

# Slim Skinny Reference Guide<sup>®</sup> (SSRG)

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# Coping With Your Chronic Disease





This "Slim Skinny Reference Guide: Coping with your Chronic Disease" is part of the COPD Foundation's *Slim Skinny Reference Guide*<sup>®</sup> series which has been taken from the *COPD Big Fat Reference Guide*<sup>®</sup>.

To access the complete *COPD Big Fat Reference Guide*<sup>®</sup>, visit www.copdbfrg.org.

The mission of the COPD Foundation is to develop and support programs which improve the quality of life through research, education, early diagnosis, and enhanced therapy for persons whose lives are impacted by Chronic Obstructive Pulmonary Disease (COPD).

# **Coping With Your Chronic Disease**

We all have things we have to cope with in our lives. We all face stressful times. But now you have a new problem to face: living with a chronic lung disease—chronic obstructive pulmonary disease (COPD\*). You were probably stunned when you first learned you had this disease. If you had never heard of COPD, it may have sounded scary. You may have felt overwhelmed. Or perhaps you felt relief to finally know what was causing your breathing problems. Or perhaps it took awhile for the idea that you have a chronic disease to sink in.

Learning about a chronic illness causes many different emotional responses. In this *Slim Skinny Reference Guide*<sup>®</sup> we provide you with information about these common reactions. We also give you suggestions on how to deal with

this new stress. Ideas for coping with many emotional problems are provided.



\*COPD is an umbrella term used to describe the progressive lung diseases including: emphysema (em-fa-see-ma), chronic bronchitis (kron-ick-brawn-kie-tis), refractory (re-frac-ta-ree) asthma (az-ma) and some forms of bronchiectasis (brawn-key-eck-tay-sis). If you have COPD you have trouble moving air in and out of your lungs because of damage to the airways and/or the air sacs.

#### **Recognizing and Dealing with Stress**

We feel stress when what we need to do feels bigger than our ability to do these things. We all handle stress using our own talents and ideas.

But too much stress can be overwhelming. It can make us feel frustrated and tired. We may feel helpless. When we feel like this, adding one more problem in our lives can make us feel as though we are unable to handle even our simplest life chores. **Remember**: this Guide is not a substitute for professional counseling. If needed, your doctor can give you names of mental health professionals with whom you can talk. (See the "Getting Help From Professionals and Peers" section of this booklet.)

#### **Stress Affects Your Body and Health**

Our bodies are constantly making changes to meet the demands of each new situation. This is true for times of stress. During a dangerous situation, our bodies have acute stress reactions. Hormones are released. Our heart rate and blood pressure are increased. Our blood flow is increased to help the legs, brain and lungs deal with the new problem.

**Chronic stress** reactions occur when our bodies are in a tensed response state for a long period. If we do not manage our stress well, our bodies can be affected. The brain, heart, muscles and lungs can become overloaded. Many medical problems have been linked to chronic stress.

But through simple methods we can learn to manage our stress. These methods can help us calm our immediate reactions to stress. We can relieve long-term tension. And we can maintain a healthy balance in our lives.

# Some Methods for Helping with Stress Are:

• Listening to music: This is most helpful if you are able to do this without being distracted. Try lowering the lights. Sounds of nature (ocean, birds, waterfalls) can also be soothing.

• Exercise and stretching: Exercise is a great stress reliever. Stretching exercises, such as yoga, can provide great relief. Lying down and tightening and releasing your muscles can be very soothing. Start with your



face muscles. Move all the way down your body from your head to your toes.

- Talking About Your Feelings: Sharing your feelings with someone who cares can be a real comfort. It helps to feel you are understood.
- **Personal or Group Therapy:** There are professionals who focus on reducing stress. Therapists can help you with managing stress. Or you might prefer help from a workshop or support group. Your doctor or local hospital should be able to help you find all of these.
- **Relaxing with Meditation:** This is a way of relaxing the mind. You sit in a comfortable position and let your thoughts float away.
- **Relaxing with Biofeedback:** This is a way of getting information on how your body is working. Monitors are used to track your heart rate and muscle tension. A therapist guides you through relaxation exercises. The monitor shows you which exercises relax your body the most. This teaches you how to relax your body on your own.
- **Education:** There is much information in books and on the internet about reducing stress.

#### **Stress Causes Emotional Responses**

Stress doesn't just affect us physically. It also causes us to have emotional responses. How you responded to finding out you have COPD may be similar to the feelings people have when they experience

a major loss. Your emotions may be like the emotions felt at the loss of a job, the loss of a marriage or even a death in the family.

There is a known set of emotions related to a loss. It is known as the "grieving process." There are five stages. As you deal with the idea that you have COPD, you may have many of these grieving emotions. The Grieving Emotions Are:

**Denial:** Learning you have a chronic disease, COPD, is shocking. You might find yourself saying, "That doctor

# For family and friends — helping someone in denial:

Don't take anything personally. Be a good listener. If you feel the denial has gone on too long, avoid telling them what you think they should do or feel. Tell them what you are feeling. Don't blame them for your feelings.

doesn't know what he's talking about." Or you might say, "So I have COPD, no big deal." Perhaps you have stopped joining in social events. You may be avoiding your family and friends. It is ok to want time alone. But let your friends and family know you need this time. You don't want to push them away completely.

# For family and friends — helping someone in the anger stage:

Remember the anger is not directed at you. It is directed at the situation. Understand that this anger is part of a process. It is a sign of change. Give yourself a break from the person if you need it. But tell them you are not deserting them. **Anger:** It is normal to be angry about upsetting, life-changing information. You may think it is unfair that you have this disease. You may think, "Why me?" You may be angry at yourself for smoking. You may be angry at your doctors. You may be angry with them because there is no cure. You may be angry with your family. You may think they don't understand what you are going through. It is O.K. to be angry. Ignoring your anger can make it come out in other ways. You may nag others. Or constantly point out their flaws. Try to find a way to vent your anger without hurting anyone else. Talk with a trusted friend. Confide in your pastor. Or write about your feelings in a journal.

**Bargaining because of guilt and regret:** During this stage people want to make up for past mistakes. You may feel guilty about having COPD. You may feel guilt or regret about not taking better care of yourself. You may feel guilty about smoking. You may regret spending too much time at work and not enough with family. You may feel like time is running out. We "bargain" when we make a promise based



on the hope of getting a result we want.
 This phase can be positive. It can help
 you review what is important to you.
 It can help you make changes.

#### For family and friends helping someone in the bargaining stage:

Acknowledge their feelings. Remember that bargaining may be related to quiet guilt. Remember the past cannot be undone. Support their efforts to resolve unfinished business.

**Depression Can Create More Depression:** Depression causes us to be tired. We don't want to do much of anything. We may neglect caring for ourselves and our homes. This neglect can also be depressing. To get out of this cycle of depression try:

- Eating a well balanced diet. Avoid junk food.
- Exercising: It can improve your mood.
- · Seeking out friends: Limit the time you spend alone.
- · Sharing your feelings: Talk with friends, family or your doctor.

If none of the above efforts help your depression, you may need to seek help from a mental health professional.

**Sadness and Depression:** Everyone feels sad or depressed from time to time. Feeling depressed can also make you feel weak and tired. At this stage you may begin to think about how this disease will affect your life. You may be worried about finances. You may be concerned about your independence. Or you may be worried about your role in your family. After thinking about these issues, you can begin to prepare yourself. You can begin to cope.

#### For family and friends helping someone in the depression stage:

Help them have a realistic view of how their disease may affect their life. Share with them how you view it. Your realistic view may actually be much better than the one they have in their head. Let them know you are willing to listen.

Other non-grieving, but common emotional responses to stress:

**Confusion:** The stress of finding out you have a chronic disease can make you feel like you need to do something right away. But the disease is new to you. So, you may feel uncertain about what you can or should do. This urge to do something before you have enough information can lead to confusion. Be patient. This is not the time to make big changes. Allow some time to pass. You don't have to

#### For family and friends helping someone in the confused phase:

Avoid trying to "fix things." Assure them that you will be there to support them. Tell them that together you will work through this difficult time.

take leaps and bounds. You can take tiny, steady steps.

**Anxiety and Panic:** Anxiety is a feeling that something bad is going to happen. It is being fearful about something unknown. It is a nervous feeling. When the anxiety becomes intense it becomes panic. During an "attack" your heart may feel like it is racing and pounding. Many people experience an occasional panic attack. If you suffer repeated panic attacks, you should find a mental health professional who treats panic disorders.



During an attack you can follow a 3-step plan to help it stop:

- 1) Get in a position that will help your breathing muscles work better. Sit. Lean forward with your arms on your lap or a table.
- 2) Breathe in through your nose. Pucker your lips like for a kiss.

#### A Panic Attack Can Cause:

- A very fast heartbeat
- Difficulty breathing
- A sense of terror
- Dizziness, nausea
- Chest pains
- Hot flashes or sudden chills.
- Tingling in the fingers or toes

Breathe out through these pursed lips. Breathe out for longer and longer periods.

3) Relax all of your muscles not involved in breathing. Drop your shoulders. Let your arms go limp. Close your eyes and relax.

Fear: After finding out you have a chronic disease, you may become obsessed with fears of your death. This may happen even though you have years of life left. You may feel you've been given a death sentence. Death is not something that is talked about a lot. But if you have guestions, you may want to talk with someone about your fears. You may want to ask your doctor about what will happen as your disease gets worse. You may want to know what decisions your family will have to make. Asking these guestions is hard. Getting the answers may also be hard. But when you have addressed these fears, you can move to the next phase: acceptance.

Acceptance of your disease does not mean you have given up. It means you understand you cannot control everything in your life. It shows you are ready to move on. This can be a time of reflection and renewal. Reaching acceptance does not mean you will never feel the other emotions again. You may feel anger, depression and other emotions again. This does not mean you will have a set-back. But you may have new periods of sorting out your feelings again. This can lead to a better understanding of yourself and others.

#### **Skills for Coping with Stress**

We all have coping skills that we have used throughout our lives. What skill or plan we use to cope usually depends on the situation. What works for coping in one situation, may not work in another. There is not really one coping style that is better than all others. The more coping styles you are aware of, the better able you can handle stress and problems.

#### **Coping Styles:**

- **Confrontive coping:** An aggressive effort to change a situation. It involves some risk-taking.
- **Distancing:** An effort to detach yourself. Involves making light of the situation.
- Self-controlling: An effort to control one's feelings and actions.
- **Seeking social support:** An effort to get support from others. Support may be anything from emotional help to financial assistance.
- Accepting responsibility: Involves admitting your role in the problem. Also includes an effort to make things right.
- Escape-avoidance: An effort to avoid or escape the problem.
- **Planful problem-solving:** Involves a logical effort to change the situation.
- Positive reappraisal: A focus on personal growth.

Coping styles that worked for us at one time in our lives may not work for us as we get older. Consider the above list of coping styles. Think of times when you have used the different styles. Which were more helpful? Do you tend to use one or two styles more than others? Are there some coping styles that you never use? You should find that the *active* coping styles solve problems better than the *passive* ones.

#### Using Communication to Cope:

Getting others to understand what we mean is not always easy. Communication can be complicated. Good communication involves more than just choosing the right words. Our gestures, tone of voice, the look on our faces and even silences are all part of our message. These things tell far more than the words we speak. We have all had frustrating conversations. At those times, it seemed no matter how hard we tried we could not get the other person to understand us. Why are some conversations hard and some easy? The following tips may help.

#### Tips for Improved Communication

- Choose assertive communication: This type of communication is neither passive nor aggressive. It involves communicating your personal rights and feelings. But it does not include abusing the rights of others. Passive communication is weak and self-sacrific-ing. Aggressive communication is self-centered, hostile and demanding.
- Use exact language. Avoid the general: General statements such as, "You always do that," sound like an attack. Avoid the words "always" and "never."
- Know when the time is right for certain discussions: Avoid talking when you or the person listening does not have enough time to complete the talk fully. If the talk must be ended early, agree to pick it back up later, where you left off. If possible, avoid a "hot topic" too close to bedtime. Also avoid a "hot topic" when you know the other person is occupied with other matters.
- **Be a good listener:** Active listening means giving feedback to the other person. This will let them know if they have been understood.

This is very important when talking about difficult topics.

- Don't place blame. Avoid using "should": It is easy to look around for someone to blame when things go wrong. Or we may have regrets and may blame ourselves. Finding the blame for problems focuses our thoughts on the past. If you hear yourself using the word "should" you may be blaming someone.
- **Don't try to mind-read or expect it from others:** Remember, just because something seems obvious to you, doesn't mean that it is obvious to anyone else.
- Develop trust by taking some risks: Friendships are based on trust. We build trust by choosing to share information about ourselves with others. This may mean sharing something that may make them think less of us. To build trust we sometimes have to take risks about what we share.
- Let it all out: Sometimes the best thing to do is "let it all out." It can sometimes be a huge relief to let out all our pent-up emotional frustrations in one big outburst. One safe place to do this is with a professional therapist. They are trained to listen to



emotional outbursts.

#### Getting Help from Professionals and Peers

If you decide to seek help with coping with your emotions or dealing with the stress of living with a chronic disease, there are many resources available to you.

**Mental health professionals:** To choose a mental health professional, get a list from your insurance company. Ask your doctor for help. Friends and family may also be able to help. They may have had good experiences with one counselor. In addition, your employer may have an Employee Assistance Program. This program can help you find a professional. You may need to meet with several counselors before you find someone with whom you feel comfortable.

**Support Groups:** The COPD Foundation or your local branch of the American Lung Association can tell you if there is a COPD support group in your area. Many people with COPD find that these groups have the special understanding they need.



Visit www.copdfoundation.org or www.lungusa.org for a list of support groups in your state. Your local hospital may also have lists of support groups in your area. Choose a group that feels right to you and meets your needs. Groups led by health professionals are usually educational. Groups led by their members are usually emotionally supportive. An ideal group should have no more than 15 people.

**Faith:** For many people, having faith in a higher power gives them the strength to meet life's challenges. To explore faith in your life you may want to talk with a minister, priest, rabbi or spiritual guide. Or you may want to join a support group at your church.

#### **Reflecting on What is Important to You**

All of us have stress in our lives. Learning how to cope with this stress can decrease how it negatively affects our physical and emotional health. Having a diagnosis of COPD may give you the opportunity to stop and reflect. What is most important to you? What makes your life meaningful? What do you want to make sure continues in your life? What things are okay to give up? What things will you fight to hold on to?

Determine what is important to you in your life. Recognize and understand the common emotional responses that having a chronic disease can cause. Develop good communication skills to express yourself. Appreciate the thoughts and feelings of others. Know how to reach out for help from others.

These steps will help you plan for a rewarding life for you and your family.

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#### www.copdfoundation.org

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# **End-of-Life Issues**





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## **End-of-Life Issues**

Talking about death or "end of life" is not easy for anyone. Most of us have some fears about it. Sometimes our family members do not want to talk about it. It can be too painful for them to think

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about losing a loved one. Sometimes even doctors are not at ease with the topic. It may be hard for them because they are so focused on health and finding cures.



Often when we ask questions about death we are told to "think positively." But just thinking positively may not help you know how to plan for your death. It does not answer your questions about your future. Not knowing where to turn for answers can make you feel depressed and frustrated.

