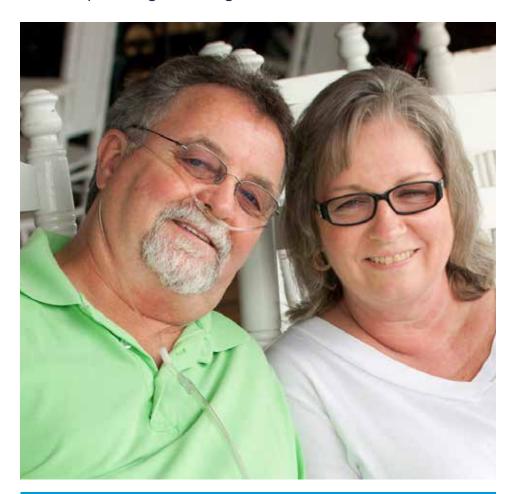


Around the Clock With Chronic Lung Disease

Helpful Tips to Manage Every Day Activities for People Living with Lung Disease



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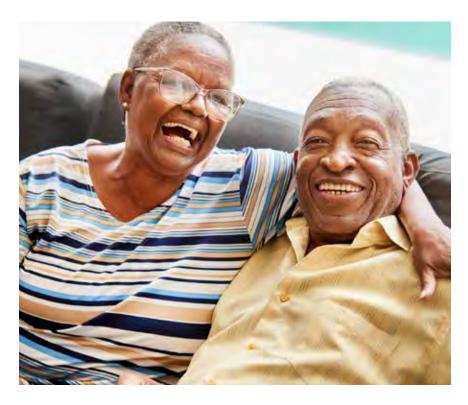
Introduction

Living with a chronic lung disease like pulmonary fibrosis or chronic obstructive pulmonary disease (COPD) can make doing every day actvities, like bathing or running errands, more difficult. This booklet provides helpful advice and suggestions to conserve your energy and get more done.

Starting from the moment you wake up, you can use the helpful tips and advice in this booklet to make living with lung disease a little easier—both at home and while on the go. Best of all, most of the tips don't require special equipment or big changes to your routine.

You can do more and feel better when you manage your lung disease.

We can help.



Tips to Conserve your Energy

When it comes to living as fully as you can with lung disease, how to conserve energy is one of the most important things to learn. By using less energy to complete each task, you will have more energy to use throughout the day.

There may be different times of the day when you have more energy. During this time, try to be more active but take a break when you are getting tired or short of breath.

Remember the 5 P's:

- Pace yourself between activities and take breaks.
- Plan ahead and try not to do too many "heavy" tasks in one day.
- Position yourself upright when sitting and standing.
 Try to avoid leaning or bending too much.

Don't take on more than you can handle comfortably and when you feel tired, **REST**.

- Prioritize what is important to get done and what can be done later.
- Pursed lip breathing can help when you feel short of breath.

If you find different tasks difficult or you cannot do them safely, ask your friends or family for help. Ask your doctor about pulmonary rehabilitation. Pulmonary rehabilitation is a program that includes exercise, lung disease education, and support. Your doctor may also recommend an in home assessment by an occupational therapist.

Now let's take a look at activities in a typical day...

Waking Up

For some people, waking up is difficult. And if you're not feeling your best, it can be a real chore. Here are some hints to start your day right:

- Waking to the sound of soft music is much more pleasant than hearing an alarm. Or, you might try an alarm that wakes you up with gradually increasing light.
- Do a few stretching and relaxation exercises while still lying down.
- Before standing up, do some of your dressing while sitting on the edge of the bed. At night, leave your robe and slippers or clothes where they are easy to reach from your bedside.
- Store clothes you wear often in the dresser drawers that are easiest to reach. This saves on bending.
- Put items worn most often, such as socks and underwear, in the most convenient places. Store seldom-used things in bottom drawers and on high shelves.

Making Your Bed With Ease

While you are still in bed, pull up the top sheet and blanket on one side.

Smooth them out.

Exit from the unmade side, which is then easy to finish!

Even easier: simply pull a comforter over the entire unmade bed.

