

## Obsessive-compulsive disorder (OCD)

### WHAT IS OBSESSIVE-COMPULSIVE DISORDER (OCD)?

Obsessive-compulsive disorder (OCD) is a chronic debilitating medical condition characterised by obsessions and compulsions. Obsessions are unwanted, distressing ideas, images or impulses, which repeatedly enter an individual's mind; compulsions are repetitive mental or behavioural acts that the person feels obliged to perform in an attempt to reduce the distress created by the obsessions. However, compulsions are not inherently enjoyable, are often extremely time-consuming and do not result in the completion of a useful task.

Although there may in some cases be overlapping symptoms, OCD should not be confused with obsessive-compulsive personality disorder (OCPD).

Despite its name, OCPD does not involve obsessions and compulsions. OCPD refers to a personality, i.e. chronic pattern of behaviour that involves being preoccupied with order, and includes traits such as perfectionism and inflexibility.

Importantly, both these conditions can cause significant distress for the person and the people with whom he/she shares relationships. Only a few people with OCD have OCPD.

### WHAT CAUSES OCD?

There is no single, proven cause of OCD. It is likely that both genetic and environmental factors are involved; i.e. multifactorial causality.

The old belief that OCD was the result only of life experiences has given way before the growing evidence that neurobiological factors are a primary contributor to the disorder. Research suggests that OCD is related to faulty communication between the front part of the brain (the orbital cortex) and deeper structures (the basal ganglia). These brain structures use serotonin, a neurotransmitter (chemical "messenger" between nerve cells). It is believed that an insufficient level of serotonin is prominently involved in OCD. Dopamine systems may also play a role in OCD.

Another theory is that OCD involves various auto-immune reactions (in which the body's disease-fighting mechanism attacks normal tissue). Evidence to support this is that OCD sometimes starts in childhood in association with strep throat (a sore throat caused by infection with streptococcus bacteria).

Research suggests that genetics may play a role in development of the disorder in some cases, and a number of genes may contribute to its development. Genetic links are still being studied worldwide – for example the recent collaborative project between the members of the international Obsessive-Compulsive Foundation Genetics Consortium to do a whole genome association scan on DNA samples from OCD patients from all over the world -, but there is significant evidence to suggest that OCD does sometimes run in families, and identical twins have a 70% chance of sharing the disorder.



## WHO GETS OCD AND WHO IS AT RISK?

OCD is a fairly common disorder, affecting between 1% and 3.3% of people.

Onset can begin at any time from preschool age to adulthood (usually before the age of 40 years). Males most commonly start having symptoms as children or as teenagers; females often develop symptoms a bit later, in their late teens or early twenties. One-third to one-half of adults with OCD report that their illness started in childhood. It is just about equally common in males and females.

When a parent has OCD, there is a slightly increased risk that his/her child will develop the condition. However, similar rituals are not inherited. For example, a child may have checking rituals, while her mother presents with contamination fears and washes compulsively.

OCD is not primarily related to stress or psychological conflict, and can be seen in all kinds of personality types. Interestingly, many patients report that their OCD (severity, distress, impairment) increases when their levels of stress increase (e.g. before or during exams).

OCD may also be influenced by hormonal functioning. In females, in particular, the influence of hormones on the development or manifestation of OCD may not be underestimated. For example, many females report an increase in their obsessive-compulsive (OC) symptomatology in their pre- / menstrual periods, or OCD onset with pregnancy or shortly after childbirth. Menopause has also been suggested to mark the onset of OCD in some females.

OCD often occurs along with mood disorders such as depression and bipolar affective disorder (manic depression). In fact, studies of clinical samples have shown that 29.6% - 43% of OCD patients have comorbid depression.

This contributes to the extent of impairment associated with OCD. Indeed, research has also shown that co-existence of OCD and depression is related to chronicity and severity of obsessive-compulsive symptoms, poor response to treatment and bad prognosis.

## SYMPTOMS AND SIGNS OF OCD

OCD usually involves both obsessions and compulsions, although in rare cases, one may be present without the other.

### Obsessions:

Obsessions are defined as recurrent and persistent thoughts, impulses or images that the person feels unable to control or prevent. Obsessions are usually experienced as senseless, disturbing and intrusive, and patients try to ignore or suppress them. Anxiety, fear, disgust or doubts often accompany the obsessions.

