telephone 773.661.9530 • *fax* 773.661.9535
e-mail *info@BeyondOCD.org* • www.BeyondOCD.org

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Relief *from* OCD

A Guide for People with Obsessive Compulsive Disorder

You Are Not Alone

According to the most recent, large-scale community study of mental health in adults across the United States:

- 1.2 % of the adults met full criteria for OCD in the 12 months prior to the study;
- 2.3% met criteria for OCD at some point in their lives – that's over 5 million Americans, or approximately 1 in 40 adults; and
- more than one quarter of the adults in the study experienced obsessions or compulsions at some time in their lives – over 60 million people.

Moreover, the World Health Organization has ranked OCD as one of the top 20 causes of illness-related disability, worldwide, for individuals between 15 and 44 years of age.

Everyone knows someone with OCD. If you or a loved one suffers 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 frequently?

Worry, while driving, that you hit or ran over someone, causing you to go back to the scene of the imagined crime to check again and again?

Experience various impulses or urges that compel you to organize, arrange, redo or "even up" things, words, numbers or thoughts until they feel "just right?"

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

Fear being contaminated by dirt, germs, chemicals, AIDS? Fear contaminating others?

Ask repetitive questions or seek reassurance from others over and over again?

Practice excessive, unreasonable rituals triggered by religious or moral concerns?

Have obsessive fears about your sexual orientation, even though there is no evidence to support those fears?

Experience unwanted, intrusive thoughts, mental images and/or impulses that are disturbing or inappropriate, such as killing someone or acting out sexually?

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. Left untreated, the disorder can cause anguish and rob people of precious time and life's joys – sometimes even their jobs, schooling, marriages or lives.

There's no reason to be afraid or ashamed to seek treatment. OCD is a disorder, just like asthma or diabetes. Learning to manage this 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 neurobiological problem. An abundance of research indicates that the disorder responds well to a special kind of therapy called cognitive behavior therapy (CBT), 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 thoughts, images, or impulses that trigger repetitive behaviors or mental rituals. Many people use the terms "obsessive," "compulsive" and "OCD" incorrectly, leading to myths about the disorder.

OCD is not characterized by 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 problems may suffer from treatable mental illnesses, they do not have OCD.

Here are some common myths:

Myth: *Characters with OCD in movies and TV programs accurately portray the disorder.*

FACT: Films and TV shows 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. Although the exact cause of OCD is unknown, some combination of biological, genetic, behavioral, cognitive, and/or environmental factors is responsible for the development of the disorder.

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

FACT: While parental and family factors may contribute to the maintenance of OCD symptoms, there is no evidence that these factors cause OCD.

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 also make the symptoms of many already-existing 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 socioeconomic group. OCD is far more common than once thought and is associated with high levels of impairment. The financial cost of OCD to the U.S. economy is estimated to be in excess of $8 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 thoughts, impulses, or images that are intrusive, unwanted and disturbing. Although most people with OCD realize their obsessions are irrational, they believe the only way to relieve their anxiety or discomfort is by performing compulsions.

Compulsions are repetitive actions or mental rituals intended to relieve the distress 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 some of the most common OCD symptoms:

Obsession	*Compulsion*
FEAR *of* CONTAMINATION	*Washing/cleaning*
FEAR *of* HARM, ILLNESS *or* DEATH	*Checking*
FEAR *of* VIOLATING RELIGIOUS RULES (SCRUPULOSITY)	*Praying*
NEED *for* SYMMETRY	*Arranging or "evening up"*
NEED *for* PERFECTION	*Seeking reassurance*
NEED *to* HAVE SOMETHING "JUST RIGHT"	*Repeating*
FEAR *of* DISCARDING SOMETHING IMPORTANT	*Hoarding***

***Although hoarding has been considered a subtype of OCD, some forms of hoarding are unrelated to OCD. Therefore, non-OCD hoarding will likely be considered a distinct disorder in the future.*

OCD is a chronic but treatable medical condition. Most people are able to experience relief from their OCD symptoms through cognitive behavior therapy. With CBT, people with OCD learn how to change their thought patterns and behaviors; it helps "retrain the brain." 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 or her 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. Qualified mental health professionals frequently use diagnostic interviews to determine the presence of OCD. They also use other tools that measure the severity of obsessions and compulsions, the most common of which is the Yale-Brown Obsessive Compulsive Scale (Y-BOCS).

