An OCD-UK information guide for people affected by Obsessive-Compulsive Disorder

OCD-UK is the leading national charity, independently working with and for children and adults affected by Obsessive Compulsive Disorder (OCD)
Around 1.2% of the population are thought to be affected by Obsessive-Compulsive Disorder (OCD) and it is actually listed amongst the top 10 most debilitating illnesses by the World Health Organisation in terms of loss of income and decreased quality of life.

And the chances are you’re reading this booklet because you are amongst that 1.2% and because at some time or another you have felt upset, scared, and alone. But rest assured, there is hope, OCD can be treated successfully and beyond the illness there is a life full of opportunities to experience.

OCD-UK is unique in the respect that it is a service user-led charity for people affected by OCD. Whatsmore it is run by people that have experienced OCD first hand, and who can help and inspire you towards the ultimate goal of recovery.

The most important way they do this is by providing you with knowledge. Because, as many ex-sufferers will tell you, with OCD knowledge comes power. With power comes the strength to overcome the illness once and for all.

It is hoped that this guide will be just the starting point in clarifying some of the details about OCD, in terms of its symptoms and possible treatments, and that it will offer you hope and encouragement to embark on your own personal road to recovery.

## Contents

- About OCD-UK ........................................... 3
- OCD - An Introduction ............................... 4
- Obsessions - An explanation .................... 5
- Compulsions - An explanation ................. 6
- OCD spectrum disorders ....................... 7
- Understanding OCD ............................... 8
- Treatments ............................................ 10
- Cognitive Behaviour Therapy (CBT) ....... 12
- Medications .......................................... 14
- What causes OCD? ................................. 16
- The many faces of OCD ......................... 18
- Family, Friends and Carers (FFC) .......... 22

OCD-UK would like to thank all of our volunteers for their contributions towards compiling this information guide. We remain grateful for the kind support and commitment that all of our fantastic volunteers provide our charity.
OCD-UK is the leading national charity, independently working with and for children and adults affected by Obsessive-Compulsive Disorder (OCD).

It is our belief that everyone affected by this illness should receive care, support and treatment of the very highest quality.

By working with sufferers, their families, health professionals and researchers, we aim to develop and share our experiences and knowledge to help people gain a better understanding of Obsessive-Compulsive Disorder and to ultimately help reduce the effect it has on people’s lives.

We do this by providing accessible and effective support services, and by campaigning for improved access to quality treatment and care.

We also facilitate a safe environment for sufferers to communicate with each other and provide mutual understanding and support.

**How can you help make a positive difference to sufferers’ lives?**

Perhaps by making a one-off donation (every penny really does make a difference), or by becoming a member of OCD-UK, or participating in a fundraising event, which will help us achieve our goals and make a real difference to the lives of people affected.

**Find out about more about OCD**

For more detailed information about Obsessive-Compulsive Disorder and details of how you can get involved and help OCD-UK, please visit our website at [www.ocduk.org](http://www.ocduk.org)
Obsessive–Compulsive Disorder (OCD) is a serious anxiety-related condition where a person experiences frequent, intrusive and unwelcome obsessive thoughts, often followed by repetitive compulsions, impulses or urges. OCD presents itself in many guises, and people are often surprised to learn that it goes far beyond the common perception of excessive hand washing or the repetitive checking of light switches. We hope this information guide will offer you a better insight into what OCD is, and the different ways in which it can manifest itself.

Who does it affect?
It may surprise you to know that Obsessive Compulsive Disorder affects as many as 12 in every 1000 people (1.2% of the population) from young children to adults, regardless of gender or social or cultural background. Based on current estimates for the UK population, there are potentially around 741,504 people living with OCD at any one time.

Furthermore, the illness can be so debilitating and disabling that the World Health Organisation (WHO) has ranked OCD in the top ten of the most disabling illnesses of any kind, in terms of lost earnings and diminished quality of life.

Equally as disturbing is the fact that sufferers often go undiagnosed for many years. This is partly due to the lack of understanding of the condition by individual sufferers and health professionals alike and the intense feelings of embarrassment, guilt and sometimes even shame, associated with what is often called the ‘secret illness’, can often prevent sufferers from seeking appropriate treatment. It is not uncommon for a sufferer to wait an average of 10–15 years before seeking help for the condition.

OCD has two main features, the Obsessions and the Compulsions.
In general, the **obsessions** experienced by OCD sufferers take the form of persistent and uncontrollable thoughts, images, impulses, worries, fears or doubts. They are often intrusive and disturbing by nature, and significantly interfere with the ability to function on a day-to-day basis.

The occurrence of these obsessive thoughts usually produces a feeling best described as anxiety, but some patients report that what they feel is not anxiety, but general unease, tension and discomfort.

For the most part, people with OCD very often realise that their obsessive thoughts are irrational, but they believe the only way to relieve the anxiety caused by them is to perform compulsive behaviours, often to prevent perceived harm happening to themselves or, more often than not, to a loved one. Some sufferers, however, are not able to recognise the intrusive nature of their thoughts, and the very fact that they are having them can cause them extreme distress.

The problem is that the person with OCD will become besieged by the obsessive thoughts. In fact the word ‘**obsession**’ comes from the Latin ‘obsidere’ which means ‘to besiege’. Naturally the sufferer neither wants nor welcomes the obsessional thoughts and will go to extreme lengths to block and resist them. Invariably they return within a short period of time, often lasting hours if not days, which can leave the person both mentally and physically exhausted and drained. This causes deep anguish and despair.

