

Caring for Yourself or a Family Member

Living Well with COPD



MaineHealth

WWW.MAINEHEALTH.ORG

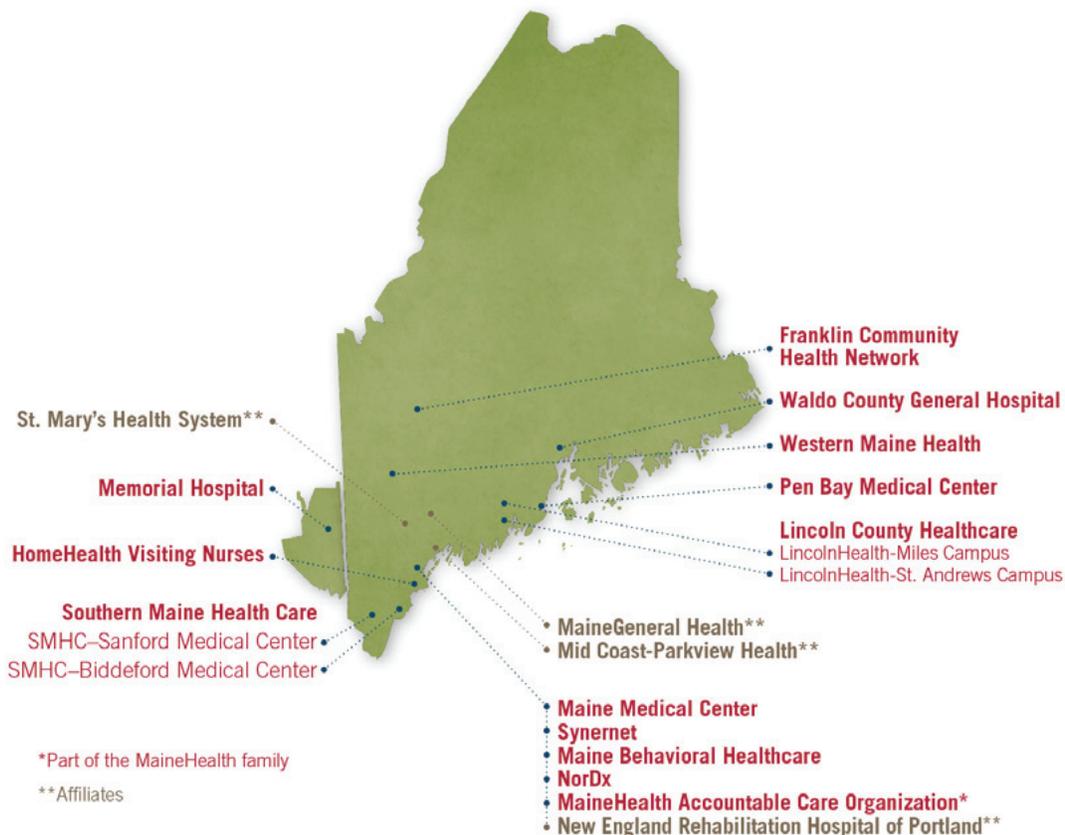
Welcome

This guide was created by the MaineHealth Lung Health Program for people with Chronic Obstructive Pulmonary Disease (COPD) and those who care for them. We hope you find this guide helpful.

MaineHealth and the Lung Health Program

MaineHealth is a not-for-profit family of leading high-quality providers and other healthcare organizations working together to make their communities the healthiest in America.

The Lung Health Program has been working to improve the quality of life for adults living with COPD. The program works to improve the coordination of COPD care among people with COPD and their families, community COPD educators, care managers, doctors, nurses and respiratory therapists.



How to Use This Guide

Living Well with COPD: Caring for Yourself or a Family Member is for people with COPD and their families. The guide is divided into 10 sections.

You may want to read the section that seems most helpful first.

- Read each section carefully, and jot down notes or questions that you have.
- Take your questions with you when you see your doctor or nurse.
- Keep this guide handy, and refer to it often.
- Share the information with family, friends and those who help care for you.

Throughout the guide, the word **you** is used to mean the adult with COPD, even though a family member or friend may be reading the guide.

The words in **bold** in the guide will appear in the glossary on page 62, where you will find their meanings.

For More Information

For more information about COPD and the COPD program, visit our website at www.mainehealth.org/COPD.

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1 Healthy Lungs and Lung Disease

Your lungs are part of a group of organs and tissues that all work together to help you breathe. This system is called the respiratory system. The job of the respiratory system is to move oxygen from the air into your blood and get waste gases out of your body. Oxygen is very important to your heart, brain, muscles and all other parts of your body. Good health habits like making healthy food choices, exercising and reducing the stress in your life will help you breathe easier.



How Lungs Work

With healthy lungs, you breathe air in through your nose and mouth, and air travels down your windpipe (**trachea**), through your air passages or airways (**bronchial tubes**) and to the air sacs (**alveoli**) deep within your lungs.

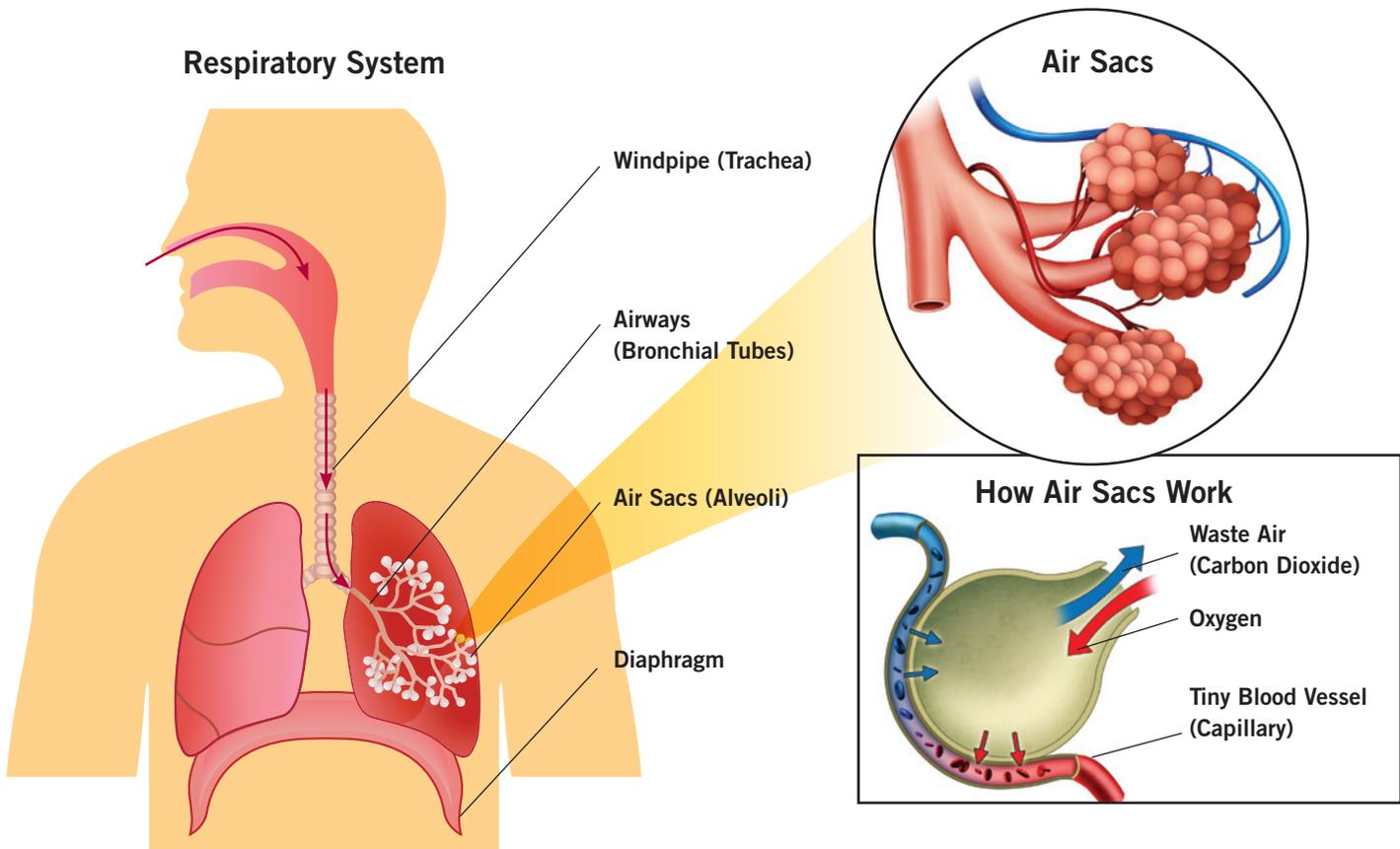
The air sacs are elastic and get bigger (expand) and smaller (contract) easily, like blowing up a balloon and allowing it to deflate. There are tiny blood vessels all around the air sacs. Oxygen from the air you breathe passes easily into the blood vessels. The blood then carries the oxygen to all parts of your body.

As your body uses oxygen, waste air called **carbon dioxide** (CO₂) is made. The waste air is carried by the blood vessels back to your lungs

and passes into the air sacs. When you breathe out, the waste air is exhaled up your airways and out of your lungs.

Most of the work of breathing is done by a large muscle called the **diaphragm**. The diaphragm sits below your lungs and moves down as you breathe in and up as you breathe out.

Your airways have special cells that help keep your lungs free of dust and infection. These cells make mucus (**sputum**) that traps dirt and germs. Tiny hairlike structures called cilia sweep mucus up into your larger airways and windpipe to make coughing up mucus easier.



What Is COPD?

COPD stands for Chronic Obstructive Pulmonary Disease. COPD includes emphysema, bronchitis and asthma. You may have only emphysema, only bronchitis or only asthma, or you may have more than one of these lung diseases at the same time.

