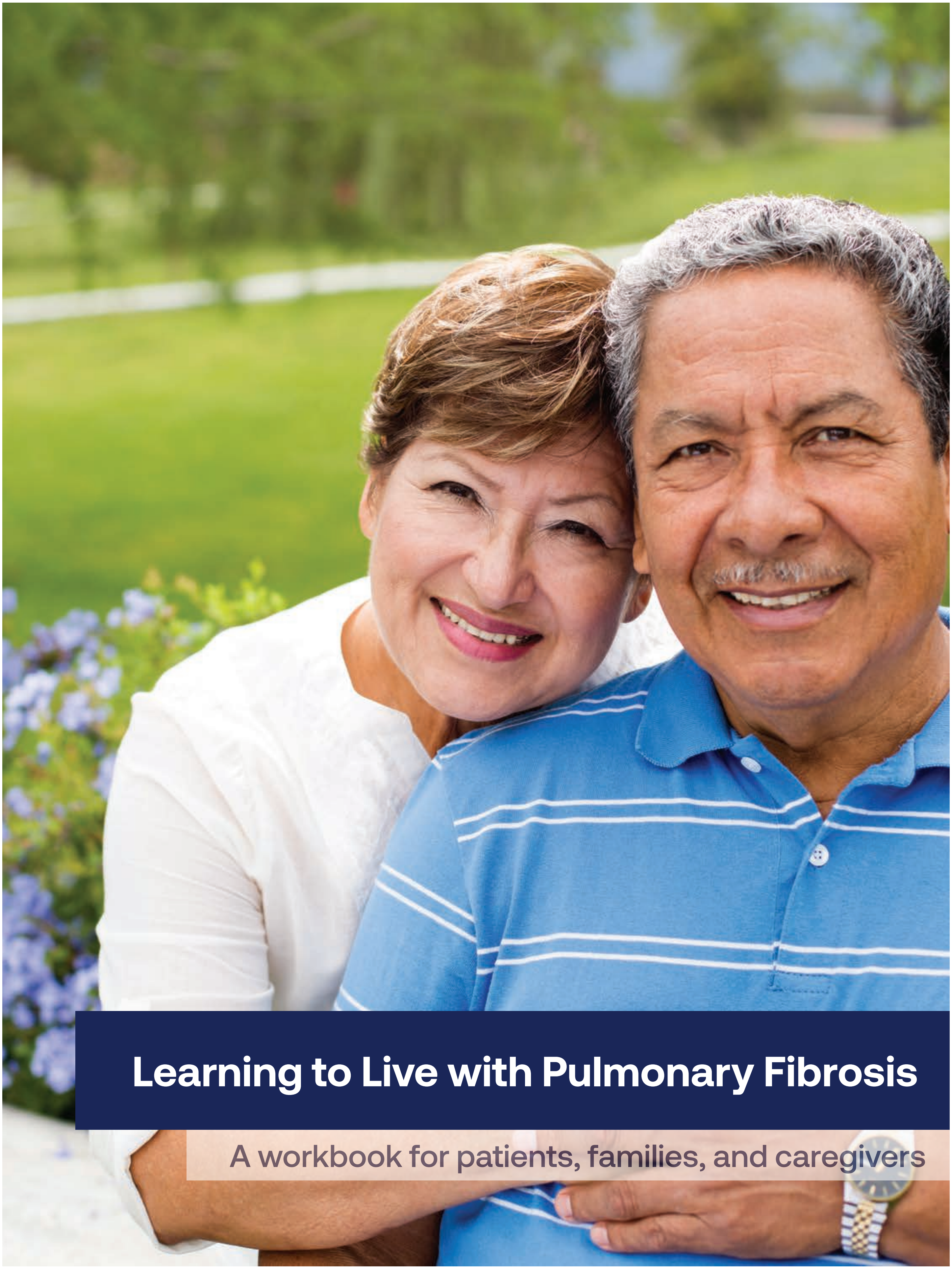


Learning to Live with Pulmonary Fibrosis

A workbook for patients, families, and caregivers

This Workbook Belongs To:

____

Today, I am dedicated to learning more about living with pulmonary fibrosis and taking steps to improve how I manage the disease.

How to Use the Workbook

This workbook can be used as an interactive self-help guide or as part of FREE education and support provided by a Lung Health Navigator. Lung Health Navigators are trained medical professionals who work for the American Lung Association and can guide you through the workbook as you learn about pulmonary fibrosis and answer your questions each step of the way.

To get started, call 1-866-252-2959 or go to Lung.org/navigator.

Setting Goals

Living with pulmonary fibrosis (PF) can be challenging. Use the information in this workbook and start a conversation with your healthcare provider and loved ones about your goals.

To get started, write down some of the activities, hobbies or goals you would like to do but feel you cannot because of your PF.

Some examples may include becoming more active or getting back into gardening. You may also like to have less side effects from medications or feel better about leaving the house while using oxygen.

What are my goals?

____

____

____

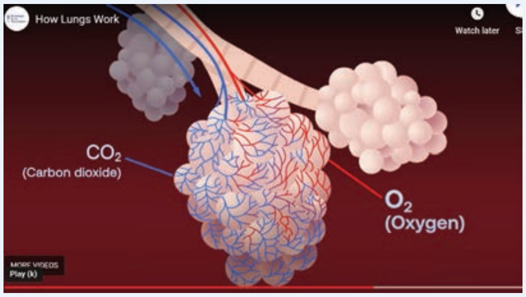
The information in this workbook does not replace the medical advice of your healthcare provider. Always consult your healthcare provider about your health questions or concerns.

Contents

This workbook was developed with generous support from the Feldman Family Foundation.

The Respiratory System

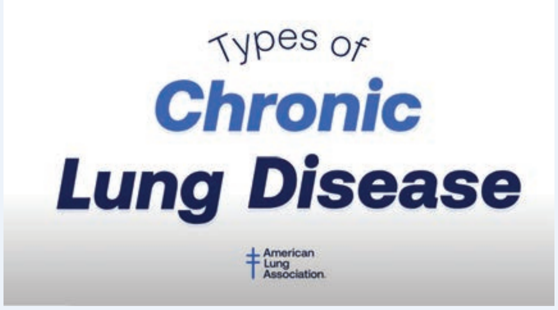
How the Lungs Work (Animation)



There are three main types of chronic lung disease, and each type affects various parts of your lungs:

- Obstructive (such as asthma or COPD)
- Restrictive (such as pulmonary fibrosis)
- Vascular (such as pulmonary hypertension)

Types of Chronic Lung Disease (Animation)



Types of Chronic Lung Disease

American Lung Association

Always make sure you are scanning a QR code from a trusted source.

How to use the camera on your smartphone or tablet to read a QR code:

1. Open the camera, then point the camera on the phone so that the code appears on the screen.
2. Tap the notification that appears on the screen to go to the website or video.

Chapter 1: Understanding Interstitial Lung Disease and Pulmonary Fibrosis

To understand pulmonary fibrosis, you first need to learn about interstitial lung disease.

Interstitial (in-ter-sti-shill) refers to a group of chronic lung diseases that cause inflammation and/or scarring of lung tissue between the air sacs (alveoli) and blood vessels. You saw in the How the Lungs Work animation in the introduction section how important it is to get oxygen from the air sacs to the blood vessels so oxygen can fuel every part of your body. Interstitial lung diseases disrupt this important process.

Here's how:

1. The air sacs in your lungs get injured by an irritant such as dust, smoke, a virus or bacteria, medications or radiation.
2. Your body responds to this injury with an inflammatory response. This is a normal reaction, and the goal is to remove the irritant and repair the damaged tissue.
3. But, at times, the damage ISN'T fully repaired so your body keeps attacking the site of the irritant to try to fix it but ends up causing damage which is called chronic inflammation. When you have chronic inflammation in and around the air sacs of your lungs, you have interstitial lung disease.
4. Some people with inflammatory interstitial lung disease have an immune response that just won't quit, and it leads to scarring of the inflamed tissue. The scarring makes the tissue thicker and is then called pulmonary fibrosis.

You can have interstitial lung disease and NOT have pulmonary fibrosis, but you can not have pulmonary fibrosis and not have interstitial lung disease. Think of it like this: not every dog is a black lab, but every black lab is a dog.

Pulmonary Fibrosis (PF)

In PF, the tissues between and around the tiny air sacs (alveoli) and blood vessels (capillaries) in the lungs are thick, stiff, and scarred.

- There are more than 200 types of PF and over 250,000 people in the United States are living with PF.
- When your lung tissue is scarred and stiff, it makes it harder for you to breathe in air and your lungs cannot fully expand. This means your lungs cannot fill up with air as well as they should. The scarring in the lungs impairs your air sacs from properly exchanging oxygen and carbon dioxide.
- Acute exacerbations may happen when there is a sudden worsening of disease. This leads to worsening shortness of breath, lower oxygen levels and worsening cough. This can be serious and may require immediate medical attention (learn more on page 22).

Idiopathic Pulmonary Fibrosis or IPF is the most common type of PF. "Idiopathic" means it is not known why your lung tissue has become scarred and thick. Each year, approximately 25,000 people in the United States are diagnosed with IPF.

Causes of PF

Among other reasons, viral infections and exposure to tobacco smoke are risk factors of PF and may cause your lungs to become scarred. When possible, it is important to know your cause of PF because medications do not treat all types of PF the same.

Mark the cause or type of PF that you have been diagnosed with:

☐ Asbestosis related (from breathing in asbestos)
☐ Medication induced (certain medications which may include chemotherapy or other medications that affect the lungs)
☐ Genetic (another family member also has PF)
☐ Radiation induced (past or present radiation to your chest)
☐ Environmental (exposure to animals or mold)
☐ Autoimmune (another medical condition like rheumatoid arthritis and scleroderma)
☐ Occupational (past or present exposure to dust, chemicals, fumes, and/or vapors)
☐ Idiopathic (a cause cannot be found)

Symptoms

Not everyone living with PF will have the same symptoms. You may find certain symptoms affect your quality of life more than others.

