

Struggling to talk about OCD?

A booklet for young people, families and carers to use when a young person is finding it hard to talk about how they feel and what they are struggling with. (For teens aged 13 and over)



About this booklet

OCD can make you feel lonely and isolated, especially if you are struggling to talk about it to loved ones or carers. It's completely normal to find it difficult to talk about your worries, and most people don't find it easy. However, talking to your loved ones or carers about how you feel can be really helpful. If they know how you feel, it might be easier for them to know how to help.

If you are struggling to talk about what you are worrying about, the behaviours you are struggling with or how you feel, this booklet might help. Sometimes, even saying what you are worried about out loud to other people face-to-face can be too tricky and this is why we created this booklet. Before we begin, let's look at some of the basics of OCD...

Obsessions

The **O** in OCD stands for 'obsessions'. Obsessions are unwanted and uncontrollable intrusive thoughts, and these can be images, impulses, worries, feelings and doubts too. Some examples of intrusive thoughts are worrying about getting germs on you, getting horrible images of something bad happening to someone you love or worrying that you are a 'bad person'.

Intrusive thoughts are very normal, in fact everyone gets them from time to time. These intrusive thoughts become obsessions when they become bothersome, generate feelings of anxiety, and make us feel responsible for those thoughts and that we need to do things to stop the worry.

Compulsions

The **C** in OCD stands for 'compulsions'. Compulsions are behaviours and actions such as checking, washing, asking people questions repeatedly, avoiding certain objects, places or people, counting, ordering, tapping (and so on). These behaviours are carried out to try to make the worry go away, to try to become certain that the worry isn't real or to try to stop the perceived threat (worry) from happening.

Disorder

The **D** in OCD stands for 'disorder', which sounds scary – but all this means is that the worries you are having and the behaviours you are doing to try to stop those worries are becoming difficult for you cope with, they are getting in the way of other things and causing you distress. Everyone has intrusive thoughts, and most people do some behaviours from time to time to try to stop worrying about things, for example checking the door is locked more than once. However, this only becomes a disorder when it has become very distressing and is getting in the way of other things like school, college, university, work or enjoyable hobbies.

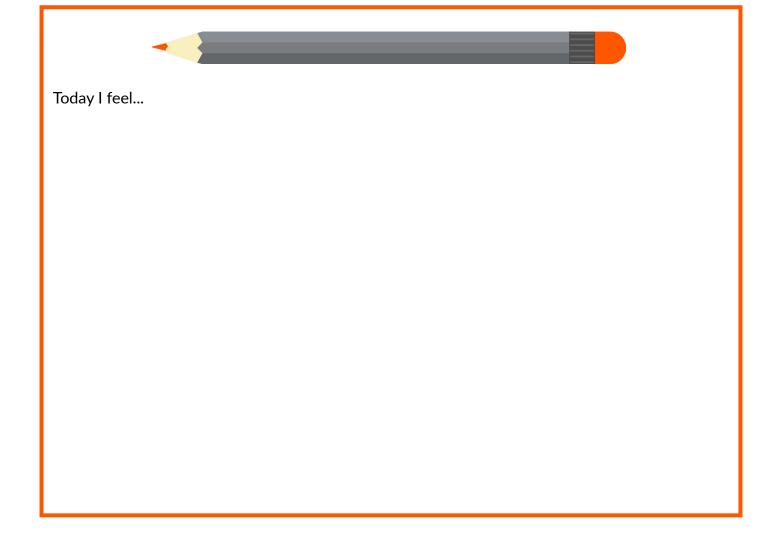
The good news is you can get better from OCD!! You don't always have to feel this way, and you may just need a bit of help from your loved ones or carers and people who know a lot about OCD (such as a therapist or psychiatrist) to help you to feel better.



Today

Let's begin by looking at how you feel today. The people who care about you want to help, but sometimes they can find it hard to know how. Explaining how you feel can help them to understand your feelings, which might help them to support you better.