Bathing and Grooming

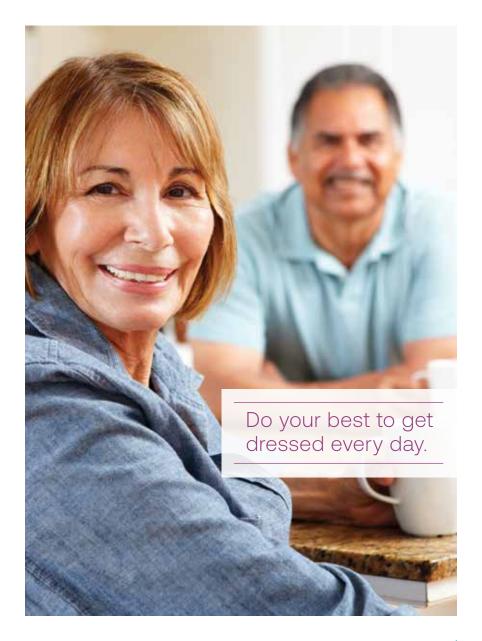
- Use assistive devices or durable medical equipment in the bathroom like a handheld showerhead, shower chair, tub transfer bench and grab bars. Talk with your healthcare provider about how to order this type of equipment.
- Put on a terry cloth robe right after bathing. This eliminates the effort of drying altogether.
- Avoid excess humidity. Leave the bathroom door open and be sure to use the bathroom exhaust fan.
- If you feel weak, don't take a bath or shower when you are alone.
- Be sure to wear your oxygen while bathing. If you use oxygen through a long tube, pass the tube over the shower door or curtain rod. This keeps the tube out of the way and makes bathing easier.
- It's okay to remove the nasal cannula briefly to wash your face, shave or apply makeup.
- Sit down to do your hair, shave or apply make up.
- Strong scents can be irritating and unpleasant. Avoid toiletries that are heavily perfumed or use unscented products.
- Avoid elaborate hairstyles that need daily setting or extended use of hand-held hair dryers.
- Choose grooming products in gel or liquid form. Avoid using aerosols or sprays, except those prescribed by your healthcare provider.
- If you have accidental loss of urine brought on by coughing, overexertion or stress, a variety of discreet, inexpensive adult-incontinence products are available.



Dressing

- Avoid wearing clothes that restrict chest and abdominal expansion. Tight-fitting clothes make breathing more difficult.
- Try wearing cotton underclothing. It may be more comfortable than nylon if temperature extremes bother you. Or, try newer, high-tech fabrics that wick moisture away from the body.
- Place your underwear inside your pants and put on both together.
- Wear slip-on shoes or those with Velcro® fastening. You won't have to bend over to tie shoelaces.
- Use a long (12"-18") shoehorn to make it easier to put on any kind of shoe. Sock aids are also available so you don't have to bend over.
- Avoid wearing shirts that are tight around the neck. For men, collared polo shirts, turtlenecks or a colored t-shirt under an open-neck sport shirt can be attractive and comfortable. On more formal occasions, a clip-on tie is a good compromise between formality and comfort.
- Wearing suspenders may be more comfortable than using a belt.
- Choose socks and stockings without elastic bands.
 The elastic may bind the leg and restrict circulation.
- Most women find that slacks and socks are much easier to put on than pantyhose.
- Women may find camisoles a comfortable and pretty substitute for bras. If this isn't an option, avoid underwire bras and consider a front closure for ease.

Stay warm with a large shawl. A shawl is much easier to put on and take off than a sweater. This makes it great for occasional shivers.



Medication

- It is important to store medications safely. Keep them away from heat, moisture, bright light, pets and small children.
- For each prescription, figure out how long it will last and mark on a calendar when to reorder. This may save you from running out of important medications.
- If your pharmacy plan offers the service, sign-up for automatic refills or to get phone alerts when its time to reorder.
- Don't hesitate to ask for more information about your medication. Also, be sure to tell your healthcare provider if your medication doesn't seem to be working or if you stopped taking the medication.
- Keep a record of medications you are allergic to or that cause you bothersome side effects.
- Never take more or less of a medication without talking to your healthcare provider.
- Never use anyone else's medication.



Inhalation Therapy

- If you need breathing or nebulizer treatments, store and use your equipment in the place that offers the easiest access and most comfort. A small table with a drawer or a flat-topped desk works well.
- Read, watch a show or listen to a podcast while taking a treatment. Using headphones will make it easier to hear while the machine is running.
- Have a small clock handy to time your treatments.
- Put a thick pad, such as folded fabric or newspaper, under your equipment. It will be much quieter.
- Check the hose connection if you aren't getting enough mist. Vibrations can cause these to loosen. Hand-tighten to fix.
- Clean and dry all equipment as directed. Ask your supplier for instructions and a demonstration.
- When you disassemble your equipment to clean it after a treatment, the plastic hose may be difficult to pull loose. Try pulling it off while the machine is still running. The added "push" of the compressor helps loosen the hose.
- Some machines have a small air filter that should be washed, dried and changed regularly. Ask your supplier for extra filters. They are easy to change.
- Cover and protect your equipment to prevent contamination between uses.



