Relief *from* OCD

A Guide for People with Obsessive Compulsive Disorder

OCD Chicago

You Are Not Alone

Obsessive Compulsive Disorder (OCD) was once considered rare, but doctors have learned that millions of people around the world suffer from it.

- OCD afflicts approximately six million to nine million Americans – that's between two percent and three percent of the population.
- OCD strikes about one in 40 adults and about one in 100 school-aged children.
- OCD is the fourth most common psychiatric diagnosis, after phobias, substance abuse and major depression.
- OCD ranks among the 10 leading causes of disability worldwide, according to the World Health Organization.

Everyone knows someone with OCD. If you or a loved one suffer from this disorder, take heart – you are not alone, and proper treatment can improve your life dramatically!

Do you . . .

Spend too much time washing and cleaning?

Check and recheck door locks, stove knobs, appliances and switches many times?

Look in on your child repeatedly, or frequently re-visit any object or location that you associate with harm or danger?

Worry while driving that you ran over someone, causing you to go back and check again and again?

Feel compelled to organize, arrange, re-do or "even up" things, words, or thoughts until they feel "just right?"

Accumulate an excessive amount of useless objects such as old newspapers, magazines, junk mail or containers?

Fear contaminating others?

Ask repetitive questions or seek reassurance from those around you over and over?

Practice excessive, unreasonable observances or rituals triggered by religious fears?

Experience unwanted, intrusive mental images that are disturbing or inappropriate?

Engage in senseless activities such as counting or tapping to temporarily decrease anxiety or fears?

If your answer to any of these questions is yes, you may have OCD. The good news is that effective treatment is available that can help you learn to manage your symptoms and start living a happier and more productive life.

OCD Is Treatable

OCD is a common and treatable medical condition. If left untreated, the disorder causes anguish that can rob people of precious time and life's joys – sometimes even their jobs, marriages or lives.

There's no reason to be afraid or ashamed to seek treatment. OCD is an illness, just like asthma or diabetes. Learning to manage the disorder can dramatically boost your peace of mind and improve your quality of life.

Far too often, people with OCD suffer in silence, unaware that their symptoms are caused by a biological problem. Significant scientific advances have revealed that the disorder responds well to a special kind of therapy called cognitive behavior therapy, sometimes in combination with medication.

If you or someone you love has OCD, consider reading this guide as a first step toward finding relief from this potentially devastating disorder.

What OCD Isn't

People who have Obsessive Compulsive Disorder experience unreasonable fears that trigger repetitive behaviors, thoughts, images or mental rituals. Many people use the terms *obsessive*, *compulsive* and *OCD* incorrectly, leading to myths about the disorder.

OCD does not include stalkers and "obsessed" fans, workaholics, compulsive liars, compulsive shoppers, gamblers or people with phobias such as fear of heights or flying. While many people with these other problems may suffer from treatable mental illnesses, they do not have OCD.

Here are some common myths:

Myth: *Characters with OCD in movies and television shows accurately portray the disorder.*

FACT: TV programs and movies often mistake or exaggerate Obsessive Compulsive Disorder symptoms or play it for laughs. People with OCD know it's no laughing matter.

Myth: *People with OCD are just quirky and could stop their behaviors if they really wanted to.*

FACT: OCD is not a matter of personality or will power. Many scientists believe that rituals associated with the disorder are triggered when certain brain chemicals malfunction. Appropriate treatment "retrains the brain" and actually changes brain chemicals involved with OCD symptoms.

Myth: *OCD behavior is caused by problems with family dynamics, self-esteem or childhood trauma.*

FACT: While the precise cause of OCD is not known, research strongly suggests that it is a medical condition involving certain brain chemicals that do not function properly.

Myth: *Stress causes OCD, and people with the disorder just need to learn to relax.*

FACT: A stressful event can trigger the onset of obsessions and compulsions, but it does not cause the disorder. It's true that stress can make many illnesses worse, and OCD is no exception.

What Is OCD?

Obsessive Compulsive Disorder is a neurobiological disorder that affects men, women, and children of every race, religion, nationality and socio-economic group. Approximately six million to nine million Americans have OCD. It is the fourth most common mental disorder in the United States, and its economic impact has been estimated at $8.4 billion per year.

OCD is diagnosed when obsessions and compulsions:

- Consume excessive amounts of time (an hour or more each day)
- Cause significant distress
- Interfere with daily functioning at work or school, or with social activities, family relationships and/or normal routines.

Obsessions are persistent, uncontrollable worries, fears or doubts that are intrusive, unwanted and disturbing. People with OCD realize that their obsessions are irrational, but they think the only way to relieve their anxiety is to perform their compulsions.

Compulsions are repetitive actions or mental rituals intended to relieve the anxiety caused by obsessions. For example, a person with an obsessive fear of intruders may check and recheck door locks repeatedly. Any relief provided by the compulsions is only temporary, however, and ends up reinforcing the obsession, creating a gradually worsening cycle of OCD behavior.

Here's a list of the most common OCD symptoms:

Obsession	*Compulsion*
FEAR *of* **CONTAMINATION** *or* **GERMS**	*Washing/cleaning*
FEAR *of* **HARM** *or* **DANGER**	*Checking*
FEAR *of* **LOSS**	*Hoarding*
FEAR *of* **VIOLATING RELIGIOUS RULES**	*Praying*
BODY-RELATED FIXATIONS	*Grooming*
NEED *for* **SYMMETRY**	*Arranging or "evening up"*
NEED *for* **PERFECTION**	*Seeking reassurance*

OCD is a chronic but treatable medical condition. Most people can learn to stop performing their compulsions and decrease the intensity of their obsessions through cognitive behavior therapy. This kind of therapy teaches people with OCD how to change their anxious and ritualistic thought patterns and behaviors. Some people also benefit by adding medication to their treatment plan.

