

# Expert Consensus Treatment Guidelines for Obsessive-Compulsive Disorder: A Guide for Patients and Families

If you or someone you care about has been diagnosed with obsessive-compulsive disorder (OCD), you may feel you are the only person facing the difficulties of this illness. But you are not alone. In the United States, 1 in 50 adults currently has OCD, and twice that many have had it at some point in their lives. Fortunately, very effective treatments for OCD are now available to help you regain a more satisfying life. Here are answers to the most commonly asked questions about OCD.

## WHAT IS OBSESSIVE-COMPULSIVE DISORDER?

Worries, doubts, superstitious beliefs—all are common in everyday life. However, when they become so excessive—such as hours of hand washing—or make no sense at all—such as driving around and around the block to check that an accident didn't occur—then a diagnosis of OCD is made. In OCD, it is as though the brain gets stuck on a particular thought or urge and just can't let go. People with OCD often say the symptoms feel like a case of mental hiccups that won't go away. OCD is a medical brain disorder that causes problems in information processing. It is not your fault or the result of a "weak" or unstable personality. Before the arrival of modern medications and cognitive behavior therapy, OCD was generally thought to be untreatable. Most people with OCD continued to suffer, despite years of ineffective psychotherapy. Today, luckily, treatment can help most people with OCD. Although OCD is usually completely curable only in some individuals, most people achieve meaningful and long-term symptom relief with comprehensive treatment.

### What are the symptoms of obsessive-compulsive disorder?

OCD usually involves having both obsessions and compulsions, though a person with OCD may sometimes have only one or the other. Table 1 lists some common obsessions and compulsions. OCD symptoms can occur in people of all ages. Not all obsessive-compulsive behaviors represent an illness. Some rituals (e.g., bedtime songs, religious practices) are a welcome 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 or dying. Only when symptoms persist, make no

sense, cause much distress, or interfere with functioning do they need clinical attention.

1. **Obsessions.** Obsessions are thoughts, images, or impulses that occur over and over again and feel out of your control. The person does not want to have these ideas, finds them disturbing and intrusive, and usually recognizes that they don't really make sense. People with OCD may worry excessively about dirt and germs and be obsessed with the idea that they are contaminated or may contaminate others. Or they may have obsessive fears of having inadvertently harmed someone else (perhaps while pulling the car out of the driveway), even though they usually know this is not realistic. Obsessions are accompanied by uncomfortable feelings, such as fear, disgust, doubt, or a sensation that things have to be done in a way that is "just so."

2. **Compulsions.** People with OCD typically try to make their obsessions go away by performing compulsions. Compulsions are acts the person performs over and over again, often according to certain "rules." People with an obsession about contamination may wash constantly to the point that their hands become raw and inflamed. A person may repeatedly check that she has turned off the stove or iron because of an obsessive fear of burning the house down. She may have to count certain objects over and over because of an obsession about losing them. Unlike compulsive drinking or gambling, OCD compulsions do not give the person pleasure. Rather, the rituals are performed to obtain relief from the discomfort caused by the obsessions.

### 3. Other features of obsessive-compulsive disorder

- OCD symptoms cause distress, take up a lot of time (more than an hour a day), or significantly interfere with the person's work, social life, or relationships.

Table 1. Typical OCD Symptoms

Common Obsessions	Common Compulsions
Contamination fears of germs, dirt, etc.	Washing
Imagining having harmed self or others	Repeating
Imagining losing control of aggressive urges	Checking
Intrusive sexual thoughts or urges	Touching
Excessive religious or moral doubt	Counting
Forbidden thoughts	Ordering/arranging
A need to have things "just so"	Hoarding or saving
A need to tell, ask, confess	Praying

---

This guide was prepared with the help of the Obsessive-Compulsive Foundation and includes recommendations contained in the Expert Consensus Treatment Guidelines for Obsessive-Compulsive Disorder.

- Most individuals with OCD recognize at some point that their obsessions are coming from within their own minds and are not just excessive worries about real problems, and that the compulsions they perform are excessive or unreasonable. When someone with OCD does not recognize that their beliefs and actions are unreasonable, this is called OCD with poor insight.
- OCD symptoms tend to wax and wane over time. Some may be little more than background noise; others may produce extremely severe distress.

