

A Patient's Guide to **Chronic Obstructive Pulmonary Disease**



If you have COPD, learn more about what it is, treatments and improving your quality of life

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What is COPD?

Chronic Obstructive Pulmonary Disease (COPD) is a series of chronic, progressive lung diseases that make it hard to breathe. COPD includes: emphysema, chronic bronchitis, and some forms of bronchiectasis.

What are the signs and symptoms of COPD?

- Increased breathlessness
- Frequent coughing (with or without sputum)
- Wheezing
- Tightness in the chest

What causes COPD?

- Cigarette smoking is the leading cause of COPD
- Pipe, cigar, and other types of tobacco smoke also can cause COPD, especially if the smoke is inhaled
- The majority of people with COPD smoke or previously smoked
- However, up to 25 percent of people with COPD never smoked
- Long-term exposure to other lung irritants — such as air pollution, chemical fumes, or dusts — also may contribute
- A rare genetic condition, alpha-1 antitrypsin (AAT) deficiency, can also cause the disease

What Color Am I Today?

GREEN ZONE: "All Clear" - GOAL

I am doing well today

- No increase in shortness of breath
- Usual activity and exercise level
- Usual amounts of cough and sputum
- Slept well at night
- Good appetite

YELLOW ZONE: TAKE ACTION!

I am having a bad day and/or COPD flare-up

- More breathless than usual
- Less energy for daily activities
- Increased or thicker phlegm/mucus
- Using inhaler/ nebulizer more often
- Swelling of ankles more than usual
- More coughing than usual
- I feel like I have a "chest cold"
- Poor sleep and my symptoms woke me up
- My appetite is not good
- My medicine is not helping

RED ZONE: "EMERGENCY"

I need urgent medical care

- Severe shortness of breath even at rest
- Not able to do any activity
- Not able to sleep because of breathing
- Fever 101.5°F, shaking or chills
- Feeling confused or very drowsy
- Chest pains
- Coughing up blood

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Pulmonary Doctor: _____

Phone Number: _____

Pharmacy: _____

Phone Number: _____

What to do:

- Keep up the good work
- Take your medicines
- Use your oxygen as prescribed
- Continue your regular exercise and diet plan
- Avoid cigarette smoke, other inhaled irritants and allergens at all times

What to do:

- Call your doctor or home health agency immediately if your symptoms do not improve:

Name: _____

Phone Number: _____

Home Health Agency Name: _____

Nurse: _____

Phone Number: _____

What to do: Call 911 or

- Get help and go to the emergency room
- While getting help, immediately do the following:
 1. Use your quick relief medication
 2. Use oxygen as prescribed
 3. Use pursed lip breathing

.....
Machine/Oxygen Help Company: _____

Phone Number: _____

COPD Triage Line: 860-696-9468

Tips to Save Your Energy

Plan ahead - planning your day saves time and energy:

- Figure out your best times for activity
- Schedule activities at the time of day when you have the most energy
- Plan rest breaks after meals and throughout the day
- Alternate between rest and activity

Prioritize your efforts:

- Use your energy wisely
- Be realistic about how much you can do
- Save energy for the things that matter the most of you
- Learn which tasks you need help with

Ask the questions:

- Can anyone else do this for me?
- How can I do this more simply?

Positioning yourself:

- Sit on a stool in the shower
- Install handrails if needed, as well as a hand held shower
- Arrange toiletries where you can reach them easily
- Take your time while showering
- Leave the door ajar to let the steam out
- Wear your oxygen
- Use a robe, sit and dry yourself and rest before getting dressed
- While dressing, put your pants on first and then your shirt
- Wear slip-on or Velcro shoes
- Sit down to brush your teeth or hair

Setting up your work and living space:

- Use work areas that are at a comfortable height
- Sit down whenever you can
- Keep items handy that you use often (toiletries/pots/pans/dishes/tools)
- Store items between shoulder and waist level to limit climbing, bending and reaching

Pace yourself:

- Don't rush
- To be most efficient, work at a relaxed, steady pace
- Break tasks into small steps
- A lot of people rush to avoid shortness of breath, however, rushing actually uses more energy

Practice your breathing:

Pursed lip Breathing

- Inhale slowly through your nose until your lungs fill up with air
- Purse your lips like you would if whistling
- Breathe out slowly while keeping your lips pursed
- Take twice as long to breathe out as you do to breathe in

