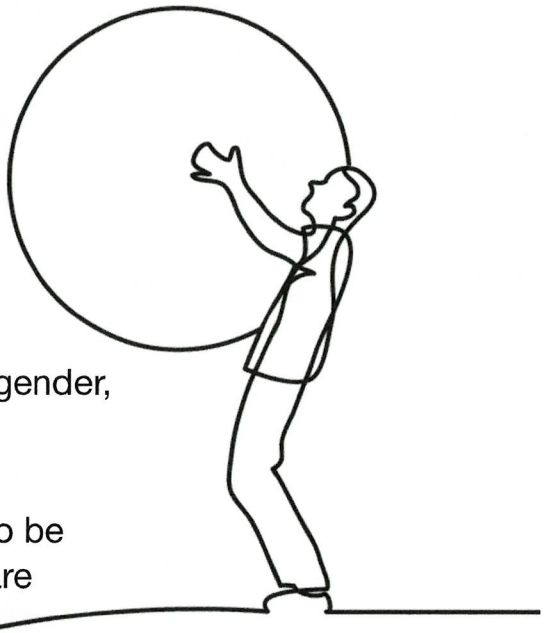
WHY DO I HAVE OCD?

Nobody knows exactly why one person has OCD and another hasn't.

Some experts have looked at the possibility that OCD is genetic because it can run in families. But despite lots of studies, researchers have so far failed to identify a specific gene responsible for OCD. Other experts believe OCD is caused by environmental factors like things we learn as we grow up.

Some people first notice significant OCD symptoms after experiencing difficult life events such as someone close dying, family problems, changing schools or bullying.

Some young people who develop OCD often feel very responsible for preventing harm happening to themselves or other people such as their parents or pets. Any or all of these factors could contribute to someone getting OCD, but we simply don't know for sure.



OCD can affect anyone - regardless of gender, age, race or background.

The most important thing to know is that you haven't done anything wrong to be affected by OCD. It doesn't mean you are bad, crazy, evil or weak.

OCD IS NOT YOUR FAULT!

OCD is a medical condition that can be treated. Some people think that OCD can only be managed but with the right support you can fully recover.

AM I THE ONLY YOUNG PERSON WITH OCD?

NO!

You are not alone.

OCD is thought to affect 1–2% of the population and studies have shown that OCD can affect 2–4% of children.

Symptoms began in childhood for over half of adults with OCD. That's why knowing you have OCD and getting help as soon as possible, will help your recovery journey to begin.

OCD-UK work with young people across the UK who have chosen to become Young Ambassadors. They are inspirational in their desire to support other young people with OCD. You can see the work they have been doing on our website:

www.ocduk.org/ocdukya

The next pages of this guide contain OCD stories shared by some remarkable young people, just like you.

L - AGE 15

My OCD experience has been quite tough, because it started when I was so young at around 4 years of age. I struggled to sleep as every night I was too scared to even try. I would scream at my parents, crying for them to stay with me so I wouldn't get hurt and I'd know they were safe.

Eventually, after a few sessions of therapy I managed to rely less on my parents but I was still very anxious. I would walk around close to walls so I would feel safe, take hours on one meal so I wouldn't choke and read all night so I would fall asleep without noticing. I knew that once I was asleep I was fine but in the hours before, just lying in my bed, all these thoughts would rush through my head which would make me sweat and get my heart racing.

Although by the age of around 12, I had managed to calm these fears, I still find it difficult to watch some films or TV shows as the worries and intrusive thoughts come flooding back.

The most disturbing thoughts for me have been sexual. Thinking about bad things I 'want' to do to other people and what I 'want' them to do to me. I now know that I don't want any of these things and I understand that I'm not the only one who has to deal with these visions, but when I was younger it was tough.

My advice to others would be to have confidence in yourself to overcome OCD. Therapy is always worth trying. Not everyone you meet will understand what's going on with your OCD because of stereotypes and lack of knowledge, so you have to be very patient but find someone to talk to whether it's a parent, best friend, therapist or even your hamster because it's always helpful!

N - AGE 16

It was very difficult living in a household where my parents knew very little about mental health and often would ignore it due to cultural differences. Most of my obsessions are based around routines, and cleaning is heavily involved. I wash my hands a minimum of thirty times a day, but some days are worse than others. My hands are left raw and often bleed from how sore they are. It takes me around an hour each night to get into my shower, and then another hour to have the shower and get into bed. Some nights I just sleep on the sofa due to being so exhausted from the day.