Oxygen

If you use supplemental oxygen, have your supplier explain how to use your all your oxgen equipment. Also, ask your supplier if they have a respiratory therapist (RT) on staff to answer your questions. Write down the oxygen supplier's emergency phone number and find out what procedures to follow in case of technical questions or concerns about the equipment.

Questions about oxygen amount and usage are for your doctor to answer. Keep in mind:

- It is important to to know how long your oxygen will last you. Time your outings so you don't run short.
- When using supplemental oxygen, remember to inhale through your nose (a good idea anyway). Inhaling through your mouth can be very drying. Some portable systems only trigger a flow of oxygen when you inhale through the nose.
- · Clean and change your oxygen supplies like nasal cannulas, face masks or nasal prongs regularly.
- Have backup equipment like a large oxygen tank and tell your electric company, police, and fire departments that you use oxygen equipment at home. Plan for power outages and consider buying a backup generator. Ask your neighbors to check in on you if there is a power outage.

Talking About Your Equipment

Don't be embarrassed by the occasional attention your oxygen unit and tubing may attract. Most people know what they are. Those who are not familiar with this equipment are interested in learning what it is. People appreciate your taking the time to explain what it does and why you must use it.

Housekeeping

You may find some chores such as housekeeping difficult to do the way you use to. Give the 5 P's a try when organizing your home.

- Work in stages. Pace yourself and do small tasks, then rest.
 Avoid doing too much at one time or in one day.
- A light, wheeled utility cart with shelves can help you carry and move things in your home.
- Use a pair of long-handled pickup tongs (these look like giant scissors) to retrieve things from high, hard-to-reach places. Most medical supply companies stock these type of gadgets.
- Pickup tongs that expand in a criss-cross fashion make it possible to pick up very small objects without bending.
 Try slipping a small piece of rubber tubing over each end.
 This makes it easier to grasp things.

Tackling Heavy Lifting on the Stairs

Taking things downstairs is not often a problem. Carrying items up may be a different story. For best results:

- Inhale through your nose for two counts, then exhale through pursed lips as you lift the item and climb two or three steps.
- 2. Put down the item and rest.
- 3. Repeat as needed.

This may be a little slow, but it helps meet the need. It is a good idea to have a chair to sit on or a sturdy table to lean on at the top of the stairs, too.



- Use a vacuum that is easy to handle and maintain. A HEPA filter that helps keep dust out of the air is also a good feature. Vacuum a small area and then rest
- Try some of the new cloths and tools that collect dust rather than spread it around. And if you must do a dusty job, always wear a mask.
- Avoid cleaning products that are aerosols or contain ammonia, bleach or other harmful chemicals.
- Never mix cleaning products together. It can be very dangerous to your health.
- Have good ventilation and an adequate supply of fresh air at all times
- If you choose to use an air cleaner in your home, avoid any device that produces ozone, a lung irritant. Also be sure the device you choose is big enough for the room you want to clean. To learn more before buying, visit epa.gov/iaq.

In the Kitchen

- Don't try to get everything done at once. Set small goals and pace yourself. Almost all jobs can be divided into sections.
- Plan your meals when you are neither hungry nor tired. Light, well-balanced meals are too important to leave to impulse.
- When cooking, sit down during the prep work of cutting and chopping.

Planning Your Mealtimes

Five to six small meals are always better than three large ones. The more room the stomach takes up, the less room there is for air in the lungs. Prolonged digestion after a big meal takes blood and oxygen to the stomach and away from other parts of the body. This can cause shortness of breath.



- Use convenience foods when desired, but remember that many packaged foods have high salt and sugar contents. Learn to read labels.
- Keep plenty of drinking water in the refrigerator, and be sure to stay hydrated.
- Make a double or triple amount of your recipes. Freeze the excess in meal-sized cooking/serving containers and enjoy some heat-and-serve meals when you need an easy day.
- Microwave ovens reduce kitchen time and temperatures. A slow-cooking electric Crock-Pot® may make things easier, too.
- When cooking, always use the exhaust fan or make sure there is good ventilation. Fumes from a gas stove can be irritating.
- If you are bothered by the heat, try using a small portable fan when cooking. In fact, a portable fan is useful in any room. A fan can cool you off and may also help to overcome shortness of breath brought on by exertion or stress
- When cleaning up after a meal, gather all items that need to go into the refrigerator. Then sit down and put them away.
- Keep your most used pots and pans on the stove. Instead of putting away your dishes and utensils, reset the table for the next meal.