Common symptoms of PF include:

- Shortness of breath
- Dry cough
- Tiredness (fatigue)
- Chest pain (discomfort)

Other signs and symptoms of PF include clubbing or widening of the fingers or toes, unexplained weight loss, loss of appetite, low oxygen levels or lung sounds called "crackles."

Diagnosis and Monitoring Disease Progression

There is no single test that can diagnose PF. In addition to a detailed medical history and physical exam, your healthcare provider will likely order the following tests or procedures:

Pulmonary function tests are a group of breathing tests that measure how your lungs work. A spirometry test can measure how much air goes in and out of your lungs. A lung diffusion test can measure how much oxygen moves from your lungs into the bloodstream.

Imaging test such as a CT scan, High Resolution Computed Tomography (HRCT) or X-ray help get a picture of changes in your lungs.

Arterial blood gas testing or pulse oximetry can measure the oxygen levels in your blood.

Exercise test like a six-minute walk test can help assess your need for supplemental oxygen.

Other tests or procedures that may be used to diagnose PF include a bronchoalveolar lavage or lung biopsy. A bronchoalveolar lavage collects fluid from the lungs. A lung biopsy removes a sample of your lung tissue to study it more carefully for disease.

To monitor how your PF is progressing, your healthcare provider will track new or worsening symptoms, changes in oxygen needs, a drop in pulmonary function tests or increased fibrosis appearing on CT scans.

Life Expectancy

Pulmonary fibrosis has a variable prognosis. Most people diagnosed with pulmonary fibrosis experience disease progression. This means your lungs develop more scar tissue as time goes by, resulting in worse symptoms.

Nobody can tell with certainty if you will have a steady or slow decline, or if your symptoms will remain stable for years. There are over 200 lung diseases with scarring in the lungs, and not all types of PF experience the same progression.

You should talk to your healthcare provider about factors that may likely cause it to progress more quickly. Your provider will likely also be able to provide more information based on your overall health, type of PF and treatment plan. While there is no known cure for PF, there are existing treatments that may slow the rate of progression.

Other Health Conditions

People living with PF may be diagnosed with other health conditions, known as co-morbid conditions. It is important to manage and treat all your health conditions, not just PF. Tell your healthcare team about all your health conditions. Keep a record of all the prescribed and over-the-counter medications you take because some may interfere with treatments for other health conditions.

Put a checkmark next to the health conditions you are living with:

☐ Anxiety
☐ Depression
☐ Chronic obstructive lung disease (COPD)
☐ Cancer
☐ Pulmonary hypertension
☐ Sleep apnea
☐ Diabetes
☐ Heart disease
☐ High blood pressure
☐ Arthritis
☐ Gastroesophageal reflux disease (GERD)
☐ Autoimmune disease
☐ ____________________
☐ ____________________
☐ ____________________
☐ ____________________

Sleep

A good night's sleep can help you feel well rested, may help reduce your stress level and improve your mood. With PF and especially IPF, you may have more difficulty falling asleep and staying asleep. If you have an underlying sleep disorder like obstructive sleep apnea, it is important to follow your treatment plan which may include using a CPAP machine.

If you have poor sleep quality, a drop in your oxygen level, snore or have trouble breathing at night, you should speak with your healthcare provider about options available to you.

Chapter 2: Partnering With Your Healthcare Team

Members of Your Healthcare Team

A **respiratory therapist** can perform lung function tests, provide disease specific education, and offer support. You may collaborate with a respiratory therapist at a pulmonary rehabilitation center, hospital, or clinic.

A **pulmonologist** is a doctor who can confirm you are accurately diagnosed and provide you with the most advanced PF knowledge, treatment, and management options.

When to see your provider:

You may need to see your pulmonary doctor once or twice year, but it could be more if your PF is progressing, or you have symptoms that are hard to control.

A **primary care provider** may see you at regular visits and monitor your PF and other medical conditions.

When to see your provider:

You should see your primary care provider at least two times a year but it may be more often if you have other health conditions.

Coordinating and communicating with all your providers is important. Other members of your healthcare team may include:

- Pharmacists
- Occupational therapists
- Lung transplant team
- Internists
- Nutritionists or dietitians
- Mental health counselors, social workers or psychologists
- Cardiologist
- Durable medical equipment (DME) and oxygen suppliers
- Rheumatologist
- Immunologist

It is important to find a doctor who is an expert at treating pulmonary fibrosis. To find a center near you, visit Care Center Network | Pulmonary Fibrosis Foundation.

My PF Team

Keep track of the key members of your healthcare team.

Primary care provider	Address	Phone Number
Pulmonologist	Address	Phone Number
Pharmacy	Address	Phone Number
Oxygen supplier	Address	Phone Number
Durable medical equipment (DME) company	Address	Phone Number
Pulmonary rehabilitation center	Address	Phone Number
Emergency contact	Address	Email and Phone Number

Medical Insurance Information

Insurance provider	ID number	Phone number
Secondary insurance provider	ID number	Phone number
Prescription card provider	ID number	Phone number

Communicating With Your Healthcare Team

Prepare a list of your concerns or questions before your next appointment. Download form or use the copy in the back of the workbook to get started. Getting Ready for Your Next Office Visit.

American Lung Association.

Getting Ready for Your Next Office Visit

Appointment Information

Provider Name: ____________________

Date: ____________________

Address: ____________________

Reason for Visit: ____________________

Other Healthcare Providers I Am Seeing

Name: ____________________ Phone: __________

Reason to see this healthcare provider: ____________________

Name: ____________________ Phone: __________

Reason to see this healthcare provider: ____________________

Name: ____________________ Phone: __________

Reason to see this healthcare provider: ____________________

Prescribed and Over-the-Counter Medicines and Supplements

Name of Drug/Supplement	Dose	Frequency	Prescribed/Recom

Name of My Pharmacy: ____________________ Phone: __________

1-800-LUNGUS

Symptoms I Have Been Experiencing

Coughing		Feeling nervous	
Chest tightness		Rapid heartbeat	
Wheezing		Head/nose stopped up	
Unable to exercise		Restlessness	
Feeling tired		Fever	
Need to clear throat repeatedly		Stroking chin or throat	
Dry mouth		Increased use of quick-relief inhaler	
Waking up at night		Other:	

How frequently these symptoms occur: ____________________

When the symptoms begin: ____________________

Things I do to relieve these symptoms: ____________________

Additional Concerns and Questions

____

____

____

Next Steps

Notes from my healthcare provider: ____________________

____

Tests to schedule: ____________________

____

Next appointment (Day/Time): ____________________

American Lung Association.

1-800-LUNGUSA | Lung.org

Medical Costs and Financial Help

PF medications, appointments and treatments can be expensive. Talk to your healthcare provider about your concerns.

Your provider may recommend options like:

- Contacting the health system's social work, case management or patient financial advocacy department for help paying for medications or medical visits.
- Finding medications that are equally effective but less expensive or covered by your insurance.
- Figuring out eligibility requirements for prescription aid programs through drug companies, pharmacies and non-profits that provide access to free or low-cost medications.
- Finding foundations or organizations that offer grants to help with medication costs.
- Accessing quality and affordable health insurance at reduced rates.

My questions about options to reduce the cost of my PF care: ____________________

____

____

____

____

Need help signing up for health insurance or finding financial assistance programs? Contact the **Lung HelpLine** at **1-800-LUNG- USA**.

Chapter 3: Treatment Options

Medications

There is no cure for interstitial lung disease, but medications may slow the disease progression and reduce your symptoms. The medications you are prescribed are based on the cause of your PF.

Medications that treat fibrosis (scarring)

Types of medication: This medication may slow the progression of new scarring in the lungs. There are currently two, FDA-approved, anti-fibrotic drugs available to treat IPF: nintedanib (Ofev®) and pirfenidone (Esbriet®).

How they work: These medications come in pill form. They work by potentially slowing how quickly additional scarring happens.

Key points:

- These medications do not improve your lung function or get rid of the scar tissue you already have.
- Common side effects depend on which medication you take but may include nausea, rash, stomach pain, upset stomach, diarrhea or loose stools, dizziness, tiredness, vomiting, loss of appetite, acid reflux, weight loss or joint pain. You may also have high blood pressure and be checked for changes in your liver function.

Medications that treat inflammation (swelling)

Types of medication: This medication may slow down or eliminate the chronic inflammation occurring in your lungs. This will help prevent new scar tissue from forming. It depends on what type of lung disease you have if there is a treatment that can help stop further inflammation.

How they work: These medications may come in pill, inhaler or nebulized form. They work by potentially slowing or reversing the inflammatory response.

Key points:

- Anti-inflammatory medications like corticosteroids are not prescribed to treat PF but may be prescribed to reduce inflammation in certain interstitial lung diseases.
- If you use an inhaler or nebulizer, the device must be used correctly for you to get the most benefit from the medication. To make sure you are getting the medication you need, ask a healthcare provider or pharmacist to review your technique regularly.

Watch How-To-Videos and step-by-step downloadable instructions for using an inhaler or nebulizer:

⚠ Before stopping or reducing a prescribed medication, talk to your healthcare provider about why you want the change. It helps start a conversation about your treatment goals and how to manage side effects or financial challenges.

Managing Medication Side Effects

There is not a one-size-fits-all way to manage side effects. Your healthcare provider may change your medication or suggest strategies to address your side effects.