It is ok and you are not "giving up" if you ask end-of-life questions. You may want to know:

- What will happen to me as I die?
- Will it be painful?
- What treatment choices do I have?

This *Slim Skinny Reference Guide*<sup>®</sup> cannot fully answer all of your questions. But there is some general information here that may help you and your family prepare for the future.

## **Common End-of-Life Concerns**

Fear of suffocating: Many lung disease patients are afraid their death will feel like they are drowning or being smothered.

Remember: extreme shortness of breath can be treated with oxygen. Also, medicines called sedatives (said-ah-tives) can be taken. These calming drugs can reduce the feeling of struggling for a breath. During the final stages of lung disease, the lungs are not able to breathe out carbon dioxide. This causes carbon dioxide **narcosis** (nar-coe-sis). This means that the high level of carbon dioxide can have a sedative or calming effect. This leads to a state of drowsiness and then finally, to a coma.

**Pain control:** Many people are concerned that they or their loved one not suffer pain as the end-of-life is near. End stage lung disease does not usually require pain control. However, many people are worried about pain when they talk about end-of-life issues. Your doctor may first suggest over-the-counter medicines. You may have taken these before. If these medicines are not working, your doctor will want to know more about your pain. Your doctor may ask: Does your pain come and go? Do you have pain all the time? How you describe your pain will help your doctor find its cause. Pain medicines come in many forms and strengths. Your doctor may suggest a pill, capsule or liquid medicine. If these do not help, some medicines can be given by a patch on the skin. Other medicines can be given by shot or by small pumps attached to needles placed under the skin.

During the end stage of your lung disease, your doctor will take all steps needed to make sure you are given comfort. You and your family should talk with your doctor about where you wish to be during this stage of life. You might choose to be in the hospital.

Or you might choose hospice care, perhaps at home. (Hospice care is given to patients at the end stage of their disease. Patients getting hospice care usually have less than 6 months to live. It focuses on no suffering, managing symptoms and giving comfort. It can be provided at home or in a facility. It is covered by Medicare and often Medicaid.)

During this stage of life, some people want to visit with close friends and family. Other people do not want to spend too much time with too many visitors. You

#### Other Comfort Measures:

Meditation (med-ee-tay-shun) Relaxation exercise Imagery Hypnosis (hip-no-sis) Support groups Pastoral and spiritual support

should feel free to tell your family your wishes about this.

Do not feel that you have to put off discussing any of these issues until the end is near. You may want to talk about these issues long before you need to make any decisions. This will give you and your family enough time to talk about all your wishes and concerns.

#### **Making End-of-Life Plans**

Being prepared will help you to live more fully and comfortably in your final days. You and your family should talk about your disease and all your treatment choices. If you wait until you are very sick and in the hospital, you may not be able to make your wishes known. Your family members may be asked to make decisions for you. They could make a decision that you would not have wanted.

It is important for you to talk with your family and your doctor about:

- Being in the hospital—do you want to stay there or have hospice care at home?
- The use of **ventilators** (*vin-ta-lay-tors*) –this is a machine that breathes for you when you no longer can.
- **Cardiopulmonary resuscitation** (*car-dee-oh-puhl-mon-airy ree-su si-ta-shun*) (CPR)—this is an emergency medical procedure done when a person's heart stops or they stop breathing.

Often the best way to make your wishes known is to prepare Advance Directives.



#### **Advance Directives**

Advance directives can be one or more documents that explain what you do and do not want done for you at the end-of-life stage. The list is written out so that your wishes can be followed even if you are not able to talk. Advance directives can be written in many ways. You can get special forms from your doctor or the hospital. A lawyer can help you prepare them. Or many groups have information about preparing advance directives. *(See the Groups sidebar)*. They offer free forms and online help.

Advance directives do not have to be complex legal documents. They can be short, simple statements about what you do or do not want done. You can choose to simply write your wishes down.

You may want to have what you have written read by your doctor or lawyer. You should also have it **notarized** (no-tore- rized). (This means it is signed by a notary public. By signing it, the notary confirms the document was signed by you.) Copies should be given to your family and your doctor. You should also talk with your family and doctors. This is very important. **The best way to make sure your** wishes are followed is to put them in writing AND talk with your family.

Advance directives may be:

- A living will
- A **durable** (*der-rah-bull*) medical power of attorney
- A resuscitation directive

#### *Groups That Offer Advance Directives Help:*

American Medical Association

American Academy of Family Physicians

American Bar Association

American Association of Retired Persons

American Cancer Society

U.S. Living Will Registry

#### **Living Will**

A living will has information about medical procedures that you may or may not want done to keep you alive. Some of the examples of issues addressed in a living will are:

- If it is known that you will not wake up or will not be able to use your body in a meaningful way, do you want to be kept alive? Do you want to be on **mechanical ventilation** (meh-can-ni-cal ven-ti-lay-shun)? This means a machine would breathe for you.
- If you will not wake up, do you want to be fed through a feeding tube? A feeding tube gives you liquid food to help you stay alive. The tube is passed through your nose or into your stomach through a small hole.

A living will can be very specific. Or, it can be a broad statement of what you do and do not want. A living will should be a guide to help your family understand your wishes. They might be asked to make decisions for you if you are unable.

## **Durable Medical Power of Attorney**

A Durable Medical Power of Attorney paper allows you to select a trusted person to make medical decisions for you.

Hospitals and doctors do not want to make your medical decisions. This is true even if you have a living will.

The person named in your Durable Medical Power of Attorney only has the right to make *medical* decisions for you. This document does not allow the person to make financial or other decisions for you.

#### **Resuscitation Directives**

When your heart stops working or your breathing stops, cardiopulmonary resuscitation or CPR is begun. This is done to try and restart your heart or breathing. There may be certain situations in which you might choose that CPR not be done. If you do not want CPR done in these situations you can create a document asking that you be listed as "DNR—do not resuscitate."

#### And finally...

For many people, the final stage of their life is a time to do many of the things they put off. Some people describe this time of life as a happy period. It can be a time when family and friends come together and share. For some, this stage gives them the chance to find answers to long-held problems. Many people see this stage of their life as a chance to share what they have learned with others. And still others find comfort in spending time alone. **What we decide is meaningful and is different for each of us.** 

"I wanted a perfect ending. Now I've learned, the hard way, that some poems don't rhyme, and some stories don't have a clear beginning, middle and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next. Delicious ambiguity." — Gilda Radner, actress, comedian.



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# Recognizing and Treating Exacerbations





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### What is an Exacerbation?

An important part of managing your lung disease, is knowing when your symptoms are changing. You can have no symptoms or unchanging symptoms for a long time. But then suddenly you could have new breathing problems. These flare-ups of your lung disease are **exacerbations** (*x*-saa-cer-bay-shun). These can be very serious. They even cause you to be in the hospital. Knowing what to do when you have one of these flare-ups is very important.

\*COPD is an umbrella term used to describe the progressive lung diseases including: emphysema (em-fa-see-ma), chronic bronchitis (kron-ick-brawn-kie-tis), refractory (re-frac-ta-ree) asthma (az-ma) and some forms of bronchiectasis (brawn-key-eck-tay-sis). If you have COPD you have trouble moving air in and out of your lungs because of damage to the airways and/or the air sacs.

#### **Changes in Signs and Symptoms**

The first step in coping with a flare-up or exacerbation is watching for changes in your symptoms. The quicker you know you are starting to have problems, the quicker you and your doctor can deal with it. Coughing, feeling breathless and having a lot of mucus is common for COPD patients. But being able to tell just a "bad day" from a serious exacerbation is important. Some things that might cause you to just have a "bad day" are: weather, barometric changes, emotions, allergies, higher altitude and using an empty inhaler. A true exacerbation or flare up is much worse than just a bad day.

#### **Knowing When You are Having an Exacerbation**

Warning signs that a flare-up is happening or about to happen are different for each person. You will know best when your breathing problems are getting worse. But sometimes, some signs of a problem will be noticed by your friends and family first. Make sure your friends and family are aware of the signs below. The most common signs and symptoms of a flare up or exacerbation are:

- You have more trouble breathing, even when resting
- You have more wheezing
- You are coughing more
- You are producing more mucus
- The mucus looks different. It may have changed color from clear to yellow or green. It may contain blood or may be thicker and sticky
- You have tightness in your chest
- Your hands and feet are swollen from fluid
- You are more forgetful, sleepy, confused and slurring your speech
- You are irritable. You have a change in your personality



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In addition, an exacerbation may come with:

- An increased period of feeling tired and a long period of having no energy
- Fever
- Changes in the color of your skin—to a blue or ashen color. This may be seen in the fingertips or lips
- More morning headaches, dizzy spells and restlessness
- A need to increase your oxygen, if you are on oxygen
- Rapid breathing
- Rapid heart rate

#### Counting Your "Respirations" or Breathing Rate for One Minute:

- 1) Place your hand on your upper chest to feel it rise and fall. Each rise and fall counts as one "respiration."
- 2) Look at your watch. Count the number of respirations in 30 seconds. Multiply this number by two.

#### IMPORTANT: Know your heart rate and rate of your breathing.

As a person with COPD, it is important that you know what your heart rate and breathing rates are when you are feeling good. These are called your **"baseline"** rates.

When you start to feel a flare-up coming on, take your heart rate and breathing rate. Compare these to the baseline rates.

Knowing if your breathing and heart rates have increased will help you talk to your doctor about your flare-up. Your doctor will use this information to help decide how to treat your exacerbation.

#### **Counting Your Heart Rate for One Minute:**

- 1) Find the heart beat or pulse in your neck. Put your index and middle finger to the side of your throat, under your chin. Don't press too hard. Don't rub.
- 2) Look at your watch. Count your heart beat for 6 seconds.
- 3) Add a "0" to that number. This equals the number of times your heart is beating each minute.

#### Note

A pulse oximeter (ox-sim-meh-ter) is a device which measures your heart rate and the amount of oxygen in your blood. It is placed on your finger.



# What Causes a Flare-up or Exacerbation?

An infection in your lungs is almost always the cause of an exacerbation. These infections may be caused by viruses or bacteria. **Antibiotics** *(an-tee-by-ah-ticks)* are medicine that can be given for an infection caused by bacteria. These drugs do not help with infections caused by viruses.

But many times, when a person with COPD gets an infection from a virus, they also get a second infection from bacteria. This happens because the virus has caused more mucus to be made. And the virus has made the lungs irritated. Together, this causes more bacteria to grow in the lungs. This can lead to a bacterial infection.

So, antibiotics are almost always used to treat serious exacerbations.

Other causes of exacerbations include: sinus infections, indoor and outdoor air pollution, pulmonary edema and blood clots to the lungs.


### You Can Reduce How Often You Have Exacerbations and How Serious They Are

You can not totally prevent exacerbations. But you can reduce how often you have them. And you can reduce how serious they are, if you work to stay as healthy as possible.

### Tips for reducing exacerbations:

- Wash your hands often. This will help prevent infections.
- Avoid close contact with people who have colds or the flu.
- Get a flu and **pneumonia** (*new-moan-ya*) shot each year. This is a very important way to protect yourself.
- Help your lungs work their best by always taking your COPD medicines. These maintenance medicines that your doctor has prescribed for you can help reduce exacerbations. The Food and Drug Administration (FDA) has approved several drugs (inhaled bronchodilators and inhaled steroids) for this use.
- Use antibiotics quickly for infections or sinus problems.
- Use hand-held **spirometry** (*spee-rom-meh-tree*) to know easily how well your lungs are working (see box).

### Hand-held Spirometry Devices:

- Measure how well your lungs are working.
- Measure how much air you can blow in 1 second.
- Are helpful in knowing when an exacerbation is starting.
- Are small and can fit in your pocket for easy travel.



### Have a Plan for How to Treat Your Exacerbation

You and your doctor should create a written plan for dealing with very serious exacerbations. This plan may include adding to or changing the medicines you normally take. Your doctor may prescribe oral steroids for you during the flare up. You may need to take more of your medicines than you usually take. Or if you are



not using an inhaled steroid, you may need to during the exacerbation. You may also need to be given oxygen.

If you have a written plan, you may be able to deal with your exacerbation at home. But there will be times when your flare up is so bad you will need to see your doctor. Or you may even need to go to the Emergency Room and you may be admitted to the hospital. Sometimes it can be hard to know when to contact your doctor or when to go to the hospital. **You should talk with your doctor about the guidelines below.** 

Knowing when to call the doctor and when to go to the hospital:

- 1) If you do not have a written plan to follow (that your doctor has agreed to) you should call your doctor within 24 hours if you have one or more of the following:
  - Shortness of breath or wheezing that does not stop after using your inhaler
  - Change in color, smell, amount or thickness of the mucus you cough up
  - New or increased ankle swelling (that lasts even after a night of sleeping with your feet up)

- You wake up short of breath more than once a night
- You are very tired and this lasts more than one day
- You have a fever that lasts
- 2) Go directly to the Emergency Room or call 911 if you are having the following:
  - Confusion, slurring of speech or sleepiness during a serious lung infection
  - Loss of alertness or two or more of:
    - Increase in seriousness of symptoms, such as trouble breathing at rest
    - Struggling to use your upper chest or neck muscles to try to breathe
    - A large increase in how fast your heart is beating
    - A large increase in how fast you are breathing (your respirations)
  - Any severe shortness of breath or chest pain or any other severe symptoms

### Things NOT to do during an exacerbation

Do not take extra doses of **theophylline** (thee-oh-fi-leen).

Do not take codeine or any type of cough **suppressant** (sue-press-ant).

Do not use over-the-counter nasal sprays for more than three days.

Do not smoke.

Do not wait more than 24 hours to call your doctor, if your symptoms continue.



#### Many Types of Drugs Are Used to Treat Exacerbations:

Drugs that help open up narrowed airways: **short-acting beta2-agonists, anticholinergic** (an-tee-cole-i-ner-jics) **bronchodilators** (brawn-coe-die-lay-ters), **theophylline**.

Drugs that prevent bronchospasms (when the muscles around the lungs' bronchial tubes tighten): **long-acting bronchodilators**.

Drugs to treat lung infections (these are usually given at the first sign of an infection): **antibiotics.** 

Drugs that help you loosen and cough up mucus: **expectorants** (x-peck-tore-ants).

Drugs that reduce lung irritation and lessen your symptoms overall: **oral steroids.** 







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# Exercise for Someone with COPD







This "Slim Skinny Reference Guide: Exercise for Someone with COPD" is part of the COPD Foundation's *Slim Skinny Reference Guide*<sup>®</sup> series which has been taken from the *COPD Big Fat Reference Guide*<sup>®</sup>.

To access the complete *COPD Big Fat Reference Guide*<sup>®</sup>, visit www.copdbfrg.org.

The mission of the COPD Foundation is to develop and support programs which improve the quality of life through research, education, early diagnosis, and enhanced therapy for persons whose lives are impacted by Chronic Obstructive Pulmonary Disease (COPD).

# **Exercise for Someone with COPD**

We all know we should exercise. But it is easy to find excuses for not exercising. We're too tired. We don't feel well. We can't find the time. And many of us just find it too boring!



In addition, if you have COPD\* you may think that you can't exercise. You may think it will make you feel too short of breath. Or you may feel that it is not safe for you. You may think it will make your lung disease much worse. But actually, avoiding exercise can make you more unfit. You lose fitness when you stop exercising. The less you do, the less you are able to do.