#### **When does obsessive-compulsive disorder begin?**

OCD can start at any time from preschool age to adulthood (usually by age 40). One third to one half of adults with OCD report that it started during childhood. Unfortunately, OCD often goes unrecognized. On average, people with OCD see three to four doctors and spend over 9 years seeking treatment before they receive a correct diagnosis. Studies have also found that it takes an average of 17 years from the time OCD begins for people to obtain appropriate treatment. OCD tends to be underdiagnosed and undertreated for a number of reasons. People with OCD may be secretive about their symptoms or lack insight about their illness. Many healthcare providers are not familiar with the symptoms or are not trained in providing the appropriate treatments. Some people may not have access to treatment resources. This is unfortunate since earlier diagnosis and proper treatment, including finding the right medications, can help people avoid the suffering associated with OCD and lessen the risk of developing other problems, such as depression or marital and work problems.

#### **Is obsessive-compulsive disorder inherited?**

No specific genes for OCD have yet been identified, but research suggests that genes do play a role in the development of the disorder in some cases. Childhood-onset OCD tends to run in families (sometimes in association with tic disorders). When a parent has OCD, there is a slightly increased risk that a child will develop OCD, although the risk is still low. When OCD runs in families, it is the general nature of OCD that seems to be inherited, not specific symptoms. Thus a child may have checking rituals, while his mother washes compulsively.

#### **What causes obsessive-compulsive disorder?**

There is no single, proven cause of OCD. Research suggests that OCD involves problems in communication between the front part of the brain (the orbital cortex) and deeper structures (the basal ganglia). These brain structures use the chemical messenger serotonin. It is believed that insufficient levels of serotonin are prominently involved in OCD. Drugs that increase the brain concentration of serotonin often help improve OCD symptoms. Pictures of the brain at work also show that the brain circuits involved in OCD return toward normal in those who improve after taking a serotonin medication or receiving cognitive-behavioral psychotherapy. Although it seems clear that reduced levels of serotonin play a role in OCD, there is no laboratory test for OCD. Rather, the diagnosis is made based on an assessment of the

person's symptoms. When OCD starts suddenly in childhood in association with strep throat, an autoimmune mechanism may be involved, and treatment with an antibiotic may prove helpful.

#### **What other problems are sometimes confused with OCD?**

- Some disorders that closely resemble OCD and may respond to some of the same treatments are trichotillomania (compulsive hair pulling), body dysmorphic disorder (imagined ugliness), and habit disorders, such as nail biting or skin picking. While they share superficial similarities, impulse control problems, such as substance abuse, pathological gambling, or compulsive sexual activity, are probably not related to OCD in any substantial way.
- The most common conditions that resemble OCD are the tic disorders (Tourette's disorder and other motor and vocal tic disorders). Tics are involuntary motor behaviors (such as facial grimacing) or vocal behaviors (such as snorting) that often occur in response to a feeling of discomfort. More complex tics, like touching or tapping tics, may closely resemble compulsions. Tics and OCD occur together much more often when the OCD or tics begin during childhood.
- Depression and OCD often occur together in adults and, less commonly, in children and adolescents. However, unless depression is also present, people with OCD are not generally sad or lacking in pleasure, and people who are depressed but do not have OCD rarely have the kinds of intrusive thoughts that are characteristic of OCD.
- Although stress can make OCD worse, most people with OCD report that the symptoms can come and go on their own. OCD is easy to distinguish from a condition called posttraumatic stress disorder, because OCD is not caused by a terrible event.
- Schizophrenia, delusional disorders, and other psychotic conditions are usually easy to distinguish from OCD. Unlike psychotic individuals, people with OCD continue to have a clear idea of what is real and what is not.
- In children and adolescents, OCD may worsen or cause disruptive behaviors, exaggerate a pre-existing learning disorder, cause problems with attention and concentration, or interfere with learning at school. In many children with OCD, these disruptive behaviors are related to the OCD and will go away when the OCD is successfully treated.
- Individuals with OCD may have substance-abuse problems, sometimes as a result of attempts to self-medicate. Specific treatment for the substance abuse is usually also needed.
- Children and adults with pervasive developmental disorders (autism, Asperger's disorder) are extremely rigid and compulsive, with stereotyped behaviors that somewhat resemble very severe OCD. However, those with pervasive developmental disorders have extremely severe problems relating to and communicating with other people, which do not occur in OCD.