Just as a person with diabetes can learn to manage the disease by changing his diet and exercise habits – and perhaps taking medication – a person with OCD can learn to manage symptoms so they won't interfere with daily life.

Antonio worried constantly about germs and feared that he would contaminate his family. Every night when he came home from work, he undressed in the garage, put his clothes in the washing machine, and took a shower that sometimes lasted for two hours. On the weekends, he preferred to stay home rather than "risk" going out and picking up germs. His marriage deteriorated, and his children missed spending time with their dad. When Antonio finally found the right therapist, she helped him learn how to manage his symptoms so he could enjoy family life again.

Diagnosis

There is no laboratory test that can identify OCD. A qualified mental health professional can diagnose the disorder by conducting a specific type of interview – most use the Yale-Brown Obsessive Compulsive Scale (Y-BOCS), which is a questionnaire about obsessions and compulsions.

Causes

While the exact cause of OCD is unknown, scientific research indicates that OCD is a neurobiological illness that may be triggered when certain brain chemicals malfunction. The disorder appears to be at least partly genetic in some cases. Stress does not cause OCD, although a stressful event may trigger its onset, and obsessions and compulsions can worsen in times of stress.

Scientists believe that an area within the brain's frontal cortex may be impaired in people who have the disorder. This part of the brain sends out alarms of possible danger. People who do not have OCD filter such messages and disregard the unreasonable ones. In people with OCD, however, the structure that normally filters such messages malfunctions, causing the person to take these messages seriously.

For example, anyone who is using a knife in the kitchen might have a fleeting thought of hurting a loved one. Most people know that they would never do that and easily dismiss the idea. Someone with OCD, however, may not be able to ignore the thought, which becomes a terrifying obsession.

The parts of the brain that prioritize incoming information and help organize decisions and behaviors may also malfunction in people with OCD, making it difficult for some to make decisions or organize efficiently.

Responding to an obsessive thought by performing a compulsive ritual reinforces the brain pathway associated with OCD. Appropriate treatment actually changes the brain so that it functions more normally by weakening old neurological pathways and strengthening new ones.

Related Conditions

Some people with OCD also have other mental health problems, such as major depression, attention deficit disorder or another anxiety disorder. When two diagnoses occur in the same individual they're called "comorbid." Some conditions that tend to exist with OCD are thought to be biologically linked to the disorder as part of an obsessive-compulsive "spectrum." A cognitive behavior therapist can help identify and determine how to treat these related disorders.

These disorders can be related to OCD:

- **MAJOR DEPRESSION.** Symptoms can include a persistent sad, empty or hopeless mood, loss of interest in pleasurable activities, decreased energy, trouble concentrating, insomnia or oversleeping, weight gain or loss, thoughts of death or suicide, and irritability.
  Resource: National Institute of Mental Health – www.nimh.nih.gov/publicat/depression.cfm

- **ANXIETY DISORDERS.** OCD is classified as an anxiety disorder. Other anxiety disorders include Generalized Anxiety Disorder, Post-Traumatic Stress Disorder, Panic Disorder (panic attacks), Social Anxiety Disorders and specific phobias such as fear of snakes or heights. *Resource: Anxiety Disorders Association of America – www.adaa.org*

- **EATING DISORDERS.** Anorexia nervosa, bulimia and binge eating are disorders that involve serious disturbances in eating behaviors. Approximately 40% of people with anorexia also have OCD. *Resource: National Eating Disorders Association – www.edap.org*

- **TOURETTE SYNDROME OR TIC DISORDERS.** Motor and vocal "tics" are involuntary movements, facial expressions and vocalizations that include blinking, shrugging, sniffing, humming or uttering exclamations.
  Resource: Tourette Syndrome Association of America: www.tsa-usa.org

- **BODY DYSMORPHIC DISORDER.** BDD is characterized by a preoccupation with an imagined or exaggerated defect in one's personal appearance. People with BDD are often obsessed with a perceived flaw and overwhelmed by negative thoughts about the way they look, even if others believe they look fine.
  Resource: Mayo Clinic Tools for Healthier Lives – www.mayoclinic.com/health/body-dysmorphic-disorder/DS00559

- **TRICHOTILLOMANIA AND SKIN-PICKING.** Compulsive hair-pulling ("Trich") and skin-picking are considered body-focused repetitive behaviors.

  Resource: Trichotillomania Learning Center – www.trich.org

- **ATTENTION DEFICIT DISORDERS.** ADD and ADHD (Attention Deficit Hyperactivity Disorder) can occur in children and adults. Symptoms include inattentiveness, hyperactivity and impulsivity.

  Resource: Children and Adults with Attention Deficit/Hyperactivity Disorder – www.CHADD.org

- **ASPERGER'S SYNDROME.** An autism spectrum disorder, Asperger's is characterized by problems with communication, social interaction and patterns of thought. Many people with Asperger's have obsessive interests in certain subjects, but focusing on these interests brings them pleasure, unlike OCD, which produces anxiety.

  Resource: National Institute of Child Health & Human Development – www.nichd.nih.gov/health/topics/asperger_syndrome.cfm

Cheryl found herself praying for hours every day because of her obsessive thoughts and fear of hell. She had to perform the prayers a certain way each time or start over from the beginning if they weren't "right." When she finally saw a cognitive behavior therapist, she learned she had a form of OCD called scrupulosity. The two of them worked with Cheryl's pastor to help her learn to manage the symptoms, and her faith became a source of comfort rather than anxiety.

True or False?

Other people don't have these kinds of thoughts.

FALSE. Even people without OCD sometimes have troubling thoughts; it's just that people with OCD aren't able to ignore them because of a difference in the way their brains process information.

A person should be able to control his or her thoughts at all times.

FALSE. Many people with OCD incorrectly believe that if they were "mentally healthy" or "properly self-disciplined" they could limit their thoughts and images to those they consider to be morally appropriate, healthy or positive. The truth is, that's impossible! Human imagination and creativity involve being able to think of anything at any time, whether or not it seems to fit the occasion or personal beliefs of the individual.

