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For better
mental health

Obsessive-compulsive disorder

Understanding obsessive-compulsive disorder

Obsessive-compulsive disorder (OCD) is described as an anxiety disorder. An obsession is a repeated unwanted thought or urge; a compulsion is a repetitive activity that you feel you have to do. OCD can be unpleasant and frightening.

This booklet aims to help you understand OCD and what treatments and help are available.

Contents

What is obsessive-compulsive disorder?

"I have, among other things, obsessive-compulsive disorder. It rules my every waking hour."

Obsessive-compulsive disorder (OCD) has two main parts: obsessions and compulsions.

Obsessions are unwelcome thoughts, idea or urges that repeatedly appear in your mind; for example, thinking that you have been contaminated by dirt and germs, or worrying that you haven't turned off the oven. These obsessions are often frightening or seem so horrible that you can't share them with others. The obsession interrupts thoughts that you would rather have, and makes you feel very anxious. Often it will make you worry that you or other people are going to be harmed.

Compulsions are repetitive activities that you feel you have to do. This could be something like repeatedly checking a door to make sure it is locked or washing your hands. The aim of the compulsion is to 'put right' the distress caused by the obsessive thoughts and relieve the anxiety you are feeling. You will be unlikely to feel any pleasure from carrying out the compulsion but you might find yourself doing it again and again.

Most people with OCD experience both obsessions and compulsions, but some people experience only obsessive thoughts, and some people have compulsions without knowing why.

If you have OCD, you know that the obsessional thoughts are your own. This makes it different to a psychotic disorder, such as schizophrenia, where people feel that certain unwelcome thoughts and ideas come from outside themselves.

OCD is described as an anxiety disorder. Other anxiety disorders include phobias and panic disorder which can share symptoms with OCD such as recurrent intrusive thoughts and fear. OCD is also known to have a close association with depression, and some people find obsessions appear or get worse when they are depressed.

How common is OCD?

Minor obsessions and compulsions are common. We all worry, occasionally, about whether we've left the gas on, or the locked the door, and we describe people as being obsessed with work or football. However, these are not normally unwanted thoughts and they do not interfere with daily life. Many people also carry out small, everyday rituals like not stepping on cracks. These rituals might help people feel safe, but are not normally considered problems.

If you are diagnosed with OCD, the problems are so severe that they have stopped you from being able to live your life the way that you want to. You may understand that the way you are behaving is irrational, and feel ashamed and alone because of it. This shame often stops people from asking for help, and can lead to a delay in diagnosis and treatment. Many people try to cope alone until the symptoms are so severe they can't hide them any more.

You may not realise how common such problems are. It is thought that 1 to 2 per cent of the population have OCD that is severe enough to disrupt their normal life, and it can affect people of all ages and from all backgrounds; however, the onset of OCD symptoms is normally in early adulthood, with most cases emerging before the age of 25.

What are the common signs of OCD?

"I don't wash my hands obsessively or check over and over again. Instead I have thoughts – thoughts so real I check to see whether my hands have moved and hit someone across the face, as my thoughts tell me I just have."

Although everyone will have their own unique experiences, there are several common obsessions and compulsions.

Common obsessions

The three most common themes are unwanted thoughts about harm or aggression, unwanted sexual thoughts and unwanted blasphemous thoughts.

Some examples of obsessions include:

- fearing contamination – e.g. from dirt and germs in a toilet
- imagining doing harm – e.g. thinking that you are going to push someone in front of a train
- intrusive sexual impulses – e.g. worrying that you will expose yourself at work
- excessive doubts – e.g. thinking that you have cancer despite having no symptoms
- 'forbidden' thoughts – e.g. thinking about abusing a child
- a fear of failing to prevent harm – e.g. feeling that you are responsible for security at work.

Common compulsions

The most common compulsions involve repeatedly washing or checking. Some examples might be:

- repeating actions – e.g. touching every light switch in the house five times
- ordering or arranging – e.g. keeping food organised by colour in the fridge
- washing – e.g. always washing hands six times with soap and six times without soap after using the toilet
- checking – e.g. reading through an email ten times before sending it to make sure it doesn't have any mistakes in it
- touching – e.g. only buying things in the supermarket that you have touched with both hands
- praying – e.g. repeating a mantra again and again whenever you hear about an accident
- focusing on a number – e.g. having to do everything three times, or buy three of every item when you are shopping.

