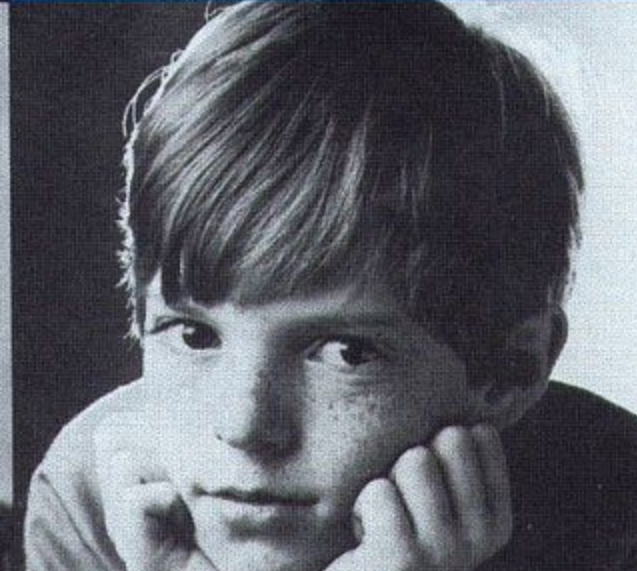


Understanding
O*bsessive*
C*ompulsive*
D*isorder*



At one time or another, perhaps you've thought your kids were a little "obsessed" with an idea or activity.

Maybe your teenage son wants to be a rock star and spends hours practicing his guitar. Or your 10-year-old daughter takes forever to shower and dress.

But what if your child's behavior is causing problems? What if your son washes his hands dozens of times a day? Or if your daughter is so convinced she has a dreaded disease that she can't concentrate in school? You may wonder if other kids act this way.

If your child has obsessive compulsive disorder (OCD) the answer is, "Yes, many other children act this way." This brochure will address some of your concerns and help you better understand OCD.

**"You get worried, so you have to do all this stuff."
— child with OCD**

These thoughts and actions are so time-consuming and extreme that they can virtually take control of the lives of people with OCD and their families. OCD can leave a child too exhausted to play with friends or concentrate in school.

If your child has OCD, he or she is not alone. OCD, which is a type of anxiety disorder, is more prevalent than many other better-known childhood ailments, such as juvenile diabetes. Of the approximately five million Americans—that's one in every 50 people—who have OCD, about one million are children and adolescents.

On average, OCD first occurs at nine or ten years of age. Some children develop symptoms as early as age three, and half of all adults with OCD had symptoms by age 15. During childhood and adolescence, OCD is more likely to affect boys than girls.

What Is Obsessive Compulsive Disorder (OCD)?

**"It's all just so time consuming. I have wasted so much time on this."
—child with OCD**

A Biological Brain Disorder

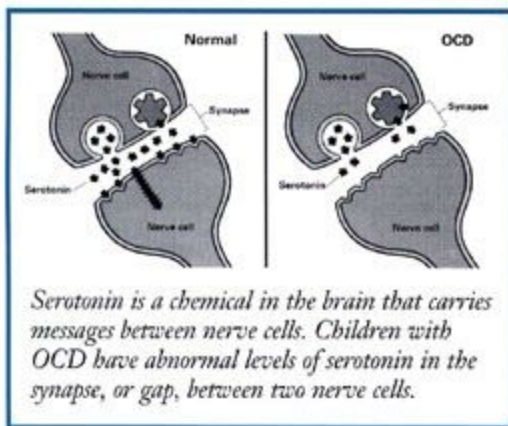
**"It was such a relief to know. I thought I was really insane, or that something was really wrong with me."
—child with OCD**

In the medical world, "obsessions" and "compulsions" have much more precise meanings than they do in everyday life. OCD gets its name because people who have it suffer from constant, unpleasant, uncontrollable obsessions that cause overwhelming anxiety. This causes them to repeatedly act out compulsions, ritualistic behaviors that have no purpose other than to ease the anxiety.

For example, one child with OCD may become convinced that if she doesn't repeatedly count to a certain number, bad luck will come to her. Another child cannot relax unless his toys are organized in a certain way.