Benefits of Exercise	What You See and Feel
Helps your heart pump blood and send oxygen to your body	You will have improved use of oxygen
Improves how your blood circulates. Helps with the exchange of oxygen and carbon dioxide	You will become less short of breath
Improves energy level	You will be less tired
Increases muscle strength and endurance	You will be able to do more
Improves sleep	You will be able to sleep more soundly. You will wake up refreshed
Helps your posture. Helps you be able to breathe better	You will use less energy
Makes you aware of your body. You will be able to better know what makes you feel worse	While exercising you will be more aware of what makes your symptoms worse You will learn how to control them
It's fun! You can relieve stress	It will help you improve your mood. It will help you control anxiety

\*COPD is an umbrella term used to describe the progressive lung diseases including: emphysema (em-fa-see-ma), chronic bronchitis (kron-ick-brawn-kie-tis), refractory (re-frac-ta-ree) asthma (az-ma) and some forms of bronchiectasis (brawn-key-eck-tay-sis). If you have COPD you have trouble moving air in and out of your lungs because of damage to the airways and/or the air sacs. The chart above shows many benefits of exercise. But the most important benefit of exercise for COPD patients is how it can improve shortness of breath. Feeling short of breath can make you limit your daily activities. The less active you are, the less you are actually able to do. But you can learn to coordinate your breathing with your activities. This will help you use less energy. You will be able to be more active. (See the "Matching Breathing with Effort" section.) For people with moderate to severe COPD, a small amount of exercise can improve how the heart and lungs work.

# **But First, Talk With Your Doctor**

Before you start an exercise program you need to talk about it with your doctor. Your doctor may want you to have an exercise tolerance test. This is done using a treadmill or stationary bike. The test helps decide how much exercise you can do safely. Your heart function and how well oxygen is getting to your body will be measured while you exercise. You doctor may then give you an "exercise prescription." This will have details about how hard, how long and how often you should exercise. If you have moderate to severe COPD, your doctor may refer you to a pulmonary (*puhl-mun-nairy*) rehabilitation (*ree-haa-bii-li-tay-shun*) program. (See the side bar at the end of this Guide.)

# **Matching Breathing with Effort**

Shortness of breath is one of the main reasons people with COPD think they cannot exercise. Everyone experiences shortness of breath when exercising. But people who do not have COPD are able to adjust their breathing to meet their increased need for oxygen. When you are short of breath, you feel like you cannot get enough oxygen in your lungs. This may make you feel like you need to breathe faster. When you breathe faster, you will be unable to empty your lungs before the next breath. This is what causes the feeling of shortness of breath. For someone with COPD, breathing out for a longer period of time is helpful. This empties your lungs. It prepares you for the next breath.



Matching your breathing to your movements can reduce shortness of breath. It will also help deliver more oxygen to your working muscles. Coordinating or matching your breathing takes effort and practice. Pursed-lip breathing and breathing from your diaphragm (*die-a-fram*) can help you match your breathing with movement. (Your diaphragm is the muscle that separates the chest cavity from the stomach. The diaphragm is the main muscle we use for breathing. When the diaphragm muscle tightens, the lungs expand.)

**Pursed-lip breathing:** In pursed-lip breathing, the lips are almost closed while breathing out. Doing this increases the pressure needed for breathing out. This forces the airways to stay open a



little longer. This helps you breathe out more of the air in your lungs. Pursed-lip breathing:

- Reduces your breathing rate
  - Keeps your airways open longer
  - Improves the exchange of oxygen and carbon dioxide
- Reduces the work of breathing (neck and upper arm muscles are not needed)

• Increases the amount of time you can exercise

To use pursed-lip breathing: Breathe in through the nostrils. Breathe out slowly. Do not force the air out. Breathe out through lips pursed like you would blow out a candle or whistle. Breathe out two to three times longer than you breathe in.

Pursed-lip breathing should be used during and after exercise. It should be used with any activity that makes you feel short of breath.

**Breathing from the diaphragm:** This type of breathing is also called abdominal (*ab-dah-min-ul*) breathing. Your abdomen should move down when you breathe in. It should rise as you breathe out.

To practice abdominal breathing:

- Place one hand on your abdomen. Place one hand on your upper chest.
- Focus your breathing on your abdomen.
- As you breathe out, the hand on your abdomen should lower.
- As you breathe in, the hand on your abdomen should rise.
- Breathe in through the nose. Breathe out slowly through pursed lips.
- Practice this 2 to 3 times a day for 5 to 10 minutes. Start by doing it while lying on your back. Then try it while sitting. Then try it while standing. Finally, try it while doing an activity.

As you become more comfortable with this type of breathing, you can use it to reduce your feelings of shortness of breath. You can use it:

- With stair climbing
- With long walks
- After carrying or lifting
- When showering
- With all daily activities
- When exercising

For more information on how changing your breathing can help you with specific activities, see the COPD Foundation's Big Fat Reference Guide<sup>®</sup>, Chapter 12-B, pages 10-14. This Guide may be found at www.copdbfrg.org.

# **Starting an Exercise Program**

After you've talked with your doctor and after you've learned to use your breathing in a different way, you are ready to consider an exercise program. Getting started can actually be the hardest part. Let's work through the excuses you may be using to avoid starting an exercise program.

- You may think you are "too tired." Exercise can actually help you feel less tired and give you more energy.
- You may think you are too busy. Think about all the things you do in a day. How much time do you spend on each of these things? How many of these activities are more important than your health? To start, you only need to find 20 minutes in a day. (Over time you can increase to 30, 45, or 60 minutes.)
- You may think you are too sick to exercise. Ask your doctor to create a program that is right for you. The right exercises can actually help you feel better and less sick.

To start a program, consider what you like to do. Exercise is easier if it is fun for you. Consider asking a friend or family member to join you.

You may feel short of breath when doing your daily activities. If you do, you will need to begin your exercise program slowly. Your program should be supervised.

If you are fairly active you can create a program that will improve your strength. You can create a program that will improve your ability to be active for longer periods.

Start by making personal goals. Think about these questions:

Do you want to decrease your feelings of being short of breath during your daily activities?

### Choose An Exercise You Enjoy:

- Take a class with others
- Follow a video in your own home
- Work out in a gym with a trainer
- Walk outdoors
- Swim
- Dance
- Bike

*Do you want to have energy to join in family, social or professional activities?* 

What specific activities do you want to be able to do again?

### What is a Good Exercise Program?

An exercise program should have:

- Warm up and stretching: This will prepare you for the exercise. It will also help prevent injury. Stretching helps you improve the types of movements you are able to do. This is called your flexibility. You should stretch 5 times a week at least. You should stretch to the point of mild discomfort. Breathe in while you stretch. Breathe out while you hold the stretch. Hold each stretch for 10 to 30 seconds. Repeat each stretch 3 to 5 times.
- Cardiovascular (car-dee-oh-vas-cue-ler) exercise: This increases your blood circulation. It also improves your lung and heart function. There are many ways to do this type of exercise. You can ride a bike, walk on a treadmill or take a walk. You should do this type of exercise once a day, 3 to 5 times per week. You should try to progress to doing this for 20 or 30 minutes at a time. (Talk with your doctor about how long you should do this type of exercise). Warm-up first. You can do this by doing the exercise at a lower effort for 3 minutes. You should also cool down after the exercise, for 3 minutes.
- **Muscle strengthening:** This is done using free weights or resistive bands. It will improve your ability to work without getting tired. Making your muscles stronger will help you be able to perform more tasks. Stronger muscles will help you be more active with less effort. There are muscle strengthening exercises for the upper body and lower body. Building up the large muscles of

the lower body will decrease your feelings of shortness of breath. Strengthening the exercises of the arms and shoulders will help you improve how you do activities using these muscles. These activities may include dressing, showering or housework. You should do this type of exercise 3 times a week. Do each strength exercise 10 times. Try to move to doing each exercise 20 times.

To get the most benefit, you should exercise on a regular schedule. You will receive the most benefit from doing a moderate amount of activity on most, if not all, days of the week. But you will still have some benefit if you only exercise three times per week.

\*For more information about the parts of an exercise program see Chapter 12-B of the Big Fat Reference Guide® (www.copdbfrg.org).

# How Will I Know if I Am Exercising Enough or Even Too Much?

Exercising at a moderate level will help you increase your endurance. This means it will help you be able to be more and more active. Moderate exercise also helps improve how your lungs work.

The "Borg Scale of Perceived Exertion with Exercise" can help you decide if you are exercising at a moderate level. "Perceived Exertion" means: how hard you think you are exercising. This scale can help you decide how well you are exercising. It can also help you stay at a moderate level of activity.

You do not need any special skills or equipment to use the Borg Scale. Using the scale allows you to check on how you are doing without stopping to check your pulse rate.

When you are exercising, try to estimate how hard you think you are working. Don't think about any one factor such as leg pain or shortness of breath. Focus on your inner feeling of effort. Rate your effort as honestly as you can.

0	Nothing at all
0.5	Very, very weak
1	Very weak
2	Weak (light)
3	Moderate
4	Somewhat strong
5	Strong (heavy)
6	
7	Very strong
8	
9	
10	Maximal (the most you can work)

#### Borg Scale of Perceived Exertion

Your goal should be to exercise at a 3 or 4 level on the scale. You may feel that you cannot adjust your breathing. You may feel too short of breath. Or you may have aches that last longer than 20 or 30 minutes after exercising. If you feel any of these, reduce your exercise level to a 1 or 2 on the scale.

When should I not exercise? When you are seriously ill, a very low level of activity is best. This may include sitting in a chair and minimal walking. When you have recently been in the hospital, you will need to be supervised during light walking and light weight training. When you are having unusual symptoms, lower your exercise level. Talk with your doctor.

Yes, Safe to Exercise	No: Not safe to Exercise
I feel tired	I feel nauseated
I feel shaky	I am having leg pain that I cannot explain
I have a headache	I am having chest pain
I am coming down from a steroid burst	I am out of oxygen
l am too busy	I have a fever or strep throat
I am bored and feeling lazy	
I am having a bad day	



When should oxygen be used? If you are currently on oxygen, you will need to exercise with it. Your doctor will need to prescribe an oxygen "flow rate" for activity. This flow rate will be different from the flow rate you use while resting. You will need to adjust your flow rate for about five minutes before you begin exercising. If your exercise is too intense for you, your oxygen prescription may need to be changed. Or you may just need to slow down. Do not adjust your oxygen without talking with your doctor.

### **Record Your Success and Have Fun**

Many people find it helpful to keep a record of their exercise. You can record when you exercised, how long and how hard. As you improve, these records may encourage you to continue.

You may also want to consider if you prefer to exercise alone or in a group. Some hospital's have support groups for people with lung disease. They may allow you to exercise together in a supervised setting. Mall and rec centers also have walking clubs and group classes. Exercising with others can be motivating.

Finding an exercise program you can stick with can be hard. The key to success is finding something that is fun for you. And don't forget to reward yourself when you reach small goals. These small goals are the steps to reaching your larger goals.

The information in this Guide is not meant to replace a medical evaluation or information from your doctor. You should ALWAYS talk with your doctor about any exercise program before you start it. Your doctor can help you know how much and how often you should exercise.

### **Pulmonary** (puhl-mun-nairy) **Rehabilitation** (ree-haa-bii-lit-ay-shun)

A pulmonary rehabilitation program is good for someone with COPD who has not regularly exercised. It is also good for someone who cannot do daily living activities without getting tired and short of breath. These programs use a team approach to help you reach goals. The team helps you improve your quality of life. The team includes:

- Doctors
- Nurses
- Respiratory therapists
- Physical therapists
- Counselors
- Exercise therapists
- And more.

Some insurers will not pay for pulmonary rehab. If you are denied, ask your doctor to send them a letter. Your doctor can explain to your insurance company why you need the program.

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# Understanding Lung Disease Tests





This "Slim Skinny Reference Guide: Understanding Lung Disease Tests" is part of the COPD Foundation's *Slim Skinny Reference Guide*<sup>®</sup> series which has been taken from the *COPD Big Fat Reference Guide*<sup>®</sup>.

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# **Understanding Lung Disease Tests**

When you are sick, your doctor exams you, listens to you and asks you questions. This helps him or her make a **diagnosis** (*die-ag-know-sis*). (A diagnosis explains what is wrong with you.) Your doctor may also conduct tests on you. These also help in deciding what illness you have and why. People who have symptoms of lung disease (out-of-breath, coughing, tiredness, wheezing) may be given many different tests. These may include:

- Pulmonary (puhl-mun-nairy) function tests: tests that measure how well your lungs are working.
- Chest X-rays or CTs (computed tomogram)
- Lab tests: arterial (*r-tear-ree-el*) blood gases and pulse oximetry (*ahk-sim-e-tree*)



### **Pulmonary Function Tests**

These tests measure how well the lungs are working. They also measure how well the lungs are moving oxygen to the blood. These breathing tests use special equipment. They are done by trained staff in a hospital or doctor's office. Most people with chronic obstructive pulmonary disease (COPD)\* have pulmonary function test results that are not normal. This means the airways in the lungs are blocked and air is trapped.

\*COPD is an umbrella term used to describe the progressive lung diseases including: emphysema (em-fa-see-ma), chronic bronchitis (kron-ick-brawn-kie-tis), refractory (re-frac-ta-ree) asthma (az-ma) and some forms of bronchiectasis (brawn-key-eck-tay-sis). If you have COPD you have trouble moving air in and out of your lungs because of damage to the airways and/or the air sacs. Before the tests you will be told how to prepare for them. You may be told to:

- 1) Wear loose clothing.
- 2) Avoid large meals before the test.
- 3) Stop using some of your medicines before the test.

Pulmonary function tests include **spirometry** (*spi-rom-e-tree*), lung volume tests and **diffusing** (*dee-few zeen*) **capacity** (*kuh-pa-ci-tee*) tests. Descriptions of these tests are provided here.

# Spirometry

**Spirometry** (*spi-rom-e-tree*) is the simplest lung function test. It is done by breathing into a tube, with a mouthpiece, that you hold in your mouth. You may be asked to breathe as hard as you can. You may be asked to do this three or four times.



### Spirometry measures:

- How *much* air you can breathe in and out
- How *fast* you can breathe out that air

REMEMBER: With any test, if you do not understand what you are being asked to do, ASK QUESTIONS. And, if at any time you feel dizzy or faint, stop and tell the person giving you the test. Here are the specific ways this test will measure your breathing:

• Spirometry measures the amount of air you breathe out in one complete breath. This is called the Forced Vital Capacity

(FVC) measure. You will be asked to breathe in as fully as you can. Then you will blow out as hard and fast as you can until you cannot blow any more. (This measure is sometimes called the 6-second Force Expiratory Volume (FEV6). In these cases you will breathe out for just 6 seconds.) **Results:** Normal range is considered to be 80 to 120 percent (of the predicted normal value – see "Results EXAMPLE" sidebar). This test can be normal or near normal in some COPD patients.