Getting Outside

People with chronic lung disease differ from each other in their reactions to weather. Some like it hot, some like it cold, some damp, some dry. No matter which, if it's your kind of day—try to get out and enjoy it. To make the most of your outings:

- Check the daily air quality report for your area at airnow.gov or from your local weather report or newspaper.
 Use the report when making plans for the day. This is important because many people with lung disease may have worsening symptoms because of air pollution and pollen.
- Try to get a warm, lightweight coat for winter. Down is ideal. It's warm and light. A heavy winter coat can wear you out before you are through the front door.
- Wear a long, warm scarf in cold weather. If it gets too cold or windy, cover your nose. Or, if you prefer, wear a cold-weather mask.
- Using a cane-seat or a rolling walker with a bench seat is a real help if you walk outdoors often. These give you something to lean on and a place to sit if you feel like resting.

Gardening

If you enjoy gardening, there are a number of ways to make it easier. Remember to take your medications before you start, and keep these tips in mind:

- Break the work into tasks you can manage easily. Rest as needed.
- Consider using a riding mower, preferably with a self-starter.
- Sit or use a garden kneeler to do planting, and use standing aids.
- Choose easy-to-handle, lightweight tools, including a garden hose that rolls up on its own reel.
- Try raised-bed gardening. Because the planting area is higher, you bend over less.
- If you don't have space for a garden, you may be able to have a window box or several shelves for inside plants. Even in a limited space, growing things can be one of the most rewarding pursuits.



Transportation Considerations

- If you have trouble walking, you may be entitled to a "handicapped" parking permit. Contact your state motor vehicle department for an application.
- Many communities provide free, low-cost or specialarrangement transportation for older adults or people with disabilities.
- If you drive and must put gas in the car yourself, try to get upwind from the pump. That way you won't breathe the fumes.
- Whenever possible, avoid travel during rush hours when more vehicles are on the road and pollution may be greater.
- Carry a cell phone to call for help in an emergency.
- Practice doing breathing exercises while waiting for red lights to change. In fact, you should take a couple of minutes, or even seconds, to do breathing exercises whenever you can.

Preparing for Travel

Living with lung disease should not stop you from traveling and doing the things you enjoy. Whether your trip is long or short, a lung disease travel pack is important.

You should include items like daily and as needed medications, your medication delivery devices like spacers or a nebulizer, copies of your COPD or Asthma Action Plan, copies of your medication prescriptions, health insurance card, contact information for your healthcare providers, and chargers or portable batteries for your portable oxygen concentrator.



Traveling

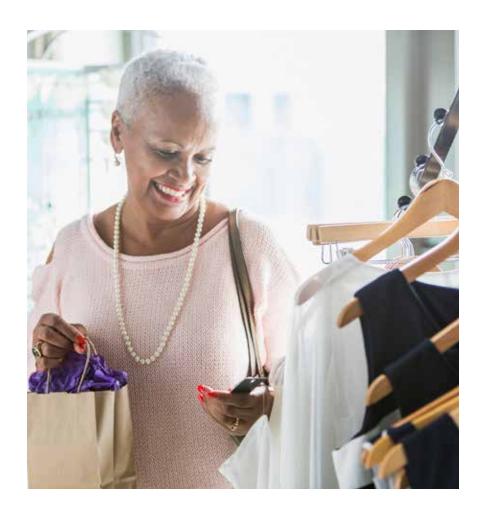
- When you travel alone—travel light. Get a small suitcase on wheels.
- Carry your medications with you. Don't put them in your checked baggage.
- Arrange for any oxygen and/or therapy equipment needed during travel and at your destination.
- Traveling with oxygen requires planning. Before booking any travel by air, land or sea, be sure to talk to your healthcare provider and check the requirements of the specific carrier(s).
- Ask for assistance when using a train, bus or at air terminals. Get help carrying luggage anytime you feel it's too much to manage on your own.