If your child does have OCD, the diagnosis comes at a time of great progress in our understanding of this disorder. Researchers are making great strides in determining the causes of OCD.

Experts have found that OCD is linked to abnormal levels in the brain of a natural chemical called serotonin. Serotonin is a neurotransmitter, which means its job is to send brain signals from one nerve cell to the next. Experts believe serotonin helps control repetitive behaviors. Therefore, medications that impact the amount of serotonin in the brain may be effective in treating OCD.



Although no gene has yet been identified, the brain disorder that causes OCD runs in families. In fact, 20 percent of all youngsters with OCD have a family member with the disorder. Some experts believe that it's the serotonin imbalance, not the disorder itself, that's inherited.

And while stress does not cause OCD, a stressful event like the death of a loved one, the birth of a child, or a divorce can trigger its onset.

Remember that OCD, like diabetes and asthma, is caused by biological factors. And, fortunately, most people with OCD benefit from treatment.

**Is It
OCD
or
Just
a Habit?**

"He would tell me: 'Mom, I have to walk past this place time and time again, and I don't know why.'" —parent of son with OCD

Because obsessions and compulsions can be confused with typical childlike behaviors, it's essential to distinguish between ordinary behavior and OCD. Elaborate childhood

rituals—at bedtime, for instance—are perfectly normal and expected. In fact, any change in routine can upset a small child. Older children can be very strict about rules and games, and teenagers may seem obsessed with their hobbies. Even adults may feel compelled to double-check whether the door is locked, or to "knock on wood" to ensure good luck.

Common Obsessions in Children and Adolescents

- Fear of contamination or serious illness
- Fixation on lucky or unlucky numbers
- Fear of intruders
- Need for symmetry or exactness
- Excessive doubt

Common Compulsions in Children and Adolescents

- Cleaning/Washing (handwashing, showering)
- Counting/Repeating (counting objects, counting to a certain number)
- Touching (walls, tables)
- Arranging/Organizing (putting items in a particular order)
- Checking/Questioning (lights, appliances, doors, homework, repeating questions)
- Collecting/Hoarding (old objects, mail, trash)

Obsessions and compulsions are considered a true disorder only when the thoughts or behaviors are so severe, distressing or time-consuming that they interfere with everyday life and relationships.

The following chart illustrates some general differences between ordinary behavior and OCD. It is not a diagnostic tool. Only an eval-

uation by a qualified health professional can diagnose OCD.

OCD can be a difficult disease to recognize because older children and teens may be so embarrassed that they go to great lengths to keep their symptoms a secret, insisting that nothing's wrong. So it's not unusual for parents to be unaware that their child has OCD. Sometimes families simply adapt to



their children's behavior.

Unlike older children and adults with OCD, preschoolers may be too young to realize that their thoughts and actions are irrational. They may simply refer to what they do as "silly" or "necessary" or not mention it at

all, and parents may assume it's just a passing phase.

Despite the hidden nature of this disorder, experts have found that certain common obsessions and compulsions are experienced by many children and teenagers with the disorder, although symptoms may change over time.

Although children experience many of the same obsessions and compulsions as adults, they often express their disorder in special ways. For example, they frequently involve family members in their rituals, such as insisting that laundry be washed multiple times, demanding that homework be checked repeatedly, and expressing outrage if household items are in disarray. At school, a child with OCD may keep re-reading textbook passages or may repeatedly write and erase test answers until, ultimately, grades suffer.