Most people don't realize they have COPD at first. The signs start slowly. As COPD gets worse, you may feel short of breath when doing simple things like making your bed or washing your hair. Many people blame their lack of energy or limited breath on aging. They may cut back on or stop doing activities they enjoy like shopping with their friends, attending their grandchildren's events or gardening.

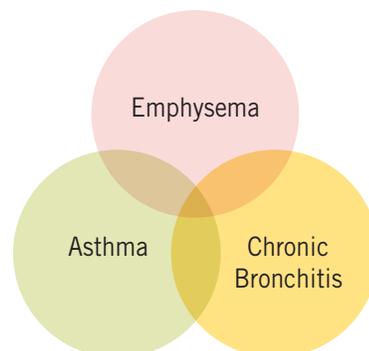
Symptoms of COPD:

- shortness of breath climbing stairs or walking
- breathing faster or harder to catch your breath
- mucus when you cough
- feeling tired or lacking energy
- coughing
- wheezing
- colds that last for weeks instead of days

Chronic Obstructive Pulmonary Disease

- C** Chronic: disease that cannot be cured by medicines and does not go away
- O** Obstructive: damage to the airways that makes breathing out difficult and may cause you to trap air in your lungs
- P** Pulmonary: related to the lungs
- D** Disease: illness or condition

COPD is another word for asthma, emphysema and chronic bronchitis, and can be any combination of these diseases.



Asthma is a disease of the airways.

When asthma is not under control:

- your airways become swollen and can fill with mucus
- your airways become narrow from the mucus
- the muscles around the airways tighten, making it hard to breathe out

Emphysema is a disease that damages your air sacs and causes airways to narrow or become blocked.

Emphysema causes:

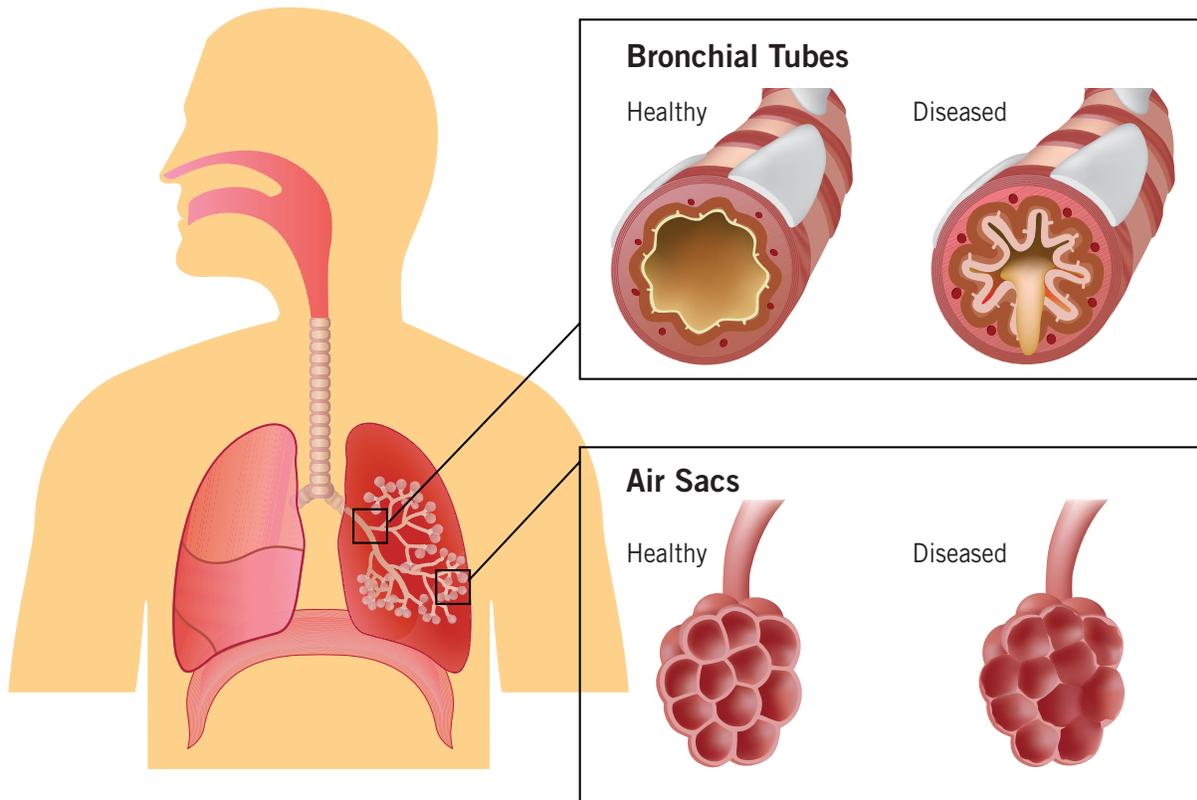
- your air sacs to not open and close easily
- **air trapping** in your lungs, making breathing out difficult
- oxygen in your blood to be low and waste air to build up

Chronic bronchitis is a disease that damages the airways.

Chronic bronchitis causes:

- airways to become irritated and swollen
- a buildup of mucus that can block airways, making it difficult to get air in and out

COPD is not reversible. The lung damage you have will not go away with medicine, but there are many things you can do to keep the damage from getting worse. Diagnosing COPD early and working with your doctor will help you to stay healthy and to continue doing the things you enjoy.



2 COPD: Causes



What Causes COPD?

Tobacco smoke

Smoking is the number one cause of COPD in the United States. Smoke from tobacco products, including secondhand smoke, has over 7,000 harmful chemicals. These chemicals can cause irritation and swelling in your lungs. This can lead to permanent lung damage. Over 70 of these chemicals also cause cancer.

Some people with COPD have never smoked but have been around people who smoke and get sick from **secondhand smoke**.

Secondhand smoke

Secondhand smoke is the smoke from a burning cigarette, cigar, pipe or hookah. Breathing in secondhand smoke can cause:

- COPD
- symptoms of COPD or asthma to be worse
- lung infections and bronchitis
- irritation in the nose and throat



* remember

**Tobacco smoke is not just from cigarettes.
Cigars and pipes can also damage your lungs.**

Thirdhand smoke

Thirdhand smoke is the tobacco particles that stay on surfaces long after burning tobacco has been put out. Thirdhand smoke clings to hair, skin, clothes, furniture, drapes, walls and carpets. The smoke particles build up over time and are hard to get rid of. They do not go away by airing out a room or opening a window or using a fan or air conditioner. Thirdhand smoke is becoming a greater concern for non-smokers.

Tobacco can cause:

- heart disease
- stroke
- smoking-related chronic diseases

Genetic disease Alpha-1

Some people are born with a genetic disease called **alpha-1-antitrypsin** (ALF-a-ONE-anty-TRIP-sin) deficiency, or alpha-1. Alpha-1 can cause COPD.

- This disease makes your lungs very sensitive to chemicals and pollutants in the air.
- Alpha-1 can cause COPD at a young age.
- Alpha-1 can be treated with medicines to slow down the lung damage.

You can have a blood test to find out if you have this disease. Anyone with COPD that is younger than 40 years old should be tested.

Lung infections

Having severe lung infections (**pneumonia**) as a child or adult can damage your lungs and cause COPD. Staying healthy and getting a yearly influenza (flu) vaccination can help prevent lung infections.

Chemicals and pollutants



Breathing in chemicals and **pollutants** can cause COPD and other lung diseases. The air in your home or workplace can worsen COPD.

Smog

Mold

Mildew

Work-related materials

- coal dust
- **silica**
- **asbestos**

Smoke

- cooking
- heating
- woodstoves



Fumes

- paint
- cooking fuels
- perfumes
- deodorants
- car exhaust

Spray products

- bug spray
- cleaners
- hair spray
- air fresheners

Diagnosing COPD 3



How Does Your Doctor Know You Have COPD?

Besides COPD, there are many illnesses that can make you feel short of breath. Your doctor may run tests to find out if you have COPD or a different lung disease. This is important to know so that your doctor can give you the right medicine to help with your symptoms.



Here are some questions that your doctor or nurse may ask you:

- Do you have trouble breathing? _____
- Do you cough a lot and wheeze?

- Do you have a lot of mucus?

- How often do these things happen?

- Do they limit what you can do?

- What things make your breathing worse?

- Are you a smoker? _____
- Do you live or work with someone who smokes?

- Is there air pollution where you live or work?



Spirometer

You may be asked to take a breathing test

This breathing test is called **spirometry** (spy-ROM-uh-tree) or a pulmonary function test. It measures how much air you can breathe in and out and how fast you can breathe out. It also measures how well oxygen is moving from your lungs into your blood. The respiratory therapist or nurse may give you a medicine during the test. This breathing test may be done in your doctor's office or in a lab at the hospital.

* remember

If you have COPD, see your doctor every 6 months for a checkup and have a breathing test every year.

Other tests your doctor may order:

- ABG (arterial blood gas)
- chest x-ray
- CT scan
- pulse oximetry
- blood tests
- mucus (sputum) culture
- exercise test
- electrocardiogram (EKG)
- echocardiogram

Equipment used for pulmonary function testing



4 COPD and Other Conditions

People who have COPD often have other chronic illnesses at the same time. These other illnesses are called **comorbidities** (ko-mor-bid-i-teez).

Many of these other illnesses share a common cause. For example, using tobacco can cause both COPD and heart disease.



Chronic Illnesses with COPD

Some health illnesses that often occur with COPD are:

- diabetes
- heart disease
- high blood pressure (**hypertension**)
- osteoporosis
- osteoarthritis/rheumatoid arthritis
- obstructive sleep apnea (OSA)
- depression
- sinusitis
- allergic rhinitis
- gastroesophageal reflux disease (GERD)—acid reflux
- lung cancer

Having other chronic illnesses can make managing COPD more difficult. It's important to know how to manage these other illnesses and learn more about how they can affect your breathing.

tips

Gastroesophageal reflux disease (GERD)

In some people, the tube (**esophagus**) that connects the stomach to the mouth becomes irritated by stomach acid that backs up. This is called **reflux**. Reflux can cause heartburn or an acid taste in your mouth. Everyone has some reflux, but it is considered gastroesophageal reflux disease, (GERD) when it happens often. COPD can increase your risk of GERD. Tell your doctor or nurse if you have heartburn or reflux.

