

UNDERSTANDING OBSESSIVE-COMPULSIVE DISORDER

Caregiver: Get the Facts

What does it mean when a health care professional says “obsessive-compulsive disorder”?



Hearing a health care professional say your youth or young adult has obsessive-compulsive disorder (OCD) can be confusing. The good news is that the emotions and behaviors you have been concerned about are actually symptoms of a treatable disorder. By engaging in treatment and entering recovery, people with OCD can feel better and lead full, meaningful lives. Recovery does not necessarily mean a cure. It does mean that people are actively moving toward wellness.



Honestly, receiving a diagnosis was a relief. We had spent so long searching for an answer to what our son was experiencing.



—Malisa, Parent

It is important to talk with a health care provider about treatment options and additional information. Your provider may be a child and adolescent psychiatrist, general psychiatrist, psychologist, pediatrician, social worker, or other health care provider. If you are concerned that your youth or young adult may have OCD, it is important to seek a thorough evaluation. The evaluation includes talking about their symptoms, blood and urine tests, and perhaps other tests to ensure that there is no underlying medical condition that could be causing the symptoms. It is also important to ensure that he or she can tolerate medication, if recommended as part of a treatment plan.

What do we mean by recovery?

Recovery is a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.¹

Recovery focuses on wellness and resilience, encouraging [people] to participate actively in their own care.²



Substance Abuse and Mental Health Services Administration

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What is OCD?

OCD involves recurring, persistent, and unwanted thoughts (obsessions) or urges (compulsions) that cause distress or excessive worry. These obsessions and compulsions are intrusive and interfere with daily activities. Obsessions can have themes such as: fear of contamination or germs, distress when things are not orderly or symmetric, horrific thoughts involving harm to others or themselves, or unwanted thoughts regarding sex, religion, or aggression. Obsessions are typically linked with compulsions—behaviors performed as a response to the obsession—for example, repeated hand-washing in response to an obsession about germs. Youth or young adults with these compulsions may strictly adhere to rules or rituals, such as putting on clothes in a specific order, which, if not done precisely, must be repeated. These urges are far stronger than simply double-checking something (*Is the stove turned off?*). The feelings seem irresistible, and trying to avoid them can cause anxiety and distress that may significantly interfere with daily life. For many people with OCD, symptoms tend to wax and wane over time.

OCD can be an ongoing and recurrent disorder. The outcome for OCD is better than originally thought. Many children and youth will stop having symptoms over time or, with treatment, their symptoms will get better. Symptoms that continue into adulthood can be managed. Treatments that involve medications, psychotherapy, and other elements of an individualized treatment program can help your youth or young adult improve coping skills, manage symptoms, enhance daily functioning, and lead a full, meaningful life. An individualized treatment program can include positive family or peer support.



What caused this?

Researchers and health care professionals do not completely understand what causes OCD. It is unlikely that a single factor causes OCD. However, research has linked OCD to changes in the structure or function of several areas in the brain, factors in a person's environment, and personal factors such as how one copes with stressful life events. Traumatic experiences can also contribute to the development of psychiatric disorders. If your child has experienced a traumatic incident, it is critical to share that information with their mental health specialist and pediatrician.

Should I have known?

It is very difficult for parents to know if their youth or young adult is acting like a typical youth or young adult or if their behaviors are actually symptoms of OCD. Teenagers may be moody and are reluctant sometimes to talk openly about thoughts or behaviors. Perhaps you tried to ask questions, but were not able to get answers. Working with a trained health care professional is important to help assess your youth or young adult's situation and understand how to start moving forward.

What do we mean by resilience?

Resilience is the ability to respond to stress, anxiety, trauma, crisis, or disaster. It is critical in recovery [from mental disorders].³

What are the treatment approaches?

OCD can be managed in many ways, including the use of psychotherapy, or with a combination of medication and therapy. You should discuss treatment options with your youth or young adult and their health care provider, and make decisions based on individual health goals and priorities. Youth or young adults of consenting age may need to provide written consent for parents or caregivers to participate on the treatment team. Many factors influence decisions, including the severity of symptoms. They should always include your youth or young adult's preferences, health goals and ambitions. It is important to talk to your child's health care providers about other types of treatment, such as complementary medicine, as well as programs that can provide additional support related to education, employment, housing, and vocation and career development. It is also important to encourage good self-care, such as a healthy diet, exercise, sleep, and abstinence from illicit drugs. Understanding specifically how treatment works will help you to play an active role in your youth or young adult's recovery.

Medications

Medications may help to manage many of the symptoms of OCD (particularly a class of medications called selective serotonin reuptake inhibitors or SSRIs). Each person reacts differently to these medications. For that reason, the prescribing health care professional may try different doses and different kinds of medication before finding the most effective approach for your youth or young adult. To find the most effective dose may take time and patience. For some people with mild or moderate cases of OCD, the health care professional may not need to prescribe medication.

