



obsessive compulsive disorder



an information guide for
young people

CD-UK is the leading national charity, independently working with and for young people affected by Obsessive Compulsive Disorder (OCD)

Registration Charity Number: 1103210



so many

Questions



what is *OCD*?

OCD (Obsessive-Compulsive Disorder) comprises two parts – obsessions and compulsions. Obsessions are unwanted, intrusive, upsetting thoughts or images which come into your head and cause you distress. Compulsions are the actions or rituals which you carry out in order to get rid of, prevent or 'neutralise' the obsessions. People with OCD also carry out compulsions to try to relieve the anxiety caused by the obsessions.

Common examples of *obsessions*

- worrying that you or something/someone is contaminated
- worrying about HIV/AIDS
- worrying that everything needs to be arranged symmetrically or at perpendicular angles etc
- worrying about causing harm to yourself or others
- unwanted or unpleasant sexual thoughts and feelings
- intrusive violent thoughts
- worrying that something terrible will happen unless you check repeatedly

Common examples of *compulsions*

- excessive washing
- excessive cleaning
- checking that items are arranged 'just right'
- mental rituals or thought patterns to 'neutralise' an obsessional thought
- counting to a certain number in your head
- avoiding places/situations where your OCD is usually at its worst
- checking that you have done something correctly, e.g. that you have locked the door, switched the gas off, switched the oven off, closed the window etc

Some people will not have any physical compulsions with their OCD, all their compulsions will be carried out in the head, this is sometimes referred to as a form of OCD called **Pure 'O'**. The compulsions manifest as unseen mental rituals, but they are compulsions nonetheless, which is why the term Pure 'O' is somewhat imprecise.



So many worries

How many people does OCD affect?

OCD is thought to affect about 1.9% to 3 % of young people. As an example, in a typical secondary school of 1000 pupils, there may be around 20 young people with OCD. There are approximately 12 million under 16s in the UK, so it is estimated that about 300,000 of these will have OCD.

Do I have OCD?

There is no medical test which can say for certain whether or not you have OCD, as it's not like other illnesses where there are blood tests which can be carried out to give a conclusive result. There are, however, questionnaires which your mental health professional may ask you to fill in to help him/her determine whether or not you are suffering from OCD.

There are a number of online self diagnostic tests for OCD, but these are not reliable, even as a guide and therefore should be avoided. You can however find more information about OCD symptoms on websites such as those listed at the back of this guide.

What should I do if I think I have OCD?

If you have OCD it may be stopping you from getting on with your life and doing the things that you enjoy. Therefore, if you think you have OCD you should speak to someone you trust about it; this could be a:

- parent
- older sibling
- aunt or uncle
- teacher at school/college
- school nurse
- doctor

They should be able to help you get an appointment with your GP, who can then advise you on the best way forward. Many people find it very difficult confiding in someone about their OCD, but it really is the best way to break the OCD cycle and set you on the way to recovery and to the life which you deserve to lead free of OCD!

OCD-UK has created a simple 'ice breaker' handout for you to hand to a GP or parent that explains you may have OCD. You can download this free of charge from the OCD-UK website.

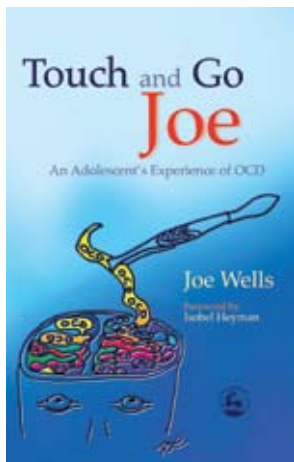
Joe's story

Twelve years ago I developed the first signs of diagnosable OCD. At the age of 8 I became overly concerned with contamination and poisoning. A few years later these worries were replaced with new worries relating to religious anxieties which took an even firmer grip over my life. Later the religious thoughts changed to thoughts about my family dying and then thoughts about losing my soul.

When I was 11, a newly qualified GP failed to diagnose me in favour of staring at me with an 'I'm out of my depth' look on his face and asking me a few bewildering questions; 'do you think this could be a psychological thing?', "do you hear voices?". This strengthened my fear of people finding out about these thoughts and compulsions and it wasn't until a year or two later when my OCD had become so severe that it was seriously interfering with my life that I returned to a different GP who referred me on to CAMHS (Child And Adolescent Mental Health Services) to have CBT treatment. After 2 or 3 years of using CBT alongside medication, support from my family, relaxation techniques and a lot of willpower I got to the point where I considered my self free from OCD's control. I wouldn't say that I was 'cured' of OCD but I believe that I am now in control of my OCD as opposed to my OCD being in control of me. It wasn't easy (in fact more often than not it was very hard) and it wasn't always a smooth journey, but I got there in the end and I can't describe how much being free from OCD was worth the struggle to get there.