Research shows that attempting to control your thoughts – or believing that you should be able to control them – actually leads to more horrific images and frightening or repugnant thoughts. Cognitive behavioral therapists teach people with OCD to accept their thoughts and avoid responding to them with rituals or avoidance.

Having a bad thought means I want something bad to happen.

FALSE. Just as writers of thriller or mystery novels are not "sick" because they imagine cruel murders and kidnappings, people with OCD who obsess about horrific or sexually inappropriate thoughts are not at risk for acting on them.

Performing my rituals is the only way to reduce my anxiety and keep bad things from happening.

FALSE. Research shows that performing rituals actually makes OCD worse. Rituals temporarily reduce anxiety but end up reinforcing the need to "neutralize" the obsessions by doing even more rituals. Cognitive behavioral therapists teach people how to manage their OCD symptoms without rituals and to recognize that the idea of bad things happening is faulty, "magical thinking."

My anxiety will never go away.

FALSE. Most people with OCD fear that their anxiety will increase to a point where they "can't take it" or that they'll get permanently "stuck" in a chronic state of anxiety. Research shows that people cannot get stuck in an anxiety state or be harmed mentally or physically by experiencing anxiety or panic. With the right kind of treatment, anxiety levels peak and then fade, sometimes disappearing completely.

Because OCD is related to brain chemicals, medication is the only way it can be treated.

FALSE. Medications can be helpful, especially if the symptoms of OCD are so overwhelming that it seems impossible to learn to resist the OCD. Research shows, however, that both cognitive behavioral therapy and medications change the way the brain functions. In fact some studies show that appropriate therapy is more effective than medication in treating the symptoms. Everyone with OCD should consider this option for treatment.

I need to know "why" I have OCD in order to get better.

FALSE. People with this belief are under the false impression that their OCD is caused by a terrible personality flaw, past mistake or sin. They hope that if only they could understand this cause then they would be relieved of their OCD. Fortunately, the appropriate treatment works for the vast majority of people with OCD, regardless of the exact cause of their disorder.

People would think I was "crazy" if they knew about my OCD.

TRUE AND FALSE. Unfortunately, a social stigma and lack of information about mental illness still exist, but awareness about OCD is on the rise. Most people find they receive more support and understanding when they explain their symptoms to their family, friends and colleagues because then their behaviors are no longer misunderstood.

Hannah was an excellent student and got accepted to a top college. Once at school, she started spending hours rearranging things in her dorm room so that everything was "even." The books were aligned by size and color on the shelves, the hangers in her closet were exactly two inches apart, and she made and remade her bed many times a day. She missed a lot of classes, and her relationship with her roommate suffered. When she sought help at the Student Health Center, a nurse referred her to the right kind of therapist who helped her manage her symptoms and focus on her studies.

Treatment Works!

A special kind of therapy called cognitive behavior therapy (CBT) is the treatment of choice for all forms of OCD. It is recommended by nationally recognized institutions such as the National Institute of Mental Health, Mayo Clinic and Harvard Medical School. Some studies show that more than 85 percent of the people who complete a course of CBT experience a significant reduction in OCD symptoms.

In many cases, this type of therapy alone is highly effective in treating OCD. For some people, a combination of CBT and medication is most effective. Medication may reduce anxiety enough for a person to start, and eventually succeed in, therapy. Often medication is used only temporarily until the individual learns to manage symptoms through therapy sessions.

Cognitive Behavior Therapy

It's important to find a trained cognitive behavior therapist experienced in treating OCD – usually a psychologist with a Ph.D., Psy.D., M.A. or M.S. degree, or a specially trained social worker. CBT is the only form of therapy strongly supported by research for the treatment of OCD. Unfortunately, many mental health professionals do not have this type of training.

A cognitive behavior therapist uses two techniques: cognitive therapy plus exposure and response prevention (ERP). The therapist may also teach certain other skills, such as self-monitoring, stress management techniques and social skills.

Cognitive Therapy

This form of therapy helps an individual identify and modify patterns of thought that cause anxiety, distress or negative behavior – perfectionism or the tendency to overestimate danger, for example.

Exposure and Response Prevention (ERP)

ERP uses controlled, gradual exposures to the situations that trigger a person's obsessions and compulsions. Over time, the person learns to respond differently to these triggers, leading to a decrease in the frequency of compulsions and the intensity of obsessions. OCD symptoms often become so mild that they're easily ignored; sometimes they disappear.

This type of therapy deliberately creates anxiety, but at a level the client is ready to tolerate and for the purpose of getting better. It takes courage to begin ERP, but participants usually find that exposures are not as difficult as they had imagined. And as their fears fade and they see early success, the boost in confidence gives them motivation to continue with more difficult exposures.

The first step in ERP is for the person to describe in detail the obsessions and compulsions and rank them from the least bothersome to the most difficult. Then, beginning with the easiest symptoms, the therapist designs "exposures" or challenges that put the individual in situations that trigger obsessions. The person then avoids performing compulsive behaviors ("response prevention") for increasingly longer periods of time. Through repeated exposures, individuals with OCD realize that anxiety increases temporarily, peaks and then decreases when they avoid performing compulsions.

In cases where creating the actual situation that triggers a compulsion is impossible, therapists can use imagined exposures, visualizations and recordings that can effectively increase anxiety levels for ERP exercises.

When therapeutic exposures are repeated over time, the associated anxiety shrinks until it is barely noticeable or actually fades entirely. The person then takes on more challenging exposures until they, too, become manageable. Effective ERP leads to "habituation," which means people learn that nothing bad happens when they stop performing compulsive rituals.

