



HOW to HELP your child

A Parent's Guide to OCD

○ Obsessive Compulsive Foundation
of Metropolitan Chicago



If your child has Obsessive Compulsive Disorder:

- You are not alone.
- You and your child are not at fault.
- The right kind of treatment can help your son or daughter.

DOES YOUR CHILD HAVE:

- *Persistent, disturbing worries, doubts, or fears?*
- *Unreasonable, repetitive religious rituals?*
- *Uncontrollable, inappropriate thoughts or mental images?*
- *Habits or patterns of behavior that interfere with daily life?*
- *A tendency to ask repeatedly for reassurance?*
- *A need to do things “just right?”*
- *Problems with frequent lateness or slowness?*
- *Repetitive urges to wash, organize or check?*
- *Urges to hoard useless objects?*
- *A tendency to avoid certain places or activities?*

Your child may have *Obsessive Compulsive Disorder (OCD)*, a common and treatable medical condition that affects more than one million children in the United States alone. Thanks to enormous advances in scientific research, effective treatment is now available for OCD.

If you are the parent of a child with OCD, you may feel alarmed and confused. Your child’s behavior does not make sense, and you might not know how to respond or where to turn for help. The torment of this disorder can disrupt the pleasures of childhood, interfere with family life and friendships, and cause problems at school.

You are not to blame for your child’s OCD, and neither is your child. Obsessive Compulsive Disorder is a medical condition, like asthma or allergies. Scientists believe that a difference in the way the brain processes certain chemicals leads to obsessions and compulsions.

For many years, Obsessive Compulsive Disorder was considered rare and untreatable. Research has revealed that OCD is a common neurobiological illness that affects men, women, and children of all races, religions, and socioeconomic backgrounds. Fortunately, effective treatment is now available through a form of cognitive behavior therapy that works by training the brain to respond differently to obsessions.

Children with this disorder are suffering and need effective treatment to cope. There is no reason to feel ashamed to seek help. Proper diagnosis and treatment can teach your child to regain control and manage the disorder. OCD is an enemy you and your child can learn to defeat together.

As a parent, you are in a powerful position to help your child by:

- understanding OCD
- finding the right therapist to provide treatment
- learning how to recognize and respond to symptoms at home

You may also need to help teachers understand how OCD affects your child at school. Proper treatment can give your child the skills needed to manage the disorder both at home and in the classroom.

Because OCD can be treated, you and your child can look forward to the future with optimism and hope. With proper treatment, your child can learn to manage the symptoms and return to the childhood pleasures of fun, learning, and friendship.





EVEN THOUGH MOVIES and television shows sometimes treat OCD as a joke, it's very serious to the people who have to live with it every day and to their family members. Once considered a rare disorder, doctors have learned that OCD affects millions of people around the world.

- Approximately five million to six million Americans have OCD – that's between 2 percent and 3 percent of the population.
- If OCD affects only two other family members, that means some 21 million people in the United States are touched by the disorder.
- OCD strikes about one in 50 adults and about one in 100 school-aged children.
- OCD is the fourth most common psychiatric diagnosis, after phobias, substance abuse and major depression.
- OCD ranks among the 10 leading causes of disability worldwide, according to one international study.



What is OCD?

Approximately one out of 100 children develops Obsessive Compulsive Disorder. When a child has OCD, a difference in the way his or her brain processes information results in uncontrollable worries and doubts called “obsessions.” The child then performs “compulsions” – repetitive rituals or habits – in an effort to decrease the anxiety caused by the obsessions. But the decrease is only temporary, because performing the compulsions reinforces and strengthens the obsessions, creating a worsening cycle of OCD behavior.

OCD is diagnosed when obsessions and compulsions are time-consuming, cause significant distress, and interfere with daily functioning in school, social activities, family relationships, or normal routines.

Obsessive Compulsive Disorder is more common than juvenile diabetes, but it can be difficult to diagnose. Kids tend to hide their symptoms out of confusion and embarrassment. Many parents and teachers do not recognize signs of the disorder.

Because scientific knowledge about OCD is based on recent discoveries, many doctors have not been trained to diagnose this disorder. Even some mental health professionals are still not aware of the effective treatments that are now available.

The availability of appropriate treatment has dramatically improved the outlook for children with OCD. Children can gain control of their symptoms and learn strategies to manage recurrences.