Below you will find some space to write down how you are feeling. If you are struggling to word it yourself, there is also a section on the next page where you can use some checkboxes instead.



Are you struggling to write down how you feel today? That's ok, it's very normal for people to struggle to say how they feel. Below you will see some checkboxes so you can use some examples we have included instead. You might feel lots of things at once, so you can tick as many boxes as you need to.

Today I feel
Anxious
Hopeful
Confused
Better than yesterday
Tired
Not in the mood to talk
Scared
Angry
Sad
In the mood to talk
Overwhelmed
I am not sure how I feel today



Worries

It can be hard to put into words what you are worrying about sometimes, so below you will find a list of common obsessions for you to tick instead of saying your worries out loud. Don't worry if you can't relate to any of the common obsessions listed below, you can fill in your own on the next page. If you tick next to any of the obsessions listed below, but you are not yet ready to talk about it further, put a star next to it. Whoever reads this will then know that you don't feel ready to talk about it just yet.

I worry that if something hasn't been done 'just right', something bad will happen
I worry that I have upset someone and can't remember
I worry that harm will come to others, or myself, because of an action I have/haven't done
I worry that I am unclean or contaminated
I worry that I, or others around me, will get a disease or an illness
I worry about my sexuality and 'who I am'
I worry about being sick/vomiting
I worry that if I say my worries out loud they will come true
I worry about the safety and security of my house (e.g. fires or unlocked doors or windows)



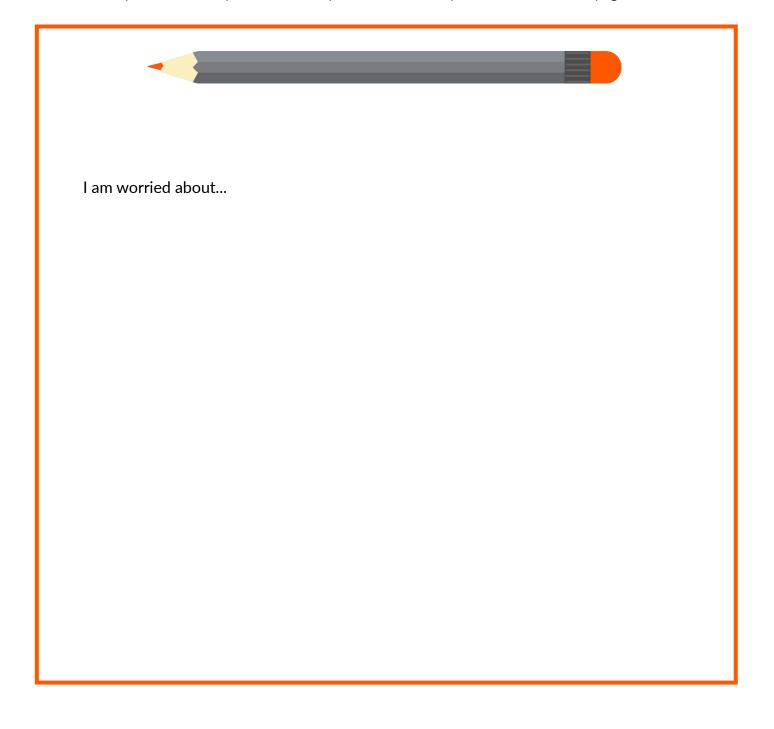
Some worries are harder to talk about, these worries can sometimes be referred to as more 'taboo' intrusive thoughts. Everyone has thoughts like this from time to time, but people with OCD experience a different reaction to them because they feel responsible for those thoughts, which makes them feel compelled to carry out compulsions to stop the worries from happening, to make sure they don't come 'true' or to try to find certainty about them. You will find a list of some of the most common 'taboo' intrusive thoughts below. You don't have to fill in anything you don't want to, and like before, if you tick one that you aren't ready to talk about yet, you can put a star next to it.

