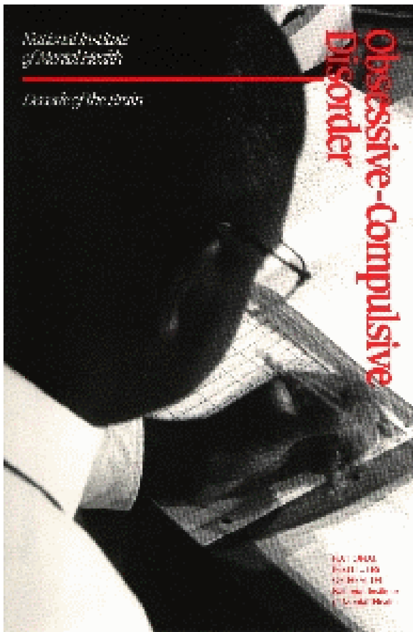
NIMH
National Institute of Mental Health

Obsessive-Compulsive Disorder



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What is OCD?

Obsessive-compulsive disorder (OCD), one of the anxiety disorders, is a potentially disabling condition that can persist throughout a person's life. The individual who suffers from OCD becomes trapped in a pattern of repetitive thoughts and behaviors that are senseless and distressing but extremely difficult to overcome. OCD occurs in a spectrum from mild to severe, but if severe and left untreated, can destroy a person's capacity to function at work, at school, or even in the home.

The case histories in this brochure are typical for those who suffer from obsessive-compulsive disorder--a disorder that can be effectively treated. However, the characters are not real.

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How Common Is OCD?

For many years, mental health professionals thought of OCD as a rare disease because only a small minority of their patients had the condition. The disorder often went unrecognized because many of those afflicted with OCD, in efforts to keep their repetitive thoughts and behaviors secret, failed to seek treatment. This led to underestimates of the number of people with the illness. However, a survey conducted in the early 1980s by the National Institute of Mental Health (NIMH)--the Federal agency that supports research nationwide on the brain, mental illnesses, and mental health--provided new knowledge about the prevalence of OCD. The NIMH survey showed that OCD affects more than 2 percent of the population, meaning that OCD is more common than such severe mental illnesses as schizophrenia, bipolar disorder, or panic disorder. OCD strikes people of all ethnic groups. Males and females are equally affected. The social and economic costs of OCD were estimated to be $8.4 billion in 1990 (DuPont et al, 1994).

Although OCD symptoms typically begin during the teenage years or early adulthood, recent research shows that some children develop the illness at earlier ages, even during the preschool years. Studies indicate that at least one-third of cases of OCD in adults began in childhood. Suffering from OCD during early stages of a child's development can cause severe problems for the child. It is important that the child receive evaluation and treatment by a knowledgeable clinician to prevent the child from missing important opportunities because of this disorder.

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Key Features of OCD

Obsessions

These are unwanted ideas or impulses that repeatedly well up in the mind of the person with OCD. Persistent fears that harm may come to self or a loved one, an unreasonable concern with becoming contaminated, or an excessive need to do things correctly or perfectly, are common. Again and again, the individual experiences a disturbing thought, such as, "My hands may be contaminated--I must wash them"; "I may have left the gas on"; or "I am going to injure my child." These thoughts are intrusive, unpleasant, and produce a high degree of anxiety. Sometimes the obsessions are of a violent or a sexual nature, or concern illness.

Compulsions

In response to their obsessions, most people with OCD resort to repetitive behaviors called compulsions. The most common of these are washing and checking. Other compulsive behaviors include counting (often while performing another compulsive action such as hand washing), repeating, hoarding, and endlessly rearranging objects in an effort to keep them in precise alignment with each other. Mental problems, such as mentally repeating phrases, listmaking, or checking are also common. These behaviors generally are intended to ward off harm to the person with OCD or others. Some people with OCD have regimented rituals while others have rituals that are complex and changing. Performing rituals may give the person with OCD some relief from anxiety, but it is only temporary.

Insight

People with OCD show a range of insight into the senselessness of their obsessions. Often, especially when they are not actually having an obsession, they can recognize that their obsessions and compulsions are unrealistic. At other times they may be unsure about their fears or even believe strongly in their validity.

