



# Obsessive Compulsive Disorder (OCD)

a conversation guide to help people with  
OCD receive high-quality care

**Health Quality  
Ontario**

*Let's make our health system healthier*

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Health Quality Ontario is committed to helping patients, health care providers, and organizations improve the quality of health care in Ontario.

We know that not everyone across the province receives the right care, every time.

So, to help address gaps in care, we produce quality standards, which outline **what quality care looks like** for specific conditions, such as obsessive–compulsive disorder (OCD). Quality standards are **based on current best evidence and input from patients, caregivers, and health care providers**.

[Download Health Quality Ontario’s quality standard for obsessive–compulsive disorder to read more.](#)

# The following pages contain questions to help you and your health care providers work together on a care plan for your OCD.

This patient guide is based on information from Health Quality Ontario's quality standard for obsessive-compulsive disorder. It is not meant to be a complete guide to OCD but a tool to help you talk with your health care providers about the topics that matter to you.

OCD is often associated with anxiety, but it isn't an anxiety disorder. For information about anxiety disorders, please read our patient guide on [anxiety disorders](#).

Our goal: to empower you to ask for and receive the best quality care.

# What is obsessive–compulsive disorder?

We all have habits that keep our day-to-day lives on track. Sometimes, repeated thoughts, images, or urges can take over in ways that we can't control and get in the way of our lives. You might think, "This is just how I'm wired," but when obsessions and compulsions become too much, they can have a negative effect on your relationships and other things that are important to you. This can be a sign of a mental health condition known as obsessive–compulsive disorder.

## **What's an obsession?**

With OCD, you may have obsessions: repeated thoughts, images, or urges. They can be upsetting and prompt recurring behaviour or thought processes in response.

## **What's a compulsion?**

Compulsions are specific actions or rituals meant to soothe the fear or distress surrounding the obsessions, and they can take many forms. For example, constant cleaning might ease anxious thoughts about germs. In some cases, compulsions may keep people from social situations that are related to their obsessions—such as avoiding large gatherings if they fear germs.

Most people have some obsessive thoughts or compulsions at some point. But obsessive-compulsive disorder affects only about one in 40 adults. For those with OCD, obsessions and compulsions take up a lot of time and emotional energy.

## Learn more

There's a lot of information out there about OCD, and it can be challenging to know what's reliable. The patients, caregivers, and clinicians we spoke with to put this guide together told us these are resources they find useful:

- [Obsessive–Compulsive Disorder: A Handbook for Patients and Families](#): This handbook from the Frederick W. Thompson Anxiety Disorders Centre at the Sunnybrook Health Sciences Centre is for people with OCD and related disorders, their family and friends, and for anyone else who may find it useful.
- [The International OCD Foundation \(ICODF\)](#): Information about OCD, including tools and resources for you and your family (brochures, books, multimedia, fact sheets).
- [Big White Wall](#): A safe and anonymous online peer support community that's available anytime, anywhere.
- [Youth Wellness Hubs Ontario](#): “One-stop shops” offer help for mental health and other issues for young people between 12 and 25 years old
- [ConnexOntario \(1-866-531-2600\)](#): A 24/7 information and referral service that is free and confidential for people experiencing mental illness, problems with alcohol and drugs, and/or gambling
- [Kids Help Phone \(1-800-668-6868\)](#): National service offering bilingual professional counselling, information, referrals, and support for young people by phone, live chat, and texting

Though these resources may not always say the same thing as what's in the quality standard for OCD, we hope you find them useful.

# Start talking

You might have mixed feelings about your OCD symptoms. While some people get relief from their obsessions and compulsions, not having control of your thoughts or actions can be upsetting. What's more, getting a proper diagnosis can take time, which can be frustrating, too.

Talk to your health care providers about your symptoms and how you feel. These conversations help in getting a diagnosis and treatment that is right for you.

Learning about OCD is the first step. Self-help, therapy, and/or medication can help you manage symptoms and get back to a healthy and rewarding life. A specific type of therapy, called cognitive behavioural therapy with exposure and response prevention is particularly effective.