I worry that I have hurt someone and can't remember
I worry that I will hurt myself or other people
I worry that I am capable of doing awful things
I worry a lot about my faith/religion and that I am bad for having certain thoughts
I worry that I am sexually attracted to someone I shouldn't be (e.g. family members, children, animals)
I am worried I could contaminate people with my bodily fluids or be contaminated by theirs
I worry that I might have said or done something that goes against my morals (e.g. racism, homophobia)



Any other worries?

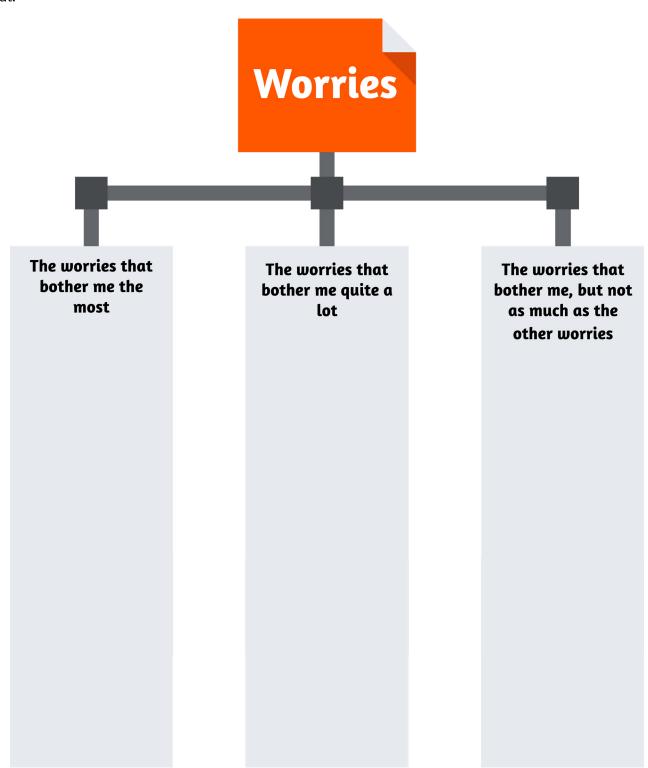
Are you worrying about anything else that might not have been listed in the specific tick boxes above? If so, that's ok, and very normal. Lots of people have other worries which might be more personal to them because that's usually how OCD works, it fixates on things that matter to us because that will bring us the most distress. If there are any other worries you have which you want to share, you can use this blank page here...



Rating worries

If the people who care about you know which worries bother you the most, they might be able to help you better, or they might find it easier to find the right words to say. If you can, would you like to try rating your worries? The left column is for the worries which bother you the most, the middle is for the worries which bother you a lot (but not as much as the worries in the left column) and the column on the right is for the worries which bother you somewhat, but not as much as the worries in the other two columns do. It is ok if you find that they all bother you a similar amount, that's very normal too.

If you are struggling to write down some of the worries from the tick box page, you could draw a different shape next to each box you have ticked and use that shape in this section to prevent you from having to write it out.



Self-compassion

Self-compassion means being kind and understanding toward ourselves when we suffer, fail, or feel inadequate, rather than ignoring our pain or being self-critical. It involves comforting and soothing ourselves, connecting with our innate compassion for others, and motivating ourselves with encouragement.



Well done for getting this far with the booklet. As a charity which is run by people who all have lived experience of OCD, we know how hard it can be to be honest about what you are worried about, how you are feeling, and what you are struggling with. So, from us, well done, and please be kind to yourself.

If you have got to this point and you are struggling to fill in some parts of this booklet, don't worry, that's normal. You still deserve self-compassion and kindness. OCD is hard to deal with, and it can make us feel many different things all at once. Just because you are struggling with this booklet now, it doesn't mean you always will. You could try to take a break for now and maybe come back to it another time or day when you are feeling ready.

