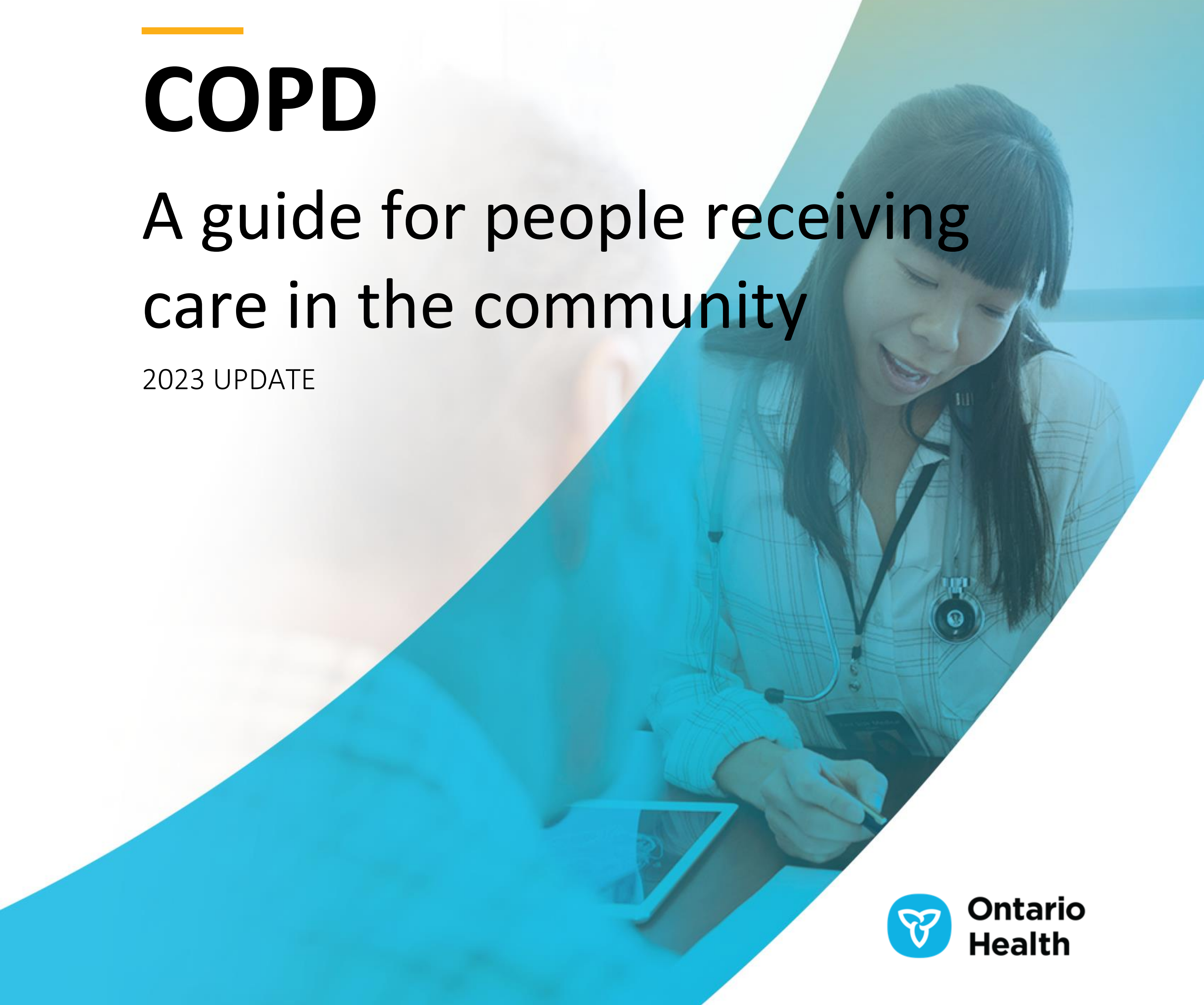
QUALITY STANDARDS

COPD

A guide for people receiving care in the community

2023 UPDATE



Ontario Health

Ontario Health is committed to improving the quality of health care in the province in partnership with patients, health care professionals, and other organizations.

To do that, Ontario Health develops quality standards. These are documents that outline what high-quality care looks like for conditions or processes where there are large differences in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. These quality standards set out important steps to improve care. They are based on current evidence and input from an expert committee that includes patients, caregivers, health care professionals, and researchers.

This patient guide accompanies the quality standard on chronic obstructive pulmonary disease (COPD). It outlines the top 14 areas where providers can take steps to improve care in the community for people with COPD. The patient guide also includes suggestions on what to discuss with your health care providers, as well as links to helpful resources.

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
- Respirologists (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 their 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 more 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 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 and 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.

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

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

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, psychological, social, and spiritual needs.

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 with 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.