Diaphragmatic breathing

- Sit or lie on your back so you feel relaxed
- Place one hand on your upper chest so you can feel the movement of your chest
- Place your other hand on the center of your stomach so you can feel the movement of your diaphragm
- Breathe in slowly through your nose. Let your stomach muscles relax and move outward
- Tighten and pull your stomach muscles in as you breathe out slowly through pursed lips
- Take twice as long to breathe out as you do to breathe in

Breathing tips:

- Use pursed-lip and diaphragmatic breathing while you perform tasks
- Exhale when you use effort, for example stairs, carrying items, etc...
- Don't hold your breath
- Exhale as long as you can between breaths
- Remember it is okay to be short of breath
- Don't panic... you are in control. Pace yourself and do your pursed-lip breathing

The anxiety breathlessness cycle:

- Anxiety can lead to shallow breathing and muscle tension
- Controlling your anxiety is important to prevent or decrease shortness of breath
- For many people, emotions and the fear of not being able to breathe can cause shortness of breath
- Shortness of breath can lead to anxiety. This makes you feel more tired and robs you of energy — it can be a vicious cycle

Tips to break the cycle:

- Stay active but pace yourself
- Learn to recognize situations that make you short of breath and plan for them
- Do things you enjoy. Make time for pleasant activities in your day

Your COPD Treatment Plan

Treating your lungs:

- **Medications:** some medications are quick-relieving medications to help diminish your symptoms. Other medications are prescribed to keep your airways from becoming inflamed. These are often referred to as maintenance medications. Take your medications as prescribed.
- **Oxygen therapy:** oxygen therapy is a medical treatment, prescribed by a provider, if you meet certain criteria. For people with COPD, oxygen therapy can be a helpful part of the treatment plan. Oxygen may be prescribed for use with activity, during sleep or continuously.

Preventing COPD from progressing:

- Quit smoking
- Take your medications regularly as prescribed
- Prevent infection by washing hands, oral care and immunizations
- Avoid spending time around people with respiratory infections, such as colds or the flu. Avoid crowds during the winter seasons and discuss air travel with your doctor

Medication Questions to Ask Your Provider or Pharmacist

- What do I do if I miss a dose of medication?
- Is my pharmacy able to fill my inhaled medications?
- Do I have any medication changes?
- If there are medication changes, can they be written down?
- Can I take all my medications together, and what is the proper sequence?
- Are there any medication side effects I should know about?
- Are herbal remedies, vitamins, supplements or teas safe to take with my prescribed medications?

Using Oxygen Safely

Oxygen “Do’s”

- Keep yourself and your oxygen away from anything that could cause a fire. This includes matches, candles, cigarettes, gas burners, fireplaces and other sources of open flame or sparks
- Keep oxygen unit at least five feet away from heat sources, such as space heaters, furnaces, and radiators
- Turn your oxygen off when not in use
- Have working smoke detectors, fire extinguishers and Carbon Monoxide (CO) detectors
- Have a backup tank or concentrators that run on batteries in case of a power outage

Oxygen “Don’ts”

- Don’t smoke and don’t allow others to smoke in your house
- Don’t use aerosol sprays near oxygen unit as aerosols are very flammable
- Don’t use vapor rubs, petroleum jelly, or oil-based hand lotion as they are flammable. Use water-based products instead
- Don’t use oxygen while using a gas stove or grill
- Don’t put oil on the oxygen unit
- Don’t use the unit with greasy hands

Exercise and Keeping Active

Keep active. Exercise is an important part of your treatment.

If you are prescribed oxygen with activity make sure to wear it at the prescribed flow rate. Check your oxygen saturation before you begin to exercise and when you are done (Oxygen saturations should be greater than 88%).

Stretching (refer to attached sheet for actual stretches)

- It is important to stretch before and after aerobic activity
- Do each stretch for 1-3 repetitions
- Hold each stretch for 10 seconds and work up to a 20-second hold. Do not bounce

Aerobic exercises:

Goal: 30 minutes, 3-5 times a week

- Start slowly by walking in your home and increase your time gradually in small increments. For example, add 1-2 minutes every day until you reach 30 minutes
- As you get stronger walk outdoors, at shopping malls, gyms, etc...
- If you prefer, ride a stationary bike or treadmill and follow the same guidelines
- Remember, it is ok to feel moderately short of breath — it is a sign that you are pushing yourself. But you should stop and rest if you feel severely short of breath. (Refer to Borg scale on following page)

Strength training:

Goal: 12-15 repetitions, 3 times a week (every other day)

- You can strengthen your muscles from a sitting position
- Use light weights if you have them, or even items such as water bottles or soup cans. This can be just as effective for upper body exercises

Upper body:

- Bicep curls
- Elbow extensions (for triceps)
- Rowing (for shoulders)
- Lateral raises

Lower body:

- Seated leg extension
- Leg lift – knee up to a 90-degree angle
- Sit to stands, 10-15 reps (if you don't feel strong enough, hold on to a counter and do knee bends, 10-15 reps)

How short of breath do you feel? – BORG Scale

- 0 Nothing at all
- 0.5 Very, very slight (just noticeable)
- 1 Very slight
- 2 Slight (light)
- 3 Moderate – **it's okay to feel this way when you exercise**
- 4 Somewhat severe – **you may need to slow down**
- 5 Severe (heavy) – **stop exercising, sit to catch your breath, do your pursed lip breathing, don't resume exercising until shortness of breath has resolved**
- 6
- 7 Very severe
- 8
- 9
- 10 Very, very severe (maximal)

Take Care of Your Emotional Health and Manage Stress

Take time to relax

It is important to know that your body needs relaxation to reduce stress and help prevent the dyspnea (shortness of breath) cycle. Plan on 20 minutes a day. Get positioned comfortably in silence or listen to soft music. Consider a yoga or meditation class. Also remember that pursed lip and diaphragmatic breathing can also be relaxing.

When dealing with the things that cause you stress, keep the 4 A's in mind:

- **AVOID** a stressor when you can (for example, if someone is smoking when you are attempting to quit, leave the room)
- **ALTER** how you deal with stress (for example, if you're stressed because the phone keeps ringing, turn the ringer off)
- **ACCEPT** a stressor you cannot change such as having to take daily medications or wear oxygen. Remind yourself that it is normal to feel frustrated about changes in your health
- **ADAPT** to some stressors by changing how you feel about them. Instead of focusing on how hard you assume a new exercise program will be, think about the benefits

Quit Smoking

Quitting smoking is the most important thing you can do to help COPD from getting worse.

Remember you don't have to quit alone:

- Talk to your healthcare provider about your plans to quit.
Ask about products that can help you
- Join a support group
- Call 1-800-QUIT-NOW for additional support

There is no safe tobacco – that includes e-cigarettes, cigars or pipes. All of these contain nicotine and other chemicals that harm your body and lungs. No delivery method is safe for your health.

Start the Conversation

One conversation can make all the difference — tell your family about your COPD.

COPD is a serious illness; for some patients, close monitoring and taking medications at home are not enough to keep them feeling well and out of the hospital.

Part of living with COPD is planning, including advance care planning. This begins with what is important to you and thinking about:

- Your healthcare
 - Your life and how you want to live
 - What gives you joy?
 - What gives your life meaning?
-

You don't need to rush into talking about advance care planning. Just think about it....

You can start by writing a letter — to yourself, your family, or a friend. Having a practice conversation with a friend can help. You will come to realize advance care planning isn't about dying — it's about figuring out how you want to live the rest of your life. For more information on this topic and to help you with talking to others, visit www.theconversationproject.org.

Then consider the following:

- Who do you trust to speak for you if you can't speak for yourself?
- Have you asked them?
- What would you want them to say for you? Choosing a “healthcare representative” can help. A healthcare representative is a person you trust to make sure your wishes are carried out if you are unable to speak for yourself

Some things to keep in mind when planning for the future:

- An Advance Directive (A Healthcare Representative and/or a Living Will) can help your family and medical team in medical emergencies
- They are used only when you cannot speak for yourself
- Everyone should have an Advance Directive

If you want to understand more about Advance Care Planning there is a website that is simple and easy to use to help you think about the medical care you might need in the future. To learn more visit www.prepareforyourcare.org.

Connecticut has free templates on the internet. To learn more go to: www.ct.gov/ag/lib/ag/health/yourrightstomakehealthcaredecisions-2011version.pdf

What Is Palliative Care?

If you are having trouble starting an end-of-life conversation, our palliative team can support you in this process. Just ask your provider for more information.

Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms and stress of serious illnesses. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with the patient's doctors to provide an extra layer of support. It is appropriate at any age and at any stage of a serious illness and can be provided along with curative treatment.

To learn more visit www.getpalliativecare.org.

If you can, talk with your family and your doctors about your feelings and care wishes.