In the next section, we will be looking into some of the behaviours (compulsions) which you are struggling with. Remember, if you need a break from filling out this booklet, you can always pause here and come back to it later.



Behaviours

This section is for sharing which behaviours you are struggling with the most, which are referred to as 'compulsions' like we mentioned earlier. Just like with worries, it can be hard to talk about some of the behaviours you might be doing and struggling with, and that is completely normal. Just like before, we have a section here with some tick boxes to help with that. Here are some common behaviours which some people with OCD sometimes struggle with...

I spend a lot of time re-doing certain tasks because it doesn't feel right/I haven't done them right
I have to ask people for lots of reassurance
I repetitively try to remember past events in my head
I have to repetitively clean things or myself
I avoid eating certain foods due to worries of being unwell
I have to check sell by dates of food packets repetitively
I have to open doors with elbows or sleeves in case I catch an illness
I have to avoid saying certain words in case bad things happen

I struggle throwing things away, even something small like a piece of rubbish or a wrapper
I spend a lot of time arranging my things in a specific order
I have to tell someone what I am worrying about before I go to bed
I have to throw things away or avoid them because they feel unlucky
I have to think about a good thought to cancel out a bad thought
I need to check the locks in the house, and other items, to keep myself and others safe (e.g. taps, windows, plug sockets, the oven)
I have to count to a specific number when I am doing something, either out loud or in my head
I have to say a certain phrase in my head, or out loud, when I am doing something, to stop something bad from happening
I have to check that other people are safe (e.g. checking loved ones got to work safely or checking they are breathing)
I avoid certain TV shows and films because I worry that they might relate to my worries
I google things to get reassurance about my worries (e.g. googling health symptoms or searching for what is 'normal')

Just like with worries, some compulsions are harder to talk about, especially if you have been doing some compulsions for some time now and you are worried about telling people what you have been struggling with. Here is a list of some other types of compulsions which are very, very common. However, people often don't talk about these types of compulsions due to things like embarrassment and shame. There is nothing to be embarrassed about with OCD, and your loved ones are not going to judge you – they just want to help.



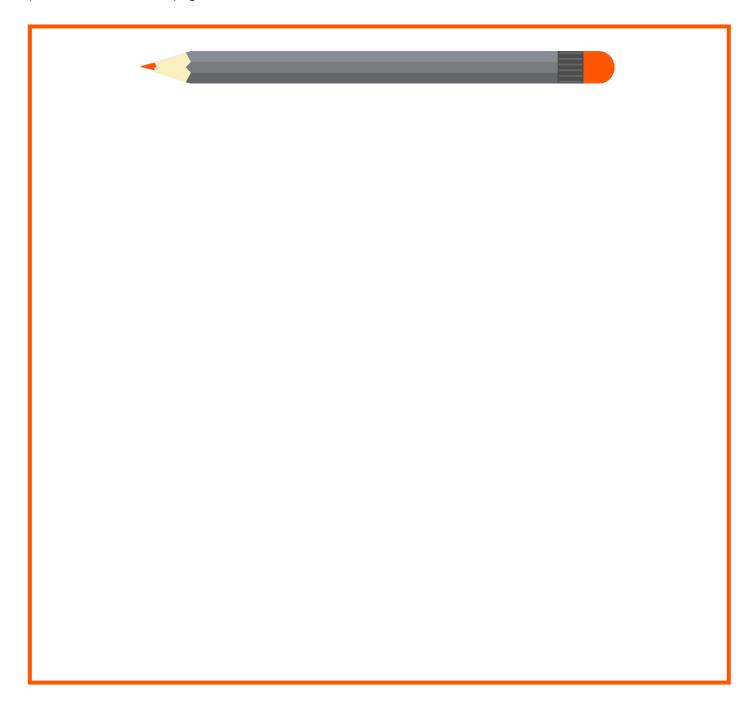
You don't have to fill in anything you don't want to, and like before, if you tick a box that you aren't ready to talk about yet, you can put a star next to it.

