

The background is a complex, layered composition of blue tones. It features several hands in various poses, some reaching out or holding objects. A large sun with rays is visible in the upper left. Numerous curved arrows point in various directions, suggesting movement or a cycle. The overall aesthetic is clean and modern, with a focus on human elements and natural motifs.

International OCD Foundation

WHAT YOU NEED TO KNOW ABOUT
Obsessive Compulsive Disorder

What Is Obsessive Compulsive Disorder (OCD)?

*Imagine that your mind got stuck
on a certain thought or image . . .*

Then this thought or image got replayed in your mind
over and
over again
no matter what you did . . .

You don't want these thoughts - it feels like an avalanche . . .

Along with the thoughts come intense feelings of anxiety . . .

Anxiety is your brain's warning system. When you feel anxious it feels like you are in danger. Anxiety is an emotion that tells you to respond, react, protect yourself, DO SOMETHING . . .

On the one hand, you might recognize that the fear doesn't make sense, doesn't seem reasonable yet it still feels very real, intense, and true . . .

Why would your brain lie?

Why would you be experiencing feelings if they weren't true?

Feelings don't lie . . .

Unfortunately, if you have OCD, they do lie. If you have OCD, the warning system in your brain is not working correctly. Your brain is telling you that you are in danger when you are not.

When scientists compare pictures of the brains of groups of people with OCD, they can see that on average some areas of the brain are different compared to individuals who don't have OCD.

Those tortured with this disorder are desperately trying to get away from paralyzing, unending anxiety.

How Will I Know if I Have OCD?

Only trained therapists can diagnose OCD.

They will look for three things:

- The person has obsessions.
- He or she does compulsive behaviors.
- The obsessions and compulsions take a lot of time and get in the way of important activities the person values (working, going to school, etc.)

Obsessions:

- Thoughts, images, or impulses that occur over and over again and feel out of the person's control.
- The person does not want to have these ideas.
- He or she finds them disturbing and unwanted, and usually knows that they don't make sense.
- They come with uncomfortable feelings, such as fear, disgust, doubt, or a feeling that things have to be done in a way that is "just right."
- They take a lot of time and get in the way of important activities the person values (socializing, working, going to school, etc.).

What Obsessions are not...

- It is normal to have occasional thoughts about getting sick or about the safety of loved ones.

Compulsions:

- Repetitive behaviors or thoughts that a person engages in to neutralize, counteract, or make their obsessions go away.
- People with OCD realize this is only a temporary solution, but without a better way to cope they rely on the compulsion as a temporary escape.
- Can also include avoiding situations that trigger their obsessions.
- Time consuming and get in the way of important activities the person values (socializing, working, going to school, etc.).

What Compulsions are not...

- Not all repetitive behaviors or "rituals" are compulsions. Bedtime routines, religious practices, and learning a new skill involve repeating an activity over and over again, but are a welcome part of daily life.
- Behaviors depend on the context: Arranging and ordering DVDs for eight hours a day isn't a compulsion if the person works in a video store.

Common Obsessions in OCD*

Contamination

- Body fluids (examples: urine, feces)
- Germs/disease (examples: herpes, HIV)
- Environmental contaminants (examples: asbestos, radiation)
- Household chemicals (examples: cleaners, solvents)
- Dirt

Losing Control

- Fear of acting on an impulse to harm oneself
- Fear of acting on an impulse to harm others
- Fear of violent or horrific images in one's mind
- Fear of yelling out insults or swearing
- Fear of stealing things

Perfectionism

- Concern about evenness or exactness
- Concern with a need to know or remember
- Fear of losing or forgetting important information when throwing out something
- Unable to decide whether to keep or to discard things
- Fear of losing things

Harm

- Fear of being responsible for something terrible happening (examples: fire, burglary)
- Fear of harming others because of not being careful enough (example: dropping something on the ground that someone might slip on and hurt themselves)

Unwanted Sexual Thoughts

- Forbidden or perverse sexual thoughts or images
- Forbidden or perverse sexual impulses about others
- Obsessions about homosexuality
- Sexual obsessions that involve children or incest
- Obsessions about aggressive sexual behavior towards others

Religious Obsessions (also called Scrupulosity)

- Concern with offending God or blasphemy.
- Excessive concern with right/wrong or morality.

Other Obsessions

- Concern with getting a physical illness or disease (not by contamination e.g., cancer)
- Superstitious ideas about lucky/unlucky numbers, certain colors

* Reprinted with permission by New Harbinger Publications, Inc. This is an adaptation of the OC Checklist which appears in S. Wilhelm and G. S. Steketee's, "Cognitive Therapy for Obsessive-Compulsive Disorder: A Guide for Professionals" (2006). www.newharbinger.com

Common Compulsions in OCD*

Washing and Cleaning

- Washing your hands too much or in a certain way
- Excessive showering, bathing, tooth brushing, grooming or toilet routines
- Cleaning household items or other objects too much
- Doing other things to prevent or remove contact with contaminants

Checking

- Checking that you did not/will not harm others
- Checking that you did not/will not harm yourself
- Checking that nothing terrible happened
- Checking that you did not make a mistake
- Checking some parts of your physical condition or body

