

Guide to Living with Chronic Lung Disease

Chronic Obstructive Pulmonary Disease and Other Lung Diseases

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Lung Disease

Introduction

You may have noticed you were coughing up mucus or you felt breathless when walking fast. When you saw the doctor and were told you had a chronic lung disease, perhaps you felt shocked, fearful or that it was too much to take in. The good news is, there are things you can do to manage the disease and live well. There is no cure, but treatment can ease the symptoms and slow the disease.

This handbook teaches some simple facts about lung disease and how you can feel better by changing your habits and learning new ways to handle your symptoms. Let's begin.

What is COPD?

COPD is a term for a group of lung diseases that makes it hard to get air in and out of your lungs. The letters stand for chronic obstructive pulmonary disease.

- Chronic means always present; it does not go away.
- Obstructive means the airways to the lungs are blocked by mucus or swelling.
- Pulmonary means it has to do with the lungs.
- Disease means there is damage to the lungs.

COPD includes chronic bronchitis and emphysema. The form the disease takes is different for each person.

Emphysema

Damage to the small airways and air sacs of the lungs make it hard to breath in or out. The air sacs are like balloons that can no longer return to normal size. Thus, when you breath out, old air is trapped, making it hard for fresh air that brings oxygen to enter the lungs.

Chronic bronchitis

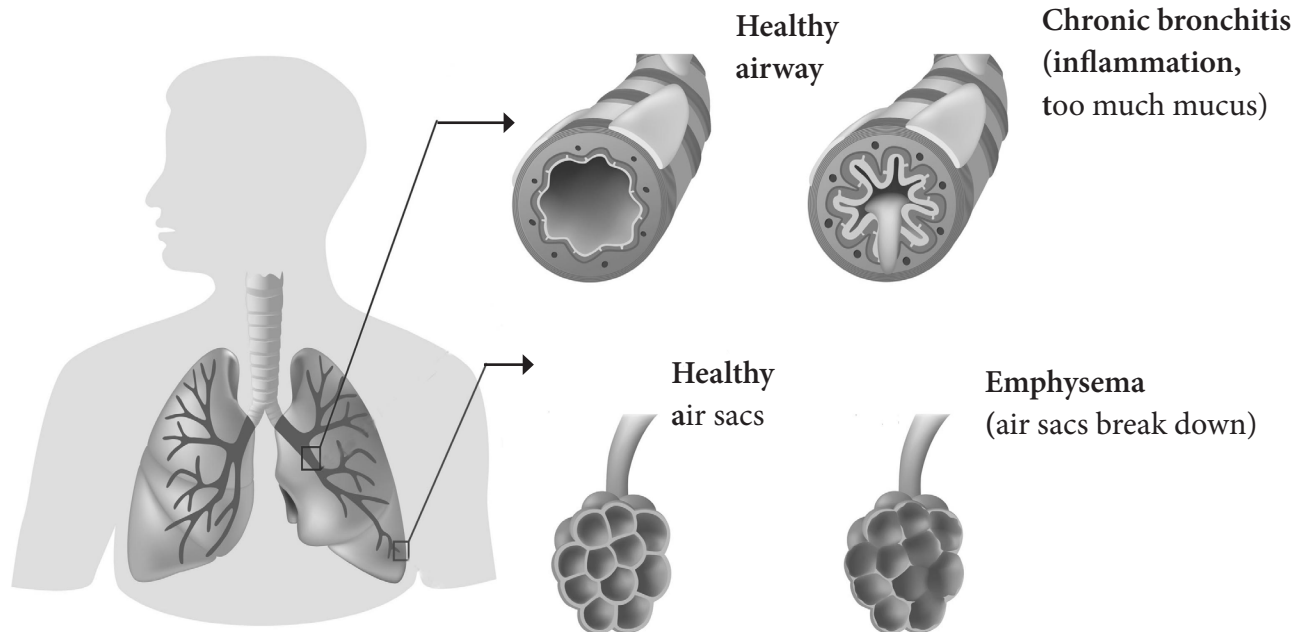
The body makes a great deal of mucus that causes coughing, mostly in the morning. Because of the mucus, it's easy for the airways to get infected. The airways are also swollen, red and sore, making it hard to breath.