Where should you start the conversation? The topics listed here can help to guide discussions with health care providers as you come up with the right care plan together.

- Getting assessed
- Learning about OCD
- Managing OCD
- Follow-up care and planning for the future
- Help for family and caregivers

You might not get all your answers in one visit or from one provider. **It's OK to ask lots of questions and to get advice from a range of health care providers.**

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## Write it down

It may help you to take notes as your symptoms develop and change. Having written details on hand when you talk with your care providers will help you give a more complete description of your experience.

Consider making your notes right in this electronic file, or in a printed copy, and use this guide each time you visit and review your care plan with your health care providers.

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## About you

OCD is about more than its symptoms. Tell your health care providers about yourself—your physical health, your emotional health, and anything else that’s going on that can give them some context. Any extra information can help them shape your care plan.

### Some things you might want to discuss with your health care providers:

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- Your mental and physical symptoms
- Whether you’re scared or self-conscious about talking about them
- Whether certain things at home, work, or school make your symptoms better or worse
- Whether there’s a family history of OCD or mood disorders
- Whether you have other physical or mental health concerns
- Any treatments you’ve tried in the past, and whether they worked
- If drug or alcohol use is having a negative impact on your life
- Your goals for treatment and recovery
- Who you want involved in your care (partner, friend, family member)



## **Start talking: Getting assessed**

Many people don't seek help until their OCD symptoms are severe and have a major effect on their daily lives. Try to share as many details about your symptoms with your doctor or another health care provider as you can. Building a strong relationship with your health care providers can help you get the care and support you need.

### **Some things you might want to ask your health care providers:**

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How do we figure out if I have OCD?

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Might I have other mental health conditions, too?

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What are my treatment options?

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How can I get the treatment I need?

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Will I get better?

*“There were so many things that I had assumed were just part of my personality or part of my brain. Like, I just had an overactive brain and would see horrible things happening to people. Doing the assessments was so useful ... That really opened up to me all the things that I could work on.”*

PERSON WITH OCD

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## **Start talking: Learning about OCD**

The more you know about OCD, the more you'll understand what's happening and how to manage going forward. Keep in mind that your OCD is only a small part of who you are—you're still you. With the right information, self-help resources, and support from health care providers, you can develop ways to cope and make decisions about your care.

### **Here are some things you might want to ask your health care provider:**

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What do I need to know about OCD?

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What do people who have OCD usually experience over time?

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What self-help resources, such as workbooks or websites, do you recommend?

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What should my family and caregivers know about my OCD?

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What can I can do to help myself? How can self-care help manage my OCD?

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What peer support groups are available in my area?

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## **Start talking: Managing OCD**

### **1. Cognitive behavioural therapy**

Cognitive behavioural therapy (or CBT) is a type of psychotherapy that helps you replace negative thinking patterns with positive ones.

For OCD, this type of therapy usually includes guided exercises and tasks to help you face your fears by gradually exposing you to situations that trigger anxiety, and then encouraging a different response. This approach is known as exposure and response prevention.

#### **Here are some things you might want to ask your health care provider:**

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How can CBT with exposure and response prevention help me manage my OCD?

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What does the therapy involve?

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Are there any risks?

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What do I do during the therapy?

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How often will I have appointments?

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When will I start to feel better? What should I do if I don't feel better or my symptoms are getting worse?

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Who should I see for CBT with exposure and response prevention? What kind of training do they have? How can I find a health care provider who is a good fit for me?

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Will I have to pay for treatment? How much does it cost? Are there free or low-cost options?

*“[The therapy] was presented to me kind of like fitness. Like, ‘We’re going to teach you how to exercise, and then you go forth and you exercise. And if you want to keep building skills, you keep doing these things’ ... And that was just so helpful. It’s been many years now, and taking care of my mental health has been really enjoyable ... It’s about building health instead of waiting for an illness to manage. I found that was such an effective approach.”*

**PERSON WITH OCD**

## 2. Medication

Some medications that treat depression are also used to treat OCD. For example, your doctor may prescribe an antidepressant known as a *selective serotonin reuptake inhibitor* (SSRI), which works by increasing levels of a naturally occurring chemical in the brain called serotonin.

