Obsessive-Compulsive Disorder

About this leaflet

This leaflet is for anyone who has problems with obsessions or compulsions, their family and friends – and anyone else who wants to find out more.

In this leaflet you can find:

- what it is like to have OCD
- how to help yourself
- what help is available
- places to get help
- other sources of information
- references to research and policy documents.

Introduction

"He's an obsessive football fan" - "she's obsessive about shoes" - "he's a compulsive liar". We use these expressions when we talk about people who do something again and again, even when others can't see any reason for it. It isn't usually a problem and, in some lines of work, can even be helpful. However, the urge to do or think certain things repeatedly can dominate your life unhelpfully.

So, if:

- you get awful thoughts coming into your mind, even when you try to keep them out

or

- you have to touch or count things or repeat the same action like washing over and over

you could have Obsessive Compulsive Disorder (OCD).

What is it like to have OCD?

Liz  "I'm afraid of catching something from other people. I spend hours bleaching all the surfaces in my house to stop the germs, and wash my hands many times each day. I try not to go out of the house if possible. When my husband and children come back home, I ask them in great detail where they have..."
been, in case they have visited somewhere dangerous, like a hospital. I also make them take off all their clothes, and wash themselves thoroughly. Part of me realises these fears are stupid. My family are sick of it, but it has gone on for so long now I can't stop".

John  "My whole day is spent checking that nothing will go wrong. It takes me an hour to get out of the house in the morning, because I am never sure that I've turned off all the electrical appliances like the cooker, and locked all the windows. Then I check to see that the gas fire is off five times, but if it doesn't feel right I have to do the whole thing again. In the end, I ask my partner to check it all for me again anyway. At work I am always behind as I go through everything several times in case I have made a mistake. If I don't check I feel so worried I can't bear it. Its ridiculous I know, but I think if something awful did happen, I'd be to blame".

Dawn  "I fear I will harm my baby daughter. I know I don't want to, but bad thoughts keep coming into my head. I can picture myself losing control and stabbing her with a knife. The only way I can get rid of these ideas is to say a prayer, and then have a good thought such as "I know I love her very much". I usually feel a bit better after that, until the next time those awful pictures come into my head. I have hidden away all sharp objects and knives in my house. I think to myself "you must be a horrible mother to think like this. I must be going mad".

**OCD has three main parts:**

1. the thoughts that make you anxious (obsessions)
2. the anxiety you feel
3. the things you do to reduce your anxiety (compulsions).

**What you think (obsessions)**

- **Thoughts** - single words, short phrases or rhymes that are unpleasant, shocking or blasphemous. You try not to think about them, but they won't go away. You worry that you might be contaminated (by germs, dirt, HIV or cancer), or that someone might be harmed because you have been careless.
- **Pictures in your mind** - showing your family dead, or seeing yourself doing something violent or sexual which is completely out of character - stabbing or abusing someone, or being unfaithful. We know that people with obsessions do not become violent, or act on these thoughts.
- **Doubts** - you wonder for hours whether you might have caused an accident or misfortune to someone. You may worry that you have knocked someone over in your car, or that you have left your doors and windows unlocked.
- **Ruminations** - you endlessly argue with yourself about whether to do one thing or another so you can't make the simplest decision.
- **Perfectionism** - you are bothered, in a way that other people are not, if things are not in the exactly the right order, not balanced or not in the right place. For example, if books are not lined up precisely on a bookshelf.

**The anxiety you feel (emotions)**

- You feel tense, anxious, fearful, guilty, disgusted or depressed.
- You feel better if you carry out your compulsive behaviour, or ritual - but it doesn't last long.

**What you do (compulsions)**

- **Correcting obsessional thoughts** - you think alternative 'neutralising' thoughts like counting, praying or saying a special word over and over again. It feels as though this prevents bad things
from happening. It can also be a way of getting rid of any unpleasant thoughts or pictures that are bothering you.

- **Rituals** - you wash your hands frequently, do things really slowly and carefully, perhaps arrange objects or activities in a particular way. This can take up so much time that it takes ages to go anywhere, or do anything useful.

- **Checking** - your body for contamination, that appliances are switched off, that the house is locked or that your journey route is safe.

- **Avoidance** - of anything that is a reminder of worrying thoughts. You avoid touching particular objects, going to certain places, taking risks or accepting responsibility. For example, you may avoid the kitchen because you know you will find sharp knives there.