Resistance

Most people with OCD struggle to banish their unwanted, obsessive thoughts and to prevent themselves from engaging in compulsive behaviors. Many are able to keep their obsessive-compulsive symptoms under control during the hours when they are at work or attending school. But over the months or years, resistance may weaken, and when this happens, OCD may become so severe that time-consuming rituals take over the sufferers' lives, making it impossible for them to continue activities outside the home.

Shame and Secrecy

OCD sufferers often attempt to hide their disorder rather than seek help. Often they are successful in concealing their obsessive-compulsive symptoms from friends and coworkers. An unfortunate consequence of this secrecy is that people with OCD usually do not receive professional help until years after the onset of their disease. By that time, they may have learned to work their lives--and family members' lives--around the rituals.

Long-lasting Symptoms

OCD tends to last for years, even decades. The symptoms may become less severe from time to time, and there may be long intervals when the symptoms are mild, but for most individuals with OCD, the symptoms are chronic.

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What Causes OCD?

The old belief that OCD was the result of life experiences has been weakened before the growing evidence that biological factors are a primary contributor to the disorder. The fact that OCD patients respond well to specific medications that affect the neurotransmitter serotonin suggests the disorder has a neurobiological basis. For that reason, OCD is no longer attributed only to attitudes a patient learned in childhood--for example, an inordinate emphasis on cleanliness, or a belief that certain thoughts are dangerous or unacceptable. Instead, the search for causes now focuses on the interaction of neurobiological factors and environmental influences, as well as cognitive processes.
OCD is sometimes accompanied by depression, eating disorders, substance abuse disorder, a personality disorder, attention deficit disorder, or another of the anxiety disorders. Co-existing disorders can make OCD more difficult both to diagnose and to treat.
In an effort to identify specific biological factors that may be important in the onset or persistence of OCD, NIMH-supported investigators have used a device called the positron emission tomography (PET) scanner to study the brains of patients with OCD. Several groups of investigators have obtained findings from PET scans suggesting that OCD patients have patterns of brain activity that differ from those of people without mental illness or with some other mental illness. **Brain-imaging studies of OCD** showing abnormal neurochemical activity in regions known to play a role in certain neurological disorders suggest that these areas may be crucial in the origins of OCD. There is also evidence that treatment with medications or behavior therapy induce changes in the brain coincident with clinical improvement.

Recent preliminary studies of the brain using magnetic resonance imaging showed that the subjects with obsessive-compulsive disorder had significantly less white matter than did normal control subjects, suggesting a widely distributed brain abnormality in OCD. Understanding the significance of this finding will be further explored by functional neuroimaging and neuropsychological studies (Jenike et al, 1996).
Symptoms of OCD are seen in association with some other neurological disorders. There is an increased rate of OCD in people with Tourette's syndrome, an illness characterized by involuntary movements and vocalizations. Investigators are currently studying the hypothesis that a genetic relationship exists between OCD and the tic disorders.
Other illnesses that may be linked to OCD are trichotillomania (the repeated urge to pull out scalp hair, eyelashes, eyebrows or other body hair), body dysmorphic disorder (excessive preoccupation with imaginary or exaggerated defects in appearance), and hypochondriasis (the

fear of having--despite medical evaluation and reassurance--a serious disease). Genetic studies of OCD and other related conditions may enable scientists to pinpoint the molecular basis of these disorders.
Other theories about the causes of OCD focus on the interaction between behavior and the environment and on beliefs and attitudes, as well as how information is processed. These behavioral and cognitive theories are not incompatible with biological explanations.

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Do I Have OCD?

(link to screening test)

A person with OCD has obsessive and compulsive behaviors that are extreme enough to interfere with everyday life. People with OCD should not be confused with a much larger group of individuals who are sometimes called "compulsive" because they hold themselves to a high standard of performance and are perfectionistic and very organized in their work and even in recreational activities. This type of "compulsiveness" often serves a valuable purpose, contributing to a person's self-esteem and success on the job. In that respect, it differs from the life-wrecking obsessions and rituals of the person with OCD.

