Chapter Five

Obsessive-Compulsive Disorder: Caught in a Mind Trap

It's common to hear people refer to themselves as "obsessed" with a hobby or "compulsive" about housecleaning. Everyone understands that it's just a figure of speech. Sure, you may find yourself preoccupied with the woodworking project in your garage or the unfinished novel on your desk when you should be concentrating on work. Or you may like the shirts in your closet arranged just so or your bed made a particular way. But these thoughts, habits, and quirks aren't doing you any serious harm, and you can usually set them aside if they get to be too much trouble.

For people with obsessive-compulsive disorder (OCD), however, simply turning off unwanted thoughts and behaviors isn't an option. They are plagued by repeated, distressing thoughts, called obsessions, that they feel unable to control. The thoughts aren't just excessive worries about real-life concerns. Instead, they're exaggerated fears and anxieties that have little basis in reality. Yet once these thoughts push their way into the person's mind, they refuse to leave no matter how much distress and inconvenience they cause.

Such intrusive thoughts give rise to so much anxiety that people are driven to find something—anything—that will bring relief. True compulsions are repetitive behaviors or mental acts that people feel compelled to perform in response to obsessions in order to prevent some feared consequences or harm from happening. For example, teens who are obsessed with contamination might wash their hands to get rid of the germs that they're sure are lurking there, despite the fact that their hands are already clean. Since their obsession is so intense, a quick splash under the faucet isn't enough to ease their fears. Instead, they may wash their hands again and again, or they may develop complicated hand-washing routines, such as scrubbing each finger a specific number of times. Afterward, their anxiety is reduced, but only temporarily. The anxious thoughts soon come back, and so does the need to wash their hands. It's little wonder that teens whose OCD symptoms take this form often wind up with hands that are red, chapped, and bleeding from constant scrubbing.

OCD can take myriad other forms, but, in one way or another, it always leads to negative consequences. One teen may become so preoccupied with checking and rechecking that her homework is in her backpack that she never actually makes it to class. Another may spend so much time silently counting everything in sight that he winds up isolated in a world of his own for hours on end.

One Family's Story

For 14-year-old Justin, the first hints of trouble appeared a few years ago while he was vacationing with his family in Canada. As his mother, Laura, remembers it, "We were walking along a

path near the river when he reached out his leg and kicked me. I said, 'Hey, what did you do that for? You almost tripped me.' And he said, 'Well, I had touched you with my right leg, so I had to touch you with my left leg to even things out.'"

For most families, this would be one of those funny little incidents that is soon forgotten. In Justin's case, however, the compulsion to "even things out" soon became much more noticeable and disturbing. At school, he was disrupting class by flipping the light switch on and off repeatedly. "There was a three-toggle light switch in the classroom, and he had to get them all on or off at exactly the same moment," says Laura. At home, he had trouble typing on a keyboard or playing the piano, because he had to get the keystrokes exactly even, too.

Simply holding a conversation with Justin became excruciating. Laura remembers, "You would say, 'Hello, Justin.' And he would just stare at you blankly for a few seconds before he would finally respond." At first, Laura was mystified, but eventually she learned the reason for the awkward delays. "If someone said something, before the conversation could move on, he had to repeat it silently backward. So during those seconds when he seemed to be just staring, he was actually repeating whole sentences backward in his mind."

Justin began seeing a cognitive-behavioral therapist. He went twice a week at first, then once a week, then only occasionally for "refresher" sessions as needed. He also started taking medication to help control his symptoms. "He's doing very well," says Laura. Today, he plays saxophone, and he sometimes still gets the urge to even up the way he fingers the keys. When he's writing, he also sometimes wants to retrace the letters. The difference is that now he understands what's happening, and he and his mother have learned strategies for responding.

"He tells me right away when he's having problems," says Laura. In response, she and Justin usually work out a plan for helping him confront his anxiety. "Once in a while, I'll still bring him to the therapist's office for a refresher, but not often. Together, we can usually deal with it on our own now."

Rituals and Routines

As Justin found, it *is* quite possible to get better control of obsessive thoughts and the compulsive behaviors that often go along with them. It isn't easy, though. OCD is a tenacious illness, as anyone who has ever dealt with it will tell you. "It's an amazing sickness," says one father whose 16-year-old son only recently developed symptoms. "Things as simple as getting into the shower—things that you or I would take for granted—have become this elaborate ritual for him."

To understand the hold that obsessions can have on an adolescent, it helps to compare them to something more familiar: worries. When you worry, you feel distressed and anxious, but your specific thoughts vary from day to day as circumstances change. Obsessions, in contrast, are more stable. The same upsetting thoughts, impulses, or mental images come back time and again. Although the precise content of these thoughts varies from one person to the next, they often involve concerns about being dirty or sinful, or anxiety over something terrible that might happen. Each time the obsessive thoughts return, they stir up feelings of distress, fear, disgust, or shame.

Since these feelings are so unpleasant, people often try to neutralize them with another thought or action. That's where compulsions come into play. For example, consider a teen who is obsessed with the idea that her books will be stolen if she

doesn't check her locker. She may try to neutralize this upsetting thought by checking to make sure that the books are still there. Eventually, she might wind up compulsively checking her locker many times a day—behavior that interferes with her ability to get to class on time and socialize with her friends between classes. At some point, she may recognize that her locker-checking has gotten out of hand. Yet she finds the compulsion to check it again almost impossible to resist.