What's OCD		What's Not
<i>A teenager who has to lather and rinse an exact number of times while showering.</i>	Cleaning/Washing	<i>A teenager who spends 15 minutes washing and styling her hair every morning.</i>
<i>A child who repeatedly checks that the light switch is in the off position, even though it's obvious the light is off.</i>	Checking/Questioning	<i>A child who double-checks that the light is off as she leaves the room, just as her parents asked her to do.</i>
<i>A boy who collects used matches as protection against his house burning down.</i>	Collecting/Hoarding	<i>A boy who collects pennants of all his favorite sports teams.</i>
<i>A girl who can't stop skipping over cracks in the sidewalk until she has done it a certain number of times, for fear that her mother will be harmed if she doesn't.</i>	Counting/Repeating	<i>A girl who laughs with friends while skipping over sidewalk cracks reciting, "Step on a crack, break your mother's back."</i>
<i>A boy who cannot leave home unless he has tied his shoe-laces with loops that are exactly the same size.</i>	Arranging/Organizing	<i>A boy who enjoys arranging groceries on store shelves as his first part-time job.</i>

Diagnosing OCD

"It's embarrassing.
You don't want people
to think you are some
kind of weirdo."
— teenager with OCD

Fortunately, doctors have specific criteria for diagnosing OCD in children and adolescents. A doctor probably will begin by taking an extensive history of your child's behavior and development. The more background information (examples and patterns of obsessions and rituals) you give your child's doctor, the easier it will be for him or her to make a diagnosis. Because there is no way to biologically test for OCD, the doctor will make a diagnosis based on your information and an in-depth evaluation of your child.

One of the many tools at your doctor's disposal when evaluating OCD is a lengthy questionnaire called the Children's Yale-Brown Obsessive Compulsive Scale. This instrument measures the presence and degree of the symptoms and how much a youngster tries to resist them. Other assessment tools include the Children's Leyton

The Children's Yale-Brown Obsessive Compulsive Scale is considered one of the best instruments for measuring OCD symptoms. It rates the severity of both obsessions and compulsions in five ways:

1. Amount of time occupied daily by symptoms
2. Degree symptoms interfere with school and friends
3. Level of distress caused by symptoms
4. Effort needed to resist symptoms
5. Degree of control over the symptoms

Choosing a Doctor

Your child's OCD is not your fault. However, as a parent, getting medical help for your child is your responsibility. The following steps should help you through the process:

Find a competent health care provider

One of the professionals most qualified to treat a child with OCD is a *child and adolescent psychiatrist*. This specialist is best able to evaluate all aspects of a child's development and behavior, to make a diagnosis and to recommend treatment. A psychiatrist can provide behavioral therapy and prescribe medication.

Get a referral

Ask your child's pediatrician or family physician, teacher, principal or school guidance counselor, or a trusted friend or relative for names of child and adolescent psychiatrists in your area. You can also check with the organizations listed under "Resources" at the end of this brochure.

Talk to the doctor yourself first

Interview the doctor before bringing your child in, so that you are comfortable with his or her skills and demeanor. Explain that you suspect your child has OCD and that you would like to know more about his or her experience treating this disorder.

Stay involved

Always remember that treating a child with OCD will require close ongoing collaboration between you and your child's psychiatrist or healthcare provider.

Obsessional Inventory, the Anxiety Disorders Interview for Children, the Clinical Global Impairment Scale, and the National Institute of Mental Health Global Obsessive Compulsive Scale.



Because it's not uncommon for a child with other psychiatric conditions to exhibit symptoms of OCD, or for a child with OCD to have more than one disorder, the doctor must determine whether other related disorders are affecting your child.

It's important to realize that due to a child's young age or to the shame and secrecy associated with the disorder, interviewing a child with OCD will present special challenges for the doctor. It's often a slow process. But once a child starts talking about his or her OCD, there is usually an outpouring of relief.

Treating OCD

"When my psychologist told me that other people had it, too, I couldn't believe it!"
— parent of child with OCD

Although OCD is a chronic condition for which there is no cure, with proper treatment it can be controlled so that children with the disorder can lead productive, happy lives. The preferred treatments for OCD are drug therapy, behavior therapy, or a combination of both.

Drug Therapy: Talk to your child's psychiatrist about the medication most appropriate for your son or daughter.

The most effective medications for treating OCD are those that help raise the level of serotonin in the brain. Currently there are only two such drugs that have been cleared by the U.S. Food and Drug Administration (FDA) for treating OCD in children: LUVOX® (fluvoxamine maleate) Tablets, a selective serotonin reuptake inhibitor (SSRI), and Anafranil® (clomipramine hydrochloride), a tricyclic antidepressant.