Repeating

- Rereading or rewriting
- Repeating routine activities (examples: going in or out doors, getting up or down from chairs)
- Repeating body movements (example: tapping, touching, blinking)
- Repeating activities in “multiples” (examples: doing a task three times because three is a “good”, “right”, “safe” number)

Mental Compulsions

- Mental review of events to prevent harm (to oneself, others, to prevent terrible consequences)
- Praying to prevent harm (to oneself, others, to prevent terrible consequences)
- Counting while performing a task to end on a “good”, “right”, or “safe” number
- “Cancelling Out” or “Undoing” (example: replacing a “bad” word with a “good” word to cancel it out)

Other Compulsions

- Collecting items which results in significant clutter in the home (also called hoarding)
- Putting things in order or arranging things until it “feels right”
- Telling, asking, or confessing to get reassurance
- Avoiding situations that might trigger your obsessions

* Reprinted with permission by New Harbinger Publications, Inc. This is an adaptation of the OC Checklist which appears in S. Wilhelm and G. S. Steketee’s, *Cognitive Therapy for Obsessive-Compulsive Disorder: A Guide for Professionals* (2006). www.newharbinger.com

OCD: Frequently Asked Questions

John Greist

Clinical Professor of Psychiatry, University of Wisconsin; International OCD Foundation Scientific Advisory Board

Maggie Baudhuin, MLS

Coordinator, Madison Institute of Medicine, Inc.

How common is OCD?

Our best estimates are that about 1 in 100 adults – or between 2 to 3 million adults in the United States – currently have OCD.^{1,2} This is roughly the same number of people living in the city of Houston, Texas.

There are also at least 1 in 200 – or 500,000 – kids and teens that have OCD. This is about the same number of kids who have diabetes. That means four or five kids with OCD are likely to be enrolled in any average-size elementary school. In a medium to large high school, there could be 20 students struggling with the challenges caused by OCD.³

OCD affects men, women and children of all races and backgrounds equally.

At what age does OCD begin?

OCD can start at any time from preschool to adulthood. Although OCD does occur at earlier ages, there are generally two age ranges when OCD first appears. The first range is between ages 10 and 12 and the second between the late teens and early adulthood.

Is OCD inherited?

Research shows that OCD does run in families and that genes likely play a role in the development of the disorder. Genes appear to be only partly responsible for causing the disorder though. No one really knows what other factors might be involved, perhaps an illness or even ordinary life stresses that may induce the activity of genes associated with the symptoms of OCD.

Some experts think that OCD that begins in childhood may be different from the OCD that begins in adults. For example, a recent review of twin studies³ has shown that genes play a larger role when OCD starts in childhood (45-65%) compared to when it starts in adulthood (27-47%).

Is OCD a brain disorder?

Research suggests that OCD involves problems in communication between the front part of the brain and deeper structures. These brain structures use a chemical messenger called serotonin. Pictures of the brain at work also show that in some people, the brain circuits involved in OCD become more normal with either serotonin medicines or cognitive behavior therapy (CBT).

For more information on the most effective type of CBT for OCD called Exposure and Response Prevention, turn to page 8.

There are no laboratory or brain imaging tests to diagnose OCD. The diagnosis is made based on the observation and assessment of the person's symptoms .

What are common obstacles to effective treatment?

Studies find that it takes an average of **14 to 17 years** from the time OCD begins for people to obtain appropriate treatment.

- **Some people choose to hide their symptoms**, often in fear of embarrassment or stigma. Therefore, many people with OCD do not seek the help of a mental health professional until many years after the onset of symptoms.
- Until recently, there was **less public awareness of OCD**, so many people were unaware that their symptoms represented an illness that could be treated.
- **Lack of proper training** by some health professionals often leads to the wrong diagnosis. Some patients with OCD symptoms will see several doctors and spend several years in treatment before receiving a correct diagnosis.
- **Difficulty finding local therapists** who can effectively treat OCD.
- **Not being able to afford** proper treatment.

How effective are treatments for OCD?

The best treatment for most people with OCD should include one or more of the following four things: A CBT intervention called Exposure and Response Prevention (see page 8), a properly trained therapist (see page 9), medicine (see pages 10-12), and family support and education (see pages 14-15).

Most studies show that, on average, about 70% of patients with OCD will benefit from either medicine or cognitive behavior therapy (CBT). Patients who respond to medicine usually show a 40 to 60% reduction in OCD symptoms, while those who respond to CBT often report a 60 to 80% reduction in OCD symptoms.

However, medicines have to be taken on a regular basis and patients must actively participate in CBT for the treatments to work. Unfortunately, studies show that at least 25% of OCD patients refuse CBT, and as many as half of OCD patients discontinue medicines due to side effects or for other reasons.

1 National Institute of Mental Health

2 Ruscio AM, Stein DJ, Chiu WT, Kessler RC. "The epidemiology of obsessive-compulsive disorder in the National Comorbidity Survey Replication." *Molecular Psychiatry*. 2008 Aug 26.