Types of OCD

Obsessive thoughts lie at the heart of OCD. However, the compulsive rituals and routines they prompt are easier to see, so it is these behaviors that are used to classify subtypes of the disorder. Below are the seven most common OCD types. Keep in mind, though, that many people develop more than one kind of compulsive behavior.

. . . many people develop more than one kind of compulsive behavior

- Washers and cleaners—Some teens with OCD are obsessed with thoughts of contamination by germs, bodily secretions, or toxic chemicals. To counter such concerns, many wash their hands excessively—the most common compulsion in young people. Others develop complicated showering rituals or clean their room for hours on end. These same teens may also go to great lengths to avoid any contact with contaminated objects. For example, they might refuse to touch an object that has been dropped on the floor.
- Checkers—These teens are consumed with worries about potential calamities. To neutralize their worries, they repeatedly check to make sure that they've taken some protective action. For example, teens who worry obsessively

about burglars may check that the doors to the house are locked—not once or twice, but again and again. Teens with this type of OCD sometimes become stuck for hours in a repetitive thought loop of worrying and checking, worrying and checking.

- Repeaters—Like checkers, these teens are obsessed with potential catastrophes. The difference is that they feel driven to perform repetitive, protective rituals that have no logical connection to the feared event. For instance, a teen consumed by thoughts of his baby sister dying might feel as if the only way to keep this from happening is to repeatedly dress and undress until the disturbing thoughts pass.
- Orderers—These teens are plagued by a general sense of discomfort that arises whenever things are not in perfect order. To reduce their discomfort, the teens devote considerable time to ordering, arranging, straightening, or trying to make things symmetrical. Such teens may become extremely upset if their possessions are rearranged. To them, it's critical that everything be in the "right" place.
- Hoarders—These teens are obsessed with worries about not having what they'll need in the future. Some actively collect objects that most of us would consider useless. Others simply avoid throwing things away. Of course, many teens, like adults, are avid collectors. But while a typical teen might want to collect CDs, a hoarder might keep not only the CDs, but also the bags they came in.
- Mental ritualizers—These teens, like the others described above, engage in compulsive behaviors to keep the anxiety caused by obsessive thoughts at bay. The difference is that their rituals are performed entirely in their minds. The most common mental rituals are praying, counting,

and silently repeating certain words or phrases. One mother says her son imagined a "flipping man," who flipped first one way and then the other, over and over.

- Pure obsessives—While the vast majority of teens with OCD engage in compulsive rituals, a few don't. Pure obsessives have repeated, distressing thoughts, but they haven't developed any compulsive behaviors for reducing the anxiety that results. Examples include disturbing impulses to hurt loved ones or shameful images of sexual acts that come to mind. These upsetting thoughts keep returning again and again, and the person feels unable to stop them.

Red Flags to Watch For

Do you think your teen may be suffering from OCD? These are some warning signs that your teen might need help:

- Having upsetting thoughts that keep coming back
- Being unusually worried about dirtiness or sinfulness
- Doing things over and over again
- Showing increased preoccupation with minor details
- Washing hands, showering, or cleaning excessively
- Checking door and window locks repeatedly
- Being inflexible about the way things are arranged
- Doing things a set number of times
- Hoarding or collecting an excessive amount of junk
- Taking much longer than usual to do simple tasks
- Acting as if daily life has become a struggle
- Seeking repeated reassurance about safety

The complete diagnostic criteria for OCD can be found in the Appendix.

Compelled to Act

While compulsions can be classified into broad categories, the specific forms they take are as unique as the individuals who have them. Following are a few examples that were shared by the parents interviewed for this book.

- "My oldest boy was putting on some deodorant, and the cap fell out of his hand and grazed Sammy's shoulder. It was like a medical emergency. The cap was infected! It touched his shoulder! Sammy had to take another shower and change all his clothes."—Father of a 16-year-old
- "We have a flagstone patio in the back, and the stones are a reddish color, a bluish color, and a grayish color. She could only step on the blue ones."—Mother of a 13-year-old
- "He does things in three sets of three, whether it's tapping the glass on the table, tapping the fork before he picks it up, lifting his eyebrows. It all happens in sets of three."—Mother of a 13-year-old
- "He can't throw anything out. He hoards stuff, even if it's broken. It's like, if you throw something out, it's going to change the whole order of things."—Mother of a 13-year-old
- "He counts everything. He counted the dots on the television one day until he got to the point where he couldn't look at the TV anymore."—Father of a 13-year-old
- "The first thing I noticed was when my son told me he saw some writing on someone else's test during spelling, so he purposely misspelled a word. He was worried about cheating when he wasn't really cheating. Then I kept him home from school for half a day, and he worried that he wasn't really sick. After that, he went downhill so quickly. He was tormented by his thoughts to the point where he couldn't stop crying, and he was banging his head because the thoughts wouldn't stop."—Mother of an 11-year-old

OCD in Adolescents

At one time, OCD was considered a rare condition in children and adolescents. Today, we know otherwise. Research suggests that as many as 1% of young people may have the disorder. Before puberty, boys are more likely than girls to have OCD. After puberty, though, girls catch up. The prevalence of OCD during adolescence is about equal between the sexes.