Imagining life with more free time and without crippling anxiety helps many people with OCD stay motivated to stick with ERP until the end of treatment. Following therapy, people can look forward to returning to work or finding a better job, restarting an active social life, or taking up new hobbies to fill the hours that used to be consumed by obsessions and compulsions.

An ERP Example

Someone with contamination obsessions who washes his hands compulsively might say that touching a doorknob in a public place with one finger would trigger low-level but noticeable anxiety and that grasping moist faucet handles in a public restroom would trigger a higher level of anxiety. In both cases, the associated compulsion is excessive hand-washing.

The therapist may design an exposure in which the client starts by touching a doorknob with one finger and then refrains from washing his hands for 30 seconds. The exposure would be repeated and washing avoided for two minutes, and so on, with each prevention getting longer, until the client does not wash at all. The next exposures might be grasping the doorknob with the whole hand, touching the faucet handle with one finger, etc.

Before his wife got treatment for her OCD, Ted used to buy certain groceries that she felt were "uncontaminated," open doors for her so she wouldn't have to touch doorknobs, and run the dishwasher three times per load. Her therapist explained that his participation in her compulsions made them worse, and she taught him how to be supportive rather than enabling.

Medication

Antidepressants known as selective serotonin reuptake inhibitors (SSRIs) can decrease levels of obsessions and anxiety and help people succeed in therapy. They may be prescribed by a psychiatrist for moderate to severe OCD, often on a temporary basis until the person is able to manage the disorder with therapy alone.

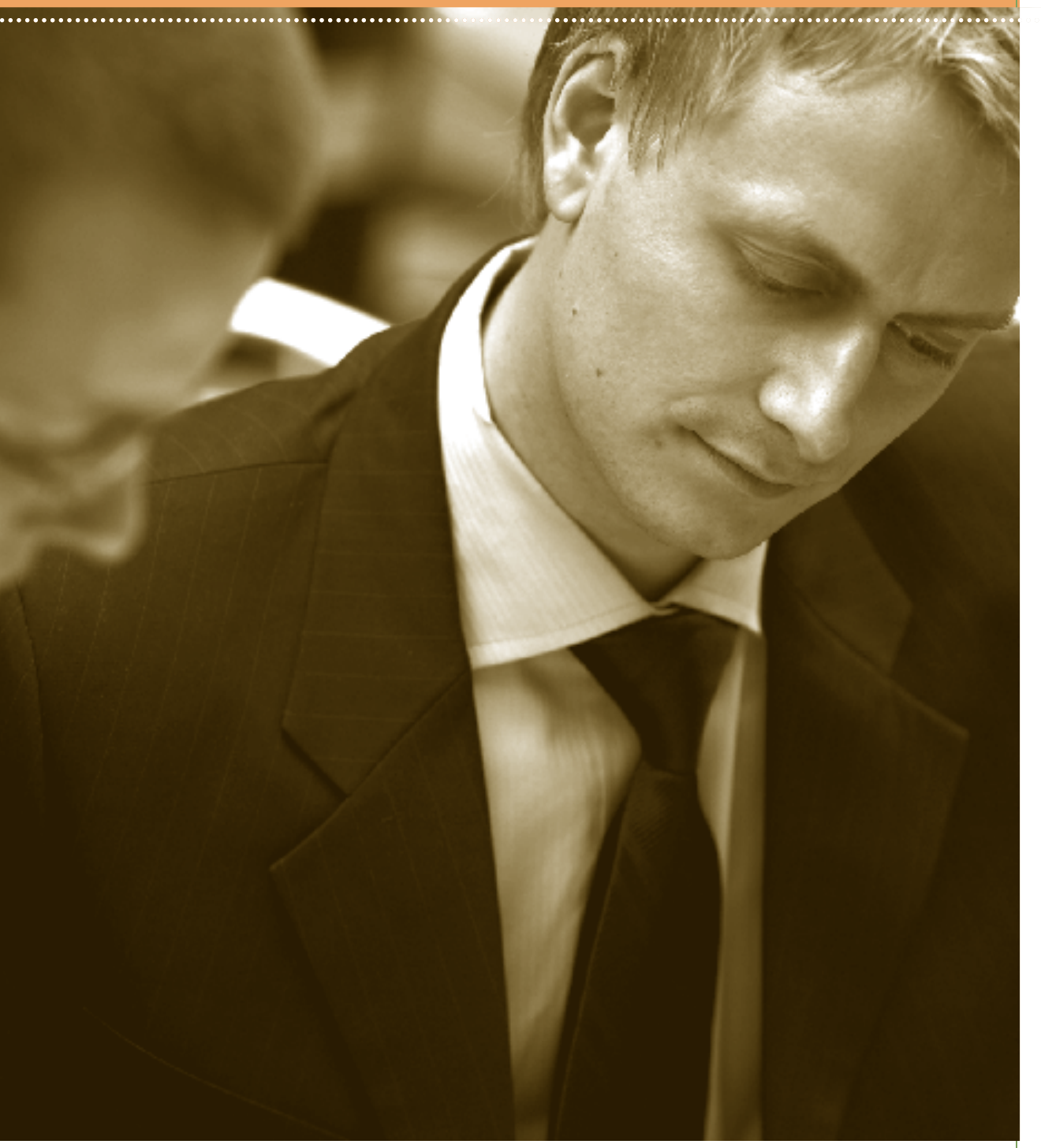
Some people with OCD respond favorably to the first medication prescribed; others must try more than one to experience a decrease in symptoms. Sometimes an SSRI combined with another medication delivers the best results. These types of medication can take up to 10 or 12 weeks to be fully effective. CBT can start at any time during this period, depending on the individual's tolerance level.

Many experts believe that CBT tends to be faster-acting and more cost-effective over time than medication, and it does not involve the risk of side effects. Studies seem to show lower relapse rates when CBT is discontinued versus when medication is discontinued. Research also shows that this therapy is likely to be more effective in reducing OCD symptoms than medication alone. For these reasons, knowledgeable treatment providers urge people to use medication as a supplement to CBT, and only when recommended.