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.**

Summary of the top 14 areas to improve care for people with COPD

Quality Statement 1: Diagnosis Confirmed With Spirometry

What the standard says

People clinically suspected of having COPD have spirometry testing to confirm diagnosis within 3 months of developing respiratory symptoms.

What this means for you

If you have respiratory symptoms that do not 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.

Quality Statement 2: Comprehensive Assessment

What the standard says

People with COPD have a comprehensive assessment to determine the degree of disability, risk of acute exacerbation, and presence of comorbidities near the time of diagnosis and on an annual basis. The severity of airflow limitation, as initially determined by spirometry testing to confirm diagnosis, is reassessed when people's health status changes.

What this means for you

If you have been diagnosed with COPD, your health care professional should examine you thoroughly. They should ask you about your physical health, your mental health, your medical history, what medications you are taking, how you spend your time, and how you are feeling.

You may also need tests at a hospital, lab, or clinic, like blood tests or breathing tests.

Quality Statement 3: Goals of Care and Individualized Care Planning

What the standard says

People with COPD discuss their goals of care with their future substitute decision-maker, their primary care provider, and other members of their interprofessional care team. These discussions inform individualized care planning, which is reviewed and updated regularly.

What this means for you

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, psychological, social, and spiritual needs.

You are at the centre of your care, and you should have a say in planning your care. If you want, your family members, other chosen caregivers, or a substitute decision-maker can also be involved.

You will get care for COPD from your primary care provider (family doctor or nurse practitioner). You may also see other health care professionals with different skills in caring for people with COPD, like a respirologist (a doctor who specializes in lung health), a nurse, an occupational therapist, a respiratory therapist, a pharmacist, a physiotherapist, or a social worker.

Together with you and your chosen caregivers, these health care professionals make up your care team.

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 is 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 a "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.

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 are 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 are taking, how you spend your time, and how you are 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.

Quality Statement 4: Education and Self-Management

What the standard says

People with COPD and their caregivers receive verbal and written information about COPD from their health care professional and participate in interventions to support self-management, including the development of a written self-management plan.

What this means for you

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 self-management. What you can do to take care of yourself will be 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, stop 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 your family, friends, and community
- Wash your hands frequently to help prevent catching a cold or the flu

Quality Statement 5: Promoting Smoking Cessation

What the standard says

People with COPD are asked about their tobacco-smoking status at every opportunity. Those who continue to smoke are offered pharmacological and nonpharmacological smoking-cessation interventions.

What this means for you

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

There are different types of treatment that can help, like counselling, nicotine replacement therapy, and other medications.

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

You can also refer yourself to the Smoking Treatment for Ontario Patients (STOP) Program.

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.

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**.

Quality Statement 6: Pharmacological Management of Stable COPD

What the standard says

People with a confirmed diagnosis of COPD are offered individualized pharmacotherapy to improve symptoms and prevent acute exacerbations. Their medications are reviewed at least annually.

What this means for you

Medications are an important part of managing COPD. They can help you manage your day-to-day symptoms. They can also prevent and manage acute exacerbations of COPD, called “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 your COPD. If you are not feeling well on your current medications, talk with your health care professional to see if there is another type of medication you can try.

Quality Statement 7: Vaccinations

What the standard says

People with COPD are offered influenza, pneumococcal, and other vaccinations, as appropriate.

What this means for you

The flu and other 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, COVID-19, whooping cough (if you did not get it when you were a teenager), and shingles (if you are aged 50 years or older).

Your caregivers and family members should also be encouraged to get appropriate vaccines to help protect you.

Quality Statement 8: Specialized Respiratory Care

What the standard says

People with a confirmed diagnosis of COPD are referred to specialized respiratory care when clinically indicated, after receiving a comprehensive assessment and being offered treatment in primary care. This consultation occurs in accordance with the urgency of their health status.

What this means for you

At some point, your health care professional may determine that you need to see a physician who specializes in lung health. This is usually a respirologist, but it might also be a general internist, or a family physician or nurse practitioner with expertise in lung health.

Before you are referred to a lung specialist, your health care professional should assess you thoroughly and give you medication to help manage your symptoms.

If you are referred to a lung specialist, your health care professional should let you know when your appointment with the specialist is. They should also let you know what they hear back from the specialist after your visit.

Quality Statement 9: Pulmonary Rehabilitation

What the standard says

People with moderate to severe, stable COPD are referred to a pulmonary rehabilitation program if they have activity or exercise limitations and breathlessness despite appropriate pharmacological management.

What this means for you

It is important for your health that you exercise and stay active. 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 a 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 for you 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 for you to stay active once the program is over.

Quality Statement 10: Management of Acute Exacerbations of COPD

What the standard says

People with COPD have access to their primary care provider or a health care professional in their care team within 24 hours of the onset of an acute exacerbation.