When younger children develop OCD, they often have trouble articulating the obsessive thoughts that underlie their compulsive behaviors. By comparison, teens are often more capable of discussing their obsessions. The most common obsessions in young people deal with contamination and dirtiness, and the most common compulsions involve washing and cleaning. Other common compulsions in this age group include checking, ordering, hoarding, and counting.

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Unfortunately, OCD in young people often goes undiagnosed and untreated. For one thing, young people with OCD may be secretive about their symptoms. For another thing, although OCD has received more attention in recent years, many physicians, teachers, and others who work with young people are still unfamiliar with the disorder. This means it may be up to parents to bring the problem to the professionals' attention and, if appropriate, ask for a referral to a mental health care provider.

Tic Disorders and Tourette's Syndrome

Adolescents with OCD often have other disorders as well. Among the most common coexisting conditions are tic disorders and

Tourette's syndrome. A tic is a sudden, rapid, repetitive movement or vocalization that serves no useful purpose. Examples of motor tics include repeated, nonfunctional head jerking, facial grimacing, eye blinking, and tongue protruding. Examples of vocal tics include repeated, nonfunctional clicking, grunting, sniffing, and coughing. Vocal tics can also involve the repeated uttering of meaningless sounds or words.

Up to 30% of people with OCD report having had tics at some point in their lives. From 5% to 7% have full-blown Tourette's syndrome, a neurological disorder characterized by frequent, multiple tics. For Tourette's to be present, the person must have had multiple motor tics and at least one vocal tic at some point in the illness, although not necessarily all at the same time. On TV, people with Tourette's are often depicted as having coprolalia, a complex vocal tic that involves uttering obscenities. In reality, though, only a small fraction of people with Tourette's ever develop coprolalia.

Immediate family members of people with OCD have an increased risk of developing tic disorders. The reverse is also true: Close relatives of people with Tourette's and other tic disorders have a heightened risk of OCD. Research suggests that in some, but not all cases, OCD and Tourette's may represent alternate expressions of the same genetic variation.

Obsessive-Compulsive Spectrum Disorders

The existence of a genetic link between OCD and tic disorders, including Tourette's syndrome, seems clear. Some researchers have suggested that a similar link might exist between OCD and so-called "obsessive-compulsive spectrum disorders"—a group of disorders that, on the surface at least, resemble obsessions or compulsions and may respond to some of the same treatments as OCD. The concept of an obsessive-compulsive spectrum is still

One Boy, Two Challenges

Seventeen-year-old Ryan has both OCD and Tourette's. Over the years, his tics have taken many forms: humming, grunting, blinking, grimacing, shrugging, and jerking his leg, to name just a few. At one point, he even jerked his neck so much that he gave himself whiplash. Ryan's OCD has taken a variety of forms as well, including an obsession with contamination. "If he handled chemicals in science class, he was afraid that a residue would stay on his hands and get in his food and kill him," his mother says.

The combination of OCD and Tourette's made Ryan's early adolescent years quite difficult for both him and his family. Today, however, Ryan has learned to manage his symptoms and get on with his life with the help of therapy, medications, and his family's support. A high school senior, he's looking forward to college. His mother says, "Now, whenever we go to a TSA [Tourette Syndrome Association] or OCF [Obsessive-Compulsive Foundation] function, we meet parents who are where we were five years ago. For them, I think it helps being able to talk with us and meet Ryan, because they know we've been through it. It helps them, and it's gratifying for us."

open to debate, however. Although a number of mental and behavioral disorders are more common in people with OCD than in the general population, it's unclear which ones actually share a common genetic cause or biological pathway.

Conditions that seem to be associated with a higher-than-average lifetime risk of OCD include:

- Body dysmorphic disorder—A disorder in which people become so preoccupied with some imagined defect in their appearance that it causes serious distress or significant problems in their everyday life.
- Trichotillomania—A disorder in which people feel driven to pull out their own hair, leading to noticeable hair loss.

- Hypochondriasis—A disorder in which people become preoccupied with the idea that they have a serious illness, based on their misinterpretation of harmless bodily signs and sensations.
- Anorexia nervosa—An eating disorder in which people have an intense fear of becoming fat, so they severely restrict what they eat, often to the point of near starvation.
- Bulimia nervosa—An eating disorder in which people binge on large quantities of food, then purge by forced vomiting, laxative or diuretic abuse, or excessive exercise.

More research on the relationship between these disorders and OCD is needed. It's worth noting that there are significant differences as well as similarities among all of these conditions. Nevertheless, studies suggest that there might indeed be a shared genetic mechanism underlying OCD and some of these disorders. For example, a study published in *Biological Psychiatry* in 2000 found a hereditary link between OCD and both body dysmorphic disorder and abnormal "grooming" behaviors, such as trichotillomania.

Other Related Problems

It's not uncommon for teens with OCD to have another anxiety disorder, too, such as a specific phobia, panic disorder, social anxiety disorder, or generalized anxiety disorder. OCD can also occur alongside depression, although this may be less common in teens than in adults.

In addition, learning disorders appear to be relatively common among young people with OCD. Such disorders affect teens' performance in school or their ability to function in everyday situations that require reading, writing, or math skills. When students with OCD have learning disorders,

Table 2. What's the Difference?

