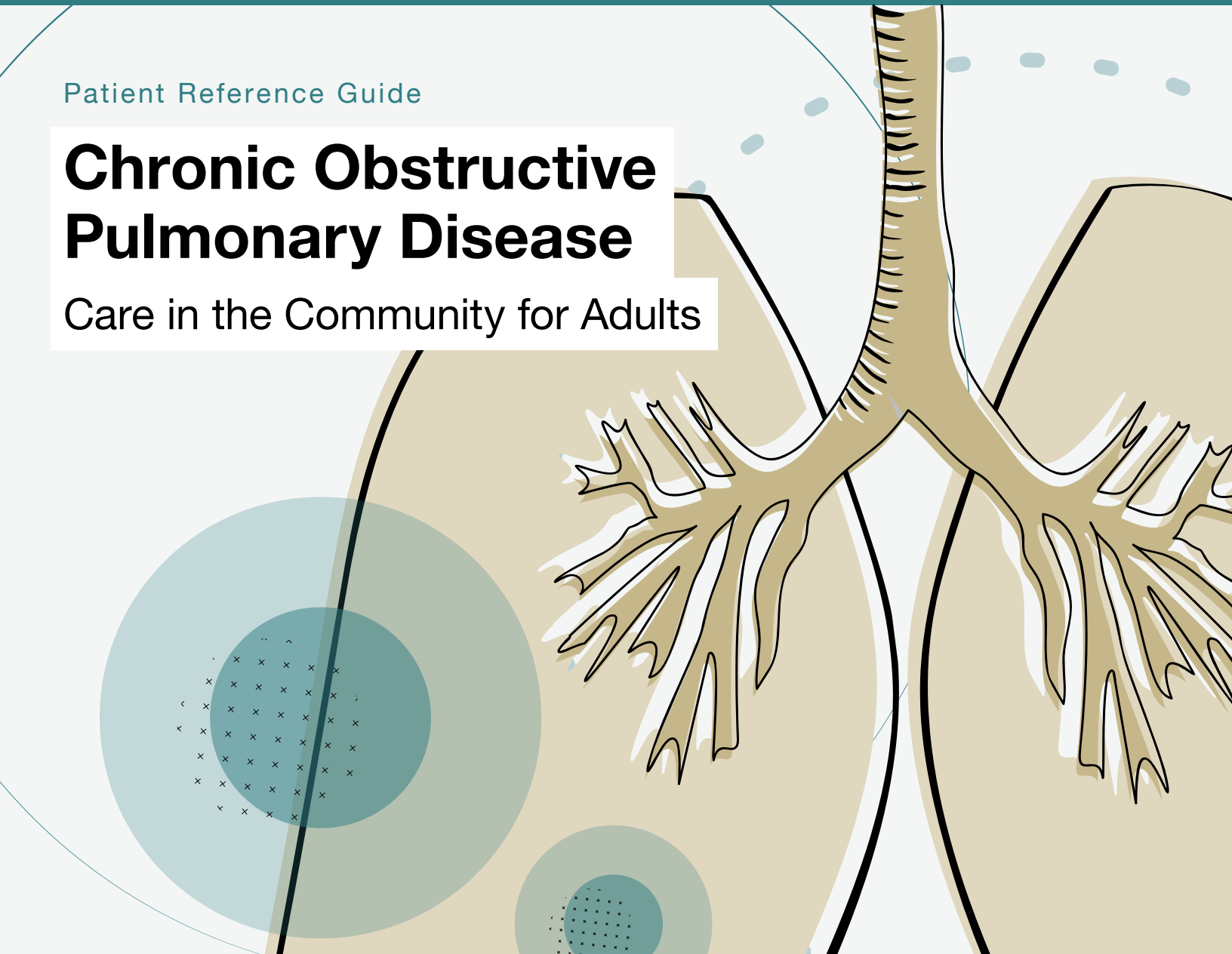


Patient Reference Guide

Chronic Obstructive Pulmonary Disease

Care in the Community for Adults



Quality standards outline what high-quality care looks like. They focus on conditions or topics where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care people should receive.

This guide addresses variations and gaps in care in Ontario that need attention when it comes to diagnosing, assessing, managing, and treating people with chronic obstructive pulmonary disease (COPD) in the community. It is based on the best available evidence and was created in partnership with people with COPD, their caregivers, and health care professionals.

The quality standard, available on our website, contains more information. You can find it at hqontario.ca.