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Treatment of OCD; Progress Through Research

Clinical and animal research sponsored by NIMH and other scientific organizations has provided information leading to both pharmacologic and behavioral treatments that can benefit the person with OCD. One patient may benefit significantly from behavior therapy, while another will benefit from pharmacotherapy. Some others may use both medication and behavior therapy. Others may begin with medication to gain control over their symptoms and then continue with behavior therapy. Which therapy to use should be decided by the individual patient in consultation with his or her therapist.

Pharmacotherapy

Clinical trials in recent years have shown that drugs that affect the neurotransmitter serotonin can significantly decrease the symptoms of OCD. The first of these serotonin reuptake inhibitors (SRIs) specifically approved for the use in the treatment of OCD was the tricyclic antidepressant clomipramine (Anafranil[R]). It was followed by other SRIs that are called "selective serotonin reuptake inhibitors" (SSRIs). Those that have been approved by the Food and Drug Administration for the treatment of OCD are flouxetine (Prozac[R]), fluvoxamine (Luvox[R]), and paroxetine (Paxil[R]). Another that has been studied in controlled clinical trials is sertraline (Zoloft[R]). Large studies have shown that more than three-quarters of patients are helped by these medications at least a little. And in more than half of patients, medications relieve symptoms of OCD by diminishing the frequency and intensity of the obsessions and compulsions. Improvement usually takes at least three weeks or longer. If a patient does not respond well to one of these medications, or has unacceptable side effects, another SRI may give a better response. For patients who are only partially responsive to these medications, research is being conducted on the use of an SRI as the primary medication and one of a variety of medications as an additional drug (an augmenter). Medications are of help in controlling the symptoms of OCD, but often, if the medication is discontinued, relapse will follow. Indeed, even after symptoms have subsided, most people will need to continue with medication indefinitely, perhaps with a lowered dosage.

Behavior Therapy

Traditional psychotherapy, aimed at helping the patient develop insight into his or her problem, is generally not helpful for OCD. However, a specific behavior therapy approach called "exposure and response prevention" is effective for many people with OCD. In this approach, the patient deliberately and voluntarily confronts the feared object or idea, either directly or by imagination. At the same time the patient is strongly encouraged to refrain from ritualizing, with support and structure provided by the therapist, and possibly by others whom the patient recruits for assistance. For example, a compulsive hand washer may be encouraged to touch an object believed to be contaminated, and then urged to avoid washing for several hours until the anxiety provoked has greatly decreased. Treatment then proceeds on a step-by-step basis, guided by the patient's ability to tolerate the anxiety and control the rituals. As treatment progresses, most patients gradually experience less anxiety from the obsessive thoughts and are able to resist the compulsive urges.
Studies of behavior therapy for OCD have found it to be a successful treatment for the majority of patients who complete it. For the treatment to be successful, it is important that the therapist be fully trained to provide this specific form of therapy. It is also helpful for the patient to be highly motivated and have a positive, determined attitude.
The positive effects of behavior therapy endure once treatment has ended. A recent compilation of outcome studies indicated that, of more than 300 OCD patients who were treated by exposure and response prevention, an average of 76 percent still showed clinically significant relief from 3 months to 6 years after treatment (Foa & Kozak, 1996). Another study has found that incorporating relapse-prevention components in the treatment program, including follow-up sessions after the intensive therapy, contributes to the maintenance of improvement (Hiss, Foa, and Kozak, 1994).
One study provides new evidence that cognitive-behavioral therapy may also prove effective for OCD. This variant of behavior therapy emphasizes changing the OCD sufferer's beliefs and thinking patterns. Additional studies are required before the promise of cognitive-behavioral therapy can be adequately evaluated. The ongoing search for causes, together with research on treatment, promises to yield even more hope for people with OCD and their families.

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How to Get Help for OCD

If you think that you have OCD, you should seek the help of a mental health professional. Family physicians, clinics, and health maintenance organizations may be able to provide treatment or make referrals to mental health centers and specialists. Also, the department of psychiatry at a major medical center or the department of psychology at a university may have specialists who are knowledgeable about the treatment of OCD and are able to provide therapy or recommend another doctor in the area.