OCD can look a lot like several other mental disorders. In addition, it's not always easy to tell the difference between OCD rituals and run-of-the-mill superstitions or quirky habits. This chart outlines some key distinguishing features.

OCD is sometimes confused with . . .	*Compared to OCD, this condition leads to . . .*
Generalized anxiety disorder	Excessive worries about real-life concerns. In contrast, OCD leads to exaggerated worries with no basis in reality.
Depression	Persistent brooding that seems appropriate to the person. In contrast, people with OCD regard their obsessions as inappropriate and intrusive.
Eating or body image disorders	A preoccupation with eating, body weight, or appearance. In contrast, OCD isn't limited to just these concerns.
Substance abuse or gambling addiction	An activity that people are driven to repeat because it gives them pleasure. In contrast, people with OCD are driven to repeat compulsions because the actions temporarily reduce the anxiety caused by obsessions.
Superstitions or quirky habits	Rituals or routines that aren't overly time-consuming and don't cause significant distress or impairment. In contrast, OCD is pervasive and leads to impairment in daily functioning.

they frequently have problems with handwriting, math, or expressive written language. Diagnosing a learning disorder can be complicated by the presence of OCD, however. That's because OCD itself sometimes interferes with the speed and efficiency with which students do their work. It can be hard to tell

the difference between a student who is slowed down in school by OCD rituals and one who is hampered by a learning disability.

Causes and Contributors

OCD has been around for centuries. Writings from the Middle Ages describe religious compulsions and differentiate them from religious devotion. More recently, OCD has been documented in countries around the world. Not surprisingly for such a dramatic and pervasive illness, a number of theories have been advanced about the causes of OCD. At one time or another, the disorder has been attributed to everything from moral weakness to overly strict toilet training.

More recently, as scientific evidence has accumulated, the focus has shifted from emotional explanations to biochemical and genetic ones. Contrary to what you might think, there is no evidence that OCD is caused by childrearing practices or learned attitudes, such as an emphasis on cleanliness or a belief that certain thoughts are unacceptable. Instead, there is a substantial and growing body of research linking OCD to abnormal functioning of brain circuitry.

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The Serotonin Hypothesis

Brain imaging studies of people with OCD have revealed patterns of activity that differ from those seen in both healthy individuals and people with other mental illnesses. In particular, the brains of people with OCD often have abnormalities in

circuits linking the orbital cortex, located at the front of the brain, to the basal ganglia, located deeper inside. Interestingly, other imaging studies have shown that these abnormalities in brain activity often disappear after treatment with either cognitive-behavioral therapy (CBT) or medication. Such studies provide graphic evidence that both therapy and medication can directly alter the way the brain works.

Serotonin, a chemical messenger that has been linked to both anxiety and depression, plays an important role in communication between these brain structures. One theory, known as the serotonin hypothesis, points to low serotonin levels as the root cause of OCD-related changes in brain function. The strongest evidence for this theory comes from studies that show a decrease in OCD symptoms among people who take selective serotonin reuptake inhibitors (SSRIs), medications that increase the available supply of serotonin in the brain.

Genetic Factors

Further evidence for the biological roots of OCD can be found in the family histories of many people with the disorder. There is a tendency for OCD to run in families. The risk of OCD is greater if a parent has it, and it's further increased if the parent developed OCD in childhood or if there are multiple relatives with OCD, Tourette's syndrome, or tics. You might think this tendency could be explained by children imitating the compulsive rituals they've seen their parents perform. However, in studies where both a parent and a child have OCD, the symptoms are usually dissimilar. For instance, a parent who compulsively cleans might have a child who compulsively checks or counts. This bolsters the argument that heredity rather than learning accounts for the family connection. So far, researchers have identified one genetic mutation that may play a role in

certain cases of OCD. This mutation occurs in a serotonin transporter gene that helps regulate the amount of serotonin in the brain. A particular change in this gene reduces the amount of available serotonin and increases the risk of OCD or OCD-like symptoms. A few people have two different changes in this same gene, and the double whammy seems to be related to more severe OCD.

Of course, not everyone who develops OCD has a relative with the disorder. For those who do, however, the family connection is often a source of support and understanding. "In a way, I'm so glad that I went through the same kind of thing," says one father with OCD, whose 13-year-old son has the same condition. "When I was a kid, my parents didn't seem to know that they could do something to help. But because I've been through it myself, I understand how important it is to get help for my son."

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Environmental Factors

As we've seen, OCD has its roots in biology and genetics. Parenting practices and family interactions don't cause the disorder. Nevertheless, once the disorder is present, a teen's home life both affects and is affected by OCD. For one thing, young people with OCD often try to involve family members in their rituals. One father says that his 16-year-old son with OCD demanded that everyone in the household wash their hands in a certain way. "He would stand there and watch you, and if you did it wrong, he expected you to do it again and again and again until you got it right." This same boy also declared his bedroom off limits. After his brother went into the room one day, the boy demanded that the room be decontaminated.

"Change the sheets, change the pillowcases, sterilize the doorknobs, sterilize the TV clicker and the remote control for the stereo. Everything had to be sterilized," his father says.