Other lung diseases

Other chronic lung diseases, such as asthma, cystic fibrosis or interstitial lung disease, cause similar problems with breathing.

This guide contains information that will help anyone with lung disease to breathe and live better.

Chronic Obstructive Pulmonary Disease



What causes lung disease?

The number one cause of COPD is many years of smoking. Other causes are breathing in dust, unhealthy fumes or living with a smoker.

Asthma is triggered by factors in the environment and the cause is not fully understood.

It is also possible to inherit a lung disease, such as cystic fibrosis. Some people are born with low levels of a protein that protects the lungs, AAT (alpha-1 antitrypsin). Having too little of the AAT protein puts you at risk for emphysema.

How do you diagnose a lung disease?

Common symptoms are coughing, shortness of breath, wheezing, coughing up mucus and feeling very tired. The doctor will ask you some questions and may do a number of tests.

The exam may include:

- A physical exam
- A breathing test (spirometry test).
- A test to measure your oxygen levels
- X-rays and CT scans of the lungs.

Treating Lung Disease

How your medicines help

Medicines can help you breathe better. You will take most of your medicines with an inhaler. These medicines help relax tight muscles around the airways and reduce coughing and shortness of breath. Your doctor will tell you which type to take. It is important that you know how to take your medicine so that it works for you.

The medicine you use every day (controllers)

- Helps control your symptoms over time.
- May take a few days to make you feel better.
- Should be used even when you feel good.

The medicine you use for shortness of breath (rescue medicines)

- Helps you feel better quickly.
- Is used when you have sudden shortness of breath.
- Should be with you at all times.

Other medicines

Steroids may be taken with an inhaler or as a pill. These medicines reduce the swelling and redness of the airways.

Antibiotic medicine helps keep you from getting sick. An infection in the lungs is very serious for people with lung disease. This medicine kills germs (bacteria) that cause illnesses such as bronchitis or pneumonia.

Depending on your needs, you may take medicines to reduce fluids in your body, relieve anxiety or to help thin mucus.

Oxygen therapy

Your doctor will have you use oxygen when tests show there is not enough of it in your blood.

Oxygen therapy makes you feel better because it

- Helps you feel more alert.
- Improves thinking.
- Makes it easier to be active.
- Helps your heart work better.
- May relieve shortness of breath.

There are many ways to deliver oxygen. Your doctor will work with you to find the best device for you. You may use oxygen all the time or only for certain activities.

Using your oxygen

- You will need to learn when to use oxygen, how to use it and how to care for your equipment.
- Use the exact rate of oxygen your doctor tells you to use for each activity. Do not lower or raise the flow rate without your doctor's advice.
- Oxygen has no side effects and is not habit forming when used as directed.

Tips for safe use of oxygen

High levels of oxygen can make some things burst into flame. Follow these safety rules:

- Store in an open area away from heat and flames (furnace, heaters or stoves).
- Never use oil-, grease- or alcohol-based products on equipment.
- Do not smoke within 10 feet of an oxygen source.
- Do not use products with petroleum on your face (Vaseline, Vicks or A and D ointment).
- Always use the liter flow your doctor prescribes.
- Keep the tank secure in the stand.
- Post “No Smoking” signs near the oxygen.
- If there is a problem with the equipment, call the service. Never try to repair it yourself.

Managing your lung disease

It is important to understand how to take your medicines and when to call your doctor. Have your doctor or a pharmacist show you how to use your inhaler. There are many different types.

You can find fact sheets and videos on using specific inhalers at <http://www.fpanetwork.org/inhaler>.

If your inhaler does not have a dose counter for telling when it is time to get a refill, there are dose trackers on the website. Your rehab team can also give you these sheets.

