

# Obsessive–Compulsive Disorder (OCD)

Suggestions on what to discuss with your health care providers to help you receive high-quality care





# What is obsessive-compulsive disorder?

We all have habits that keep our day-to-day lives on track. But some people may experience repeated thoughts, images, or urges that they can't control. When these obsessions and compulsions become too much, they can have a negative effect on a person's life. This can be a sign of a mental health condition known as obsessive-compulsive disorder, or OCD.

## What's an obsession?

Obsessions are repeated thoughts, images, or urges. They can make life challenging. For example, if you're preoccupied with germs or contamination, doing simple things—like brushing your hair or putting on shoes—can be complicated. And obsessions can be upsetting. For example, you might have unwanted thoughts about sex, religion, or violence that interrupt simple conversations with friends, or your work.

## What's a compulsion?

Compulsions are specific actions or rituals meant to soothe the fear or distress surrounding an obsession. For example, you may feel the urge to count things over and over or check that the front door is locked. Or you may want constant reassurance that you haven't done something bad.

Although it may be difficult, talking with your health care providers about your concerns and symptoms can help you get effective treatment and feel better. The most common treatment options for OCD include self-help, education, cognitive behavioural therapy, or medication. Your health care providers can help you manage symptoms and get back to a healthy and rewarding life.



## Did you know?

Most people have some obsessive thoughts or compulsions at some point. But OCD affects only about one in 40 adults.

This guide can help you get ready for conversations with your health care providers. It shares what you can expect and suggests things to discuss, like:

- [Getting help or a diagnosis](#)
- [Treatment options](#)
- [Follow-up care and planning for the future](#)
- [Helpful resources](#)

The questions included in this guide are optional. You're in control, so you can choose which ones you want to ask. There may also be other questions you want to add.



## Are you in crisis? If you feel you need immediate help:

Contact your family doctor or nurse practitioner

Go to the nearest hospital or emergency room

Call 9-1-1

Call Telehealth Ontario at 1-866-797-0000

Call a helpline:

- Kids Help Phone: text CONNECT to 686868 or call 1-800-668-6868
- ConnexOntario: 1-866-531-2600
- [Ontario Distress Centres](#): Find a number for a crisis centre near you

## If you're a family member or friend:

You're an important part of the care team, and this guide can help you support your family member or friend as they manage and treat their OCD. Throughout the guide, there are questions you can ask their health care providers, too.



# Talking about: getting help or a diagnosis

Many people don't ask for help until their OCD symptoms have a serious effect on their lives. Reaching out to a health care provider, such as your family doctor or nurse practitioner, is a good first step. Try to share as many details about your symptoms as you can. Building a strong relationship with your health care provider can help you get the care and support you need.

Remember, OCD is about more than its symptoms. Tell your health care provider about yourself: your physical health, your emotional health, and anything else that can create a complete picture of your condition. For example, you can share:

- Whether you're scared or self-conscious about talking about your symptoms
- Whether certain things at home, work, or school make your symptoms better or worse
- How your OCD symptoms affect your relationship with family, co-workers, and friends
- Whether there's a family history of OCD or any mood disorders like depression or bipolar disorder
- 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

This information will help your health care provider decide if you show signs of OCD. If you do, they will do a more formal assessment (or refer you to someone who will) to confirm whether you have OCD, how severe it is, and what the next steps should be.

## Questions you can ask your health care provider:

- How do we figure out if I have OCD?
- What do I need to know about OCD? What do people with OCD usually experience over time?
- Will I get better?
- What should my family and significant others know about my OCD?

*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**



## Write it down

It can help to take notes during the visit. If it's hard to get down all the details, ask a friend or family member to take notes for you. That way, you can focus on the conversation with your health care provider and go back to the notes later.

### **If you're a family member or friend:**

You can play an important role in helping your family member or friend with OCD to manage their symptoms. Find out how you can offer support and make sure you feel supported, too. Questions you can ask the health care provider include:

- What do I need to know about this diagnosis?
- What can I do to help and support my family member or friend with OCD?
- As a parent or guardian of a child with OCD, how can I support them both at home and at school?
- Who should I contact if I have questions?
- What resources or support groups can help me as I support someone with OCD?

### **What is accommodation?**

It's common for people to reassure a friend or family member with OCD. Changing your own behaviour to soothe their worries is known as accommodation. For example, if they're concerned about germs, you might "accommodate" that worry by taking a shower as soon as you get home every day. Or, if they're distressed about intrusive thoughts, you may be constantly reassuring them by telling them everything's okay.

These actions are meant to help, but they only work in the short term. To help your friend or family member in the long term, it may be important to limit or stop accommodation behaviours. Don't stop these behaviours suddenly. Instead, talk with your friend or family member, and their health care provider, about how to work together to reduce these accommodation behaviours.

### **You can ask a health care provider:**

- Where can I learn more about accommodation behaviours and OCD?
- How can I best support my friend or family member with OCD?



# Talking about: treatment options

There are different ways to treat OCD, and your treatment plan will be designed just for you. The more you know about OCD, the more you'll understand about what's happening and how to manage going forward. 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.

Self-help, therapy, and/or medication can help you manage your symptoms and get back to a healthy and fulfilling life. A specific type of therapy, called “cognitive behavioural therapy,” or CBT, is very helpful, and should include “exposure and response prevention.” This therapy helps with addressing your repeated thoughts, images, or urges, and finding other ways to respond to them.

## Education and self-help

Learning about OCD is the first step. Your health care provider will recommend educational resources, like books, online tools, or support groups that can help you manage your symptoms as part of your treatment.