It's important to work with a psychiatrist who is experienced in prescribing and monitoring different OCD medications and can assess their effectiveness, advise about possible side effects and, if the medication must be discontinued, provide instructions for tapering off the dosage. SSRIs should never be discontinued abruptly.

After her son was born, Julie began worrying obsessively about his safety. She checked on him while he napped and at night – not once or twice, but dozens of times. She checked his bottles over and over to make sure she hadn't put anything dangerous, like pesticides or broken glass, in them. She finally sought help and realized she had "postpartum OCD." Once she completed treatment, she was finally able to start enjoying motherhood.

Michael used to check and recheck his work for hours, looking for errors because he needed to make sure everything was "perfect," and he had an obsessive fear of embarrassment. Once a rising star in his company, he started missing deadlines, and his job performance suffered. His therapist helped him think differently about his work and see that he'd been overestimating the significance of making an error. His anxieties decreased significantly, and his manager started giving him new responsibilities.



Treatment Challenges

Effective treatment can help most people with OCD achieve significant relief from their symptoms. Unfortunately, getting the appropriate treatment, sticking with a treatment plan and maintaining treatment gains can be challenging. Knowing what to expect ahead of time can make all the difference.

Under-Diagnosis and Under-Treatment

OCD is too often under-diagnosed and under-treated, even though it is a relatively common illness and effective treatment is available. There are a number of reasons why:

- Some people hide their symptoms and do not seek help. Many do not know that OCD is an illness and that treatment is available; others are reluctant to admit that they need help. OCD is a medical condition, like high blood pressure or allergies, and there's no reason to be ashamed to seek treatment.

- Avoidance is not always recognized as a symptom. Some people with OCD avoid places, events, objects and even people because of uncontrollable, irrational fears. For example, a person with contamination obsessions may avoid public restrooms or refuse to borrow a pen. In these cases, avoidance is a compulsive behavior. Continued avoidance strengthens obsessions and worsens the disorder.

- OCD can involve unwanted disturbing thoughts, including violence, sexuality, blasphemy and illness. Some people with OCD are uncomfortable discussing disturbing thoughts, even with a treatment provider. A person with OCD normally has no desire to act on these thoughts, which recur precisely because they are so upsetting. Cognitive behavior therapists are trained to work with people whose lives are impaired by such unwanted thoughts.

- Change can be difficult. It takes courage to make changes and face fears, particularly if the obsessions and compulsions have existed for many years. Some people with OCD are afraid to undergo treatment, but living with untreated OCD is vastly more painful than any discomfort associated with treatment.

- Not all physicians know how to diagnose and treat the disorder. At routine check-ups, some doctors do not ask questions about a patient's mental health. Some doctors – even psychiatrists – have not been trained to recognize symptoms of the disorder, while others prescribe only medications because they aren't aware that CBT is the treatment of choice.

- Some psychologists and psychiatrists still rely on unproven, ineffective theories. Psychoanalytic therapy and therapy that focuses on family dynamics, early childhood trauma or issues of self-esteem are not effective treatments for OCD. While other forms of therapy such as marriage and family counseling can help with some of the difficulties that can accompany OCD, only CBT can reduce symptoms of the disorder.

- Common but less familiar symptoms may not be understood as forms of OCD. The disorder can take many forms and is not limited to familiar types such as washing and checking. Examples of symptoms that can go unrecognized as OCD include:

  - Procrastination
  - Difficulty making decisions
  - Asking repetitive questions
  - Reassurance-seeking
  - Avoidance of people, places, objects or events

- Some people with OCD are unable to afford treatment. Those without health insurance or whose insurance policies do not fully cover mental health care sometimes struggle to get the treatment they need. Some cognitive behavior therapists offer fees on a sliding scale to low-income clients, making it more affordable.

  If a therapist recommends the use of medication in connection with therapy, patients may be able to obtain drugs at a reduced price. A number of resources offer information about prescription assistance, including the Partnership for Prescription Assistance (1-888-4PPA-NOW or www.pparx.org) and NeedyMeds (www.needymeds.com).

Treatment Resistance

Most people who undergo a course of cognitive behavior therapy for OCD will experience a significant reduction in symptoms. Those who don't do well in treatment should consider these possible obstacles to success:

- ***Comorbid disorders.*** A mood disorder such as major depression or bi-polar disorder, alcoholism or substance abuse, or other comorbid disorder can interfere with success in therapy and may require separate treatment.

- ***Lack of communication with therapist.*** Open and honest communication about the exact nature and frequency of obsessions and compulsions is a must so that the therapist can design effective exposures. People often fear revealing all of their obsessions, either because they feel ashamed of their thoughts or because they believe that therapy could not help particular obsessions or compulsions that seem the most difficult. Keeping certain aspects of your OCD secret will impair your therapist's ability to help you overcome your OCD.

- ***Insufficient exposures.*** Exposures must be sufficiently challenging, and "homework" of daily exposures must be completed between therapy sessions.

- ***Infrequent sessions.*** Therapy sessions are generally scheduled weekly, but in some cases may need to be more frequent – even daily – or conducted in a residential treatment setting.

- ***Improper session location.*** Therapy sessions may be more effective if they are held in locations that trigger obsessions and compulsions – in a person's home, car or outdoors, for example. Some therapists will conduct sessions out of the office, or by telephone.

- ***Family interference.*** Family members who participate in an individual's compulsive rituals, provide reassurance or enable avoidance behavior can sabotage success in therapy. Sometimes a family member can be trained to act as a "coach" to keep track of exposures and discourage behavior by others that perpetuates the rituals.

- ***Wrong choice of therapist.*** Someone who does not succeed with one therapist may enjoy excellent results with another. The personality fit may not be right, or that therapist may not design challenging, appropriate exposures. The therapist may also be inexperienced. Ask for a second opinion, request a referral or interview other therapists to find a good match.