- **Hoarding** - of useless and worn out possessions. You just can't throw anything away.

- **Reassurance** - you repeatedly ask others to tell you that everything is alright.

**How common is OCD?**

About 1 in every 50 people suffer from OCD at some point in their lives, men and women equally. That adds up to over 1 million people in the U.K. Famous sufferers may have included the biologist Charles Darwin, the pioneer nurse, Florence Nightingale, the actress Cameron Diaz, and the soccer player David Beckham.

**If you gamble, eat or drink 'compulsively', do you have OCD?**

No. The words 'compulsive' and 'obsessive' are sometimes used to describe people who gamble, drink alcohol, shop, use street drugs – or even exercise too much. However, these behaviours can be pleasurable. The compulsions in OCD never give pleasure – they are always felt as an unpleasant demand or burden.

**How bad can OCD get?**

It varies a lot, but work, relationships and family life are all more productive and satisfying if you are not constantly having to cope with OCD. Severe OCD can make it impossible to work regularly, to take part in family life – or even to get on with your family. In particular, they may become upset if you try to involve them in your rituals.

**Are people with OCD 'mad'?**

No - but you may be reluctant to seek help if you think that others will think you are mad. It's common to feel ashamed or try to hide this problem. Although you may worry that you will lose control, we know that people with OCD don't.

**Other conditions similar to OCD**

- Body dysmorphic disorder, or 'the distress of imagined ugliness'. You become convinced that part of your face or body is the wrong shape, and spend hours in front of a mirror checking and trying to cover it up. You may even stop going out in public.

- An urge to pull out your hair or eyebrows (Trichotillomania).

- A fear of suffering from a serious physical illness, such as cancer (Health anxiety or hypochondriasis).

- People with Tourette's syndrome (where a sufferer may shout out suddenly, or jerk uncontrollably) often have OCD as well.
• Children and adults with some forms of autism, like Asperger's syndrome, can appear to have OCD because they like things to be the same, and may like to do the same thing over and over again.

**When does OCD begin?**

Many children have mild compulsions. They organise their toys very precisely, or avoid stepping on cracks in the pavement. This usually goes away as they grow older. Adult OCD usually begins in the teens or early twenties. Symptoms can come and go with time, but sufferers often don't seek help until they have had OCD for many years.

**What is the outlook without help or treatment?**

Many people with mild OCD improve without treatment. This does not usually happen with moderate to severe OCD, although there may be times when the symptoms seem to go away. Some will slowly get worse, for others the symptoms get worse when they are stressed or depressed. Treatment will usually help.

**What causes OCD?**

**Genes:** OCD is sometimes inherited, so can occasionally run in the family.

**Stress:** Stressful life events bring it on in about one out of three cases.

**Life changes:** Times where someone suddenly has to take on more responsibility – for example, puberty, the birth of a child or a new job.

**Brain changes:** We don't know for certain, but if you have the symptoms of OCD for more than a short time, researchers think that an imbalance of a chemical called serotonin (also known as 5HT) develops in the brain.

**Personality:** If you are a neat, meticulous, methodical person with high standards you may be more likely to develop OCD. These qualities are normally helpful, but can slip into OCD if they become too extreme.

**Ways of thinking:** Nearly all of us have odd or distressing thoughts or pictures in our minds at times - "what if I stepped out in front of that car?" or "I might harm my child". Most of us quickly dismiss these ideas and get on with our lives. But, if you have particularly high standards of morality and responsibility, you may feel that it's terrible to even have these thoughts. So, you are more likely to watch out for them coming back - which makes it more likely that they will.

**What keeps OCD going?**

Surprisingly, some of the ways in which you help yourself can actually keep it going:

• Trying to push unpleasant thoughts out of your mind - this usually only makes the thoughts return. For example, try not to think of a pink elephant for the next minute – you will probably find it difficult to think of anything else.

• Thinking 'safe' or 'correcting' thoughts. For example, you spend time putting right a disturbing thought with another thought (like counting to ten) or picture (such as seeing a person alive and well).

• Rituals, checking, avoiding and seeking reassurance will all make you less anxious for a short time
especially if you feel that this might prevent something dreadful from happening. But, every
time you do them, you strengthen your belief that they stop bad things from happening. And so
you feel more pressure to do them.... and so on.