Dry, hacking cough

- Try over the counter or prescription medications or cough drops.
- Identify, reduce, or avoid your exposure to triggers or things that worsens your cough. Triggers may include strong smells, chilly air, humidity, or temperature changes.
- Talk to your healthcare provider about other causes like postnasal drip.
- Stay hydrated and keep water or a drink with you.
- Coughing may cause you to lose control of your bladder. Try products in your underwear that keep you dry if you have urine leakage.

Gastroesophageal reflux disease (GERD) or acid reflux

- Take your medication as prescribed. Some medications you will need to take with food.
- Angle your upper body upright while sleeping.
- Keep track and avoid the foods that trigger or worsen your symptoms.
- Ask your provider about over the counter or prescription medications.

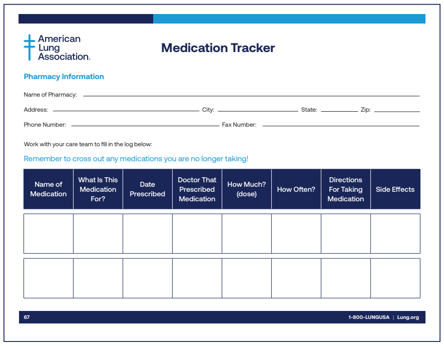
Diarrhea or loose stools

- Avoid fried, spicy, sugar free, dairy, and other foods that would be considered triggers.
- Follow medication instructions on when to eat foods.
- Keep a food diary to track which foods are more likely to cause you diarrhea.
- Talk to your provider about anti-diarrhea, over the counter or prescription medications.
- Severe diarrhea may cause dehydration. Drink plenty of water.

Write down any side effects that bother you and the ways you are managing them.
Discuss this information with your healthcare provider.

Medication Tracker

Keep a record of the medications, vitamins and supplements you are taking. Bring a copy of the medication tracker to your medical appointments to share with your healthcare provider. Copies of the Medication Tracker can be found in the back of the workbook.



American Lung Association.

Medication Tracker

Pharmacy Information

Name of Pharmacy: ____________________

Address: ____________ City: ____________ State: ______ Zip: ______

Phone Number: ____________ Fax Number: ____________

Work with your care team to fill in the log below:

Remember to cross out any medications you are no longer taking!

Name of Medication	What Is This Medication For?	Date Prescribed	Doctor That Prescribed Medication	How Much? (dose)	How Often?	Directions For Taking Medication	Side Effects

67 1-800-LUNGUSA | Lung.org

Supplemental Oxygen

Supplemental oxygen is a medical treatment prescribed by your healthcare provider when you are not breathing in enough oxygen on room air. Supplemental oxygen, sometimes called oxygen therapy, is not addictive. **It will:**

- Help you stay active.
- Improve your shortness of breath.
- Increase your oxygen level to help keep every organ in your body healthier.

My Oxygen Prescription

Most people using supplemental oxygen should aim to have their oxygen saturation in the 90s. Work with your provider to make sure you are getting the right amount of oxygen and keep track of your oxygen levels using a pulse oximeter.

My oxygen levels should be at: ____________________

Type of oxygen equipment I use:

____

____

____

When do I use it?

☐ At rest ____________________, flow rate ________________

☐ With activity ________________, flow rate ________________

☐ At night ____________________, flow rate ________________

☐ At altitude __________________, flow rate ________________

Talk to your healthcare provider or oxygen supplier about how to maintain your oxygen equipment and supplies.

Things to Know when Using Oxygen Therapy (Video)

Types of Oxygen Delivery Devices

When choosing your oxygen delivery device, it is important to understand your oxygen prescription and discuss your hobbies, activities and lifestyle with your healthcare provider. The type of device you need will also depend on your flow rate or liters per minute (LPM) and when you need oxygen.

Home concentrators draw in air, remove other gases and deliver purified oxygen. Home oxygen concentrators can deliver oxygen continuously (at a steady rate) and need to be plugged into an outlet. Getting Started with a Home Oxygen Concentrator (Video)

Portable oxygen concentrators (POC) work like a home concentrator but are smaller and can travel with you. POCs need to be plugged into an outlet or have rechargeable batteries. POCs deliver oxygen continuously or through a pulse dose. You should be tested using a POC to make sure it meets your oxygen needs.

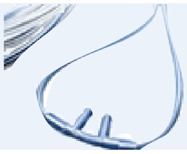
The settings on a POC are not always equal to your flow rate or LPM. Talk to your healthcare provider or oxygen supplier before buying a POC.

Getting Started with a Portable Oxygen Concentrator (Video)

Oxygen tanks are metal cylinders that store compressed oxygen. The tanks come in different sizes. The smaller the tank, the less oxygen it can hold. Oxygen tanks do not run on electricity or a power source. You will need to work with your oxygen supplier to refill or replace the tanks. Oxygen tanks are a good backup to have on hand for a power failure. Getting Started with Metal Tanks (Video)

Liquid oxygen is compressed and cooled at an extremely low temperature. Most systems provide a high concentration of oxygen and do not need electricity. Liquid oxygen usually has both a stationary storage unit you keep at home and a portable container you can take with you. Liquid oxygen may be an option for people with a high flow rate. It may not be available in all areas of the United States. Getting Started with Liquid Oxygen (Video)

Oxygen Supplies and Accessories

	**Oxygen tubing** connects your cannula or mask to your oxygen tank or concentrator. A nasal cannula has prongs that fit into your nostrils and helps you breathe in the oxygen.
	A **face mask** can be placed over your mouth and nose and holds available oxygen as you take each breath.
	A **humidifier** can add moisture to the oxygen stream and can help ease nasal and sinus dryness. Consider a humidifier if your oxygen flow rate is continuous at 4 LPM or higher.

For people who have higher oxygen flow needs, an **oxymizer nasal cannula or pendant** can increase the inspired amount of oxygen and extend the time the tank or battery lasts.

A nasal cannula or mask should be replaced every 2-4 weeks or if you've been sick. Oxygen tubing should be replaced every two months.

Checking your Oxygen Levels

A pulse oximeter or pulse ox is a simple, quick, and safe way to measure oxygen levels. If you have poor circulation, darker skin color or thick skin, among other reasons, there may be inaccurate or inconsistent results.

Bring your personal pulse oximeter to your healthcare provider appointments to compare accuracy and ask about when to check your oxygen levels and when to share abnormal or inconsistent readings.

Using Supplemental Oxygen Safely

Oxygen is a safe gas and is non-flammable, however it makes fires easier to start and spread quickly. Always follow the safety instructions from your oxygen supplier and do not change your oxygen flow rate without talking to your healthcare provider.

Be sure to:

- Keep away from heat and flames.
- Do not use aerosols, vapor rubs or oils.
- Follow directions on using and storing your equipment safely.

Oxygen Safety Reminders:

- Do not smoke or allow others to smoke near you. Post “No Smoking” signs in and outside your home.
- Keep sources of heat and flame five feet away from where your oxygen unit is being used or stored. Always have a working fire extinguisher and smoke alarm.
- While wearing oxygen, do not cook with gas or use any electrical appliances like hair dryers, curling irons, heating pads or electric razors.
- Do not use aerosol sprays such as air fresheners or hairspray near the oxygen unit. Aerosols are flammable.
- Use only water-based lotions or creams. Avoid using vapor rubs, alcohol-based hand sanitizer, petroleum jelly or oil-based hand lotion. Never use your oxygen equipment with oily or greasy hands.
- Always turn off your oxygen equipment when it is not in use. Store oxygen concentrators upright and tanks in a holder or lying down to avoid getting knocked over.
- Do not store your oxygen equipment in an enclosed space, like a closet or trunk, and keep your oxygen concentrator several inches away from walls or curtains.
- Long tubing may be a tripping hazard. Never cut your tubing or use more than a 50-foot-long piece.
- Plug your concentrator directly into an outlet and do not plug anything else into that outlet. Do not use an extension cord.

Be Prepared

Tell your oxygen supplier if your oxygen is running low and allow for plenty of time to deliver refills. When you go out, make sure you have enough oxygen for your entire trip. Avoid being without oxygen by bringing back-up tanks, batteries or chargers for your POC. If you use oxygen tanks when out, be aware of how much time you have based on the tank’s size, your flow rate and setting.

Have a question about using supplemental oxygen?
Contact the **Lung HelpLine** at **1-800-LUNG- USA**.

Lung Transplant

A lung transplant might be a treatment option if your condition is severe despite being on optimal treatments. A lung transplant is a serious surgery but if successful, can improve your quality of life and life expectancy. Over half of lung transplants performed are on people living with pulmonary fibrosis.

During the lung transplant, either one or both diseased lungs are replaced with healthy lungs from a donor. Double lung transplants are more common, but if you receive one lung, your other lung will remain in your chest. Your new healthy lung should work well enough to take over all the required breathing your body needs.

Step 1: Start A Conversation With Your Healthcare Provider

Your provider may recommend a center, but you are also free to choose one on your own. Always check with your insurance provider about which centers are covered under your plan. Consider how many transplants each center does per year, as well as survivor rates. This information is available on the Scientific Registry of Transplant Recipients (SRTR) at srtr.org. Take time to learn about other services provided at the center, like help with travel arrangements, find post-recovery housing and support groups. The center you choose will be a long-term partnership in your care, so the location is important to consider.

Step 2: Preparing for the Initial Visit

You will have to undergo an extensive evaluation to make sure that transplant is the right choice for you. The transplant team needs to know if your body can handle the stress of the procedure and recovery process.

To prepare, you should:

- Be up to date on recommended vaccinations, manage your other health conditions, dental appointments and primary care visits. (see Prevent Infectious Lung Diseases).