No matter how irrational and inconvenient such demands might seem, parents are often tempted to comply in an effort to keep the peace and temporarily relieve their child's obvious distress. In other cases, parents go along because they are baffled by the bizarre-seeming requests and don't know what else to do. While these are understandable reactions, parents who cooperate with the OCD actually wind up strengthening their child's dysfunctional behaviors.

Strep Infection

Finally, some cases of childhood OCD may be set in motion by a strep infection. Observant doctors had noticed that, in a few children, OCD or tics started very suddenly and dramatically after a case of strep throat. This observation led to the identification of a disorder called PANDAS (short for pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections). For a diagnosis of PANDAS to be made, a child must have either OCD or a tic disorder that started between age 3 and puberty. As time goes on, the symptoms must show a pattern of dramatic ups and downs. Typically, they worsen suddenly, then slowly and gradually get better over time. But if the child catches another strep infection, the OCD or tic symptoms abruptly worsen again.

Researchers are just starting to explore the mechanism behind PANDAS. In rheumatic fever, another disorder triggered by strep, the body's immune system goes awry. Instead of just attacking strep bacteria, antibodies produced by the immune system also mistakenly attack heart valves, joints, or certain

First-Person Singular

Want a glimpse inside your teen's mind? These memoirs written by individuals with OCD describe what it's really like to live with the disorder.

- Colas, Emily. *Just Checking: Scenes from the Life of an Obsessive-Compulsive.* New York: Washington Square Press, 1998.
- Summers, Marc, with Eric Hollander. *Everything in Its Place: My Trials and Triumphs with Obsessive Compulsive Disorder*. New York: Tarcher/Putnam, 2000.
- Traig, Jennifer. *Devil in the Details: Scenes from an Obsessive Girlhood.* New York: Little, Brown and Company, 2004.
- Wilensky, Amy S. *Passing for Normal*. New York: Broadway Books, 1999.

parts of the brain. It's believed that something similar might happen in PANDAS. Antibodies may set off an immune reaction that damages the basal ganglia, a cluster of nerve cells in the brain that play a key role in movement and behavior.

By definition, PANDAS is a childhood disorder. But as scientists learn more about the strep-OCD connection, it's quite possible they'll find that adolescents and adults can have immune-mediated OCD as well. Just because your child has had strep throat in the past doesn't necessarily mean that it's the cause of his or her OCD, however. Almost all school-age children catch strep throat at some point, but very, very few get OCD as a result. PANDAS is only considered as a diagnosis when there is a very close relationship between the start or worsening of OCD or tics and a preceding strep infection.

Diagnosis and Treatment

OCD is a brain disorder, so the best treatments for it are ones that actually change the way the brain works. Research has shown that both CBT and medications can have this effect. Recently, the lead author of this book was co-principal investigator on a study that evaluated the effectiveness of CBT, an SSRI medication, or a combination of the two for treating OCD in children and adolescents. The study was a randomized controlled trial—the gold standard in clinical research—that involved 112 young people seen at three university treatment centers.

All three treatments were more effective than a placebo (sugar pill) at reducing symptoms. Taken together, the results from the three centers showed that young people did better on a combination of CBT and an SSRI than on either treatment alone. However, for young people who were treated at the University of Pennsylvania, CBT alone worked as well as the combined treatment. This highlights the fact that the way therapists provide CBT is an important factor in determining how effective it is. The study also underscores just how successful state-of-the-art treatments can be. Among the University of Pennsylvania patients, almost two-thirds in both the CBT alone group and the combination group had few or no symptoms after 12 weeks of treatment.

Getting a Diagnosis

The first step toward finding treatment for your teen is to seek a professional diagnosis of the problem. While this sounds straightforward, it is complicated by the fact that a number of other mental and behavioral disorders can resemble OCD. To make an accurate diagnosis, a mental health professional will ask questions about your teen's past history and current symptoms.

The professional will conduct a diagnostic interview with the teen and observe his or her behavior. Since you know your child's current lifestyle and developmental history so well, you may also be asked to provide information.

Most teens have a few private rituals that make little sense, but are harmless and even comforting. For instance, they might turn down the bed the same way each night or knock on wood to prevent bad luck. Such rituals don't necessarily mean that a teen has OCD. To qualify as a disorder, the symptoms need to persist and cause significant distress or interfere with the teen's day-to-day life. Another cardinal feature that the professional looks for is "neutralizing." This means that rituals are performed specifically to counteract the anxiety provoked by certain thoughts or to reduce the chances that feared consequences will occur.

It's never good news to discover that your child has an illness. Yet once a diagnosis of OCD has been made, many parents say they are relieved to finally have a name to put to the problems their teen has been experiencing. "We had been alone, struggling, not understanding what was happening. So having a diagnosis was actually a big relief," says one mother. "Then the next stage was realizing that there was something to be done. It wasn't just this terrible thing that had happened. There was help for it, and that was the second great relief."

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Cognitive-Behavioral Therapy

CBT is the key element in the treatment of most teens with OCD. It helps people recognize and change self-defeating

thought patterns as well as identify and change maladaptive behaviors. One particular form of CBT, known as exposure and response prevention (EX/RP; also called exposure and ritual prevention), has proved especially beneficial for treating OCD. The exposure component involves having people confront the thoughts or situations that provoke their obsessional distress, while the response prevention part means they voluntarily refrain from using compulsions to reduce their distress during these encounters. When people repeatedly face their fears without resorting to their compulsions, their anxiety gradually decreases over time. The anxiety lessens after repeated exposures to an anxiety-provoking situation, a process that psychologists refer to as habituation.