- Spirometry measures how much of the air you blew out was breathed out during the first second. This is called the Forced Expiratory (x spy ruh torey) Volume in the First Second (FEV1) measure. Results: A reduced FEV1 measure means there is blockage to the flow of air out of your lungs. Your doctor will follow this number over time. The FEV1 measure is a good way to track if your COPD has become worse.
- Spirometry measures <u>the percentage</u> of your total breath that was breathed out during the first second of the FVC test. This is called *the Ratio*.
  It is your FVC (or FEV6) divided by your FEV1. This result is given as a percentage.

### A Spirometry Results EXAMPLE:

A person with COPD may say, "I have only 30 percent lung function." They are usually referring to their FEV1 value. Here's what they mean. The predicted normal measure (for someone without lung disease) for FEV1 might be 3 liters. The COPD patient's FEV1 is 1 liter. So their "percentage of predicted FEV1" is 33 percent. (The percentage is their result, 1, divided by the normal result, 3. This equals 33 or rounded to 30 percent.)



**Results:** The average person can breathe out 60-90 percent of their breath during the first second. This decreases with age. For COPD patients, this percentage is lower than normal.

• Spirometry measures how fast you breathe out air between 25 percent of your breath and 75 percent of your breath. This is called the Mid-Breath Forced Expiratory Flow (FEF<sub>25-70</sub>).

Your doctor will compare your spirometry results with what is normal for a person of your age, size and sex. This is called comparing to "normal values." Your doctor may also have you do the spirometry test before and after you are given an inhaled medicine. This medicine is called a **bronchodilator** (*brawn-coe-die-lay-ter*). It helps open up the lungs' airways.

After the spirometry test, your doctor will decide how serious your COPD is. Your doctor can do this by using the FEV1 measure you had, after you inhaled the medicine. The doctor will use a percentage of predicted FEV1 to give your COPD a "grade." The grade will be mild, moderate, severe or very severe. These grades help your doctor decide the best treatment for you. See the chart below for more details on these grades or stages.

Stage or Grade of COPD*	FEV1 Percent Predicted	
Mild	80 percent or more (but with a low FEV1/FVC ratio)	
Moderate	50 to 80 percent	
Severe	30 to 50 percent	
Very Severe	Less than 30 percent	

\*The above grades match the Global Initiative for Chronic Obstructive Lung Disease (GOLD) definitions. Other groups may define the stages of COPD differently.

### **Peak Flow Testing**

The peak flow is a very simple test. You blow out as fast as you can into a tube. The peak flow test is used a lot in asthma. There is evidence it may have a role with COPD. Peak flow testing cannot make a diagnosis of COPD. But an abnormal peak flow suggests that something is not right. Further testing, such as spirometry, can better define the problem. It is simpler and less expensive than spirometry.

# **Lung Volumes**

There are other tests that measure how well you are able to breathe. **Total Lung Capacity** (TLC) is the amount of air your lungs can hold when you start breathing in. **Residual Volume** is the amount of air left in your lungs after you breathe out all the air you can.

These two lung volume tests are important. They can be measured in several ways:

- **Nitrogen Washout:** You breathe in pure oxygen. The air you breathe out is collected. It is studied to find out how much nitrogen is in it.
- Helium Dilution: You breathe a mixture of helium and oxygen.
- **Body Box:** You sit in a clear plastic or glass box. You breathe small panting breaths. This test is very accurate.

# **Diffusing Capacity**

The third type of lung function test your doctor may order for you is the **diffusing capacity** (dee-few-zeen) (kuh-pa-ci-tee) **test (DCLO).** This test measures how well oxygen is moving from your lungs into your blood. This test also involves breathing into a tube while seated.



Example of a body box

When your lungs move oxygen to the blood, this is called **diffusion** *(dee-few-zjun)*. How well your lungs do this is your lungs' *diffusing capacity.* There are three major factors involved in this:

- 1) How much lung tissue, filled with air, is in contact with blood?
- 2) How thick are the air sac walls? (Oxygen is moved into the blood in the lungs' air sacs. These are called **alveoli** (*al-vee-oh-lee*)).
- 3) How many red blood cells are there? (Red blood cells carry the oxygen from the lungs through the body.)

**Results:** The results of this test can tell your doctor if there is damage to the air sacs in your lungs and if so, how much. If you have COPD and get a low DCLO measure, some or all of your lung blockage is caused by **emphysema** (*em-fa-see-ma*). Emphysema occurs when the air sacs in the lungs are destroyed.

# **Chest X-rays and CT Scans**

A chest X-ray is done by having you sit or stand with your chest pressed to an X-ray machine. You are asked to take a deep breath and hold it. The X-ray machine takes a type of picture of your chest. Sometimes a side view of your chest is also taken. Unfortunately a chest X-ray is not a good test for examining lung disease or COPD.

A much better test is a computed tomogram or CT of the lungs. These tests are high-tech X-rays.

**Results:** CT scans are good for diagnosing emphysema and bronchiectasis, two types of COPD. A **high resolution** (*rez-oh-lew-shun*) CT scan can find emphysema in people whose lung function is normal. CT scans can also find other problems that may not be seen on a normal chest X-ray.

### Lab Tests

An **arterial** (*r-teer-re-el*) **blood gases** test may be ordered by our doctor. This test will show how well your lungs are getting oxygen into your blood and carbon dioxide out of your blood. (You breathe in oxygen. It is passed into your blood in the tiny air sacs in the lungs. Carbon dioxide is passed out of the blood and into the lungs. Carbon dioxide is the waste that is created when your tissues and muscles are active. You breathe out carbon dioxide.) For this test, blood is taken out of your arm, usually near your wrist. The blood is taken from an artery. Arteries are large blood vessels

that carry blood filled with oxygen from the lungs through the body. Several measurements are taken from this blood sample. They are:



### • Your blood's acid/base or "pH"

**balance:** Body fluids are mostly water. But they also contain acids and bases. Your body tries to keep a balanced pH. A pH *below* 7.35 means you have too much acid in your body. This is called **acidosis** (*aa-see-doe-sis*). A pH *above* 7.45 means you have too much base. This is called **alkalosis** (*al-kah-loe-sis*).

- The level of carbon dioxide in the blood: This is done by measuring the pressure the carbon dioxide applies in the blood sample. This is called the "partial pressure of carbon dioxide from arterial blood" or PaCO<sub>2</sub>.
- The level of oxygen in the blood: This is done by measuring the pressure the oxygen applies in the blood sample. This is called the "partial pressure of oxygen from arterial blood" or PaO<sub>2</sub>.
- The percentage of hemoglobin in your red blood cells that are carrying oxygen: Hemoglobin (*he-mow-glow-bin*) is a protein in the red blood cells. These proteins carry oxygen all through your body. This percentage is called "arterial oxygen saturation" or SaO<sub>2</sub>.

A **pulse oximetry** (*ahk-sim-e-tree*) test is another way of measuring the amount of oxygen in the blood. But this test is done without taking a blood sample. The amount of oxygen is only *estimated*. A pulse oximeter is used for this simple test. This small device is clipped to your finger or an ear lobe. It gives fast results.

Hemoglobin that carries oxygen is a different color from hemoglobin *not* carrying oxygen. Blood carrying oxygen is bright red. The oximeter shines a special light through the skin. It measures how much of the light is absorbed by the hemoglobin. This is used to get the percentage of hemoglobin carrying oxygen. Or, the amount of oxygen in the blood.

Pulse oximetry is very good for measuring oxygen levels while walking, exercising or sleeping. It can help with deciding if there is a need for oxygen therapy. (See the *Slim Skinny Reference Guide®: Oxygen Therapy*). But this simple test is not as accurate as the

#### Blood Cell Parts Measured in a CBC:

**Red blood cells:** These contain hemoglobin which carries oxygen. Long periods of low oxygen will cause the number of these cells to increase.

*Hemoglobin:* This is the protein in red blood cells that carries the oxygen. The count of this can increase during periods of low oxygen (as with red blood cells).

Platelets: This is a part of the blood that helps form clots.

*White blood cells:* also called leukocytes. They are part of our immune system. They help our bodies fight infection. They move to the area where an infection has started.

**Hematocrit** (he-maa-toe-crit): This is the percentage of blood that are red blood cells. There can be a difference between the red blood count and the hematocrit. This can mean the red blood cell size is not normal. (The cells may be too small when the body does not have enough iron. The cells can be too large when the body does not have enough vitamin B<sub>12</sub>.)

arterial blood gases tests. So, for patients with severe COPD, the arterial blood gases test is used more.

Other common lab tests your doctor may order are a complete blood count (CBC), and a basic chemistry profile. (See the CBC sidebar.)

### **Alpha-1-Antitrypsin Tests**

A disease called **Alpha-1-Antitrypsin** (al-fa-one-an-tee-trip-sin) **Deficiency** (dee-fi-shin-see) is known to cause COPD. People with Alpha-1 have a much lower than normal level of the blood protein called alpha-1-antitrypsin. This protein protects the lungs from irritation caused by breathing in toxins. Alpha-1 is a **genetic** (*ja-net-ick*) disorder. This means it is passed from parents to their children. You can find out if you have Alpha-1 through a simple blood test. Everyone with COPD should be tested for Alpha-1. This is very important because there is a specific treatment for Alpha-1. It can slow the progress of COPD. (For more information on Alpha-1-Antitrypsin Deficiency, visit the Alpha-1 Foundation's website at

www.alpha-1foundation.org or AlphaNet at www.alphanet.org)

### **Cardiopulmonary Exercise Testing**

### (car-dee-oh-puhl-mun-nairy)

This is an exercise test your doctor may order to help define how limited you are. It is done on an exercise bike or a treadmill. It differs from the "usual" cardiac stress tests. It gives information not only on how your heart works during exercise but also how your lungs work. It also gives information about how your muscles work and how your heart, lungs and muscles work together. It can



help decide how much of your breathing problem is related to your heart, your lungs, or your muscles. Often the test can help your doctor to set up an exercise program specifically for your needs.

### 6 Minute Walk

This is a walking test. It measures how far you can walk in 6 minutes. It allows your doctor to determine your activity level and how much oxygen you may need.

# And finally...

The most common lung disease tests have been explained here. But, it is not possible to explain every detail of every test. This information should be used only as a guide. If you have guestions or concerns about your specific test results, **ASK YOUR DOCTOR**.



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# This Slim Skinny Reference Guide® (SSRG) was created by the COPD Foundation.

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The contents of the Slim Skinny Reference Guide are for information purposes only. The content is not intended to be a substitute for professional medical advice, diagnosis or treatment.

# **COPD** Medicines





This "Slim Skinny Reference Guide: COPD Medicines" is part of the COPD Foundation's *Slim Skinny Reference Guide*<sup>®</sup> series which has been taken from the *COPD Big Fat Reference Guide*<sup>®</sup>. To access the complete *COPD Big Fat Reference Guide*<sup>®</sup>, visit www.copdbfrg.org.

The mission of the COPD Foundation is to develop and support programs which improve the quality of life through research, education, early diagnosis, and enhanced therapy for persons whose lives are impacted by Chronic Obstructive Pulmonary Disease (COPD).

# **COPD Medicines**

Chronic Obstructive Pulmonary Disease\* – COPD – can almost always be treated. Exercise, medicine and oxygen can all help improve your symptoms. Together, these three things can help you lead as normal a life as possible with your lung disease.

(See the Slim Skinny Reference Guides: Exercise and Diet for Someone with COPD and Oxygen Therapy for more information on these topics. Or refer to the COPD Foundation's COPD Big Fat Reference Guide® at www.copdbfrg.org.)

\*COPD is an umbrella term used to describe the progressive lung diseases including: emphysema (em-fa-see-ma), chronic bronchitis (kron-ick-brawn-kie-tis), refractory (re-frac-ta-ree) asthma (az-ma) and some forms of bronchiectasis (brawn-key-eck-tay-sis). If you have COPD you have trouble moving air in and out of your lungs because of damage to the airways and/or the air sacs.



# What Do COPD Medicines Do?

The many medicines prescribed for lung disease work in many ways. These medicines:

- Reduce the narrowing of the tubes in the lungs. Air flows through the **bronchial** (*brawn-key-el*) tubes. When the narrowing of the tubes is improved, breathing is easier.
- **Relieve air trapped in the lungs.** Air becomes trapped in the lungs when the lungs are damaged by **emphysema** (*em-fa-see-ma*). With emphysema (one type of COPD) the lungs' air sacs are damaged. The lungs lose their springiness. Air is trapped and this causes a feeling of shortness of breath.
- Reduce swelling and irritation in the lungs. With chronic bronchitis (*kron-ick*) (*brawn-kie-tis*), another type of COPD, the airways of the lungs are often inflamed or irritated.
- Reduce the amount of mucus created in the lungs. Coughing is a common symptom of COPD. Coughing causes the lungs' passages or tubes to be irritated. Irritated passages produce mucus.
- Help with removing mucus from the lungs. Mucus that is not removed can block the airways. And infections can occur, making your lung disease symptoms much worse.
- Fight infections. Lungs damaged by COPD are more likely to become infected. Infections make COPD symptoms much worse.
- Prevent or treat exacerbations (*x-saa-sir-bay-shuns*). These are times when your COPD symptoms become much worse.



- Improve how your lungs work or function.
- Make your life better by making you feel better.

Your doctor may prescribe medicines for you that must be taken every day. These are called "maintenance medicines." They are very important for helping you control your symptoms. Or you may have medicines that are taken "only when needed." This is called "PRN." Most people with COPD must take medicines every day. These medicines can make you feel better and able to do more.

# **Types of Medicines for COPD**

Medicines prescribed for COPD are listed here. These medicines are grouped by how they work. These groups are called "drug classifications." The side effects that may be caused by each group of drugs are also provided here. Common side effects are listed, but this does not mean that you will have all or even any of these side effects. The most common side effects are listed so that you will recognize them should they occur.

# **Beta-agonists**

Beta-agonists drugs are used to relax the muscles around the lungs' airways. These muscles become tightened and the airways more narrow when the lungs become irritated. These drugs are a type of **bronchodilator** (brawncoe-die-lay-ter) because they help open up the lungs' airways. Beta-agonists are made with **adrenaline** (ah-dren-ah lin). This is a natural hormone. It causes a burst of energy when you are scared, startled or excited. Breathing in a beta-agonist drug with an inhaler is best. This method reduces side effects occurring in the rest of your body.

#### A Note About Side Effects

All drugs – both those prescribed and over the counter – can have side effects.

Some side effects, such as a dry mouth, are easily handled. Others such as unusual heart beats, may mean your medicine must be changed or stopped.

No list of side effects can list all the problems.

Always discuss any strange symptoms or side effects with your doctor.

# **Beta-agonists Side Effects**

Mild side effects	Shaking, trembling, anxiety, headaches, nervousness, trouble sleeping, dizziness, increased heart rate
More serious side effects	Asthma attacks, chest pain, serious heart rhythm problems
Most severe side effects	Changes in electrical activity of heart, low potassium, seizures

There are many different types of beta-agonist drugs. They may last from 3 hours to more than 12 hours. *Fast-acting beta-agonists* are used as "rescue" medicines. They provide very fast relief of symptoms. They start to work within 5 minutes. These rescue drugs may be needed after exercise. Or they may be needed if you are around toxins that irritate your lung disease. These toxins may include smoke, dust, pollution or fumes from cleaning products.

*Long-acting beta-agonists* can last for 12 hours or more. The FDA approved one that lasts for 24 hours in July of 2011. They are not used as rescue drugs. These long-acting drugs are used on a routine basis to keep the airways open.