3 March, J. & Benton, C. (2007). *Talking Back to OCD*. (pp.10-11). The Guilford Press.

What is Exposure and Response Prevention (ERP) Therapy?

Traditional psychotherapy (or talk therapy) attempts to improve a psychological condition by helping the patient develop “insight” into their problems. Although this traditional approach to psychotherapy may be of benefit at some point in a person’s recovery, it is important that people with OCD try cognitive behavior therapy (CBT) first, as this is the type of treatment that has been shown to be the most effective.

CBT is actually made up of a large group of therapy strategies. The most important strategy in CBT for OCD is called “Exposure and Response Prevention” (ERP). “Exposure” refers to confronting the thoughts, images, objects and situations that make you anxious. At first glance, this doesn’t sound right. You have probably confronted these things many times only to feel anxious over and over again. It is important to keep in mind that you have to do the second part of the treatment as well – Response Prevention. Once you have come in contact with the things that make you anxious, you make a choice to not do the compulsive behavior. Again, this might not seem correct to you. You may have tried many times to stop compulsive behavior only to see your anxiety skyrocket. The last point is key – you have to continue to make the commitment to not give in and do the compulsive behavior **until you notice a drop in your anxiety**. In fact, it is best if you stay committed to not doing the compulsive behavior at all. The drop in your anxiety that happens when you stay “exposed” and “prevent” the compulsive “response” is called **habituation**. This might be a new idea for someone with OCD – that your anxiety will start to decrease if you stay in contact with the things you fear and don’t do the compulsive behavior.

Another Way to Think about ERP

If you begin to think of anxiety as information, what information is it giving you when it’s present? That you are in danger – or more accurately, that you might be in danger. “Might be” in danger is important to consider here. The experience of anxiety does not feel like a “might”, it feels like a truth: “I am in danger”. This is one of the most cruel aspects of this disorder. It has taken over your alarm system, a system that is there to protect you. When you are facing an actual danger, like crossing a street and seeing a truck speeding toward you, your brain puts out information that you are in danger by making you feel anxious. The anxiety creates motivation to do something to protect yourself. The behaviors you do to protect yourself can actually save your life (getting out of the way of the oncoming truck!). Unfortunately, in OCD your brain tells you that you are in danger a lot! Even in situations where you “know” that there is a very small likelihood that something bad might happen. Now consider your compulsive behaviors as your attempts to keep yourself safe when you “might be” in danger. What are you telling your brain when you try to protect yourself: that you must be in danger. In other words, your compulsive behavior fuels that part of your brain that gives out to many unwarranted danger signals. In order to reduce your anxiety and your obsessions, you have to stop the compulsive behavior. What do you have to risk by not protecting yourself? It feels like you are choosing to put yourself in danger. Exposure and Response Prevention alters your OCD and alters your brain because you actually find out whether you were in real danger or not.

What to Look for in a Therapist*

For a list of therapists who treat OCD, please visit our website: www.ocfoundation.org

Some therapists are better at treating OCD than others. It is important to interview therapists to find out if they know how to do Exposure and Response Prevention (ERP) therapy well. Their responses to your questions are a good guide to what you want to know about a new therapist. If he or she is guarded, withholds information, or becomes angry at your requests for information, you should probably look elsewhere. If the therapist appreciates how important a decision this is for you and is open, friendly, and knowledgeable, you may have a gem of a therapist! Your relationship with the therapist is important, especially since they will be asking you to do things that you find uncomfortable. **Remember:** You have a perfect right to ask questions. This is your life and health!

What Should I Ask?

The following checklist can help guide your search for the right therapist.

- “What techniques do you use to treat OCD?”**
Note: If the therapist is vague about or does not mention cognitive behavior therapy (CBT) or Exposure and Response Prevention (ERP), use caution.
- “Do you use Exposure and Response Prevention (ERP) to treat OCD?”**
Note: Be cautious of therapists who say they use CBT, but won't be more specific.
- “What is your training and background in treating OCD?”**
Note: Listen for therapists who say that they went to a CBT psychology graduate program or did a post-doctoral fellowship in CBT. If therapists say they are a member of the International OCD Foundation (OCDF) or the Association for Behavioral and Cognitive Therapies (ABCT) this is also a good sign. Also listen for therapists who say that they have attended specialized workshops or trainings offered through the OCDF or ABCT.
- “How much of your practice currently involves anxiety disorders?”**
- “How much of your practice currently involves working with individuals with OCD?”**
- “Do you feel that you have been effective in your treatment with individuals with OCD?”**
- “What is your attitude toward medicine in the treatment of OCD?”**
Note: If they are negative about medicine, this is a bad sign as medicine is an effective treatment for OCD.
- “Are you willing to leave your office if needed to do behavior therapy?”**
Note: It is sometimes necessary to go out of the office to do effective Exposure and Response Prevention (ERP).

* Adapted from: *“How To Choose a Behavior Therapist”* by Michael Jenike, MD

OCD Medicine

Michael A. Jenike, MD

Professor of Psychiatry, Harvard Medical School;

Chairman, International OCD Foundation Scientific Advisory Board

Which medicines help OCD?