In this guide, we use the following terms:

Health care professional: the many types of people who may be part of your health care team, including:

- Primary care providers, such as a family doctor or nurse practitioner
- Respiriologists (doctors who specialize in lung health)
- Nurses
- Occupational therapists
- Respiratory therapists
- Pharmacists
- Physiotherapists
- Psychologists
- Social workers

Substitute decision-maker: someone who makes care and treatment decisions for you if you are mentally incapable of making decisions for yourself

This guide is for people with chronic obstructive pulmonary disease (COPD) and your caregivers.

It can help you know what to ask for when getting care and help make sure you get the best care.

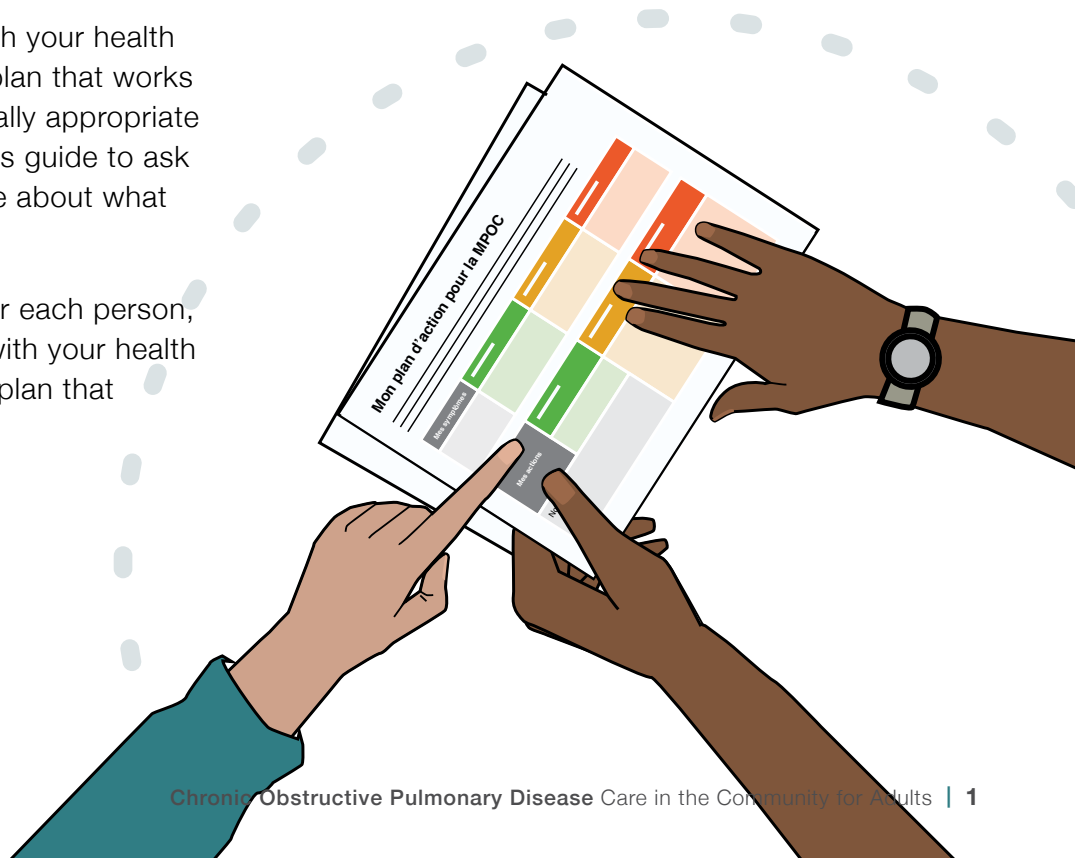
Living with COPD can be hard because chronic lung disease affects many aspects of your life. Some people find out they have COPD after being very sick or hospitalized; others find out before the disease gets too serious. Regardless of when you get diagnosed, you might feel sad, anxious, frustrated, or confused. These reactions are normal and may take time to sort out. However, there are effective treatments to help you deal with COPD and many things you can do as well to take care of yourself, feel better, and enjoy a good quality of life.

If you or someone you care about has COPD...

You can use this guide to work with your health care professional to make a care plan that works for you, including access to culturally appropriate care. We encourage you to use this guide to ask informed questions and learn more about what types of care can help.

Care plans can be very different for each person, so it is important to work closely with your health care professional to create a care plan that works for you.

Here are some things to consider.



What Is COPD?