- ***Inappropriate therapy.*** CBT, sometimes accompanied by medication, is the only treatment for OCD that is supported by scientific evidence. Research does not support the use of treatments such as hypnosis, herbal or homeopathic remedies, psychoanalysis, relaxation therapy, eye movement desensitization reprocessing (EMDR) or dietary changes.

- ***Lack of support.*** Talking to others who have learned to master their symptoms can encourage a person with OCD to undertake the challenge of therapy and boost the likelihood of success. Joining a local support group, participating in an online support group or contacting OCD Chicago or the national Obsessive Compulsive Foundation are good ways to find people with similar experiences.

If Symptoms Return

Obsessive Compulsive Disorder is a chronic condition. Symptoms can be managed, but they sometimes resurface in the same or a different form. For example, a person with checking compulsions may succeed in therapy but then experience contamination obsessions emerging several years later.

Cognitive behavior therapists stress the importance of following through with exposures after the course of therapy is complete and teach people to recognize and respond to new or returning symptoms, particularly during stressful times. Booster or refresher therapy sessions may be necessary from time to time to reinforce treatment gains. Typically, follow-up treatment requires fewer sessions than the original course of therapy.

Choosing a Therapist

Many psychotherapists do not have the proper training to diagnose and treat OCD; only a qualified cognitive behavior therapist can provide effective, appropriate treatment. Asking questions of a therapist can help determine whether he or she is competent to treat the disorder.

The relationship with your therapist is very important – you will have to discuss uncomfortable fears and behaviors and be willing to take on ERP exercises the therapist prescribes. Finding a therapist who is right for you is critical to your success in overcoming OCD.

Questions to ask a therapist:

- Are you trained to use cognitive behavior therapy to treat OCD?
- Where did you obtain your training?
- How many clients with OCD have you successfully treated?
- Are you ever willing to leave the office for treatment sessions?
- Will you conduct therapy sessions by telephone if necessary?
- Are you licensed to practice in this state?
- What techniques do you use to treat this specific form of OCD?

Avoid a treatment provider who:

- Claims that the main technique for managing OCD is relaxation or talk therapy
- Believes that OCD is caused by childhood trauma, toilet training, self-esteem issues or family dynamics
- Blames parents or one's upbringing for OCD
- Seems guarded or angry at questions about treatment techniques
- Claims that medication alone is a treatment for OCD.

Self-Help Books

Unfortunately, a shortage of nearby therapists or lack of insurance coverage prevents some people from obtaining treatment from a qualified mental health professional. These people can gain a better understanding of OCD and its treatment by reading books about the disorder. Not all books about OCD are accurate and reliable, however, so look for recommended books on page 31 and at www.ocdchicago.org.

Getting Started

If you're ready to put yourself on the road to recovery from OCD, here's what you can do:

- Become aware of and take notes about your obsessions and compulsions, including the places and events that tend to trigger them, how strong they are and how long they last.
- Find a trained cognitive behavior therapist experienced in treating OCD (see previous page) and schedule an appointment.
- Learn about OCD by reading this guide, visiting www.ocdchicago.org and choosing books from the recommended reading list on page 31.
- Join OCD Chicago (or another local affiliate of the Obsessive Compulsive Foundation) to receive information about treatment, events and publications.
- If possible, attend the Obsessive Compulsive Foundation's annual conference to hear speakers discuss treatment and the latest research and developments.
- Consider joining a support group led by a professional (see page 30).

OCD and the Family

OCD affects the whole family. When untreated, it can be frustrating and exhausting for spouses, siblings and children, and it can interfere with relationships and daily functioning.

OCD strains marriages and family life by creating emotional and financial burdens. Social life suffers. Household chores pile up or get distributed unevenly, causing resentment for those who carry the heavier burden and feelings of inadequacy and shame for the person with OCD.

Family members often believe they're being helpful when they participate in compulsive behaviors. For example, a spouse may agree to sanitize the home, prepare special food, or check and re-check locks. Sometimes a loved one with OCD will ask family members to reassure them over and over again, or to help them avoid things that cause anxiety.

But participating in OCD behaviors strengthens the disorder by reinforcing the obsessive fears. And protecting a family member from the negative consequences of obsessions and compulsions can decrease the motivation for obtaining treatment. For example, a wife who helps her husband with his morning checking compulsions so that he won't be late for work makes it less likely that he'll seek treatment. Negative reactions are also damaging – criticism, nagging and hostile responses to OCD behavior can cause stress that reinforces the disorder.

Sometimes family members discourage a loved one from seeking treatment out of fear that they will be blamed for the OCD. This fear involves a misunderstanding of the disorder. No one causes OCD; it's a medical condition.

Family involvement in treatment is necessary for a loved one's recovery. A cognitive behavior therapist can help family members gradually change the way they respond to OCD symptoms. It's important to apply gradual changes with the understanding of the person who has the disorder because sudden changes in responses can cause anger and stress that worsen symptoms. A therapist can also help the family learn how to support the person who is trying to overcome OCD and celebrate small and large successes along the way.

OCD at Work and School

Untreated OCD can significantly interfere with a person's ability to function in the workplace or classroom. Distracting obsessions, time-consuming compulsions, avoidance behaviors, and the urge to seek reassurance can prevent an employee or student from paying attention and completing work on time. Employees risk receiving unfavorable performance reviews, being passed over for promotions or even losing their jobs. For students, untreated OCD can lead to poor grades and social problems.

Studies show that most people with OCD tend to be very intelligent, but they may need to obtain appropriate treatment to enjoy success at work or at school. A cognitive behavior therapist can target behaviors and help individuals decide whether or not to discuss the disorder with supervisors, co-workers or teachers.