LUVOX® Tablets is the first SSRI cleared by the FDA for treating OCD in children as well as adults.

In a study of children being treated with LUVOX® Tablets, symptoms began to decrease after only one week, with the most improvement at eight weeks. LUVOX® Tablets also was well-tolerated; only three children taking fluvoxamine dropped out of the study due to adverse effects, none of which were considered serious. Most commonly observed side effects include agitation, hyperkinesia (increased muscle function), depression, dysmenorrhea (painful menstruation), flatulence and rash.

Decreased appetite and weight loss have been observed with the use of fluvoxamine as well as with other SSRIs. Regular monitoring of weight and growth is recommended.

If a drug fails to help completely, or symptoms recur, consult your physician for further guidance. Experts often recommend waiting at least eight weeks before changing or adding medications.

If your child refuses to take medication, your doctor can offer suggestions. Always encourage your child to tell you about any side effects he or she may experience, and





report those side effects to the doctor.

Behavior Therapy:

Most experts agree that behavior therapy is an effective treatment for OCD. Behavior therapy will teach

your child how to break the connection between his or her fears and the resulting compulsive behavior. Through a process called exposure and response prevention, your child is gradually exposed to situations that cause anxiety, and is encouraged not to perform anxiety-reducing rituals. For instance, the therapist asks a child who has obsessions about handwashing to play with finger paints for an hour without washing his or her hands. Because most people can't remain anxious for more than 45 minutes, the child eventually realizes that nothing bad will happen and becomes less anxious. With repeated therapy, the child learns to take stock of the obsessive feeling and separate it from the compulsion to perform a ritual.

It's essential that you be involved in the behavior therapy process. This not only ensures that behavioral techniques are carried through at home, but helps you establish control and feel more confident. If your child refuses to be involved in the therapy process, let your doctor know immediately.

Many doctors agree that behavior therapy in combination with medication can be especially effective. Before beginning any treatment, it's important for you to understand the chronic nature of OCD and that symptoms tend to come and go. The sooner the disorder is treated, the better the results are likely to be. Treatment for OCD is a commitment, but it does work.

Raising a Child with OCD

"The school knows. The teachers have given my child a lot of support."
—parent of child with OCD

Being a parent of a child with OCD is not easy, and your child's symptoms can leave you bewildered, drained and downright frustrated. But taking a few simple steps can help make the process easier for you and other family members:

■ **Accept the problem and be realistic:** Parents who pretend there's nothing wrong or insist that stubbornness is the problem only hold their child back from a happier life. Don't expect your child to be just like everyone else, but seek medical help to relieve your child's symptoms.



■ **Learn about OCD and be prepared:** Read as much as you can on the subject and contact the organizations listed at the end of this brochure. Talk to your child's psychiatrist and become a co-therapist to your child. Common sense doesn't necessarily work; you'll need to learn new parenting techniques.

■ **Be supportive:** Once your child is old enough, discuss OCD with him or her. Listen to his or her concerns and try to keep communication clear and simple.

■ **Don't be an accomplice:** Many children with OCD involve their parents

in their rituals. Parents, eager to keep the peace, may actually make it easier for their child to act out his or her compulsions. This is referred to as "enabling." If treatment is to work, you must help your child give up the compulsive behavior. Set rules and stick to them.

■ **Work with your child's teachers:**

If the OCD symptoms are disrupting your child's school performance, map out a strategy and set priorities with his or her teacher for managing the problem. If your child's OCD is not active at school, talk to the doctor about notifying teachers. You may decide to inform them about your child's OCD treatment and how treatments can improve his or her ability to learn.

- **Be positive:** Remember that OCD is nobody's fault. Avoid feeling guilty or that your child's disorder is a personal insult. OCD is not caused by bad parenting. And try not to be critical of your child; he or she already may have a low self-image.