People can practice EX/RP either in real-life settings or in their imagination. Either way, they have a chance to put their fears to the reality test. When a ritual isn't performed and yet terrible consequences don't occur, it helps people recognize the flaws in their thinking. Once they've recognized that their fears are unrealistic, their thoughts, beliefs, and behaviors change.

For example, let's say a teen with a hand-washing compulsion was worried that touching "germy" doorknobs would make her sick. Even though she was forced to touched doorknobs every day, and even though she didn't become ill as a result, she might tell herself, "Yes, I touched the doorknob, and I didn't get sick, but that's only because I washed my hands so carefully." During EX/RP, the teen would not only touch a doorknob, but also refrain from washing her hands afterward. Over time, when she still didn't get sick, she would come to realize that her old belief about the necessity of constant washing wasn't accurate. She could then work to replace that belief with a more accurate one; for instance, "I've touched doorknobs many times before, and they didn't make me sick. Doorknobs are not dangerous."

Among adults, CBT is the best established treatment for OCD. For adolescents with the disorder, expert consensus guidelines published in the *Journal of Clinical Psychiatry* in 1997 recommended CBT, either alone or combined with medication, as the first-choice treatment. For many types of compulsions—including washing and cleaning, ordering, repeating, counting, and hoarding—the guidelines recommended EX/RP as especially useful.

A Typical Treatment Protocol

In a study funded by the National Institute of Mental Health, this book's lead author and her colleague John S. March used a treatment protocol for OCD that has since been widely emulated. This typical protocol consists of 14 visits spread out over 12 weeks. The treatment can be divided into five phases:

- Psychoeducation (weeks 1 and 2)—The therapist presents information about the nature of OCD, the risks and benefits of CBT, and the specifics of the treatment plan.
- Cognitive training (weeks 1 and 2)—The therapist teaches the patient to use cognitive tactics for resisting OCD. As one part of the training, patients are taught to use constructive self-talk to reward and encourage their own efforts to resist OCD.
- Mapping OCD (week 2)—The therapist explores the patient's experience of OCD, including specific obsessions, compulsions, triggers, and avoidance behaviors.
- EX/RP (weeks 3 through 12)—The patient uses EX/RP to confront anxiety-provoking situations while resisting the urge to resort to rituals or avoidance behaviors. The patient starts with situations in which the OCD symptoms are relatively easy to resist, then gradually works up to more and more challenging situations. In addition to

working directly with the therapist, the patient practices EX/RP in homework assignments.

- Relapse prevention (weeks 11 and 12)—The patient practices coping skills that can be used if the symptoms flare up again in the future. Such skills can help keep a brief flare-up from turning into a full-fledged, long-lasting return of symptoms.

Although this is a typical protocol, your own teen's treatment might differ a bit, depending on factors such as the severity of the symptoms, the presence of other disorders, the preferences of the therapist, your teen's response to the treatment, and the number of sessions covered by your insurance plan. Some variation is to be expected. But if your teen's therapy doesn't include the basic elements outlined above, he or she may not be receiving effective treatment.

As a parent, you'll have an active role in your teen's CBT. The therapist should provide you with information about CBT and explain how you can best support the treatment at home. You might also be invited to participate in some of the therapy sessions. If you've become caught up in your teen's rituals, the therapist should instruct you on how and when to stop participating. Stopping too abruptly might be counterproductive if your teen doesn't yet have the necessary coping skills to deal with the ensuing distress. In that case, the therapist will guide you in stopping your participation when your teen is ready.

As a parent, you'll have an active role in your teen's CBT.

Medication Therapy

Research suggests that some teens with OCD may benefit from receiving medication in addition to CBT. The combination of

medication and CBT may be especially helpful for those with more severe symptoms and those with coexisting disorders such as Tourette's syndrome, another anxiety disorder, or depression. Fortunately, when it comes to studies of children and adolescents, more research has been done on medication therapy for OCD than for any other anxiety disorder. A growing body of evidence now supports the effectiveness of two types of medication: SSRIs and a tricyclic antidepressant called clomipramine (Anafranil).

- SSRIs—These medications are classified as antidepressants, but they're also widely used to treat anxiety disorders. They act by increasing the available supply of serotonin, a neurotransmitter that seems to play a central role in OCD. SSRIs include citalopram (Celexa), escitalopram (Lexapro), fluoxetine (Prozac), fluvoxamine (Luvox), paroxetine (Paxil), and sertraline (Zoloft). Large, well-controlled studies have shown that fluoxetine, fluvoxamine, and sertraline are effective for treating children and adolescents with OCD, and all three of these drugs have been specifically approved by the U.S. Food and Drug Administration (FDA) for that purpose. It can take a few weeks for the full effects of SSRIs to be felt, and they must be started at a low dose, since they sometimes actually worsen anxiety at first. Possible side effects include nausea, headache, nervousness, insomnia, jitteriness, and sexual problems. In 2004, the FDA also issued a warning about a small but significant risk of increased suicidal thoughts and behaviors in children and adolescents who are taking antidepressants. For more information about this warning, see Chapter 7.
- Clomipramine (Anafranil)—Clomipramine belongs to an older class of medications called tricyclic antidepressants.