## Questions you can ask your health care provider:

- What education or self-help resources, such as workbooks or websites, can help me manage my OCD?
- What support groups are available in my area?



## Resources for self-help and peer support

- [Anxiety Canada](#): Includes self-help tools and resources to help you manage your OCD:
  - [For adults](#)
  - [For children](#)
- [Big White Wall](#): A safe and anonymous online peer support community that's available anytime, anywhere

## Cognitive behavioural therapy (CBT)

CBT teaches you to notice negative thinking patterns and learn how to replace them with more positive ones. For OCD, this type of therapy usually includes guided exercises and tasks to help you find ways to respond to situations that trigger anxiety. This approach is known as exposure and response prevention.

CBT is very helpful for treating OCD for the long term. On its own, it can be just as helpful as medication; or it can be part of a treatment plan that includes medication.

### Questions you can ask your health care provider:

- Is CBT with exposure and response prevention a good choice for me?
- Who provides 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?
- Will I have to pay for treatment? 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 [then] manage. I found that was such an effective approach.*

**PERSON WITH OCD**



## Medication

Your health care provider might prescribe medication, too. For some people, taking medication for OCD may seem like a big step, but it is an effective treatment option that can help you feel better by reducing your symptoms. A common type of medication used to treat OCD is a selective serotonin reuptake inhibitor (SSRI). SSRIs are also called “antidepressants,” but they are used to treat many different conditions, including OCD.

Depending on a few different factors, like how well you’ve responded to other treatment, how severe your OCD is, and your preferences, your doctor may advise that you take medication right away. But many people try non-medication options first, like self-help or CBT with exposure and response prevention.

If your health care provider suggests medication, they should explain the risks and benefits so that you can make an informed decision about what’s right for you.

### Questions you can ask your health care provider:

- Why might medication be a good choice for me?
- What are the side effects of this medication?
- When will I start to feel better? What should I do if I don’t feel better or my symptoms are getting worse?
- I’m feeling better; can I stop taking the medication?



# Talking about: follow-up care and planning for the future

Education, self-help, CBT, and/or medication can help you manage your OCD. As you start to feel better, your health care provider should monitor your progress to make sure the treatment is helping.

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 or new symptoms develop. Your treatment plan should let you know how to spot signs of returning symptoms before they get worse, how to manage them, and when you should reach out for support. The more you know and the more you plan, the better prepared you will be to face any challenges in the future.

## Questions you can ask your health care provider:

- What should I expect as things get better?
- What can I do to prevent my symptoms from getting unmanageable again?
- How often do I need to see my health care provider if I'm doing well?
- If symptoms return, can I get care right away, or will I be on a wait list?

## If you're a family member or friend, ask the health care provider:

- What are signs of symptoms that I can watch for?
- How can I support my family member or friend during this time?



# Additional resources

## Information

[International OCD Foundation \(ICODF\)](#): Information about OCD, including tools and resources for you and your family (brochures, books, multimedia, fact sheets).

[Obsessive–Compulsive Disorders: 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 anyone else who may find it useful.

## Navigation and referral services

[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, or gambling.

[Family Navigation Project at Sunnybrook](#): A non-profit program designed to provide expert navigation of the mental health and addictions service system for youth aged 13 to 26 and their families in the Greater Toronto Area (Durham, Halton, Peel, Toronto, and York).

## Helplines

[Good2Talk](#) (1-866-925-5454): A free, confidential, and anonymous helpline for post-secondary students in Ontario, with a primary focus on those aged 17 to 25. It provides professional counselling and information and referrals for mental health, addictions, and well-being.

[Kids Help Phone](#) (1-800-668-6868): Bilingual professional counselling, information, referrals, and support for young people by phone, live chat, or texting.

[Ontario Distress Centres](#): A free telephone helpline for people experiencing emotional distress (including suicidal thoughts), providing confidential and caring emotional support. Find a local distress centre near you.

## Youth programs

[Youth Wellness Hubs Ontario](#): “One-stop shops” to help youth aged 12 to 25 get help with a variety of needs, including their mental health.



# For your reference: the quality standard in brief

Ontario Health 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, Ontario Health, through its Quality business unit, produces quality standards that outline **what quality care looks like** for specific conditions and situations, such as OCD. Quality standards are based on current best evidence and input from patients, caregivers, and health care providers.

**This patient guide accompanies the quality standard on obsessive-compulsive disorder.**

If you're interested in learning more about the quality standard you can access it [here](#) or review the following statements from it that guide clinicians on how to deliver high-quality care.

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### **Identification**

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

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### **Comprehensive Assessment**

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

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### **Support for Family**

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

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### **Stepped-Care Approach for OCD**

People with OCD receive treatment that follows a stepped-care approach, providing the least intensive, most effective intervention first, based on symptom severity, level of functional impairment, and individual needs and preferences.

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### **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 and in alignment with a stepped-care approach.

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### **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 and in alignment with a stepped-care approach. Cognitive behavioural therapy with exposure and response prevention is delivered by a health care professional with expertise in OCD.

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### **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 and in alignment with a stepped-care approach.

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### **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 their clinical presentation.

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### **Support During Initial Treatment Response**

People with OCD are informed about what to expect and supported during their initial treatment response. When initial 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.

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### **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.

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### **Relapse Prevention**

People with OCD who are receiving treatment are provided with information and education about how to prevent relapse and manage symptoms if they re-emerge.

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### **Transitions in Care**

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

# What's next?

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

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

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

You may have other topics you want to cover with your care providers. It's important to speak to them about any other 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 obsessive–compulsive disorder, read the quality standard at: [hqontario.ca/qualitystandards](http://hqontario.ca/qualitystandards)