# Anticholinergics

Anticholinergic (an-tee cole-i-ner-jic) drugs also relax the muscles around the airways, but these drugs do this in a different way. These drugs block signals from the nerves that tell the airway muscles to tighten. When these drugs are used with beta-agonists, an "additive effect" occurs. This means that when you take these two types of drugs together, you get a more powerful result.

#### Side Effects of Anticholinergics

- Dryness of the mouth
- Cough, nervousness
- Headache
- Difficulty with urination (usually only seen in older men)
- Dilation of pupils in the eyes (not usually a problem when these drugs are inhaled)
- Possible heart and stroke problems (however, a large study has found this is not true)

# Glucocorticosteroids (glue-coe-kort-te-coe-stair-royd)

Steroids are another type of drug that can help people with COPD. The type of steroid that helps COPD is called a **glucocorticosteroid**. (These types of steroids are not the type of steroids that athletes use to get bigger muscles.)

These types of drugs may be given:

- With an inhaler (a device that helps you breathe in medicine)
- With a nebulizer (a device that delivers medicines in a fine spray or mist)
- By mouth as a pill or capsule
- By shot into muscle
- Through an I.V.

**Inhaled steroids** are used to reduce airway irritation or inflammation. Inhaled steroids are the safest type of glucocorticosteroids. When steroids are inhaled, the side effects are less serious. One side effect of inhaled steroids is an infection of the mouth called "thrush." Thrush causes a very bad sore throat, extreme redness of the tongue and white patches in the mouth.



# CAUTION Must Be Taken When Stopping Systemic Steroids.

Steroids occur naturally in our bodies. They are produced by the adrenal glands in the kidneys. When you take "systemic" steroids (orally, by shot or by IV) for long periods of time, your kidneys stop making steroids.

When it is time for you to stop taking these systemic steroids, the dose must be gradually reduced. This will tell your adrenal glands to start making steroids again.

If you stopped these steroids suddenly, your kidneys would not have time to produce your own steroids. So, your body would be without steroids. The lack of enough steroids can cause death.

By slowly reducing your steroid dose, your adrenal glands will know to start making steroids again.

You may need steroids in the future. If so, tell you doctor if you stopped taking steroids within the last year.

**Systemic steroids** enter your blood and travel through your entire body. They may be taken by mouth in pill form, through an I.V. or by shot. These steroids can be very helpful during times when your symptoms are suddenly worse. Such times are called exacerbations. This is really the only time systemic steroids are given to COPD patients. Your doctor may put you on these drugs for 10 to 14 days. If you are only on them for 10 to 14 days, your doctor may have you continue the full dose until the end of the treatment course.

Steroid side effects usually occur when they have been used for long periods of time at high doses.

Effect to Hormones	changes in menstrual cycle, weight gain, fullness of face, moodiness, depression
Effects to Fluids and Electrolytes	salt and water retention, high blood pressure, loss of potassium
Effects to Eyes	increased eye pressure, clouding of vision, blurred vision
Effects to Skin	more body hair, acne, easy bruising, thinning of skin, wounds don't heal well
Effects to Nutrition	increased appetite, stomach and throat irritation, ulcer symptoms
Effects to Muscles	muscle weakness or cramps
Effects to Bones	joint pain, thinning of bones, bone breaks, loss of blood to bones causing pain.
Effects to Immune System	suppression of the immune system causing more risks of infections

Side Effects of Steroids

NOTE: For more information about steroids' side effects and how you can reduce these problems, see the COPD Foundation's COPD Big Fat Reference Guide<sup>®</sup>, Chapter 3-B. The Big Fat Reference Guide<sup>®</sup> can be accessed at www.copdbfrg.org. If you are taking these systemic steroids for longer periods of time, the drugs will need to be tapered off rather than stopped abruptly (see the caution box). When taking systemic steroids you should always make sure you understand completely how to use them and when to stop. Discuss this with your doctor.

# *Theophylline* (thee-oh-fi-leen) and *Aminophylline* (a-meen-no-fi-leen)

These drugs have been prescribed for breathing problems for over 100 years. They are closely related to caffeine. They are not prescribed as often anymore because of their possible severe side effects. Side effects include: nausea, vomiting, shakiness and sleeplessness. Severe side effects may include seizure and death.

# *Phosphodiesterase* - 4 (PDE4) inhibitors (fos-foe-die-es-ter-ase in-hib-it-tors)

This is the latest class of COPD medications for adults with severe COPD to decrease their number of flare-ups or the worsening of COPD symptoms (exacerbations). The FDA approved of the first one, in March of 2011. Roflumilast should not be used to treat sudden breathing problems (acute bronchospam). PDE4 inhibitors may cause serious side effects including mental health problems and weight loss. Other common side effects include diarrhea, weight loss, nausea, headache, back pain, flu-like symptoms, insomnia, dizziness and decreased appetite.

Phosphodiesterase-4 inhibitors are prescribed to reduce the risk of future COPD exacerbations in patients with severe COPD associated with chronic bronchitis and a history of exacerbations. PDE4 inhibitors are taken as a once daily oral tablet.





## Anti-leukotrienes

**Leukotrienes** *(lew-coe-try-eens)* are chemicals produced by the body. These chemicals cause airways to tighten. Anti-leukotrienes block the effect of these chemicals. They help open airways. These drugs are usually given to people with asthma. They have not been shown to help with usual COPD care. But these drugs do help people who have a mixture of both COPD and asthma. These drugs may also help people with COPD when they have seasonal colds and sinus problems. These drugs can affect the liver. Blood tests to check the liver must be done often.

# **Mucolytics**

People with COPD can have breathing problems when too much mucus

# CAUTION: Allergies to antibiotics are common.

A rash or hives can occur.

*Some allergic reactions can be life-threatening.* 

If you are allergic to one antibiotic, you could be allergic to others.

Always tell your doctor about any medicine allergies you have. is made in their lungs. It can be difficult to cough up the mucus. COPD patients with bronchitis (*brawn-kie-tis*) or bronchiectasis (*brawn-key-eck-tay-sis*) have this problem. **Mucolytics** (*mew-coe-lie-ticks*) help thin out the mucus. This makes it easier to cough up. However, mucolytics may not help all people who take them. Side effects: These drugs can cause the muscles around the bronchial tubes to tighten. This is called a bronchospasm (*brawn-coe-spaz-em*). To avoid these, a fast-acting bronchodilator is often used before or with the mucolytic.

# Expectorants vs. Cough Suppressants

These medicines can be bought without a prescription. However, deciding which kind to buy can be confusing. Knowing the difference between these two medicines will help you know which one to buy.

**Expectorants** (*x-peck-tore-ants*) thin out mucus that blocks air tubes. Thinning the mucus can help you cough or "expectorate" it up. Coughing helps clear the airways. This is helpful for cases of **pneumonia** (*new-moan-yah*) or during COPD exacerbations.

**Cough Suppressants** (*su-press-ants*) lessen the urge to cough. They <u>should not</u> be used if your cough sounds wet and is producing mucus. If your cough is dry without mucus, a suppressant can be helpful. It can reduce coughing. This will provide comfort and allow you to sleep.

# **Antibiotics**

**Antibiotics** (an-tee-bye-ah-ticks) are often used for COPD patients during an exacerbation. Exacerbations can be caused by bacterial infections. Your doctor may ask you to cough up a sample of your mucus. This is called a "sputum specimen." A test will be done on the sample. The types of bacteria in your mucus will be identified. This will help your doctor know which antibiotic will help you the most.

There is concern that overusing antibiotics can create bacteria that will not respond to common drugs. These are called "drug-resistant bacteria." Not all exacerbations are caused by bacterial infections. You and your doctor will need to decide together when to use an antibiotic.

# Treatment for Alpha-1-Antitrypsin Deficiency COPD

Some patients have COPD because they also have a disorder called Alpha-1-Antitrypsin Deficiency (*al-fa-one-an-tee-trip-sin dee-fi-chin-see*) (Alpha-1). Alpha-1 patients do not have enough of the blood protein called Alpha-1-Antitrypsin (AAT). These patients can receive a treatment that can be life saving. It is called **augmentation** (*awg-men-tae-shun*) **therapy**. Augmentation therapy uses AAT from healthy donors. This AAT is given to Alpha-1 patients through an I.V. It is an ongoing, life-long treatment. (For more information about Alpha-1, visit the Alpha-1 Foundation's website at www.alpha-1foundation.org or AlphaNet at www.alphanet.org.)

#### To Avoid Side Effects:

When using an inhaler, always wash out your mouth after the drug has been inhaled.

Most side effects from inhalers happen when drugs are sprayed into the mouth and left there.



# **Using Inhalers**

Some medicines for COPD must be used with an inhaler. There are two types of inhalers: *metered dose inhalers* (MDIs) and *dry powder inhalers* (DPIs). MDIs deliver a fixed dose with each use. DPIs are similar; the drug is just in powder form.

An MDI consists of a canister of medicine and a mouthpiece. Pressing the MDI releases a mist of medicine. How well you use the inhaler affects how much of the drug reaches your lungs. When inhaled correctly, the drug has a better chance to reach your airways.

#### Steps to using an MDI (without a spacer):

- 1) Remove the cap.
- 2) Hold inhaler with mouthpiece down.
- 3) Shake it.
- 4) Hold the mouthpiece 2-3 finger widths in front of your mouth.
- 5) Gently breathe out.
- 6) Tilt your head back slightly and open your mouth wide.
- 7) Press the inhaler while starting a slow, deep breath.
- 8) Continue to breathe in slowly and deeply for 5 seconds.
- 9) Hold your breath for up to 10 seconds.
- 10) Repeat steps 3-9 when more than one puff is prescribed.



# Dry Powder Inhaler (DPIs)

A dry powder inhaler (DPI) is similar to an MDI, but the drug used is in powder form. A dry powder inhaler can sometimes be easier to use because it works *with* your breathing. You do not have to time your breathing with using the DPI. You simply breathe in quickly to start the medicine flowing into your lungs.

There are some problems that can occur with DPIs: if you breathe out near the DPI, the powder can be

### A Spacer Can Help With Inhalers

A spacer is a device used with your inhaler that can:

- Help a fine mist of medicine go deeper in your lungs.
- Allow larger particles to be trapped in the spacer instead of your mouth.
- Allow you to not worry about timing your breathing with use of the inhaler.

blown out. And much of the powder can end up in your mouth. This can cause side effects. Finally, for some people, breathing in powder irritates their lungs.

# **Using Nebulizers**

A nebulizer is a device that delivers drugs in a fine spray or mist to your lungs. The drug is delivered through a mouthpiece or face mask. It is often used with beta-agonists, anticholinergics or steroids.

Sometimes nebulizers are used instead of inhalers because:

- Some drugs only come in a liquid form
- A higher dose of medicine can be given
- The medicine is given constantly for 10 to 15 minutes. This can provide relief during a bad breathing attack
- The drugs used with nebulizers are cheaper
- Some people find that using inhalers is not easy

There are some problems with nebulizers. These are:

OUTPUT

- The side effects of anxiety and rapid heartbeat are more likely
- Too much of the drug can be given
- Using a nebulizer takes more time
- The nebulizer must be carefully cleaned each time
- The nebulizer is not easy to take when traveling

NOTES

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# Nutrition Tips for Someone with COPD





This "Slim Skinny Reference Guide: Nutritional Tips for Someone with COPD" is part of the COPD \Foundation's *Slim Skinny Reference Guide®* series which have been taken from the *COPD Big Fat Reference Guide®*. To access the complete *COPD Big Fat Reference Guide®*, visit www.copdbfrg.org.

The mission of the COPD Foundation is to develop and support programs which improve the quality of life through research, education, early diagnosis, and enhanced therapy for persons whose lives are impacted by Chronic Obstructive Pulmonary Disease (COPD).

# **Nutrition Tips for Someone with COPD**

What we eat affects our health. Our bodies require water and a source of energy (food) regularly. We also need vitamins and minerals that cannot be created within our bodies. We find these in the plant and animal foods that we eat.



For someone with COPD\* a healthy diet is especially important because:

- COPD patients need more energy to do the work of breathing.
- Unplanned weight loss from eating poorly can weaken the muscles used for breathing.

\*COPD is an umbrella term used to describe the progressive lung diseases including: emphysema (em-fa-see-ma), chronic bronchitis (kron-ick-brawn-kie-tis), refractory (re-frac-ta-ree) asthma (az-ma) and some forms of bronchiectasis (brawn-key-eck-tay-sis). If you have COPD you have trouble moving air in and out of your lungs because of damage to the airways and/or the air sacs.

- A good diet can help prevent lung infections. (Lung infections can be very serious for COPD patients.)
- Eating poorly can make COPD symptoms worse. It can also decrease your ability to exercise.

# What Is a Healthy Diet?

For everyone, eating well is a balance. We must make sure we eat enough of the vitamins and minerals our body needs. But we must also make

sure we don't eat too much of some foods that may cause problems. Too much fat, too much salt, too much sugar and sometimes even too much of some vitamins and minerals can be unhealthy.

The United States Department of Agriculture (USDA) says a healthy diet is one that:

- Focuses on fruits, vegetables, whole grains, and fat-free or low-fat milk and milk foods.
- Includes lean meats, poultry (chicken and turkey), fish, beans, eggs and nuts.
- Is low in saturated fats, trans fats, **cholesterol** (*koe-less-tur-all*), salt and added sugars.



Grains, vegetables and fruits should make up most of our diet.

Calories are the fuel that helps our bodies work. Calories come from the grains, vegetables, fruits, proteins and fats that we eat. How many calories a person needs each day depends on many things. These include their age, their disease condition, how much they exercise and if they need to lose or gain weight. We can get the amount of calories and nutrients that our bodies need by following a simple rule: *Choose a food from each food group at each meal.* Each food group has nutrients that the other food groups do not have.

The USDA's recommends the following for each food group every day:

Food Groups and Subgroups	USDA Suggested Amount
Fruit Group	2 cups or 4 servings per day
Vegetable Group • Dark green vegetables • Orange vegetables • Legumes (dry beans) • Starchy vegetables • Other vegetables	<ul> <li>2.5 cups or 5 servings per day</li> <li>(3 cups per week)</li> <li>(2 cups per week)</li> <li>(3 cups per week)</li> <li>(3 cups per week)</li> <li>(6.5 cups per week)</li> </ul>
<b>Grain Group</b> • Whole grains • Other grains	6 ounces per day (3 ounces per day) (3 ounces per day)
Meats and Beans Group	5.5 ounces per day
Milk Group	3 cups per day
Oils	27 grams or 6 tsp
Optional Calories	267 calories per day

For more information about recommendations for nutrition, please read the COPD Foundation's Big Fat Reference Guide<sup>®</sup>, Chapter 5. The COPD Big Fat Reference Guide<sup>®</sup> can be found at www.copdbfrg.org.

# **Special Dietary Concerns for People with COPD**

### Unplanned Weight Loss

Being underweight is a serious health problem for a person with COPD. Even mild COPD increases the chance of being underweight.

People with COPD need more energy just to breathe. A person with COPD needs between 430 and 720 calories a day just to do

#### Did You Know?

Unplanned weight loss affects as much as 40 to 70 percent of COPD patients. the work of breathing. This is true even if he/she is not aware that they are working harder at breathing.