Depending on how severe your OCD is, your doctor may advise that you take medication right away, but many people try self-help, CBT with exposure and response prevention, or other non-medication options first.

### **Here are some things you might want to ask your health care provider:**

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Why might medication be a good choice for me? What kind of medication do you recommend?

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What are the risks of this medication?

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Are there any side effects?



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When will I start to feel better? What should I do if I don't feel better or my symptoms are getting worse?

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How long should I take this medication?

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Do I need follow-up appointments?

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Are there other treatments we should consider?

## **Start talking: Follow-up care and planning for the future**

With treatment, recovery from OCD is possible, but symptoms may change over time. You may feel better for some time, only to have old symptoms return. Your treatment plan will include information and education about preventing relapses. The more you know and the more you plan, the better prepared you will be to face any challenges in the future.

### **Some questions about recovery you might want to ask your health care provider:**

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What should I expect as things get better? How can I keep progress on track?

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How often do I need to see my health care provider if I'm doing well?

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What can I do to prevent a relapse from happening? Will I have to be put on a wait-list?

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What happens if I change health care providers? How will that affect my treatment for OCD?

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# A note to family and caregivers

If someone you care about has OCD, this whole guide is for you too.

It is hard to see your loved ones in distress, and it's common for family members and friends to want to reassure someone with OCD. For example, you may have changed your own behaviour to try to help soothe your loved one's worry and repetitive actions. Accommodating a person's worries and compulsions only help in the short-term. The ways to help improve the OCD in the long-term are the strategies discussed in this guide.

Family and caregivers play an important role in helping their loved ones manage and recover from OCD. There is no one right way to respond – talk to your loved one's health care providers for guidance, and make sure you are getting care and support for your own well-being.

## **Here are some things you might want to ask their health care provider:**

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What do I need to know about OCD and common treatments?

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What can I do to help and support this person?

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I've heard that I shouldn't accommodate their OCD behaviours. What does this mean?

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What do I need to know as the parent or guardian of a child with OCD (for example, arrangements for support at school?)

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If I have more questions, which health care provider should I contact?

**Because your well-being is just as important, you might consider asking:**

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What peer support groups for family and caregivers are available to me?

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Do you know of any workshops, family therapy sessions, or other supports for family and caregivers?

*“There has to be information out there on how to help your other children, the siblings [of the person with OCD], because it’s a tremendous struggle for them as well to understand it. So, it’s not just for the parents to get information ... The family has to work as a unit to be able to help the child with OCD.”*

**PARENT OF TEENAGE SON WITH OCD**

# What's next?

## **Remember, everybody is different.**

The support you need and the care plan you land on with your health care providers will be unique to you.

## **This conversation guide is meant as only a starting point.**

You may have other topics you want to cover with your health care providers. It's important to speak to them about any questions or concerns.

## **Need more information?**

If you have any questions or feedback about this guide, please contact us at [qualitystandards@hqontario.ca](mailto:qualitystandards@hqontario.ca) or 1-866-623-6868.

For more reading on OCD, read the quality standard at:

[hqontario.ca/qualitystandards](http://hqontario.ca/qualitystandards)

# For your reference: The quality standard in brief

The quality standard for OCD is a document for health care providers that outlines what quality care looks like for this condition. It is based on the best evidence and input from clinicians, patients, and their caregivers.

Below is a summary of the quality standard. For further reading, download the full version [online](#).

## **Identification and Screening**

People with suspected OCD are identified early and screened using recognized screening questions and validated severity-rating scales.

## **What this means for you**

Your health care professional should ask you questions about your symptoms to find out whether you might have OCD. These questions aren't used on their own to diagnose OCD, but they are an important first step.



### **Comprehensive Assessment**

People with suspected OCD, or who have screened positive for OCD, receive a timely comprehensive assessment to determine whether they have OCD and the severity of their symptoms, whether they have any comorbid conditions, and whether they have any associated functional impairment.