Common Obsessions and Compulsions

- FEAR of CONTAMINATION or GERMS *Washing/ cleaning*
- FEAR of HARM or DANGER *Checking*
- FEAR of LOSING SOMETHING VALUABLE *Hoarding*
- FEAR of VIOLATING RELIGIOUS RULES *Preoccupation with religious observances*
- NEED for SYMMETRY *“Evening up” or arranging*
- NEED for PERFECTION *Seeking reassurance or doing things
“just right”*

Symptoms

Children with OCD suffer from obsessions and compulsions that distress them significantly enough to interfere with daily functioning and relationships.

OBSSESSIONS are persistent fears or doubts and upsetting thoughts or images that a child cannot ignore or dismiss.

COMPULSIONS are repetitive actions or rituals intended to relieve the anxiety caused by the obsessions. The relief is temporary, however, because performing compulsions ultimately reinforces the obsessions. Some compulsions are physical, such as washing, checking, tapping, or walking in a certain pattern. Others are mental, such as silent counting or compulsive praying.

Sometimes obsessions and compulsions appear related. For example, a child with an obsessive fear of intruders may check door locks repeatedly. A child with an obsessive fear of disease may wash excessively.

Other obsessions and compulsions are linked only in the child's mind. A child with OCD may fear that harm will come to her family unless she taps in a particular pattern or avoids using certain numbers.

Parents may not be aware of the full extent of a child's symptoms because many of them occur in the mind and others are easily hidden or disguised. A mom or dad may notice that the child avoids certain things, seems distracted, inattentive or irritable, repeatedly seeks reassurance or confesses minor transgressions, or cannot tolerate uncertainty. A cognitive behavior therapist can help determine whether these behaviors are caused by OCD.

OCD symptoms tend to wax and wane and sometimes change from one form of the disorder to another. For example, symptoms might shift from washing to checking. A child's symptoms may improve for a time and then worsen. Sometimes there is no obvious reason for the change, and at other times a trigger can be identified.

Proper treatment teaches the child to identify OCD when it changes form and provides skills for coping with new symptoms. From time to time, booster or refresher treatment sessions can reinforce the child's coping skills and teach him or her to manage any new OCD symptoms.

Diagnosis

No laboratory test can identify OCD, but a mental health professional who is knowledgeable about the disorder can conduct a specific type of interview to determine whether a person has OCD. Most professionals use the Yale-Brown Obsessive Compulsive Scale (Y-BOCS) to diagnose OCD—there are two versions, one for adults and one for children.

Children with OCD frequently struggle with other mental health problems, such as clinical depression, Tourette’s Syndrome, ADD/ADHD, or another of the anxiety disorders (panic disorder, generalized anxiety disorder, etc.). Your child’s behavior therapist will help determine which behaviors are symptoms of OCD and help you understand treatment options that may be available for related disorders.



Causes

Scientists understand that Obsessive Compulsive Disorder is a neurobiological illness, caused by an imbalance in certain brain chemicals. Although the precise cause is not fully understood, the disorder appears to be at least partly genetic and, in some cases, may be activated by a strep infection.

OCD is not caused by a parenting style, nor is it a sign of misbehavior or lack of self control. Stress does not cause OCD, although a stressful event or life change can trigger its onset. Some common examples include:

- death of a loved one
- birth of a sibling
- divorce
- transition to a new school year
- move to a new house or new community
- vacation time
- other illness

OCD is a neurobiological illness, caused by an imbalance in certain brain chemicals.

Like most illnesses, the disorder is sensitive to stress, and a stressful event may worsen symptoms or lower a child's ability to cope.

The age of onset for children can be as young as three years old when there is a strong family history of OCD. More commonly, symptoms begin at around 10 years of age. Boys tend to develop OCD between the ages of seven and 12, while girls more frequently develop symptoms in adolescence.

When a child has OCD, the area of the brain that filters information tends to malfunction, causing the child to focus on thoughts that normally are easily dismissed or ignored. Abnormalities in a brain chemical called serotonin may be at the root of the disorder. The medications that have proven most effective in treating OCD affect the serotonin systems.

Scientists believe some children are genetically predisposed to develop Obsessive Compulsive Disorder. Approximately 20 percent of all kids with OCD have a family member with the disorder.

Some studies suggest that a strep infection may trigger the sudden onset of symptoms in children who are genetically predisposed to the disorder. PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections) is a term that refers to pediatric OCD and/or tic disorders that are thought to be caused by strep antibodies that attack specific parts of the brain. Keep in mind that the vast majority of strep infections do not lead to obsessions and compulsions, and most childhood OCD is not related to infections.