Most drugs that help OCD are known as antidepressants. Eight of these drugs worked well in studies:

- fluvoxamine (Luvox®)
- sertraline (Zoloft®)
- citalopram (Celexa®)
- escitalopram (Lexapro®)
- fluoxetine (Prozac®)
- paroxetine (Paxil®)
- clomipramine (Anafranil®)
- venlafaxine (Effexor®)

Have these drugs been tested?

Anafranil has been around the longest and is the best studied. There is growing evidence that the other drugs are also effective. In addition to these carefully studied drugs, there are hundreds of case reports of other drugs being helpful. For example, **duloxetine (Cymbalta)** has been reported to help OCD patients who have not responded to these other medicines. It seems that for most people, high doses of these drugs are required to work. The studies done to date suggest that the following doses may be needed:

- Luvox (up to 300 mg/day)
- Zoloft (up to 200 mg/day)
- Celexa (up to 80 mg/day)
- Lexapro (up to 40 mg/day)
- Prozac (40-80 mg/day)
- Paxil (40-60 mg/day)
- Anafranil (up to 250 mg/day)
- Effexor (up to 375 mg/day)

How do these medicines work?

It remains unclear why these particular drugs help OCD. We do know that each of these medicines affect a chemical in the brain called serotonin. Serotonin is used by the brain as a messenger. If your brain does not have enough serotonin, your brain isn't working quite right. Adding these medicines to your system can help boost your serotonin and get your brain back on track.

Are there side effects?

Each of these drugs has side effects. Most patients have one or more side effects. The patient and doctor must weigh the benefits of the drug against the side effects. It is important for the patient to be open about problems that may be caused by the medicine. Sometimes an adjustment in dose or switch in the time of day that the medicine is taken is all that is required.

Who should not take these medicines?

- **Women who are pregnant or are breastfeeding.** If severe OCD cannot be controlled any other way, these medicines seem to be safe. Many pregnant women have taken them without difficulty. Some OCD patients use exposure and response prevention to minimize medicine use during the first or last trimester of pregnancy.
- **Very elderly patients** should avoid Anafranil as the first drug tried since it has side effects that can interfere with thinking and can cause or worsen confusion.
- **Patients with heart problems** should use special caution if taking Anafranil.



Should I take these medicines only when I am feeling stressed?

No. This is a common mistake. These medicines are meant to be taken daily. They are not taken like typical anti-anxiety medicine (when you feel upset or anxious). It is best not to miss doses if possible, but sometimes missed doses are prescribed by your doctor to help manage side effects.

What if I feel as if I've failed because I need a medicine to help me?

A way to think about the use of medicines for OCD is to compare your illness with a medical disorder like diabetes. OCD is a brain disorder and a medical illness. Just as a diabetic needs insulin to live a normal life, some OCD patients need medicine to function normally.

How long does it take for these medicines to work?

It is important not to give up on a medicine until you have been taking it as prescribed for 10 to 12 weeks. Many patients feel no positive effects for the first few weeks of treatment but then improve greatly.