The provisions of federal and state disability laws may apply to some people with OCD. The summaries here offer only general information about some of these laws; consult an attorney experienced in discrimination law for specific questions regarding disability accommodations or benefits.

For more information about disability rights, visit www.bu.edu/cpr/jobschool/index.html.

Americans with Disabilities Act (ADA)

Under the ADA, an employer with 15 or more employees may not discriminate against an individual with a disability who is otherwise qualified for the job if the individual can perform the essential functions of the job with or without a reasonable accommodation. For current information about the ADA, call 1-800-514-0301 or visit www.usdoj.gov/crt/ada/.

Family Medical Leave Act (FMLA)

Employers with at least 50 employees within a 75-mile area, and all public employers, must provide an employee with up to 12 weeks' unpaid medical leave within a 12-month period during which their jobs are protected. The leave can be used to care for a seriously ill spouse, child or parent, or to obtain care for the employee's own serious health problem. For current information about FMLA, call 1-866-4-USWAGE or visit www.dol.gov/esa/whd/fmla/.

Social Security Benefits

An individual who is completely disabled from working may seek disability benefits from Social Security or another applicable disability policy. For information about social security benefits, call 1-800-772-1213 or visit www.ssa.gov/disability/.

Medicare and Medicaid

Certain low-income families and individuals who cannot afford to pay for medical care can apply for benefits under Medicare or Medicaid. For more information, call 1-800-MEDICARE or visit www.cms.hhs.gov/.

Section 504 of the Rehabilitation Act of 1973

This law applies to employers and organizations that receive financial assistance from any federal department or agency, including many hospitals, nursing homes and human services programs. Such organizations and employers may not deny individuals with disabilities an equal opportunity to receive program benefits and services. For more information, call 1-800-368-1019 or visit www.hhs.gov/ocr/504.html.

Kevin's mother couldn't throw out useless objects. She constantly worried that she would accidentally discard something valuable, so she hoarded worthless items like old newspapers and junk mail. The piles and boxes of paper took over her house and garage to the point where her home was unsafe and an eyesore. Kevin finally got her to see a therapist, who diagnosed both OCD and depression. His mother is now on medication and working with the therapist to throw away years of accumulated junk.

Support Groups

Many people complete a course of CBT and learn to manage the disorder without ever joining an OCD support group, but some people do benefit from participating in a group. While support groups can be beneficial, they cannot take the place of proper treatment.

An OCD support group should focus on CBT as the appropriate treatment and, if possible, a trained therapist should conduct or oversee meetings. A good support group can provide role models for recovery, a place to celebrate victories over OCD, and a confidential place to seek encouragement for a difficulty or relapse. Meetings can renew one's resolve to do exposures and help family members better understand and support their loved one with OCD.

For information about support groups in the Chicagoland area, visit www.ocdchicago.org. People who live in areas without OCD support group meetings may participate in online groups such as http://groups.yahoo.com/group/OCDSupportGroups/links. If you're interested in forming a support group, check out the tips in "Help Yourself: A Guide to Organizing an Anxiety Disorder Self-Help Group" at www.adaa.org/GettingHelp/SupportGroups.asp.

Questions To Ask Before Joining A Support Group

- *Does the group insist on anonymity and confidentiality?*
- *Is there a fee?*
- *How often does the group meet, and where?*
- *Is there a facilitator? If so, what are his or her qualifications?*
- *How many members are in the group and how many have gotten better?*
- *How long has the group existed?*
- *Who participates? (Some groups are limited to people with OCD, while others invite family members and friends, professionals, or psychology students.)*
- *Do meetings include only open discussion, or are there also programs such as films, lectures, speakers or planned discussion topics?*

Recommended Reading

Stop Obsessing! How to Overcome Obsessions and Compulsions
by Edna Foa, Ph.D. and Reid Wilson, Ph.D.

Freedom From Obsessive Compulsive Disorder: A Personalized Recovery Program for Living with Uncertainty
by Jonathan Grayson, Ph.D.

Getting Control
by Lee Baer, Ph.D.

The OCD Workbook, Second Edition
by Bruce M. Hyman, Ph.D. and Cherry Pedrick

Obsessive Compulsive Disorders: A Complete Guide to Getting Well and Staying Well
by Fred Penzel, Ph.D.

Overcoming Obsessive Thoughts: How to Gain Control of your OCD
by Christine Purdon, Ph.D. and David A. Clark, Ph.D.

For Families

Loving Someone with OCD: Help for You and Your Family by Karen J. Landsman, Kathleen M. Rupertus, and Cherry Pedrick

Obsessive Compulsive Disorder: New Help for the Family
by Herbert L. Gravitz, Ph.D.

"Bad Thought" OCD

The Imp of the Mind
by Lee Baer, Ph.D.

Washing

Overcoming Compulsive Washing
by Paul R. Munford, Ph.D.

Checking

Overcoming Compulsive Checking
by Paul R. Munford, Ph.D.

Scrupulosity

The Doubting Disease: Help for Scrupulosity and Religious Compulsions
by Joseph W. Ciarrocchi

Obsessive-Compulsive Disorder: A Guide for Family, Friends, and Pastors
by Robert Collie, Th.D.

Hoarding

Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding
by David F. Tolin, Randy O. Frost, and Gail Steketee

Overcoming Compulsive Hoarding
by Fugen Neziroglu, Ph.D., ABBP, Jerome Bubrick, Ph.D., Jose A. Yaryura-Tobias, MD

Memoirs and Novels

Devil in the Details: Scenes from an Obsessive Girlhood
by Jennifer Traig

Just Checking
by Emily Colas

Kissing Doorknobs
by Terry Spencer Hesser

Frequently Asked Questions

Q: What causes OCD?

A: While the exact cause is not yet known, many scientists believe OCD is triggered by certain brain chemicals that do not function properly. The proper treatment can help the brain function more normally.

Q: What is the proper treatment for OCD?