The list opposite details just some examples of commonly occurring obsessions that affect people with OCD:

- Worrying that you or something/someone/somewhere is contaminated.
- Worrying about catching HIV/AIDS or other media publicised illnesses such as Bird Flu or Swine Flu.
- Worrying about causing physical or sexual harm to yourself or others, and having Intrusive violent thoughts.
- Unwanted or unpleasant sexual thoughts and feelings, including those about sexuality or fear of acting inappropriately towards children.
- Worrying that you have caused an accident whilst driving.
- Having the unpleasant feeling that you are about to shout out obscenities in public.
- Worrying that everything needs to be arranged symmetrically or at perpendicular angles so everything is ‘just right’.
- Worrying that something terrible will happen unless you check repeatedly.
Compulsions can either be repetitive physical behaviours and actions, or mental thought rituals that are performed over and over again in an attempt to relieve the anxiety caused by the obsessive thoughts. Avoidance of places or situations, to prevent triggering these obsessive thoughts, is also considered to be a compulsion. Sadly any relief that the compulsive behaviours provide is only temporary and short lived, and often reinforces the original obsession, creating a gradual worsening cycle of the OCD.

In most cases OCD sufferers recognise their compulsive actions are senseless and irrational, but none-the-less feel bound to carry them out in order to prevent harm coming to themselves or loved ones. Often a person with OCD will feel a heightened sense of responsibility to perform the neutralising behaviour, simply because they feel doing so will prevent harm coming to themselves or loved ones. What’s more sufferers sometimes have an overwhelming urge to obtain that ‘just right’ feeling with no other reason than to feel comfortable.

For example; people without the illness will wash their hands when they are dirty and ‘see’ that they are dirty. In contrast someone with OCD will ‘feel’ their hands are dirty, and therefore keep washing until they ‘feel’ clean. The list below details just some examples of commonly-occurring physical or mental compulsions that affect people with OCD (in brackets are types of obsessional thoughts that may trigger such compulsive behaviours):

- Excessive washing of one’s hands or body (thought of being contaminated, by chemical or body fluids).
- Excessive cleaning of clothes or rooms in the house, (thought of having come into contact with germs from the outside or perceived contaminants from bodily fluids).
- Checking that items are arranged ‘just right’ and constantly adjusting inconsequential items, until they are aligned to feel ‘just right’ as opposed to looking aligned (thought that something bad may happen if not aligned correctly).
- Mental rituals or thought patterns such as saying a particular phrase, or counting to a certain number, to ‘neutralise’ an obsessional thought (thought that something bad may happen if not carried out).
- Repeatedly opening and sealing letters / greetings cards that one has just written, maybe hundreds of times (fear of writing something offensive within the letter/card).
- Constant checking of light switches, handles, locks etc to prevent perceived danger from flooding, break in, gas leak or fire.
- Avoiding particular places, people or situations to avoid an OCD thought (be it fear of harming, or contamination).
- Saying out loud (or quietly) specific words in response to other words (to prevent disaster happening).
- Avoidance of kitchen knives and other such instruments, (for example locking them in a drawer) to prevent coming into contact with them (thought of harming someone).

A compulsion can either be overt (i.e. observable by others), such as checking that a door is locked, or covert (cognitive) (an unobservable mental act), such as repeating a specific phrase in the mind, or avoiding people, objects or situations.

Overt compulsions typically include checking, washing, hoarding or symmetry of certain motor actions.

Covert compulsions, or ‘cognitive compulsions’, as they are sometimes referred to, are the carrying out of mental actions, as opposed to physical ones. Examples include mental counting, compulsive visualisation and substitution of distressing mental images or ideas with neutralising alternatives.

Another key compulsive behaviour, particularly where the sufferer lives with another person, is the need to seek constant ‘reassurance’. This in itself is another compulsion.
There are a number of disorders which researchers have long believed to be biologically linked to OCD, and thus have been categorised as **OCD spectrum disorders**. These include:

- Body Dysmorphic Disorder,
- Compulsive Skin Picking
- Tourette Syndrome
- Trichotillomania

However, it is now felt that Body Dysmorphic Disorder is perhaps the closest linked of all these disorders to OCD, with the others being different conditions in their own right, although the common factor in all of these conditions is that they do all involve, to some degree, the presence of repetitive thoughts, behaviours or urges.

When two diagnoses occur in the same individual they are referred to as ‘comorbid’.

Many people with these other conditions will also be comorbid and display OCD type symptoms, and be diagnosed with OCD which is why they are still considered to be related disorders.

**Body Dysmorphic Disorder (BDD)**

Body Dysmorphic Disorder (BDD) is often called the ‘imagined ugliness’ disorder. It was formerly known as Dysmorphophobia and is an anxiety disorder whereby a person is abnormally preoccupied with an imagined or slight defect in their physical appearance.

**Compulsive Skin Picking**

Compulsive Skin Picking (CSP), also known as Dermatillomania, is an impulse control disorder and is characterised by the habitual and excessive picking of skin lesions, or the excessive scratching, picking, gouging or squeezing of otherwise healthy skin, to the extent of causing bleeding, bruising, infection, and/or permanent disfigurement. These behaviours are carried out solely to relieve the anxiety or urges being experienced by the sufferer.

**Tourette Syndrome**

Tourette Syndrome (TS) is a neurological disorder characterised by sudden rapid, involuntary movements called tics, which occur repeatedly. It is thought to be an inherited neurological condition which affects more than 300,000 children and adults in the UK. In most instances it starts in childhood, and for about half of children with TS, the condition continues into adulthood.

**Trichotillomania**

Trichotillomania (Pronounced: trick-oh-till-oh-may-nee-ah) is a type of psychological disorder known as an impulse control disorder. Its defining characteristic is the recurrent, compulsive pulling of the hair out at the root, from places like the scalp, eyebrows, or eyelashes, sometimes causing baldness. Pulling may also occur from less common locations including the pubic area, perirectal area, or any other body region.

**Other Disorders**

There are also a number of other disorders which often affect people with OCD. Although these conditions are not in the OCD spectrum of disorders, they run alongside the OCD and are often a consequence of OCD. These include Depression, Emetophobia, Panic Attacks and Self-Harm.
Understanding what drives a person to continue performing the seemingly nonsensical and repetitive behaviours, that Obsessive-Compulsive Disorder (OCD) creates, is difficult, but partly it is due to the perception of the perceived level of danger and threat that a person with OCD believes may cause harm to themselves or a loved one.

