### Living with COPD An Everyday Guide for You and Your Family<sup>®</sup>

American College of Physicians<sup>®</sup> INTERNAL MEDICINE | Doctors for Adults

### Start Today!

This guide was developed by doctors, nurses, pharmacists, and patients, many of whom are in these pictures.

This guide will help you learn to make small changes that will make big differences in how you feel.

Get started now! The sooner you start, the sooner you'll begin to feel better!

## This Guide Will Help You:



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### Chapter 1: Live Well With COPD

When you have COPD, taking care of yourself is important.

By learning to take care of yourself, you will:

- Breathe easier.
- Have more energy.
- Feel better.

This guide is filled with tips from people with COPD. Use these tips to start taking better care of yourself, one step at a time.

You can't cure COPD, but you can still live a good life.



"I feel better when I make myself get out of the house and do something."



"I can still do many of the things I used to do, like play harmonica. Now I just need to pace myself."

### Facts About COPD (<u>Chronic Obstructive Pulmonary Disease</u>)

COPD is a lung disease. People with COPD have a hard time getting air in and out of their lungs.

COPD can make people:

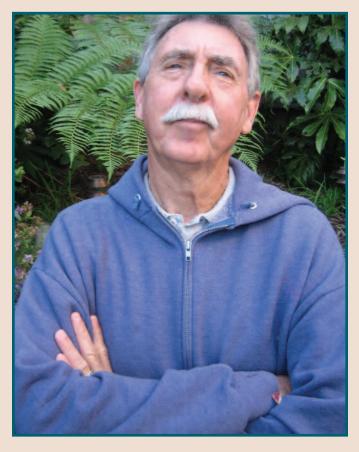
- Feel like they can't catch their breath.
- Cough a lot.
- Cough up more mucus or phlegm.
- Feel like their chest is tight.

People with COPD may feel:

- Frustrated.
- Tired.
- Scared or worried.
- Irritated or upset.
- Embarrassed.
- Depressed.

COPD may also be called **chronic bronchitis** or **emphysema**.

Most people get COPD from smoking. However, some people get it from being around other people who smoke or from breathing dirty air.



"I was always afraid when I couldn't catch my breath. This book helped me know what to do. Now I'm not so afraid."

### Chapter 2: Get The Most From Your Medicines

Most medicines for COPD are inhalers. Some inhalers are used every day. Others are used only when your breathing gets worse.

#### Medicines to use every day:

- Use these medicines every day, even when you feel good.
- These medicines only work if they stay in your lungs all the time.
- These medicines may take several days to make you feel better.
- Some doctors call these medicines **controllers** because they help you control your COPD.



"I didn't think my controllers did any good. But when I started using them every day, I breathed better and needed to use my rescue medicines less."

### Medicines to use when your breathing gets worse:

- These medicines help you feel better quickly if you can't catch your breath.
- They are called **rescue** medicines.
- Carry your rescue medicine with you all the time.

Your doctor will tell you which inhalers to use every day and which inhalers to use only when your breathing gets worse.

#### **Other medicines:**

- Your doctor may prescribe a **pill** to reduce COPD flare ups.
- Your doctor may prescribe **oxygen** to help you breathe easier.
- When you are sick, your doctor may prescribe **steroid pills** or **antibiotic pills**.

### Get The Most From Your Inhaler

Using your inhaler right will help you:

- Breathe easier.
- Have more energy.
- Feel better.

Always make sure your inhaler is clean and the mouthpiece is not blocked before you use it.



"I didn't realize I was using my inhalers wrong. My breathing got easier when I started using them the right way."

#### There are two main types of inhalers:



Mist Inhalers (puffers)



**Dry Powder Inhalers** 

### How To Use Your Mist Inhaler <u>With</u> A Spacer

1. Remove the cap and shake well.

- 2. Put the mouthpiece of the inhaler into the spacer.
- 3. Sit up straight or stand up. Breathe out like you normally do.
- 4. Close your lips tightly around the end of the spacer.
- 5. Breathe in **slowly** and deeply through your mouth. Once you have started breathing in, press down on the inhaler while you finish breathing in.
- 6. Hold your breath for 10 seconds, or as long as you are able. Then breathe out slowly.
- 7. Wait 1 minute before taking a second puff.
- 8. Rinse your mouth out or brush your teeth. This will keep you from getting an infection in your mouth.