What You Can Do

1. Lose weight if you are overweight.
2. If you smoke, try to quit. Smoking can make GERD worse.
3. Raise the head of your bed by 6 inches.
4. Don't wear tight-fitting clothes.
5. Eat smaller meals.
6. Stop eating or drinking at least 3 hours before bedtime.
7. Limit fried and fatty foods, caffeine, alcohol, sodas and carbonated drinks, chocolate, peppermint, citrus fruits and juices.
8. Limit tomatoes, tomato juice and tomato-based foods.

Heart disease

Heart disease is often called cardiovascular disease. Cardiovascular disease affects your heart and your blood vessels and may include:

- high blood pressure (**hypertension**)
- **coronary artery disease**—angina, heart attack, high cholesterol
- **stroke**
- **heart failure**
- **peripheral vascular/arterial disease**
- high blood pressure in the lungs (**pulmonary hypertension**)
- heart failure caused by lung disease (**cor pulmonale**)

There is no cure for heart disease. Once you have it, you'll always have it. The good news is that there are many things you can do to manage your heart disease and prevent future problems.

Learn more about cardiovascular disease:

www.mainehealth.org/cvh

tips

What You Can Do

1. Talk with your doctor or nurse about a healthy eating plan.
2. Stay at a healthy weight.
3. Get at least 30 minutes of physical activity 5 days of the week.
4. Check your blood pressure regularly.
5. Use your medicines correctly.
6. Quit smoking and avoid secondhand smoke.
7. Reduce stress through yoga, meditation or other relaxation exercises.



Diabetes

What is diabetes? Most of the food you eat is broken down into a sugar called glucose. **Insulin** brings sugar into your body's cells so that it can be used for energy. When you have diabetes, your body does not make enough insulin, or the insulin may not work correctly. This may keep the sugar from moving into your cells. This leads to high levels of sugar building up in your bloodstream.

Some of the medicines that you take for COPD, especially steroids, may cause an increase in your blood sugar. Lung or other infections may also increase your blood sugar.

There is no cure for diabetes, but there are many different things you can do to manage your blood sugar and reduce the risk of serious health problems.

Common signs of high blood sugar include:

- blurry vision
- the need to urinate (empty your bladder) often
- being very thirsty
- always feeling hungry
- frequent infections

Learn more about diabetes:

www.mainehealth.org/diabetes



tips

What You Can Do

1. Talk with your doctor or nurse about a healthy eating plan.
2. Get at least 30 minutes of physical activity 5 days of the week.
3. Use your medicine correctly.
4. Test your blood sugar.
5. Talk with your doctor or nurse about your diabetes plan.

Osteoporosis

Osteoporosis is an illness in which your bones become brittle and fragile from a loss of calcium or lack of vitamin D. It may lead to a higher risk of broken bones (fractures).

You are more likely to have osteoporosis if you:

- don't get enough calcium or vitamin D in the food you eat
- had surgery to lose weight
- spend a lot of time sitting or lying in bed
- don't do any weight-bearing exercise like walking, running, jumping and weight lifting
- drink more than two alcoholic drinks a day
- use tobacco
- are underweight

Use of steroids and other medicines

Medicines used to treat COPD flare-ups like prednisone, cortisone and inhaled steroids can increase your risk of osteoporosis.



tips

What You Can Do

1. Talk with your doctor or nurse about a healthy eating plan.
2. Get at least 30 minutes of physical activity 5 days of the week.
3. Quit smoking and avoid secondhand smoke.
4. Take your medicines and vitamins correctly.
5. Ask your doctor about a **bone density test**.

Depression and anxiety

COPD may make you feel sad, scared, stressed or even angry. It is common to feel this way.

Symptoms of depression:

- lack of energy
- weight loss
- trouble sleeping
- feeling frustrated or overwhelmed
- feeling tired all the time
- feeling helpless
- little interest or pleasure in doing things

Symptoms of anxiety:

- being fearful of the unknown
- feeling like something bad is about to happen
- feeling nervous
- trouble breathing or catching your breath
- a sense of terror
- dizziness
- chest pains
- tingling in your toes or fingers

If depression and anxiety are getting in the way of living your life or causing you stress, get help. Talk with your doctor or nurse about seeing a behavioral health professional.

tips

What You Can Do

1. Attend pulmonary rehabilitation classes.
2. Get at least 30 minutes of physical activity most days of the week.
3. Learn to control your breathing.
4. Attend a support group for people living with COPD.
5. Spend time with family and friends.
6. Listen to music or meditate.
7. Do something you enjoy every day. Make yourself the most important person for a brief period every day.
8. Talk to a behavioral health professional.

IMPORTANT! If you need information and help right away, contact:

Maine Suicide and Crisis Hotline:

1-888-568-1112

National Suicide Prevention Lifeline:

1-800-273-8255

Obstructive sleep apnea

Obstructive sleep apnea (OSA) is a condition that can cause you to stop breathing during sleep. These pauses in breathing usually last 10 seconds or longer and cause the oxygen in your blood to drop. OSA can occur more often if you have COPD and can lead to heart failure, high blood pressure and memory problems.

Signs that you may have OSA:

- You are sleepy during the day, even after sleeping all night.
- You snore or make choking sounds when you sleep.
- You have been seen to have pauses during sleep.
- You wake up in the morning with a headache.

You are more likely to have OSA if you

- have severe COPD
- are overweight
- have nasal congestion
- have acid reflux
- use high doses of inhaled steroids
- smoke

Talk with your doctor or nurse if you have any of these symptoms. If you have OSA, treating your OSA may also improve your COPD.

tips

What You Can Do

1. Ask your doctor or nurse about testing for OSA.
2. Talk with your doctor or nurse about a healthy eating plan.
3. Stay at a healthy weight.
4. Get at least 30 minutes of physical activity 5 days of the week.
5. Quit smoking and avoid secondhand smoke.
6. Use your **continuous positive airway pressure (CPAP)** device as recommended by your doctor.

How to Treat COPD 5



Quitting Smoking

If you smoke, it is very important to try to quit. Quitting smoking is the most important thing you can do for your health. It can improve your COPD and prevent it from getting worse. Quitting can reduce the number of COPD flare-ups and lung infections, and reduce your risk of lung cancer. If you, a friend or a family member have COPD and want to quit smoking, ask your doctor or nurse for help. In Maine you can also call the Maine Tobacco HelpLine for free help over the phone. Free medicine to help you quit may also be available.

If you live with or are around a tobacco smoker:

- ask them to smoke outside away from people
- ask them not to smoke in your house
- ask them not to smoke in your car or truck

To help you quit smoking

- Get help to quit from family or friends, a health professional or the Maine Tobacco Helpline: 1-800-207-1230.
- Try to lower your stress.
- Talk to others or join a group to quit.
- Change your routine to not include smoking or reminders of smoking.
- Go to places where you know people aren't going to smoke.
- Make a list of reasons why you want to quit.
- Keep your hands and mind busy with things to do or think about.
- Read a book, listen to music or take a walk.
- Choose healthy foods as snacks.
- Clean out the car, or other places, of anything that reminds you of smoking.

For more information and help, contact
THE MAINE TOBACCO HELPLINE
If you live in Maine: **1-800-207-1230**
National helpline: **1-800-quitnow**

Medicines to help you quit smoking

Your doctor or nurse may talk to you about using **nicotine replacement** medicines to quit smoking. There are many different types:

- nicotine patch
- nicotine inhaler
- nicotine gum
- nicotine nasal spray
- nicotine lozenge

These medicines replace some of the nicotine you are no longer getting when you quit smoking. This can reduce cravings and make it easier to quit. People may use one or more kinds of nicotine replacement products. Which nicotine replacement product is best for you depends on how much you smoke, how soon you smoke after you wake up and other medicines you take.

People may also take bupropion (Zyban) and varenicline (Chantix) to help them quit. These medicines require a prescription.

Check with your doctor or nurse to see which medicines are right for you.

Vaping devices

Vaping devices are electronic items that produce steam vapor when smoked. The U.S. Food and Drug Administration (FDA) has not approved these items as a tool to help you quit smoking.

Learn more about quitting smoking:

www.thequitlink.com
www.smokefree.gov
www.cdc.gov



Nicotine patches

COPD Medicines

Although there is no cure for COPD, there are medicines that can help you feel better and reduce how often you have flare-ups.

Most COPD medicines are breathed into your lungs through an **inhaler** or **nebulizer**.

Inhalers

contain medicine as a mist or powder that is sprayed into your mouth and breathed into your lungs.

Nebulizers

are devices that turn liquid medicine into a mist that you can breathe into your lungs.

Both **quick-relief (rescue)** and **long-acting (controller) medicines** can be given through an inhaler or nebulizer.

The amount of medicine (**dose**) and kind of medicine you take will depend on your type of lung disease. Your doctor will prescribe the medicines that are best for you.

remember

Clean your nebulizer to prevent breathing in germs and getting a lung infection. Follow the cleaning instructions that come with your nebulizer.



Nebulizer treatment

Quick-relief (rescue) medicines

These contain **bronchodilators** that help open up your airways, making it easier to breathe. You should take them when you:

- are more short of breath than usual
- are wheezing
- are coughing more often than usual
- feel your chest is tight

These medicines start to work in a few minutes and last a few hours.