At the age of 15 I started writing about my experiences and a year later those writings were published as 'Touch and Go Joe, an Adolescent's Experience of OCD' which has now sold over 3,000 copies worldwide and been translated into two foreign languages. I have travelled all over the country raising awareness of OCD by talking about my experience. I am now free to follow my interest in comedy and am beginning to make a name for myself on the stand-up comedy circuit.

Philosopher Friedrich Nietzsche said that he who has a "why" can endure any "how". Being free from OCD, being able to live my life without it getting in the way, having the confidence to speak to large groups and to perform stand-up comedy is my "why" and that long struggle against OCD, which at times seemed hopeless, was the "how".



Joe's book Touch and Go Joe, an Adolescent's Experience of OCD can be purchased direct from OCD-UK.



why?

Why do I have *OCD*?

No-one knows exactly why one person has OCD while another hasn't.

Some scientists believe that there some people have a genetic predisposition to OCD, e.g. if a parent or other close relative has OCD, then they are more likely to suffer from OCD too.

Some experts believe OCD is caused by psychological learned factors, the OCD symptoms are a result of a person perhaps being more prone to worrying for example. Some young people who develop OCD often feel very 'responsible' for causing or stopping harm happening to themselves or other people like their parents. This feeling of being 'very responsible' can increase the chances of OCD, as can other awful events like someone close dying or bullying through your childhood. Although it is important to remember that OCD is no-one's fault.

Others believe that OCD is influenced by low levels of a neurotransmitter (chemical in the brain) called serotonin.

The fact is we simply don't know what causes OCD, it could be a combination of all of these factors, we simply don't know why some get it whilst others don't.

It's important to remember that OCD is a medical condition that can be treated, just like if you have asthma or diabetes. You haven't done anything 'wrong' to be affected by OCD, nor does it mean you are a 'bad', 'crazy', 'evil' or a 'weak' person.

OCD can affect anyone, of either gender, of any age, from any walk of life, even sports stars and famous celebrities have also talked about having OCD symptoms in the past.

it can be treated!



Sarah's story

I've had OCD since I was about 6 and have always felt 'different'. I found out it was OCD when I read an agony aunt letter in a magazine talking about OCD when I was 13. I immediately recognised myself and my symptoms in the letter but felt too embarrassed to tell my parents or seek medical help. At the time I told a few of my close friends but always kept it from the people who could really help or who I feared losing.

For as long as I can remember I've always had an obsession with numbers, feeling as though they have significance to things that happen in life. My OCD makes me believe that 3 is a bad number and if I do something 3 times, such as touch something 3 times, eat 3 things, then bad things will happen. Over time it's gone from there being no specific bad thing that will happen to it becoming a fear of my mother dying. This causes terrible anxiety and fear meaning I have no power over resisting compulsions. At the same time there was always a fix in the form of doing something 4 times. The number 4 and any multiple of 4 was always the 'lucky' number, making everything OK. Although this makes everything good it means I have to touch things up to 40 times before it feels 'right' – very exhausting and time consuming.

However, these aren't the only ways in which OCD controls me. Everything has to be even and symmetrical for me, for example if I scratch one arm the other has to be scratched too. My OCD tends to be much worse in times of stress or just before bed, mainly when I can't be in control of everything. Before I go to bed I have lengthy rituals to complete, such as touching the light-switch around 28 times and ensuring my phone is in the correct position on my bed; altogether it takes me around half an hour to complete my rituals before I can sleep.

During my GCSE's my OCD spiralled out of control and I knew that it was time to get help. Friends I have made through OCD-UK who have recovered from OCD gave me the courage to go to the doctors, something that terrified me for weeks before my appointment. The doctor was very understanding and it was nothing like the ordeal I had thought it would be; this made me realise how important it is to get medical help. Currently I am waiting for an appointment with a psychologist and I am looking forward to learning how to deal with my OCD and get on with the rest of my life. It can get better with the correct help.

I have also told my parents and am getting amazing support from them and from friends with and without OCD.

Even though OCD feels like a curse, I know I can beat it and it has led me to see the world from a different perspective as well as making amazing new friends.

the Dr was very understanding



*there is
help!*

Can OCD be treated?

Yes! the first kind of help they would offer is CBT (Cognitive-Behavioural Therapy) – carried out in conjunction with a cognitive-behavioural therapist or a clinical psychologist who will talk with you about your OCD fears.