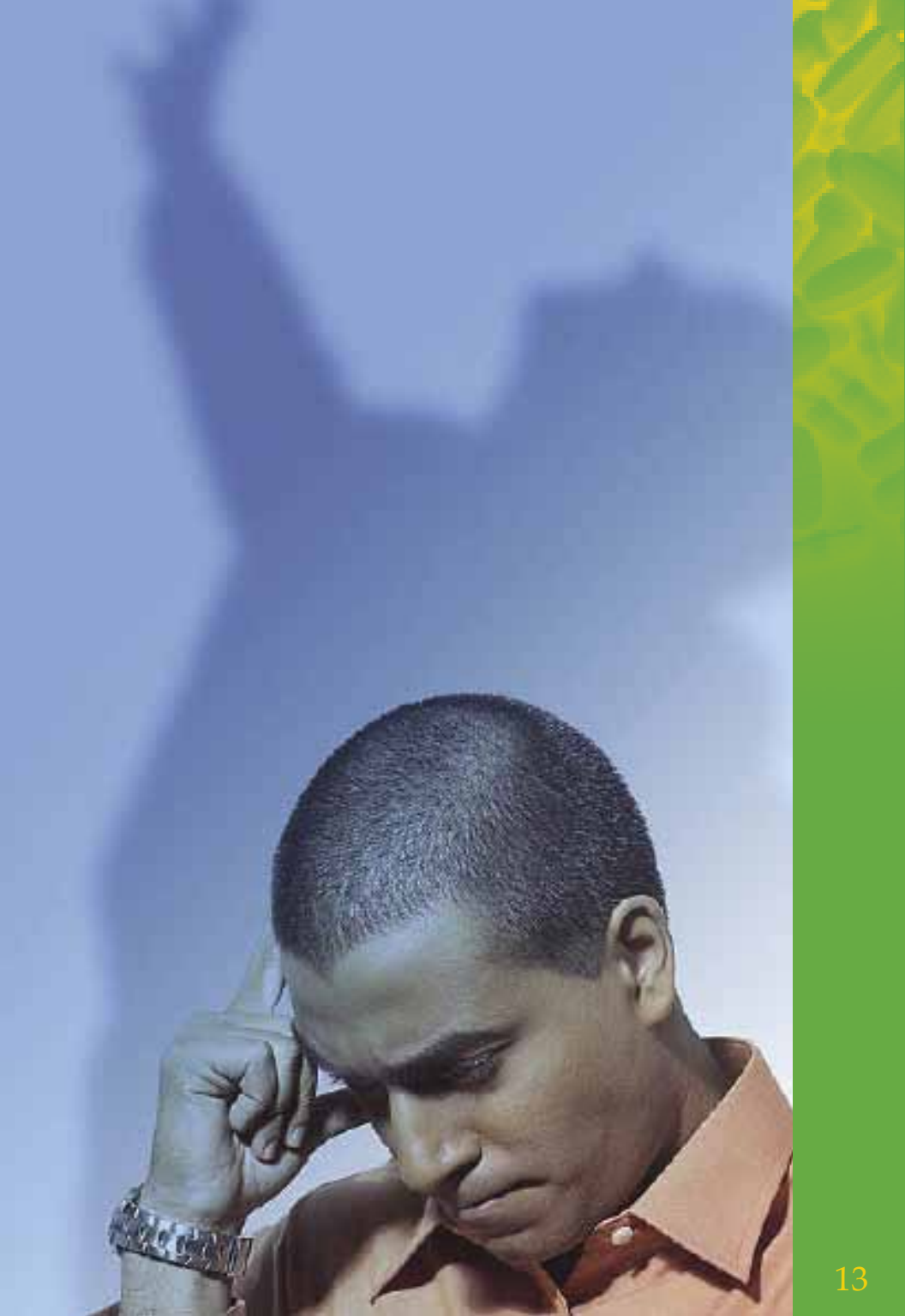
The main problem with solely using medicines to treat OCD is that you may not even know if the medicine is helping if you are not doing CBT. Some people have a noticeable response to medicine without CBT/ERP, but most patients can be better and not even know it if their OCD has become a habit or a way of life. One way of looking at it is that the medicine may help correct the chemical or neurological problem in the brain, but you need behavior therapy to help correct the behaviors that have become ingrained in your lifestyle. Therefore, I usually recommend that all OCD patients get CBT/ERP, and most patients use a combination of CBT/ERP and medicines. This maximizes the chances for a good response. Most OCD experts that see a lot of patients would agree with this approach.

Do I need other treatments in addition to medicines?

Most psychiatrists and OCD therapists believe that combining behavior therapy, consisting of exposure and response prevention, and medicine is the most effective approach.

How can I get these medicines if I cannot afford them?

Drug companies give doctors free samples of some medicines. Doctors give these samples to patients who cannot afford the cost of the medicines. Most drug companies also have programs that help patients get these and other medicines free or at a reduced cost. For more information, visit: www.pparx.org or call 1-888-477-2669.



If a family member has been told they have OCD you have surely asked: "What can I do to help?" Here are some steps you can take:

1. Learn about OCD

Education is the first step. The more you learn, the more you will be able to help the person with OCD. You can:

- Read books on OCD
- Join the International OCD Foundation
- Attend OCD support groups
- Research online

2. Learn to recognize and reduce "Family Accommodation Behaviors"

Family Accommodation Behaviors are things families do that enable OCD symptoms. Families are constantly affected by the demands of OCD. Research shows that how a family responds to the OCD may help fuel OCD symptoms. The more that family members can learn about their responses to OCD and the impact they have on the person with OCD, the more the family becomes empowered to make a difference! Here are some examples of these problematic behaviors:

- **Participating in the behavior:** You participate in your family member's OCD behavior along with them. *Example:* washing your hands whenever they wash their hands.
- **Assisting in avoiding:** You help your family member avoid things that upset them. *Example:* doing their laundry for them so that it is cleaned the "right" way.
- **Helping with the behavior:** You do things for your family member that lets them do OCD behaviors. *Example:* buying large amounts of cleaning products for them.
- **Making changes in Family Routine:** *Example:* you change the time of day that you shower, or when you change your clothes.



- **Taking on extra responsibilities:** *Example:* going out of your way to drive them places when they could otherwise drive themselves.
- **Making changes in leisure activities:** *Example:* your family member gets you to not leave the house without them. This affects your interests in movies, dinners out, time with friends, etc.
- **Making changes at your job:** *Example:* you cut back on hours at your job in order to take care of your family member.

3. Help your family member find the right treatment

The best treatment usually includes medicine, cognitive behavior therapy, and family education and support.

4. Learn how to respond if your family member refuses treatment

- **Bring books, video tapes, and/or audio tapes on OCD into the house.** Offer the information to your family member with OCD or leave it around (strategically) so they can read/listen to it on their own.
- **Offer encouragement.** Tell the person that through proper treatment most people have a significant decrease in symptoms. Tell them there is help and there are others with the same problems. Suggest that the person with OCD attend support groups with or without you, talk to an OCD buddy through online support groups, or speak to a professional in a local OCD clinic.
- **Get support and help yourself.** Seek professional advice/support from someone that knows OCD and talk to other family members so you can share your feelings of anger, sadness, guilt, shame, and isolation.
- **Attend a support group.** Discuss how other families handle the symptoms and get feedback about how you can deal with your family member's OCD. To find a list of support groups in your area, visit www.ocfoundation.org



What Is Life Like For Children and Teens Who Have OCD?