- COPD is an illness that blocks the flow of air into and out of the lungs. It is chronic, which means it does not go away, and it is progressive, which means that symptoms typically get worse over time. COPD is also sometimes called chronic bronchitis or emphysema.
- The most common cause of COPD is smoking, but people who have never smoked can also develop COPD.



Symptoms

The symptoms of COPD mainly involve the lungs and affect breathing. These chronic respiratory symptoms include:

- A cough that doesn't go away
- Breathlessness that doesn't go away
- Chest tightness
- Coughing up mucus regularly
- Frequent lung infections
- Tiredness and breathlessness during activity or exercise
- Wheezing

How Can I Know If I Have COPD?

- If you have respiratory symptoms that don't go away, you can have a breathing test called spirometry (also called a lung function test or a pulmonary function test).
- Spirometry is the only way to officially diagnose COPD.
- This breathing test determines if there is an airflow blockage in the lungs and, if there is a blockage, how severe it is.

Who Will Care for Me If I Have COPD?

- You are at the centre of your care, and you should have a say in planning your care to make sure it aligns with your goals, values, and preferences. If you want, your family members, other chosen caregivers, or **substitute decision-maker** can also be involved.
- You will get care for COPD from your family doctor or nurse practitioner. As your disease progresses and your needs change, you may also see other health care professionals with different skills in caring for people with COPD.
- Some different types of health care professionals who care for people with COPD are:
 - Respirologists (doctors who specialize in lung health)
 - Nurses
 - Occupational therapists
 - Respiratory therapists
 - Pharmacists
 - Physiotherapists
 - Psychologists
 - Social workers
- Your health care professionals want to get to know you well. The more they know about you and your goals, the better they can help create a care plan and provide support that meets your physical, psychosocial, and spiritual needs.

What Is a Substitute Decision-Maker?

As your illness progresses, there may be times when you are not able to consent to treatment and you require someone to make those decisions on your behalf. This person will be your substitute decision-maker.

It's important to make sure you know who your substitute decision-maker will be if you become incapable of making health decisions for yourself. By law, Ontario's *Health Care Consent Act* automatically assigns a substitute decision-maker for you, but you can change who your substitute decision-maker is by preparing a legal document called "Power of Attorney for Personal Care."

Once you have confirmed who your substitute decision-maker is, talk with them regularly about your wishes, values, and beliefs. This will help them make the right decisions for you, if needed. If your wishes change, keep them informed.

For more information, excellent resources are available from Speak Up Ontario: speakupontario.ca

- Because COPD is a disease that gets worse over time and does not go away, and can progress differently for each person, your health care professionals should talk to you about receiving additional support, which might also be called palliative care support.
- **Palliative care** support is NOT just for the end of life and will look different depending on the stage of your illness and what your needs are at a given time. For some people, it can begin as early as the time you are diagnosed with COPD to help manage your symptoms and the impact of your condition. Palliative care support can include health advice, resources, treatment, and other help from your health care professionals. It can come in many forms, like an office visit with one of your health care professionals, a telephone call with a registered nurse, a phone number to call when you are in pain or having trouble managing your symptoms, or a home visit.

What Is Palliative Care?

Palliative care is a philosophy of care that aims to relieve suffering and improve quality of life for people with a progressive, life-limiting illness, and for families and caregivers too.

It can help improve your quality of life at ANY stage of illness and is not just for end of life. It can begin around the time you are diagnosed with COPD and be provided by your family doctor or nurse practitioner and the other health care professionals in your care team.



Will I Have Many Appointments for COPD?

- You should see your health care professional once or twice a year, or more often if your COPD symptoms are more severe.
- These regular appointments let your health care professional see how you are doing and make changes to your care if needed. These appointments also give you and your caregivers the chance to ask questions about COPD or the care you're getting.
- During these regular appointments, you will get a physical check-up. Your health care professional should also ask you about your physical health, your mental health, your medical history, what medications you're taking, how you spend your time, and how you're feeling.
- You may have some more appointments to:
 - Get tests done, like blood tests or other breathing tests
 - Help you quit smoking if you smoke
 - Get prescriptions for medications and adjust your medications if needed
 - Get vaccinations
 - Learn more about COPD and help you stay active
 - Help you manage day-to-day symptoms like breathlessness and anxiety
 - Help you manage stress, depression, and anxiety
 - Get oxygen
 - Help you deal with symptom flare-ups and recovery after a flare-up
- These appointments may be in person at a clinic, lab, or hospital, or in your home. Some appointments to check in with you may also happen over the phone or by electronic communication, like email or a video call.