Like SSRIs, tricyclic antidepressants also affect the concentration and activity of serotonin in the brain. Clomipramine, in particular, was the first drug to be systematically studied in children and adolescents with OCD. Studies found it to be effective, and it received FDA approval as a treatment for OCD in this age group. However, clomipramine is more likely to cause troublesome side effects than SSRIs, so it's usually not a first-choice treatment. Possible side effects include drowsiness, dry mouth, upset stomach, constipation, sexual problems, changes in appetite or weight, bladder problems, and increased heart rate. The FDA warning about the risk of suicidal thoughts and behaviors applies to clomipramine, too.

What to Expect

Different teens respond differently to treatment for OCD. In general, CBT is the cornerstone of treatment. But if CBT alone doesn't provide enough relief, the treatment provider may change to more intensive CBT or add an SSRI. If a combination of CBT and an SSRI isn't sufficient, the treatment provider may change to more intensive CBT, switch to a different medication, or add a second medication.

"I think the important thing to know about OCD is that, with the right treatment, it does get better," says the mother of a 13-year-old with the disorder.

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Whatever treatment is chosen, the effects usually don't start to be felt for a few weeks. It's important for your teen to give any treatment a fair trial before deciding that it isn't working well enough. This generally means sticking with it for at least 10 weeks. For most

patients, gains achieved with CBT tend to last over the long haul without the need for continuing treatment. On the other hand, for many patients, gains achieved with medication last only as long as the person keeps taking the medicine.

Supporting Your Teen at Home

One of the most helpful things you can do for your teen with OCD is to educate yourself about the illness. Your teen's therapist should supply some basic information about the disorder, but don't stop there. "I did a lot of research," says one parent. "I went to the OCF [Obsessive-Compulsive Foundation] online. And I got some books, and I did a lot of reading." A second parent says, "We have a good psychiatrist who put me in touch with the mother of another child with OCD shortly after my son's diagnosis. This woman was a world of help and, most importantly, she gave me hope that things would get better."

Keys to Communication

The more you know about OCD, the better able you'll be to talk to your teen about it. You can build your teen's self-esteem by making it clear that the problem is the illness, not the person who has it. Criticism just raises your teen's anxiety level and makes OCD that much harder to resist. On the other hand, when you approach any problems in a nonjudgmental way, you let your teen know that you understand what he or she is going through and that you're there to help.

Teens with OCD are often secretive about their symptoms out of a misplaced sense of shame, guilt, or embarrassment. As one mother says, "My daughter hid her symptoms. We weren't seeing everything that she was doing, and she wasn't telling us

Taking Care of You

It's easy to get so caught up in helping your teen that you forget to take care of yourself. Yet raising a teenager with OCD can be very stressful. Here's how other parents keep the stress from spiraling out of control.

- Enlist the help of supportive family and friends. "My daughter's OCD caused some tension in our family. My mother-in-law and mother didn't understand it. But my husband and I were on the same page, and that made a big difference."—Mother of a 16-year-old with OCD
- Join an in-person or online support group. "Joining the OCD and Parenting group was great. There were other people who would say, 'Yeah, my kid did that, and this is what worked for us and what didn't.'"—Mother of a 13-year-old with OCD (OCD and Parenting is an online support group available through Yahoo! Groups [health.groups.yahoo.com/group/ocdandparenting]. To find a face-to-face support group in your area, contact the Obsessive-Compulsive Foundation or Anxiety Disorders Association of America.)
- Keep a current crisis in perspective. "It's worse right before it gets better. There's this initial, awful period when the therapy isn't working yet, but it's like the storm before the calm. Once you get over that hump, things are so much better."—Mother of a 16-year-old with OCD
- Seek treatment for yourself if you need it. "I've seen therapists myself from time to time. Last year was so difficult, and I was crying every day, too. Things seemed so awful, and I was freaking out. Seeing a therapist really helped me."—Mother of a 13-year-old with OCD

about them. She was doing things that she couldn't stop, and she knew that was 'crazy,' so she didn't want us to know about it."

Encourage communication, but don't insist that your teen share more than he or she feels comfortable talking about. As time goes on, and as the treatment starts to take hold, your teen may open up more. When this happens, try to listen

nonjudgmentally to whatever your teen has to say. Let your teen know that it's okay to talk about unpleasant thoughts and feelings as well as pleasant ones. Encourage your teen to examine these thoughts and feelings realistically. But refrain from offering simplistic advice, such as "Stop worrying!" or "Just stop it." Nobody dislikes the OCD symptoms more than your teen. If it were that easy to stop, your teen would undoubtedly have done so already. Instead, let your teen know that you realize how difficult it is, but that you're confident he or she can beat the disorder.

Nobody dislikes the OCD symptoms more than your teen.

Working with Your Teen's Teacher

So much of your teen's life centers around school. It should come as no surprise that OCD often affects social or academic functioning in the school setting. The degree of impairment varies widely from student to student, though. Some teens with OCD manage to keep their symptoms almost completely hidden at school. Others need only minor accommodations in the classroom, while still others require more extensive accommodations and special educational services.