Only a small number of those with OCD have the collection of personality traits called obsessive compulsive personality disorder.

der (OCPD). Despite its similar name, OCPD does not involve obsessions and compulsions, but rather is a personality pattern that involves a preoccupation with rules, schedules, and lists; perfectionism; an excessive devotion to work; rigidity; and inflexibility. However, when people have both OCPD and OCD, the successful treatment of the OCD often causes a favorable change in the person's personality.

### HOW IS OBSESSIVE-COMPULSIVE DISORDER TREATED?

The first step in treating OCD is educating the patient and family about OCD and its treatment as a medical illness. During the last 20 years, two effective treatments for OCD have been developed: **cognitive-behavioral psychotherapy (CBT)** and medication with a **serotonin reuptake inhibitor (SRI)**.

#### Stages of Treatment

- **Acute treatment phase:** Treatment is aimed at ending the current episode of OCD.
- **Maintenance treatment:** Treatment is aimed at preventing future episodes of OCD.

#### Components of Treatment

- **Education:** This is crucial in helping patients and families learn how best to manage OCD and prevent its complications.
- **Psychotherapy:** Cognitive-behavioral psychotherapy (CBT) is the key element of treatment for most patients with OCD.
- **Medication:** Medication with a serotonin reuptake inhibitor is helpful for many patients.

### EDUCATION

#### Is there anything I can do to help my disorder?

Absolutely yes. You need to become an expert on your illness. Since OCD can come and go many times during your life, you and your family or others close to you need to learn all about OCD and its treatment. This will help you get the best treatment and keep the illness under control. Read books, attend lectures, talk to your doctor or therapist, and consider joining the Obsessive-Compulsive Foundation. A list of recommended readings and information resources is given at the end of this handout. Being an informed patient is the surest path to success.

#### How often should I talk with my clinician?

When beginning treatment, most people talk to their clinician at least once a week to develop a CBT treatment plan and to monitor symptoms, medication doses, and side effects. As you get better, you see your clinician less often. Once you are well, you might see your clinician only once a year.

Regardless of scheduled appointments or blood tests, call your clinician if you have:

- Recurrent severe OCD symptoms that come out of nowhere
- Worsening OCD symptoms that don't respond to strategies you learned in CBT

- Changes in medication side effects
- New symptoms of another disorder (e.g., panic or depression)
- A crisis (e.g., a job change) that might worsen your OCD

#### What should I do if I feel like quitting treatment?

It is normal to have occasional doubts and discomfort with your treatment. Discuss your concerns and any discomforts with your doctor, therapist, and family. If you feel a medication is not working or is causing unpleasant side effects, tell your doctor. Don't stop or adjust your medication on your own. You and your doctor can work together to find the best and most comfortable medicine for you. Also, don't be shy about asking for a second opinion from another clinician, especially about the wisdom of cognitive-behavior therapy. Consultations with an expert on medication or behavioral psychotherapy can be a great help. *Remember, it is harder to get OCD under control than to keep it there, so don't risk a relapse by stopping your treatment without first talking to your clinician.*

#### What can families and friends do to help?

- Many family members feel frustrated and confused by the symptoms of OCD. They don't know how to help their loved one. If you are a family member or friend of someone with OCD, your first and most important task is to learn as much as you can about the disorder, its causes, and its treatment. At the same time, you must be sure the person with OCD has access to information about the disorder. We highly recommend the booklet, "Learning to Live with Obsessive Compulsive Disorder" by Van Noppen et al. (Information on obtaining this and other educational resources is given at the end of this handout.) This booklet gives good advice and practical tips to help family members help their loved ones and learn to cope with OCD. Helping the person to understand that there are treatments that can help is a big step toward getting the person into treatment. When a person with OCD denies that there is a problem or refuses to go for treatment, this can be very difficult for family members. Continue to offer educational materials to the person. In some cases, it may help to hold a family meeting to discuss the problem, in a similar manner to what is often done when someone with alcohol problems is in denial.
- Family problems don't cause OCD, but the way families react to the symptoms can affect the disorder, just as the symptoms can cause a great deal of disruption and many problems for the family. OCD rituals can tangle up family members unmercifully, and it is sometimes necessary for the family to go through therapy with the patient. The therapist can help family members learn how to become gradually disentangled from the rituals in small steps and with the patient's agreement. Abruptly stopping your participation in OCD rituals without the patient's consent is rarely helpful since you and the patient will not know how to manage the distress that results. Your refusal to participate will not help with those symptoms that are hidden and, most important, will not help

the patient learn a lifelong strategy for coping with OCD symptoms.