You may want to take your quick-relief inhaler before you start anything that makes your breathing more difficult, such as:

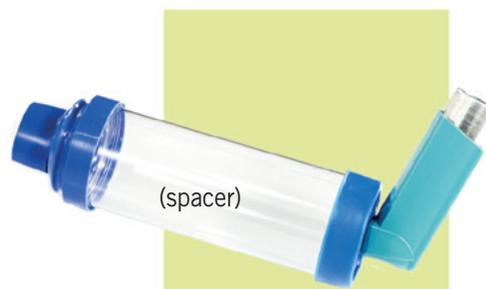
- taking a shower
- doing housework
- climbing stairs
- walking a long distance
- exercising



Soft mist inhaler



Metered dose inhaler (MDI)



MDI with a spacer

Long-acting or controller medicines

Long-acting or controller medicines are taken once or twice a day to help to prevent shortness of breath and flare-ups of your COPD. Controller inhalers may have one or two medicines in them that help keep your airways open. Controller inhalers work slowly and last 12-24 hours. They need to be taken every day.

Do not use long-acting controller medicines for sudden shortness of breath.

What side effects should I watch for when using a quick-relief or controller medicine?

- fast or irregular heartbeat, pounding heart (palpitations)
- feeling nervous or restless
- shakiness or trembling
- bad taste in your mouth
- dry mouth
- sore throat
- hoarse voice
- headache
- trouble sleeping
- feeling sick to your stomach
- urinating (emptying your bladder) more often or trouble urinating
- trouble seeing or worsening **glaucoma**

These side effects can last for a few minutes and may go away after a few days of using your inhaler. Using a spacer with your metered dose inhaler (MDI) can help reduce side effects.

Tell your doctor, nurse or respiratory therapist if you have any of these side effects. Your doctor may have you stop or change your medicines.

There are different types of inhaler devices. The type your doctor or nurse prescribes depends on which medicine you need.



Handihaler



Pressair



Diskus



Ellipta

Steroids

Corticosteroids (kor-ti-ko-ster-oids), also called anti-**inflammatory** medicines, decrease swelling in the airways in your lungs. Steroids used to treat COPD are usually taken through inhalers. It may take several days or weeks to notice a change in your breathing. Inhaled steroids may be combined with other medicines in one inhaler.

What side effects should I watch for with inhaled steroid medicines?

- sore throat
- hoarse voice
- infections in the mouth and throat (**thrush**)

To lessen these side effects, brush your teeth, rinse, gargle and spit after each time you use a steroid inhaler. If your steroid medicine comes in an MDI, use it with a spacer to reduce side effects.

Steroids can also be given as a pill or through an IV (**intravenous**). These kinds of steroids are usually given for a flare-up of your COPD. If you have a bad flare-up, you may need to be treated in the hospital.

What side effects should I watch for with pill or IV steroid medicines?

The high doses of steroids in tablet or intravenous form (or smaller doses given for long periods of time) may cause problems including:

- bruising of the skin
- weight gain
- brittle bones (**osteoporosis**)
- high blood sugar levels if you have diabetes
- cloudy eyesight (**cataracts**)
- swelling of the ankles or feet
- upset stomach

Some people find that taking their steroid tablets at mealtime reduces stomach upsets. Talk with your doctor or nurse if you have any concerns about taking steroid tablets.

tips

1. Know how to use your inhalers correctly.
2. Always use a spacer with your MDI to reduce side effects and increase how much medicine gets into your lungs.
3. If you need more than 1 puff of medicine, wait 60 seconds before taking the next puff.
4. Gargle, rinse and spit after using your steroid inhalers.
5. Store your inhalers away from sunlight, heat and humidity.
6. Clean your nebulizer to prevent breathing in germs and getting a lung infection. Follow the cleaning instructions that came with your nebulizer.
7. Carry a list in your wallet or purse of all the medicines you take, including over-the-counter medicines and vitamins.
8. Always bring this list when seeing your doctor or nurse. If you are having trouble breathing and cannot talk, this list will be helpful to the doctor who is treating you.

Combination medicines

Combination medicines contain two different types of medicine in the same inhaler or nebulizer solution. While each of these medicines can be taken in separate inhalers, it is often easier for people to take both medicines in one inhaler.

Most inhalers come with a dose counter so you know how many doses of medicine you have left in your inhaler. Because COPD medicines come in many different types of inhalers, it is very important to have your doctor, nurse, respiratory therapist or pharmacist show you the correct way to use each inhaler.

Other medicines for COPD

Theophylline medicines are a type of bronchodilator taken as a pill. Theophylline relaxes the muscles in your airways making it easier to breathe.

Roflumilast is a pill that may reduce the number of flare-ups you have.

Both of these medicines can cause upset stomach, diarrhea and headache. Talk to your doctor if you have these side effects.

remember

Always use a spacer with your metered dose inhaler (MDI).

Managing Your Mucus

People with COPD are at higher risk for getting bacterial infections in their lungs. Signs of lung infection include:

- increased cough or shortness of breath
- increased mucus (**sputum**)
- mucus color changes from clear or white to green, yellow or brown

Call your doctor or nurse if you have these symptoms.

Some people with COPD have a lot of mucus in their airways, which makes breathing difficult and can increase the risk of developing a lung infection.

Making sure you are drinking plenty of water and non-caffeinated beverages can help to keep mucus loose and easier to cough out.

There are medicines called **mucolytics**, that can help to break up the mucus, making it easier to cough it up. Your doctor may order these medicines if you have difficulty coughing mucus up out of your lungs. Many of these medications are available at your pharmacy without a prescription. Always check with your doctor and pharmacist before using any over-the-counter medicine.

Another option available to help clear mucus is a handheld device that creates a vibration in your airways. This device, called a positive expiratory pressure (PEP) device, can help move mucus up to where you can cough it out easier.



PEP device



Antibiotics

If you get a lung infection, your doctor or nurse may order antibiotics. Antibiotics are medicines used to treat bacterial infections. They are not used for treating the common cold or flu.

There are many different antibiotics used to treat infections. The type and dose of antibiotic depends on the type of infection you have.

It's important to take all your antibiotics as recommended by your doctor or nurse even if you are feeling better.



Questions to ask your doctor or nurse about antibiotics:

How long do I need to take the antibiotics?

What are the common side effects?

What are signs of allergic reaction?

What should I do if I don't get better?

Cough medicines

Mucus can make it harder to breathe and can put you at higher risk for a lung infection. Coughing helps clear the mucus in your lungs. Your doctor or nurse may prescribe a cough **expectorant**. This medicine does not stop the cough, but it helps loosen the mucus so that it is easier to cough up mucus.

If a dry cough is keeping you awake at night, tell your doctor or nurse. They may give you a cough **suppressant** to help you cough less.

Never take a cough suppressant without asking your doctor or nurse.



Breathing Exercises

Breathing exercises help you move air in and out of your lungs more easily and reduce shortness of breath. Pursed-lip breathing helps keep airways open longer so you can breathe waste air out more effectively.

Your **diaphragm** is a large muscle below your lungs that does most of the work of breathing. People with COPD often use the muscles in their neck and shoulders and between their ribs to breathe instead of using their diaphragm. This takes more energy and can make you more short of breath.

Try these breathing tips to make breathing easier and use less energy.

To practice pursed-lip breathing:

- Breathe in slowly through your nose for a count of 2.
- Purse your lips like blowing out a candle or whistling.
- Breathe out slowly through your pursed lips for a count of 4.
- Your breath out should be at least twice as long as your breath in.

To practice diaphragmatic breathing:

- Sit or lie down in a comfortable position with your head and back supported.
- Place one hand on your belly and the other on your chest.
- Breathe in slowly through your nose down to your belly. Keep your belly muscles relaxed, making your belly round. Keep your chest relaxed.
- Blow out through pursed lips.

If you start to feel short of breath during exercise or regular activities, try this:

- Stop what you are doing.
- Sit down, relax your shoulders and do pursed-lip breathing until you catch your breath.
- Continue your exercise or activity, doing pursed-lip breathing as you go.



Practice pursed-lip breathing and diaphragmatic breathing when you are relaxed and not short of breath. Practice will make these exercises easier and more natural.

Controlled coughing

Coughing is a normal way to clear mucus from your lungs. COPD can cause you to have more mucus and more frequent coughing. With COPD, your cough may be weak and coughing up mucus may be hard. Explosive or uncontrolled coughing can cause airways to collapse, making it hard to get mucus out.

Controlled coughing and huff coughing are good ways to clear mucus. These come from deep within the lungs and have just enough force to loosen and carry mucus through the airways without causing them to narrow and collapse.

To practice controlled coughing:

- Sit in a chair or on the edge of your bed with both feet on the floor.
- Lean forward slightly and fold your arms across your belly.
- Take a deep, slow breath through your nose.
- Press your arms against your belly.
- Cough once to loosen mucus.
- Cough again to move the mucus forward.
- Coughs should be short and sharp.
- Breathe in slowly.
- Relax.
- Repeat these steps if you still have more mucus to raise.



Controlled coughing can help you feel less short of breath and save energy.

To practice huff coughing:

- Sit in a chair or on the edge of your bed with both feet on the floor
- Raise your chin slightly.
- Take a deep, slow breath through your nose.
- Press your arms against your belly.
- Hold your breath for a few seconds.
- Force the breath out your mouth in one quick burst of air while keeping the back of your throat open.
- Do 2 or 3 huff breaths.
- Then rest for 5 to 10 breaths.
- Repeat the huffs until you feel you have cleared mucus or you become tired.
- Once you feel secretions in your larger airways, try a regular cough.

If you start to get tired or short of breath, go back to relaxed breathing, using pursed lips when you breathe out. Your doctor, nurse or respiratory therapist may recommend a PEP device to help loosen mucus, making it easier to cough up.

Surgical Options to Treat COPD

There is no cure for COPD, but there are ways to help you live well with it. Surgery is an option for some, but not all, people with COPD.

Lung volume reduction surgery

Lung volume reduction surgery takes out the diseased parts of one or both of your lungs.

This surgery is not for everyone with COPD. The surgeon may only consider this surgery for you if you:

- do not smoke
- have participated in pulmonary rehabilitation classes
- are strong enough to have this surgery
- are taking your medicines correctly

Lung transplant surgery

Lung transplantation is another surgical option to treat COPD. The surgeon may replace one or both of your lungs with donor lungs during this surgery. It is important to know that lung transplant surgery requires a donor lung that is a match for you.