### Common obsessions:



- Worrying excessively about dirt or germs and that you may become contaminated or contaminate others
- Imagining you have harmed yourself or others; having doubts about safety issues (such as whether you have turned off the stove)
- Fearing something terrible will happen or that you will do something terrible
- Preoccupations with symmetry, or a need to have things "just so"
- Intrusive sexual thoughts
- Intrusive violent or repulsive images
- Excessive religious or moral doubt or guilt; intrusive blasphemous images
- Excessive doubting or indecision: "should I - shouldn't I?"
- A need to tell, ask or confess

## Compulsions:

Compulsions on the other hand, are defined as repetitive and ritualistic behaviour or mental acts, often performed according to certain "rules"

### Common compulsions:

- Washing or cleaning: such as showering repeatedly or washing your hands until the skin is red and painful
- Checking: such as repeatedly checking that you have turned off the stove or locked the front door
- Repeating: such as repeating a name or phrase many times to ease anxiety
- Completing: performing a series of steps in an exact order or repeating them until you feel they are done perfectly
- Repetitive ordering, arranging or counting of objects
- Hoarding: collecting useless items you may repeatedly count or order
- Excessive and repetitive praying
- Repetitive touching

Unlike compulsive drinking or gambling, OCD compulsions are not pleasurable and are often performed to obtain relief from obsessions, i.e. to decrease the extreme anxiety created by these obsessions. For example, you may repeatedly check that you have turned off the stove because of an obsession about burning the house down or you may count certain objects repeatedly because of an obsession about losing them.

Not all obsessive-compulsive behaviours are OCD. Some rituals (such as religious practices, exercise routines) are part of daily life. Normal worries, such as contamination fears, may increase during times of stress, such as when someone in the family is sick. You may have OCD if your obsessions or compulsions

- Cause you marked distress
- Persist and take up a lot of time (over an hour a day). People with OCD may spend hours each day performing compulsive acts
- Significantly interfere with your normal routine, work, social activities or relationships
- Are senseless



People with OCD are usually aware that their obsessions or compulsions are excessive or senseless, and are more than just normal worries. "OCD with poor insight" is diagnosed when someone with OCD does not recognize that his or her beliefs and actions are unreasonable or excessive.

OCD symptoms usually have a "waxing and waning" course, i.e. tend to come and go over time, and vary in intensity. Some symptoms may be mild and fairly easy to ignore; others cause severe distress and disability.

As noted before, people with OCD also often have depression or depressive symptoms, including:

- Guilt
- Sadness
- Low self-esteem
- Anxiety
- Fatigue

Some stressors may even worsen OCD symptoms; examples of such environmental stressors include the following:

- Abuse
- Changes in living situation
- Illness
- Occupational changes or problems
- Relationship concerns
- School-related problems

## HOW IS OCD DIAGNOSED?

OCD tends to be under-diagnosed. Because of the stigma of mental illness, people may hide symptoms and avoid seeking professional help. Not surprisingly, OCD has been described as a "secretive illness".

People with OCD may also be unaware that they have a recognizable and treatable illness. Thanks to recent awareness campaigns and destigmatization efforts by the media and mental health organizations, this situation is improving. Some health professionals are, however, still unfamiliar with OCD symptoms.

There are no laboratory tests for OCD; diagnosis is based on assessment of your symptoms. Your doctor will ask you, and often people close to you, about your symptoms, and pose specific questions about the type of obsessions or compulsions you experience. You will also be asked how much time you spend doing rituals/obsessing every day. (For example, if you take more than an hour per day performing senseless rituals, you may have OCD.)

Your doctor will also check whether a medication or drug you may be taking at the time is not making your symptoms worse.

## HOW IS OCD TREATED?



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Combining antidepressant medication and cognitive-behavioural therapy (CBT) has been found to be the most effective treatment for OCD. Treatment of OCD is a long-term commitment. Both kinds of treatment may take several months to be effective, but a good response is often seen in time. The patient's commitment and active participation in treatment, together with the support of his/her family, and a good trusting relationship with a therapist, is of the utmost importance in recovery.