- Negative comments or criticism from family members often make OCD worse, while a calm, supportive family can help improve the outcome of treatment. If the person views your help as interference, remember it is the illness talking. Try to be as kind and patient as possible since this is the best way to help get rid of the OCD symptoms. Telling someone with OCD to simply stop their compulsive behaviors usually doesn't help and can make the person feel worse, since he or she is not able to comply. Instead, praise any successful attempts to resist OCD, while focusing your attention on positive elements in the person's life. You must avoid expecting too much or too little. Don't push too hard. Remember that nobody hates OCD more than the person who has the disorder. Treat people normally once they have recovered, but be alert for telltale signs of relapse. If the illness is starting to come back, you may notice it before the person does. Point out the early symptoms in a caring manner and suggest a discussion with the doctor. Learn to tell the difference between a bad day and OCD, however. It is important not to attribute everything that goes poorly to OCD.
- Family members can help the clinician treat the patient. When your family member is in treatment, talk with the clinician if possible. You could offer to visit the clinician with the person to share your observations about how the treatment is going. Encourage the patient to stick with medications and/or CBT. However, if the patient has been on a certain treatment for a fairly long time with little improvement in symptoms or has troubling side effects, encourage the person to ask the doctor about other treatments or about getting a second opinion.
- When children or adolescents have OCD, it is important for parents to work with schools and teachers to be sure that they understand the disorder. Just as with any child with an illness, parents still need to set consistent limits and let the child or adolescent know what is expected of him or her.
- Take advantage of the help available from support groups (for addresses and phone numbers, see the end of this hand-out). Sharing your worries and experiences with others who have gone through the same things can be a big help. Support groups are a good way to feel less alone and to learn new strategies for coping and helping the person with OCD.
- Be sure to make time for yourself and your own life. If you are helping to care for someone with severe OCD at home, try to take turns "checking in" on the person so that no one family member or friend bears too much of the burden. It is important to continue to lead your own life and not let yourself become a prisoner of your loved one's rituals. You will then be better able to provide support for your loved one.

## PSYCHOTHERAPY

Cognitive behavioral psychotherapy (CBT) is the psychotherapeutic treatment of choice for children, adolescents, and adults

with OCD. In CBT, there is a logically consistent and compelling relationship between the disorder, the treatment, and the desired outcome. CBT helps the patient internalize a strategy for resisting OCD that will be of lifelong benefit.

### What is CBT?

The BT in CBT stands for behavior therapy. Behavior therapy helps people learn to change their thoughts and feelings by first changing their behavior. Behavior therapy for OCD involves **exposure and response prevention (E/RP)**.

- **Exposure** is based on the fact that anxiety usually goes down after long enough contact with something feared. Thus people with obsessions about germs are told to stay in contact with "germy" objects (e.g., handling money) until their anxiety is extinguished. The person's anxiety tends to decrease after repeated exposure until he no longer fears the contact.
- For exposure to be of the most help, it needs to be combined with **response or ritual prevention (RP)**. In RP, the person's rituals or avoidance behaviors are blocked. For example, those with excessive worries about germs must not only stay in contact with "germy things," but must also refrain from ritualized washing.

Exposure is generally more helpful in decreasing anxiety and obsessions, while response prevention is more helpful in decreasing compulsive behaviors. Despite years of struggling with OCD symptoms, many people have surprisingly little difficulty tolerating E/RP once they get started.

- **Cognitive therapy (CT)** is the other component in CBT. CT is often added to E/RP to help reduce the catastrophic thinking and exaggerated sense of responsibility often seen in those with OCD. For example, a teenager with OCD may believe that his failure to remind his mother to wear a seat belt will cause her to die that day in a car accident. CT can help him challenge the faulty assumptions in this obsession. Armed with this proof, he will be better able to engage in E/RP, for example, by not calling her at work to make sure she arrived safely.
- Other techniques, such as thought stopping and distraction (suppressing or "switching off" OCD symptoms), satiation (prolonged listening to an obsession usually using a closed-loop audiotape), habit reversal (replacing an OCD ritual with a similar but non-OCD behavior), and contingency management (using rewards and costs as incentives for ritual prevention) may sometimes be helpful but are generally less effective than standard CBT.

People react differently to psychotherapy, just as they do to medicine. CBT is relatively free of side effects, but all patients will have some anxiety during treatment. CBT can be individual (you and your doctor), group (with other people), or family. A physician may provide both CBT and medication, or a psychologist or social worker may provide CBT, while a physician manages your medications. Regardless of their specialties, those treating you should be knowledgeable about the treatment of OCD and willing to cooperate in providing your care.