The surgeon may consider this surgery for you if you:

- need to use oxygen all the time
- have severe COPD that is not helped with medicines
- are strong enough to have the surgery and agree to take the medicines needed after the surgery

Talk with your doctor and a surgeon to see if this surgery is an option for you.

For more information on surgical options to treat COPD:

www.cts.usc.edu/lungvolumereductionsurgery.html

www.uchospitals.edu/specialties/thoracic-surgery/lvrs.html

6 Using Oxygen to Live Well with COPD

Being told you need to use oxygen can be confusing and scary. You may be uncomfortable and self-conscious with having to use the oxygen tanks or other devices. But using oxygen will help you breathe easier and have more energy.



What Is Oxygen?

Oxygen comes from the air we breathe. Every part of your body needs oxygen to work. When our lungs are damaged, it can be harder to get oxygen from the air we breathe.

Why would I need extra oxygen?

When the oxygen in your blood is low, your heart has to work harder. You may have trouble breathing, and you may breathe faster. Your doctor, respiratory therapist or nurse may do a blood test or measure the oxygen in your blood with a **pulse oximeter**. These tests will help your doctor decide if the oxygen in your blood is too low and if you need extra oxygen. Talk to your doctor or nurse if you:

- have trouble breathing; especially when you are trying to move around
- have trouble remembering things
- feel tired after a good night's sleep
- feel like you have no energy
- have headaches when you wake up
- have trouble sitting still
- feel irritable or like you are always in a bad mood
- have swelling in your ankles

When to use your oxygen

Your doctor or nurse will recommend how much oxygen to use and when to use it. Ask your doctor if buying your own **pulse oximeter** would be helpful to you.



Oxygen Supply

There are many different kinds of oxygen equipment. Ask your doctor, respiratory therapist or nurse which device is best for you. You will need a device for home and a portable device to use when you are outside your home. You will also need to choose a company to supply your oxygen and oxygen devices.



Questions you should ask when choosing an oxygen supply company:

- Do you accept my insurance? What is covered by my insurance? _____
- Are you a national company? Will you help with travel plans? _____
- Where is your office? What hours are you open? _____
- What types of oxygen devices do you provide? _____
- How often will deliveries be made to my home? _____
- How often will the equipment be checked? _____
- How soon can you replace equipment that is not working? _____
- Is someone available 24 hours a day if I need help? _____
- How long will it take to call me back when I call with a question or I need help? _____
- How often will a respiratory therapist come to my home? _____



Concentrator

Oxygen Devices

Concentrators

An oxygen concentrator is a machine that runs on electricity. This means it needs to be plugged into an outlet. Air is pulled into the concentrator, where it is filtered and becomes only oxygen. A 25- to 50-foot tube attaches to the concentrator so that you can move around your house while you are using it. Because the concentrator runs on electricity, your oxygen company will supply you with oxygen tanks to use in case you lose power.

Portable concentrators

You can use a portable concentrator when you are not at home. These concentrators are smaller and lighter and run off a rechargeable battery. There are many types of portable concentrators. Your doctor or respiratory therapist can help you choose the best device for your needs.

Gas cylinders

Gas cylinders, also called compressed gas, are steel or aluminum tanks filled with pure oxygen. Tanks come in different sizes. Smaller tanks can be carried in an over-the-shoulder carrier or backpack-style bag.

Smaller tanks weighing 1-8 pounds are used when you are away from your home. The tank size that is best for you will depend on the amount of oxygen you need.

Larger tanks can be used as a backup for a concentrator.

It is important to secure tanks in a holder to

keep them from falling over or rolling around in your home or in the car.

Filling your oxygen cylinders at home

You can use a home oxygen system to refill your portable oxygen tanks at home so that you do not need to store as many tanks in your home. Your oxygen supply company will help decide if this is a system that is right for you.

Liquid oxygen

Liquid oxygen is oxygen in a liquid form that comes in a large tank. Smaller portable tanks can be filled from the larger tank and used when you go out. Liquid oxygen is usually ordered for people who need higher amounts of oxygen. Your doctor may order liquid oxygen if he feels this is the best choice for you.



Gas cylinder

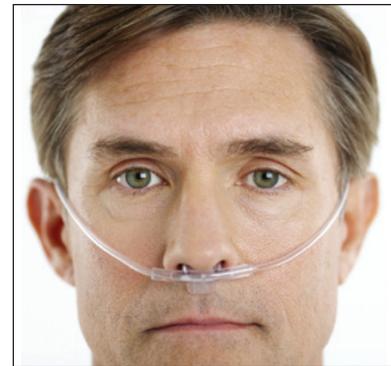
Using Oxygen

How will the oxygen get into my body?

Oxygen flows from your concentrator or tank through tubing called a cannula. Your oxygen supply company will provide you with cannulas and extension tubing. You should change your cannula every 1-2 weeks. Do not use extension tubing longer than 50 feet.

Oxygen delivery systems provide oxygen in either a **continuous flow** or a **pulse dose**. With a continuous flow, the oxygen is running constantly through the tubing into your nose and throat.

With a pulse dose, oxygen flows when you breathe in through your nose, and then stops flowing as you breathe out. Pulse dose devices are sometimes called conserving devices because they allow the oxygen in the portable tank to last longer. Pulse dose devices do not work well for everyone. Ask your doctor or respiratory therapist which device is right for you.



Cannula

Safety

Oxygen is very flammable. Notify your electric company and fire department if you use oxygen.

Follow these safety tips:

- Never smoke around oxygen devices or while wearing oxygen.
- Never allow others to smoke in your home or around you.
- Keep your oxygen cylinders at least 6 feet away from gas stoves, fireplaces, woodstoves, candles and open flames.
- Do not use an electric razor while using oxygen.
- Do not use petroleum jelly, oils or grease on or near equipment or tubing.
- Always tie or place oxygen tanks in a holder so they won't fall over.

Traveling with Oxygen

Can I travel with oxygen?

Traveling with oxygen either by car or airplane takes planning, but it can be done.

Traveling by car

If you are driving, make sure to bring extra tanks and supplies to last throughout the trip. Bring extra tubing, batteries and chargers. If you will be gone for several days or weeks, oxygen supplies can be delivered to where you are traveling. Contact your oxygen supplier for information.

Traveling by plane

If you are flying, you must contact the airlines at least 4 weeks before leaving. The airline will tell you what information they need before you fly. Oxygen tanks are not allowed on the airplane. Most portable concentrators are allowed. If you do not have a portable concentrator, your oxygen supply company can provide one to you for a fee. Make sure you have extra batteries and your charger. Be sure to charge your concentrator while you are waiting to board the plane.

Oxygen supply companies may not allow you to take their concentrator out of the country. If you are traveling outside of the country, you can contact the Airline Oxygen Council of America for help at www.AirlineOxygenCouncil.org.



Travel checklist

Traveling with oxygen takes a little more planning. Use this checklist to make the most of your trip!

- Ask your doctor before traveling.**
Check with your doctor to see if you are well enough to travel, especially if you've been hospitalized recently.
- Contact your travel company.**
Call your airline, cruise ship or bus company at least 4 weeks before departure to check for any special requirements.
- Call the airline to make sure your portable oxygen concentrator is on the approved list.**
- Complete the paperwork.**
You may need a letter from your doctor that lists all of your medicines, including oxygen.
- Take enough medicine to last the entire trip and extra days for possible delays.**
Remember to pack all medicine and supplies in your carry-on bag and keep a list of medicines with you at all times.
- Take a copy of your oxygen prescription.**
You will need to show the prescription for your oxygen to travel personnel, so be sure to carry it with you.
- Contact your oxygen supply company at least 4 weeks before leaving for your trip.**
Tell them where you are going so they can assist in arranging oxygen when you reach your destination.
- Know how to use your portable oxygen concentrator.**
Try operating on all types of power: AC, DC, battery. Test how long your batteries last at your dosage or liter flow level. Pack power cords and batteries for all your electrical equipment.
- Confirm arrangements with your oxygen supply company at least 24 hours before leaving.**

Take this contact information with you:

Your doctor:

_____ Phone # _____

Your oxygen supply company:

_____ Phone # _____

Your pharmacy:

_____ Phone # _____

Person to contact in case of emergency:

_____ Phone # _____

Staying Healthy 7



Saving Your Energy

Because of your COPD, you will need to make some lifestyle changes. Saving energy, also called **energy conservation**, is an important step.

Here are some ways you can save your energy every day:

Decide what needs to get done

- Ask yourself what is most important to you.
- Think about what you need to do today.
- Skip the things that aren't as important.

Plan ahead

- Make a schedule. Be sure to plan time for activities and rest breaks.
- Think about what time of the day you have the most energy — morning or afternoon?
- Do your hardest tasks when you have the most energy.
- Give yourself time to get extra rest before an important event.
- Avoid doing tasks when it is very hot or cold since it uses more energy.

- Have things ready before you begin a task.
- Think about what you may need from upstairs before going downstairs (so that you do not have to make extra trips up and down stairs).
- Schedule plenty of time—rushing requires more energy!

Take a break

- Schedule rest periods into your day.
- Spend some time with your legs raised to prevent swelling in your ankles.
- After you do a chore that uses a lot of energy, do a task that uses less energy like paying bills, reading or making phone calls.
- When walking, stop if you begin to feel tired or have trouble breathing.
- Take breaks to sit as needed. Practice deep, controlled breathing.
- When walking up stairs, stop often to rest. Breathe in as you rest. Breathe out through pursed lips as you take a step up.



Do tasks sitting down

- Set up a comfortable work area where you can reach everything you need.
- Sit in a comfortable chair with good back support.

Keep things in easy reach

- Keep things you use often in a convenient place.
- Keep heavier items like toaster ovens and heavy dishes at waist height to avoid extra lifting.
- Put chairs or stools around your home so you can sit while working or take breaks when walking.
- If you can, set up your bedroom and bathroom on the ground floor of your home.

