Quality Standards

Patient Reference Guide

Chronic Obstructive Pulmonary Disease

Care in the Community for Adults

November 2017



Health Quality Ontario

Let's make our health system healthier

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

This guide addresses variations and gaps in care in Ontario that need attention when it comes to diagnosing. assessing, managing, and treating 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.

A more detailed version of this quality standard, written for health care professionals, is available on our website. You can find it at hqontario.ca.

This guide is for people with chronic obstructive pulmonary disease (COPD) and your caregivers. It can help you know what to ask for when receiving care and to make sure you receive the highest-quality care.

Living with COPD can be difficult. Chronic lung disease affects many aspects of your life, and you may feel frustrated at times. However, there are effective treatments and many things you can do to take care of yourself, feel better, and enjoy a good quality of life.

If you or someone you care about has COPD or may have 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. Use this information 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 make a plan that works for you.

Here are some things to consider.

What Is COPD?

- COPD is a disease that blocks the flow of air into and out of the lungs. It is also sometimes called chronic bronchitis or emphysema.
- COPD is a serious illness, but there are treatments for it and things you can do to stay as healthy as possible.
- The most common cause of COPD is smoking.
- The symptoms of COPD are:
 - Breathlessness that doesn't go away
 - Chest tightness
 - A cough that doesn't go away
 - Coughing up mucus regularly
 - o Frequent lung infections
 - Tiredness during activity or exercise
 - Wheezing

Diagnosis and Assessment

- If your health care professional thinks you might have COPD, you should be given a breathing test called spirometry (also called a lung function test or a pulmonary function test). This test is done to confirm whether or not you have COPD.
- If you have been diagnosed with COPD, your health care professional should thoroughly examine you. They should 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 also need tests at a hospital, lab, or clinic, like blood tests or breathing tests.
- Your health care professional wants to build a relationship of trust with you. The more they know about you and your goals, the better they can help create a care plan that meets your needs.
- Your health care professional should explain COPD to you, including how the disease will progress, what treatment options are available to you, and what you can do to take care of yourself.

What You and Your Care Team Can Do

- You are at the centre of your care team, and you should be involved in all decisions made about your care. If you want, your family members or other chosen caregivers can also be involved.
- You might receive care for COPD from your family doctor or nurse practitioner only, or from a number of health care professionals and providers with different training and skills, like a respirologist (a physician who specializes in lung health), nurse, respiratory therapist, pharmacist, occupational therapist, physiotherapist, or social worker. Even if these health care professionals work in different places, they should work together to make sure you get the best care. Together, these health care professionals make up your care team.
- You should see your health care professional once or twice a year, or more often if your COPD symptoms are more severe. This lets 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.
- You, your caregivers, and your health care professional should work together to create a plan for you to stay as healthy as possible. This is called a written self-management plan or a COPD action plan. This plan describes your medications and how to take

them, things you can do on a daily basis 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. Some things you can do are:
 - Stop smoking: quitting smoking is the most important thing you can do to slow the progression of COPD
 - Take your medications regularly
 - Make sure you know how to use your inhaler and other medications properly
 - Eat healthy foods
 - Exercise safely: talk with your health care professional about what kinds of exercise would be good for you
 - o Get enough sleep
 - Stay connected with family, friends, and your community
- If you smoke tobacco, your health care professional should talk with you about how to quit. There are different types of treatment that can help, like counselling, nicotine replacement therapy, and medications. You can work with your health care professional to find the best one for you.

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.
- The first medication you should be offered is an inhaler called a short-acting bronchodilator. You take this to relieve symptoms right away.
- Depending on your symptoms, your health care professional may offer you a second type of inhaler called a long-acting bronchodilator or a maintenance inhaler. You take this on a regular basis, even when your symptoms are under control. This type of inhaler can help prevent flare-ups.
- Your health care professional should explain how and when to take your medications. They should also ask you to show them how you use your inhaler. Together, you can make sure you are confident using it.
- There are many different medications and inhalers that can help manage the symptoms of COPD and prevent and manage flareups. If you are not feeling well on your current medications or inhaler, talk with your health care professional to see if there's another type of medication or inhaler you can try.

Vaccinations

 The flu and some infections, like pneumonia (a lung infection) and meningitis (an infection of the brain and spine), can make COPD symptoms worse. You should be offered a flu shot every year. You should also be offered pneumococcal vaccinations, which can prevent infections like pneumonia and meningitis.

Pulmonary Rehabilitation

- If you are taking your medication 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 programs are designed for people with COPD. They are offered in a hospital or clinic. These programs involve education about COPD to help you understand and manage your symptoms. They also include a personalized, supported exercise program to increase your fitness, and they provide emotional and peer support.

Oxygen Therapy

- 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.
- 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 administered by a small tube with prongs that is placed under your nose.
- 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. Some people with COPD take oxygen
 therapy for a short period of time while they recover from a flareup, whereas other people with COPD take oxygen therapy on a
 long-term basis.

Dealing With Flare-Ups

- It is important to recognize when you experience a flare-up of your symptoms so you can prevent it from getting worse. These include:
 - o Breathlessness that is worse than usual
 - More coughing than usual
 - o Producing more sputum (coughed-up mucus) than usual
 - o A change in the colour or thickness of sputum
- If you experience a flare-up of your symptoms, follow your written self-management plan or COPD action plan. If your flare-up lasts 48 hours or your symptoms get worse, contact your health care professional right away.
- If you have been hospitalized for a flare-up, you should see your health care professional within 7 days of leaving the hospital. This lets your health care professional check how you're doing and make any needed changes to your care plan, including your medications. At this visit, you can also ask questions to make sure you understand what has happened to you and what you need to do to take care of yourself.
- If you have been hospitalized for a flare-up and your health care professional determines that you need to see a lung specialist, you should see this specialist within 30 days of leaving the hospital.
- If you have been discharged from the hospital after a flare-up, your health care professional should talk with you about trying a pulmonary rehabilitation program to help improve your symptoms and regain your strength so that you can get back to the activities you enjoy.

You and your health care professional should be aware that some treatments and programs described in this guide are not publicly covered, and you may need to pay for these services directly or through private insurance.

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

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

Draft—do not cite. Report is a work in progress and could change following public consultation.

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.

A more detailed version of this quality standard, written for health care professionals, is available on our website. You can find it at hontario.ca.

About Health Quality Ontario

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by a single-minded purpose: **Better health for all Ontarians.**

Our quality standards are concise sets of statements outlining what quality care looks like for conditions where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. They are based on the best available evidence and are developed in collaboration with clinical experts from across the province, and patients and caregivers with lived experience with the condition being discussed.

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

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