Therapy

Cognitive behavioral therapy (CBT), may be used alone (for mild or moderate conditions) or in combination with medications (for more severe symptoms or if symptoms do not improve with CBT alone). This kind of treatment also helps your youth or young adult to enhance their resilience skills and develop behaviors and routines that can protect them from experiencing frequent, severe, or prolonged symptoms. One approach is Exposure and Response Prevention. This is a technique through which an individual is exposed to the thoughts, images, objects, or situations that trigger anxiety, obsessive thoughts, and/or compulsions. The therapist will support the person in resisting these compulsions with the hope of decreasing anxiety and helping them to be better able to resist the compulsion (behavior) associated with the obsession (thought).

Support

Peer and family support are also important for people with OCD. Family members with positive attitudes, caregivers, and peers who are recovering from similar disorders can be great assets to a comprehensive treatment team. As a partner on this team, you can help to identify problems early, provide important support and encouragement to help your youth or young adult and help them stay focused on reaching their treatment goals. Additionally, talking with other caregivers who also have a child diagnosed with OCD can help you to learn more and know what to expect. You may benefit from having someone further along in the process with whom to discuss your own questions, thoughts, and feelings.



Knowledge is power!

**The more you know
you about the system
and the diagnosis,
the stronger you
will be in advocating
for your child
and their
specific needs.**

—Regina, Parent

Is this my fault?

No, it is not. Decades of medical research provide evidence that OCD and other mental health disorders can be the result of a complex interaction of genetics and biological, environmental, social, physical, and emotional influences. None of the contributing factors alone are sufficient to cause OCD. Your youth or young adult is not to blame and neither are you.



How common is this disorder?

The rate of pediatric OCD are around 1% to 2% in the United States and elsewhere. There appear to be two peak periods for OCD across the life span, one occurring in preadolescent children and a later peak in young adult life (mean age, 21 years).^{4,5}



How can I help?

Parents, caregivers, and family members can be important partners in treatment and recovery from OCD. You can play a major role by monitoring symptoms and responses to medication changes and by encouraging your youth or young adult to stick with their treatment plan. Alert your health care provider if your youth or young adult uses drugs, excessive caffeine, nicotine, or alcohol, which is frequently used in an attempt to self-medicate symptoms of OCD but may worsen the disorder. Seek help immediately if your youth or young adult has thoughts or plans of harming themselves or others (For more information, see the hotline and website below*). Consult with a health care provider about the best way for friends and family to react to any compulsive behaviors or requests by the youth or young adult for reassurance. There is significant evidence that your involvement can improve treatment outcomes. Your own self-care is also an important part of caring for a child with a mental health disorder. Self-care may include talking to your own mental health professional, friends, or family, as well as joining a local support group through the National Federation of Families for Children's Mental Health or the National Alliance on Mental Illness, exercising, getting a good night's sleep, or meditation.

* **National Suicide Prevention Lifeline: 1-800-273-LIFE (8255).** <http://www.suicidepreventionlifeline.org>

EDUCATION



TREATMENT



SUPPORT



RECOVERY
AND
RESILIENCE

Where can I learn more and get support?

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American Academy of Child and Adolescent Psychiatry

http://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/Facts_for_Families_Pages/Obsessive_Compulsive_Disorder_In_Children_And_Adolescents_60.aspx

American Academy of Pediatrics-Information for Families

<http://www.healthychildren.org/English/health-issues/conditions/emotional-problems/Pages/Obsessive-Compulsive-Disorders-in-Children.aspx>

American Academy of Pediatrics-Information for Families (English & Spanish)

<http://www.healthychildren.org/English/health-issues/conditions/emotional-problems/Pages/Obsessive-Compulsive-Disorders-in-Children.aspx>

American Psychiatric Association

<http://www.psychiatry.org/obsessive-compulsive-disorder>

American Psychological Association

<http://www.apa.org>

HelpGuide.Org

<http://www.helpguide.org/articles/anxiety/obsessive-compulsive-disorder-ocd.htm>

International OCD Foundation (IOCDF)

<http://www.iocdf.org>

Kids Health-Information for Parents

<http://kidshealth.org/parent/emotions/behavior/OCD.html>

National Alliance on Mental Illness (NAMI)

<http://www.nami.org/Learn-More/Mental-Health-Conditions/Obsessive-Compulsive-Disorder>

National Center for Complementary & Integrative Health

<https://nccih.nih.gov/health/integrative-health>

National Federation of Families for Children's Mental Health

<http://www.ffcmh.org>

National Institute of Mental Health

<http://www.nimh.nih.gov/health/topics/obsessive-compulsive-disorder-ocd/index.shtml>

National Suicide Prevention Lifeline

<http://www.suicidepreventionlifeline.org> / 1-800-273-LIFE (8255)

Ok2Talk

<http://ok2talk.org>

Substance Abuse and Mental Health Services Administration

<http://www.samhsa.gov/disorders/mental>

Substance Abuse and Mental Health Services Administration

(SAMHSA) National Helpline
<http://www.samhsa.gov/find-help/national-helpline>

The Family Run Executive Director Leadership Association

<http://www.fredla.org>

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