A: The treatment of choice for OCD is cognitive therapy and exposure and response prevention (ERP), sometimes accompanied by medication.

Q: If I take medication for OCD, will I have to be on it forever?

A: Many people use medication on a temporary basis until they succeed in managing their symptoms through cognitive behavior therapy. In severe cases, people may need to use medication for longer periods of time.

Q: How does exposure and response prevention work?

A: Working with a cognitive behavior therapist, the person creates a list of his or her obsessions and compulsions, ranking them from the least troubling to the most difficult. Starting with the least challenging symptoms, the person agrees to participate in situations that tend to trigger the OCD and then not respond with a compulsion for increasingly longer periods of time. For more information on ERP, see page 16.

Q: What should I do if I have both OCD and depression?

A: Mood disorders such as major depression can occur with Obsessive Compulsive Disorder and should be discussed with the therapist who is treating the OCD. Depression can be treated with medication and therapy; some of the same medications used to treat depression are also used to treat OCD.

Q: How do I know this is "really" OCD?

A: A cognitive behavior therapist or other qualified mental health treatment provider can conduct a specific kind of interview to determine whether symptoms are caused by OCD. Sometimes a person has more than one psychological condition – for example, OCD and trichotillomania (hair pulling). A cognitive behavior therapist is qualified to treat many conditions that can occur with OCD.

Q: How long does cognitive behavior therapy take?

A: The usual treatment time for cognitive behavior therapy is between eight and 12 weekly sessions. Depending on the severity of symptoms and the person's willingness to do "homework" in between therapy sessions, treatment may take longer and/or more frequent sessions may be necessary. The proper treatment takes a fraction of the time most people have spent struggling with their symptoms.

Q: Is there anything that family members can do to help a loved one with OCD?

A: It's up to the person with OCD to do the work of cognitive behavior therapy and, if necessary, take prescribed medication. Family members can play an important role by learning about OCD, offering encouragement, and providing support, but they need to resist the urge to participate in compulsions, reassure or accommodate avoidance behaviors. It's also important for family members to avoid criticizing or nagging, which can cause stress and anger that can make symptoms worse.

Q: Is cognitive behavior therapy expensive?

A: Like any type of health care, there is a cost for this therapy which may be covered by medical insurance. Some therapists offer their services on a sliding scale to make it affordable for low-income clients. Therapy in a group setting is often less expensive than private individual sessions, but it's important to distinguish between group therapy, which is a form of treatment, and support groups, which are not. Support groups can be helpful (see page 30), but they are not a replacement for appropriate treatment.

The cost of living with untreated OCD can be very high. It wastes time and energy, interferes with academic and job success, and takes a high toll on relationships and happiness. In comparison, the cost of treatment is money well spent.

Q: I called all the psychiatrists and therapists on my insurance plan, and none of them practice CBT. What should I do?

A: Consider making a formal appeal to your insurance company. It may be required to pay for an out-of-network provider if it cannot offer the standard for treatment in-network, and CBT is well-established as the standard for treatment of OCD.

Q: My therapist referred me to a psychiatrist for medication. I don't have insurance, and I can't afford the prescription. What can I do?

A: Your prescription may cost less if your psychiatrist prescribes a generic form of the medication. Check with local and online pharmacies to find the lowest prices on generic drugs. Depending on your financial situation, you may be able to find help through the organizations mentioned on page 21.

Q: I have had OCD for most of my life. Is it too late to seek help?

A: People of any age can succeed in treatment – many experts believe that the length of time a person has had the disorder does not predict whether treatment will be successful. The only thing standing between you and learning to manage your OCD is a willingness to try the effective treatments. Imagine how much more you'd enjoy every single day if you were free from your obsessions and compulsions. One patient with the disorder recovered after suffering for 66 years!

Q: Will I be cured after treatment with CBT?

A: At this point, there's no "cure" for OCD – the goal is to manage the disorder the same way people manage allergies, asthma or diabetes. OCD symptoms are likely to vary in intensity over time, depending on various stressors in your life – for example, illness, major life changes, moves, marriage or divorce, and other changes in routine. People can learn to use cognitive behavioral techniques that can help them prevent symptoms from interfering with their lives.

Q: How hard is it to manage OCD?

A: Learning to manage OCD can be hard work – just like many worthwhile goals in life – but those who have succeeded in treatment consider the benefits more than worth the effort.

Obsessive Compulsive Disorder is a medical problem that requires diagnosis and treatment by a qualified treatment provider. This guide is not intended to provide, or to take the place of, medical care.

Any laws or regulations mentioned in this guide are for informational purposes only and do not constitute legal advice. For more information about these laws and how they apply to an individual case, please consult an attorney experienced in the appropriate area of practice.

OCD Chicago Can Help

OCD Chicago's mission is to increase public and professional awareness of OCD, educate and support people with OCD and their families, and encourage research into new treatments and a cure. We serve adults and children with the disorder, their families and the mental health professionals who treat them, and we're the only Chicago area organization dedicated solely to OCD.

OCD Chicago reaches out with compassion and encouragement to those affected by this potentially devastating but treatable neurobiological disorder. We're dedicated to assuring people with OCD that they are not alone and helping them manage the disorder.

Visit our web site at www.ocdchicago.org for:

- Up-to-date information about OCD and related disorders
- Books, articles, events, and links to other web sites
- Personal stories by people with OCD and their family members
- A self-screening test for OCD
- A list of support groups in the Chicagoland area

For a list of treatment providers in metropolitan Chicago, request an information packet online at www.ocdchicago.org or call 773.880.1635. For information about treatment providers in other areas, visit the national Obsessive Compulsive Foundation's web site at www.ocfoundation.org, or call their office in New Haven, CT, at 203.401.2070.

If you found this publication valuable and would like to help bring this type of information to people with OCD and their families, please consider making a tax-deductible contribution to OCD Chicago. We rely solely on donations from the public.

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