When the number of calories you are taking in is too low to meet your energy needs, your body breaks down fat and muscle. It does this for energy. This

causes muscles to become weak. This also causes weight loss. A bad cycle begins: the muscles used to breathe are weakened. This causes shortness of breath. This causes a decrease in appetite. This causes more weight loss. And the cycle continues.

If you are underweight, you will need to increase the number of calories you eat on a daily basis. To add more calories to your diet:

- Mix a teaspoon of butter, margarine or olive oil into hot foods.
- Eat mayonnaise instead of salad dressing.
- Use a lot of peanut butter.
- Use honey for sweetening and as a snack.
- Drink milkshakes made with high fat ice cream. Try adding protein power or egg substitutes for more protein and added calories.
- Keep high calorie snacks around: olives, walnuts, raw almonds and dried fruits.
- Add flaxseed oil or olive oil to cottage cheese with fruit.
- String cheese is easy. It is 80 calories per stick.

# **COPD Symptoms Cause Too Much Weight-Loss**

The most common reason people with COPD lose weight is they lose their appetite. Some say they eat less because the food does not taste as good as it used to. Others say they get too tired to make meals. For some, chewing, swallowing and breathing all at the same time is just too much work. Chewing and swallowing adds to the feeling of shortness of breath. Feeling bloated from swallowing air

and not getting enough exercise can make you feel like not eating. And sometimes medicine side effects cause loss of appetite. Drugs can also cause problems with absorbing nutrients from food.

#### To make foods easier to chew:

- Cook vegetables until they are soft.
- Mince or grind up meats.
- Dip breads in liquid.
- Eat pasta, mashed potatoes, thick soups, creamed soups, casseroles.
- Try fruit smoothies, milk shakes and eggnog.

#### To improve your appetite:

- Make meal time as pleasant as possible. Add soft music and candlelight. (But only if you are not on oxygen.)
- Do not talk about stressful topics at the table.
- Eat many snacks throughout the day. Keep them handy.
- When you know you should eat but are not hungry, eat some of your favorite foods.

#### But What if You Weigh More Than You Should?

Being overweight can make your lung disease symptoms worse: You may not be able to expand your chest as well as you should. This will affect your breathing.

Your chances of developing other medical problems increase.

Increased weight adds to your body's oxygen demands.

*Try to lose weight gradually. Extreme dieting is unhealthy. Eat fewer calories. Become more active.* 

To find out more about what your ideal weight should be, visit the COPD Foundation's Big Fat Reference Guide<sup>®</sup>, Chapter A-5, pages 7-9. You may also want to read Chapter A-6 and B-11. These chapters focus on exercise.

#### To decrease shortness of breath:

- Try to rest 30 minutes before meals.
- If you become short of breath, use pursed-lip and deep breathing.
- Sit upright and lean forward with your elbows on the table. Put your feet on the floor. This will give you the greatest expansion of the lungs.
- Eat foods that are easy to chew (see above).
- If you are on continuous oxygen, ask your doctor if you should increase your flow rate during meals.
  (Do not increase your oxygen without talking with your doctor first).
- Relax before and after meals. Anxiety causes shortness of breath.

#### To reduce tiredness:

- Check out "Meals on Wheels" (www.mowaa.org). This service (or one like it) can provide you with a nutritious, low cost meal. This will keep you from having to prepare a meal.
- Eat 6 small meals instead of 3 big ones. Digestion requires energy. Energy requires oxygen. If you eat smaller meals you use less oxygen.
- Eat your larger meals earlier in the day.
- Rest before eating, but don't lie down after meals.

• •

- Use easy-to-make recipes.
- Ask family or friends to help with making meals.

• Don't think that eating more carbohydrates will give you more energy. Sweets, cookies, cakes and pies—simple carbohydrates can cause you to hold in too much carbon dioxide. This can cause tiredness.

## To reduce bloating:

- Try to not rush your meals.
- Do not eat when you are short of breath. This can cause you to swallow air. This will make the bloating worse.
- Eat several small meals.
- Drink fluids one hour before and one hour after a meal. This will decrease the amount of food in the stomach at one time.
- Avoid foods that cause gas and bloating. These may be onions, cabbage, sauerkraut, broccoli, Brussels sprouts and beer.
- Eat less fried, fatty foods. High-fat foods are digested slowly. They can cause a feeling of bloating.
- Lactose may cause bloating. It is found in milk, yogurt, cottage cheese and fat-free sherbets.
- Avoid being **constipated** (con-sti-pay-ted) by adding lots of fiber and fluid to your diet.

# Important Dietary Guidelines for People with COPD Protein

Protein is very important for COPD patients. It produces **antibodies** *(ant-tee-bodies)* that fight infection. Lack of protein can reduce the lungs' ability to fight infections in people with COPD.

The main sources of protein are meat, fish, eggs, poultry, legumes and dairy products.

# To Get More Protein in Your Diet

- Add skim milk powder to hot milk, cereal, eggs, soups, casseroles, gravies and ground meat dishes. This will add extra protein and calcium to your diet.
- Add chopped, high protein poultry, meats, cheese or legumes to soups and casseroles and vegetables. Nuts also can be added.
- Blend finely chopped hard-boiled egg or egg substitute into a sauce, gravy or soup.
- Include high protein snacks such as pasteurized eggnog, instant breakfast and puddings in your diet.
- Have peanut butter, bean dips, nuts, cottage cheese or other cheese with snacks to add additional protein and calories.
- Try using double strength milk (add 1 cup powdered milk to 1 quart whole milk).

# **Fluids**

Drinking enough fluids is very important for people with COPD. It helps thin out and clear out lung secretions. Oxygen therapy can be very drying. Fluids keep you hydrated. People with COPD should drink 8 to 12 cups of caffeine-free liquids per day. Water may be the best fluid to choose. It prevents constipation. Fruit juices, decaffeinated coffee and tea are also good choices. Milk is also a good fluid choice. It provides needed nutrients.

### Sodium or "salt"

Too much salt in your diet can cause you to retain fluids. It can also increase your blood pressure and shortness of breath. Your doctor may ask you to reduce the amount of salt you eat.

### Calcium (cal-see-um)

Calcium helps with lung function, muscle contraction and blood clotting. It works with **magnesium** (mag-knee-zee-um).



Calcium also plays an important role in making our bones strong, helping the immune system and transporting nerve impulses.

Many people with COPD take **corticosteroid** (*kort-te-coe-stair-royd*) drugs. These drugs can speed up the loss of calcium in both men and women. They affect hormones that control the deposit of calcium into the bone. **Osteoporosis** (*ah-stee-oh-pah-row-sis*), a condition of weak bones, can occur. Corticosteroids are only

# To Reduce Sodium or Salt in Your Diet:

- Do not use added salt while making food or for food served at the table.
- Read labels and ingredients on all foods. Avoid those that contain salt.
- Read the sodium content on the labels. Look for products having less than 140 mg sodium per serving or labeled "low sodium."
- Avoid those foods that have more than 140 mg of sodium per serving.

These include:

- Cured smoked and canned meats, bologna, frankfurters, ham and salami
- Regular canned vegetables, soups and vegetable juices
- Salted snacks (nuts, pretzels, chips)
- Regular frozen meals
- Foods in brine (pickles, olives, sauerkraut, feta cheese)
- Regular processed cheeses
- Seasoned salt, meat tenderizer, MSG, soy sauce, barbeque sauce

needed for short periods of time in COPD patients. But you should talk with your doctor about the risk of osteoporosis and your calcium and Vitamin D intake.

Dairy products are the main source of calcium. People who cannot eat dairy must choose their foods carefully to make sure they get enough calcium. Calcium is not easily absorbed. And just because a food has calcium does not mean your body can absorb the calcium. Vitamin D is important for calcium to be absorbed. So your diet must include good sources of Vitamin D. Adults up to age 50 should have 200 international units (IU) or 5mcg of calcium per day. Adults 51 to 70 should have 400 IU or 10 mcg of calcium daily. Two cups of milk can satisfy the daily adult need for calcium.

## Magnesium

**Magnesium** (mag-knee-zee-um) is the "fuel" that makes muscles work. It is also an important mineral that is involved in blood clotting, muscle contraction and protein production. Magnesium also works with calcium to help control the activity of the **bronchial** (brawn-key-el) tubes (airways in the lungs). A low level of magnesium weakens the muscles. This is true for the breathing muscles. So people with COPD should eat foods rich in magnesium. The average American only eats three-fourths of the recommended amount of magnesium. The recommended amounts for people between 19 and 30 are: 400 mg daily for men, 310 mg for women. For those older than 31: 420 mg daily for men, 320 mg for women.

Magnesium is found in the chlorophyll or green pigment of plants. Dark green vegetables are rich natural sources of magnesium. Magnesium may also be found in whole grains, beans, peas, lentils, tofu and some seafood. Chocolate contains some. Foods made from refined flours (like white bread) have 80 percent less magnesium than whole grain flours.

# Phosphorus

**Phosphorus** (foss-for-us) plays a role in all living cells. It helps in the building and repairing of tissues. And it plays a role in the formation of bone. Adults should have 700 mg of phosphorus each day. Most people get this amount by eating meat, poultry, eggs and milk products. A lack of enough phosphorus is rare in healthy adults. But people with COPD are at risk for not having enough phosphorus. The low levels are likely caused by drug side effects. Some of the medicines taken by COPD patients have been linked to low phosphorus levels. The drugs can cause large amounts of phosphorus to be released from the kidneys. A poor diet can also cause low phosphorus levels.

Talk with your doctor about your phosphorous levels. Phosphorous is not measured in routine blood work. Having enough phosphorous is important for lung function.

## Potassium

**Potassium** (*poe-taa-see-um*) is required for muscle contractions. It is very important for the heart muscle. High or low levels of potassium can cause an irregular heartbeat.

Some **diuretics** (*die-you-reh-ticks*) cause the kidneys to release large amounts of potassium from the body. If you are taking diuretics, your doctor will check your potassium levels. You can keep a good potassium level by

# *Milk Does NOT Create More Mucus*

Many people believe that drinking cow's milk will create extra mucus in their nose, throat and lungs. This is not true. The fats in milk can leave a soft, filmy coating in your throat and mouth. This may make you feel like you have extra mucus in your throat. Milk is an important part of a good diet. It contains calcium, protein, vitamins A, D and B-12 and riboflavin.

eating foods high in it. These include: milk, yogurt, winter squash, tomatoes, apricots, cantaloupe, bananas, oranges, prunes, carrots, potatoes, raisins, spinach and dates.

# The Relationship Between Drugs and Nutrients

Some COPD medicines can have an effect on your nutritional needs. In addition, the foods you eat can change a drug's effectiveness.

For more information about the relationship between drugs,

nutrients and food, talk with your doctor. You may also want to read the COPD Foundation's *Big Fat Reference Guide®*, Chapter B-10, pages 14-17. The COPD *Big Fat Reference Guide®* can be found at www.copdbfrg.org.



#### A Fluid-Restricted Diet

At some point you may be "retaining fluid." Your doctor may put you on a fluid-restricted diet. Ask your doctor or dietitian to help you plan what to eat and drink. Fluid retention can be caused by medicines. It can also be caused by your COPD. And sometimes it is caused by eating too much salt.

### Good Nutrition is Key to Managing Your Lung Disease

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A good, nutritious diet is very important for anyone. But it is most critical for someone with COPD. Keeping an ideal weight supports your lungs as they work. Good nutrition gives your body the energy it needs do the work of breathing and staying active. Good nutrition can help you have a better quality of life.

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# This Slim Skinny Reference Guide® (SSRG) was created by the COPD Foundation.

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# Oxygen Therapy





This "Slim Skinny Reference Guide: Oxygen Therapy" is part of the COPD Foundation's *Slim Skinny Reference Guide*® series which have been taken from the *COPD Big Fat Reference Guide*<sup>®</sup>.

To access the complete *COPD Big Fat Reference Guide*<sup>®</sup>, visit www.copdbfrg.org.

The mission of the COPD Foundation is to develop and support programs which improve the quality of life through research, education, early diagnosis, and enhanced therapy for persons whose lives are impacted by Chronic Obstructive Pulmonary Disease (COPD).
## What is Oxygen Therapy?

The lungs work by bringing in the "good air" and getting rid of the "bad air." You breathe in oxygen and it is passed into your blood through the tiny air sacs or alveoli in the lungs. Carbon dioxide is the waste that is created when your tissues and muscles are active. Carbon dioxide is passed out of the blood and into the lungs. You breathe out carbon dioxide. If you have lung disease you may, at some point, need oxygen therapy. Oxygen therapy means you breathe in extra oxygen from an oxygen tank. You may need this oxygen because the oxygen level in your blood is low. Chronic obstructive pulmonary disease (COPD\*) can damage your lungs. This makes it hard for your lungs to put the oxygen you breathe in,

into your blood. Oxygen therapy is a medical treatment. It must be prescribed by a doctor. For people with COPD, oxygen therapy can be a helpful part of their treatment plan.

\*COPD is an umbrella term used to describe the progressive lung diseases including: emphysema (em-fa-see-ma), chronic bronchitis (kron-ick-brawn-kie-tis), refractory (re-frac-ta-ree) asthma (az-ma) and some forms of bronchiectasis (brawn-key-eck-tay-sis). If you have COPD you have trouble moving air in and out of your lungs because of damage to the airways and/or the air sacs.

# What Happens to My Body When I Have Low Oxygen Levels?

When the oxygen level in your blood is low, it is called **hypoxemia** *(hi-pock-see-me-ah).* Low oxygen levels can affect many parts of your body.

Low oxygen in the blood can cause:

- The tubes of the lungs to become smaller. This can cause the heart to pump harder. Over time this strains the heart. It can become larger and weaker.
- Your body to make more red blood cells. Red blood cells carry oxygen through the body. By creating more red blood cells, the body is trying to deliver more oxygen. In some people this can cause blood clots, headaches and high blood pressure.
- Harm to your brain. Your ability to pay attention may be reduced. You may have memory and even speech problems. You may have trouble problem-solving and doing complex tasks.
- Problems exercising. Your ability to exercise or do physical activities may be reduced. Your muscles may become weaker.

Very low levels of oxygen in your blood can lead to confusion, coma and even death.

## **Deciding If You Need Oxygen Therapy**

Your doctor will use a couple of tests to decide if you need to be on oxygen. The first test is the most accurate. This test of **arterial** (*r-tear-ree-el*) **blood gases** can tell how well your lungs are getting oxygen into your blood and carbon dioxide out of your blood. For this test, blood is taken out of your arm, usually near your wrist. The blood is taken from an

#### Oxygen Therapy CAN Help

If the oxygen in your blood is low, getting oxygen therapy can help. In fact, getting oxygen can reverse all those bad effects that happen when blood oxygen levels drop. Oxygen can reduce shortness of breath. It will allow you to exercise longer and harder. It will help you think and remember better. And it will help you sleep better. Oxygen therapy CAN make a difference in how you feel.

artery. Arteries are large blood vessels that carry blood filled with oxygen from the lungs to the rest of the body. This test measures both the oxygen and carbon dioxide levels in your blood. Knowing how much carbon dioxide is in your blood is important to your doctor in deciding if you need to receive oxygen.