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What the Family Can Do to Help

OCD affects not only the sufferer but the whole family. The family often has a difficult time accepting the fact that the person with OCD cannot stop the distressing behavior. Family members may show their anger and resentment, resulting in an increase in the OCD behavior. Or, to keep the peace, they may assist in the rituals or give constant reassurance.
Education about OCD is important for the family. Families can learn specific ways to encourage the person with OCD to adhere fully to behavior therapy and/or pharmacotherapy programs. Self-help books are often a good source of information. Some families seek the help of a family therapist who is trained in the field. Also, in the past few years, many families have joined one of the educational support groups that have been organized throughout the country.

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CONTINUING RESEARCH

Research into treatment for OCD is ongoing in several areas--ways of increasing availability of effective behavior therapy; cognitive therapy; relapse prevention; methods of reducing medication in patients who have a history of being unable to tolerate medication, such as small, liquid doses of flouxetine or the use of intravenous clomipramine; and neurosurgery, a new approach to treatment-refractory OCD. In the very few centers where neurosurgery has been performed as a clinical procedure, candidates are generally restricted to those who have failed to respond to conventional treatments, including behavior therapy and pharmacotherapy.
In addition to research into treatment modalities, NIMH researchers are conducting studies into possible linkage of OCD to some autoimmune diseases (diseases in which infection-fighting cells, or antibodies, turn against the body, trying to destroy it). Other NIMH-supported studies compare behavior therapy, pharmacotherapy, and a combination of both.
Anecdotal reports of the successful use of electroconvulsive therapy (ECT) in OCD have been published over the past several decades. Most often, the benefit from ECT has been short lived, and this treatment is now generally restricted to instances of treatment-resistant OCD accompanied by severe depression.

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If You Have Special Needs

Individuals with OCD are protected under the Americans with Disabilities Act (ADA). Among organizations that offer information related to the ADA are the ADA Information Line at the U.S. Department of Justice, (202) 514-0301, and the Job Accommodation Network (JAN), part of the President's Committee on the Employment of People with Disabilities in the U.S. Department of Labor. JAN is located at West Virginia University, 809 Allen Hall, P.O. Box 6122, Morgantown, WV 26506, telephone (800) 526-7234 (voice or TDD), (800) 526-4698 (in West Virginia).
The Pharmaceutical Research and Manufacturers Association publishes a directory of indigent programs for those who cannot afford medications. Physicians can request a copy of the guide by calling 800-762-4636 (800-PMA-INFO).

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For Further Information

For further information on OCD, its treatment, and how to get help, you may wish to contact the following organizations:

Anxiety Disorders Association of America
8730 Georgia Ave, Suite 600
Silver Spring, MD 20910
Phone: (240) 485-1001
Fax: (240) 485-1035
Internet: http://www.adaa.org

Makes referrals to professional members and to support groups. Has a catalog of available brochures, books, and audiovisuals.

Association for Advancement of Behavior Therapy
305 Seventh Ave.
New York, NY 10001
Telephone 212-647-1890
http://server.psyc.vt.edu/aabt/

Membership listing of mental health professionals focusing on behavior therapy.

Madison Institute of Medicine
Obsessive Compulsive Information Center
7617 Mineral Point Road, Suite 300
Madison, WI 53717-1914
Telephone: 608-827-2470
Fax: 608-827-2479
http://healthtechsys.com/mimocic.html

Computer data base of over 13,000 references updated daily. Computer searches done for nominal fee. No charge for quick reference questions. Maintains physician referral and support group lists.

Freedom From Fear
308 Seaview Ave.
Staten Island, NY 10305
Telephone: 718-351-1717
http://www.freedomfromfear.com

Offers a free newsletter on anxiety disorders and a referral list of treatment specialists.

Obsessive-Compulsive Foundation, Inc.
337 Notch Hill Road
North Branford, CT 06471
Phone: (203) 315-2190
Fax: (203) 315-2196
E-mail: info@ocfoundation.org
Internet: http://www.ocfoundation.org/

Offers free or at minimal cost brochures for individuals with the disorder and their families. In addition, videotapes and books are available. A bimonthly newsletter goes to members who pay an annual membership fee of $45.00. Has over 250 support groups nationwide. Can refer to mental health professionals and treatment facilities in your area with experience in treating OCD by mail.