- Maintain a healthy weight. There are weight ranges that transplant centers aim for the best outcomes. If you are not within the weight range, ask your healthcare provider about options or to be referred to a dietician (see PF and Nutrition).
- Work to build up your stamina, endurance and exercise capacity. Your healthcare provider may recommend attending a pulmonary rehabilitation program, exercise routine and/or making sure your oxygen needs are addressed (see Pulmonary Rehabilitation).

- Stay free of nicotine, tobacco, drugs and alcohol. An evaluation team will want to see that you are tobacco-free for at least six months (see Benefits of Quitting Tobacco Use).
- Talk to your caregivers and family about the support you will need throughout the lung transplant process.
- Organize your health and legal documents and finances (see Advanced Care Planning).
- Talk to your insurance provider about what your plan covers. Most plans, including government run programs, will pay for lung transplant, but there will likely be some out-of-pocket costs. Your plan could have requirements about where you get a transplant and may require you get permission from them first.

Step 3: The Initial Visit

During the initial visit, the lung transplantation team will review your medical records and run tests like a CT scan, pulmonary function tests, and a six-minute walk test. These tests can determine the urgency for a lung transplantation. This visit can also determine any contraindications or reasons why you may not meet the criteria. Based on the results of your initial visit, the lung transplant team will determine if you can proceed to be evaluated for a lung transplantation.

Step 4: The Evaluation

During the evaluation, the lung transplant team will complete multiple tests, lab work, screenings and procedures to determine if your body is healthy enough for major surgery. The evaluation may take around five to seven days and during this time you will meet with a social worker, infectious disease doctor, surgeon, psychiatrist and other members of the lung transplantation team. Once the testing is complete, a multidisciplinary team of medical providers like surgeons, nurses, and pulmonologists will review the results and determine if you would benefit from a lung transplantation. You may also find talking to someone who went through a lung transplantation to be helpful.

Step 5: The Transplant Wait List

If you are approved for a transplant, you may be on the waitlist for a few months or even up to a few years. You could also get called the next day so it's important to be ready. During this time, you should work closely with your care team and continue good health practices.

You should always have your phone on you and be prepared to go at a moment's notice. Plan and pack a bag with everything you will need during your stay at the hospital. It is not uncommon to have a 'practice run' where you get the call but it turns out that the lung isn't the perfect fit for you. In this case, you'll go home and wait for another call.

Step 6: During the Surgery

Lung transplant surgery is a serious surgery that can take between 6 and 12 hours, depending on whether you are having a single or bilateral lung transplant. You will receive medication to keep you unconscious, pain free and your vitals will be monitored throughout the surgery. Your surgeon will remove the diseased lung(s), connect the donor lung(s) to its new airway, and connect the blood vessels to the lung(s) and your heart.

Step 7: Recovery in the Hospital

Your initial recovery will take place in the intensive care unit (ICU). You will be given medicine to help with pain and anti-rejection medicine to suppress your immune system and prevent your body from attacking and rejecting your new lung(s).

It may take between 2-5 days after surgery for you to be able to breathe on your own. Until then, you will be on a mechanical ventilator which allows your new lungs to get stronger and ready to breathe on their own. Once you come off the ventilator, you will work with the care team to help you move from the ICU to a step-down unit. During this time, you will continue to be monitored by your healthcare team, given medication and learn about life post-transplant.

Recovery time will vary from person to person, but between the ICU and the step-down unit, you may spend between 7-21 days at the hospital.

Step 8: Life After Surgery

If you do not live close to the hospital, you will need to stay close to the hospital for up to 3 months in case complications arise. Follow the detailed instructions from the lung transplantation team. These instructions may include information about the recovery process, how family and caregivers should be involved, and signs of infection and rejection.

Stay up to date with your health appointments. You will need visits with your healthcare provider, blood testing, lung function tests, chest x-rays, and bronchoscopy with biopsy to check the health of your lungs and body. Your immune system will be particularly vulnerable, and it is best to avoid crowds and those who are sick.

My questions about a lung transplantation:

Clinical Trials

A clinical trial is a form of research that looks at the safety and effectiveness of a treatment, device or management approach. Every medication approved to treat PF has gone through a clinical trial. By joining in a clinical trial, you can access new PF treatments and help other people in the future living with PF.

Starting The Conversation With Your Healthcare Provider About Clinical Trials

Before joining in a clinical trial, you will want to know how it works, where to find information and understand the next steps. **Talk to your provider and fill in the responses.**

What are the benefits of enrolling in a clinical trial?	Are there any trials that would be a good fit for me?	What are my next steps to get started and enroll?	Questions for my healthcare provider?

Clinical trials happen across the country and each trial has qualifications to join. You can find clinical trials near you at Lung.org/clinical-trials or call the **Lung HelpLine** at 1-800-LUNG USA.

Understanding Acute Exacerbations

An acute exacerbation is a worsening of your symptoms and is serious, requires medical attention and may be life-threatening. Acute means it happens suddenly.

During an acute exacerbation, you may experience:

- More shortness-of-breath
- Worsening cough
- Lower oxygen levels

You may also have other symptoms like tiredness, fever or flu-like symptoms. Work with your healthcare provider to monitor your everyday symptoms, the steps you should take when your symptoms get worse and when you should get immediate medical care.

Reduce Your Risk of Triggering an Acute Exacerbation

You won't always know why you had an exacerbation, however there are some ways you may be able to reduce them from occurring.

- Stay up to date with vaccinations to protect yourself from infectious lung diseases.
- Wash your hands regularly with soap and water. Limit your exposure to others who are sick.
- Avoid irritants such as strong scents, fumes or smoke.
- Manage GERD if you have acid reflux.
- Tell your surgeon if you have PF before undergoing surgery. Although rare, anesthesia may increase your risk of exacerbation.

Treatment for an Acute Exacerbation

Your healthcare provider will review your medical history, symptoms and order tests to find the cause of the exacerbation and to rule out other health conditions.

Treatment depends on the cause of the exacerbation but may include the use of steroids to reduce inflammation or antibiotics if the exacerbation is caused by an infection. To manage symptoms, you may be given more oxygen and other medications.

Tips on Recovering from a PF Exacerbation

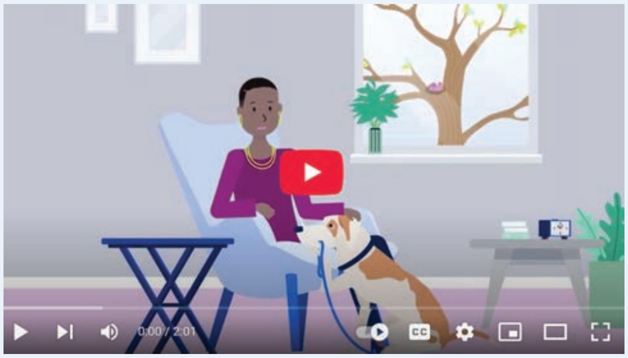
- **Allow Yourself Time to Rest**
  Depending on the severity of your exacerbation, recovery may last a few days to several weeks or months. During this time, you will need to drink plenty of water and get extra rest.
- **Ask for Help**
  Pace yourself and rest as you move between activities. Conserve your energy and ask your friends, family and caregivers to help.
- **Medications**
  Take your medication as directed and use supplemental oxygen as prescribed by your healthcare provider. Part of your recovery plan may include taking additional medication to help reduce your fever or improve your symptoms.

Follow Up with Your Appointments

After an exacerbation, your lung function and ability to exercise may be lower. This may put you at risk for future exacerbations. It is important to follow up with your health care provider.

You may receive a referral to attend pulmonary rehabilitation, quit smoking or begin using or increasing your oxygen flow rate. Keep those appointments and follow through with those recommendations.

Watch the animation about Recovering from a Severe Lung Infection



Pulmonary Rehabilitation

Pulmonary rehabilitation (rehab) is a way to meet new people, exercise and learn how to improve your lung health. Pulmonary rehab covers topics such as breathing techniques, nutrition, and improving your emotional health.

Pulmonary rehab includes a team of doctors, nurses, respiratory therapists, dietitians and exercise specialists who work with you to create a plan that meets your needs. There are small groups so you can connect with other people living with PF and other lung diseases.

Goals for Attending a Pulmonary Rehab Program

Check the boxes that best describe your goals for attending pulmonary rehab:

☐ Exercise safely and be active

☐ Understand how to conserve energy during daily activities

☐ Manage changes in mood or emotions (anxiety, panic, and depression)

☐ Use supplemental oxygen safely

☐ Connect with other people living with PF

☐ Prepare for or recover from a lung transplant

☐ Other ______________________________

☐ Other ______________________________

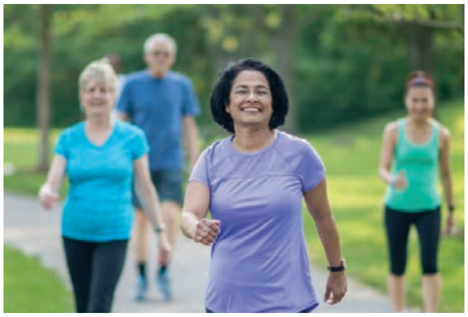
Get Started with Pulmonary Rehab

The first step is to talk with your provider about your goals and decide if pulmonary rehab is a good fit for you. If so, your provider can help you find a program near you and provide a referral.

You should also contact your health insurance to check your benefits and see if you have any out-of-pocket costs.

To see a listing of the pulmonary rehabilitation centers in your state, visit aacvpr.org/Program-Directory or call the Lung HelpLine at 1-800-LUNG USA (1-800-586-4872).

Physical Activity



Physical activity and exercise can boost your energy levels, improve your body's use of oxygen, may help reduce stress, anxiety and depression.

Before you get started, ask your healthcare provider what type of exercises will help you the most, how often and how long you should exercise, your oxygen needs while active and any safety concerns you have.