S. Evelyn Stewart, MD
Assistant Professor, Harvard Medical School; International OCD Foundation Scientific Advisory Board

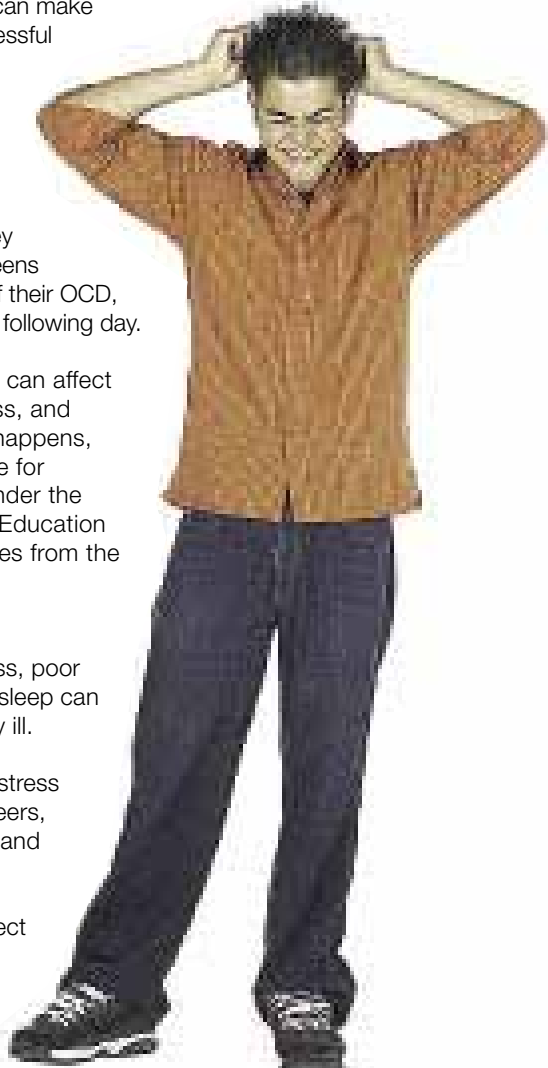
At least 1 in 200 children and teens in the United States have OCD. Understanding the special impact that the disorder has on their lives is important in helping them get the right treatment. Some common issues of OCD in children and teens follow:

Disrupted Routines: OCD can make daily life very difficult and stressful for kids and teens. In the morning, they feel they must do their rituals right, or the rest of the day will not go well. In the evenings, they must finish all of their compulsive rituals before they go to bed. Some kids and teens even stay up late because of their OCD, and are often exhausted the following day.

Problems at School: OCD can affect homework, attention in class, and school attendance. If this happens, you need to be an advocate for your child. It is your right under the Individuals with Disabilities Education Act (IDEA) to ask for changes from the school that will help your child succeed.

Physical Complaints: Stress, poor nutrition, and/or the loss of sleep can make children feel physically ill.

Social Relationships: The stress of hiding their rituals from peers, time spent with obsessions and compulsions, and how their friends react to their OCD-related behaviors can all affect friendships.



Problems with Self Esteem:

Kids and teens worry that they are “crazy” because their thinking is different than their friends and family. Their self-esteem can be negatively affected because the OCD has led to embarrassment or has made them feel “bizarre” or “out of control.”

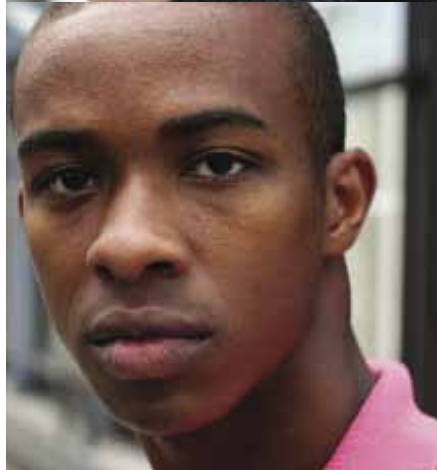
Anger Management Problems:

This is because the parents have become unwilling (or are unable!) to comply with the child’s OCD-related demands. Even when parents set reasonable limits, kids and teens with OCD can become anxious and angry.

Additional Mental Health

Problems: Kids and teens with OCD are more likely to have additional mental health problems than those who do not have the disorder.

Sometimes these other disorders can be treated with the same medicine prescribed to treat the OCD. Depression, additional anxiety disorders, and Trichotillomania may improve when a child takes anti-OCD medicine. On the other hand, Attention-Deficit Hyperactivity Disorder, tic disorders, and disruptive behavior disorders usually require additional treatments, including medicines that are not specific to OCD.



Treatment of OCD in Children and Teenagers

S. Evelyn Stewart, M.D.

*Assistant Professor of Psychiatry, Harvard Medical School
International OCD Foundation Scientific Advisory Board*

Aureen Pinto Wagner, Ph.D.