Cooking and cleaning

- Sit instead of stand when you are cooking meals, washing dishes, folding laundry and other chores.
- Space out cleaning—don't do all the rooms in one day.
- Don't use harsh chemicals and spray cleaners.
- Use long-handled tools like reachers so you don't have to bend or reach.
- Cook meals in batches and freeze leftovers so that you can cook less often.
- Use the dishwasher or let items dry in a drying rack.

tips

1. Focus on your breathing.
2. When you are active, take deep, controlled breaths.
3. Fill your lungs fully—take belly breaths.
4. Don't forget to exhale—breathe out to remove the waste air from your lungs.



Showering and bathing

- Use a shower seat to rest while bathing.
- Sit when washing your face, brushing your teeth, combing your hair, and getting dressed.
- Use a long-handled brush to wash your back, legs and feet.
- Use your oxygen while bathing. Hang the tubing over the shower door or curtain.
- Wrap in a terry cloth robe instead of toweling off. It will absorb much of the water.

Getting dressed

- Store the clothes you wear most often at waist level.
- Lay out your clothes the night before.
- Wear clothes that button, zip or fasten in the front. It will make getting dressed easier and will use less energy.
- Dress your lower body first.
- Use a sock aide and long-handled shoe horn so you don't have to bend to your feet.
- Use elastic shoelaces so you can slip into your shoes or sneakers.



Let your family and friends help. They might not know what you need if you don't tell them. It is okay to ask others for help.

Lifting and carrying heavy objects

- Use a rolling cart to push heavy things instead of carrying them.
- If you need to carry heavy things, make more trips.
- Put fewer items in each grocery bag and less laundry in each basket.
- Carry things close to your body.

Tips for shopping

- Call ahead before going shopping to make sure stores will have the items you need.
- Write your grocery list in the order you'll find things in the store.
- If you don't know where things are located, ask for a map or for help. Ask the bagger to bag refrigerator items together.
- Let store employees help carry things or bring the bags to your car.
- Bring a family member or friend. Let them carry your bags into the house.
- When you get home, bring in the refrigerator bags first. Leave the other bags until after you have rested.

Controlling Stress and Anxiety

Managing a chronic illness like COPD can be stressful. As your lung disease gets worse, at times you may feel more short of breath and may not be able to do all the things you normally do. This can cause you to be anxious and frustrated.

Ways to manage your stress and anxiety:

- yoga
- meditation
- prayer
- listening to music
- relaxation exercises
- guided imagery
- going to counseling or joining a support group for people with COPD
- physical activity

tips

Relaxation Activity

Sit in a comfortable chair with your back supported. Keep your feet flat on the floor and rest your hands on your thighs. Close your eyes.

1. Take slow, deep breaths in through your nose.
2. Breathe out slowly through pursed lips.
3. Sit quietly, listening only to your breathing.
4. Tense your toes, and then relax them.
5. Tense your thighs, and then relax them.
6. Tense your arms and hands, and then relax them.
7. Shrug your shoulders, and then relax them.
8. Tighten the muscles in your face, and then relax them.
9. Take four more slow, deep breaths, and then open your eyes.
10. Take slow, and deep breaths in through your nose and breathe out through pursed lips for a few minutes before standing up.

Maintaining Intimacy

Living with COPD not only is difficult for you but can cause concern and sadness for the people that love you. Your partner may be worried that sex will be too tiring for you. Talking about your feelings and fears with your partner will help decrease those concerns. Being intimate may be holding hands, touching, hugging or sexual activity. Enjoying the warmth and closeness of your relationship is most important.

Shortness of breath and medicines can affect your sexual ability. Talk with your doctor or nurse if this happens. They may be able to change your medicine to lessen this side effect.

Tips to improve sex for you and your partner:

- Use a quick-relief (rescue) inhaler 15 minutes before you begin.
- Consider sexual activity in the morning, when you are most rested.
- Wait 2-3 hours after a meal.
- Use pursed-lip breathing to control your breathing.
- Use your oxygen, if prescribed.
- Don't rush; take your time.
- Choose a position that is the most comfortable for your breathing.
- Keep the room cool and comfortable.

You are still the same loving person you were before being diagnosed with COPD. Don't be afraid to share intimacy with your partner. Talk to your doctor or nurse about any concerns you have about sex.



Exercise

Having COPD can make it hard to breathe. Even though you may feel the need to slow down or do less, staying active will make you stronger. Regular exercise is a very important part of managing COPD.

How exercise helps COPD

You may be afraid that exercising will make you short of breath. Everyone gets short of breath with exercise. When you are not active, your muscles lose strength and it becomes harder to do physical activities.

Exercise can help:

- strengthen your muscles
- improve your flexibility
- reduce shortness of breath
- improve your balance
- you be active for a longer time

Exercising may be hard to do at first, but it will get easier as you get stronger. Learning to control your breathing and improving your strength help reduce feelings of shortness of breath.

Types of exercise

There are many types of exercise that help strengthen your muscles. Choosing something you enjoy will make doing that activity easier and more fun. You do not need to go to a gym or buy equipment to exercise. You can include exercise as part of your daily activities.

Exercise includes:

- walking
- cycling or bike riding
- swimming
- yoga
- weight lifting



How hard you exercise is important. Use the “talk test”—if you are walking with a friend and you can’t talk due to shortness of breath, you are working too hard.

How to exercise with COPD

Using pursed-lip breathing will help you control your shortness of breath. At first, you may only be able to do a few minutes of exercise at a time. Slowly increase the amount of time you exercise every week.

Start slowly

- Warm up your muscles by walking for 5 minutes at the start of every exercise.
- If your doctor or nurse has prescribed a quick-relief inhaler, use it 15 minutes before you exercise.
- Use your oxygen if prescribed by your doctor or nurse.
- Keep track of the type of exercise and how long you exercise each day.
- Wait an hour or so after eating to do any exercise or activity.
- Pace yourself.
- Exhale slowly as you push, pull or lift something.
- Do not hold your breath while exercising.
- On days you have less energy, break exercise into shorter periods. For example, you can do two 15-minute periods rather than 30 minutes.

To help you stick with it

- Make exercise part of your day—take the stairs or park farther away so you have to walk.
- Exercise when you have the most energy.
- Exercise with a friend or a group.
- Try new things so you don't get bored.

When to stop exercise:

- if you have chronic pain and it gets worse
- if you feel dizzy, have chest heaviness or feel very short of breath

Always cool down and stretch after exercise. Stretching allows your heart rate to come down, improves your flexibility and helps prevent sore muscles. Ask your doctor or nurse if there are exercises you should not do.



Pulmonary Rehabilitation

Pulmonary rehabilitation is a program led by specially trained medical staff that helps people with COPD learn to manage their lung disease. Through exercise, education, and the support of others, you will learn how to live well with COPD. Pulmonary rehabilitation is a great way to start an exercise program.

Pulmonary rehabilitation includes:

- exercise to improve your overall physical fitness
- breathing exercises to reduce shortness of breath
- energy-saving tips to improve your ability to do daily tasks
- education about your lung disease and how to best manage your symptoms
- tips to control stress and anxiety
- help to quit smoking
- support from staff and other people living with COPD

Pulmonary rehabilitation can help:

- improve your quality of life
- improve your ability to care for yourself
- allow you to go back to work or to do the things you like
- reduce hospital stays
- manage your COPD symptoms

Ask your doctor, nurse or respiratory therapist about a pulmonary rehabilitation program in your area. Learning about your lung disease and how to manage your symptoms will help you live a healthier life with COPD.



8 Nutrition



Staying at a Healthy Weight

Staying at a healthy weight is an important part of managing your COPD. Ask your doctor or nurse what you should weigh.

A healthy weight helps you:

- breathe easier
- keep your muscles strong
- fight off infections

COPD makes you use more energy to breathe. You may need to eat and drink many more calories each day than a person without COPD. A lack of appetite, depression or not feeling well can cause you to become underweight.

Being underweight can cause:

- weakness
- feeling tired
- more frequent lung infections

To gain weight, try eating and drinking:

- whole grain breads and cereals
- fresh fruits and vegetables
- high-fat proteins like whole milk, cheese, yogurt and nuts
- high-protein shakes to add calories between meals

Being overweight can cause:

- your heart and lungs to work harder
- your breathing to be more difficult
- an increased need for oxygen

To lose weight, try eating and drinking:

- more fresh fruits and vegetables than bread and pasta
- low-fat proteins such as lean meats and low-fat dairy products



tips

1. Skip sugary drinks. Most have a lot of calories with little or no nutritional value. Choose water or milk instead.
2. Stop eating before you feel full.
3. Watch your portions. Eat at home as much as possible and use the plate picture to help guide you. Check food labels for portion size.
4. Avoid trendy diets. Anything that sounds too good to be true probably is.
5. Get at least 30 minutes of physical activity 5 days of the week.
6. Vitamin pills and other supplements should not replace a healthy diet. The best way to get vitamins is through the foods you eat.

Dividing Your Plate

Fruits and vegetables:

Make half your plate fruits and vegetables. Try different kinds and colors of vegetables and fruits. Add slightly more vegetables to your plate than fruit.

Grains:

Make at least half of your grains whole grains, such as whole wheat bread and pasta, or brown rice. This will help you stay regular and healthy.

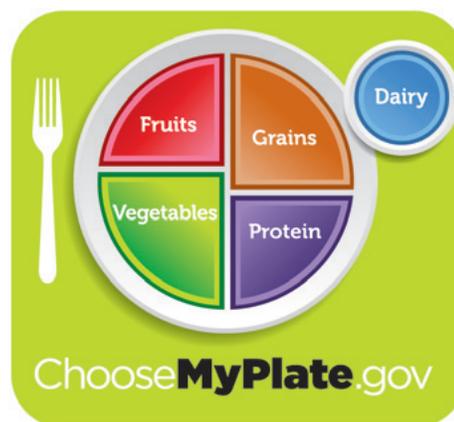
Protein:

Choose a variety of protein foods, such as fish, lean poultry or lean meat. Beans and other legumes are also good choices.