Avoidance

You might find that some objects or experiences make your obsessions or compulsions worse, and try to avoid them as a result. For example, if you fear contamination, you might avoid eating and drinking anywhere except in your own home. Avoiding things can have a major impact on your life.

Cultural differences

OCD is found in different parts of the world and does not seem to be restricted to one culture. The core experiences of obsessions and compulsions are similar, but the content is likely to reflect concerns that are

relevant to the local situation. For example, people who belong to a particular religion might find their obsessions come in the form of blasphemous thoughts.

What causes OCD?

There are different theories about why OCD develops, but none of these theories have been found to fully explain every person's experience.

One theory suggests that OCD develops because of 'dysfunctional' beliefs and interpretations. If you experience OCD, you might have exaggerated beliefs about your responsibility for situations and find that your reaction is out of proportion; for example, many people might think about wanting to kill someone but attach no meaning to this and forget about it. However, if you interpret this as something that might happen, and develop a compulsion to try and counteract it, an OCD 'cycle' could begin. Cognitive behavioural therapy (CBT) has been developed to help people think about their beliefs and interpretations. See p.7 for more information.

Some psychological theories suggest that OCD is caused by personal experience. It is thought that if you have had a painful childhood experience or suffered trauma or abuse you might 'learn' to use obsessions and compulsions to cope with anxiety. It could also be that one or both of your parents may have had similar anxiety and shown similar kinds of behaviour, (such as obsessional washing) and you were affected by this. However, this theory does not explain why people who cannot point to any painful experiences might experience OCD.

Biological explanations have suggested that lack of a brain chemical, serotonin, has a role in OCD; although experts disagree about what that role is. It's unclear whether changes in the levels of this chemical are a cause or effect of the problem, but some medication is based on adjusting these levels. Studies have also looked at genetic factors and how different parts of the brain might be involved, but have found nothing conclusive. Biological theories do not provide any explanation for why one person might develop a contamination obsession while another develops a doubting obsession. None of these theories provides a full explanation for the causes of OCD, but they might help you to gain some insight into your own situation.

What sort of treatment is there?

The symptoms of OCD can clearly be very distressing, and have a serious impact on your life. Unfortunately there is no instant cure, but there are a number of different treatments and coping strategies that might help you overcome your symptoms. You may want to get professional help, or work out your own strategies. There is no right or wrong way to feel or thing to do, and you might find that different approaches help you at different times.

As a first step, you might visit your GP, who may refer you to a psychiatrist or psychologist (see p.9 'How can I access help?' for more information about accessing treatment). When doctors make a diagnosis of OCD, they use a list of medical criteria. The diagnosis is based on how many of these criteria you meet, and it also tells you how severe your problem is, and therefore what sort of treatment might work for you. They are likely to ask you direct questions about possible symptoms such as:

- Do you wash or clean a lot?
- Do you check things a lot?
- Is there any thought that keeps bothering you that you'd like to get rid of but can't?
- Do your daily activities take a long time to finish?
- Are you concerned about putting things in a special order or are you very upset by mess?
- Do these problems trouble you?

NICE (The National Institute for Health and Clinical Excellence) recommends 'stepped' treatment for OCD based on the severity of your symptoms and the way you have responded to other treatments. (See p.8, 'The stepped model', for more information.) You should be given an explanation of all of your options, and your views and wishes should be considered. You cannot be forced to undertake any treatment of any kind unless you are detained under the Mental Health Act. See Mind's booklet *The Mental Health Act 1983: an outline guide*.

Cognitive behaviour therapy

CBT is a form of counselling or therapy which aims to identify connections between thoughts, feelings and behaviour, and to help develop practical skills to manage them. It can be done one-to-one, or in a group. There is considerable evidence to suggest that this therapy is especially effective in dealing with OCD. See Mind's booklet *Making sense of cognitive behaviour therapy*.

The behavioural element (also known as Exposure Response Prevention – ERP) is strongly recommended for treating OCD. This aims to help you feel less anxious about obsessive thoughts, and make you less likely to engage in compulsive behaviour by helping you to confront the problem situation and resist the urge to carry out the compulsive behaviour. For example, if you fear contamination from door handles and wash your hands excessively as a result, you might build up to a therapy session where you repeatedly touch a door handle and do not then wash your hands.