■ **Nurture other family relationships:**



OCD can be rough on your marriage and others in your family. If you have children without OCD, they may feel neglected or be teased by their friends. Spend quality time with these other important family members. If possible, locate a sibling

support group where they can discuss their feelings.

- **Don't isolate yourself:** Counseling and support groups can be extremely helpful to parents trying to cope with OCD.

Resources

The following organizations and resources provide information and support for families dealing with OCD and other psychiatric problems.

Organizations:

American Academy of Child and Adolescent Psychiatry

3615 Wisconsin Avenue, NW
Washington, D.C. 20016-3007
(800) 333-7636 or (202) 966-7300
<http://www.aacap.org>

Professional society and referral source for board-certified child and adolescent psychiatrists.

Anxiety Disorders Association of America (ADAA)

11900 Parklawn Drive, Suite 100
Rockville, MD 20852
(301) 231-9350

Promotes the prevention and cure of anxiety disorders, including OCD, and works to improve the lives of people who suffer from them.

Association for the Advancement of Behavior Therapy

305 Seventh Avenue
New York, NY 10001
(212) 647-1890

Organization of professionals who use behavioral therapy.

Federation of Families for Children's Mental Health

1021 Prince Street
Alexandria, VA 22314-2971
(703) 684-7710

Parent-run organization focusing on the needs of children and adolescents with emotional, behavioral or mental disorders, and the needs of their families.

Freedom From Fear

308 Seaview Avenue
Staten Island, NY 10305
(718) 351-1717

Patient advocacy group for people with anxiety disorders.

National Alliance for the Mentally Ill (NAMI)

200 North Glebe Road, Suite 1015
Arlington, VA 22203-3754
(800) 950-6264

(703) 524-7600 (for bookstore, materials)

Advocacy group dedicated to improving the lives of people with severe mental illness and the lives of their families, too.

National Institute of Mental Health (NIMH)

c/o Information Resources and Inquiries Branch
Room 7C-02
5600 Fishers Lane
Rockville, MD 20857
(301) 443-4513

Government agency that conducts and supports research on mental illness and mental health.

National Mental Health Association

1021 Prince Street
Alexandria, VA 22314-2971
(703) 684-7722

Nonprofit organization that addresses all issues related to mental health and mental illness.

National OCD Information Hotline

(800) NEWS-4-OCD (800-639-7462)

OCD Resource Center Website

<http://www.ocdresource.com>

Provided as a service from Solvay Pharmaceuticals, Inc. and Pharmacia & Upjohn, Inc.

Obsessive Compulsive Foundation

P.O. Box 70

Milford, CT 06400

(203) 879-5669

<http://pagas.prodigy.com/ahwillen/ocf.html>

Dedicated to finding a cure for OCD and improving the welfare of people with OCD. Has extensive resources related to childhood OCD.

Child Psychopharmacology Information Service

University of Wisconsin, Dept. of Outpatient Psychiatry

8001 Research Park Blvd., Rm. 1568

Madison, WI 53719-1179

(608) 263-6171

Provides information on medication treatment for children.

Obsessive Compulsive Information Center

c/o Dean Foundation

2711 Allen Boulevard

Middleton, WI 53562

(608) 827-2300

Provides physician and support group referrals as well as library research.

Books and Pamphlets:

OCD: A Guide by John Greist, M.D.

Madison, WI: OC Information Center, 1991

The Boy Who Couldn't Stop Washing

by Judith Rapoport, M.D.

New York: E. P. Dutton, 1989

Over and Over Again: Understanding Obsessive Compulsive Disorder

by Fugen Neziroglu, Ph.D. and Jose A. Yaryura-Tobias, M.D.

Lexington, MA: Lexington Books, 1991

Obsessive Compulsive Disorder in Children and Adolescents: A Guide

by Hugh Johnston, M.D.

Madison, WI: Child Psychopharmacology

Information Service, 1993

It's Nobody's Fault: New Hope and Help for Difficult Children and Their Parents

by Harold Koplewicz, M.D.

New York: Times Books, 1996

It's Not All in Your Head

by Susan Swedo and Henrietta Leonard

New York: Harper Collins, 1996

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