Treatment Works

Effective treatment for OCD is available through:

- a special kind of psychotherapy known as “exposure and response prevention” (ERP), or
- a combination of ERP and antidepressant medication that affects levels of the neurotransmitter serotonin

Some children can learn to manage their OCD with ERP therapy alone. However, many experts believe that the most successful form of treatment is a combination of ERP and medication. Often, medication can be used on a temporary basis to ease OCD symptoms enough for the child to succeed with ERP.

Exposure and Response Prevention Therapy

ERP, which is a form of cognitive behavior therapy, is the only form of psychotherapy proven effective in treating Obsessive Compulsive Disorder. It is recommended by nationally recognized institutions such as the National Institutes of Mental Health, Mayo Clinic, and Harvard Medical School. Some studies show that more than 80 percent of the people who complete a course of ERP therapy experience a significant reduction in OCD symptoms.

Exposure and response prevention puts participants in situations that expose them to their obsessions and simultaneously prevents them from performing the compulsions they use to ease the accompanying anxiety. Although ERP therapy deliberately induces anxiety, it does so in a controlled and gradual way for the purpose of getting better.

For example, a child with contamination obsessions might be asked to touch a doorknob – this act is called an “exposure” because it exposes her to her fear of germs and creates anxiety. The response prevention part of the therapy then keeps her from washing her hands, which is the compulsion she feels driven to perform to ease the anxiety.

It's important to find a mental health professional who has experience in treating children using ERP therapy.

The result is that anxiety levels get higher temporarily, peak, and then subside. This process is repeated for longer periods of time and followed by increasingly challenging exposures.

Effective ERP leads to “habituation.” When participants repeat the same act over and over again and see that nothing bad happens, they build up a tolerance and their anxiety levels go down dramatically. For some, their anxiety actually disappears.

While ERP does not work for everyone, most people gain significant – even dramatic – relief from their OCD symptoms. Proper diagnosis and prompt, appropriate treatment significantly improve your child’s chances of learning to manage the disorder and return to a happy and productive childhood.

Not all therapists are trained and experienced in conducting ERP with children. It is important to find a cognitive behavior therapist who is trained and has experience treating children using ERP. A clinician who practices ERP is usually a psychologist with a Ph.D., Psy.D., M.A., or M.S. degree, or a specially trained social worker. Be sure the therapist is willing to conduct treatment outside the office, if necessary.

Preparing for ERP

After scheduling an appointment with an experienced cognitive behavior therapist, prepare for your visit by taking notes about your child’s behavior and your questions and concerns. Familiarize yourself with OCD by referring to the materials listed at the end of this publication. You can also help prepare your child for treatment by using the books listed for children of various ages.

Your child's success in learning to manage symptoms depends on obtaining the appropriate kind of therapy.

ERP is not traditional “talk therapy.” It works by using exercises and other active techniques that teach the child to respond differently to obsessive urges and thought patterns.

OCD does not respond to forms of therapy that explore issues of self-esteem, peer pressure, family dynamics, or early childhood junctures such as toilet training in the belief that working on these issues will help a child's OCD. Although talk therapy is not an effective treatment for OCD, it can be helpful for other matters, such as family issues and peer relationship problems.

Most children in ERP therapy meet with their therapist once a week, although more frequent meetings may be appropriate in severe cases that require intensive treatment. A typical course of ERP takes 10 to 15 weeks. Changes in your child's symptoms may not be apparent for several weeks, and significant changes can take 10 weeks to occur. If no significant change is apparent after 10 or 15 weeks, discuss the treatment plan with your child's therapist.

An inpatient treatment center may be an option in extremely severe cases or when no outpatient ERP is available.

Much information exists on the Internet and in books and articles, but not all of it is accurate and reliable. Avoid deceptive advertising and be wary of miracle treatments and cures.

Learning about OCD will prepare you to take an active role in your child's treatment. Your child's therapist will develop “homework” for your child and help you understand how to deal with symptoms at home.

A parent's commitment and dedication are crucial to a successful outcome. Parents whose children have gone through ERP often wish they had understood the disorder and obtained help sooner.

Providing a child with treatment requires a family's time and effort. Many parents find it helpful to simplify their lives and clear their schedules for a time while their child is in therapy. Recognize that treatment is hard work for your child. Be prepared to support him or her by following the therapist's instructions at home.

Medication

ERP is the first line of treatment for OCD in children. Many children can learn to manage the disorder with ERP therapy alone. However, if a child's symptoms are severe and debilitating, or if therapy does not provide sufficient relief, antidepressant drugs that selectively affect the neurotransmitter serotonin may ease symptoms enough for the child to succeed in ERP therapy.