*Clinical Associate Professor of Neurology, University of Rochester
International OCD Foundation Scientific Advisory Board*

Cognitive-Behavioral Therapy

Experts agree that cognitive-behavioral therapy (CBT) is the treatment of choice for youngsters with OCD. Working with a trained CBT therapist, children and adolescents with OCD learn that they are in charge, not OCD. Using a CBT strategy called exposure and response prevention (ERP), youngsters can learn to do the opposite of what the OCD tells them to do, by facing their fears gradually in small steps (exposure), without giving in to the rituals (response prevention). ERP helps them find out that their fears don't come true, and that they can habituate or get used to the scary feeling, just like they might get used to cold water in the swimming pool. For example, a teenager who repeatedly touches things in his room to prevent bad luck will learn to leave his room without touching anything. He might feel very scared to do this at first, but after some time, the anxiety goes away as he gets used to it. He also finds out that nothing bad happens.

At first, ERP may sound scary to many children and teenagers, and they may not be ready to try it. It is important to find a CBT therapist who is experienced in working with children with OCD, and who can carefully get them ready for ERP by making it child-friendly. When youngsters understand how exposure and habituation work, they may be more willing to tolerate the initial anxiety experienced during ERP, because they know it will increase and then subside. Parents need to be involved in their child's treatment as well, under the therapist's guidance.

When Should Medicine be Considered for Children with OCD?

Both CBT and medicine effectively treat OCD in children and adolescents. Their use is supported by the treatment guidelines of the American Psychiatric Association (APA) and the American Academy of Child and Adolescent Psychiatry (AACAP). Medicines should only be considered when there are moderate to severe OCD symptoms.

What Kinds of Medicines Help OCD in Children?

Antidepressants are usually the first kind of medicine that a doctor will try. Your doctor might refer to these medicines as "Selective Serotonin-Reuptake Inhibitors" (SSRI's) or "Tricyclics" (TCA's):

Selective Serotonin-Reuptake Inhibitors (SSRI's):

- citalopram (Celexa[®])
- escitalopram (Lexapro[®])
- fluvoxamine (Luvox[®])
- fluoxetine (Prozac[®])
- paroxetine (Paxil[®])
- sertraline (Zoloft[®])

Tricyclic Antidepressant (TCA):

- clomipramine (Anafranil[®])

Will Medicine 'Cure' my Child's OCD?

OCD medicines control and decrease symptoms, but do not "cure" the disorder. OCD is usually well controlled when proper treatment is in place. Symptoms often return when the child stops taking the medicine.

How Long Does It Take for OCD Medicines to Work?

All OCD medicines work slowly. It is important to not give up on a medicine until it has been taken at the right dose for 10 to 12 weeks. Studies have also shown that improvement of childhood OCD can continue for at least a year after starting medicine.

Are These Medicines Approved for Use in Children?

Only four OCD medicines have been approved by the FDA for use in children: clomipramine (Anafranil[®]), fluoxetine (Prozac[®]), fluvoxamine (Luvox[®]) and sertraline (Zoloft[®]), but doctors can prescribe any OCD medicines to children if they feel it is needed.

What Dose is Needed?

The best dose of OCD medicine should be determined on an individual basis. Children should start at a lower dose than adolescents. But OCD symptoms often require the use of higher, adult-sized doses.



(continued on page 20)

If the child has difficulty swallowing pills, a liquid or other version may be available. The following dose ranges may be necessary:

- fluvoxamine (Luvox[®]): 50-300 mg/day
- fluoxetine (Prozac[®]): 10-80 mg/day
- sertraline (Zoloft[®]): 50-200 mg/day
- paroxetine (Paxil[®]): 10-60 mg/day
- citalopram (Celexa[®]): 10-60 mg/day
- escitalopram (Lexapro[®]): 10-20 mg/day
- clomipramine (Anafranil[®]): 50-200 mg/day

Which OCD Medicine Should Be Tried First?

A child's response to each of the OCD medicines varies. No two children respond in the same way. In general, clomipramine (Anafranil[®]) is usually not given first because of its side effects.

Factors that may guide the medicine choice include:

- positive response to a certain drug by other family members
- presence of other disorders
- potential for side effects
- cost or availability



How Helpful Are These Medicines?

In the largest child OCD treatment study to date (POTS)¹, remission (absence of any major symptoms) occurred in about 1 in 5 children on medicine and in more than half of those with medicine and cognitive behavior therapy (CBT). In addition, many more children had improvement (but not full remission). Some patients will have no response at all, which does not mean that other medicines will not help.

Are There Side Effects?