Causes

While the exact cause of OCD is unknown, research indicates that OCD is a neurobiological illness that is the result of some combination of biological, genetic, behavioral, cognitive, and/or environmental factors:

Biological: OCD is associated with (1) a malfunction of certain brain chemicals – especially serotonin – as well as dopamine and glutamate; and (2) overactivity in a circuit in the brain involving areas known as the orbitofrontal cortex, striatum, and thalamus. Moreover, sudden-onset OCD may be triggered by strep or other viruses (mono, flu).

Genetic: In general, studies of twins with OCD estimate that genetics contributes approximately 45 - 65% of the risk for developing the disorder.

Behavioral: Because rituals temporarily reduce the distress associated with obsessions, people are more likely to do these rituals whenever obsessions occur.

Cognitive: Some people misinterpret intrusive thoughts (which virtually all human beings experience) as personally important or revealing about their true character. For example, anyone who is using a knife in the kitchen might have a fleeting thought of hurting a loved one. Most people know they would never harm anyone and easily dismiss the idea. Someone with OCD, however, may not be able to ignore the thought, misinterpreting it as evidence that he or she is a potential murderer who may be locked up. In these cases, intrusive thoughts may develop into terrifying obsessions.

Environmental: Traumatic brain injuries have been associated with the onset of OCD. Also, while traumatic life events are not the cause of OCD, they may trigger the illness.

Related Conditions

When two diagnoses occur in the same individual they're called "comorbid" disorders. According to the U.S. mental health study previously mentioned, 90% of the adults who reported OCD at some point in their lives also had at least one other comorbid condition, including anxiety, mood, impulse control (AD/HD, oppositional-defiant), and substance use disorders. A trained mental health professional can diagnose these conditions and provide appropriate treatment.

These disorders may occur with OCD:

- **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 fears of snakes or heights.

  Source: Anxiety & Depression Association of America – www.adaa.org

- **MOOD DISORDERS.** Major Depressive Disorder and Bipolar Disorder. Depression is more intense than a "bad mood," lasts more than two weeks, and can make usual activities difficult to carry out. Bipolar disorder is marked by extreme changes in mood, thought, energy and behavior.

  Source: Depression and Bipolar Support Alliance – www.dbsalliance.org

- **ATTENTION-DEFICIT/HYPERACTIVITY DISORDER (AD/HD).** The three types of AD/HD are: (1) predominantly inattentive type; (2) predominantly hyperactive-impulsive type; and (3) combined type. Symptoms of AD/HD can occur in both children and adults.

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

- **AUTISM SPECTRUM DISORDERS (ASD).** People with ASDs have difficulties with communication, social interaction, and repetitive behaviors. People with Asperger syndrome (the mildest and highest-functioning form of ASDs) have obsessive areas of interest. These bring them pleasure, however, unlike OCD obsessions, which produce distress.

  Source: National Institute of Mental Health – http://www.nimh.nih.gov/

- **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.

  Source: National Eating Disorders Association – www.nationaleatingdisorders.org

- **TOURETTE SYNDROME (TS) OR TIC DISORDERS.** Tics are sudden, rapid, involuntary and recurring motor movements (such as blinking, shrugging shoulders) and vocalizations (such as sniffing or humming). TS involves both motor and vocal tics that occur for more than a year and are evident before 18 years of age.

  Source: Tourette Syndrome Association of America: www.tsa-usa.org

- **BODY DYSMORPHIC DISORDER (BDD).** BDD is characterized by a preoccupation with an imagined or exaggerated defect in one's 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.

  Source: Mayo Clinic – www.mayoclinic.com

- **TRICHOTILLOMANIA,** or compulsive hair pulling, as well as skin-picking and nail biting, are considered body-focused repetitive behaviors.

  Source: Trichotillomania Learning Center – www.trich.org

Cheryl found herself praying for hours every day because of her obsessive thoughts and fears that she would go to 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. Virtually everyone in the world has troubling, intrusive thoughts on occasion. It's just that people with OCD aren't able to ignore them because they believe those thoughts must be important and, therefore, worthy of attention.

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. Challenge yourself right now by trying NOT to think about a pink elephant!

Research shows that attempting to control your thoughts – or believing that you should be able to control them – actually leads to having more frequent and disturbing images and thoughts. Cognitive behavior 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. Thinking something is not the same as doing it. Just as writers of murder mysteries aren't "sick" because they imagine cold-blooded killings, people with OCD who obsess about violent or sexually inappropriate thoughts aren't 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 indicates that performing rituals actually makes OCD worse. Rituals temporarily reduce distress but end up reinforcing the need to "neutralize" the obsessions by doing even more rituals. Cognitive behavior 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 this is not the case. In fact, the human body has a wonderful capacity for what is called "habituation": anxiety will eventually go down without doing anything but letting time pass.

