

# Pulmonary Fibrosis

FOUNDATION

## Oxygen Basics

A step-by-step guide to using supplemental oxygen





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### Have questions about oxygen that aren't answered in this guide?



Call the PFF Oxygen Information Line Monday to Friday between 9:00 a.m. and 5:00 p.m. CT at 844.825.5733. The PFF Oxygen Information Line is staffed by trained professionals who can provide further information about topics such as oxygen safety and equipment.

## INTRODUCTION



Every cell in your body needs oxygen to function. When you take a breath, oxygen moves down your airways into the small air sacs and then into your bloodstream. The area where the oxygen crosses into the blood is called the interstitium. Interstitial lung disease (ILD) or pulmonary fibrosis (PF) cause this area to be swollen or scarred, which can decrease your oxygen levels, especially when you are active. Oxygen levels can be measured by taking a blood sample or, more often, by placing a device called a pulse oximeter on your finger or forehead.

Use of supplemental oxygen may prevent breathlessness, increase your ability to maintain an active lifestyle, and help decrease stress on organs. Although no studies have shown that supplemental oxygen prolongs life in pulmonary fibrosis patients, some studies demonstrate that supplemental oxygen extends life in patients living with chronic obstructive pulmonary disease (COPD). For some PF patients with prolonged low oxygen levels (or who need oxygen 24 hours a day), use of oxygen can lower the stress on the heart and blood vessels in the lung.

The Pulmonary Fibrosis Foundation (PFF) is pleased to provide these step-by-step tips for starting and safely using oxygen at home and when traveling, as well as detailed information on Medicare coverage of supplemental oxygen.

## OXYGEN FUNDAMENTALS

### Possible signs and symptoms

Many people who need supplemental oxygen experience shortness of breath or fatigue. Other possible signs that you're not getting enough oxygen include irritability, blue fingertips or lips, rapid heartrate with activity, and ankle swelling. However, some people may not experience symptoms even when they're not getting enough oxygen into their bloodstream. Some patients with PF can experience breathlessness during exertion even when their oxygen levels are normal. This is due to scarring, which makes the lungs stiffer, requiring more "work" to breathe.

### BOOST YOUR OXYGEN IQ

New users sometimes ask if supplemental oxygen is addictive. The answer is no – use oxygen as prescribed by your healthcare provider.

### Determining your need for supplemental oxygen

Your healthcare provider can test your need for supplemental oxygen by measuring your oxygen levels while you are at rest, during walking or exercising, or during sleep. The six-minute walk test is commonly used to determine whether you need supplemental oxygen while walking. Your healthcare provider will decide which tests are right for you. You'll need a face-to-face visit with your healthcare provider and testing for insurance purposes.

If your healthcare provider finds your oxygen levels are low during testing, he or she will determine whether you need supplemental oxygen, when you need it (at rest, during activity, and/or during sleep), and how much you need in each setting.

### Your healthcare provider's role

In addition to identifying your supplemental oxygen needs, ordering appropriate testing, and providing a prescription and supporting documentation, your healthcare provider will work with the company supplying your supplemental oxygen and assist you in determining your oxygen equipment needs for use at home, with activities outside the home, and for travel.

### BOOST YOUR OXYGEN IQ

A recent study found that patients who received education from healthcare providers about supplemental oxygen were less likely to have problems with their oxygen than those who didn't receive education or were only educated by the person delivering their oxygen.

### Components of an oxygen prescription

Only your healthcare provider can change your oxygen prescription, which will include:

- When to use your oxygen (during sleep, rest, or activity, or at altitude)
- How much oxygen you need for each activity (the number setting if you use pulse flow, or liters per minute if you use continuous flow)
- What type of oxygen equipment fits your lifestyle and oxygen requirements
- A Certificate of Medical Necessity (required by Medicare and many other insurers)

### Your supplemental oxygen company's role

The company supplying your supplemental oxygen will provide a basic oxygen system, including equipment and disposable supplies like nasal cannulas or humidifiers. The company will also share information on using your equipment safely and properly, provide 24-hour emergency service for equipment malfunctions or power outages, verify insurance coverage, and bill your insurer.

# OXYGEN EQUIPMENT

## Types of oxygen systems

Work with your healthcare provider and supplemental oxygen supplier to identify the oxygen system that best fits your lifestyle and oxygen requirements. Some things to consider: how active you are, how many steps or stairs are in your home, how often you leave home and how long you're gone for, your physical strength, and your personal preferences. The types of systems available vary between companies.

Most patients will receive an in-home, stationary unit as well as a portable system that allows them to leave home.