### How To Use Your Mist Inhaler <u>Without</u> A Spacer

- 1. Remove the cap and shake well.
- 2. Sit up straight or stand up. Breathe out like you normally do.
- 3. Hold the inhaler 2 finger-widths from your mouth.
- 4. Breathe in **slowly** and deeply through your mouth. Once you have started breathing in, press down on the inhaler and finish your breath.
- 5. Hold your breath for 10 seconds, or as long as you are able. Then breathe out slowly.
- 6. Wait 1 minute before taking a second puff.
- 7. Rinse your mouth out or brush your teeth. This will keep you from getting an infection in your mouth.











### How To Use Your Powder Inhaler (Disc Style)

- 1. Hold inhaler level. Push first lever to open.
- 2. Push second lever until it clicks. This will put the medicine into the right place.
- 3. Sit up straight or stand up. Breathe out like you normally do.
- 4. Close your lips tightly around the end of the inhaler. Breathe in deeply through your mouth.
- 5. Hold your breath for 10 seconds, or as long as you are able. Then breathe out slowly.

6. When you are done, close the inhaler. Then rinse your mouth out or brush your teeth. This will keep you from getting an infection in your mouth.











### How To Use Your Powder Inhaler (Egg Style)

- 1. Take out one medicine capsule.
- 2. Open the inhaler and put the capsule in the hole. Then close the inhaler. It should click.
- 3. Hold the inhaler with the mouthpiece facing up. Press the button one time to get the medicine ready.
- 4. Sit up straight or stand up. Breathe out completely.
- 5. Close your lips tightly around the mouthpiece. Breathe in deeply through your mouth.
- 6. Hold your breath for 10 seconds, or as long as you are able. Then breathe out slowly.
- 7. Repeat steps 5 and 6 to make sure you got all the medicine out of the capsule.
- 8. Open the inhaler, take out the capsule, and throw the capsule away.



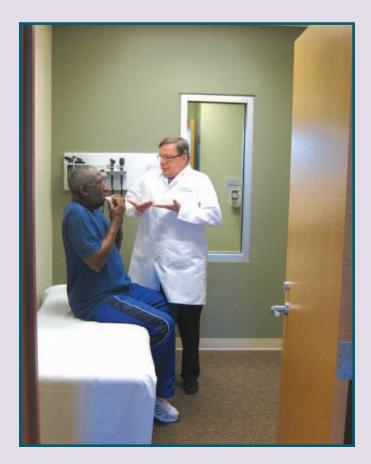








### Get The Most From Your Inhalers



- Always bring your inhalers with you when you go to the doctor. The doctor can show you how to get the most from your inhalers.
- Use your spacer with your inhaler.
- Once a week, use soap and warm water to rinse out your spacer, then let it air dry. Or put it in the dishwasher.

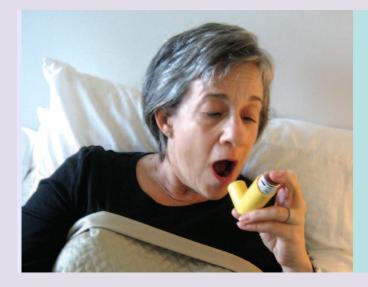


"I just wash and rinse out my spacer when I do the dishes. It's part of my routine."

# Tips For Using Inhalers



"When I started using a spacer, I noticed that my puffer worked a lot better."



"When I wake up in the middle of the night because I can't breathe, I use my rescue medicine right away. Then I can get right back to sleep."



"It's hard for me to tell when my inhaler is empty, so I asked my pharmacist for a counter."

### Take Your Medicines

Most people with COPD need to take one or more medicines. These can be inhalers, pills or both.

Make sure you understand when and how to take the medicine. Tell your doctor or pharmacist how you plan to take them and ask if that is ok.

Don't stop taking your medicine unless your doctor tells you to stop.

Call your doctor if your medicines:

- Don't have refills.
- Make you feel sick.
- Are too expensive.
- Cause any side effects.

Take all your medicines to every doctor's visit. That way you and your doctor can keep better track of your medicines.

Bring your medicines with you if you will be away from home.

Ask your family and friends for help with your medicines.

Call your pharmacist if you have a question about missed pills.





# Using Oxygen

Your doctor will tell you if you need extra oxygen.

If your COPD is severe, oxygen will help you:

- Catch your breath.
- Be more active.
- Sleep better.
- Have more energy.
- Live longer.

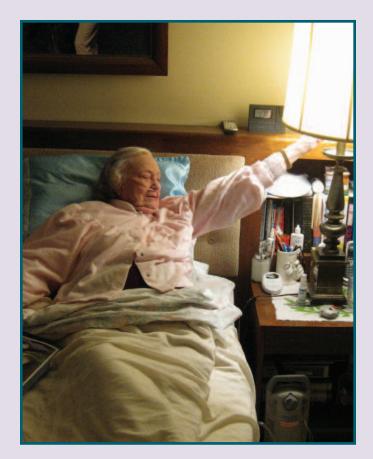
The more you wear oxygen, the more it will help you. Use it every night while you sleep. Use it as many hours of the day as you can.