Each appointment will last up to one and a half hours, and you will probably also be asked to carry out some sort of 'homework' on your own between sessions. He/she will then help you to gradually face your fears. This should also involve a form of therapy called ERP (Exposure and Response Prevention). During ERP you will gradually be exposed to an OCD trigger and helped to avoid carrying out the OCD ritual. Through this technique, you should learn that the anxiety will eventually die down and disappear, without you carrying out your OCD ritual(s). ERP can be hard, but you will never be forced to do something you don't want to. Your therapist will guide you through the process, rather than force you through it.

medication

SSRI medication

SSRI medication (selective serotonin-reuptake-inhibitors) – prescribed by your GP or a psychiatrist is the other recommended treatment for OCD. Some people, especially when their OCD has gone on for a long time and is very entrenched find that they need the additional support of SSRI medication to help them along the road to recovery from OCD. SSRIs work by preventing the neurotransmitter serotonin from being reabsorbed into the brain quickly, thus elevating your mood and reducing anxiety. SSRIs are medicines which are also used against depression, which often occurs amongst people with OCD.

Taking medication is not a failing, many people use medication like 'water wings' until they feel confident enough to tackle OCD and CBT on their own.

CBT is suggested by NICE (National Institute of Clinical Guidelines) as the first line of treatment for young people with OCD. However, due to long waiting lists in parts of the country, some doctors will recommend that you try SSRIs whilst waiting for CBT to become available. Some OCD sufferers use CBT and SSRIs at the same time, as they find that the SSRIs take the edge off the anxiety so that they can fully engage with the CBT. SSRIs can take a while to work and you may also have to try a few different types of SSRI medication to find one which works for you.

Some people are more susceptible to side-effects than others, so you should be monitored by your prescribing doctor. It's also important to remember that a medication which is effective for one person may not work so well for another, so a little 'trial and improvement' by your doctor is needed.

Once your OCD symptoms have reduced to a more manageable level it is usually advised that you remain on medication for between 6 months and a year to avoid a relapse. If you no longer wish to remain on medication then it's vital you discuss this with your doctor rather than stopping the medication on your own. Reducing SSRIs needs to be done slowly, carefully and under medical supervision.





my parents ? do i have to tell them .

Do I have to tell my parents if I want to see my GP?

On the whole it is helpful to get the support of your family, as fighting OCD can be very challenging. However if you prefer your GP will see you and talk with you without either of your parents being present. He/she can refer you for CBT without telling your parents and can also prescribe medication for you if appropriate to do so. Some teenagers with OCD prefer not to tell their parents about their OCD, whereas others find that it's helpful to have their parents' support; it's really a personal choice.

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

private & confidential

what else you need to know

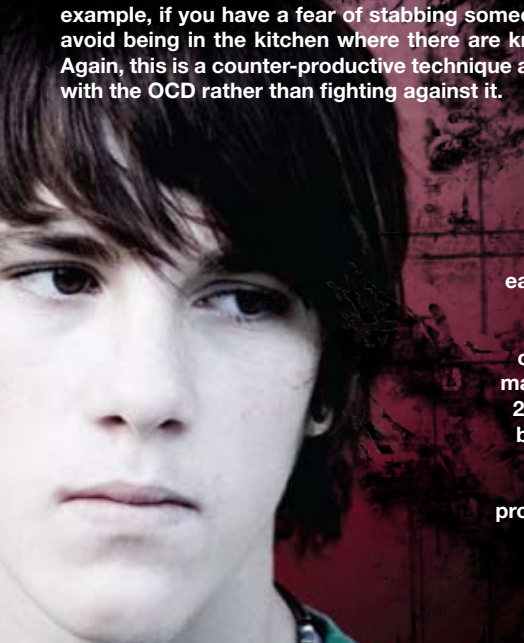
What is 'Reassurance' / 'Avoidance'?

Reassurance and avoidance are two techniques which are often used by OCD sufferers in a bid to reduce their anxiety. However, they are both counter-productive as they feed the OCD rather than minimising it.

Reassurance is when a sufferer involves other people in their rituals. For example this could be asking your mum or dad or friend if something is contaminated, if your hands are clean, if you've hurt or upset someone. Whilst reassurance is extremely effective in the short term at relieving anxiety, its long-term effect is to strengthen the OCD, so should be avoided whenever possible. For example the more you ask for reassurance, the more you will find you want to ask for it the next time you have an OCD obsessional thought.

Your therapist might ask to meet with your family so that he/she can help them with the best ways of tackling the reassurance seeking behaviour in a gradual way.

Avoidance is when a sufferer deliberately avoids going to certain places or meeting with certain people etc because they find that their OCD increases when they are in these situations. For example, if you have a fear of stabbing someone then you might avoid being in the kitchen where there are knives and scissors. Again, this is a counter-productive technique as it is co-operating with the OCD rather than fighting against it.



Fighting OCD is not easy, but with the help and support of the people around you it can be achieved. You may also find you have 2 steps forward and 1 back, this is perfectly normal and shows that you are making progress with the OCD.