If you take several medicines, it may help to make a chart or use a pillbox to track how and when to take them. Call your health care team with any questions.

Call your doctor if your medicines:

- Make you feel sick
- Don't have a refill
- Cost too much
- Cause side effects.

Learning about palliative care

When health problems are serious, palliative care can help. This is care that brings an extra level of support and comfort to patients and family. If you have another chronic disease, such as diabetes, you may also want the extra support.

A palliative care plan may ease pain and help you cope with stress or practical concerns. The plan is based on your values and choices. We offer this care to people of all ages, at any stage of an illness. To learn more, talk to your doctor or care team.

Living better with lung disease

- Know how to use your medicines.
- Use oxygen therapy
- Manage flare-ups
- Quit smoking.
- Breathe clean air. Stay away from cigarette smoke, dust, insect spray, paint fumes. On days with poor air quality, stay indoors or wear a mask if you go out.
- Use breathing exercises to manage shortness of breath.
- Use coughing to clear your lungs.
- Exercise and eat healthy foods
- Conserve your energy and control stress
- Get flu and pneumonia shots. Stay away from people with colds or flu.

Flare-ups

At times, your symptoms may suddenly get worse. These are known as flare-ups. They are usually caused by an infection in the lungs, although cold or polluted air may be the cause.

Signs of a flare-up include:

- Increased shortness of breath
- Coughing more often
- Coughing up more mucus
- Mucus that is yellow or green, has an odor or is bloody
- Shallow or rapid breathing
- Increase in heart rate
- Fever higher than 101°F (38°C)
- Swollen hands and feet
- Feeling very tired
- Trouble thinking clearly.

Keep your doctor's number near the phone. It is important to call as soon as you see signs of a flare-up. Your doctor may prescribe new medicines such as steroids or antibiotics. Or you may need to use a nebulizer. This machine turns liquid medicines into a vapor that you inhale.

Tips for reducing flare-ups

- Wash your hands often.
- Get flu and pneumonia shots each year.
- Avoid close contact with people who have flu or colds.
- Always take your medicines.
- Use antibiotics for sinus or lung infections.

Quitting Smoking

Quit smoking if you haven't already

Quitting smoking is the single best thing you can do to slow lung disease.

If you've tried to quit in the past, you know how difficult it is. Don't give up! Over time, smokers learn from repeated tries what it takes to quit for good.

Planning to quit

Make a plan for quitting. Pick a quit date and tell your family and friends when you plan to stop smoking.

- Get rid of all items related to smoking—cigarettes, ashtrays, and lighters.
- Stay away from places that make you want to smoke.
- You might seek out a support person or group.
- Find a hobby that will keep your hands busy.

Benefits from quitting

20 minutes after quitting

- Your heart rate drops to a normal level.

12 hours after quitting

- Your carbon monoxide blood levels drop to normal.

2 weeks to 3 months after quitting

- Your risk of having a heart attack begins to drop.
- Your breathing improves.

1 to 9 months after quitting

- Your coughing and shortness of breath decrease.

1 year after quitting

- Your added risk of coronary heart disease is half that of a smoker's.

5 to 15 years after quitting

- Your risk of having a stroke is reduced to that of a non-smoker.
- Your risk of getting cancer of the mouth, throat or esophagus is half that of a smoker's.

10 years after quitting

- Your risk of dying of lung cancer or getting bladder cancer is about half that of a smoker's.
- Your risk of getting cervical cancer or cancer of the larynx, kidney or pancreas decreases.

– American Lung Association

What makes you want to smoke?

Learn what things make you want to smoke (your triggers). Then stay away from your triggers. Some common ones: drinking coffee or alcohol, talking on the phone, watching TV and driving.

If you cannot stay away from these things, change how you do them. Choose a different room to drink your coffee or talk on the phone. Drive a new route to work.

Sometimes feelings can be triggers, such as when you feel bored, nervous, stressed or hungry.

Ask your doctor about medicines to help you stop. Make sure that they do not affect other drugs you are taking.