Oxygen can cause fires.

- Don't smoke while you use oxygen.
- Don't use oxygen near the stove or fireplace.
- Keep a fire extinguisher near your oxygen.

Prepare for if your electricity goes out.

- Have a back-up tank.
- Call the power company and tell them you are on oxygen.





# Get The Most Out Of Oxygen



"At first I was embarrassed to use my oxygen in public, but people don't really seem to care."



"I didn't want to start oxygen because I was afraid I would never get off of it. Now when I use it, I sure feel better."



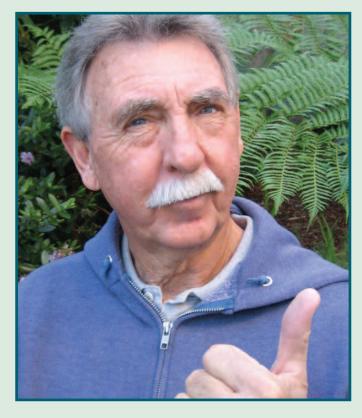
"My oxygen supply company helped me get a portable oxygen tank that I can take with me everywhere I go. Now I feel like I can do more."



"When I use oxygen, my lips and nose get dry. Lip balm helps."

### Chapter 3: Learn Breathing Exercises

Breathing and coughing exercises can help you open up your lungs and feel better. Some people with COPD think these exercises help them breathe better than anything else they do. Use them especially when you get scared.



"Doing these breathing exercises helps me feel in control of my COPD!"



"I used to panic when I felt like I couldn't catch my breath. Now I use my breathing exercises when I get in trouble."

# Pursed Lip Breathing

Pursed lip breathing can open up your lungs and help you relax when you can't get enough air. Practice this exercise a couple of times each day. Use it when you can't catch your breath or you are feeling worried.

- Take a slow breath in through your nose. While you breathe in, count to two: "One... two..."
- 2. As you breathe out, pucker or purse your lips as if you were blowing bubbles. While you breathe out, slowly count to four: "One... two...three... four..."
- 3. Repeat. Doing this 4 or 5 times can slow down your breathing and make it easier to get the air you need.

### **Remember:**

Don't breathe out too fast. Blow out like you are blowing bubbles, not like you are blowing out a candle.







### The "Good Cough"

Coughing this way a few times can help you clear the mucus or phlegm out of your lungs. It doesn't tire people out like a normal cough. Some people call this cough a **huff cough** or **forceful cough**.

- Slow your breathing down by doing pursed lip breathing 3 or 4 times. Breathe in, one...two.... Breathe out, one...two....three...four.
- Let your belly push out as you take a slow, deep breath in. Fill your lungs almost all the way.
- 3. Hold your breath while you count to four: "One...two... three...four..."
- 4. Tilt your chin up, and open your lips.

 Use your belly to push the air out of your lungs in short, quick bursts. Make a sound like "huh, huh, huh".









# Tips For Catching Your Breath



"When I climb the stairs, I stop and rest each time I breathe in, and I step up each time I breathe out."



"I always do my pursed lip breathing while I am getting dressed. It helps me control my breathing."



"I know now that I can't walk and talk at the same time. I just stop walking when I want to say something."

### Chapter 4: Be More Active

Staying active is good for your heart and lungs. Any exercise will help you feel stronger and breathe easier.

#### **Start Smart**

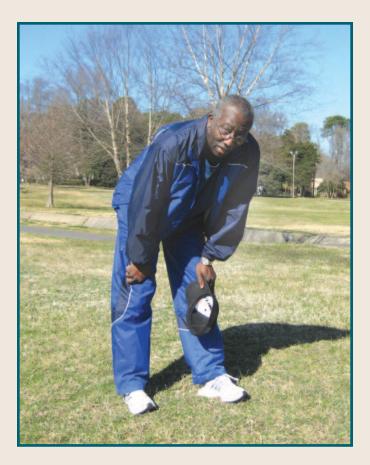
Build your strength slowly. Exercise until you have a little trouble breathing and it takes you 1 or 2 minutes to recover. Then start again.

You may be able to push yourself a little bit by doing more of the things you normally do, like:

- Doing housework.
- Working in your yard or garden.
- Playing with your grandchildren.

#### Be patient when you start

It takes a while for your body to get used to a new activity. The more active you are, the more you will be able to do.