Dairy:

Dairy products include milk, cheese and yogurt.

Talk with your doctor or nurse or a registered dietician to better understand your nutritional needs.



What Foods Should I Eat Less Often?

These foods will make it hard for you to maintain a healthy weight:

- diet foods and drinks
- sweets, such as cookies, cakes, pies and sugary drinks

Foods with a lot of added salt like:

- processed foods such as cold cuts and bacon
- canned soups and vegetables
- microwave foods with high sodium (salt)

Foods that may cause gas

Some foods may cause gas and bloating and make it harder for you to breathe. Limit how much you eat or drink of these items:

- caffeinated drinks such as soda, coffee and tea
- carbonated drinks
- melons
- cucumbers
- radishes
- peppers
- beans
- broccoli
- cauliflower
- cabbage
- brussels sprouts
- onions
- fried foods



Meals

When preparing meals:

- Rest before preparing a meal.
- Sit down while preparing meals.
- When preparing a meal, make extra to freeze and use on a day when you do not feel well.
- Choose foods that don't require a lot of chewing and are easy to prepare.
- Rest after a meal; clean up after resting.
- Include foods from all food groups at each meal.

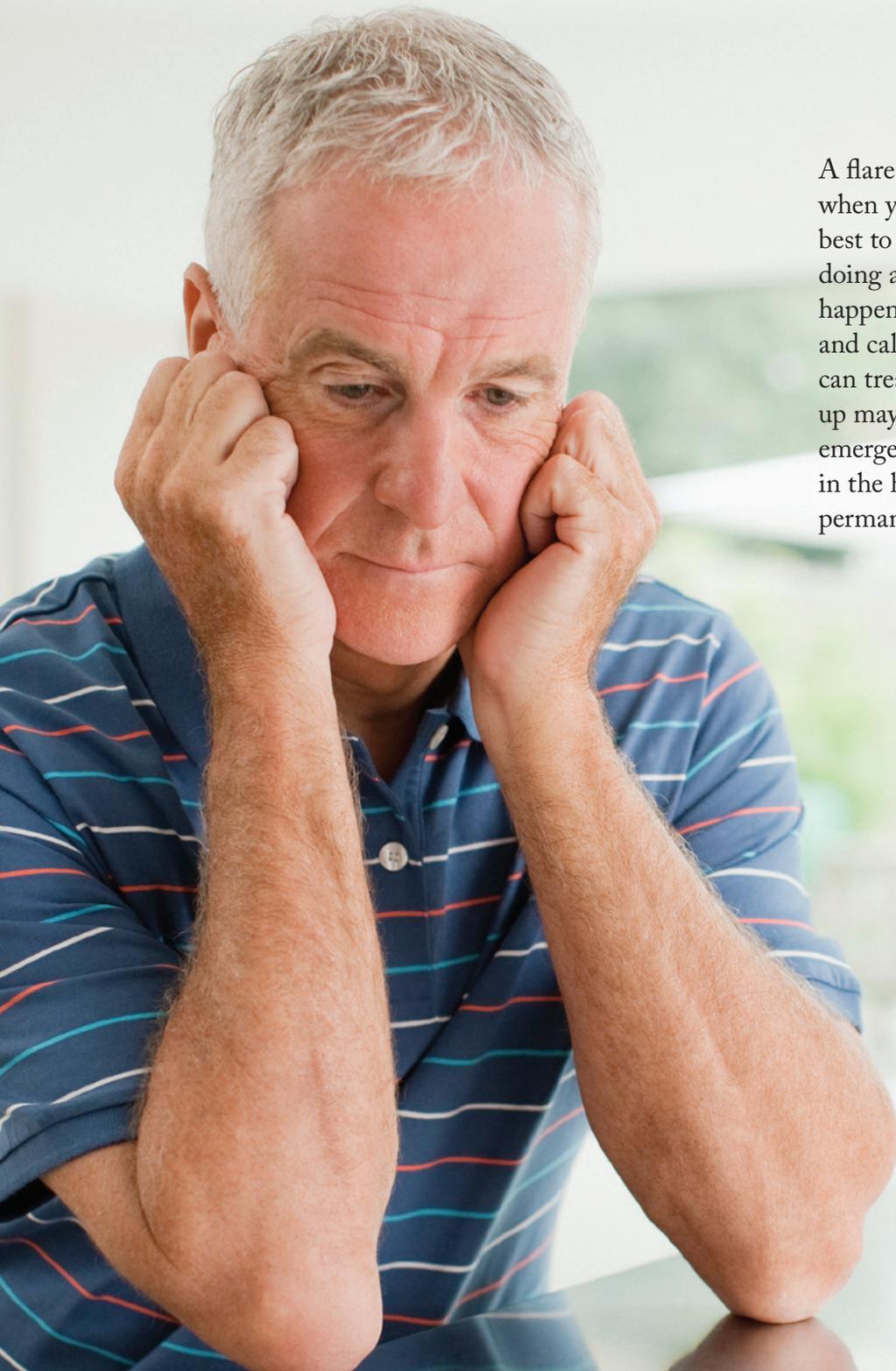
tips

For Enjoying Mealtime

1. Eat 5 to 6 small meals per day, rather than 3 large ones.
2. Eat your main meal early in the day; this will boost your energy levels for the whole day.
3. Use oxygen (if prescribed) while you eat.
4. Use your quick-relief (rescue) inhaler (if prescribed) 15-20 minutes before meals.
5. Eat with friends or family.
6. Try not to drink too much with your meal so you have more room for nutritious foods.



Flare-Ups 9



A flare-up or **exacerbation** (ex-ac-er-ba-tion) is when your everyday symptoms get worse. It is best to avoid a flare-up, but sometimes despite doing all the right things, a flare-up can happen. The sooner you realize this change and call your doctor or nurse, the sooner they can treat the flare-up. If you wait, the flare-up may last longer and require a visit to the emergency department or an overnight stay in the hospital. A severe flare-up can cause permanent damage to your lungs.

remember

You could be having a flare-up if your rescue (quick-relief) medicines don't seem to be helping.



When You Have a Flare-Up

Look for these common signs of a flare-up:

- change in your mucus amount and color
- more frequent coughing
- increased shortness of breath with activities or at rest
- wheezing
- coughing up blood
- fever or chills
- confusion or restlessness
- not wanting to eat
- fast heartbeat
- swelling in your hands or feet
- feeling more tired than usual

The most common causes of a flare-up are:

- lung or sinus infections
- very hot and humid weather
- very cold weather
- air pollution
- tobacco smoke
- not taking your medicines the right way
- strong smells
- mold
- pollen
- stress

How to Prevent Flare-Ups

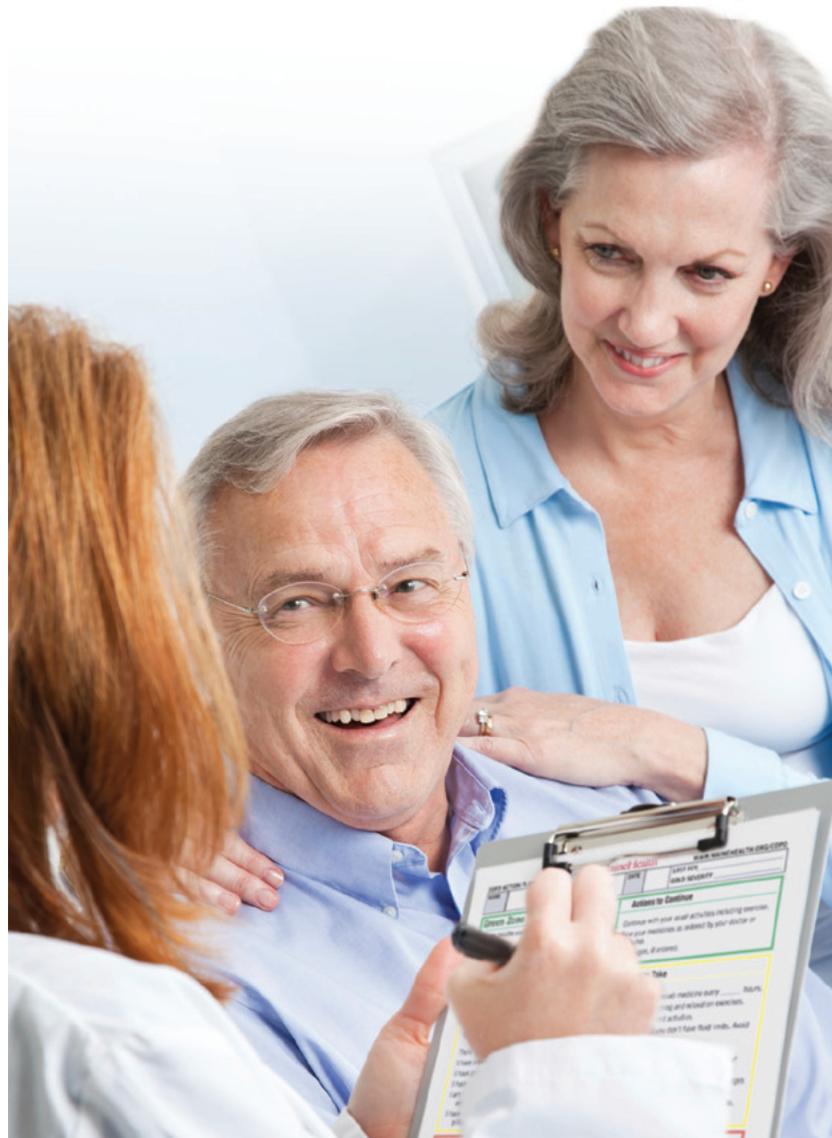
- Get an influenza (flu) vaccine every fall.
- If you are 65 years old or older, get a pneumonia vaccine.
- Stay away from people who have a cold or the flu.
- Get rest and sleep.
- Make healthy eating choices.
- Get your body moving every day.
- Clean your nebulizer as recommended by the manufacturer.
- Take your medicines as prescribed by your doctor or nurse.
- Cover your nose and mouth when it's very cold or windy outside.
- Stay inside if it's very hot or humid or if pollen levels are high outside.
- Use a fan or air conditioner.
- Stay away from fumes, tobacco and wood smoke, and strong smells.