The second test to measure your blood oxygen level is **pulse oximetry** (*ahk-sim-e-tree*). But this test is done without taking a blood sample. The amount of oxygen is only *estimated*. A pulse oximeter is used for this simple test. This small device is clipped to your finger or an ear lobe. It is able to read the oxygen level directly through your skin. This pulse oximeter can be used by anyone. It gives fast results. But pulse oximetry cannot measure your blood carbon dioxide level or other elements in your blood. Pulse oximetry is not as reliable as the arterial blood gases test. But it can be done while you are exercising or sleeping.

The decision to try oxygen therapy may be made during a hospital stay. A lung infection or **exacerbation** (*x-saa-cer-bay-shun*) can cause oxygen levels to drop. If oxygen is started during this time, the need for it should be reviewed one to three months later. You may not need long term oxygen therapy.

Before your doctor writes a prescription for oxygen, there are guidelines that must be met. The results of your blood tests will show if you meet these guidelines. The medical guidelines must be met for Medicare or insurance to pay for the oxygen costs. (For more information on these guidelines, see the COPD Foundation's Big Fat Reference Guide<sup>®</sup>, Chapter 5-B.)

## **Choosing an Oxygen Supplier**

After you have a prescription for oxygen, you will need to choose an oxygen supplier. First, check with your insurance provider. They may have contracts with specific suppliers. If you have the freedom

to choose, shop for the best service. Asking the questions below should help you compare companies:

- Are you a national company?
- Where are you located?
- What systems do you provide? Why do you provide those systems?
- How often are deliveries made?
- Will you help make plans for oxygen delivery if I decide to travel?
- What is the response time in case of emergency?
- What is the turn-around time to replace bad equipment?
- How often will the respiratory therapist come to my home?
- How often will equipment be checked or serviced?
- What will this cost me?
- If I purchase a system will you still provide service?
- Do you have customer feedback you can share?
- Are you licensed and accredited? By which groups? Have you been accredited by Medicare/Medicaid? By the Joint Commission on Accreditation of Health Organizations? (Both groups have standards that must be followed.)

#### Your Oxygen Prescription

*The prescription your doctor writes will include:* 

- Info about if you need oxygen for rest, exercise and/or sleep. And how much.
- How many hours a day oxygen should be used.
- Info about if you should use a pulse oximeter during activity and sleep.
- What type of oxygen system you should use.

### **Types of Oxygen Systems**

There are two types of oxygen systems: *stationary* and *portable*. There are also storage systems that can be used to fill portable systems. This combines the two types.

#### Stationary Systems

(These systems can provide a lot of oxygen. But they limit movement.)

System	Features
Oxygen Concentrator	Has an electric motor. Needs electricity source. Removes nitrogen from room air to make oxygen. Relatively small. Weighs 22-70 lbs. Can have 50 ft tubing for movement. Must be in open, ventilated area. Must have regular check-ups and filter changes. <i>MUST have back-up</i> oxygen in case of power failure.
Reservoir for Liquid Oxygen	Liquid oxygen in large tank. Weighs about 124 lbs. Tank is filled by supplier twice a month. No electricity needed. Good for use at home or for filling portable systems. <i>Caution: must be used to prevent spills.</i> <i>Liquid oxygen can injure skin on contact.</i>
Compressed Gas Oxygen	Large steel or aluminum tank. Very heavy. Not easily moved. Must be secured to prevent falling over. Good as back up to concentrator. <i>Not good for someone</i> <i>needing continuous flow oxygen.</i>
Portable Systems	
Oxygen Concentrators	Lighter portable models. Have electrical connections for cars. Or can have battery packs.
Portable Liquid Oxygen Units	Can be filled easily from large liquid reservoir. May come with a conserving device.* Allows for longer periods away from home.
Compressed Gas in Smaller Cylinders	Portable. Small. Weighs between 0.7 lbs and 7.9 lbs. With a conserving device,* can last (at 2 liters/minute) from 1 to 5 hours. Good as back-up for concentrators. Not good for continuous, long-term oxygen.

\*See side bar on following page about conserving devices

#### **Portable Systems**



Evergo Portable OxygenConcentrator Photo courtesy of Phillip Respironics



Invacare XPO2<sup>™</sup> POC Photo courtesy of Invacare Corporation



Eclipse POC Photo courtesy of SequalTechnoloigies, Inc.



LifeChoice® Portable Oxygen Concentrator Photo courtesy of Inova Labs

## Ways to Take In Oxygen or Oxygen Delivery Systems

In addition to choosing a type of oxygen system, you will need to decide how you want to receive or take in the oxygen. There are four ways the oxygen can be delivered to you. These are:

• Nasal cannulas: This is plastic tubing that is connected to your oxygen source. On the other end are two small prongs that rest in your nose. The tubing is held in place by also resting on your ears. This device is simple and cheap. The oxygen is diluted with

#### **Oxygen Conserving Devices**

Oxygen conserving devices help reduce the size and weight of portable oxygen systems. By reducing the needs for replacing or refilling tanks, costs are reduced. The types of conserving devices are: reservoir cannulas and pulsed delivery systems. For more information about these conserving devices, see the COPD Foundation's Big Fat Reference Guide<sup>®</sup>, Chapter B-5. room air before it enters the lungs. Oxygen is delivered in continuous flow. This can be drying to the nasal passages.

- Face masks: This plastic mask fits snugly over the mouth and nose. It delivers a higher concentration of oxygen. Can be uncomfortable. Makes talking hard. Cannot be worn while eating and drinking.
- **Transtracheal Oxygen:** This is a catheter (a plastic tube) inserted through the skin of the neck into the windpipe below the Adam's apple. Oxygen is delivered directly

into the windpipe or **trachea** (*tray-key-uh*). The oxygen is not diluted. So, your required amount of oxygen can be delivered with a reduced oxygen flow rate. This makes a tank last much longer.

So costs are lower. This is also a great option for people who want to remain active. It requires detailed self-care instructions. It is not a good option for people who have frequent infections or exacerbations.

## Will Medicare or Insurance Cover Oxygen Therapy?

Home oxygen therapy and equipment is covered by Medicare under "durable medical

#### Did you know that...

- It is estimated that 1 million Americans use home oxygen.
- Home oxygen therapy costs more than \$1 billion a year.
- It is the most expensive, non-surgical treatment reimbursed by Medicare.

equipment." Medicare pays a monthly amount for home oxygen. It covers oxygen equipment and supplies. Medicare and most insurance companies pay 80 percent of the allowable costs for a stationary system. But insurance policies can differ. Talk with your insurer. Your doctor may prescribe a specific system for you. But your supplier may find it hard to provide this system. They may not get paid enough by Medicare or your insurance for some systems. You, your doctor and your supplier will need to work together to solve this problem.

## **Tips for Safety**

• Oxygen canisters should be kept 5-10 feet away from gas stoves, fireplaces, woodstoves, candles and other open flames.

BE SAFE! Know these SAFETY TIPS for using Oxygen

- Do not use electric razors while using oxygen. Sparks could occur.
- Do not use oil, grease or petroleum-based products on or near the equipment. Avoid petroleum-based lotions and creams on your face or upper chest. These products can catch on fire very easily.

- Make sure there is NO SMOKING in your home or car when oxygen is in use.
- Tie oxygen cylinders to fixed objects. They can become shooting missiles if knocked over.
- Be careful around oxygen tubing to avoid tripping.
- Know the safety checks provided by your oxygen supplier. Keep their phone numbers (including emergency contact) near a phone.
- Do not try to fix broken equipment.
- Have smoke detectors in your home. Make sure they are working. Check them monthly.
- Keep a fire extinguisher in your home. Have an escape route planned in case of fire.
- Let the fire department, gas and electric and phone companies know when you start receiving oxygen. Ask for a "priority service listing." This will help when there is a power or phone failure.

## And Finally...Can I Really Live My Life on Oxygen?

Being told you need to be on oxygen can make you feel frustrated, scared and confused. You may feel people will view you as "handicapped." You think it will be a hassle to be attached to an oxygen tank. You think it will change all the plans you had. And, finally, thinking about being on oxygen forces you to realize how serious your lung disease really is. If you are thinking or feeling any or all of the above, consider this:

Oxygen therapy will help you feel less tired, less out-of-breath and healthier. You may actually be able to DO MORE than you could before.

It is one of the most important ways you can manage your lung disease.

AND, it may help you live longer.



	NOTES		

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# Traveling With COPD







This "Slim Skinny Reference Guide: Traveling with COPD" is part of the COPD Foundation's *Slim Skinny Reference Guide*<sup>®</sup> series which has been taken from the *COPD Big Fat Reference Guide*<sup>®</sup>.

To access the complete *COPD Big Fat Reference Guide*<sup>®</sup>, visit www.copdbfrg.org.

The mission of the COPD Foundation is to develop and support programs which improve the quality of life through research, education, early diagnosis, and enhanced therapy for persons whose lives are impacted by Chronic Obstructive Pulmonary Disease (COPD).

## **Traveling with COPD**

Having a chronic lung disease does not mean you have to give up traveling. People with COPD\* can still take vacations, visit friends and family and see the world. You will just need to do a little extra planning. You can have a safe and fun trip. The information in this Guide can help you plan for it.

> \*COPD is an umbrella term used to describe the progressive lung diseases including: emphysema (em-fa-see-ma), chronic bronchitis (kron-ick-brawn-kie-tis), refractory (re-frac-ta-ree) asthma (az-ma) and some forms of bronchiectasis (brawn-key-eck-tay-sis). If you have COPD you have trouble moving air in and out of your lungs because of damage to the airways and/or the air sacs.



## Important Travel Tips for People with COPD

#### 1) ALWAYS discuss your travel plans with your doctor.

Your doctor will tell you if you are well enough to travel. Tell your doctor how long you will be gone and how you will travel. Make sure your doctor knows about the weather and climate of the place to which you are traveling. This could have an effect on your health.

- 2) Create a folder of important medical papers. Put these with your travel papers. Make sure you can easily get to this folder at any point during your trip. You should include a list of the medicines you are taking. If you are on oxygen, include your oxygen prescription. You may also want to include a letter from your doctor. The letter can include a brief outline of your condition. It should state that you are fit to travel.
- **3) Keep a list of all important contact information and phone numbers.** This list should include your doctor and your emergency family contact. It should also include the airline, train or cruise line on which you are traveling. Also include a contact person at your final stop. This list should be kept in your travel folder.
- 4) Get the name and location of a doctor and hospital in the city to which you are traveling. You should have this information just in case you need care while away. Your doctor can help you with this. It is most important to have this info if you have planned a long visit.
- **5) Have all of your medicines refilled. Take enough for your entire trip.** If you are traveling by plane, keep some medicines in your carry-on bag. Make sure all medicines are labeled. They should be in their original containers.
- 6) Review your health insurance before you leave. Some policies do not cover you while you are out of state or out of the country. You may want to get a temporary policy. A travel agent can help you with this.

7) It is best to have a travel partner (spouse or friend). Make sure he/she knows about your special needs. Your travel partner should understand your medicines. They should also understand how to handle oxygen equipment.

## **Traveling With Oxygen**

If you are on oxygen therapy, you will need to make plans for having oxygen with you as you travel. Your home oxygen supplier can help you. National chains can get in touch with their branch offices for you. Local suppliers are often members of a network of oxygen suppliers.

Discuss your entire trip with the oxygen supplier. It is best to provide details in writing to one contact person. Keep a record of this contact person. Faxing or emailing the plans you discuss is best. You will need to provide the following info:

- Your name, address and phone number.
- Your doctor's name and phone number.
- Your oxygen prescription. This must include your flow rate. It should list the type of system and equipment you need. You should also list any tubing, cannulas, humidifiers or nebulizers you may need.
- Your departing city, airport or port.
- A name, address and phone number of a contact person at your final travel stop.
- A name and number of an emergency contact.
- If traveling by plane, your airline, flight number and departure gate number. You should also include any stops or layovers and your arrival airport and arrival gate.



If you need continuous oxygen and are traveling by plane, you must work with your airline for your oxygen needs. (See the following section).

If you will be staying in a hotel, let the front desk know about your oxygen needs. Tell them that a supplier may deliver the oxygen before you arrive. Ask the supplier if a hotel worker can sign for the oxygen delivery. The supplier may not deliver without your signature. If this is true, have the delivery ticket emailed to you. Sign it and fax it back to the supplier before you leave for your trip. When you check in, have the oxygen delivered to your room. Or if it has not arrived yet, let the front desk know that it will be arriving soon.

Confirm all of your needs verbally and in writing. Review each part of your trip. Question any concerns. Make needed changes. The plans for traveling with oxygen can be tiresome. But if you plan ahead for your oxygen needs you will have more freedom. And you will enjoy your travels more.

## **Traveling by Plane**

**Oxygen needs on the plane:** There are some special issues that COPD patients need to know when flying. Airplane cabins are pressurized for high altitudes. This means there is less oxygen in

#### CAUTION:

Many people think that the emergency oxygen masks on a plane can be used by people who need oxygen during the flight. THIS IS NOT TRUE. Only 15 to 20 minutes of oxygen is provided through these masks. This oxygen is ONLY for emergency use if the plane loses cabin pressure. the air of the plane during a flight. This is not usually

a problem for people with healthy lungs. But it can cause people with COPD to be at risk of having low oxygen levels in their blood. This is called **hypoxemia** (high-poc-see-me-ah).

If you need oxygen during exercise or sleep, you may also need it for air travel. Talk with your doctor well before your trip. Your doctor will decide if you need to plan to have oxygen on the plane. You will need to give yourself enough time to have oxygen supplied, if you need it. If your doctor decides you do need to have oxygen on the plane you may take your own. The Federal Aviation Agency (FAA) now allows passengers to bring their own (or rented) portable oxygen concentrators on board a plane. The equipment must be one of their approved units. To find out which units are FAA approved, visit

www.airlineoxygencouncil.org. You must bring enough batteries for the equipment, for the entire flight. A flight across country could take between 3 and 6 large batteries. You should also bring extra tubing, cannulas, T-connectors, a cylinder wrench and electric adaptors. You will be prepared for any situation. Keep all of these items in your carry-on bag.

Before the FAA began allowing passengers to bring their own oxygen onto planes, airlines provided the oxygen for a

fee. If you prefer to use the airline's oxygen, tell them before you purchase your ticket. You will probably be directed to the airline's medical desk or officer. You will need to provide your doctor's name and number. The medical officer will talk directly with your doctor. Your doctor may need to send in a special form with information about your needs. Most airlines need two weeks advance notice to provide oxygen. (Some airlines can make these plans in 48 hours). It is best to plan well in advance. The cost of oxygen from an airline can range from \$75 to \$150.

If you choose to purchase oxygen from the airlines, it is only for use in the plane. Airlines will not supply you with oxygen for use between flights. They will not provide you with oxygen for going to baggage claim areas. If you need oxygen in the airport, you will need to make arrangements with a supplier for each part of your trip.

**Request a wheelchair:** Consider asking for a wheelchair when you make your plane reservations. It can be a long walk to your gate. You might also have a long wait at the security check-in. A wheelchair will give you easy movement through the airport.