Some medicines replace nicotine: Nicotine patch, gum, lozenges, inhalers and nasal sprays can help lower the urge to smoke.

Ask your doctor about pills that help you quit: these include bupropion (Wellbutrin) and Chantix. They work in your brain to reduce the urge to smoke.

What to do when you want to smoke

Have a plan for what you will do when your triggers make you feel like smoking.

The urge to smoke lasts 3 to 5 minutes. If you can distract yourself, the urge will pass.

- Chew some gum or suck on hard candy.
- Do breathing exercises.
- Take a walk.
- Read through a list of the reasons you want to quit.
- Eat crunchy snacks like apples, carrots or celery sticks.
- Go to the gym.
- Hold a stress ball.
- Do something you enjoy (play a game, call a friend).

Medicines to help you quit

Staying Healthy

Pulmonary Rehabilitation

Your doctor may prescribe a rehab program that teaches you skills for living and breathing better. You will learn about lung disease, exercise and breath retraining. Topics may include saving energy during daily tasks and getting emotional support. Using your new skills will require some changes in lifestyle. Your team can help you set goals.

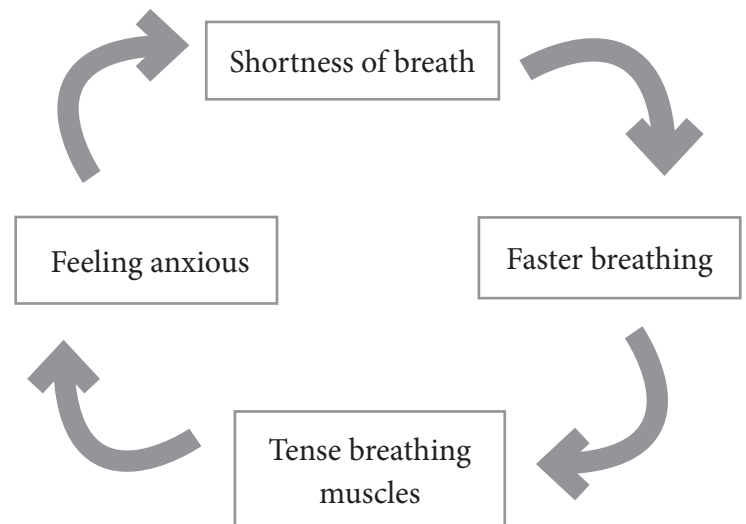
You will work with a team that may include doctors, nurses, and respiratory and exercise therapists. It may also include counselors, pharmacists and dietitians (who can help with healthy food choices).

Change is not easy, but you can prepare for it by knowing what to expect.

- **Expect new emotions.** You may feel scared or angry about the need to make changes. Talk to your team or people close to you.
- **New skills take time to learn.** Be patient with yourself as you learn new skills. With effort, you will be stronger and able to do more, and breathing will get easier.
- **Get the support you need.** Change is not easy. Let family, friends and group members know how they can help you. You can also share your own tips and ideas with members of your rehab group.

Shortness of breath and anxiety (dyspnea)

When stress builds to anxiety or fear, breathing can be affected. A cycle of stress may begin and build:



If you learn how to relax, you can prevent such events. Pulmonary rehab teaches you how to recognize your stress and relax your body.

You may find it helpful to pray, meditate, do yoga, or listen to relaxing music. Some people close their eyes and imagine a restful place. Feel the wind or sun or waves—whatever relaxes you.

The breathing methods that follow can help to prevent and relieve stress or anxiety.

Breath retraining

You can learn techniques that make it easier to bring air into and out of your lungs. With practice, you will have less shortness of breath during exercise or daily activities.

Pursed-lip breathing

Pursed-lip breathing can open your lungs and help you relax when you can't get enough breath.

To practice:

1. Relax your neck and shoulders. Breathe in through your nose as you count slowly 1 . . . 2.
2. Pucker your lips as if you are going to whistle and breathe out slowly as you count 1 . . . 2 . . . 3 . . . 4 . . .
3. Do this 4 or 5 times to slow your breathing and help you get the air you need.
4. Blowing bubbles is good practice for learning how to do the out breath.