Exercising Safely

Whether you are just getting started or if you exercise on a regular basis, it is important to exercise with care. If you are having trouble getting started or worried about safety, ask your healthcare provider about options to address your concerns.

Tips for Exercising Safely:

- Monitor your oxygen levels while active. Your oxygen levels may drop while you exercise or during activity. Some pulse oximeters have better oxygen level readings while you move and sweat.
- Consider pulse oximeters that connect to your phone through Bluetooth and can monitor your heart rate and step count.
- Use supplemental oxygen while you exercise, if prescribed. Ask your healthcare provider if you need to increase the oxygen flow rate while you are active.
- Use a rollator, walker, cane or other walking equipment or other adaptive equipment as needed. Consider a rolling cart if your oxygen device is too heavy to carry.
- Start slowly. Exercising for too long or too intensely may cause injury, shortness of breath and leave you feeling tired or fatigued after.
- Falls can happen suddenly and can cause serious injury. Use a handrail if you are climbing steps and consider using a walker, cane or other mobility devices to maintain your balance while walking.
- Exercise with a friend, family member or neighbor. Invite them to join you for a walk around a local park or an outdoor or indoor track.
- Avoid exercise when you are sick, have an exacerbation, have a fever or infection or are feeling weak or dizzy.
- Rest when you start to feel out of breath. Focus on getting your breathing under control and watch your oxygen levels. Use pursed lip breathing if you find it helpful.
- Stay hydrated and avoid exercising outside on days with extreme temperatures, unhealthy air, wind or other poor weather conditions.

Types of Exercises

Create a weekly activity schedule that includes exercises like strength, endurance and stretching.

Stretching Exercises

Stretching is a good way to begin and end your exercise sessions. Stretches should be done slowly, and you may find sitting upright in a chair helps you stay balanced. Over time, stretching will help increase your flexibility.

Endurance Exercises

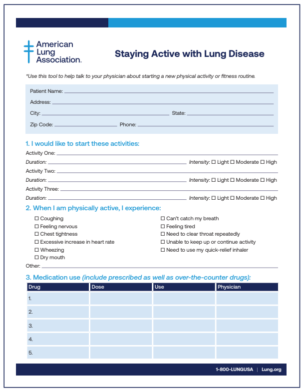
Endurance exercises increase your heart rate and breathing. Activities like walking, jogging, biking and swimming help your body use oxygen better, increase your energy level and reduce your shortness of breath.

Resistance Exercises

You may find that your muscles are weaker if you have lost weight, recovered from a respiratory infection or if you have not exercised in a while. Resistance exercises help improve your strength. Squats or lunges are examples of muscle strengthening exercises.

Balance Exercises

Balance helps you stay stable and upright as you do different activities. Leg exercises like a single leg balance can help improve your coordination.



American Lung Association.

Staying Active with Lung Disease

**Use this tool to help talk to your physician about starting a new physical activity or fitness routine.*

Patient Name: ______________________
Address: ______________________
City: ______________ State: ______________
Zip Code: __________ Phone: ______________

1. I would like to start these activities:

Activity One: ______________________
Duration: ______________ *Intensity*: ☐ Light ☐ Moderate ☐ High
Activity Two: ______________________
Duration: ______________ *Intensity*: ☐ Light ☐ Moderate ☐ High
Activity Three: ______________________
Duration: ______________ *Intensity*: ☐ Light ☐ Moderate ☐ High

2. When I am physically active, I experience:

☐ Coughing
☐ Feeling nervous
☐ Chest tightness
☐ Excessive increase in heart rate
☐ Wheezing
☐ Dry mouth
☐ Can't catch my breath
☐ Feeling tired
☐ Need to clear throat repeatedly
☐ Unable to keep up or continue activity
☐ Need to use my quick-relief inhaler

Other: ______________________

3. Medication use *(include prescribed as well as over-the-counter drugs):*

Drug	Dose	Use	Physician
1.			
2.			
3.			
4.			
5.			

1-800-LUNGUSA | Lung.org

Use the Staying Active with Lung Disease tool to guide your conversation.

Eliminate Your Exposure to Tobacco Smoke

Tobacco products like cigarettes and vaping may worsen your PF and cause it to progress faster. Quitting is one of the most important steps you can take to improve your health. It is never too late to quit.

Benefits of Quitting Tobacco Use:

- Your PF may progress more slowly.
- Your medications may work better.
- You may be eligible for a lung transplant.
- You may breathe easier.
- You will lower your risk of developing other health conditions like lung cancer or heart disease.

Developing a Quit Plan is the first step to quit smoking and vaping! Write down your responses to these prompts and share them with your healthcare provider.

I am most likely to use tobacco products at this time of day or doing this activity: ____

____

____

____

I am motivated to quit tobacco use because: ______________________________

My planned quit day is: ____

I am most interested in these medications or nicotine replacement therapy: __________

____

____

____

My preferred options for enrolling in a tobacco cessation program are: _____________

____

My questions or concerns are: ____

____

Support is Available

You do not have to quit tobacco use on your own. There are online, over the phone and in person programs and resources to help you.

Ask your family and friends to be supportive, encouraging and patient as you start your quit journey. If you would like additional support, contact your local health department or hospital about quit smoking or tobacco cessation programs in your area.

1-800-QUIT NOW is a national network of each state's Quitline. This service provides free counseling, connection to community programs and may offer free nicotine replacement therapy like the patch or gum.

Call the **Lung HelpLine** at **1-800-LUNG USA** to speak with a Certified Tobacco Treatment Specialist or learn about Freedom From Smoking at **Lung.org/ffs**.

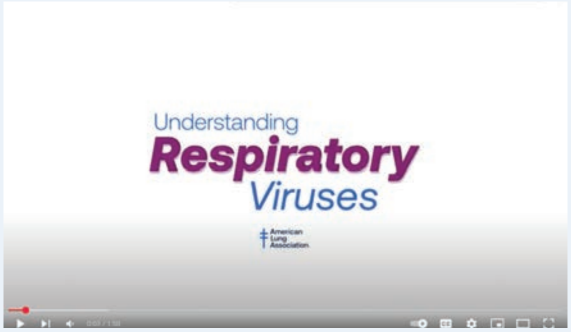
Prevent Infectious Lung Diseases

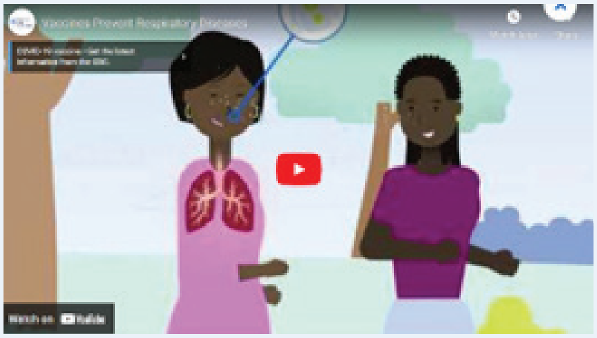
The germs that cause infectious respiratory diseases like the flu or colds can be spread through coughing, sneezing or touching infected objects or surfaces. When your lungs are scarred, it is harder for your body to recover from infectious respiratory illnesses. This puts you at risk of serious complications.

Your healthcare provider may recommend the following respiratory vaccinations:

- Influenza (flu) every year
- COVID-19 as new vaccines are recommended
- Pneumococcal pneumonia
- Tdap to protect against pertussis (whooping cough)
- RSV (respiratory syncytial virus)

Use the QR codes to learn more about respiratory viruses and how vaccines work to prevent them:





My Vaccination Tracker

Keep track of your vaccinations. There may be some vaccinations that need more than one dose. Ask your healthcare provider when you should schedule an appointment for the follow-up dose.

Vaccine	Date Given	Schedule	Side effects
Influenza-flu	*9/5/2023*	*Once a year*	*None noticed*

Talk to your healthcare provider or pharmacist about vaccine-related questions, concerns and benefits. Still have questions? Call the **HelpLine** at **1-800-LUNG USA**.

Tips for Reducing your Exposure to Germs:

Avoid crowded spaces or wear a mask that fits closely to your face during times when there is a lot of illness spreading in your community.

If you are sick, stay home and take time to recover. Limit your contact with others who are sick. Clean and disinfect areas of your home that are touched often.

Throughout the day, wash your hands with soap and water for at least 20 seconds. Dry your hands with a paper towel or a clean towel.

Prepare for Disasters and Emergencies

Emergencies and disasters can happen at any time. Create a plan before disaster strikes.

Fill in your responses for each step.

Tell family, friends and loved ones about your emergency plan.

Who is part of my emergency plan? ______________________________

Go to page 11 for the phone numbers of your support network and your medical team. If you use oxygen, ask two neighbors to check on you in the event of a power outage.

Neighbor 1 and phone number: ______________________________

Neighbor 2 and phone number: ______________________________

Alert fire, police and your power company about any medical equipment that needs electricity (oxygen concentrator, CPAP or BiPAP machine, nebulizer or ventilator).

Non-emergency phone numbers:

Fire:______________________________

Police: ______________________________

Power: ______________________________

Keep car adapters and extra batteries for your medical equipment (like a nebulizer or POC) in one place. Have back-up oxygen or metal tanks ready in case of a power outage.

Where this is stored: ______________________________

Keep your medical cards, medication, extra copies of prescriptions and other documents together.

This information can be found: ______________________________

Test smoke and carbon monoxide alarms regularly and replace the batteries at least twice a year. Do this in the fall and spring.

If you use oxygen or need power for medical equipment, consider registering for a special need or an emergency shelter.

Location of the shelter: ______________________________

Other important information: ______________________________

____

____

Consider buying products to help you during emergencies like a portable air cleaner ahead of wildfire season or a generator in case of a power outage. These items are often out of stock during an emergency.