## Medication

Medications most commonly prescribed for OCD are antidepressants called selective serotonin reuptake inhibitors (SSRIs), notably, fluoxetine (Prozac), sertraline (Zoloft), paroxetine (Aropax), fluvoxamine (Luvox), and citalopram (Cipramil).

Another medication used is clomipramine (Anafranil), which is a non-selective SRI, meaning it affects other neurotransmitters besides serotonin, and might have more side effects.

The SSRIs are usually easier for people to tolerate. All these antidepressants are equally effective, although for any particular person one agent may be better than another.

Most people notice some benefit from these medications after four to six weeks, but it is necessary to try the medication for 10 to 12 weeks to see whether it works or not. If you do experience distressing side-effects, your doctor can try reducing the dose, or adding or switching to a different medicine. Indeed, when the medication (an SSRI) has proved ineffective after 10 to 12 weeks, a different SSRI can be tried.

Alternatively, another medication can be added to the first, or adding CBT may render treatment more effective.

Very importantly: Before deciding that a treatment has failed, your therapist needs to be sure that the treatment has been given in a large enough dose for a sufficient period of time.

Fewer than 20% of people treated with medication alone will have their symptoms resolved completely, so medication is often combined with CBT for better results. The need for medication depends on the severity of your OCD and your age.

In milder OCD, CBT alone may be used initially, but medication may be added if CBT proves ineffective. People with severe OCD or complicating conditions (such as depression) often start with medication, adding CBT once the medicine has provided some relief.

In younger patients doctors are more likely to use CBT alone. However, if a trained cognitive-behavioural psychotherapist is unavailable, medication may be used.

## Cognitive-behavioural therapy (CBT)

Behaviour therapy helps you learn to change your behaviour and feelings by changing your thoughts. Behaviour therapy for OCD involves exposure and response prevention (E/RP), and cognitive therapy.



Exposure involves gradually exposing yourself to feared stimuli. For example, people with contamination obsessions are encouraged to touch "dirty" objects (like money) until their anxiety recedes. Anxiety tends to decrease after repeated exposure until the contact is no longer feared.

Exposure is most effective if combined with response or ritual prevention, in which rituals or avoidance behaviours are blocked. If, for example, you wash your hands compulsively, your therapist may stand at the sink with you and encourage you not to wash your hands until the anxiety recedes. As such, E/RP may be quite stressful, but it is effective in reducing anxiety and rituals in the long run. All exercises during therapy are discussed and agreed upon before implementation.

Cognitive therapy, the other component in CBT, is often added to E/RP to help reduce the exaggerated thoughts and sense of responsibility that often occurs in OCD. Cognitive therapy helps you challenge the faulty assumptions of your obsessions, and so bring anxiety and the urge to respond with compulsive behaviour under control.

Gradual CBT involves practice with the therapist once or twice a week and doing daily E/RP "homework". Homework is necessary because many of the elements that trigger OCD occur in your own environment and often cannot be reproduced in the therapist's office. According to research, people who complete CBT have a 50%–80% reduction in symptoms after 12–20 sessions.

Intensive CBT, which involves two to three hours of therapist-assisted E/RP daily for three weeks, may work even more quickly. In rare cases where OCD is very severe or complicated by another illness, or involves severe depression or aggressive impulses, hospitalization may be recommended for intensive CBT.

Other techniques, such as thought stopping and distraction (suppressing or "switching off" OCD symptoms) may sometimes be helpful.

## Other treatments

In adults with very severe OCD, neurosurgery (e.g. high-frequency electrical deep brain stimulation (DBS)) to interrupt specific malfunctioning brain circuits may be recommended.

DBS of specific brain targets, introduced in the early 1990s for tremor (e.g. in Parkinson's disease), has gained widespread acceptance as a treatment method because of its less invasive, reversible, and adjustable features and is now utilized for an increasing number of movement and psychiatric disorders. The use and efficacy of this method for OCD is still under investigation.

People with OCD may have substance-abuse problems, sometimes as a result of attempts at self-medication, and this usually also needs specific treatment. Also, when someone with OCD also presents with bipolar disorder, it has been suggested that the bipolarity takes precedence in treatment considerations.

## MAINTENANCE TREATMENT



Once OCD symptoms are eliminated or greatly reduced, these gains must be maintained. Most experts recommend monthly follow-up visits for at least six months and continued treatment for at least a year before trying to stop medication or CBT.