### Pulmonary Rehabilitation Can Help

Your doctor may suggest you go to pulmonary rehab (pulmonary rehabilitation).

#### Pulmonary rehab can help you...

- Feel better.
- Be more confident.
- Build your strength.
- Learn more breathing exercises.
- Deal with stress.
- Stop smoking.

Pulmonary rehab can help you feel better whether your COPD is mild or severe.



"I like exercising with other people. Pulmonary rehab taught me new ways to breathe easier."



"The staff at pulmonary rehab knew the right exercises for me. It gave me more confidence."

### Be Active. Be Safe.

- Ask your doctor whether you can go to pulmonary rehab.
- Always bring your rescue inhaler with you when you exercise.
- Exercise inside if it is smoggy or very humid.
- Drink plenty of water.
- Push yourself but don't overdo it.







"At the grocery store I rest on my shopping cart when I get tired."

# People With COPD Say...



"If I get dressed in the morning, I am more likely to go out and be more active."



"I feel safer when I walk with somebody."



"I plan ahead. When I work in the yard, I have something to sit on if I get tired."

# You Can Do It!

### **Everyone with COPD should get regular exercise.**

Being active is good for your lungs and heart. It also will make you feel better! Try one of these ideas, or write down 1 or 2 things you can do to help be more active.

- I will exercise until I have to rest for 1 or 2 minutes. When I catch my breath, I will do it again.
- I will ask my doctor if pulmonary rehab is right for me.
- I will take a short walk every day.
- I will find a partner to exercise with.
- I will get up and move around during TV commercials.

I will work in the yard 2 days this week.

### Chapter 5: Plan For When Your Breathing Gets Worse

Notice any change in the way you feel.

If you are having trouble breathing, wheezing more, or feeling more tired than usual:

- Rest.
- Try breathing exercises.
- Use your rescue medicine.



"I know I am having a bad day when it feels like my lungs are shutting down. The harder I try to breathe, the worse it is."

Be aware of the times when your breathing gets **much** worse than usual.

Signs to watch out for:

- You are wheezing **much** more than usual.
- Your rescue medicines aren't working like they normally do.
- You are coughing more, or coughing up a different color phlegm or mucus.
- You have a fever.
- You are scared or worried.
- Your legs are swelling more than usual.

If you notice any of these problems, call your doctor. Make sure you tell them you are having trouble breathing.

#### You may need to call 911 if:

- You are breathing very fast and hard and your rescue medicine doesn't help.
- Your chest feels tight for more than 5 minutes.
- Your lips, hands, or feet turn blue.
- You can't finish a sentence in one breath.

### Tips to keep from getting sick:

- Stay away from people who have colds.
- Wash your hands a lot when you are around someone with a cold or the flu.
- Get your flu shot every October or November.
- Make sure you have had your pneumonia shot.



"I've learned to call the doctor when I am having a really bad day with my breathing."

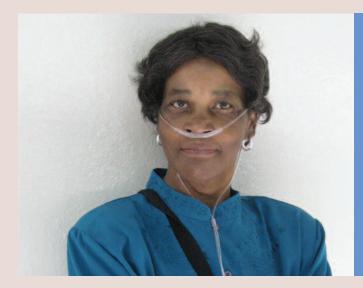


"I don't want to get sick. When I am around someone who has a cold, I wash my hands a lot."

# People With COPD Say...



"I pay attention now to how I am feeling. It tells me what I should do for my COPD."



"With my COPD I have good days and bad days. Now, I have a plan for what to do on bad days. "



"Yes, I have COPD, but I don't let it get me down."

### Chapter 6: Free Yourself From Smoking

If you are reading this chapter, you are ready to take an important step toward quitting smoking.

You probably have tried to stop smoking before. For most people, it takes many tries.

Some people think quitting is impossible, but that's just not true. Millions of people have stopped smoking. So can you!



"Quitting was the hardest thing I've done in my life. It took me six tries, but I finally did it."

"I smoked for almost 50 years. I quit for my grandchildren."



### What Makes You Want To Smoke?

Knowing your triggers can help you stay away from things that make you want to smoke.

These are triggers for many people:

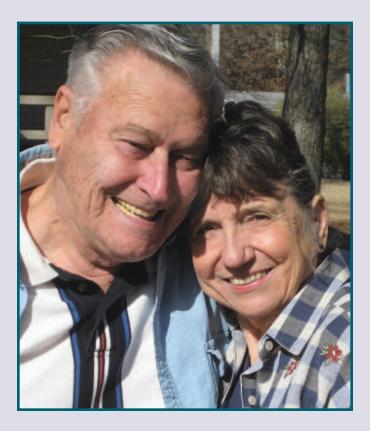
- Talking on the phone.
- Watching television.
- Driving.
- Drinking coffee or alcohol.