**How to get the most out of psychotherapy**

- Keep your appointments.
- Be honest and open.
- Do the homework assigned to you as part of your therapy.
- Give the therapist feedback on how the treatment is working.

**Commonly asked questions about CBT**

- **How successful is CBT?** While as many as 25% of patients refuse CBT, those who complete CBT report a 50%–80% reduction in OCD symptoms after 12–20 sessions. Just as important, people with OCD who respond to CBT usually stay well, often for years to come. When someone is being treated with medication, using CBT with the medication may help prevent relapse when the medication is stopped.
- **How long does CBT take to work?** When administered on a weekly basis, CBT may take 2 months or more to show its full effects. Intensive CBT, which involves 2–3 hours of therapist-assisted E/RP daily for 3 weeks, is the fastest treatment available for OCD.
- **What is the best setting for CBT?** Most patients do well with gradual weekly CBT, in which they practice in the office with the therapist once a week and then do daily E/RP homework. Homework is necessary because the situations or objects that trigger OCD are unique to the individual's environment and often cannot be reproduced in the therapist's office. In intensive CBT, the therapist may come to the patient's home or workplace to conduct E/RP sessions. On occasion, the therapist may also do this in gradual CBT. In very rare cases, when OCD is particularly severe, CBT is best conducted in a hospital setting.
- **How can I find a behavior therapist in my area?** Depending on where you live, finding a trained cognitive-behavioral psychotherapist may be difficult, especially one trained to work with children and adolescents. To locate a therapist skilled in CBT for OCD, you may want to ask your physician or other healthcare provider, an academic psychiatry or psychology department, your local OCD support group, or the Obsessive-Compulsive Foundation, the Anxiety Disorders Association of America, or the Association for the Advancement of Behavioral Therapy (addresses and phone numbers are given at the end of this handout). In some cases, you may find that a local cognitive-behavioral psychotherapist has experience with depression or other anxiety disorders, but not with OCD. However, using one of the excellent treatment manuals now available, it is relatively easy to translate CBT skills from another disorder to OCD. So if there is no one immediately available, look for a skilled psychologist or psychiatrist who is willing to learn. Remember, though, if you are not getting real CBT, which involves exposure and response prevention using a list of OCD symptoms that are ranked from most difficult to easiest to resist, you are probably not getting the treatment you need. Don't be afraid to ask for a second opinion where necessary. In rare cases, traveling to a specialized center where intensive CBT is

available on an outpatient or inpatient basis may be the most practical solution.

**MEDICATION****What medications are used to treat obsessive-compulsive disorder?**

Research clearly shows that the serotonin reuptake inhibitors (SRIs) are uniquely effective treatments for OCD. These medications increase the concentration of serotonin, a chemical messenger in the brain. Five SRIs are currently available by prescription in the United States:

- Clomipramine (Anafranil, manufactured by Ciba-Geigy)
- Fluoxetine (Prozac, manufactured by Lilly)
- Fluvoxamine (Luvox, manufactured by Solvay)
- Paroxetine (Paxil, manufactured by Smith-Kline Beecham)
- Sertraline (Zoloft, manufactured by Pfizer)

Fluoxetine, fluvoxamine, paroxetine, and sertraline are called selective serotonin reuptake inhibitors (SSRIs) because they primarily affect only serotonin. Clomipramine is a nonselective SRI, which means that it affects many other neurotransmitters besides serotonin. This means that clomipramine has a more complicated set of side effects than the SSRIs. For this reason, the SSRIs are usually tried first since they are usually easier for people to tolerate.

**How well do medications work?**

When patients are asked about how well they are doing compared to before starting treatment, they report marked to moderate improvement after 8–10 weeks on a serotonin reuptake inhibitor (SRIs). Unfortunately, fewer than 20% of those treated with medication alone end up with no OCD symptoms. This is why medication is often combined with CBT to get more complete and lasting results. About 20% don't experience much improvement with the first SRI and need to try another SRI.

**Which medication should I choose first?**

Studies show that all the SRIs are about equally effective. However, to reduce the chance of side effects, most experts recommend beginning treatment with one of the selective serotonin reuptake inhibitors. If you or someone in your family did well or poorly with a medication in the past, this may influence the choice. If you have medical problems (e.g., an irritable stomach, problems sleeping) or are taking another medication, these factors may cause your doctor to recommend one or another medication to minimize side effects or to avoid possible drug interactions.