Your COPD Action Plan

Your **COPD Action Plan** is a guide to help you recognize the early signs of a flare-up and what you should do when a flare-up occurs. Your doctor, nurse or respiratory therapist will fill out this plan with you.

remember

Follow your COPD Action Plan if you have a flare-up.



10 Dealing with Advanced Illness



When You Are Dealing with Advanced Illness

There is no cure for COPD. It is a progressive lung disease that can be managed with treatment for many years. COPD will get worse over time. You will need to think about choices for the care you want to receive as you get sicker and closer to the end of life.

Although it may be hard, talking with your doctor and family about your wishes while you are feeling well is very important. By planning ahead, your doctors and family will be able to understand how you wish to be cared for and what matters most to you.

Advance care planning

Advance directives (sometimes called living wills) are forms that you fill out to let your doctor know what your healthcare goals are and what is important to you. These forms are recommended for all adults.

Advance directives include information about:

A healthcare agent (sometimes called a medical power of attorney):

This is the person you want to speak for you if you cannot speak for yourself.

Medical care:

The medical care you wish to receive if you become too sick to make decisions or communicate with others.

Treatments:

The types of treatments you do and do not wish to receive.

It is important to talk to your **healthcare agent** about what is important to you. Your agent should be someone you trust, who is willing to accept the responsibility and follow the instructions you have given. These conversations are complex and sensitive. Ask your healthcare team for help making these decisions.

After completing your Advance Directive, share it with your doctor, family and healthcare agent.

Palliative care

The goal of **palliative care** is to help people with a serious illness live fully. It focuses on preventing suffering, managing symptoms and coordinating communication between many caregivers. Palliative care is a medical specialty, and the palliative care team includes a doctor, nurse, social worker, behavioral health therapist and chaplain. The team makes sure that all the patient and family needs are met. Palliative care can be provided at any stage of an illness, from diagnosis through the end of life, and combined with ongoing treatment.

Physician Orders for Life-Sustaining Treatment (POLST)

The POLST form is a medical order stating a patient's wishes regarding treatments. The form helps to define the goals of treatment when an illness becomes more advanced so that the patient's choices are respected and followed. It must be completed by a physician, physician assistant or advanced practice nurse and is printed on special colored paper. Emergency personnel—such as paramedics, emergency medical technicians (**EMT**), and emergency doctors—will understand these orders. POLST is also helpful in guiding treatment after the initial emergency.

remember

Keep a copy of your POLST posted on your refrigerator where the emergency responders can find it.





Questions to ask yourself

Consider these issues to discuss with your doctor, nurse and family:

- What does living well mean to you as you are dealing with COPD?

- If you get sicker, what kinds of treatments would you consider having for the possibility of gaining time? _____
- When time might become short, what matters most to you?

- What treatments will help you achieve your goals?

- If your heart stops or you stop breathing, will **cardiopulmonary resuscitation** (CPR) and being placed on a breathing machine help you? _____
- What medicines can be used to ease shortness of breath and anxiety?

- What support services are available for you and your family?

- Who do you want making choices for you if you cannot speak for yourself? _____
- Where would you like to be cared for as your lung disease gets worse?

Hospice

Hospice is unique care for people closer to the end of life who want their treatment to focus on comfort. Usually people who get hospice care have a life expectancy of a few months, not years. Even if life cannot be prolonged, comfort can be provided with oxygen, medicines and other treatments by a team of healthcare professionals. This care also includes physical, emotional and spiritual care for the patient, family and caregivers. Hospice care can be provided in the home or in other settings for you and your family.

Glossary

Advance directives (sometimes called living wills): forms that you fill out once you decide what is important to you if you should get into a health crisis

Air trapping: when it is difficult to exhale completely

Allergic rhinitis: runny nose caused by allergies

Alpha-1 antitrypsin deficiency: a genetic disease that can cause COPD

Alveoli: air sacs

Arteries: blood vessels that carry oxygenated blood away from the heart to the body's cells, tissues and organs

Arterial blood gas (ABG): a blood test from an artery that measures how well your lungs are able to move oxygen into your blood and remove carbon dioxide from your blood

Asbestos: mineral that can be woven into fabrics and is used in fire-resistant and insulating materials such as brake linings

Bone density test: x-ray that measures bone loss

Bronchial tubes: air passages or airways

Bronchodilators: medicines that make you breathe better by relaxing the muscles in your air passages and keep them from squeezing

Carbon dioxide: waste air

Cardiopulmonary resuscitation: emergency lifesaving procedure that is done when someone's heart has stopped

Cataracts: clouding of the lens in your eye

Comorbidities: other chronic diseases a person has that make treating chronic disease more difficult

Continuous flow oxygen: oxygen that runs constantly through a tube into your nose and throat

Continuous positive airway pressure (CPAP): a device prescribed by a doctor or nurse to treat OSA

COPD Action Plan: a guide to help you recognize the early signs of a flare-up and what you should do when a flare-up occurs

Coronary arteries: blood vessels that supply oxygen-rich blood to your heart muscle

Coronary artery disease: a disease in which a waxy substance called plaque builds up inside your coronary arteries

Cor pulmonale: a condition that causes the right side of the heart to fail

CT scan: a picture of the inside of a part of your body

Diabetes: a condition in which your body does not make enough insulin or does not use insulin correctly

Diaphragm: a large muscle that sits below your lungs and does most of the work of breathing

Dose: amount of medicine

Echocardiogram: an **ultrasound** of the heart

Electrocardiogram: a test that checks for problems with the electrical activity of your heart

Energy conservation: saving energy

Esophagus: passage that connects the mouth and the stomach

Exacerbation: flare-up of your symptoms

Expectorant: medicine that loosens mucus so it's easier to cough up

Gastroesophageal reflux disease (GERD): acid reflux

Glaucoma: a condition of increased pressure within your eyeball, causing gradual loss of sight

Healthcare agent: the person you want to speak for you if you cannot speak for yourself

Heart failure: a condition in which your heart can't pump enough blood to meet your body's needs

Hospice: care for people closer to the end of life who want their treatment focused on comfort

Hypertension: high blood pressure

Inflammatory: swelling

Inhaler: device that contains medicine as a mist or powder

Insulin: hormone that carries sugar into your cells so that it can be used for energy

Intravenous: in a vein

Long-acting (controller) medicines: medicines taken once or twice a day that prevent shortness of breath

Lung transplantation: surgically replacing one or both of your lungs

Lung volume reduction surgery: surgically removing diseased parts of one or both of your lungs

Mucolytics: medicines that break up mucus

Nebulizer: device that turns liquid medicine into mist

Nicotine replacement: medicines that replace the nicotine you do not get when you quit smoking

Obstructive sleep apnea (OSA): a condition that causes you to have periods when you stop breathing during sleep

Osteoarthritis: mechanical wear and tear on joints

Osteoporosis: illness that makes your bones brittle and fragile

Oxygenated: combined or mixed with oxygen

Palliative care: care provided at any stage of an illness focused on preventing suffering, managing symptoms and coordinating communication between the many caregivers

Peripheral vascular/arterial disease: a condition of the blood vessels that supply the legs and feet. It leads to narrowing and hardening of the **arteries**. This causes decreased blood flow, which can injure nerves and other tissues.

Pneumonia: lung infection

Pollutants: waste materials that are harmful to air, soil or water

Physician Orders for Life-Sustaining Treatment (POLST): a medical order stating a patient's wishes regarding treatments that are commonly used in a medical crisis

Pulmonary hypertension: high blood pressure in the arteries of the lungs

Pulse dose oxygen: oxygen that flows when you breathe in through your nose and stops when you breathe out

Pulse oximeter: a machine that measures the oxygen in your blood with a clip that goes on your finger, toe or earlobe

Quick-relief (rescue) medicine: medicine that starts to work in a few minutes and lasts a few hours

Reflux: when stomach acid backs up and irritates the esophagus

Rheumatoid arthritis: when your immune system mistakenly attacks the lining of your joints, causing a painful swelling that can eventually result in joint deformity

Secondhand smoke: smoke from a burning cigarette, cigar, pipe or hookah

Silica: a very common mineral found in many materials common on construction sites, including soil, sand, concrete, masonry, rock, granite and landscaping materials. The dust created by cutting, grinding or drilling can cause lung disease and cancer.

Sinusitis: swelling of the air cavities within the passages of the nose. Sinusitis can be caused by infection, but also can be caused by allergies and irritation of the sinuses.

Spirometry: a test to see how well your lungs are working

Sputum: mucus in your lungs

Stroke: when blood flow to an area of your brain is cut off

Suppressant: medicine to help you cough less

Thirdhand smoke: tobacco particles that stay on surfaces long after burning tobacco has been put out

Thrush: infection of the mouth and throat

Trachea: windpipe

Ultrasound: a test that uses sound waves to see inside your body

Vaping devices: electronic cigarettes, cigars and pipes that produce steam vapor when smoked



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All information from this booklet comes from medical research and local experts. It is based on the most up-to-date clinical guidelines in the Global Initiative for Chronic Obstructive Lung Disease. It does not replace the advice of your doctor or nurse.

To learn more about this topic, please go to the MaineHealth Chronic Disease COPD website at www.mainehealth.org/copd.

Information and tips
to help ease your concerns
and help you live better
with COPD.

What you need to know about:

Quitting Tobacco

Food

Treatments

Staying Active

Intimacy

Staying Healthy

Getting Things Done

Questions you should ask about:

Medicine

Travel

Oxygen Use



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