What Can I Do to Take Care of Myself and Manage My COPD?

- You, your caregivers, and your health care professional should work together to help you stay as healthy as possible.
- One part of your care where you play an important role is called self-management. What you can do to take care of yourself is described in a self-management plan or COPD action plan. This plan describes your medications and how to take them, things you can do each day to stay healthy, and what to do if you experience a flare-up of your symptoms.
- A big part of living well with COPD is taking care of yourself. Here are some things you can do:
 - **If you smoke, quit smoking**
 - Take your medications as prescribed by your health care professional
 - Make sure you know how to use your inhaler and other medications properly
 - Get vaccinations recommended by your health care professional
 - Stay active and exercise
 - Eat healthy foods
 - Get enough sleep
 - Learn ways to manage stress
 - Learn to recognize the signs of a flare-up and what to do if you have one
 - If you are on oxygen therapy, use oxygen as prescribed by your health care professional
 - Stay connected with family, friends, and your community
 - Wash your hands frequently to help prevent catching a cold or the flu

Quitting Smoking

If you smoke tobacco, your health care professional should talk with you about how important it is for your health for you to quit smoking.

There are different types of treatment that can help you quit smoking, like counselling, nicotine replacement therapy, or other medications.

Talk with your health care professional to find the best options for you.



Taking Medications

- Medications are an important part of managing COPD. They can help manage your day-to-day symptoms and also prevent and manage flare-ups.
- Your health care professional should explain how and when to take your medications. If you are using an inhaler, your health care professional should ask you to show them how you use it to make sure you are confident using it.
- There are many different medications, including several types of inhalers, that can help you manage COPD. If you are not feeling well on your current medications, talk with your health care professional to see if there's another type of medication you can try.

Getting Vaccinations

- The flu and some infections, like pneumonia (a lung infection), can make COPD symptoms worse.
- You should be offered a flu shot every year.
- You should also be offered vaccines against pneumonia.

- Your caregivers and family members should also be encouraged to get vaccinated to help protect you.

Learning More About COPD and Staying Active

- Your health care professional should explain COPD to you, including how the disease will progress, what can be done to help you, and what you can do to take care of yourself.
- You can also learn more about COPD from other people who are living with COPD. This is sometimes called peer support. Peer support can happen in a formal group setting, or it can be informal, like when someone you know talks with you about their experience.
- It's important for your health that you stay active and exercise. You can talk with your health care professional about what kinds of exercise would be good for you and what medications can help you stay active. Your health care professional can also give you information about local programs on lung health and exercise.
- If you are taking your medications as directed but still have trouble being active and often feel breathless, your health care professional may suggest that you try a pulmonary rehabilitation program.

Pulmonary Rehabilitation

- Pulmonary rehabilitation programs are designed for people with COPD. They are offered in a hospital or clinic in the community. These programs teach you about COPD to help you understand and manage your symptoms. They also include a personalized, supported exercise program to improve your breathing, increase your fitness, and make it easier to do your daily activities. They also provide emotional and peer support.
- If you participate in a pulmonary rehabilitation program, your health care professional should work with you to find ways to stay active once the program is over.
- Over time, many people with COPD get to know the early signs and symptoms of a flare-up. Some people find that they start feeling generally unwell, need to rest more, have difficulty sleeping, lose their appetite, or become confused, restless, and lose interest in things. People who have health conditions in addition to COPD sometimes notice that their nonrespiratory symptoms get worse first.
- If you experience a flare-up, follow the instructions in your written self-management plan or COPD action plan. If your symptoms last 48 hours or get worse, contact your health care professional right away.

Dealing With Flare-Ups

- It is important to know when you are having a flare-up of your symptoms so that you can prevent it from getting worse. You might be starting to have a flare-up if you experience one or more of the following symptoms:
 - You are more out of breath than usual
 - You are coughing more than usual
 - You are coughing up more mucus than usual
 - There is a change in the thickness or colour of your mucus
 - There is blood in your mucus