**What if the first medication doesn't work?**

First, it is important to remember that these medications don't work right away. Most patients notice some benefit after 3 to 4 weeks, while maximum benefit should occur after 10 to 12 weeks of treatment at an adequate dose of medication. When it is

clear that a medication is not working well enough, most experts recommend switching to another SRI. While most patients do equally well on any of the SRIs, some will do better on one than another, so it is important to keep trying until you find the medication and dosage schedule that is right for you.

### **What are the side effects of these medications?**

In general, the SRIs are well tolerated by most people with OCD. The four SSRIs (fluoxetine, fluvoxamine, paroxetine, and sertraline) have similar side effects. These include nervousness, insomnia, restlessness, nausea, and diarrhea. The most common side effects of clomipramine are dry mouth, sedation, dizziness, and weight gain. While all five drugs can cause sexual problems, on average these are a bit more common with clomipramine. Clomipramine is also more likely to cause problems with blood pressure and irregular heart beats, so that children and adolescents and patients with preexisting heart disease who are treated with clomipramine must have electrocardiograms before beginning treatment and at regular intervals during treatment. Remember that all side effects depend on the dose of medication and on how long you have been taking it. If side effects are a big issue, it is important to start with a low dose and increase the dose slowly. More severe side effects are associated with larger doses and a rapid increase in the dose. Tolerance to side effects may be more likely to develop with the SSRIs than with clomipramine, so that many patients are better able to tolerate the SSRIs than clomipramine over the long term. All SRIs except fluoxetine should be tapered and stopped slowly because of the possibility of the return of symptoms and withdrawal reactions.

### **Tell your doctor right away about any side effects you have.**

Some people have different side effects than others and one person's side effect (for example, unpleasant sleepiness) may actually help another person (someone with insomnia). The side effects you may get from medication depend on:

- The type and amount of medicine you take
- Your body chemistry
- Your age
- Other medicines you are taking
- Other medical conditions you have

If side effects are a problem for you, your doctor can try a number of things to help:

- *Reducing the amount of medicine:* The doctor may gradually lower the dose to try to achieve a dose low enough to reduce side effects but not low enough to cause a relapse.
- *Adding another medication* may be helpful for some side effects, such as trouble sleeping or sexual problems.
- *Trying a different medicine to see if there are fewer or less bothersome side effects:* Even when a medication is clearly helping, side effects sometimes make it intolerable. In such a case, trying another SRI is a reasonable strategy.

**Remember: Changing medicine is a complicated, potentially risky decision. Don't stop your medicine or change the dose**

**on your own. Discuss any medication problems you are having with your doctor.**

### **Does it help to add CBT or another medication to an SRI?**

When medication has produced only a little benefit after 6 weeks, adding CBT or another medication to the SRI is also sometimes useful.

Many experts believe that CBT is the most helpful treatment to add when someone with OCD is not responding well to medication alone. When people continue to avoid the things that make them anxious or continue to do rituals, this blocks the effects of the medication. For the medication to work, therefore, the person with OCD must try to resist doing rituals. Adding CBT to medication is helpful because it teaches those with OCD to expose themselves to the triggers that make them anxious and then to resist performing rituals.

It may also be helpful to add one of the following types of medications to an SRI:

- Low dose clomipramine to an SSRI
- An anxiety-reducing medication, such as clonazepam or alprazolam, in patients with high levels of anxiety
- A high potency neuroleptic, such as haloperidol or risperidone, when tics or thought disorder symptoms are present.

These complex medication strategies are best reserved for those who have not done well with a combination of SRI and CBT.

### **What if nothing seems to work?**

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. There is little consensus among the OCD experts on what to do next when someone with OCD fails to respond to expert CBT plus well-delivered, sequential SRI trials. Switching from an SSRI to clomipramine may improve the chances that a previously non-responsive patient may have a good response. Most experts recommend considering a trial of clomipramine after 2 or 3 failed SSRI trials. Occasionally, a doctor may wish to combine an SSRI with clomipramine either to reduce side effects or to increase the potential benefits of medication. In the adult with extremely severe and unremitting OCD, neurosurgical treatment to interrupt specific brain circuits that are malfunctioning can be very helpful. In patients who have severe OCD and depression, electroconvulsive therapy (ECT) may be of benefit.