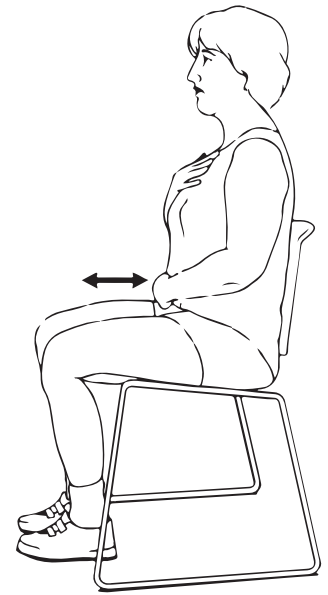


Breathing from your diaphragm

As babies, we all breathed from the diaphragm (the dome-shaped muscle under the lungs). When you are stressed, you may be breathing with the muscles of the chest, shoulders or neck. This is tiring. Correct breathing will save energy. When you use your breathing muscle, you will see or feel the rise and fall of your stomach.

To practice:

1. Place one hand over your upper chest and the other over your stomach.
2. Relax your shoulders.
3. Breathe in slowly letting the stomach move out. Keep your chest quiet.
4. Breathe out gently through pursed lips, pulling in your belly muscles.



Clearing your lungs

There are a number of ways to move mucus up and out of the airways. Your doctor can tell you about them. The huff cough is one you can learn to do by yourself.

Repeat 2 to 4 times. Spit mucus into a tissue as it comes up.

1. Sit in a chair with feet on the floor. Breathe from your diaphragm and use pursed-lip breathing to take 3 to 5 deep breaths.
2. Take a slow, deep breath.
3. Open your mouth and force the breath out as you make a “huff” sound from your throat 2 or 3 times. Some people press on the lower chest at the same time. Relax, then repeat as needed.

Breathing positions

Try these positions when you need to ease your breathing. Some of these will work better in certain situations. See which ones work for you.

Standing

When standing, lean forward from the hips and rest your forearms on something at the right height. This might be a chair, fence, a shopping cart or kitchen counter.

Sitting

Sitting uses less energy. Lean forward resting your forearms on your legs or the arms of the chair.

If you are really short of breath, try resting your head on pillow on a table.

Lying down

Try lying on your side propped up by pillows.

Stay active and exercise

Physical activity

Spending most of your day sitting is not good for your health. Staying active will help you stay healthy. Get as much activity as you can into your daily routine: do house chores or yard work, walk the dog, golf, go shopping or clean out your closets.

Find an exercise program

Exercise is planned movement that makes your body stronger and more flexible. If you are not in pulmonary rehab, talk to your doctor about how to begin an exercise program. You need to know how often to do exercise, what to avoid, and whether to use your inhaler before you begin.

You will want to start slowly and build from there. Exercise until you have some trouble breathing but can recover in one or two minutes. Then begin again.

Moving your body makes your heart and muscles stronger. As your lungs get stronger, they will use oxygen with less effort. The result is breathing will be less tiring.

Exercise offers other benefits, such as:

- Better sleep
- Lower stress
- More energy
- Lower blood pressure
- Easier weight control.

Eat a healthy diet

The food choices you make affect your weight and your energy. A dietitian can help you choose foods to create balanced meals.

Your eating plan

A healthy diet contains:

- Mostly fruits, vegetables, whole grains, low-fat milk or milk foods
- Some lean meat, chicken or turkey, fish, beans, eggs and nuts
- Small amounts of saturated fats, trans fats, cholesterol, salt and sugar

Drink plenty of fluids—6 to 8 glasses a day (unless your doctor says to limit them). Water is best and also helps prevent constipation. Drinking fluids helps thin mucus in the lungs. Oxygen therapy is drying and water will help with that. Other good fluids are coffee and tea without caffeine, juice and milk.