What I need: ____________________

____

____

Find a list of recommended supplies for building an emergency kit at **Ready.gov/Kit**.

Travel Tips

While it may require more planning and a slower pace, living with PF should not stop you from all travel.

Work with your Medical Team

- Talk to your healthcare provider about when and where you are going, how long you will be gone and how you are traveling.
- Discuss your concerns about your destination's air quality, altitude during a flight or if you are visiting a location with a higher altitude than you are used to. Often, high altitude means there is thinner or less oxygen. This may mean you need to adjust your oxygen levels.
- Ask your provider to provide a letter saying you are safe to travel, and complete other paperwork needed for your travel.
- Confirm your oxygen supplier has the correct oxygen supply needs for every part of your trip.

Talk to Others About Your Travel Plans

- Talk to hotels ahead of time and ask about working elevators, discuss your oxygen needs, on-site help with carrying luggage or any other needs during your trip.
- Contact the airline or transportation provider for instructions on transporting your oxygen equipment while traveling.
- Coordinate the use of a wheelchair as needed.
- Bring along a travel partner or someone who can assist you during your trip.

Things to Include When you Pack

- Pack your medical insurance cards and medications in your carryon luggage. Include a copy of your prescriptions in case a refill is needed and bring extra medication in case your trip is delayed.
- Pack extra batteries or chargers for your nebulizer or portable oxygen concentrator.

Other notes or travel tips:

Improve Your Indoor and Outdoor Air Quality

Particles, chemicals, or gases in the air, called pollutants, may cause or worsen your breathing-related symptoms.

Indoor Air Pollutants- Strong Odors, Chemicals and Fumes

- Read the labels of cleaning or household products and use products with low volatile organic compounds (VOCs). Products with high VOCs will include words like “warning,” “caution” or “danger.”
- Avoid using products with strong odors, including room fresheners, incense and perfumes. Ask others around you to avoid using strong scents.
- Keep your area ventilated and use an exhaust fan if you must be around any chemical or strong odor.
- Ask others not to smoke around you. This includes cigarettes, pipes, vaping, e-cigarettes, marijuana or any type of combustible device.
- Avoid using a wood burning or coal stove to heat your home unless it is an EPA-certified wood stove.
- Use the fan above your kitchen stove when cooking. This will help vent the odors and particulates outside.

Outdoor Exposures- Pollen, Weather and Air Quality

- Wear a scarf loosely around your face or a mask when it is cold and windy outside.
- On days when it is hot and humid, use an air conditioner or go to a cooling center like a public library or community center during the hottest part of the day.
- Check the pollen count at weather.com or in the weather section of your local news station. Consider staying inside on days with high pollen counts.

Check the air quality index.
You can find the air quality index for your area at airnow.gov.

Understanding the Air Quality Index

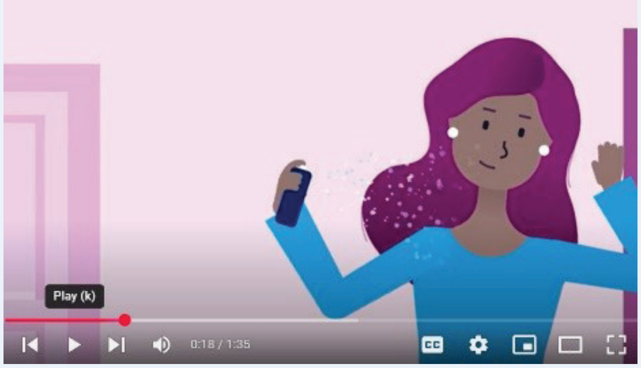
The Air Quality Index or AQI measures the current outdoor air quality where you live. You can use this information to keep informed and protect yourself during poor air quality days. Since you are living with PF, you are included in the “Sensitive Groups” category.

Name		Index Value	Advisory
🟩	Good	0 to 50	None
🟨	Moderate	51 to 100	Usually sensitive individuals should consider limiting prolonged outdoor exertion.
🟧	Unhealthy for Sensitive Groups	101 to 150	Children, active adults, and people with respiratory disease, such as PF, should limit outdoor exertion.
🟥	Unhealthy	151 to 200	Children, active adults, and people with respiratory disease, such as PF, should avoid outdoor exertion; everyone else should limit prolonged outdoor exertion.
🟪	Very Unhealthy	201 to 250	Children, active adults, and people with respiratory disease, such as PF, should avoid outdoor exertion; everyone else should limit outdoor exertion.
🟫	Hazardous	251 to 300	Everyone should avoid all physical activity outdoors.

Watch these animations to learn more:

Protecting Yourself from Unhealthy Air

VOCs and Lung Health



Chapter 5: Nutrition

PF and Nutrition

Learn about the different food groups, how to read a food label and ways to add more protein, vegetables or fruits to your diet. Visit MyPlate.gov

Healthy eating is important when you live with PF. You use more energy to breathe, and you will need to eat enough calories and protein to maintain a healthy weight. Aim to eat a balanced diet of foods that have proteins, fruits, vegetables and carbohydrates. Protein can help you maintain your strength and muscle mass. Try lean, protein-rich foods like chicken, turkey or fish.

Try to avoid foods that are high in sodium or salt, sugar, saturated fats and trans fats. Foods with a higher amount of saturated or trans fats are usually prepackaged, fast food or frozen food. Cakes and other desserts, margarine and frozen pizza also can have trans fats.

Types Of Foods To Eat When You Have Acid Reflux

It is common for people who have pulmonary fibrosis to also have gastroesophageal reflux disease (GERD). Acid reflux or heart burn happens when stomach acid comes up to your esophagus.

- **Try:** Foods with complex carbohydrates and a higher fiber count may be less likely to trigger acid reflux. This includes bread, whole-grain pasta, certain fruits and vegetables. Fruits and vegetables that may have less acidity are bananas, watermelon, cantaloupe, carrots, broccoli or squash. These foods also have vitamins, minerals and fiber that are important to your health.
- **Reduce or Avoid:** Foods that may worsen acid reflux include spicy or fried foods. Tomatoes and citrus fruits, coffee and other caffeinated products, carbonated drinks and alcohol may also worsen acid reflux. When possible, limit processed foods.

Types Of Foods When You Do Not Have An Appetite

You may find that because of your medication, worsening symptoms or less overall energy you are not hungry, or food does not taste good, and as a result, you are eating less. If this is the case, try to choose foods that will give you the most nutritional value.

- **Try:** Aim for foods with protein like lean meat, eggs, milk, fish, cheese, nuts, Greek yogurt, peanut butter or dried beans. Add foods with complex carbohydrates like whole grain bread, fruit and vegetables.
- Unsaturated fats are considered healthier fats and can be found in different oils, nuts and seeds. Talk to your healthcare provider or a nutritionist about adding a high-calorie or nutritional beverage with extra protein if needed.
- **Reduce or Avoid:** You should limit foods that have high amounts of sugar like candy, cake and soft drinks.

Types Of Foods When You Have Diarrhea Or Loose Stools

- **Try:** You may find the BRAT diet, which is made up of bananas, rice, applesauce and toast, to be helpful. You may also try adding a protein like chicken or a complex carbohydrate, such as whole grain bread or potatoes, to your diet. Try lactose free dairy products if you notice your symptoms get worse with dairy products. Stay hydrated and drink water throughout the day.
- **Reduce or Avoid:** Watch out for dairy products like milk and ice cream as these products can worsen diarrhea. Avoid foods or drinks with a high sugar content or that include sugar substitutes.

Fluids

If you have mucus, water helps to thin excess mucus in your lungs, making it easier to cough up. Try to drink water throughout the day. Sugar-free, non-caffeinated beverages may also help supplement water in your diet.

Tips for Managing Challenges While Eating and Drinking

The foods you eat often depend on your symptoms, side effects and other health conditions. You will need to work with your healthcare provider, dietitian or nutritionist to find a diet that works for you. Discuss ways to manage challenges during mealtimes.

Getting Short of Breath During Meals

- Eat slowly, take small bites of food and chew thoroughly before swallowing.
- Eat smaller meals, 4-6 times throughout the day, instead of larger meals. When you are full or bloated, your diaphragm cannot move freely making it harder to breathe.
- Take a break or pause between bites or sips. Focus on controlling your breathing. Use pursed lip breathing if you find it helpful.
- Eating can increase your body's need for oxygen, and you may find yourself tired after mealtimes. If needed, continue to use supplemental oxygen while eating.

Feeling Anxiety or Fearful During Meals

- Use coping skills to help distract you while eating.
- Talk to your healthcare provider about the anxiety you feel while eating or drinking.
- Try steamed, soft or moist foods if you are concerned about choking or if it takes a lot of energy for you to eat. You may find harder foods like steak more difficult to chew and swallow.

Members of the Patient & Caregiver Network (PCN) have access to healthy recipes and meal prepping tips. Join at Lung.org/PCN.

Weight Management

Your weight can impact your lung health. There are health risks and complications for being overweight or underweight. Talk to your healthcare provider about your ideal weight and ways to either lose, gain or maintain your weight.

My current weight: ____________

The weight my healthcare provider recommends for me: ____________________________

The type of diet my healthcare provider recommends for me:

____

Suggestions or tips to manage my weight: ______________________________________

____

____

____

____

____

____

____

____

____

Chapter 6: Cope with Your Emotions and Stressors

Anxiety and depression are common for people living with PF. There may be times when you are worried, afraid, feel down or ask questions like “what happens next?” or “why did this happen?” You do not have to go through this alone and there are steps to help you feel better.

Recognize Signs of Stress, Anxiety, Panic and Depression

Everyone has feelings of sadness, fear and worry at times. If these feelings do not go away after a few weeks then it is time to speak with your healthcare provider.