For many people with OCD there is also an overinflated sense of responsibility to prevent harm and over estimation about the perceived threat the intrusive thoughts bring. It is these factors which help drive their compulsive behaviours, because they feel responsible to try and prevent bad things happening.

The problem that OCD creates is an increase in anxiety. Whilst a normal response to an anxiety provoking situation is for the anxiety to slowly decrease after the initial event, for someone with OCD the anxiety is maintained and often increases, usually because of their overestimation of the perceived level of threat.

The problem with the anxiety is that it is proportional to a person’s perception of danger and risk. The worse the perceived consequences the greater is the fear of something bad happening.

As an example, imagine that you’ve been told that you have to walk a 30-foot-long plank, which is one foot wide and is two feet above soft ground. For most people the perceived risk would be low, the task would seem easy and so the anxiety is low and manageable, and fades quickly.

Now what if we tell you that the 30-foot-long plank, which was one foot wide and is two feet above soft ground is now just half a foot wide, and hundreds of feet above a canyon?

The level of perceived risk would be considerably higher, and the resulting anxiety will become considerably higher too, and the need to prevent that risk becomes stronger.

OCD becomes a vicious cycle. As the obsessional thought causes a person’s anxiety to increase, they become besieged by the obsessive thoughts. Naturally the sufferer neither wants nor welcomes the obsessional thoughts and will go to extreme lengths to block and resist them.

People with OCD realise that their obsessional thoughts are irrational, but they believe the only way to relieve the anxiety caused by the obsessions is to perform compulsive behaviours, often to prevent perceived harm happening to themselves or more often than not, a loved one.

Unfortunately, any relief that the compulsive behaviours provide is only temporary and often reinforce the original obsession, creating a gradual worsening cycle of the OCD.

OCD is driven by the fear of consequences, no matter how unlikely the risk.

The reality is that OCD is like a pair of Chinese handcuffs, the harder you pull to get away (the compulsions), the tighter the grip becomes (the obsessions).
You don't have to suffer
OCD can be an extremely isolating, upsetting and distressing illness. But while it can be chronic, it is also a very treatable medical condition, and seeking early intervention and appropriate treatment is the key to long term recovery.

The treatment found to be the most effective in successfully treating OCD is Cognitive Behavioural Therapy (CBT). In many cases, CBT alone is highly effective in treating OCD, but for some people a combination of CBT and medication is also effective. Medication may reduce the anxiety enough for a person to start, and eventually succeed in therapy.

However what we know is that left unchecked and untreated OCD will mushroom and feed upon itself and can have the power to consume if left unchallenged. It is therefore important to seek professional medical advice and support the moment someone recognises OCD type symptoms.

**NHS Route**

Before any kind of treatment for Obsessive-Compulsive Disorder can commence you should always consult your GP. If you are worried about doing this, we have a GP icebreaker sheet (available to download on our website) which can sometimes make that first GP visit a little easier.

While some GPs still have a limited knowledge of the wide range of symptoms of OCD, this is now slowly changing. However, the symptoms often still go unrecognised and, as a result, undiagnosed by GPs. If this happens to you, it may be that you have to tell your GP what OCD is, as well as what your symptoms are. You may also wish to refer your GP to the clinical classifications of the illness on our website and the National Institute for Health and Clinical Excellence (NICE) guidelines for the identification, treatment and management of OCD and BDD.

In general, doctors, nurses and other healthcare professionals within the NHS are all expected to follow NICE’s clinical guidelines.

When you first see a health care professional about your symptoms, it is very important that you are honest and open about your thoughts and behaviours, no matter how embarrassing they may seem. Almost certainly, they have heard it all before – and by being honest, you will help them to identify the most suitable treatment for you.

After an initial appointment your GP should refer you to your local Community Mental Health Team (CMHT) or Improving Access to Psychological Therapies (IAPT) team, or its local equivalent. Here you are likely to be seen by an appropriate clinical psychologist or psychiatrist who will ensure a correct diagnosis and recommend a course of treatment. Subsequent treatment may then involve a psychologist, psychiatrist or another mental health professional such as a community mental health nurse (CPN).

The treatment you should be offered is Cognitive Behavioural Therapy (a form of talking therapy). You may also be offered medication to help with your recovery. More about these will be discussed later on in the booklet.

Exposure and Response Prevention (ERP) should also form part of the CBT treatment. This involves being exposed in a very structured way, with the support of your therapist, to whatever it is that makes you feel anxious, without then engaging in the checking or other OCD behaviours.

Medication is not recommended as a sole treatment method, although in practice your GP may well offer drug treatment straight away because of the long waiting lists for Cognitive Behavioural Therapy. If this happens, it should be your choice whether to accept the medication, and if you do, you should also discuss the possible side effects with your GP.

In many cases, CBT alone is highly effective in treating OCD, but for some people with OCD a combination of CBT and medication is more effective.
Treatments for OCD

This usually takes the form of antidepressants which act in the Serotonin System, and they are called SSRIs (Selective Serotonin Re-uptake Inhibitor).

Occasionally you may only be offered group Cognitive Behavioural Therapy, often in an attempt to keep long waiting lists down. However, you should always request individual one-to-one therapy, even though it is sometimes helpful for people who have the same type of OCD problems to receive therapy as a group. However group therapy should not be offered to you as a sole treatment because this won’t be tailored to your individual needs and it may not have the same impact as individual treatment. Sharing sessions with other people can sometimes help you realise you’re not alone with your problem and enables each member to contribute to the progress and wellbeing of the others, but this can also be found through non therapeutic support groups.

Self Help Route
Many people with OCD decide to try and beat OCD themselves using resources they pick up from self-help books, support groups and websites like the OCD-UK website at www.ocduk.org. There are many self-help resources out there, but it is important that you are careful and do not assume everything you read on the internet is correct. Sometimes being able to run things past a trained mental health professional can be better than attempting the self-help route.