Every type of drug has potential side effects, which must always be weighed against its benefits. In general, the other

¹ The Pediatric OCD Treatment Study (POTS) Team. "Cognitive-Behavior Therapy, Sertraline, and Their Combination for Children and Adolescents with Obsessive-Compulsive Disorder: The Pediatric OCD Treatment Study (POTS) Randomized Controlled Trial." JAMA. 2004;292(16):1969-1976

drugs are safer than clomipramine (Anafranil®). Some common side effects include:

- nausea
- inability to sit still
- sleepiness or insomnia
- a heightened sense of energy

Clomipramine (Anafranil®) may also cause:

- drowsiness
- dry mouth
- racing heart
- concentration problems
- problems with urination
- weight gain

For all antidepressants in children and adolescents, the FDA has issued “black box warnings” about associated suicidal thoughts and urges. The highest risk period for this is when starting or increasing the dose of the medicine. However, a recent study found no increase in suicidal thoughts or behavior from pediatric OCD groups studied.

Are There Permanent Side Effects?

These drugs appear very safe with long-term use and side effects reverse when they are stopped. There is no current evidence that they do permanent damage to the body.

What Happens if the First OCD Medicine Doesn't Work?

It is important to understand that if the first medicine does not improve OCD, another one should be tried. Trying several OCD medicines may be needed. Many people have better results if CBT is added to drug treatment. If a drug and CBT don't work, combining more than one medicine may be tried.

Will My Child Have To Take These Medicines Forever?

Many doctors suggest that OCD treatment should continue for at least one year even after symptoms have stopped. Unfortunately, OCD drugs do not ‘cure’ the illness. When medicine is stopped, symptoms often return within a few weeks to months. If they return, most patients will respond well after restarting the medicine.



Other Resources for Finding Treatment Providers and Information

American Psychiatric Association

Phone: (888) 357-7924

Email: apa@psych.org

Website: www.psych.org

American Psychological Association

Phone: (800) 374-2721

Website: www.apa.org

Americans With Disabilities Act

U.S. Department of Justice

Phone: (800) 514-0301

Website: www.ada.gov

Anxiety Disorders Association of America

Phone: (240) 485-1001

Email: information@adaa.org

Website: www.adaa.org

Anxiety Disorders Foundation

Phone: (262) 567-6600

Email: info@anxietydisordersfoundation.org

Website: www.anxietydisordersfoundation.org

Association for Behavioral and Cognitive Therapies

Phone: (212) 647-1890

Website: www.abct.org

Bazelon Center for Mental Health Law

Phone: (202) 467-5730

Website: <http://www.bazelon.org>

Cover the Uninsured

Phone: (877) 655-CTUW

Email: info@covertheuninsured.org

Website: <http://covertheuninsured.org>

Individuals with Disabilities Education Act (IDEA)

Phone: (202) 884-8215

Website: <http://idea.ed.gov>

National Alliance on Mental Illness

Phone: (800) 950-NAMI

Website: <http://www.nami.org>

National Institute of Mental Health

Phone: (866) 615-6464

Website: www.nimh.nih.gov

National Mental Health Information Center

Phone: (800) 789-2647

Website: <http://mentalhealth.samhsa.gov>

National Suicide Prevention Lifeline

Phone: (800) 273-8255

Website: www.suicidepreventionlifeline.org

Needy Meds

Website: www.needy meds.org/genericlist.taf

Obsessive Compulsive Anonymous World Services (OCA)

Phone: (516) 741-4901

Email: west24th@aol.com

Website: obsessivecompulsiveanonymous.org

Obsessive Compulsive Information Center (OCIC)

Phone: (608) 827-2470

Email: mim@miminc.org

Website: www.miminc.org/aboutocic.asp

Partnership for Prescription Assistance

Phone: (888) 477-2669

Website: www.pparx.org

Peace of Mind

Phone: (281) 541-6255

Website: www.peaceofmind.com

Trichotillomania Learning Center (TLC)

Phone: (831) 457-1004

Email: info@trich.org

Website: <http://www.trich.org>

Yahoo OCD Support Groups (Online)

Website: health.groups.yahoo.com/group/OCDSupportGroups/links

About the International OCD Foundation

Founded by a group of people with OCD in 1986 as the Obsessive Compulsive Foundation (OCF), the International OCD Foundation is a not-for-profit organization made up of people with OCD and related disorders, as well as their families, friends, professionals and others.

The mission and goals of the International OCD Foundation are to:

- Educate the public and professionals about OCD in order to raise awareness and improve the quality of treatment provided.
- Support research into the causes of, and effective treatments for, OCD and related disorders.
- Improve access to resources for those with OCD and their families.
- Advocate and lobby for the OCD community.

Join the International OCD Foundation today!

As a member of the International OCD Foundation you will be joining a community of individuals with OCD and related disorders, their families, friends, mental health professionals and other concerned individuals.

As a member of the International OCD Foundation, you will be providing vital support to our efforts in education, assistance, and advocacy for the public and professional communities about OCD and related disorders.

Contact Us

Office: International OCD Foundation, Inc.
112 Water Street, Suite 501
Boston, MA 02109

Mailing Address: International OCD Foundation, Inc.
P.O. Box 961029
Boston, MA 02196

Voice: (617) 973-5801

E-mail: info@ocfoundation.org

Website: www.ocfoundation.org

This brochure was made possible by funding from anonymous donors.



International OCD Foundation

P.O. Box 961029
Boston, MA 02196
Tel: (617) 973-5801 • Fax: (617) 973-5803
e-mail: info@ocfoundation.org • www.ocfoundation.org