### **Answers to other questions about medications**

- If you think you might be pregnant or are planning to become pregnant, most experts prefer to treat OCD with CBT alone. However, if medications are necessary (and they may be since OCD commonly gets worse during pregnancy), it is better to use them sparingly and to select an SSRI rather than clomipramine.
- The SSRIs are preferred in patients with renal failure or co-existing heart disease who require medication.
- When another psychiatric disorder is present, your doctor will likely mix and match treatment for the other conditions

with treatment for OCD. Sometimes, the same medication can be used for two disorders (e.g., an SRI for OCD and panic disorder). In other cases, such as concurrent mania and OCD, more than one medication will be necessary (e.g., a mood stabilizer and an SRI).

- Laboratory tests are necessary before and during treatment with clomipramine but not with the SSRIs.
- The SRIs are not addictive, but it is a good idea to stop them gradually.

### **Is hospitalization an option?**

People with OCD can almost always be treated as outpatients. In very rare cases in which the OCD involves severe depression or aggressive impulses, hospitalization may be necessary for safety. When a person has very severe OCD or the OCD is complicated by a medical or neuropsychiatric illness, hospitalization can sometimes be a useful way to give intensive CBT.

### **Do I have to choose between CBT and medication?**

No single approach works best for everyone with OCD, although most people probably do best with CBT alone or CBT plus an SRI. The treatment choice will of course depend on the patient's preference. Some people prefer to start with medication to avoid the time and trouble associated with CBT; others prefer to begin with CBT to avoid medication side effects. Many, if not most, people seem to prefer combination treatment.

The need for medication depends on the severity of the OCD and the age of the person. In milder OCD, CBT alone is often the initial choice, but medication may also be needed if CBT is not effective enough. Individuals with severe OCD or complicating conditions that may interfere with CBT (e.g., panic disorder, depression) often need to start with medication, adding CBT once the medicine has provided some relief. In younger patients, clinicians are more likely to use CBT alone. However, trained cognitive-behavioral psychotherapists are in short supply. Thus, when CBT is not available, medication may become the treatment of choice. Consequently, it is likely that many more people with OCD receive medication than CBT.

Before deciding on a treatment approach, you and your clinician will need to assess your OCD symptoms, other disorders you have, the availability of CBT, and your wishes and desires about what treatment you want. Try to find a clinician who will talk to you about these possibilities so that you can make your own best choice among the options available to you.

### **What if I belong to a managed care network?**

More and more people in the United States are receiving their medical care in some kind of managed care setting (HMO, preferred provider organization, etc.). If you have OCD, it is important that you talk to your case manager or administrator to find out what types of therapy are available in your network. Many managed care programs are instituting group therapy programs as a means of providing appropriate treatment at an affordable cost.

### **What if I can't afford the medications?**

The companies who manufacture the five SRI medications listed above each have a special program to provide free medications for patients who cannot afford them. The Pharmaceutical Research and Manufacturers Association publishes a directory of programs for those who cannot afford medications, which your doctor can request by calling 202-835-3450. You or your doctor can also contact the companies directly:

- Ciba-Geigy Patient Support Program: 800-257-3273
- Lilly Cares Program: 800-545-6962
- Pfizer Prescription Assistance: 800-646-4455
- SmithKline Paxil Access to Care Program: 800-546-0420 (patient requests); 215-751-5722 (physician requests)
- Solvay Patient Assistance Program: 800-788-9277

## **MAINTENANCE TREATMENT**

Once OCD symptoms are eliminated or much reduced—a goal which is practical for the majority of those with OCD—then maintenance of treatment gains becomes the goal.

### **Maintaining treatment gains**

- When patients have completed a successful course of treatment for OCD, most experts recommend monthly follow-up visits for at least 6 months and continued treatment for at least 1 year before trying to stop medications or CBT.
- Relapse is very common when medication is withdrawn, particularly if the person has not had the benefit of CBT. Therefore, many experts recommend that patients continue medication if they do not have access to CBT.
- Individuals who have repeated episodes of OCD may need to receive long-term or even lifelong prophylactic medication. The experts recommend such long-term treatment after 2 to 4 severe relapses or 3 to 4 milder relapses.