This can cause a lot of distress and anxiety if it is not carefully managed so it is important that you understand the treatment fully and feel comfortable with your therapist.

Medication

Some people find drug treatment helpful for OCD, either alone or combined with talking treatments such as CBT.

The drugs prescribed most commonly are SSRI antidepressants, such as fluoxetine (trade name, Prozac), fluvoxamine (Faverin), paroxetine (Seroxat), escitalopram (Cipralex) and sertraline (Lustral), which are all licensed for the treatment of OCD. These drugs may have side effects, including nausea, headache, sleep disturbance, gastric upsets and increased anxiety. They may also cause sexual problems.

The tricyclic antidepressant clomipramine (Anafranil) is also licensed for the treatment of obsessional states in adults. The side effects can include a dry mouth, blurred vision, constipation, drowsiness and dizziness. For more information, see Mind's booklet *Making sense of antidepressants*.

In the past, people may have been given tranquillising drugs from the benzodiazepine group, such as diazepam (Valium), to reduce anxiety; but it is recommended that use of these medicines be limited to short periods of treatment for those people who are experiencing very severe anxiety. See *Making sense of sleeping pills and minor tranquillisers*.

Withdrawal problems may occur with all of these drugs, and it's advisable to withdraw gradually. See Mind's booklet *Making sense of coming off psychiatric drugs*.

Neurosurgery for mental disorder

Surgery on the brain – neurosurgery (previously known as psychosurgery) – is very occasionally offered in severe cases of OCD, when other treatments have been unsuccessful. This is strictly regulated under the Mental Health Act, and can't be given without consent. There is more information on this in Mind's web-based information, *Neurosurgery for mental disorder* which you can find at www.mind.org.uk

The stepped model

If you access help through the NHS then your treatment options should be in line with the NICE guidelines. See the guidelines at www.nice.org.uk for full details, but in brief:

- If your symptoms are mild then it is recommended that you are offered 'low-intensity' cognitive behavioural therapy (CBT), which means up to ten hours of therapy, possibly delivered in a group or by telephone, or with the support of self-help material.

- If you have not responded well to low-intensity CBT, or if you have moderately severe symptoms, the next 'step-up', in terms of treatment, is to be offered more intensive CBT or treatment with medication, and you may be referred to a community mental health team for support (see below).

- If this does not help, or if your symptoms are very severe then the next 'step-up' is to be offered intensive CBT and medication, and referral to more specialist support.

How can I access help?

GPs are the first access point to health care on the NHS. They can provide an assessment and diagnosis, and help you access appropriate treatment. If your symptoms are mild then you might be referred to your local IAPT (Improve Access to Psychological Treatments) programme to access CBT. Unfortunately, waiting times for psychological treatment on the NHS are often very long.

If your symptoms are moderate, or you have not found low-intensity CBT helpful, your GP is likely to refer you to a Community Mental Health Team (CMHT) where you will be given a more thorough assessment which will look at your health and social care needs. The CMHT should bring together a range of professionals such as psychiatrists, psychologists, social workers and occupational therapists.

You are entitled to say what your needs are and have a right to have an advocate, who can listen to you and speak for you. A member of your family may act as an advocate, or you can ask about an advocacy service (see *The Mind guide to advocacy*). The assessment can also include the needs of carers and relatives.

As a result of this assessment you should be provided with a care plan. This should be regularly reviewed and a care co-ordinator will be assigned regular contact with you. For more information on assessments and support, see *Community-based mental health and social care* at www.mind.org.uk

If you require more intensive support, the NICE guidelines recommend that there should be a specialist service focusing on OCD available to you. In reality, access to specialist services is patchy across the country and you may need to travel outside your local area. An advocate or the Patient Advice and Liaison Service (see p.12, 'Useful contacts') can support you if you feel you are not getting access to the treatment you require.

What can I do for myself?

Treatment of OCD often includes a combination of strategies, including self-help. You may wish to devise your own self-help programme, based on cognitive behavioural therapy techniques. Many of the organisations listed on p.12 can offer advice and details of such programmes.

Self-help groups

It can be useful to share experiences and methods of coping with others. Self-help groups can provide help, support and encouragement, whether or not you are having professional help. They can be of particular benefit if you have devised your own programme. You could contact your local Mind association or social services, who may be able to tell you if there is a group local to you. You could also try any of the organisations listed in 'Useful contacts' on p.12.