Private Therapists
When choosing a therapist, especially if paying to go private, it is important to make sure your therapist is suitably qualified to be treating you, so it is important to ask some relevant questions to allow you to gauge if your therapist seems knowledgeable enough in how to treat OCD. You can read more about this on our website, under ‘Finding a therapist’.

NICE Guidelines for OCD
The National Institute for Health and Clinical Excellence (NICE) is part of the NHS and is the independent organisation responsible for providing national guidance on treatments and care for people using the NHS in England and Wales. It is the world leader in setting high quality healthcare standards.

NICE and the National Collaborating Centre for Mental Health launched their set of clinical guidelines for the identification, treatment and management of Obsessive-Compulsive Disorder and Body Dysmorphic Disorder on 23rd November 2005.

The guidance is intended for health care professionals, patients and their carers to help them make decisions about treatment and health care. Unfortunately, despite breakthroughs in the awareness, understanding and treatment of OCD, many health professionals still do not recognise the symptoms, or know how to correctly treat the disorder. If this is the case for you, you may wish to refer your GP to the NICE guidelines for the identification, treatment and management of OCD and BDD.

To obtain copies of the guidelines, there are several options:

- Download them from our website at www.ocduk.org.
- Obtain a hard copy from OCD-UK. Please send two first class stamps when requesting your copy.
- Order copies by calling the NHS Response Line on 0845 003 7783 (national rate) and asking for: N0920 Information for the public or N0919 Quick reference guide for health professionals.
Cognitive Behaviour Therapy (CBT) is a special form of talking therapy which is the treatment found to be the most effective in successfully tackling Obsessive-Compulsive Disorder (OCD).

The principal aim of this therapeutic approach is to enable the person to become their own therapist and to provide them with the knowledge and tools to continue working towards complete recovery from OCD. What therapy will teach the person with OCD is that it’s not the thoughts themselves that are the problem; it’s what the person makes of those thoughts, and how they respond to them, that is the key to recovery.

A good way of understanding how different responses to thoughts can affect the way we behave can be demonstrated in the example below, which sufferers and non-sufferers alike will be able to relate to.

It’s the middle of the night, you’re in bed. You hear a noise from downstairs.

● You might think: ‘It’s the stupid cat again’, feel angry, put your head under the pillow and try to go back to sleep.
● You might think: ‘It’s my partner coming in, I haven’t seen them all day!’, feel happy and get out of bed to say ‘hello’.
● You might think: ‘It’s a burglar’, feel frightened and call the police.

What this example shows is that the same event can make people feel completely different emotions (angry, happy, anxious), and result in them behaving in very different ways, due to their different beliefs about the event.

In summary, it’s not the thoughts themselves that are the focus of treatment; it’s what we make of those thoughts in the first place.

Cognitive Behaviour Therapy makes use of two evidence-based behaviour techniques, Cognitive Therapy (C) that looks at how we think, and Behaviour Therapy (B) which looks at how this affects what we do. In treatment we consider other ways of thinking (C), and how this would affect the way we behave (B).

Exposure and Response Prevention therapy (ERP) is used as part of the behavioural approach to help explore alternative ways to respond to the obsessional thoughts or doubts.

What we also know from research is that almost everyone has intrusive thoughts, that are either nonsensical or alarming. The aim of CBT is not about learning not to have these thoughts in the first place, because in essence, as will be discussed later, intrusive thoughts cannot be avoided. Instead it is about helping a person with OCD to identify and modify their patterns of thought that cause the anxiety, distress and compulsive behaviours.

The goal of treatment

In treatment for OCD, one of the first things a person will be asked to do is to think of a recent specific example of when the OCD was really severe. They will be asked to go into a lot of detail, and try and understand what thought(s) (or doubts, images or urges) popped into their head at this time.

For example some intrusive thoughts might be:

● A horrible thought that I may have said something inappropriate.
● A thought that there might be blood in my food.
● A thought that I am contaminated from the toilet.

People with OCD often ask if treatment can help them get rid of these intrusive thoughts, as they are so distressing and horrible. But if you instead consider whether all intrusive thoughts are always horrible you will see that they are not. Usually people can think of an occasion when they suddenly had a thought that was helpful, such as suddenly remembering a friend’s birthday is coming up, or having a memory of a lovely holiday pop into their head.

We can conclude from this that getting rid of intrusive thoughts themselves isn’t a realistic, or sometimes, desirable goal.

It is also worth remembering that everyone has all sorts of intrusive thoughts – including the nasty ones: thoughts of harm coming to people, images of violence, urges to check things,
doubts about whether they have done something. The difference with other people is that their intrusive thoughts do not become bothersome.

The goal of treatment therefore is not to get rid of the thoughts, but to learn different ways of responding to them.

**Challenging the meaning attached to the thoughts**

In CBT the person with OCD will explore alternative meanings or beliefs about the intrusive thoughts and rituals in all their guises (for example washing, checking, writing lists, tapping, touching, repeating, cleaning, trying to get a ‘just right’ feeling, praying) and will learn what it is that ultimately keeps alive the meanings they attach to such thoughts and rituals.

So during the first few sessions a good therapist should spend time making sense of how the OCD works and what keeps it going. The idea and reason behind this is that if we can understand the factors that keep a problem alive, we can then take the next step, which is to think about alternative ways of viewing the problem and what we can then do to change it.

Therefore in CBT we look at how OCD convinces you that the rituals and compulsions performed are necessary, in order to prevent something bad happening. If such a bad outcome were to be true as a result of the thought, the sufferer would be convinced it was entirely their fault and responsibility. We also look at the possibility that OCD is a liar. All the sufferer’s coping strategies have come about in the first place to make them feel safer and less anxious, when in fact they do the exact opposite, they make the person feel unsafe and scared. Even if they provide temporary relief from anxiety, all these rituals make the meaning attached to those intrusive thoughts, images, urges and doubts feel even stronger, therefore it becomes necessary for the sufferer to keep doing the rituals continuously. Ultimately this makes the thoughts seem even more real, and like there is even more truth in them.