If you cannot stay away from the things that make you want to smoke, try to change the way you do them. Drink your coffee in a different spot, drive a different route to work, or watch television in a different room.

Sometimes feelings make people want to smoke, like being:

- Nervous or stressed out.
- Bored.
- Hungry.

Have a plan for what you are going to do when you have these feelings. This guide will help you.



### What To Do When You Want To Smoke

When you get the urge to smoke, **quickly** do something else.

- Take a few deep breaths. (Do your breathing exercises.)
- Think about something or some place that makes you feel good.
- Distract yourself with a piece of chewing gum or a healthy snack.
- Take a walk.
- Call a friend.
- Play a game or look at pictures.

Doing these things will make you want to smoke less.

"Whenever I want to smoke, I look at pictures of my grandchildren."

#### Hang in there!

A craving for a cigarette will usually go away after 3-5 minutes.



"When I get a craving, I ask myself: 'What's the worst thing that will happen if I **don't** smoke?""



"After a few minutes the urge to smoke passes. Sometimes all it takes is a walk to the mailbox."

# When You Are Ready To Quit

Pick a "quit date" to stop smoking.

Tell your friends and family you will stop smoking on your quit date.

Ask your doctor or pharmacist about medicines (or **nicotine replacements**) to help you quit smoking.

The medicines come as:

- Pills.
- Gum.
- Patches.
- Lozenges.
- Nasal spray.
- Inhalers.

On your quit date, throw away your cigarettes, ashtrays, lighters, matches, and anything else that makes you think about smoking. The harder it is to get a cigarette, the easier it will be to quit.

Quitting is not easy. Ask others for help. Get a personal quitting coach...for free. Call **1-800-QUIT-NOW** (1-800-784-8669) or a local quit line for support.









### Tips From Former Smokers The people who really understand!



"Gum or candy works for me."



"I found a friend who wanted to quit with me."



"I felt like I needed something to do with my hands. Now I draw or doodle."



"I just kept quitting until I quit."

### What To Expect When You Quit

When you first quit, you will feel bad. Everybody does. You may feel scared you can't quit and angry you have to quit. Over time though, you will notice that you feel better than you used to. This is what you can expect:

After 8 hours...you may feel cranky, on edge, and hungry. It may be hard to concentrate. You may feel tired. But the oxygen level in your blood is normal again. And your blood pressure and heart rate are going down.

**After 1 day...**you will still feel cranky and you may cough a lot. But your sense of smell and taste will start to improve.

After 3 days...you are still coughing more than usual—this is normal. But you should start noticing it is easier to breathe.



"Simple things like taking a walk got much easier when I stopped smoking." **In a few weeks...**you will be able to walk more easily. Your lungs can hold more air. You will have more energy.

**In a few months...**you will be less tired. Your cough will be better. Your breathing will be easier.

In one year...your risk of a heart attack will be halfway back to normal.

In five years...your risk of lung cancer will be halfway back to normal.

"I am back to doing the things that make me happy."



### You Can Do It!

### Here is a list of things to help you get ready to quit:

### 1. Pick a quit date. Write it here:\_\_\_\_\_

Tell your friends and family what your quit date is. Ask for their help. Ask them not to give you cigarettes...even if you ask.

### 2. Prepare for your quit date:

- Buy healthy snacks (sugar free gum, carrot sticks, sugar free hard candy).
- Talk to your doctor about pills, patches, or gum to help you stop smoking.
- Make plans to spend time with people who don't smoke and stay away from places that remind you of smoking.
  - Find a hobby that will keep your hands busy, like needlework, woodcarving, or gardening.



"I've taken up painting. I love it, and it gets my mind off wanting to smoke."

### 3. On your quit date:

- Throw away cigarettes, ashtrays, lighters, and matches from your home, car, and work.
- Start using your pills, patches, or gum.
- Stay busy with people and activities that don't remind you of smoking.
- Given the start of the start of
- Keep your hands occupied.
- Try to change your normal routine a little, like your meal time or your route to work.
- Re-read this chapter. Remind yourself to think about the things that make you happy when you get the urge to smoke.

"We quit together. Now we help each other when the smoking urge hits."



### Acknowledgements

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#### January 2014

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# My Important Numbers

Doctor:
Phone number:
Pharmacist:
Phone number:
Nurse
Nurse:         Phone number:
Dulmonary Dahah Educator
Pulmonary Rehab Educator: Phone number:
Family member:     Phone number:
Power company:         Oxygen company:
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