**Helping yourself**

- Remember - it's not your fault and you are not going 'mad'.
- Expose yourself to your troubling thoughts. This sounds odd, but it's a way of getting more
  control of them. You record them and listen back to them, or write them down and re-read them.
  You need to do this regularly for around half an hour every day until your anxiety reduces.
- Resist the compulsive behaviour, but not the obsessional thought.
- Don’t use alcohol or street drugs to control your anxiety.
- If your thoughts involve worries about your faith or religion, then it can sometimes be helpful to
  speak to a religious leader to help you work out if this is an OCD problem.
- Contact one of the support groups or websites listed at the end of this leaflet.
- Buy a self-help book such as one of those listed at the end of this leaflet.

**Getting help**

- **Cognitive Behavioural Therapy (CBT).** This is a treatment that helps you change the way you
  think and behave so you can feel better and get on with your life.

There are two types of CBT used to treat OCD - **Exposure and Response Prevention (ERP)** and
**Cognitive Therapy (CT).**

- **Exposure and response prevention (ERP)**

This is a way to stop compulsive behaviours and anxieties from strengthening each other. We know that
if you stay in a stressful situation long enough, you gradually become used to it and your anxiety goes
away. So, you gradually face the situation you fear (exposure) but stop yourself from doing your usual
compulsive rituals, checking or cleaning (response prevention), and wait for your anxiety to go away.

It's usually better to do it in small steps:

- make a list of all the things you fear or avoid at the moment;
- put the situations or thoughts you fear the least at the bottom, the worst ones at the top;
- then start at the bottom and work up, tackling one at a time. Don't move onto the next stage
  until you have overcome the last one.

This needs to be done every day for at least one or two weeks. Each time, you do it for long enough for
your anxiety to fall to less than half what it is at its worst – around 30 to 60 minutes to start with. It
can help to write down a measure of how anxious you are every 5 minutes, for example, from 0 (no
fear) to 10 (extreme fear). You will see how your anxiety rises, then falls.

You may practice some of the steps with your therapist, but most of the time you will be doing it on
your own, at a pace you feel comfortable with. It is important to remember that you do not need to get
rid of all your anxiety, just enough to manage it better. Remember that your anxiety:

- is unpleasant but won't do you any harm;
- will go away eventually;
- will be easier to face with regular practice.
There are two main ways of trying ERP:

- **Guided self-help**

You follow the guidance in a book or DVD or use a software programme on a computer, tablet or smartphone app. You also have occasional contact with a professional for advice and support, but less often. This approach may be suitable if your OCD is mild, and you have the confidence to try out ways of helping yourself.

- **Direct regular contact with a professional, on your own or in a group.**

This can be face-to-face, over the phone or by video link. This usually happens every week or two weeks to start with, and can last for between 45 and 60 minutes at a time. Up to ten hours of contact is recommended to start with, but you may need more.

**An example:**

John could not leave the house on time for work every day, because he had to check so many things in the house. He worried that the house might burn down, or he might be burgled if he did not check certain things five times each. He made a list of what he was checking, starting with the easiest to tackle. It looked like this:

1. the cooker (least feared)
2. the kettle
3. the gas fire
4. the windows
5. the doors (the most feared)

He began with step one. Instead of making sure that the cooker was switched off several times, he checked it only once (exposure). At first he felt very anxious. He stopped himself from going back to check again. He agreed not to ask his wife to check everything for him as well, and not to ask her for reassurance that the house was safe (response prevention). His fear gradually lessened over two weeks. Then he moved on to step two (the kettle) and so on. Eventually, he was able to leave the house without any of his checking rituals and get to work on time.

- **Cognitive Therapy (CT)**

Cognitive therapy is a psychological treatment which helps you to change your reaction to the thoughts, instead of trying to get rid of them. This is useful if you have worrying obsessional thoughts, but do not perform any rituals or actions to make yourself feel better. It can also be added to exposure treatment (ERP) to help overcome OCD.

**Cognitive therapy helps you to:**

**Stop fighting the thoughts**

We all have odd thoughts at times, but that is all they are. They do not mean you are a bad person or that bad things are going to happen – and trying to get rid of such thoughts just doesn't work. Relax in their presence. Treat them with mild curiosity or amusement. If even more unpleasant thoughts intrude, don't resist, let them happen, and think about them in the same way. Thoughts will often fade away when you are happy to let them stay.