In the past, my mum placed objects on my bed, such as a brush or even a piece of washed clothing and that would instantly cause me to have a panic attack, cry and scream at my mum for doing something that would be usual for any mum to do. I have rules in my room that people must follow. My main rule is that people aren't allowed to touch my bed.

CAMHS workers helped my parents to understand that what I do is all driven from anxiety and that I have OCD. Ever since then, my mum hasn't gone against my wishes and tries to follow my rules whilst I'm being supported by therapy. I know I'm the one who has to take the first steps and I've decided that I can't hold back on all the things I could be doing just because my thoughts tell me to. Life is too short to play the safe game. Thoughts are just thoughts, they only matter if you act on them. It's not going to be easy but you can only get better if you let yourself grow and accept the support that's given.

C - AGE 20

During my second year of university I was struggling with severe OCD. Before this, I'd never had any big issues with my mental health, then all of a sudden I started checking that I hadn't dropped anything, that I hadn't left anything on, that the door was locked etc. Intrusive thoughts started and I had an obsession with numbers. I had to do things a certain amount of times and complete tasks at certain times in the day e.g. sending a message at 3:37, because 3 and 7 are 'good numbers', sending messages fourteen times, typing them out hundreds of times, taking a certain amount of steps, doing things like walking, university work and eating at certain times.

I developed issues with symmetry, which made it difficult when anyone moved my things. Hoarding created strains on my relationships as my family would try to throw things away which I didn't need but I felt I had to keep, it was so difficult to explain. I struggled to eat because of the fear that food was contaminated. Eating combined all my OCD fears (food being contaminated, eating at certain times in certain amounts of bites and a need for symmetry) which resulted in me losing weight. That was when I finally decided enough was enough, I needed help.

Admitting I had an issue was one of the scariest things I've done but my life was changed within four months after a combination of medication and Cognitive Behavioural Therapy. I went from being miserable, depressed and suicidal to feeling like myself again, I couldn't believe it. My relationships, university, work and weight all went back to normal. Your life can change within a matter of months. I still occasionally have setbacks with my OCD but I'm pretty much recovered. It can be done, you're not alone.

A - AGE 21

Growing up I always thought I was different to everybody else. I remember at the age of 11, I began to have horrid thoughts about my mum and it came to be that the only way I could stop these thoughts and feelings (which I now know to be a compulsion), was to tell my mum. As you can imagine, I didn't want to tell her what I had been thinking as it would hurt her, but I couldn't stop myself.

It caused huge arguments and I once wrote a letter to my parents telling them how something was wrong with me, that I didn't want to do these things but I just couldn't stop thinking about them.

Since we didn't know what OCD really was and therefore couldn't know I had it, my mum told me that "If I thought it, then I must think it" and this has been the message I've believed for the past ten years of my life.

At the age of 21 I'd had enough of my head. I booked to see my GP and from there I was directed straight to the OCD clinic. Within one month I'd been diagnosed and was on track to start group therapy. I can easily say that group therapy was the best thing that has ever happened to me. It was daunting at first to open up, but being surrounded people who experienced the same thought process as me, hearing their stories and their thoughts and their compulsions made me realise that I wasn't alone in this world and that in itself has helped me gain more control. I'm happier now than I have ever been in my life and it's all thanks to getting the right diagnosis and the right help and I couldn't be more thankful.

WHAT DO ALL THE ABBREVIATIONS MEAN?

BDD – Body Dysmorphic Disorder
CAMHS – Child and Adolescent Mental Health Services
CBT – Cognitive Behavioural Therapy
ERP – Exposure Response Prevention
GP – General Practitioner (Doctor)
NHS – National Health Service
NICE – National Institute for Health and Care Excellence
OCD – Obsessive-Compulsive Disorder
SENCO – Special Educational Needs Coordinator
SSRI – Selective Serotonin Reuptake Inhibitor

"On the outside you can appear happy and fine but on the inside you can feel confused and frustrated."

– OCD-UK Young Ambassador

A BIG THANK YOU

TO ALL OF THE OCD-UK YOUNG AMBASSADORS WHO HAVE WORKED ON THIS GUIDE.

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COMMUNITY FUND

OCD UK

The national OCD charity, run by and for people with lived experience of OCD

WWW.OCDUK.ORG

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For further information please visit our website **www.ocduk.org**
or for peer-led support visit our online discussion forums **www.ocdfourms.org**