Shopping

- Shop during times when stores are less crowded. This
 way you will be able to move at an easy pace and avoid
 being jostled.
- Be especially careful to avoid exposure to illness during cold and flu season. If available, use the sanitizing wipes provided by some stores near the door to wipe the shopping cart handle. You may also want to wear a face mask.
- Shopping for clothing can be exhausting. To avoid having to try on clothes, learn your measurements. Write them down if needed. Then carry a small rolled-up tape measure with you. If you see clothing you like, check the sizing with the tape to see if the clothes will fit. Know the return policy of the store.
- Save your strength. Use a shopping cart to lean on as well as to carry items. Or, use a motorized cart to get around if the store supplies them.
- When grocery shopping, have all the perishables, such as milk and frozen foods, packed in a separate bag. When you get home, put away the items needing refrigeration. Leave the rest for later when you feel more energetic or when a helper can lend a hand.
- Wash your hands thoroughly when you get home. It is also a good idea to carry hand sanitizer. If you use oxygen, allow your hands to completely dry before handling the oxygen equipment.
- Shop by catalog or on the Internet. (When shopping online, use only reputable companies with a secure payment system.)
- Order groceries through a home delivery service. Many large grocery stores now offer this service.

Going Out

- Patronize smokefree businesses. If you are in a restaurant or other business where the smokefree laws are not being enforced, speak to the manager.
- In public places, if someone starts to smoke near you, politely ask them to please move elsewhere. Even though you should not have to explain the request, you may want to say something such as "I have a serious lung disease. Thanks for your courtesy."



Recreation

- Spend as much time as possible with friends. The company of good friends is one of the most important and lasting pleasures anyone can have.
- Play board games, dominoes and card games. Try a new or favorite jigsaw puzzle.
- If you are a chess or bridge buff, you might enjoy joining a club.
- If you have Internet access, email your friends and relatives, and join online support groups and chat rooms. See the next page for information about the Living with Lung Disease Support Community for one great option.
- Download games onto your computer or phone. Most phone games allow you to play against a random opponent so you always have a someone to play against. This is a great way to keep your mind active.
- Learn something new. Now is the time. Many schools and community colleges have adult classes. If you prefer to learn at home, there are hundreds of online courses to choose from.



- If you like to read, search flea markets or garage sales for cheap paperback books. Also, try swapping with friends, neighbors and relatives. Check your local library to see if they have an e-book lending program where you can download books on your e-reader for free.
- Study a language. Try home-study courses online, or find a tutor. A new language can be more fun if you find someone to practice with. A telephone or pen pal might be just the thing.
- Try to stay active and moving around. You may be able to continue a favorite activity by modifying the level of exertion.
- Your community may have fitness clubs that can set up a program to meet your needs. These are also a good place to make friends and be social.

Getting Support From People In the Know

Join a Better Breathers Club® near you to find support and comradery with others living with lung disease. Find a Club at Lung.org/better-breathers.



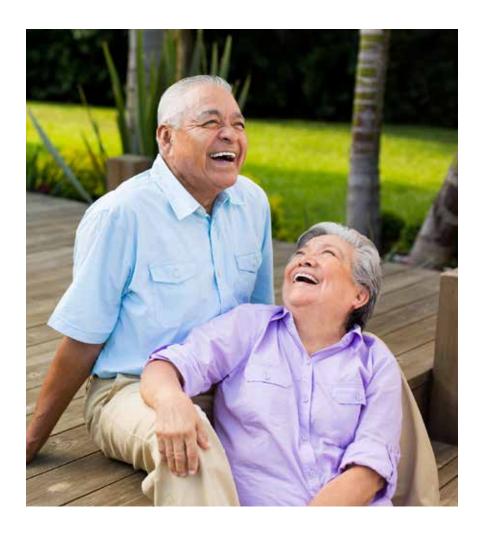
Online Support Communities are another tool for connecting with people living with lung disease like COPD, pulmonary fibrosis or lung cancer. Join these free groups to share your experiences and learn from others. Visit Lung.org/ community.

Register for the Patient and Caregiver Network, which is a nationwide, online patient support program providing lung disease management tools and virtual support groups. Join today at Lung.org/PCN

Intimacy

A loving relationship can help you manage living with chronic lung disease. But you and your partner may have questions and concerns about sexual activity. Anxiety, fear and fatigue are a few of the common concerns that can affect a relationship. Talking openly with each other about feelings either of you may have is very important.