- **Stress** is a natural, physical or emotional response to a challenge or event. It can affect how you think, feel, act and respond to a situation. Restlessness, chest pain, stomachaches, tiredness or lack of motivation are some signs of stress.
- **Anxiety** is constant, debilitating worrying that may make it hard for you to do everyday activities.
- **Panic** is a sudden episode of intense fear or anxiety. This can cause shortness of breath, shallow breathing and tense muscles.
- **Depression** is feeling down or sad and may cause you to have low energy levels, lose interest in activities you enjoy and withdraw from friends and family.

Anxiety, panic and depression are serious and should not be ignored or left untreated. Talk to your healthcare provider about changes in your feelings, thoughts or mood. Ask your provider about ways to treat anxiety and depression such as medications and counseling.

If you have thoughts of hurting yourself, talk to your healthcare provider right away or call or text the National Suicide Prevention Hotline at 988.

If you need immediate help, call 911 or go to your nearest emergency room.

My Coping Skills Toolbox

Before you were diagnosed with PF, you may have had different hobbies or interests. While you may not be able to do these hobbies the same way you used to, with adjustments, you can still do things you enjoy. Your hobbies or interests may also be used as coping skills.

Add to your coping skills toolbox things you can do when you are feeling down:

- ☐ Listen to a podcast, music or an audiobook
- ☐ Take a walk
- ☐ Journal or write down your thoughts
- ☐ Do a crossword puzzle or word search
- ☐ Get outside
- ☐ Call or invite over a friend or family member
- ☐ Read
- ☐ Draw, create artwork, write poetry or a short story
- ☐ Cook or bake something
- ☐ Play a game on your phone, the computer or with your family
- ☐ Watch your favorite television show or movie
- ☐ Spend time with pets or animals
- ☐ Try a relaxation technique
- ☐ Talk to a counselor or attend a support group
- ☐ Other: ____
- ☐ Other: ____
- ☐ Other: ____

Relaxation Techniques

Along with finding coping strategies, you may want to try muscle and visual relaxation techniques to help you relax when you are feeling stressed. Progressive muscle relaxation is an exercise that can help reduce stress and anxiety by having you slowly tense up then release or relax each muscle.

Each exercise takes only two to three minutes. At first, you may feel that these techniques do not work for you, or you are getting distracted. It is normal to have trouble focusing at first. Allow yourself time to practice until it becomes natural and then it will become soothing.

To get started using visualizing techniques or using guided imagery, close your eyes and practice a few deep breaths. Think of a place that is calming to you. It could be somewhere outdoors or inside. As you think about this place, think about the sounds, smells, the relaxing sights around you, and any physical sensations you feel.

Members of the Patient & Caregiver Network (PCN) have access to mindfulness how-to videos. Join at **Lung.org/PCN**.

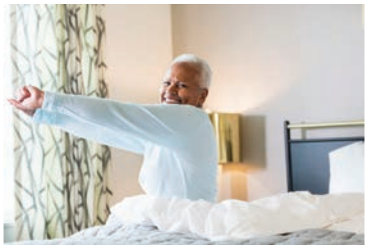
Chapter 7: Live Well with PF

Set Goals for Activities

Living with PF requires you to use more energy. Modifying how you do your activities is a way to save your energy and do more throughout the day. It is also important to remember that it is okay to go at your own pace and allow yourself grace if you do not get done everything you set out to accomplish.

Tips and Tricks for Planning your Day

Waking Up



Bathe or shower at the time of day that you have enough energy.

Plan your outfit the night before instead of in the morning.

Bathing

Work with an occupational therapist and use a handheld showerhead, shower chair, tub transfer bench and grab bars to safely bathe or shower.

Use a non-skid mat to reduce slipping when you get out of the shower. Always have a trusted friend or family member home when you bathe or let someone know you are bathing.

Use oxygen while bathing. Place the tubing over the shower door or place on the side of the shower curtain.

Reduce humidity and steam by lowering the temperature of the water. Try using the exhaust fan or leaving the door or window cracked open.

Meal Preparation

Create a shopping list and plan your meals.

Sit down during the meal prep work.

Rest before cleaning up after meals.

Keep the items you use more often like pots, pans, utensils and tableware on your stove range or counter.

Shopping

Take enough supplemental oxygen for your entire trip.

If you have a portable oxygen concentrator, have extra batteries or chargers in your vehicle.

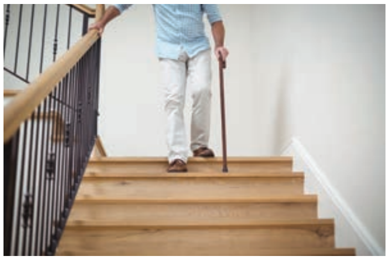
Use a mobility device such as a walker, cane, scooter, or rollator as needed.

Avoid the store's busiest hours.

Keep frozen or refrigerated items placed together in the same bag and make sure that bag gets inside your home first.

Consider online ordering with pick up or delivery.

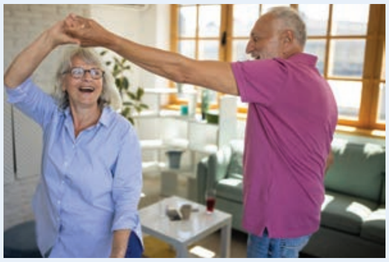
Using Steps



Use supplemental oxygen, pursed lip breathing techniques if you find it helpful, and use the handrail for support.

If you live in multi-level homes with only a bathroom on the second floor, use a commode on the main level of your home so that if you are tired, you do not have to use the steps.

Intimacy



Plan time for intimacy when you are rested.

Try different positions and other activities that are intimate but require less movement and exertion. This may include caressing, hugging, massaging, and manual stimulation.

The partner who does not have PF should make most of the movements.

Talk to your healthcare provider about using supplemental oxygen during sexual activity.

Track the times and which activities you are doing that you have worsening symptoms like shortness of breath, cough or feeling more tired. Record your symptoms, oxygen levels, what steps you are taking to recover and how long it took you to recover.

Symptoms	Oxygen levels	Steps you are taking to recover	Time to recover

Share this information with your healthcare provider.

Finding Community Resources

Friends, family and caregivers can help with some daily activities, but you may find you need outside programs or services. If there are activities of daily living that you find difficult completing safely, ask your healthcare provider about options like:

- Attending a pulmonary rehabilitation program so you can build up your activity tolerance level.
- An in-home assessment by an occupational therapist. An occupational therapist can teach you ways to manage your everyday activities and conserve energy.
- Programs or supplies covered by your health insurance company. The durable medical equipment or supplies covered under your policy may include a shower chair, commode, grab bars or a wheelchair.
- Local Area Agency on Aging for community services that are available such as meal service programs and transportation.
- Homecare agencies that may offer cleaning services and help with other daily activities.

Questions I have about community service or program providers:______________________________

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Putting the 5 Ps into Practice

Set realistic goals for yourself and use the 5 Ps to conserve energy.

Pace yourself throughout the day and take breaks or rest between activities.

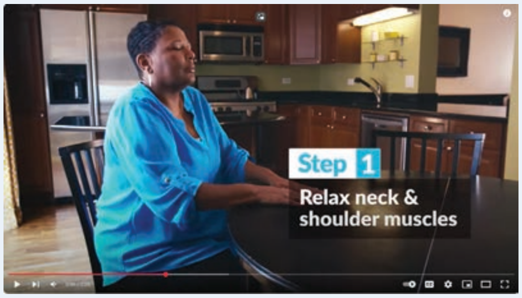
Plan your activities and break up the "heavy" tasks, like laundry, throughout the week. For example, if you have a doctor's appointment one day, do a heavier housecleaning task on a different day.

Position yourself by sitting or standing upright. Try to avoid bending or reaching whenever possible. Bending or reaching may cause shortness of breath and fatigue. Avoid staying in one position, such as standing, for too long as this is tiring as well.

Prioritize your activities by focusing on what is important for you to do now and what can be done later.

Pursed lip breathing is a deep breathing exercise. People living with PF may feel short of breath or have difficulty taking a breath in. If you find yourself short of breath, focus on inhaling and controlling your breath work.

For some people living with PF, pursed lip breathing may help with shortness of breath and may help reduce anxiety.



Scan the QR code for the Pursed Lip Breathing demonstration video:

Using the 5 Ps

Use the list above and write down the activities you need help completing, your roadblocks and how you can use the 5 Ps.

Activity or task that I need help with completing	Roadblocks for completing the activity	How can I use the 5 Ps to complete the activities?
Bringing my groceries up the steps after shopping	*I get short of breath when carrying bags up the steps*	*Prioritize bringing up the foods that are frozen or refrigerated.* *Use supplemental oxygen* *Pace yourself after each trip up the steps.* *Leave the non-perishable foods in the car until I can get help or have more energy.*

Caregiver Corner

Caregivers are unsung, everyday heroes who often find themselves in this role unexpectedly and without any formal training, education, or guidance. Caregiving looks different for everyone. If you are new to this role or having a tough time finding where you can best support and advocate for your loved one, try:

- **Learning about PF.** Knowledge is power. Learning about PF will help you better understand the disease. It can help you know what to do when your loved one's breathing becomes worse, learn ways to manage medication side effects and help with using oxygen equipment safely.
- **Providing reassurance and support.** Be your loved one's advocate and be there to lend an ear. It is also okay to encourage them to ask for help from their healthcare provider, talk to a mental health professional, or encourage them to join a support group.
- **Support their independence.** It is important to support your loved one's independence but also recognize there may be activities that are more difficult to complete than others.