The cyclical nature of the problem can be illustrated by drawing a diagram of how it works - we sometimes call it the ‘vicious flower’ – one of Professor Paul Salkovskis’s diagrams shows the general idea.

So how do we deal with all these rituals? Here is one common example, along with an idea of possible ways they may be tackled in CBT.

**Checking**

Checking is a common OCD ritual. During a course of CBT, the sufferer might be asked to try ‘behavioural experiments’ to find out what happens when they don’t check. A key stage in the evolution of CBT was the development of ‘Exposure and Response Prevention (ERP)’ which involves being exposed to whatever it is that makes a person feel anxious, without checking or carrying out other rituals. CBT then goes beyond this, by using what we call ‘behavioural experiments’ which find out what happens when a sufferer doesn’t check or perform their rituals. Rather than just riding out their anxiety in the feared situation (as in ERP), it goes further by testing out the sufferer’s belief that they could ultimately be responsible for harm by not checking or performing their rituals. The therapist will always acknowledge that there is a risk that something bad will happen if the sufferer doesn’t check, but it is the perception of the level of risk that ultimately drives the OCD, by magnifying it to be greater than it actually is.

The one guarantee is that with continued checking the OCD will always remain a problem.
In many cases, CBT alone is highly effective in treating OCD, but for some people a combination of CBT and medication is also effective. This usually takes the form of antidepressants which act in the Serotonin System called **SSRIs (Selective Serotonin Re-uptake Inhibitor)**. Medication may reduce the anxiety enough for a person to start, and eventually succeed in therapy.

We do not know exactly why SSRIs can sometimes be helpful for people with OCD, but they sometimes work by reducing the severity of the obsessive-compulsive symptoms, by ‘taking the edge off’ some of the anxiety experienced as a result of the illness.

SSRIs are usually tried first (before non-selective SRIs) because SSRIs only act on serotonin. The SSRIs usually recommended for the treatment of adults with OCD are:

**Drug Generic Name / (Trade Names)**
- Citalopram (Cipramil)
- Escitalopram (Cipralex)
- Fluoxetine (Prozac)
- Fluvoxamine (Luvox and Faverin)
- Paroxetine (Paxil and Seroxat)
- Sertraline (Lustral and Zoloft)

At the time of writing, the NICE guidelines for the treatment of OCD only recommend two of these medications for use in treating children with OCD. These are Sertraline for children aged 6 years and older and Fluvoxamine for children aged 8 years and older.

Drugs often have several names. When a drug is first discovered, it is given a chemical name, which describes the atomic or molecular structure of the drug. The chemical name is thus usually too complex and cumbersome for general use, so it is given a generic (official) name and a trade (proprietary or brand) name. The trade name is developed by the company requesting approval for the drug and identifies it as the exclusive property of that company. For example, the generic name for Prozac is Fluoxetine.

This is not an exhaustive list, and sufferers may often be prescribed additional medications to enhance or augment the effects of these SSRIs.

Typically, the process of determining the most suited medication for an individual is achieved on a trial-and-error basis. However, in order to allow its maximum effects to be adequately observed, each medication should be taken for a specified time period, usually for at least 12-16 weeks, before seeking out an alternative.

If these medications fail to work, a non-selective SRI may be prescribed. However, because it affects neurotransmitters in the brain, other than just serotonin, there are more side effects and therefore it is usually not a first choice medication for treating OCD. The non-selective SRI most commonly used for treating OCD is a Tricyclic Antidepressant (TCA) medication called **Clomipramine (Anafranil)**.

The NICE guidelines state Clomipramine should be considered in the treatment of adults with OCD or BDD after an adequate trial of at least one SSRI has been ineffective or poorly tolerated, or if the patient prefers or has had success in using the medication before.

Because body chemistry amongst individuals can vary greatly, the medication and dosage prescribed will vary from person to person, as will the side effects and benefits to the individual. Some people with OCD respond well to the first medication prescribed; others will need to try more than one, under medical supervision, to find the one that is most effective.
Despite their anxiety-reducing effects, all medications can sometimes cause unwanted side effects as well, which usually diminish as the body adjusts to them. Finding the medication that works best for you is a matter of trial-and-error. Often what works for one person may not work for someone else. This is the same with side effects, where one person may experience problems, someone else may not experience any at all. These are just some of the possible side effects that you may experience:

- Blood pressure changes
- Blurred vision
- Breathing problems
- Chills
- Confusion
- Concentration problems
- Depersonalisation
- Diarrhoea
- Discharge from the nipples
- Drowsiness
- Dry mouth
- Enlargement of the breasts
- Erection (spontaneous without sexual desire)
- Excitable more easily
- Fast or fluttering heartbeat
- Feeling sick
- Hair Loss
- Headaches or Migraine
- Increased appetite
- Memory problems
- Palpitations
- Saliva increase
- Sexual problems
- Shakiness
- Skin rashes
- Sleep disturbances
- Sore throat
- Stuffy nose
- Sweating
- Taste disturbance,
- Tingling
- Unsteadiness,
- Urine – (increase in frequency or difficulty passing water)
- Weight gain
- Yawning more

This is not a conclusive list, so should you experience any of these side effects, or others which become troublesome, it is important that you speak to your GP or psychiatrist. What is particularly serious, especially in young people, is that medication may cause thoughts of self-harm or suicide. If this happens, talk to your GP, pharmacist or mental health professional immediately. Family members should be asked to keep a close eye on young people taking medication, particularly for signs of depression, thoughts about suicide or self-harm, irritability, aggressiveness, mood changes or other unusual changes in behaviour.

### Stopping Medication

Although you may stop taking medication whenever you wish, it is sensible to reduce them gradually under supervision from your GP, or ideally your Psychiatrist. Generally speaking, these medications are not addictive, but they may sometimes have withdrawal symptoms, especially if stopped abruptly.

The NICE guidelines for the treatment of OCD recommend that if the medication has helped you, you should continue taking the medication for at least 12 months to ensure your symptoms continue to improve.

### Medication and CBT

In many cases, CBT alone is highly effective in treating OCD, but for some people a combination of CBT and medication is more effective.