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

FALSE. Medications can be helpful, especially if someone is depressed or OCD symptoms are so overwhelming that it seems impossible to learn to resist them. Research indicates, however, that both cognitive behavior therapy and medications change the way the brain functions. In fact, many studies show that cognitive behavior 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. Many people are under the false impression that their OCD is caused by a terrible personality flaw, past mistake or sin. They believe that if they only understood why they got OCD, they would be relieved of their symptoms. Fortunately, cognitive behavior therapy, appropriately administered, works for the vast majority of people with OCD, regardless of why they got the 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 their behaviors are then 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 an OCD 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 as many as 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, however, a combination of CBT and medication is most effective. Medication may help "take the edge off" and 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 behavioral 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 for the purpose of getting better, but at a level the client is ready to tolerate. It takes courage to begin ERP, but participants usually find that exposures aren't as difficult as they had imagined. And as their fears fade and they experience success, they get a boost in confidence that motivates them to continue with more difficult exposures.

The first step in ERP is for the person to provide the therapist with a detailed description of his or her obsessions and compulsions. A list is then formed in which symptoms are ranked from the least bothersome to the most difficult. Beginning with one of the easier 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 – without 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 from the list until they, too, become manageable. Effective ERP leads to "habituation," which means that anxiety will eventually go down without doing anything but letting time pass.

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 level of anxiety that was a bit higher. 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," opened doors for her so she wouldn't have to touch doorknobs, and ran 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 for OCD

Antidepressants known as selective serotonin reuptake inhibitors (SSRIs) can decrease levels of distress and help people succeed in therapy. They may be prescribed by a physician for people who have moderate to severe OCD or OCD with comorbid depression. Medications are often used 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. Although some medications may begin to work after a few weeks, it may take 10 to 12 weeks at therapeutic doses to be fully effective.

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 consistently have shown lower relapse rates when CBT is discontinued compared with the discontinuation of medication. Research also indicates that this therapy is 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 physician (a psychiatrist, for example) who is experienced in prescribing and monitoring different OCD medications, 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

A positive note – effective treatment that can help most people with OCD achieve significant relief from their symptoms is available. Getting the appropriate treatment, sticking with a treatment plan and maintaining treatment gains can be challenging, however. Knowing what to expect ahead of time can make all the difference.

Underdiagnosis and Undertreatment

OCD is too often underdiagnosed and undertreated, 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 don't 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 compulsion. Continued avoidance strengthens obsessions and worsens the disorder.
- OCD can involve unwanted thoughts with disturbing content, including violence, sexuality (homosexual, paraphilic or pedophilic obsessions), blasphemy and illness. Some people with OCD are uncomfortable discussing these 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 intrusive 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; their counterproductive ways of coping create an illusion of safety, and control may be very difficult to give up.
- Some psychologists and psychiatrists still rely on unproven, ineffective therapies to treat OCD. Psychoanalysis and therapies that focus on family dynamics, early childhood trauma or issues of self-esteem are not effective treatments for OCD. While certain forms of therapy, such as marriage and family counseling, can help with relationship problems and other difficulties that frequently accompany OCD, CBT and medication represent the cornerstone of treatment for OCD. It's important to note that meditation, yoga and exercise can complement formal treatment for OCD. Many people find these tools to be extremely effective in helping reduce anxiety and facilitating the treatment process.
- Like avoidance, there are many common but less familiar symptoms that may not be understood as signs of OCD. The disorder can take many forms and is not limited to the more familiar types of OCD such as washing and checking. Examples of symptoms that can go unrecognized include:
  - Procrastination
  - Difficulty making decisions
  - Asking repetitive questions
  - Reassurance-seeking
- 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 sliding scale fees – fees based upon one's ability to pay – making therapy more affordable.

  If a therapist recommends the use of medication in connection with CBT, 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).