Your child's therapist can refer you to a psychiatrist who can prescribe medication. Not all psychiatrists have experience treating childhood OCD, so be sure to confirm that the psychiatrist you choose has experience prescribing OCD medications for children. Treatment may involve gradual dose increases, contending with possible side effects, and using a combination of medications to achieve the best results.

OCD medication must be taken daily for a number of weeks before its effectiveness can be evaluated, and it must never be stopped abruptly.

Support

Other parents whose children have completed treatment can be a valuable source of information and support. Meeting other kids with OCD can make a world of difference to your child by helping him or her realize that the disorder is common and treatable.

Support groups and self-help groups may be available in your area. The Internet also has groups, message boards, and web sites devoted to OCD. Caution is necessary when using the web, as not every idea or treatment found online will be safe, effective, or scientifically tested.





OCD and the Family

When a child has Obsessive Compulsive Disorder, the symptoms can impact the entire family and present parenting challenges for which most moms and dads are unprepared. Siblings may feel confused, guilty, sympathetic, and resentful all at once. Parents often experience feelings of frustration, guilt, and dismay as their child's obsessions and compulsions fail to respond to reason, common sense, or traditional parenting skills.

Your child's therapist can work separately with you and your family to teach you how to respond to your child's symptoms in a helpful way. The therapist will teach family members to disentangle themselves gradually from the child's OCD, especially if they have been helping with compulsions and rituals. Accommodating symptoms strengthens the disorder, not your child. Successful treatment may require you to rethink the way you respond to OCD.

The parent is a crucial member of a child's ERP therapy team. The therapist will help you understand how to:

- recognize OCD behaviors
- talk to your child about OCD
- help your child by gradually changing your response to his or her obsessions and compulsions
- model behavior goals for your child
- support your child, not the OCD

*Accommodating
symptoms
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*Recommended
Reading*

For Parents

**Freeing Your Child from
Obsessive-Compulsive
Disorder: A Powerful,
Practical Program for
Parents of Children and
Adolescents**
by Tamar E. Chansky, Ph.D.

**What to Do When Your
Child Has Obsessive-
Compulsive Disorder:
Strategies and Solutions**
by Aureen Pinto Wagner, Ph.D.

**Helping Your Child
with OCD: A Workbook for
Parents and Children with
Obsessive-Compulsive
Disorders**
by Lee Fitzgibbons, Ph.D. and
Cherry Pedrick, RN

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

**Obsessive-Compulsive
Disorder: New Help
for the Family – Second
Edition 2005**
by Herbert L. Gravitz, Ph.D.

For Children

**A Thought Is Just A
Thought: A Story of
Living with OCD**
by Leslie Talley

**Mr. Worry:
A Story About OCD**
by Holly L. Niner

**Up and Down the Worry Hill:
A Children's Book About
Obsessive-Compulsive
Disorder and Its Treatment**
by Aureen Pinto Wagner, Ph.D.

For Teens

Kissing Doorknobs
by Terry Spencer Hesser

Not As Crazy As I Seem
by George Harrar

OCD at School

Obtaining appropriate treatment for your child's OCD can be essential for success in the classroom. Left untreated, OCD can have a devastating impact on a child's education.

Time-consuming rituals can interfere with homework and sleep. Obsessions and compulsions can increase absenteeism and tardiness. A child distracted by obsessive fears often appears inattentive. Symptoms that occur at school can result in incomplete homework and social problems. Some kids with OCD are isolated or teased. Most children with the disorder have average to above-average IQs, but many struggle to succeed in school because of their symptoms.

If symptoms are interfering with your child's education, then an educational intervention should be part of your child's treatment. Providing the school with information about the disorder can help teachers understand your child's needs so they can support your child and make any necessary adjustments. An ERP therapist can help you decide how to tell your child's teachers about OCD. Educators who understand the disorder can help build your child's social skills and self-esteem and restore his or her dignity and confidence in the classroom.

Educational consultants who specialize in accommodations for OCD and related disorders can help parents work with schools so that their child can succeed academically while learning to manage the disorder in the classroom. It is your right under the Individuals with Disabilities Education Act (IDEA) to request appropriate modifications in your child's educational environment related to OCD symptoms. These accommodations may only need to be temporary while your child is learning to manage his or her OCD.



Frequently Asked Questions

My child's obsessions are severe, and it would be traumatic for her not to do her compulsions. Would ERP be painful and difficult for her?

Your child's therapist will ask your child to rank her obsessions and compulsions in order from the mildest to the most severe. Starting slowly with the easiest symptoms, the therapist will design small challenges that will teach your child to delay compulsions briefly, then for increasingly longer periods of time.