I have to hide certain objects like knives because I am worried about being near them
I can't be near someone when they are using scissors or any other sharp object
I repetitively check my memories to check I haven't hurt someone
I have to avoid certain people, like vulnerable people, elderly people, or children in case I am a danger to them
I have to check how I feel when I am around certain people to make sure I am not attracted to them
I have to say a prayer in a particular way to make sure I am not blasphemous
I have to confess certain thoughts I have had so that I am not immoral
I avoid certain family members as I worry about being attracted to them or that I could become pregnant from being near them
I have to check my social media to make sure I haven't said anything awful on there or liked something I do not agree with



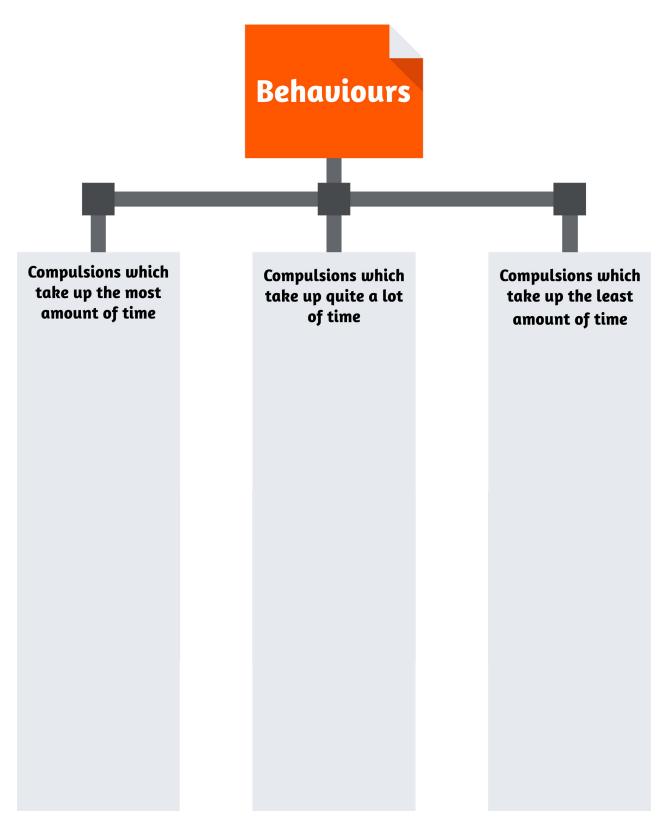
Any other behaviours?

Are you doing any other compulsions that might not have been listed in the specific tick boxes above? If so, that's ok, and very normal. Lots of people have other compulsions which might be more personal to them because that's usually how OCD works. If there are any other compulsions you have which you want to share, you can use this blank page here...



Rating behaviours

If the people who care about you know which compulsions bother you the most and take up the most amount of time, they might be able to help you better and have a more in-depth understanding of how you are struggling. If you can, would you like to try rating your compulsions? The left column is for the compulsions which take up the most amount of time, the middle is for the compulsions which take up quite a lot of time (but not as much as the compulsions in the left column) and the column on the right is for the compulsions which take up some time but not as much as the other two columns. Don't worry if you find that they all take up roughly the same amount of time, that's normal too.



Well done



If you have got to this point and you are struggling to fill in some parts of this booklet, don't worry, that's normal. You still deserve self-compassion and kindness. OCD is hard to deal with, and it can make us feel many different things all at once. Just because you are struggling with this booklet now, it doesn't mean you always will. You could try to take a break for now and maybe come back to it another time or day when you are feeling ready.

You will be pleased to know we will no longer be talking about obsessions or compulsions, and in this next section we want to explore more about what strategies will help you when you are struggling. This part of the booklet can help those who care about you to know how to respond when you are feeling anxious, distressed, or if your mood is low.