### **What this means for you**

You should be offered an assessment to determine whether you have OCD. Your health care provider should also talk with you about how bad your symptoms are, whether you have any other conditions, and whether your OCD is making it hard for you to manage your life at home, school, or work.

### **Self-Help**

People with OCD are informed about and supported in accessing self-help resources, such as self-help books, Internet-based educational resources, and support groups, considering their individual needs and preferences.

### **What this means for you**

You should be offered education and information about OCD. You should also be connected with self-help resources so that you can learn more about OCD and its treatment.

### **Support for Family and Caregivers**

People with OCD are encouraged to involve their family and caregivers during their assessment and treatment, considering individual needs and preferences. Family and caregivers are connected to available resources and supports, and provided with psychoeducation that includes the impact of accommodation behaviours.

### **What this means for you**

Consider involving your family and caregivers in your care (it can help, but the choice is up to you). If they are involved, your family and caregivers should also be offered education, information, and support. This includes information about accommodation and reassurance.

### **Cognitive Behavioural Therapy for OCD**

People with OCD have timely access to cognitive behavioural therapy with exposure and response prevention, considering their individual needs and preferences. Cognitive behavioural therapy with exposure and response prevention is delivered by a health care professional with expertise in OCD.

### **What this means for you**

You should be offered cognitive behavioural therapy with exposure and response prevention as a treatment for your OCD, considering your needs and preferences. You should be offered this therapy with a health care professional who has expertise in treating OCD.

### **OCD-Specific Pharmacological Treatment**

People with moderate to severe OCD, or people who are not responding to psychological treatment, are offered a selective serotonin reuptake inhibitor (SSRI) at an OCD-specific dose and duration, considering their individual needs and preferences.

### **What this means for you**

If you have moderate to severe OCD, or if you are not getting better with cognitive behavioural therapy with exposure and response prevention, you should be offered a type of medication called a *selective serotonin reuptake inhibitor (SSRI)*. You should take it at a dose and for length of time that are specific for OCD.

### **Monitoring**

People with OCD have their response to treatment (effectiveness and tolerability) monitored regularly over the course of treatment using validated tools in conjunction with an assessment of the person's clinical presentation

### **What this means for you**

After you start treatment for OCD, your health care professional should follow up with you to check how you are responding to the treatment. For psychotherapy, they should check in about how the treatment is working at every session. For medications, they should check how the treatment is working every week or two when the medication is started and if the dosage changes, and at least every month until your condition is stable.

### **Support for Initial Treatment Response**

When initial psychological or pharmacological treatment is not working, people with OCD are reassessed. They are offered other treatment options, considering their individual needs and preferences and in alignment with a stepped-care approach.

### **What this means for you**

If your treatment is not working, your health care professional should ask you questions to reassess your OCD and your situation. You should then be offered another treatment option, considering your needs and preferences.

### **Intensive Treatment**

When psychological or pharmacological treatment is not working, or in cases of severe OCD, people are referred for intensive treatment, in alignment with a stepped-care approach.

### **What this means for you**

If your OCD is severe or psychological or pharmacological treatments are not working for you, your health care team should refer you for specialized intensive treatment.

### **Relapse Prevention**

People with OCD who are receiving treatment are provided with information and education about relapse prevention.

### **What this means for you**

Your health care team should give you information and education about how to prevent and manage relapse. They should talk with you about:

- The nature of OCD
- What to expect when you're in recovery and no longer in treatment
- When to follow up with your health care team
- What strategies to use to manage your symptoms
- How to access mental health services if you need more support

### **Transitions in Care**

People with OCD are given appropriate care throughout their lifespan and experience seamless transitions between services and health care professionals, including from child and adolescent services to adult services.

### **What this means for you**

When you change health care professional or type of service (for example, if you return home from being in hospital), your care team should work with you to ensure a smooth transition. The care you receive should be appropriate to your age. This includes making sure that you and any new team members have the right information, and that you receive the services you need.

For more information, please visit: [hqontario.ca](http://hqontario.ca)

ISBN TBA (Print)

ISBN TBA (PDF)

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