Roadblocks to Treatment Success

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 bipolar disorder, alcoholism or substance abuse, or another comorbid disorder can interfere with success in therapy and may require treatment.
- *Lack of communication with therapist.* Open and honest communication about the exact nature and frequency of obsessions and compulsions is a must so the therapist can design effective exposures. People often fear revealing all of their symptoms, either because they feel ashamed of their thoughts, or because they believe it would be impossible for therapy to help them with obsessions or compulsions that are particularly challenging. 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 it is imperative that "homework" – daily exposure exercises – be completed between therapy sessions.
- *Infrequent therapy sessions.* Therapy sessions are generally scheduled weekly, but in some cases may need to be more frequent or conducted in an intensive treatment setting.
- *Improper location for therapy.* 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 conduct sessions out of the office, by telephone, online or via webcam technology, such as Skype.
- *Family interference.* Family members who participate in an individual's compulsive rituals, provide reassurance or enable avoidance behavior can unintentionally sabotage success in therapy. In some cases, it is helpful for a family member to 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.* An individual may not succeed with a particular therapist because the personality fit may not be right, or that therapist may not design challenging, appropriate exposures. The therapist may also lack specific knowledge and/or experience in treating OCD. If this is the case, ask for a second opinion, request a referral or interview other therapists to find a good match. A person may enjoy excellent results with another therapist.

- *Inappropriate therapy.* CBT, sometimes accompanied by medication, is the only treatment for OCD that is supported by scientific evidence. At this time, there is insufficient evidence to support the use of treatments such as hypnosis, herbal or homeopathic remedies, psychoanalysis, relaxation therapy, eye movement desensitization reprocessing (EMDR) or dietary changes. As previously mentioned, however, there are a number of excellent tools for reducing anxiety that may be used to supplement CBT and medication, including yoga, exercise and meditation.
- *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 Beyond OCD or the International OCD 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 experience contamination obsessions 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 mental health professionals lack the proper training to diagnose and treat OCD. Only a qualified cognitive behavior therapist can provide effective, appropriate CBT. Asking questions of a therapist can help determine whether he or she is competent to administer CBT.

Your relationship with your therapist is very important. Discussing your fears and behaviors may be very uncomfortable, and you must be willing to take on ERP exercises the professional prescribes. Finding a therapist who is right for you is critical to your success in overcoming OCD.

Questions to ask a therapist before committing to treatment:

- 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 or online if necessary?
- Are you licensed to practice in this state?
- What techniques do you use to treat this specific form of OCD? (You want them to mention CBT involving exposure and response prevention, or ERP.)

Avoid a treatment provider who:

- Claims that the main technique for managing OCD is relaxation or talk therapy or play therapy for children;
- 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; or
- Claims that medication alone is the most appropriate treatment for OCD.

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 exploring the wealth of material provided on our web site, www.BeyondOCD.org, including in-depth information on OCD and its treatment, perspectives written by experts in the field on many different OCD-related topics, and numerous personal success stories. You can also download (or order) any of our highly-acclaimed OCD Guides, sign up for our e-newsletters, read our blog, and even take an OCD self-screening test.
- If possible, attend the International OCD 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).

Self-Help

Unfortunately, a shortage of accessible therapists and/or a lack of insurance coverage prevent some people from obtaining treatment from a qualified mental health professional. These people can gain a better understanding of OCD and its treatment by examining professionally-reviewed self-help programs found on the Internet and smart phone applications. It is also helpful to read 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.BeyondOCD.org (click More Resources).

OCD and the Family

OCD affects the whole family. Left 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 on the part of those who carry the heavier burden as well as 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 recheck 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 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 worsens OCD symptoms.

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 as well as help the person with the disorder understand and accept the need for these changes. It's important to apply gradual changes, 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 successes – small and large – 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 academic, emotional, behavioral and social problems.

Evidence suggests that 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 or co-workers. When a school-aged child has OCD, it's usually best to talk with school personnel about the disorder.

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)

The ADA is a federal civil rights law that prohibits discrimination on the basis of disability. Title I of ADA covers employment; Title II pertains to state and local government activities, including public education, public accommodations, commercial facilities, transportation, and telecommunications. For current information about the ADA, call 1-800-514-0301 or visit www.usdoj.gov/crt/ada/.

Family Medical Leave Act (FMLA)

The FMLA entitles eligible employees of covered employers to take up to 12 weeks of unpaid, job-protected leave, in a 12-month period, for specified family and medical reasons such as caring for a child after birth or an employee's spouse, child, or parent with a serious illness. The FMLA also applies to the employee if he or she has a serious health condition. For more information about FMLA, call 1-866-487-9243 or visit http://www.dol.gov/whd/fmla.

Social Security Benefits

The Social Security and Supplemental Security Income disability programs are the largest of several federal programs that provide assistance to individuals with a disability who meet certain medical criteria. For information, call 1-800-772-1213 or visit www.ssa.gov/disability/.

Medicare and Medicaid

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

Section 504 of the Rehabilitation Act of 1973

Section 504 is a federal law designed to protect the rights of individuals with disabilities in programs and activities receiving financial assistance from any federal department or agency, including public school districts, institutions of higher education, and many health care and human services programs. For additional 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 learn to manage OCD without ever joining a support group. But some people find that making connections with others who are "in the same boat" helps them cope better and feel less isolated. Some professionally-led support groups incorporate CBT, while many are non-therapeutic.