In the chair you will get a quick security check. A wheelchair is most helpful if you have a connecting flight. You should request a wheelchair with an attendant. They will assist you to your next flight. Riding instead of walking will save your energy. It will reduce your stress. Make these plans ahead of time. The airlines may provide you with a wheelchair and attendant. Or the airlines may have a motorized cart waiting for you at your gate.

**If possible, have a travel partner:** This person should know about your needs. They should be prepared to assist you. Your travel partner should understand the oxygen system you use. They should be able to change cylinders, open the valve, attach a regulator or conserver and adjust the flow.

**Reduce the risk of infections:** The air in a plane is fairly dry. This can put you at an increased risk of getting an upper respiratory infection. Also, the close seating in a plane can put you at risk for getting an infection. Take these steps to reduce the risk of infection:

- Drink plenty of water.
- Avoid coffee, tea and alcohol.
- Ask to be reseated if you are near someone coughing or sneezing.
- Consider wearing a mask. This will act as a barrier against airborne droplets.
- Have a filled prescription for antibiotics with you. Have this as a back-up plan. Having this with you will allow you to quickly treat any infection. This may keep you from getting much sicker.

## **Traveling by Train**

Train travel can be an easy-to-use option. It does require most of the same advanced planning for oxygen needs. As with any other travel, you should discuss your oxygen needs with your doctor and your oxygen supplier. You should decide what you will need for your entire trip. With a 12-hour notice, Amtrak can help people needing oxygen. You can bring your own oxygen equipment on the train. There is no extra charge. It must weigh less than 75 lbs. Oxygen concentrators must be able to run on battery power for up to 12 hours. You should plan for enough oxygen for your entire travel time, plus an extra 20 percent. If you use oxygen, you may only travel in non-smoking areas of the train.

As with any travel, make sure you have extra equipment supplies with you. If you need oxygen in your travel city, plan ahead with a local supplier.

## **Traveling by Car**

Plan ahead when taking a trip by car. Some special considerations for car travel are:

- **Altitude:** This can cause breathing problems for you. Discuss this with your doctor. Map out your travel route. Decide your oxygen needs. Find stops along the way where tanks can be refilled.
- Air pollution: This may also cause you problems. Avoid driving during peak rush hours. Try to travel when there is less traffic. Avoid heavily traveled highways. Take back roads if possible. Keep the windows up. When weather allows, keep the air conditioning on.
- Allergens: Are you sensitive to certain allergens? Are you traveling through areas with these allergens? If so, consider taking your trip during a time of the year when these allergens are less of a problem.
- **Oxygen:** If you need oxygen, plan to have enough cylinders or tanks for the length of your travel. If you use a concentrator powered by the car's electrical system, have this system checked before you leave.



Make sure your car's battery and alternator can handle the extra demand. Secure extra cylinders. Make sure they are not banging around during the trip. Keep them in a well-ventilated area. Do not leave oxygen tanks in hot cars.

• **Be prepared:** Make sure your car has recently been serviced. Have the oil changed. Have the fluids checked. Make sure the spare tire is ok. Have a jack, jumper cables, flares, blankets and water in the car.

## **Taking a Cruise**

Many cruise lines allow passengers to travel with oxygen. The cruise lines will need to know about your oxygen needs 4 to 6 weeks before your cruise. You must get approval from the cruise line's Special Services Department or the Operations Department, before you leave. A letter from your doctor will be required. The letter should say that you are ok to travel. It should also include a brief medical history. It will need to include your current prescriptions, including your oxygen needs.

You will probably be required to make your own plans for oxygen to be delivered to the cruise ship. You should discuss these details with the cruise liner's agents before your trip. There is usually no extra charge for you to bring your oxygen on-board. You will be asked to avoid being in the smoking areas of the ship.

#### Finally,

With any travel, ALWAYS discuss your plans with your doctor. Planning ahead will help you have a safe trip. Your COPD does not have to keep you from traveling. With advance planning you can enjoy this freedom.

NOTES	

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## This Slim Skinny Reference Guide® (SSRG) was created by the COPD Foundation.

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# Understanding Lung Disease





This "Slim Skinny Reference Guide: Understanding Lung Disease" is part of the COPD Foundation's *Slim Skinny Reference Guide*<sup>®</sup> series which has been taken from the *COPD Big Fat Reference Guide*<sup>®</sup>. To access the complete *COPD Big Fat Reference Guide*<sup>®</sup>, visit www.copdbfrg.org.

The mission of the COPD Foundation is to develop and support programs which improve the quality of life through research, education, early diagnosis, and enhanced therapy for persons whose lives are impacted by Chronic Obstructive Pulmonary Disease (COPD).

# Finding out you have lung disease can be confusing and scary.

Learning more about your disease can help you know how to feel better. You will be less confused and able to manage your disease better. This will help you stay as healthy and active as possible.



## Parts of the Respiratory System

**Larynx** (lare-inks): the part of your throat that leads to the lungs. Air flows down the larynx into the lungs.

**Diaphragm** (die-a-fram): the muscle that separates the chest cavity from the stomach. The diaphragm is the main muscle we use for breathing. When the diaphragm muscle tightens, the lungs expand.

**Bronchial** (brawn-key-el) **tubes** and **bronchioles** (brawn-key-oles): the airways of the lungs. Air flows through these tubes into and out of the lungs. Bronchial tubes are the larger airways. Bronchioles are smaller airways that lead to the alveoli (see below).

**Alveoli** (al-vee-oh-lee): these are millions of tiny sacs at the very ends of the smallest tubes in the lungs. Oxygen is absorbed into the blood and carbon dioxide is released from the blood here.

*Cilia* (seal-lee-ah): tiny, hair-like fibers that line the bronchial tubes. They help move mucus up the tubes so it can be coughed out.

## How the Lungs Work

To understand your disease better, you need to know how the lungs work.

The number of times you breathe each minute is called your respiratory rate. This is controlled by your brain. You brain sends signals down

the nerves to the muscles in your chest and between your ribs. This signal tells your muscles to tighten and relax.

When you tighten and relax the muscles around your lungs, you move air in and out. When you tighten these muscles, the diaphragm moves down. The ribs move up. Air enters the lungs. When you relax the muscles, the diaphragm moves up. The ribs tilt down. Air is pushed out of the lungs.



Air travels through your nose or mouth, into the **larynx** and into the lungs. Air moves further into your lungs through the lungs airways **(bronchiole)**. The air ends up in air sacs at the ends of these airways.

These sacs are called **alveoli**. These are the actual working units of the lungs. In these air sacs, oxygen (from the air you breathed in) is absorbed into the blood. Carbon dioxide is released from your blood and breathed out.

Oxygen is then taken by the blood to all the cells in your body.

Breathing, for the most part, is something our body does for us, with no planned effort on our part.

\*COPD is an umbrella term used to describe the progressive lung diseases including: emphysema (em-fa-see-ma), chronic bronchitis (kron-ick-brawn-kie-tis), refractory (re-frac-ta-ree) asthma (az-ma) and some forms of bronchiectasis (brawn-key-eck-tay-sis). If you have COPD you have trouble moving air in and out of your lungs because of damage to the airways and/or the air sacs.

## **Types of COPD**

You have been told you have COPD. This stands for **C**hronic **O**bstructive **P**ulmonary **D**isease.

- Damage to the airways causes **chronic bronchitis**.
- Damage to the air sacs causes **emphysema**.
- Damaged and enlarged bronchial tubes causes **bronchiectasis**.

**Chronic**: This means that the disease lasts a long time and is always present.

**Obstructive**: Air flow in and out of your lungs is blocked or obstructed. This is caused by swelling and extra mucus in the tubes of the lungs which carry air in and out.

**Pulmonary**: This means that the disease is located in your lungs.

**D**isease: Your lungs have some damage. But even though a cure hasn't been found yet, your symptoms can be treated.

#### **Chronic Bronchitis**

Bronchitis occurs when the bronchial tubes are irritated and swollen. This causes coughing and shortness of breath. If mucus comes up with the cough and the cough lasts at least three months for two years in a row, the bronchitis has become **chronic bronchitis** (*kron-ick-brawn-kie-tis*).

There are hair-like fibers along the inside edges of the bronchial tubes of the lungs. These tiny hairs are called **cilia**. The cilia help

#### Symptoms of COPD

These can be different for each person, but the common symptoms are:

- Shortness of breath
- A cough that won't go away and may produce mucus
- Feeling tired, especially when exercising or doing daily activities
- Tightness in the chest

move mucus up the tubes so it can be coughed out. In chronic bronchitis, the tubes have lost their cilia. This makes it hard to cough up mucus, which causes more coughing. More coughing makes the tubes more irritated. This creates more mucus. The tubes then become swollen, making it hard to breathe. Smoking even just a little keeps the cilia from working normally. Mucus can build up in the lungs. This can cause more damage.

#### **Emphysema**

**Emphysema** (*em-fa-see-ma*) occurs when the air sacs in the lungs are destroyed. The sacs are called alveoli. The walls inside the sacs disappear. This makes the groups of small sacs become larger, single sacs. These larger sacs do not work as well as the smaller sacs. The larger sacs do not absorb oxygen as well. So, less oxygen is absorbed into the blood.



Abnormal



When the small air sacs become damaged, the lungs become stretched out. The lungs lose their springiness. The airways become flabby. It becomes hard to breathe out. Air is then trapped in the lungs. This creates a feeling of shortness of breath.

## Bronchiectasis

#### Asthma is NOT COPD.

With asthma, airflow is also blocked. But this blockage is **reversible**. The blockage that occurs with COPD is NOT completely reversible. It is often partially reversible.

Asthma and COPD are common diseases. As much as 20 percent of people with COPD also have asthma.

**Bronchiectasis** (brawn-key-ecktay-sis) is an abnormal stretching and widening of the lungs' airways. It is caused by mucus build-up. When the lungs cannot get rid of the mucus, it builds up in the airways. This causes infections in the airways. The airways become irritated and weak and start to widen. These weakened airways become damaged. All of this causes even more mucus and bacteria to build up. The airways become more infected and blocked. Breathing becomes difficult.

## What Causes COPD?

## Smoking

Most COPD is caused by breathing in unhealthy toxins or poisons. The most common toxin is cigarette smoke. **Smoking is the number one cause of COPD in the United States.** Smokers inhale over 4,000 chemicals. Over 40 of these cause cancer. When smoke enters the lungs, it causes irritation and inflammation. The body sends white blood cells to the area. The white blood cells release strong enzymes. These destroy lung tissue. Normally, the body can protect itself against these enzymes. But tobacco smoke can overwhelm these defenses. This causes the lung damage of COPD. **It is very important to quit smoking.** Stopping smoking can slow down the progress of your COPD. It will also make your treatments more helpful. Within just a few weeks of stopping smoking, your breathing, coughing and clogged sinuses can improve. Other benefits of quitting include:

- Less risk of heart disease, lung disease and cancer
- Less shortness of breath
- More energy
- No smoker's cough
- Liver functions becomes normal
- Digestion becomes normal
- Healthier world for those who live with you
- Gives you more money
- Frees you from cigarette smells and burns

#### To Stop Smoking: Make a Plan

Set a date to quit.

Remove all cigarettes from your home and car.

Use nicotine gum or patches to help or get a subscription from your doctor for other medicines that can help.

Exercise and eat right.

Reward yourself with the money you save from not buying cigarettes.

Get outside help and support: smokers quit lines, community and hospital sponsored programs and quitter's support groups.

Don't give up! Keep trying.

## **Breathing in Other Toxins**

COPD can also be caused by breathing in dusts, fumes or chemicals over a long period of time. This usually occurs at work, but can also happen at home. Harmful materials at work may include **ammonia** (*a-moan-yah*), **asbestos** (*az-best-us*), carbon monoxide, dusts and fumes. Toxins found at home can include dust, smoke, cleaners, spray products, mold and bacteria.



N-95 Dust Mask

Whether or not breathing these toxins caused your COPD, you should avoid them.

Breathing in these harmful agents can make your lung disease and breathing problems much worse. Avoiding these harmful materials is called **reducing your risk**. There are many ways you can reduce your risk of making your lung disease worse.

## *Reducing your risks by avoiding harmful agents in your home:*

Harmful Agent	Tips to Reduce Your Risk
Sprayed or "aerosolized" products: hair spray, perfume, deodorants, air fresheners	Use pump sprays and roll-on deodorants. Do not use plug-in air fresheners.
Cleaners and bug spray	Find less toxic, natural cleaners. Leave the home when cleaners or sprays are being used. Wear an N-95* respirator mask if you must use cleaners.
Dust and Dirt	Avoid shaking out rugs, vacuuming, sweeping and dusting. Have someone else do this cleaning if possible. Change filters in dryers, refrigerators, furnaces and heating vents often.
Wood-burning fireplace	Avoid using fireplaces.
Bacteria, mold and mildew	Avoid using or replace sponges often. Seal water leaks in the basement. Keep indoor humidity below 40 percent (use a humidity meter).

\*An N-95 respirator mask is a mask that can filter out 95 percent of particles in the air if fitted and worn correctly.

Air pollution can affect everyone. But breathing in smog is very bad for people with lung disease. Plan to stay indoors on days when there is a high level of pollution. (Your local news station usually reports the pollution level each day during the weather report.) Keep your windows closed on these days. Also, avoid breathing in bad fumes when traveling by car. You can do this by driving on less crowded roads and by avoiding busy rush hour times.

## A Genetic Link to COPD

A disease called **Alpha-1-Antitrypsin** (al-fa-one-an-tee-trip-sin) **Deficiency** (dee-fi-shin-see) is known to cause COPD. People with Alpha-1 have a much lower-than-normal level of the blood protein called alpha-1-antitrypsin. This protein protects the lungs from irritation caused by breathing in toxins. Alpha-1 is a **genetic** (*ja-net-ick*) disorder. This means it is passed from parents to their children. You can find out if you have Alpha-1 through a simple blood test. Everyone with COPD should be tested for Alpha-1. This is very important because there is a specific treatment for Alpha-1. It can slow the progress of COPD. (For more information on Alpha-1-Antitrypsin Deficiency, visit the Alpha-1 Foundation's website at www.alpha-1foundation.org or AlphaNet at www.alphanet.org)

# Links between COPD and Other Health Problems (Comorbidities)

Many people with COPD also have other medical problems. These can include:

- High blood pressure
- High cholesterol
- Heart disease
- Diabetes
- Osteoporosis
- Depression
- Cancer

These other conditions are called **comorbidities** (*coe-more-bid-i-tees*). These problems can cause COPD patients to be in the hospital more often.

## Why?

No one really knows why it is so common for COPD patients to have other serious medical problems. One reason may be the medicines that COPD patients must take. All medicines have side effects and risks. This is especially true for COPD medicines such as steroids. Another reason for these additional problems relates to the lung inflammation that occurs with COPD. People with COPD have inflammation in their lungs. AND

they have some inflammation in their blood. Many experts believe that this blood inflammation causes some damage to the heart, muscles and bones of COPD patients. This would help explain the other medical problems. This thinking has lead to the idea that COPD is not just a disease of the lungs. It involves many parts of the body. It is very important that you discuss other medical problems with your doctor so he/she can treat them as needed. (For more information about comorbidities. see the COPD Foundation's Big Fat Reference Guide<sup>®</sup>, Chapter 2-B. The *Big Fat Reference Guide*<sup>®</sup> can be accessed at www.copdbfrg.org)



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