*i don't
want anyone
to know*

Should I tell my friends about OCD?

You may wonder if you should talk to your friends about your OCD. There is no right or wrong answer to this question, as each person is different.

Some of your friends may not know about or understand OCD so you might have to tell them about what it is and how it affects you. You might find that talking about it with them helps you or might feel that it's something private which you don't feel comfortable sharing at the moment.

Whatever you decide is up to you. If you don't tell your friends today, you can always talk to them another day. Perhaps today is not the right time to tell friends, but maybe next week you may feel more comfortable and able to talk to them. Friends can play a very important part in your 'support system' should you need positive encouragement or just someone to listen when you are feeling low, but you shouldn't feel pressured to tell them if you don't feel happy with it.

*Someone
to listen to*

my course work suffers

Do I have to tell my school / college about OCD?

Again, this is a personal decision and there is no right or wrong answer.

Some sufferers find that their OCD affects their schoolwork and so choose to inform the school/college. It can be useful to have someone such as a school nurse or counsellor to talk to when you're struggling with OCD symptoms and it may also help you if your teachers/tutors are aware of the symptoms that are affecting you.

Struggling with OCD symptoms 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 are increasing all the time so it is likely that your teachers/tutors will be able to offer you support and assistance should you need it.

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 any meetings when informing the school, should you feel that their presence and support would be helpful. Also, many therapists are more than happy to write a letter to the school/college to explain about your OCD and how it affects you.

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




jo's story

**OCD sufferer Jo,
aged 20, also shared her experiences of OCD with us:**

When I was 15 I realised how preoccupied I was with contamination / cleanliness etc and how much time I was spending washing each day. Looking back, I can see OCD in me when I was much younger, but I didn't know what it was at that age. I later also developed a fear of sexually harming children and so I started to avoid being around children in case I did something wrong.

During my teenage years I used to make excuses to avoid doing things and going to places that I knew would trigger my OCD e.g. going to a busy shopping centre because I knew that there would be kids there. I also used to be a very keen swimmer and water-polo player but I gave up because my contamination fears meant that I was too afraid to swim in a pool. At my worst, I would spend hours in the bathroom washing and do maybe four washing machine loads in one day. I would also avoid drinking (soft drinks) and sometimes went for 2 or 3 days without drinking anything. This was because I thought that if I didn't drink then I wouldn't have to go to the toilet as often and so I wouldn't have to spend as much time washing. I feared contaminating my schoolwork so I would do my homework whilst wearing plastic/rubber gloves (the type used by people who prepare food) and would sometimes throw away work and re-write it because I thought that I had contaminated the paper. I had the same problem with pens and threw away a lot of them because of fears that they were contaminated. When I sat my GCSEs I took a big pile of pens into the exam room with me and would switch pens when I thought that one was contaminated. My exam papers must have looked very strange as they were written in different shades of blue/black!



I
feared
contamination

As a result of my OCD (or possibly as a coinciding factor) I became severely clinically depressed. I self-harmed on a regular basis, sometimes more than once a day. When I was 18 I took an overdose because I felt that I couldn't cope with the OCD any more. About 5 months later I had another serious suicide attempt and ended up spending a short time under a mental health 'section' in hospital. I had become so depressed that I couldn't see myself ever getting better.

I am not 'cured' of OCD, far from it, but I am a hundred times better than I was. I put this down to support from those around me, an excellent CBT therapist, and the right SSRI medication for me. I am lucky that I found two good therapists (one in England and one where I now live in Sweden). I also receive a lot of support from my fiancé (who is also an OCD sufferer) and I support him too – it works very well for us.

Support from those around me



Jo (pictured here) now helps support other young people affected by OCD by volunteering with OCD-UK

www.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).

The Institute of Psychiatry website at <http://psychology.iop.kcl.ac.uk/oodkids>

A nice, informal way of talking with other young people with OCD is on the OCD-UK discussion forums at www.ocdforums.org,

The National Service for Young People with OCD www.ocdyouth.info

Getting involved with OCD-UK

If you would like to help other young people with OCD, 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***.

©OCD-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 'Jolly and Grump Children's Guide to OCD' and 'A Parent's Guide to OCD' – Please send an A4 sized large letter SAE to receive your copies – be sure to state which booklet you require.

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

If you found this booklet helpful, please consider making a donation online or by texting the word OCD to 84424 to donate £1.50



Supported by
The National Lottery®
through Awards for All



OCD-UK would like to acknowledge the kind support of Dr Victoria Bream-Oldfield, Leigh Jackson, Jo Sharnan The team from the National Service for Young People with OCD and Related Disorders from the Children's department of the Maudsley Hospital in London. 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

Registration Charity Number: 1103210

OCD-UK