A healthy eating plan will help you manage your weight. If you are too heavy, it is harder to breathe because heart and lungs must work harder. If you weigh too little, you may have less energy and are more likely to get an infection.

If you have trouble eating

Avoid eating too much at one meal. Your stomach sits right under the breathing muscle (diaphragm) so a full stomach may make it harder to breathe.

Chew your food slowly with your mouth closed. This will prevent you from swallowing air. Eat several small meals a day to help prevent bloating and fullness. See [page 16](#) for resources to help with meal planning.

You may also want to avoid foods that cause gas or bloating. Everyone does not react the same to foods, so notice which foods affect you. Some foods that may cause gas are:

- Carbonated drinks
- Fried, greasy or spicy foods
- Vegetables like broccoli, Brussel sprouts, cabbage and cauliflower
- Garlic, leeks, onions
- Beans, peas or lentils
- Apples, avocados and melons
- Cucumbers, peppers, pimentos
- Corn
- Radishes.

Emotional health

Emotional health is just as important as physical health. Don't be afraid to share your feelings with your pulmonary rehab team, family and friends. They are here to help you.

The skills you learn in pulmonary rehab can make you feel better about managing your health. Below are some other ideas to help your emotions stay in balance:

- Do things you enjoy everyday.
- Stay involved with friends and family.
- Learn all you can about your disease. The more you know, the better you can manage your health.
- Share what you learn with your loved ones. Bring them along on your doctor visits. Let them know how they can help with your treatment.

Living Well Day-to-Day

Conserving energy

You can save or conserve energy by learning to do more with less effort. The key to saving energy is using your breath as you sit, stand, climb steps and do tasks during the day. When you save energy, you reduce tiredness and shortness of breath.

For example, before an activity such as standing up from a chair:

- Begin pursed-lip breathing.
- Breathe in before you stand.
- Breathe out with pursed lips as you stand up.

Pacing

Pace yourself each day. Some days you'll wake up and know if it's a day to relax or a day to tackle a project. Trust your feelings and don't take on more than you can handle.

- Never rush, walk at a slow pace.
- Plan your day and week. Limit activities each day and decide what is most important to do each day.
- Plan activity for the time of day you have the most energy. This may be right after taking your medicine.
- Wait an hour or more after meals before you exert yourself.

Simplify tasks

- Sit when possible, (such as when cooking).
- Have supplies ready before beginning a task.
- Rest often.
- Avoid bending.
- Put often-used items where you can easily reach them.
- Use a cart with wheels to carry things and make fewer trips.
- Ask yourself which tasks you can let go.

See [page 16](#) for resources on saving energy during daily tasks.

Family life

Your disease affects the people close to you. Your family and friends may serve as helpers, caretakers or support persons. They need help managing their new roles.

Suggestions for your loved ones:

- Learn about lung disease so you know what to expect.
- Join your loved one at pulmonary rehab. You will learn more about the disease and have a chance to ask questions.
- Talk to the doctor
- Take care of yourself. You may want to join a support group for caretakers.

Intimacy and sex

The need for intimacy and sex does not go away when you have a lung disease. Although you and your partner may feel anxious about sex, with planning, you can be intimate. Here are some tips to keep in mind:

- Talk with your partner about concerns you may have about sex. You are both likely to feel better. Don't be afraid to talk to your rehab team if you have questions.
- Choose times for sex when you are rested and feel your best. Use positions that use less effort, such as on your side or back.
- Plan ahead: If you have an inhaler, use it before sex. Clear your lungs if needed. If you use oxygen, set the flow rate for activity.
- You may not feel like having sex. You can still feel close and show your love by hugging, a back rub, or holding hands.

Staying well in winter

Winter weather can cause breathing problems. In cold weather you need to use more energy.

Getting dressed in winter jackets and boots takes effort. If you are not dressed warmly, you may start to shiver. Shivering uses up oxygen, leaving you short of breath.