Jeffrey Schwartz M.D., Neuropsychiatrist at the UCLA School of Medicine, applies a metaphor of the administering of drug treatment in his book *Brain Lock*.

He defines their principal purpose as similar to that served by ‘water wings’ (armbands) in the initial stages of learning to swim. They offer a means of keeping the sufferer ‘afloat’ while he or she is developing and consolidating the new psychological skills necessary to combat OCD longer-term. Thus, they are incredibly useful at the outset of treatment as a means of ameliorating the effects of psychotherapeutic intervention strategies such as CBT.
Despite scientists being unable to come up with a definitive cause for OCD, it is generally believed that the disorder is the likely result of a combination of neurobiological, genetic, behavioural, cognitive and/or environmental factors. Any one of these factors can trigger the disorder in a specific individual at any particular point in time. Below is a summary of some of the suggested theories around the cause of OCD.

**Biological Theory**
Biological causes of OCD have focused on a circuit in the brain which regulates primitive aspects of our behaviour such as aggression, sexuality, and bodily excretions. This circuit relays information from a part of the brain called the orbitofrontal cortex (front part of the brain), to another area, the striatum, and the thalamus (deeper parts of the brain). It also includes other regions such as the caudate nucleus of the basal ganglia. When this circuit is activated, these impulses are brought to your attention and cause you to perform a particular behaviour that appropriately addresses the impulse.

**Serotonin**
Abnormalities, or an imbalance, in the brain chemical, serotonin, could also be to blame. Serotonin is the chemical in the brain that sends messages between brain cells and it is thought to be involved in regulating everything from anxiety, to memory, to sleep.

Medications known as Selective Serotonin Re-uptake Inhibitors (SSRIs) are often used to treat OCD, although it is not fully known why the SSRI medications seem to help some people with OCD.

**Psychological factors**
Research has revealed a great deal about the psychological factors that maintain OCD, which in turn has led to effective psychological treatment in the form of Cognitive Behavioural Therapy (CBT).

Many cognitive theorists believe that individuals with OCD have faulty beliefs, and that it is their misinterpretation of intrusive thoughts that leads to OCD. They believe that sufferers have an inflated sense of responsibility and that they misinterpret these thoughts as being very important and significant. This leads to the development of the obsessions and the resulting compulsive behaviours.

Some researchers believe that this theory questions the biological theory because people may be born with a biological predisposition to OCD but never develop the full disorder, while others are born with the same predisposition but, when subject to sufficient learning experiences, develop OCD.

Stress and parenting styles are environmental factors that have been blamed for causing OCD, but no evidence is yet to show that stress, or the way a person interacted with his or her parents during childhood, causes the disorder. Stress does not cause OCD, although a stressful event, like being involved in or witnessing a road traffic accident, may trigger its onset. If left untreated, everyday anxiety and stress in a person’s life can also worsen symptoms of OCD. For example, problems at school or work, university exam pressures, relationship problems.

**PANDAS**
Some children begin to exhibit symptoms after a severe infection such as strep throat. The antibodies produced as a result of such an infection, when directed to certain parts of the brain, might be linked in some way to Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infection (PANDAS).

Studies suggest the infection doesn’t actually cause OCD, but triggers symptoms in children who are genetically predisposed to the disorder. It is thought that if OCD results from a strep throat infection the symptoms will start quickly, probably within one or two weeks.
**Genetic Factors**

Another interesting line of research is in the area of genetics, and recent studies have indicated that there may be a considerable genetic basis for OCD. Some research points to the likelihood that OCD sufferers will have a family member with the OCD or a related disorder. However, the theory that OCD is inherited genetically is not conclusive - for example, identical twins will not necessarily both have OCD.

**Psychoanalytic Theory**

Commonly accepted in the past, but nowadays increasingly disregarded, the psychoanalytic theory suggests that OCD develops because of a person’s fixation arising from unconscious conflicts or discomfort they experienced during infancy or childhood. This theory is now quite rightly disregarded due to the failure of psychoanalytic therapy to treat OCD.

**Depression**

Depression is also sometimes thought to cause OCD, although again opinion is split, with the majority of experts believing that depression is often a symptom of OCD rather than a cause.

**Conclusion**

There is still a great deal of theoretical contention surrounding the definitive cause of OCD. However, all of the above theories offer compelling and highly informative insights, with the possibility that a combination of the theories may eventually be identified as the actual cause of OCD. Whilst the cause is currently still being debated, sometimes vigorously by the scientists, what is not in contention is the fact that Obsessive-Compulsive Disorder is indeed a chronic, but equally a very treatable medical condition.

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**Other information guides available from OCD-UK**


Each booklet is written and designed for the target audience group. The parents guide is a contemporary A5 sized guide is aimed at parents of children with OCD, and also includes advice for teachers. It includes family friendly illustrations to help illustrate the illness, helpful for family discussions.

We are happy to supply these booklets free of charge, but please send two first class stamps for each booklet you require to help cover our P+P costs and be sure to specify which booklet/s you require.
The many faces of OCD

The explanations that follow categorise the most common forms of OCD and some of the fears associated with them. It is by no means an exhaustive list and there will always be forms of OCD that do not feature here, and obsessions or compulsions that are not listed either. However this does not mean it is definitely not OCD.

Remember - if you are experiencing distressing and unwanted obsessions and compulsions, that impact significantly on your everyday functioning, this could represent a principal component in the clinical diagnosis of Obsessive-Compulsive Disorder.

CHECKING
The repeated need to check to prevent harm to oneself, property or loved ones, or for fear of causing offence.
- Gas or electric stove knobs
- Water taps
- Door locks
- House alarm
- Appliances and lights
- Re-reading postal letters and greetings cards before sealing / mailing
- Route after driving
- Illnesses and symptoms online
- People – Calling and texting
- Reassurance
- Re-reading words or lines in a book over and over again
- Schizophrenia Symptoms

The checking is often carried out multiple times, sometimes hundreds of times, and for hours on end, resulting in the person being late for work, dates and other appointments. This can have a serious impact on a person’s ability to hold down jobs and relationships. The checking can also cause damage to objects that are constantly being checked.