**Change your reaction to your thoughts**
You learn to notice when you are having upsetting 'thoughts about thoughts' such as 'I'm a bad person for thinking like this.' You may keep a diary of these unhelpful ways of thinking, then challenge them by asking yourself:

- What is the evidence for and against this idea being true?
- How useful is this thought? What's another way to look at this?
- What's the worst/best/most realistic outcome?
- How would I advise a friend who had my problems? If different to the advice I give myself, what makes me so special?

**Deal with responsibility and blame**

You tackle unrealistic and self-critical thoughts, such as:

- placing too much importance on your thoughts (they are 'just' thoughts);
- overestimating the chances of something bad happening;
- taking responsibility for bad things happening, even when they are out of your control;
- trying to get rid of all risk in the lives of your loved ones.

**Test out unhelpful beliefs**

A common fear in OCD is that 'thinking it will make it happen'. Try looking out of the window at a building and think about it falling down. Get a really strong picture in your mind. What happens? Another upsetting belief is that 'having thoughts is as bad as carrying them out'. Imagine your neighbour is unwell and needs some shopping done. Just think about doing it. Does that make you a good person? In order to be helpful, you have to do the action. The same is true for 'bad' thoughts. It is important to learn that obsessional thoughts are not carried out in reality.

A cognitive therapist will help you to decide which of your ideas you want to change, and will help you to build new ideas that are more realistic, balanced, and helpful.

Most meetings with a therapist take place at your local GP practice, a clinic or sometimes a hospital. You might be able to have CT over the phone, or in your own home if you can't leave your house.

**Antidepressant medication**

SSRIs (Selective Serotonin Reuptake Inhibitors) can help to reduce obsessions and compulsions, even if you are not depressed. Examples include sertraline, fluoxetine, paroxetine, escitalopram and fluvoxamine. They are generally safe, but may cause side-effects in the first few days like a headache, dry mouth or feeling sick. SSRIs can be used alone, or with CBT, for moderate to severe OCD. Higher doses often work better for OCD. If treatment with an SSRI has not helped at all after 3 months, the next step is to change to a different SSRI or a medication called Clomipramine. It is best to continue medication for at least 12 months, if it is helping. These medications are not addictive, but should be gradually reduced over several weeks before stopping.

**How well do these treatments work?**

**Exposure Response Treatment (ERP)**

About 3 out of 4 people who complete ERP are helped a lot. Of those who get better, about 1 in 4 will develop symptoms in the future, and will need extra treatment. BUT, about 1 in 4 people refuse to try ERP, or else do not finish it. They may be too fearful, or too overwhelmed to do it.
Medication

About 6 out of 10 people improve with medication. On average, their symptoms reduce by half. Anti-obsessional medication does help to prevent OCD coming back for as long as it is taken, even after several years. Unfortunately, about 1 in 2 of those who stop medication will get symptoms again in the months after stopping it. This is much less likely to happen if the medication is combined with CBT.

Which approach is best for me – medication or talking treatments?

Exposure therapy (ERP) can be tried without professional help (in milder cases) and is effective and has no side-effects, apart from anxiety. On the other hand, it needs a lot of motivation and hard work, and it does involve some extra anxiety for a short time.

CBT and medication are probably equally effective. If you have only mild OCD, CBT on its own is effective.

If you have moderately severe OCD, then you could choose either CBT (up to 10 hours of contact with a therapist) or medication (for 12 weeks) first. If you are no better, then you should try both treatments. There may be a waiting list to see a professional of several months in some parts of the country.

If your OCD is severe, it's probably best to try medication and CBT together from the start. Medication alone is an option if your OCD is more than mild, and you don't feel you can face the anxiety of ERP and your OCD. It helps about 6 out of 10 people, but there is more chance that the OCD will return in the future – about 1 in 2 compared with about 1 in 4 for exposure treatments (ERP). It does have to be taken for about a year, and is obviously not ideal during pregnancy or breastfeeding.

It's worth talking these options over with your doctor who should be able to give you any further information you need. You may also want to ask trusted friends or family members.

What if the treatment does not help?

Your doctor can refer you to a specialist team, which may include psychiatrists, psychologists, nurses, social workers and occupational therapists. They may suggest:

- adding cognitive therapy to exposure treatment or medication;
- taking two anti-obsessional medicines at the same time, such as clomipramine plus citalopram;
- adding antipsychotic medication, such as aripiprazole or risperidone;
- treating other conditions (1 in 3 people with OCD also have anxiety, depression or a problem with alcohol misuse);
- working with your family and carers, to support and advise them.

If you have difficulty living on your own, they may also suggest finding suitable accommodation with people who can help you become more independent.