Support

There are many ways someone can support you when you are struggling, and different people will have different preferences and that's ok too. It's helpful if the people who care about you and are supporting you know what might help you when you are finding things challenging. Circle any suggestions below that you feel would help you, so you can share this with anyone you wish to. Some of the examples on this page have been recommended by other young people with OCD who have shared their preferences for how people can support them when they are struggling.



Don't force me if I don't feel ready to do something

Listen even if you don't have the answers

Be patient with me

Remind me of all the things I have overcome so far

Come for a walk with me

Give me some space if I ask for it

Watch a comfort show with me

Remind me to eat, have water, rest etc

Do something creative with me (drawing/ designing/writing)

Take me on a drive (or sit outside with me)

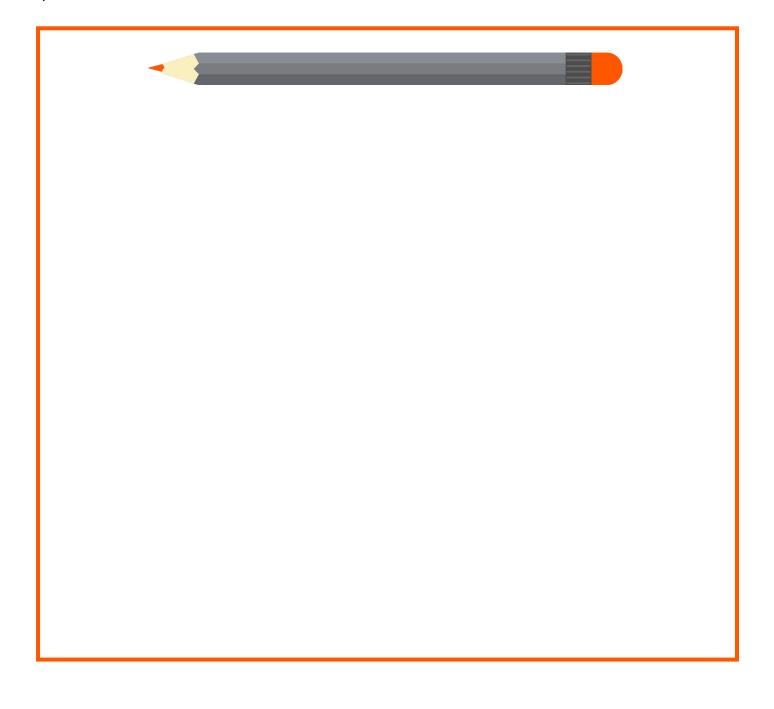
Take me away from the situation

Listen to music with me



Other ideas for support?

Here is a blank page to write down ways that people can help in case it wasn't listed on the previous page. You can also use this section to write down anything else you would like to share with someone who is supporting you.





You have reached the end of this booklet, well done for getting here! Even if you haven't been able to fill in every part of this booklet, well done for reading it and trying, that is a huge step. Remember, you can always come back to it another day and try again if you need to. The next step is to hand this booklet to any family member or carer who is supporting you. You don't have to be there when they read it if that helps you to feel more confident when passing it over.

In the meantime, if you feel it would help you to join our monthly online support groups for young people (ages 12-17) then do go ahead and visit our online support group page by clicking here or visiting our website. On the support group page, scroll down to the 'themed' group section where you will find more details about when our next young people's support group will take place. For anyone aged 18 or over, we also have a young adult online support group for those aged 18-25 too.

The support groups are a non-judgmental and supportive environment and are hosted by people who have lived experience of OCD. The aim of the groups is to create a safe space for young people to open up about their worries and communicate with other young people. If you don't feel ready to speak, it's totally ok to just listen too.

OCD might be causing a huge problem in your life right now but remember that people can and do recover. It might take some time, but recovery is worth it and when you are feeling better you will be able to do things that right now feel impossible. Recovery is possible and you will get there. Keep going, and don't forget to reach out to us if you need anything by emailing us by clicking here.

You've got this!

With very best wishes Team OCD-UK