Tourette Syndrome Association, Inc.
42-40 Bell Boulevard
New York, NY 11361-2874
Telephone: 800-237-0717
http://ba.mgh.harvard.edu

Publications, videotapes, and films available at minimal cost. Newsletter goes to members who pay an annual fee of $45.00.

Trichotillomania Learning Center
1215 Mission Street, Suite 2
Santa Cruz, CA 95060-3558
Telephone: 831-457-1004
E-mail: trichster@aol.com
http://www.trich.org

Membership fee of $35.00 includes information packet and bimonthly newsletter.

For information on other mental disorders, contact:

Information Resources and Inquiries Branch
National Institute of Mental Health
6001 Executive Boulevard, Rm. 8184, MSC 9663
Bethesda, MD 20892-9663
Telephone: 301-443-4513
e-mail: nimhinfo@nih.gov

Books Suggested for Further Reading

Baer L. Getting Control. Overcoming Your Obsessions and Compulsions. Boston: Little, Brown & Co., 1991.

DeSilva P and Rachman S. Obsessive-compulsive Disorder: that Facts. Oxford: Oxford University Press, 1992.

Foa EB and Wilson R. Stop Obsessing! How to Overcome Your Obsessions and Compulsions. New York: Bantam Books, 1991.

Foster CH. Polly's Magic Games: A Child's View of Obsessive-Compulsive Disorder. Ellsworth, ME: Dilligaf Publishing, 1994.

Greist JH. Obsessive Compulsive Disorder: A Guide. Madison, WI: Obsessive Compulsive Disorder Information Center. rev. ed., 1992. (Thorough discussion of pharmacotherapy and behavior therapy)

Jenike MA. Drug Treatment of OCD in Adults. Milford, CT: OC Foundation, 1996. (Answers frequently asked questions about OCD and drug treatments)

Johnston HF. Obsessive Compulsive Disorder in Children and Adolescents: A Guide. Madison, WI: Child Psychopharmacology Information Center, 1993.

Matisik EN. The Americans with Disabilities Act and the Rehabilitation Act of 1973: Reasonable Accommodation for Employees with OCD. Milford, CT: OC Foundation, 1996.

Neziroglu F. and Yaryura-Tobias JA. Over and Over Again: Understanding Obsessive-compulsive Disorder. Lexington, MA: DC Health, 1991.

Rapoport JL. The Boy Who Couldn't Stop Washing: The Experience and Treatment of Obsessive-Compulsive Disorder. New York: E.P. Dutton, 1989.

Steketee GS and White K. When Once Is Not Enough: Help for Obsessive Compulsives. Oakland, CA: New Harbinger, 1990.

VanNoppen BL, Pato MT, and Rasmussen S. Learning to Live with OCD. Milford, CT: OC Foundation, 1993.

Videotape

The Touching Tree. Jim Callner, writer/director, Awareness films. Distributed by the O.C. Foundation, Inc., Milford, CT. (about a child with OCD)

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Leonard HL, Swedo SE, Lenane MC, Rettew DC, Hamburger SD, Bartko JJ, and Rapoport JL. A 2- to 7-Year follow-up study of 54 obsessive-compulsive children and adolescents. Archives of General Psychiatry 50:429-439, 1993.

March JS, Mulle K, and Herbel B. Behavioral psychotherapy for children and adolescents with obsessive-compulsive disorder: an open trial of a new protocol-driven treatment package. Journal of the American Academy of Child and Adolescent Psychiatry 33:3:333-341, 1994.

Pato MT, Zohar-Kadouch R, Zohar J, and Murphy DL. Return of symptoms after discontinuation of clomipramine in patients with obsessive-compulsive disorder. American Journal of Psychiatry 145:1521-1525, 1988.

Swedo SE and Leonard HL. Childhood movement disorders and obsessive-compulsive disorder. Journal of Clinical Psychiatry 55:3 (suppl):32-37.

Swedo SE and Leonard HL. Excessively compulsive or obsessive-compulsive disorder? It's Not All in Your Head. New York, NY: HarperCollins, 1996.

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