With treatment, the outlook for most people with OCD is good. If you have very severe OCD that has not improved, you might be offered the choice of referral for a brain operation called ‘ablative neurosurgery’. This is really a last resort as there can be serious side-effects. An alternative approach being researched is deep brain stimulation, using electrical pulses.

Will I need to go into hospital for treatment?

Most people get better by attending a GP surgery, or a clinic that can be attached to a hospital.
Admission to a mental health unit will only be suggested if:

- your symptoms are very severe, you cannot look after yourself properly or you have thoughts about suicide;
- you have other serious mental health problems, such as an eating disorder, schizophrenia, psychosis or a severe depression;
- your OCD prevents you getting to a clinic for treatment.

**Which treatments do not work for OCD?**

Some of these approaches may work in other conditions – but there is not strong evidence for them in OCD:

- Complementary or alternative therapies such as hypnosis, homeopathy, acupuncture and herbal remedies – even though they sound attractive.
- Other types of antidepressant medication, unless you are suffering from depression as well as OCD.
- Sleeping tablets and tranquillisers, (zopiclone, diazepam, and other benzodiazepines) for more than two weeks. These drugs can be addictive.
- Couple or marital therapy – unless there are other problems in the relationship besides the OCD. It is helpful for a partner and family to try and find out more about OCD and how to help.
- Counselling and psychoanalytical psychotherapy. Some people find it helpful to think about the childhood and past experiences. However, the evidence suggests that facing our fears seems to work better than talking about them.

**Tips for family and friends**

- The behaviour of someone with OCD can be quite frustrating – try to remember that he or she is not trying to be difficult or behave oddly - they are coping the best they can.
- It may take a while for someone to accept that they need help. Encourage them to read about OCD and talk it over with a professional.
- Find out more about OCD.
- You may be able to help exposure treatments by reacting differently to your relative’s compulsions:
  - encourage them to tackle fearful situations;
  - say ‘no’ to taking part in rituals or checking;
  - don't reassure them that things are alright.
- Don't worry that someone with an obsessional fear of being violent will actually do it. This is very rare.
- Ask if you can go with them to see their GP, psychiatrist or other professional.

**What if there is a long wait to start CBT?**

Your GP may refer you to a local service called 'Improving Access to Psychological Therapies' (IAPT) or to a specialist mental health team. At the moment, there is a shortage of NHS professionals trained in CBT. In some areas, you may have to wait several months to start treatment. Qualified therapists are often registered with the British Association of Behavioural and Cognitive Psychotherapies. If the measures outlined in the "helping yourself" section don't help, you can start antidepressant treatment in the meantime.
Support groups

**OCD Action**
A charity for people with OCD, body dysmorphic disorder, compulsive skin picking and trichotillomania. Help and information line: 0845 390 6232; email: support@ocdaction.org.uk.

**OCD-UK**
National support group for children and adults with OCD. Advice Line: 0845 120 3778 or email: support@ocduk.org.

**Anxiety UK**
An organisation for people with anxiety problems including panic, phobias, OCD and related conditions. Provides support to sufferers, their family and carers. Live chat, email, self-help books, CDs, DVDs and resources. Helpline: 0844 775774; email: support@anxietyuk.org.uk.

Further information

**NHS Choices**
Information from the National Health Service on conditions, treatments, local services and healthy living.

**British Association for Behavioural & Cognitive Psychotherapies (BABCP)**
The main body for the different groups of professionals who offer CBT inside and outside of the NHS. It maintains standards of good practice, provides information, leaflets and keeps a register of members who can be contacted for non-NHS treatment. Tel: 0161 054 304; email: babcp@babcp.com.

**Computerised CBT**
For information on self help computer packages for anxiety, depression, phobias, panic and OCD see our leaflet on CBT or the following links:

- www.nice.org.uk/
- www.anxietyuk.org.uk/
- www.ccbt.co.uk

Further reading

**Reading Well Agency: Books on Prescription**
Reading Well Books on Prescription helps you manage your well-being using self-help reading. The scheme is endorsed by health professionals, including the Royal College of Psychiatrists, and is supported by public libraries.

Break Free from OCD: Overcoming Obsessive Compulsive Disorder with CBT by Fiona Challacombe, Victoria Bream Oldfield and Paul Salkovskis, Vermillion.

Understanding NICE guidance – information for people with OCD or body dysmorphic disorder, their families and carers, and the public

References


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