ERP is hard work, and it can be difficult for parents to see their children struggle to reach a goal. But the rewards and benefits of successful ERP are enormous.

Living with untreated OCD is vastly more painful than any discomfort associated with ERP. Early intervention helps prevent your child from missing out on important developmental milestones and activities.

Untreated OCD can worsen as a child gets older. Some adults with OCD have such severe symptoms that they are unable to work or live on their own. Committing to treatment as a top priority can give your son or daughter skills to manage the disorder for life.

I work full-time and my son is in school, but it's hard to schedule ERP appointments in the evenings or on weekends. Do we have to miss school and work for treatment?

Parents often need to miss work to get medical care for a child. Your employer's human resources department might be able to help you schedule absences for appointments.

Untreated OCD can interfere significantly with a child's education, so it makes sense for him to miss school from time to time for his therapy appointments. ERP therapy will give him the skills he needs to manage his symptoms at school and at home.

Is ERP expensive?

Like many of the things we do to help our kids succeed in the world – for example, braces and prescription eyeglasses – ERP therapy requires a financial commitment as well as our time. But the benefit of ERP therapy to a child with OCD can be priceless; it can give your child the skills to manage the disorder for life. Ask your child’s therapist about fees, and check with your health insurance plan to see if therapy is a covered benefit.

What about alternative and natural remedies?


No alternative remedies have been proven effective for OCD. It is important to check with your child’s doctor before using herbal supplements, since some herbs can interfere with prescription medications.

My daughter has been seeing a therapist whom she really likes, but her therapist is not a cognitive behavior therapist and does not practice ERP. Should we change to a new treatment provider?

ERP is the only therapy that can reduce the symptoms of OCD. If your daughter benefits from her current therapist in other ways she may wish to continue these visits. But to reduce OCD symptoms, she will need ERP.

Why can’t we just use medicine to treat our child’s OCD?

ERP therapy is the treatment of choice for Obsessive Compulsive Disorder and should be tried before medication is considered. It is possible that your child can manage OCD with therapy alone. Medication can partially relieve symptoms, but it cannot teach your child to manage the disorder. For some children, a combination of ERP therapy and medication is the most effective treatment. Some children require medication for a short time to ease OCD symptoms enough for them to succeed in ERP therapy.



While parents may assume that medication will work more rapidly than therapy, research shows that it can take as long as 16 weeks to see a benefit from OCD medication. With intensive ERP therapy, however, children may notice a reduction in symptoms in as little as a few weeks.

If your child's therapist believes that your child needs medication to succeed in therapy, he or she can refer you to a qualified doctor for a prescription.

Do we really need to see a therapist? Can't we just do ERP at home?

Only a trained and experienced cognitive behavior therapist can provide ERP for a child with OCD. Parents have an important role in the process; in fact, their participation is crucial. But parents cannot undertake the role of therapist for their child.

What if ERP doesn't work for my child?

While ERP works for most people with OCD, some do experience treatment resistance. If your child does not show significant improvement after completing a full course of ERP therapy, ask your child's therapist for suggestions and options. You can also seek a second opinion from another qualified ERP therapist. In severe cases, treatment may need to be provided in an intensive format, such as daily therapy sessions or in a residential setting.

My son's OCD seems pretty mild. Do all cases require treatment?

Very mild or "subclinical" OCD symptoms do not always require treatment. However, it is possible that the full extent of your son's symptoms are not apparent to you, either because they're mental compulsions, or because he has learned to hide or disguise certain obsessive compulsive behaviors. Your child's therapist can work with you and your son to determine whether your child's OCD is subclinical.

Obsessive Compulsive Disorder is a medical problem that requires treatment by a qualified treatment provider. *A Parent's Guide to OCD* is not intended to provide, or to take the place of, medical care. Please consult a cognitive behavior therapist trained and experienced in treating OCD in children or a qualified child psychiatrist to obtain treatment for pediatric OCD.

How OCF Chicago Can Help

The Obsessive Compulsive Foundation of Metropolitan Chicago (OCF Chicago) serves adults and children with OCD, their families, and the mental health professionals who treat them. It is the only Chicago area organization dedicated solely to OCD.

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

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

- up-to-date information about OCD
- books, articles, events, and links to other web sites
- personal stories by people with OCD and their families
- a self-screening test for OCD
- a list of support groups in the Chicagoland area

For a list of treatment providers in metropolitan Chicago, call OCF Chicago at 773.880.1635. For information about treatment providers outside the Chicago area, visit the national Obsessive Compulsive Foundation's web site at www.ocfoundation.org, or call their office in New Haven, CT, at 203.401.2070.



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