Relaxation techniques

Relaxation techniques can teach you:

- how to improve your breathing to lessen tension
- physical exercises to do to relax your muscles
- action plans to help you progress from coping with non-stressful situations, to those that you find difficult.

For local classes, search the Internet, or contact your local library or GP.

Local services

You should be able to get information about local mental health services from your GP, social services department of your council, local Mind association, Community Mental Health Team, or Patient Advice and Liaison Services (in England) or your Community Health Council (in Wales). These include details of local projects that provide services to particular communities, such as black and minority ethnic communities, women, disabled people, lesbians and gay men. You may also find details in your local phone book.

Private counselling and therapy

You are entitled to receive free CBT on the NHS. But, if you feel that you don't want to wait or that you would like more support than is being offered, you may choose to see a therapist privately. If you do see a private therapist then they should be aware of the NICE guidelines for treatment, and be appropriately qualified to offer you the support you need. See the Mind booklet *Understanding Talking Treatments* and British Association Counselling and Psychotherapy in 'Useful contacts' on p.12.

What can friends or family do to help?

This section is for family or friends who would like to support someone they know with a diagnosis of OCD.

Friends or family can help a lot just by accepting the feelings of the person with OCD and knowing that they find it difficult to cope with them. It is helpful if friends and family understand that it can be particularly difficult for someone experiencing the symptoms of OCD to acknowledge their thoughts, especially if they are shameful or embarrassing.

If the person you know with OCD is working to a self-help programme, either on their own or with a therapist of some kind, you might be able to support them with this, or go to treatment sessions with them.

Your friend or relative might ask you to go along with their compulsions; for example, not going into the bathroom until it has been cleaned. This can be disruptive and does not always help to relieve their anxiety. There is no right or wrong answer about how you can work together to deal with this, but talking about it might help.

It can be distressing to be close to someone experiencing OCD. You might find it useful to talk to other people in the same situation as you, and to find out more about these complex problems. You could try contacting one of the organisations listed overleaf in 'Useful contacts', for more information on the condition and about local support groups.

Useful contacts

Mind
web: www.mind.org.uk
Mind infoline: 0300 123 3393
(Monday to Friday 9am to 5pm)
email: info@mind.org.uk

Details of local Minds and other local services, and Mind's Legal Advice Line. Language Line is available for talking in a language other than English.

Anxiety UK (formerly the National Phobics Society)
tel. 08444 775 774
web: www.anxietyuk.org.uk
Information, counselling, helpline and online support for those suffering from anxiety disorders

British Association for Behavioural and Cognitive Psychotherapies (BABCP)
tel. 0161 705 4304
web: www.babcp.com
Can provide details of accredited therapists

British Association for Counselling and Psychotherapy (BACP)
tel. 01455 883 316
web: www.bacp.co.uk
For details of local practitioners

OCD Action
tel. 0845 390 6232
web: www.ocdaction.org.uk
Information and support specifically for people with experience of OCD

OCD-UK
tel. 0845 120 3778
web: www.ocduk.org
A charity run by people with OCD who campaign and can help with local support group information

Patient Advice Liaison Service
web: www.pals.nhs.uk
Local office contact details can be found on this website

Samaritans
Chris, PO Box 9090, Stirling FK8 2SA
helpline: 08457 90 90 90
email: jo@samaritans.org
web: www.samaritans.org
24-hour help

Further information

Mind offers a range of mental health information, covering:

- diagnoses
- treatments
- wellbeing

Mind's information is ideal for anyone looking for further information on any of these topics.

For more details, contact us on:
tel. 0844 448 4448
email: publications@mind.org.uk
web: www.mind.org.uk/shop
fax: 020 8534 6399

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Mind's mission

- Our vision is of a society that promotes and protects good mental health for all, and that treats people with experience of mental distress fairly, positively, and with respect.

- The needs and experiences of people with mental distress drive our work and we make sure their voice is heard by those who influence change.

- Our independence gives us the freedom to stand up and speak out on the real issues that affect daily lives.

- We provide information and support, campaign to improve policy and attitudes and, in partnership with independent local Mind associations, develop local services.

- We do all this to make it possible for people who experience mental distress to live full lives, and play their full part in society.

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