Non-therapeutic support groups should promote CBT as the most appropriate behavioral treatment and, if possible, a trained professional 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 during relapses and other difficult times. Meetings can renew one's resolve to do exposures and help family members better understand and support their loved one with OCD. Non-therapeutic support groups can be extremely beneficial, but they should complement – not replace – appropriate treatment.

For information about support groups in the Chicagoland area, visit www.BeyondOCD.org. People who live in areas without OCD support group meetings may participate in online groups such as those found at http://groups.yahoo.com/group/OCDSupportGroups/links.

Questions To Ask Before Joining A Support Group

- *Does the group have established ground rules, such as insisting 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?*
- *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

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

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

Getting Over OCD: A 10-Step Workbook for Taking Back Your Life
by Jonathan S. Abramowitz, Ph.D.

Obsessive-Compulsive Disorder Demystified
by Cheryl Carmin, Ph.D.

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

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.

School Personnel

Students with OCD: A Handbook for School Personnel
by Gail B. Adams, Ed.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

Understanding Scrupulosity
by Rev. Thomas M. Santa

Religious Compulsions and Fears: A Guide to Treatment
by Rabbi Avigdor Boncheck, Ph.D.

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

Hoarding

The Secret Lives of Hoarders
by Matt Paxton

The Hoarder in You
by Dr. Robin Zasio

Stuff: Compulsive Hoarding and the Meaning of Things
by Randy O. Frost and Gail Steketee

Perfectionism

When Perfect Isn't Good Enough: Strategies for Coping with Perfectionism
by Martin Antony, Ph.D.

Frequently Asked Questions

Q: What causes OCD?

A: While the exact cause is not yet known, research indicates that OCD is a neurobiological illness that is the result of some combination of biological, genetic, behavioral, cognitive, and/or environmental factors.

Q: What is the proper treatment for OCD?

A: The treatment of choice for OCD is cognitive behavior therapy (CBT) – cognitive therapy and exposure and response prevention (ERP) – sometimes with 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. Beginning with one of the easier symptoms, the therapist designs "exposures" or challenges in which the individual participates that trigger OCD symptoms. He or she then avoids performing compulsive behaviors ("response prevention") 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 often occur with Obsessive Compulsive Disorder. Any symptoms of depression should be openly discussed with the therapist who is treating the OCD. Depression can be treated with medication and therapy. In fact, 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 qualified mental health professional can conduct a specific kind of interview to make a diagnosis of OCD. Sometimes a person has more than one disorder – for example, OCD and trichotillomania (hair pulling). Qualified cognitive behavior therapists treat many conditions that occur with OCD.

Q: How long does cognitive behavior therapy take?

A: The average treatment time for CBT is approximately 12-16 weekly sessions; relief from OCD symptoms may be experienced sooner, however. Depending on symptom severity and the person's willingness to do "homework" between sessions, treatment may take longer and/or more frequent sessions may be necessary. The good news is that proper treatment takes a fraction of the time most people have spent struggling with OCD.

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. But family members can play an important role by learning about OCD, offering encouragement, and providing support. They can also help by resisting 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 CBT which may be covered by medical insurance. Some therapists offer their services on a sliding scale: fees are based upon the client's ability to pay. 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 non-therapeutic support groups. Non-therapeutic 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. In fact, 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 behavior 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. Some people have actually described relief from OCD as being able to see after having been blind.

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.

Beyond OCD Can Help

Beyond OCD is the leading provider of consumer-friendly resources to help sufferers cope with and conquer Obsessive Compulsive Disorder (OCD). We work to increase public and professional awareness of OCD, educate and support people with OCD and their families, and to encourage research into new treatments and a cure.

We reach 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.BeyondOCD.org for:

- In-depth information on OCD and its treatment, as well as related disorders
- Expert perspectives on many OCD-related topics
- Personal success stories, written by people with OCD and their family members
- Sign up for Beyond OCD's e-newsletters, "Giving Voice," and read our blog
- An OCD self-screening test
- Current news articles, events, books and links to other web sites

For a list of treatment providers, email info@BeyondOCD.org or call 773-661-9530. For an information packet, visit www.BeyondOCD.org and click Contact Us. To access OCD Guides online for individuals, parents, college students and teens, visit www.BeyondOCD.org and click OCD Guides.

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 Beyond OCD. We rely solely on donations from the public.