CONTAMINATION
The need to clean and wash is the compulsion, the obsessive fear is that something is contaminated and/or may cause illness, and ultimately death, to a loved one or oneself.
- Using public toilets
- Coming into contact with chemicals
- Touching door knobs/handles
- Using public telephones
- Waiting in a GP’s surgery or hospital.
- Touching bannisters on staircases
- Avoiding red objects and stains
- Excessive Tooth Brushing

The cleaning or washing is often carried out multiple times often accompanied by rituals of repetitive hand or body washing until the person ‘feels’ it is clean, rather than someone without OCD who will wash or clean once until they ‘see’ they are clean. The time this takes can have a serious impact on a person’s ability to hold down jobs and relationships and there is also a secondary physical health impact of the constant scrubbing and cleaning on the skin, especially the hands.

RUMINATIONS
In the context of OCD, a rumination is a train of prolonged thinking about a question or theme that is undirected and unproductive. Unlike obsessive thoughts, ruminations are not objectionable and are indulged rather than resisted. Many ruminations dwell on religious, philosophical, or metaphysical topics, such as the origins of the universe, life after death, the nature of morality, and so on.

With most ruminations it inevitably never leads to a solution or satisfactory conclusion and the person appears to be deeply pre-occupied, very thoughtful, and detached.

SYMMETRY AND ORDERLINESS
The need to have everything lined up symmetrically just ‘right’ is the compulsion, the obsessive fear might be to ensure everything feels ‘just right’ to prevent discomfort or sometimes to prevent harm occurring.
- Having everything neat and in its place at all times.
- Having pictures hanging aligned and straight.
- Having canned food items all facing the same way, usually forward.
- Having clothes on the rail all hanging perfectly and facing the same way.
- Having books lined up perfectly in a row on a bookshelf.
INTRUSIVE THOUGHTS
Intrusive thoughts, in the spectrum of OCD, are where a person generally suffers with obsessional thoughts that are repetitive, disturbing and often horrific and repugnant in nature. For example, thoughts of causing violent or sexual harm to loved ones.

Because the intrusive thoughts are repetitive and not voluntarily produced, they cause the sufferer extreme distress - the very idea that they are capable of having such thoughts in the first place can be horrifying. However, what we do know is that people with Obsessive-Compulsive Disorder are the least likely people to actually act on the thoughts, partly because they find them so repugnant and go to great lengths to avoid them and prevent them happening.

Intrusive thoughts can cover absolutely any subject, but the more common areas of OCD related concerns covers the following sub-categories:

- Relationships.
- Sexual Thoughts
- Magical Thinking - believing that:
- Religious - believing that:
- Violent Thoughts - fear of:

### Relationship Intrusive Thoughts
- Constantly analysing the depth of feelings for one’s partner, placing the partner and the relationship under a microscope and finding fault.
- Constantly needing to seek reassurance and approval from one’s partner.
- Doubts that one’s partner is being faithful.
- Doubts that one may cheat on their partner.
- Questioning one’s own sexuality, and having feelings, thoughts and impulses about being attracted to members of the same sex.

### Sexual Intrusive Thoughts
- Fearing being a paedophile and being sexually attracted to children.
- Fearing being sexually attracted to members of one’s own family.
- Fearing being attracted to members of the same sex (homosexual OCD).
- Thoughts about touching a child inappropriately.
- Intrusive sexual thoughts about God, saints or, religious figures.

### Violent Intrusive Thoughts
- Violently harming children or loved ones.
- Killing innocent people.
- Jumping in front of a train or fast moving bus.
- Acting on unwanted impulses, e.g. running someone over, stabbing someone.
- Thoughts about accidentally touching someone inappropriately, with the aim of hurting them.

### Religious Intrusive Thoughts
- Sins committed will never be forgiven by God and one will go to hell.
- One will have bad thoughts in a religious building.
- One will scream blasphemous words loudly in a religious location.
- Certain prayers must be said over and over again.
- Religious objects need to be touched or kissed repeatedly.
- One is always doing something sinful.
- Intrusive sexual thoughts about God, saints or, religious figures.

### Magical Thinking Intrusive Thoughts
- A certain colour or number has good or bad luck associated with it.
- A loved one’s death can be predicted.
- One’s thoughts can cause disasters to occur.
- Stepping on cracks in the pavement can make bad things happen.
- Whatever comes to mind can come true.
- Attending a funeral will bring death.
- Hearing the word ‘death’ will mean repeating the word ‘life’ to prevent death.
Hoarding

Long considered to be part of ‘OCD’ is the inability to discard useless or worn out possessions, commonly referred to as hoarding.

In the past it was suggested that hoarding, as a subtype of OCD, may be less responsive to treatment than other forms. However, as a result of more recent research, and due to a greater understanding of this problem, there is now significant evidence to suggest that treatment can be just as effective for this type of OCD, as with others. Hoarding is a complex form of OCD where a person has three main problems:

- They have difficulty in discarding items.
- They buy, save or collect anything and everything and are unable to throw anything away, even when space is running out.
- They have problems with organisation of items.

These problems often culminate in the hoarder living in a small area of a room, with the rest taken over by the saved or difficult to discard items. There is believed to be three categories of hoarding:

- ‘Prevention of harm’ hoarding – Prevention of bad things happening, common to other forms of OCD, where a person will fear that harm will occur if they throw things away. For example dustmen will be injured by sharp edges of discarded cans or glass objects, or that someone may be contaminated from a discarded item.
- ‘Deprivation hoarding’ – Where a person feels that they may need the object later, sometimes because of previous experience of deprivation. For example just after the Second World War many people across Europe had nothing, and so everything became valuable and reusable.
- ‘Emotional’ Hoarding – For some people hoarding becomes emotional, where perhaps, because of past traumatic experiences with people, they believe objects hold a special emotional significance. For example where a loved teddy bear can be trusted more than people, a person will develop relationships with objects rather than people.