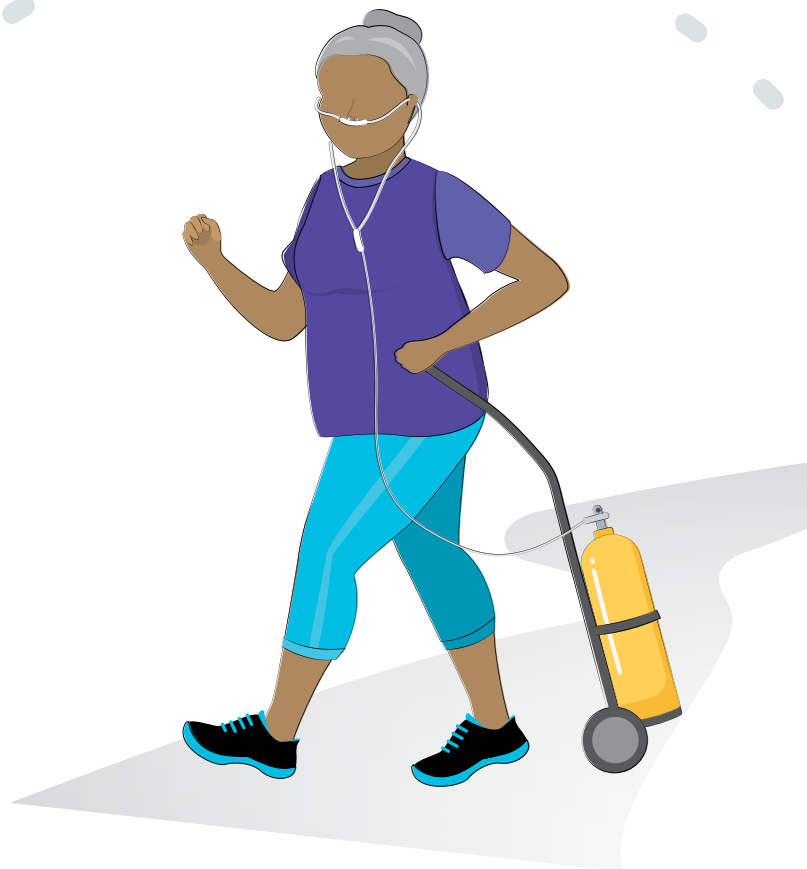
Recovering From a Flare-Up

- It can take some time to recover from a flare-up of COPD and to start to feel better, regain your strength, and get back to the activities you enjoy.
- If you have been hospitalized for a flare-up, you may need more support during recovery. When you see your health care professional after a flare-up, ask questions to make sure you understand what has happened to you and what you need to do to take care of yourself.
- Your health care professional should see you within 7 days of your leaving the hospital. This lets them see how you're doing and make any needed changes to your care plan.

- Some changes to your care plan might include:
 - Prescribing different medications
 - Involving other health care professionals in your care, like a lung specialist
 - Suggesting that you try a pulmonary rehabilitation program

Using Oxygen

- If your body is not getting enough oxygen when you breathe, you may need to start using oxygen at home. This is called oxygen therapy.
- To make sure oxygen therapy is right for you, your health care professional will have you take some tests to measure the level of oxygen in your blood. Oxygen is not used to treat breathlessness and should not be used unless you have low levels of oxygen in your blood.
- Oxygen can be supplied in different ways, like in a canister or a machine. Your health care professional will help you decide which option is best for you.
- Oxygen is usually delivered by a small tube with prongs that are placed in your nose. This is called a cannula. Sometimes oxygen is delivered through a mask.
- Some people with COPD take oxygen therapy for a short period of time while they recover from a flare-up, and other people with COPD take oxygen therapy on a long-term basis.



Living with COPD can be difficult. However, **there are effective treatments for symptoms, and there are things you can do to take care of yourself, feel better, and enjoy life.**

Everybody is different, and some options may not apply in your situation. If you have questions about your care, it is important to speak with your health care professional.

Looking for More Information?

Please contact us at qualitystandards@hqontario.ca or **1-866-623-6868** if you have any questions or feedback about this patient reference guide.

The quality standard, available on our website, contains more information. You can find it at hqontario.ca.

About Health Quality Ontario

Health Quality Ontario is the provincial lead on the quality of health care. We help nurses, doctors and other health care professionals working hard on the frontlines be more effective in what they do – by providing objective advice and data, and by supporting them and government in improving health care for the people of Ontario.

We focus on making health care more effective, efficient and affordable through a legislative mandate of:

- Reporting to the public, organizations, government and health care providers on how the health system is performing,
- Finding the best evidence of what works, and
- Translating this evidence into clinical standards; recommendations to health care professionals and funders; and tools that health care providers can easily put into practice to make improvements.

For more information about Health Quality Ontario and our quality standards, visit hqontario.ca.