OCD has the potential to affect academic performance in several ways. Students may be so preoccupied with obsessive thoughts that it's hard for them to think about anything else. Some students also develop school-related rituals, such as tracing and retracing their letters when writing, that interfere with their ability to get things done. In addition, some obsessions or compulsions are so time-consuming that they interfere with the ability to get to class, study, or do homework.

Should you talk to your teen's teachers about OCD? Discuss this with your teen first to gauge his or her comfort with sharing the information. There is always the risk that a few unenlightened people might react inappropriately. Most teachers are quite understanding and helpful, though, once they understand the nature of the problem. "My advice to other parents is to talk to the school a lot," says the father of a ninth-grader with OCD. "I've provided books to the school and given them information. I go to every school meeting. If I need to, I call the teachers or I make extra visits to the school. I think the schools appreciate it when parents are involved."

"I go to every school meeting. If I need to, I call the teachers or I make extra visits to the school."

Small Changes, Big Results

Many students with OCD are able to adapt well to ordinary classroom demands, but others struggle at school. They may benefit from temporary accommodations and special services

A Voice of Experience

Ruth is both the mother of two teenagers with OCD and a therapist who specializes in treating anxiety disorders. She's also a firm believer in the importance of keeping school personnel in the loop. Ruth offers this example: "The other night, the mom of one of my own patients called me. She has a girl who's 12 who was just having an awful OCD night and couldn't stop checking and rechecking her homework. I said to the mom, 'Take the homework away. She's done. You can call the school tomorrow and tell them it was a horrible OCD night, so she couldn't do the homework.'" Of course, this strategy works best when teachers have been forewarned about the disorder. Even better, it's helpful if the parents and teachers have discussed in advance the kinds of problems that may arise and the solutions that might be needed.

that help them succeed at school until the OCD symptoms are under better control. The mother of a ninth-grader with OCD says he has benefited from having a 504 plan—one of two types of formal plans that cover educational services for students with mental and physical disabilities. (For more information on such plans, see Chapter 7.) "It allows him to take more time on tests and to type his homework. He also has a hall pass to just leave the classroom and go to the nurse or bathroom if he's feeling overstressed. And he gets at least 2 extra days to complete homework if he's having a difficult time."

Whether you have a formal plan or just an informal agreement with your teen's teacher, small accommodations can sometimes help your teen function better at school while you wait for a treatment to take effect or if the treatment is only partially successful. The needs of each student with OCD must be considered individually, and they change over time as the student's condition improves. These are examples of the types of short-term accommodations that some students with OCD have found helpful.

Students with contamination obsessions and washing compulsions:

- Letting students be first in line at the cafeteria.
- Seating students where they are first to receive handouts.
- Giving students an extra set of "uncontaminated" books to keep at home.
- Permitting students to go to their lockers early to avoid crowded hallways.
- Allowing students to go to the bathroom whenever they feel the need. Ironically, this may actually reduce the amount of time spent obsessing over not having access to a sink. When students are ready, limiting the number of bathroom passes may be appropriate.

Students with obsessions and compulsions that lead to perfectionism:

- Letting children make check marks instead of filling in circles on tests, for students with compulsions about filling in the circles perfectly.
- Permitting assignments to be typed or recorded on audiotape rather than handwritten, for students with compulsions about making their handwriting look just so. It may also help to let such students tape record lectures instead of taking notes by hand.

Students who are slowed down by their obsessions and compulsions:

- Allowing extra time for completing tests and homework, for students who feel compelled to check and recheck their work. Alternately, it may help to set a time limit for work, and accept whatever is completed in that time.
- Assigning shorter reading passages, for students with compulsions about reading and rereading sentences, or counting all the letters or words on a page. Alternately, students might be allowed to listen to books on tape or to have someone else read to them.

Remember that these are meant to be temporary measures, not permanent solutions. The goal is to help your teen function at school until treatment is successful.

Looking to the Future

OCD tends to be a long-term condition. In one study of children and teens with the disorder, 43% still had full-blown OCD two to seven years later, and only 11% were totally

symptom-free. This study was done more than a decade ago, however, and the young people in it were initially treated with medication. The treatment for OCD is constantly being refined. Plus, evidence suggests that children and teens who start out being treated with CBT, either alone or combined with medication, learn lifelong skills that can help them maintain their improvement.

Even with CBT, your teen may not be completely cured of OCD. But there's an excellent chance that your teen can be helped to feel much better. Some residual symptoms might remain, and these symptoms may wax and wane for years. However, once your teen has mastered the basic techniques for resisting OCD, these skills can be applied whenever the disorder flares up.

Discovering that your child has OCD can be very upsetting at first. As one mother put it, "You know that scene in *Titanic* where they're in the ocean hanging onto a piece of wood? I felt like my daughter and I were hanging onto this one piece of wood, and one of us was in danger of slipping off at any instant." This mother says the thing that helped boost her optimism the most was becoming active in her local chapter of the Obsessive-Compulsive Foundation, where she had a chance to meet not only other parents, but also other people of all ages with OCD.

She says, "It helped so much for me to meet adults with OCD who had successfully overcome their symptoms and who now have jobs and families and kids. Because when your child is first struck with this disorder, you wonder if she's going to be forced to lead some marginal existence. And then you meet some of these people, and you realize that, with proper treatment, a large portion of people with OCD can lead very full lives and be very functional. And that was a real lifesaver for me, just realizing that her life was probably going to be okay."