Relapse is common when medication is withdrawn, particularly if you have not had CBT. It is recommended that you continue medication if you don't have access to CBT.

People who have repeated episodes of OCD may need to receive long-term prophylactic (preventative) medication.

## DISCONTINUING TREATMENT

If you don't need long-term medication, most experts recommend gradual discontinuation of medication, while receiving CBT booster sessions to prevent relapse. It is harder to get OCD under control than to keep it there, so don't risk a relapse by reducing or stopping your treatment without your doctor's advice.

## Education and family support

Include your family in your therapy, and educate all concerned about the illness. This will help you manage your OCD and ensure you get the best treatment.

Consider joining a support group: this helps you feel less alone and learn new strategies for coping with OCD.

When someone with OCD denies the problem or refuses to be treated, family members can help by ensuring the person has access to information about the disorder and explaining that there are effective treatments.

OCD can cause considerable disruption for other family members, who may get drawn into the ill person's rituals. The therapist can help family members learn how to become gradually disengaged from these.

A calm, supportive family can help improve treatment outcome. Ordering someone with OCD to simply stop their compulsive behaviour is seldom helpful and can make the person feel worse. Instead, praise any successful attempts to resist OCD, and focus on positive elements in the person's life. Treat people normally once they have recovered, but be alert for telltale signs of relapse. Point out any early symptoms in a caring manner.

## WHAT IS THE OUTCOME OF OCD?

OCD symptoms often create problems in daily living and relationships. In extreme cases, people become totally disabled and cannot leave home because they spend their time engaged in rituals or obsessive thoughts.



Without treatment, the disorder may last a lifetime, becoming less severe from time to time, but rarely resolving completely.

In some people, OCD occurs in episodes, with years free of symptoms before a relapse. Even with treatment, however, OCD can come and go many times during your lifetime. Although OCD is completely curable only in some individuals, most people achieve relief with comprehensive treatment.

In children and adolescents, OCD may worsen or cause disruptive behaviours, exaggerate a pre-existing learning disorder or cause problems with attention and concentration. These disruptive behaviours will often resolve or improve when the OCD is successfully treated.

### See your doctor if you:

- Suspect you or a family member may be developing symptoms of OCD.
- Experience worsening OCD symptoms that aren't relieved by strategies you learned in CBT.
- Experience changes in medication side effects.
- Have new symptoms that may indicate development of another disorder (such as panic attacks or depression).
- Are going through a life crisis that might worsen your OCD.

### CAN OCD BE PREVENTED?

At present there is no known prevention for OCD. However, early diagnosis and correct treatment can help people avoid the suffering associated with the condition and lessen the risk of developing other problems, such as depression or relationship and work difficulties.

### WHAT OCD RESEARCH IS BEING DONE IN SOUTH AFRICA?

There is an on-going OCD research project conducted at the SU/UCT MRC Research Unit on Risk and Resilience in Mental Disorders.

This Unit is also part of the above-mentioned international collaboration (the OCDFGC). The OCD project at the MRC Unit primarily focuses on investigation of the phenomenology (including OCD symptom subtyping) as well as the role of genetic factors in the development of OCD. Other factors that are also evaluated include age of onset, response to medication treatment, comorbidity of OCD spectrum disorders, personality features, history of group A streptococcal infection and rheumatic fever, and family history of OCD and other psychiatric disorders.

We are continuously updating the project and expanding the various tools used for assessment in order to keep up to international standards. Our focus now include investigation of brain-structure and -functioning in patients with OCD and the assessment thus includes both neuropsychological testing as well as brain imaging.

Participation entails a once-off consultation (and referral for treatment if required), is cost-free and takes approximately two to three hours. If scanning and neuropsychological testing are involved (in addition to the initial comprehensive diagnostic interview), 2-3 additional sessions will be needed.



Blood will be drawn from participants and their parents (if possible, if not, saliva samples would be adequate) to get to the genetic material (also known as DNA). Even though the Unit is situated in the Western Cape, there are recruitment centres in Gauteng and the Eastern Cape.

For more information, contact Prof. Christine Lochner at the MRC Unit on 021 938 9179 (email: [cl2@sun.ac.za](mailto:cl2@sun.ac.za)).

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