Often people who hoard are unable to make progress without help and support through treatment. Hoarding can also pose significant health and safety risks, and can result in significant distress and/or impairment in day-to-day living.

‘Pure O’

Commonly referred to as ‘Pure O’ by the OCD community, ‘Pure O’ is a form of OCD where people mistakenly believe that it differs from traditional OCD, in that it features no outward compulsive manifestations; instead, the anxiety-inducing obsessions take place only in the mind.

However, a person with ‘Pure O’ will still have compulsions which mainly manifest as unseen mental rituals, and they will usually also engage in compulsive behaviours like seeking reassurance from loved ones, and avoidance of particular objects, places or people. They are compulsions, nonetheless, which is why the term ‘Pure O’ is somewhat imprecise.

‘Pure O’ is like any other form of OCD, it will involve both obsessions and compulsions which are the problems that need addressing through Cognitive Behavioural Therapy (CBT).

We have created a PDF guide for download to help you understanding this often misunderstood form of OCD on our website.
Fundraise for OCD-UK and join the running team, no experience necessary!

Run for free OCD-UK and we will refund your race entry fee
Families and carers have an important role in giving practical and emotional support to someone with OCD. If you care for someone with OCD, finding out about the condition, and understanding what your loved one is going through, is perhaps the most important thing that you can do – when it comes to OCD, knowledge is power!

**Getting help**

Early intervention is vital; there is considerable proof that the sooner OCD is identified and treated, the more chance there is of a better recovery. So if you think your loved one may have OCD then the first thing to do is to speak with their GP (if they are a young child). With older children / teenagers, they might wish to speak with their GP alone, but you should still encourage them to seek help. Adults will need to be encouraged to contact their GP themselves. In some cases the person with OCD will refuse to see the GP, or may not even admit that there is a problem at all. In this case you could offer educational materials to the person, maybe leaving them around the house in the hope that he/she will pick them up to read at a later stage. You could also show them the OCD-UK website.

**Obstacles**

Whilst awareness of OCD is gradually increasing, there are unfortunately still some GPs who have a very limited knowledge of the illness. OCD-UK have created a GP ‘Ice Breaker’ which you may wish to print off our website and pass to the GP - it explains what OCD is, and that you know your loved one needs to be diagnosed and offered treatment of Cognitive Behavioural Therapy (CBT).

**Next Steps**

Once a GP visit has been made, your loved one should be referred to their local Mental Health Team (CMHT) or Improving Access to Psychological Therapies (IAPT) team or CAMHS (Child & Adolescent Mental Health Services) or the local equivalents.

Here you and/or your loved one will be able to discuss their symptoms with a health professional who knows how to diagnose and treat OCD. During the assessment with your loved one, the healthcare professional may also, with permission of your loved one, ask you some questions about the OCD. You may be asked how you deal with it on a daily basis, or what actions you take to try and reduce the anxiety.

**How you can help your loved one before and during treatment**

It is often a good idea to sit down together as a family, ideally on a good day, and discuss with your loved one that together you are all going to fight OCD, and make them aware that when you do challenge the OCD, you are challenging the illness and not them. Perhaps draw up a verbal ‘contract’ that whilst you are awaiting treatment to begin, for now you will all agree to compromise. So perhaps just for now the family will allow the OCD to impact on certain areas of the house, but that in the agreed communal areas, like the living room and kitchen, normal life will be maintained for the rest of the family.
As a general rule you should never collude with the OCD demands. This allows the person with OCD to avoid the feared situations and offers them reassurance, which in the short term lowers their anxiety, but in the long term reinforces the fear. But you know your relative; you will know when to push them hard, and when to give them an emotional arm around the shoulder and a hug for support. Emotional reassurance that they are not alone is sometimes the best reassurance of all. Your loved one’s healthcare professional should be able to give you some information about OCD and also some methods of dealing with the sufferer’s demands, without taking part in the OCD rituals.

**Looking after yourself**

It is also important that if you are the family member or friend who is closest to the sufferer you do not take too much on. It is vital to make time for yourself, and, if need be, seek support for yourself. This can be done in a number of ways:

- Visiting the OCD-UK online forums where there is a section specifically for family, friends and carers. Support from people in the same position is vital. [www.ocdforums.org](http://www.ocdforums.org)
- Just occasionally the person with OCD may have a good day where the OCD seems less severe. Make the most of them and enjoy yourselves.
- Try and take a break every now and again. Your mental wellbeing is important too. Never forget that.

Since 2004, OCD-UK has helped both adults and children with OCD, as well as their families and the mental health professionals who treat them. We are the only full-time UK organisation that is solely dedicated to OCD that is entirely service-user led.

Our ability to fulfil our mission and expand our outreach depends on the generosity of people like you. Every pound you contribute helps literally transform the lives of people who are affected by this often debilitating anxiety disorder.

So if you found this booklet helpful, please help us support other children and adults with OCD by making a donation today.

You can choose to make a single one-off donation, or perhaps you prefer to make a regular ongoing monthly donation, the choice is yours. [www.ocd.uk.org/donate](http://www.ocd.uk.org/donate)
Support OCD-UK by becoming a member from £2 per month and receive this membership package:

OCD-UK Membership Benefits

- Membership pack
- Discount on self-help materials
- Discount on OCD-UK merchandise
- Priority email support
- Priority access to conference tickets
- OCD Information leaflets
- Four copies of the OCD magazine, Compulsive Reading per year
- Online access to recordings of previous conferences – 10+ hours
- The opportunity to join a network of people affected by OCD
- Discounted attendance to our annual conference
- Opportunity to attend members social events

All this for just £24 a year!
For your convenience you can even choose how you pay your membership donation – either monthly (£2) or annually (£24).

To find out more about becoming a member or fundraising for OCD-UK take a look at our website www.ocduk.org

Please don’t throw this book away when you have finished with it; perhaps pass it on to a member of your family or to your local GP surgery.