- Keep in mind being intimate means more than just having intercourse. You can show each other love in many ways.
 You might start by saying how much you care.
- Plan sex for the time of day when you feel your best. This may be when your long-acting medication is at its peak. Waiting for a couple hours after a large meal is also a good idea.
- Use your inhaled medication beforehand, as you would for exercise, and keep your short-acting inhaler close by.
- Pace yourself and relax; it's not a race.
- If you use oxygen, use it during sexual activity. If you increase
 your oxygen flow during exercise, this might also help during
 sex. Tape the tubing in place if you need to, and leave extra
 length of tubing so you are free to move.
- Keep the room cool and comfortable and use bed covers that are not too heavy.
- Rest and do breathing exercises if you become short of breath.
- · Run a fan nearby for better airflow across your face.
- Talk to your partner about trying new positions:
 Side positions allow free breathing for both partners.



- Use pillows to provide comfortable support. Avoid positions that place your partner's weight directly on your stomach or chest.
- The partner without lung disease should do most of the moving.
- Enjoy the closeness of the relationship—the warmth, security, relaxation and tenderness it brings.

Safety and Security

- Carry a cell or cordless phone with you at all times.
 This way, if you run into trouble, you will have a way to summon help.
- The buddy phone system can be a big help and provide a feeling of security. Make arrangements to have a friend or relative call at the same time every day to make sure you are okay. If you plan to be out, let them know ahead of time to save needless concern.
- Get to know neighbors who can see your windows and arrange a signal they can see. For instance, if a shade is pulled down every evening or a certain lamp is lit, it is a sign you are okay. If this isn't done, ask your neighbors to check on you.
- Let apartment neighbors on all sides of you know if they hear you pounding, you need help.
- Somewhere near you is someone who needs your friendship and help, too. Once you have gotten in touch with others, you will be amazed to find how rewarding it can be.
- Many companies offer monitoring services. They provide a "panic button," worn on a chain around the neck, which can summon emergency help.



To Bed

- Go to bed in easy stages so you arrive there relaxed—not worn out. For example, put on your night clothes and a comfortable robe, then read or listen to soothing music for a while.
- Arrange your sleeping area so everything you may need is nearby, especially your medications, water to drink, a light and a telephone. Keep an easy-to-read list of emergency and commonly called numbers taped to the phone.
- Use some sort of night light. Even a low glow lessens the possibility of being disoriented if you wake up suddenly.
 A night light also helps you locate things you may need in a hurry.
- Move oxygen tubing out of the way if you need to get up during the night.
- Try doing some muscle-relaxing exercises, meditation or guided imagery.



Resources

The more you learn about lung disease, the more control you'll have over your condition and your life.

COPD Education | Lung.org/COPD

Use COPD self-management tools and workbooks to learn about COPD. Download the COPD Action Plan and educational workbooks like the Learning to Live with COPD and COPD Basics booklet.

Lung Health Navigator | Lung.org/Navigator

Receive one-on-one asthma and COPD education to help you understand how to manage your lung disease.

Better Breathing Techniques | Lung.org/breathing-exercises Learn how to feel better when you are short of breath. Videos demonstrate the techniques of Pursed Lip Breathing and Belly Breathing.

Online Lung Disease Basics Course | Lung.Training

Take a free, educational, online course to learn more about lung disease. Courses include but are not limited to: Asthma Basics, COPD Basics and Lung Cancer Basics.

Freedom From Smoking | Lung.org/freedom-from-smoking Quitting smoking is one of the most effective ways to help manage your lung disease. Freedom From Smoking has helped hundreds of thousands of people quit smoking for good and is available in a variety of formats

For more information on living with lung disease like COPD, pulmonary fibrosis or lung cancer, plus helpful tools and videos visit Lung.org.

For More Support, Give Us a Call

Call the American Lung Association Lung HelpLine at 1-800-LUNGUSA (1-800-586-4872) to receive free counseling with our Registered Nurses, Respiratory Therapists and Quit-Smoking Specialists.

TTY service is available at **1-800-501-1068**

About the American Lung Association

The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through research, education and advocacy. The work of the American Lung Association is focused on four strategic imperatives: to defeat lung cancer; to improve the air we breathe; to reduce the burden of lung disease on individuals and their families; and to eliminate tobacco use and tobacco-related diseases. For more information about the American Lung Association, a holder of the Better Business Bureau Wise Giving Guide Seal, or to support the work it does, call **1-800-LUNGUSA** (1-800-586-4872) or visit: **Lung.org**.



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