What this means for you

It is important to be able to tell when you are having a flare-up 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

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, become confused and restless, or lose interest in things. People who have other 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 for 48 hours or get worse, contact your health care professional right away.

Quality Statement 11: Follow-Up After Hospitalization for an Acute Exacerbation of COPD

What the standard says

People with COPD who have been hospitalized for an acute exacerbation have an in-person follow-up assessment within 7 days after discharge.

What this means for you

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 are doing and make changes to your care plan, if needed.

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

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.

Quality Statement 12: Pulmonary Rehabilitation After Hospitalization for an Acute Exacerbation of COPD

What the standard says

People who have been admitted to hospital for an acute exacerbation of COPD are considered for pulmonary rehabilitation at the time of discharge. Those who are referred to a pulmonary rehabilitation program start the program within 1 month of hospital discharge.

What this means for you

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. See quality statement 9 for more details.

Quality Statement 13: Palliative Care

What the standard says

People with COPD and their caregivers are offered palliative care support to meet their needs.

What this means for you

COPD is a disease that does not go away, and it can progress differently for each person. You and your caregivers should be given support to meet your physical, psychological, social, and spiritual needs. This support may include palliative care support.

Palliative care can help improve your quality of life at any stage of illness. It is not just for end of life. It can begin around the time you are diagnosed with COPD to help you manage your symptoms and the impact of your condition. You can receive COPD treatment and palliative care support at the same time.

Palliative care support can include health advice, resources, treatment, and other help from your health care professionals to help you manage symptoms like breathlessness and anxiety. 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.

Quality Statement 14: Long-Term Oxygen Therapy

What the standard says

People with stable COPD who have clinical indications of hypoxemia receive an assessment for and, if needed, treatment with long-term oxygen therapy.

What this means for you

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. It 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 time while they recover from a flare-up, and other people with COPD take oxygen therapy on a long-term basis.

Your health care provider should provide you with information on the proper and safe use of oxygen before you start taking it. They should reassess your need to continue using oxygen therapy 60 to 90 days after you first begin taking it, and then at least once a year.

Suggestions on what to discuss with your health care providers

Ask the care team:

- What can make my COPD worse (e.g., will fumes, dust, or pets make my symptoms worse)?
- How can I protect myself from getting an infection in my lungs?
- How can I get help to stop smoking?
- What medication should I be taking every day for my COPD, and what should I do if I miss a dose?
- Am I taking my COPD medication and using my inhaler the right way?
- How do I know when my inhalers are getting empty?
- What are the potential side effects of my medication, and when should I call a health care provider about a problem?
- What vaccinations do I need?
- When should I be referred to a specialist for my care?
- Would participation in a pulmonary rehabilitation program be helpful for me?
- When I am having a flare-up, how do I know if I need to go to the hospital?
- If I need to go to the hospital because of a flare-up, what is the best way for me to let you know and book a follow-up appointment?
- Do I need to use oxygen therapy at home?

Share with the care team:

- Any concerns you have about your condition or medication (e.g., if your symptoms are not improving or are getting worse even with your COPD medication)
- If you notice any side effects, or if you have ever had to stop a medication because of a side effect or reaction
- If you do not understand why you are taking a medication or how to take it
- If there are things that make it hard to take your medication, such as the cost or difficulty using it
- If you have any travel plans, so that they can tell you what you need (e.g., oxygen on the plane, the medications you need to bring, or who to call if your COPD gets worse)

If you are a caregiver:

You might have your own questions. It can help to identify yourself as the patient's caregiver to their health care team. This will make sure they know and respect your questions and concerns.

- Let them know what your role will be in helping the patient manage their condition
- Let them know if you need help

Learn more

The Lung Health Foundation Line 1-888-344-LUNG (5864) is available to help people find a support group, pulmonary rehabilitation program, or exercise maintenance program in their community.

The Lung Health Foundation Resource Library includes resources on strategies that can help people manage their COPD, stay out of the hospital, and live a full and active life.

The Lung Health Foundation has clinical tools such as the COPD Action Plan to help with managing your COPD.

The STOP Program, provided by the Centre for Addiction and Mental Health, can connect people to free smoking cessation medication and counselling.

The Nicotine Dependence Clinic at the Centre for Addiction and Mental Health offers several specialized outpatient treatments for anyone who wants to quit or reduce their tobacco use.

The Ontario Health quality standard for *Asthma in Adults* highlights what high-quality care looks like in the community for people with asthma 16 years of age and older. The patient guide outlines what to discuss with your family doctor or nurse practitioner to help you receive high-quality care for asthma.

Through the Pharmacy Smoking Cessation Program, community-based pharmacists can provide counselling, resources, and therapies for smoking cessation.

Need more information?

If you have any questions or feedback about this guide, please contact us at QualityStandards@OntarioHealth.ca or 1-877-280-8538 (TTY: 1-800-855-0511).

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