The cold air may cause wheezing and shortness of breath. Shoveling snow and even walking in snow and ice take more energy.

To avoid breathing problems in cold weather:

- Stay in shape with regular activity. Strong muscles can do more than weaker muscles with the same amount of oxygen.
- Conserve your energy. Look for the easy way to do things.
- Do not shovel snow.
- Never hurry. Take your time getting dressed.
- Plan ahead if you travel by bus. Get a schedule so you can avoid long waits in the cold.
- Limit the time you spend outside when it is windy, rainy, snowy or cold.
- Breathe through your nose, not your mouth. Your nose does a better job of warming cold air. If you must breathe through your mouth, a mask or scarf over your mouth may help warm the air.
- Use your breathing. Take a long deep breath and let the air out slowly through pursed lips.
- Wear winter boots or shoes that have good traction. Heavy boots will wear you out. A long-handled shoe horn can help you put on boots or shoes.
- Wear mittens instead of gloves. Mittens keep your fingers warmer.

Relaxation

It is important to learn how to relax. When you are tense or stressed, it affects your physical and emotional well-being. At times of stress, the heart may work harder and your rate of breathing increases. When you can, avoid things that cause you stress.

You can also learn to deal with stress using breathing and other methods to relax. Yoga, meditation and techniques to relax the body are practices that you may find helpful.

Traveling

You can still have fun visiting family and friends or taking trips—even if you use oxygen. In order to stay safe, you'll want to plan ahead.

Tips for travel

Talk to your doctor about your travel plans. Your doctor will know if you are well enough to go. Explain where you are going, how you are getting there and how long you will be gone. Changes in climate or altitude may affect your medicines.

Get refills for all of your medicines. You will want to take enough medicines for your trip. Be sure all medicines have labels and are in the original containers. If you are traveling by plane, keep some medicines in your carry-on bag.

Keep a list of important contact information. This should include your doctor and your emergency person. Also, your airline, train or cruise line and a contact at the place you will stay.

Have a folder for important papers: Bring copies of your prescriptions and a list of all your medicines.

Get the name and location of a doctor and hospital in the city where you are traveling. Your doctor can help you with this. This is just in case you need them, especially if you are away for a long time.

Ask your doctor what to do in case of an infection. Have a plan.

Call your medical insurer. Make sure you will have coverage during the trip. You may need to buy a temporary policy.

If you use a nebulizer, get one that is portable.

Wear a medical ID bracelet.

Use hand sanitizer often to reduce the chances of an infection.

Support for Well-being

Air quality alerts

Minnesota: To see current air quality or receive daily alerts, go to mn.enviroflash.info. For air quality forecasts in the Twin Cities metro area, call 651-297-1630 or 1-800-657-3694.

USA: Visit airnow.gov to see current air quality across the nation.

Conserving energy and meal planning

For more tips on conserving energy and meal planning, see the fact sheets at: <http://www.fpanetwork.org/inhaler>. Or, ask your care team about the fact sheets.

Support groups

Better Breathers Club: Call 1-800-LUNG-USA [586-4872] for the group nearest you. Or, visit www.lung.org.

COPD Alpha-1 Support Group: For people with A1AD (Alpha 1-antitrypsin deficiency), their families and caregivers. Call 763-219-2728.

Wellness

Pulmonary Rehabilitation programs at Fairview Health Services: Ask your doctor for a referral. This program includes monitored exercise plus classes on nutrition, the disease process, medicine use, coping skills, community resources, air quality, help to quit smoking and more. For details, contact Fairview On-Call at 612-672-7272.

QUITPLAN: A free program to help smokers quit. Call 1-888-354-PLAN [7526]. Or go to www.quitplan.com.

Other resources

American Lung Association: To receive a monthly newsletter or learn more about COPD resources, call 1-800-LUNG-USA [586-4872]. Or, visit www.lung.org.

National Home Oxygen Patient's Association: An advocacy group to support people who need extra oxygen on a regular basis. Go to www.homeoxygen.org.