### **Discontinuing treatment**

- When someone has done well with maintenance treatment and does not need long-term medication, most experts suggest discontinuing medication only very gradually, while giving CBT booster sessions to prevent relapse. Gradual medication withdrawal usually involves lowering the dose by 25% and then waiting 2 months before lowering it again, depending on how the person responds.
- Because OCD is a lifetime waxing and waning condition, you should always feel comfortable returning to your clinician if your OCD symptoms come back.

## **SUPPORT GROUPS**

Support groups are an invaluable part of treatment. These groups provide a forum for mutual acceptance, understanding, and self-discovery. Participants develop a sense of camaraderie with other attendees because they have all lived with OCD.

People new to OCD can talk to others who have learned successful strategies for coping with the illness.

**The Obsessive-Compulsive Foundation (OCF)** provides a forum for people with OCD and professionals interested in OCD. It distributes information and helps sponsor research on the nature and treatment of OCD and some related conditions. The OCF has self-help groups in many parts of the country and provides referrals to therapists, clinics, and self-help groups. OCF conducts an annual meeting at which the latest findings about OCD are presented and has recently begun training institutes to try to make CBT more widely available. Membership includes a newsletter and discounts for the annual meeting and OCF materials.

Obsessive-Compulsive Foundation  
P.O. Box 70  
Milford, CT 06460-0070  
203-878-5669  
203-874-3843 (recorded information)

You may wish to visit the OC Foundation's website: <http://pages.prodigy.com/alwillen/ocf.html>, where you'll find a list of other OCD resources on the World Wide Web as well as lots of useful information about OCD.

**The Obsessive-Compulsive Information Center** is staffed by medical librarians. It provides access to the published literature on OCD and publishes very useful guides concerning OCD and some related disorders, such as trichotillomania.

OC Information Center  
2711 Allen Boulevard  
Middleton, WI 53562  
608-836-8070

**The Anxiety Disorders Association of America** provides a central clearinghouse for people with, and professionals interested in, the diagnosis and treatment of all anxiety disorders, including OCD.

Anxiety Disorders Association of America  
6000 Executive Boulevard, Suite 513  
Rockville, MD 20852  
301-231-9350

**The Tourette Syndrome Association (TSA)** provides a central clearinghouse for people with, and professionals interested in,

the diagnosis and treatment of tic disorders. Because tic disorders often overlap with OCD, the TSA has a wealth of information about the overlap between these two conditions.

Tourette Syndrome Association  
42-40 Bell Boulevard  
New York, NY 11361-2874  
718-224-2999

**Association for the Advancement of Behavioral Therapy**  
305 Seventh Avenue, 16th Floor  
New York, NY 10001-6008  
212-647-1890

#### FOR MORE INFORMATION

We recommend the following books and videos about OCD. Most are available from the OC Foundation.

***The Boy Who Couldn't Stop Washing.*** Rapoport J. Penguin Books, 1991.

***Brain Lock.*** Schwartz J. Harper Collins, 1996.

***The Doubting Disease.*** Ciarrocchi J. Paulist Press, 1995.

***Getting Control.*** Baer L. Little, Brown, and Company, 1991.

***How I Ran OCD Off My Land: A Guide to Cognitive-Behavioral Psychotherapy for Children and Adolescents with Obsessive-Compulsive Disorder.*** March J, Mulle K. Guilford Press, in press. Available in prepublication format from the OC Foundation.

***Learning to Live with Obsessive Compulsive Disorder,*** 4th Edition. VanNoppen B, Pato M, Rasmussen S. Milford, 1997.

***Obsessive Compulsive Disorder: A Guide,*** 2nd Edition. Greist J. Obsessive Compulsive Information Center, 1994.

***Obsessive-Compulsive Disorder in Children and Adolescents.*** Johnston HF. Obsessive-Compulsive Information Center, 1993.

***Over and Over Again: Understanding Obsessive Compulsive Disorder,*** 2nd Edition. Neziroglu F, Yaryura-Tobias JA. Lexington Books, 1995.

***Stop Obsessing!*** Foa E, Wilson R. Bantam, 1991.

***The Touching Tree: A Video About a Young Child with OCD.*** Callner J. Available through the OC Foundation.

***When Once Is Not Enough: Help for Obsessive-Compulsives.*** Steketee G, White K. Harbinger Publications, 1990.

This *Guide for Patients and Families* is reprinted from J Clin Psychiatry 1997;58 (suppl 4). The Expert Consensus Treatment Guidelines Project for Obsessive-Compulsive Disorder was supported by an unrestricted educational grant from Solvay Pharmaceuticals.