Caregiving may feel like an emotional roller coaster. As a caregiver it is important for you to balance your needs and your own health. Self-care may look like:

- **Finding caregiver communities**. By joining an online support community such as Caring for Pulmonary Fibrosis or a local, in-person Better Breathers Club support group, you can connect with other caregivers and people living with lung disease like PF (see Resources, Programs and Tools for support communities).
- **Recharging yourself.** Find time each day to rest, exercise, and allow yourself time to do something for yourself. Find coping skills that work for you (see page 38 for ideas).
- **Taking care of your physical and mental health.** Caregiving may feel isolating and you may have feelings of guilt. Keep your own medical appointments and talk to your healthcare provider if you need help managing your thoughts or feelings.
- **Asking for help.** There may be times when you need a break or need to get out of the house. Do not be afraid to ask your friends or family for help. If you do not have friends or family nearby, try your local Area Agencies on Aging to find out what options there are in your community for respite care.

Notes or reflections about my caregiving role: ______________________________

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Chapter 8: Plan Ahead

While it may be a difficult topic to bring up with your loved ones and healthcare team, starting the conversation about your wishes for the future and end-of-life care should happen sooner than later. Having this conversation earlier may reduce you and your loved one's stress, uncertainty and lower your risk of having end-of-life care that does not align with your wishes.

Advanced Care Planning

An advanced directive includes a healthcare power of attorney and living will. You want both to be on file with your healthcare provider.

- A **healthcare power of attorney** is someone you choose and trust to make healthcare decisions for you if you are not able to do so yourself.
- A **living will** outlines your end-of-life medical wishes. Your healthcare power of attorney will use your living will to guide your end-of-life medical decisions.

Some states require different forms or documents to be notarized. To learn more about advanced care planning, you can contact your local Area Agency on Aging. If you are a Veteran, contact your local Veteran Affairs office for help with these documents.

Supportive Care

Living with PF is often unpredictable. As your disease progresses, you may have worsening symptoms like a cough, lower oxygen levels and extreme tiredness. You may have other health conditions like anxiety, depression or GERD which also affect your quality of life and make it harder to manage your PF.

Supportive Care Options Available to You:

Palliative care can begin at any stage of your disease. This treatment focuses on improving your quality of life, managing symptoms and making sure your wishes and treatment goals are being met.

You may consider palliative care if:

- You would like an extra layer of support to manage and treat your PF.
- You want your care to focus on improving your quality of life and reducing your symptoms.

Hospice care should be considered if you reach the end stage of your disease. Hospice care is about taking control and making choices that are right for you, not giving up. The medications you take will be reviewed with your healthcare provider to determine if you wish to continue or stop using them based on your treatment goals.

You may consider hospice if:

- You would like to STOP receiving treatment that is intended to treat PF.
- Your healthcare provider told you that you have less than one year to live.

A team of doctors, nurses, spiritual advisors, nutritionists and social workers lead supportive care programs. It is important to speak with your insurance company about coverage for these services.

Use the QR codes to watch the video How to Start a Conversation about Palliative Care and Hospice.

Download the Palliative Care Worksheet and/or Advanced Lung Care Guide.

American Lung Association.

Palliative Care and Lung Disease:
Getting the Support You Need

What is palliative care?

If you are living with a chronic lung disease like COPD or pulmonary fibrosis, palliative care may provide you with an extra layer of support. Palliative care is a specialized medical care that focuses on your needs and provides relief from symptoms and stress of the disease. The focus is on improving your quality of life.

How can palliative care help someone living with lung disease?

Treatment Planning: Palliative care teams can help you and your family understand your treatment options and goals, plan for the future and offer practical advice about talking to loved ones. They also offer assistance with making difficult decisions.

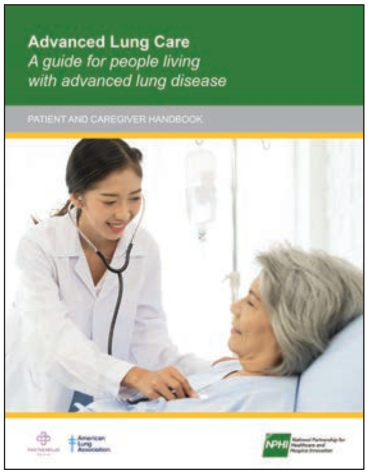
Surgery: Palliative care may be helpful in managing postoperative pain.

Stress: Palliative care may help reduce the anxiety, fear and depression that some patients with lung disease and caregivers feel as they face lung disease. This type of care may include medication, massage therapy, guided imagery, counseling and more.

Navigating the medical system: Palliative care specialists may help get all of the members of your care team on the "same page" to help you make sure you are getting the care you need. Palliative care social workers are also instrumental in helping design a discharge plan for you that meets your needs and those of your family.

First and foremost, the palliative care team is concerned with helping you and your family get the support you need.

1-800-LUNGUSA | Lung.org



Advanced Lung Care
A guide for people living with advanced lung disease

PATIENT AND CAREGIVER HANDBOOK

Chapter 9: American Lung Association Resources, Programs and Tools

Living with PF may cause you to feel alone or isolated but there is support available. Connecting with others can help you become part of a broader community. It is also helpful to hear stories of others living with PF.

Sharing your Story & Raise Awareness

When you share your story, it helps others feel they are not alone. September is Pulmonary Fibrosis Awareness Month and the Lung Association and other organizations supporting people living with PF are working hard to raise awareness of pulmonary fibrosis across the country. Learn more in the Get Involved section of Lung.org/PF.

Lung Health Navigator Program

Whether you are new to living with PF or looking for one-on-one support to manage your disease, the Lung Health Navigator Program can answer your questions and offer free, personalized PF education. Contact the Lung Health Navigator Program for free at 1-800-LUNG USA or Lung.org/Navigator.

Patient and Caregiver Network

Join our nationwide, online support program that provides direct access to lung disease management tools, education and connection to others living with lung disease. Become a member at Lung.org/PCN.

Better Breathers Clubs

Attend an in person or virtual support group to learn ways to manage your lung disease and get support from others. Find a Club in your community at Lung.org/better-breathers.

Freedom From Smoking® Program

Freedom From Smoking® is a virtual or in person tobacco cessation program that has helped more than a million people in the United States end their addiction to all tobacco products, including e-cigarettes and vaping devices. Join today at Lung.org/FFS.

Inspire Living with Pulmonary Fibrosis and Caring for Pulmonary Fibrosis Support Community

Build your online support network with others living with PF. Connect at Lung.org/community.

We want to hear from you!

Thank you for completing the Learning to Live with Pulmonary Fibrosis Workbook. We would love to hear more about your experience using this workbook. **Use the QR code or go to Lung.org/pf-survey to access the brief survey.**

Download form at **Getting Ready for Your Next Office Visit (lung.org)**

American Lung Association.

Getting Ready for Your Next Office Visit

Appointment Information

Provider Name: ____________________

Date: ____________________

Address: ____________________

Reason for Visit: ____________________

Other Healthcare Providers I Am Seeing

Name: ____________________ Phone: ____________________

Reason to see this healthcare provider: ____________________

Name: ____________________ Phone: ____________________

Reason to see this healthcare provider: ____________________

Name: ____________________ Phone: ____________________

Reason to see this healthcare provider: ____________________

Prescribed and Over-the-Counter Medicines and Supplements

Name of Drug/Supplement	Dose	Frequency	Prescribed/Recommended by

Name of My Pharmacy: ____________________ Phone: ____________________

Symptoms I Have Been Experiencing

Coughing		Feeling nervous	
Chest tightness		Rapid heartbeat	
Wheezing		Head/nose stopped up	
Unable to exercise		Restlessness	
Feeling tired		Fever	
Need to clear throat repeatedly		Stroking chin or throat	
Dry mouth		Increased use of quick-relief inhaler	
Waking up at night		Other:	

How frequently these symptoms occur: ______________________________

When the symptoms begin: ______________________________

Things I do to relieve these symptoms: ______________________________

Additional Concerns and Questions

____

____

____

Next Steps

Notes from my healthcare provider: ______________________________

____

Tests to schedule: ______________________________

____

Next appointment (Day/Time): ______________________________

Download form at Medication Tracker (lung.org)

American Lung Association.

Medication Tracker

Name of Medication	What Is This Medication For?	Date Prescribed	Doctor That Prescribed Medication	How Much? (dose)	How Often?	Directions For Taking Medication	Side Effects

Download form at Staying Active with Lung Disease (lung.org)

American Lung Association

Staying Active with Lung Disease

**Use this tool to help talk to your physician about starting a new physical activity or fitness routine.*

Patient Name: ____________________

Address: ____________________

City: ____________________ State: __________

Zip Code: __________ Phone: ____________________

1. I would like to start these activities:

Activity One: ____________________

Duration: ____________________ *Intensity*: ☐ Light ☐ Moderate ☐ High

Activity Two: ____________________

Duration: ____________________ *Intensity*: ☐ Light ☐ Moderate ☐ High

Activity Three: ____________________

Duration: ____________________ *Intensity*: ☐ Light ☐ Moderate ☐ High

2. When I am physically active, I experience:

☐ Coughing
☐ Feeling nervous
☐ Chest tightness
☐ Excessive increase in heart rate
☐ Wheezing
☐ Dry mouth
☐ Can’t catch my breath
☐ Feeling tired
☐ Need to clear throat repeatedly
☐ Unable to keep up or continue activity
☐ Need to use my quick-relief inhaler

Other: ____________________

3. Medication use *(include prescribed as well as over-the-counter drugs):*

Drug	Dose	Use	Physician
1.			
2.			
3.			
4.			
5.			

American
Lung
Association®

When you can’t breathe,
nothing else matters.®

55 West Wacker Drive, Suite 1150 | Chicago, IL 60601
1-800-LUNGUSA | Lung.org

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