### Types of stationary systems

#### Stationary concentrators



- A stationary concentrator pulls oxygen from the air in the room through special filters in the machine to produce a stream of concentrated oxygen through the tubing.
- The machine usually stays in the room where it's placed. You can use different lengths of oxygen tubing to move around your home or workplace.
- The cost of electricity for running the concentrator is not covered by insurance.
- There are two types of oxygen concentrators. Normal-flow devices go up to 5 liters per minute and high-flow devices can go up to 10 liters per minute.

#### Stationary liquid systems



- When oxygen is cooled to a very low temperature, it becomes liquid. The liquid oxygen is stored in a container. As it leaves the container, it warms up to room temperature and becomes a gas, which then flows into tubing.
- Stationary liquid systems are quiet, don't have major moving parts, and don't require a power source to operate.
- Not every supplier offers liquid oxygen, so it's important to check first before you start a contract with that company.
- The large liquid oxygen reservoir usually needs weekly refilling from your oxygen company.

### Types of portable systems

#### Compressed gas tanks



- These green and silver aluminum tanks are filled with compressed oxygen gas and come in a variety of sizes. During use, smaller tanks run out of oxygen more quickly than larger tanks.
- Some compressed gas tanks can be filled at home with a concentrator filling system; these are often referred to as transfill or home fill units and are placed on top of your stationary concentrator.
- You may choose to use a backpack or rolling option for carrying smaller compressed gas tanks. Work with your supplier and healthcare provider to find a good option for your needs.

#### Portable oxygen concentrators



- A portable oxygen concentrator (POC) is a smaller version of a stationary concentrator.
- POCs run on batteries, so you may need to carry extra batteries to keep the unit running. Battery life depends on factors such as the amount of oxygen used and POC size. POCs can be recharged via wall plug or car battery.
- Generally, the smaller the unit, the lower the oxygen output and maximum pulse or continuous flow setting, and the shorter the battery life.
- The larger POCs usually have a maximum setting of 3 on continuous flow and 6-9 on a pulse setting.
- POCs vary in weight from 3-22 lbs; the larger ones require a stroller unit on wheels.

- This type of oxygen system can be used in flight, although you must contact your airline ahead of time to ensure you can bring your POC on the plane.
- Many people requiring high-flow oxygen need more oxygen flow than a POC can provide. If you're considering a POC, please talk with your healthcare provider first to make sure this type of device will meet your needs.



### Liquid portable tanks

- Liquid portable tanks are filled from a stationary liquid system. To avoid the risk of cold burns, training is required before filling a liquid portable tank from the stationary system. Work with your supplier to make sure you understand the system.
- Weighing 3-11 lbs, these units provide a larger reservoir capacity and higher continuous flows than portable oxygen concentrators.
- Keep liquid oxygen units upright to prevent leaks.
- Not every supplier offers liquid oxygen.

### Other equipment

#### Nasal cannulas and tubing



- Stationary oxygen systems connect to 25-foot or 50-foot tubing. The part that goes into your nose is called a cannula or nasal cannula.
- Oxygen set above 6 liters per minute uses special high-flow tubing and may require a face mask instead of a cannula.
- If you use high-flow oxygen, your healthcare provider may recommend a reservoir nasal cannula. These cannulas may come in a pendant or a mustache style. Also known as an Oxmizer®, this type of cannula helps maximize delivery of oxygen. Reservoir nasal cannulas cannot get wet and shouldn't be worn in the shower.

#### Humidifiers



If you use high-flow oxygen, ask your healthcare provider about whether you need a humidifier, which can help prevent nasal membranes from drying out. Flows of 4 liters per minute and above require humidification. Humidifiers cannot be used with reservoir nasal cannulas.

### Types of oxygen flow

There are some differences between pulse or demand flow and continuous flow:

- With pulse flow (also known as demand flow), your portable oxygen system senses when you inhale and only delivers a pulse of oxygen when you breathe in, allowing tanks and batteries to last longer.
- Continuous flow provides a continuous flow of oxygen into your nose, even when you are not breathing in.
- Pulse flow and continuous flow are both prescribed as numbers, but the numbers do not mean the same thing. A continuous flow setting of 2, 3, or 4 liters per minute is different from – and usually more than – a pulse flow setting of 2, 3, or 4.
- Pulse flow isn't appropriate for all patients. Talk with your healthcare provider about the right options for you. You should be tested on a pulse flow device before using it.

\* Photo courtesy of CAIRE Inc.

## GETTING STARTED

### Safety ABCs

Follow these tips to stay safe around oxygen:

- Avoid flames, sparks, cigarettes, matches, lighters, gas stoves, pilot lights, and frayed electric cords.
- Keep compressed tanks 8-10 feet from open flames or sparks.
- Avoid petroleum-based products to moisturize your face or nose. Ask your oxygen company or your healthcare provider for names of nasal lubricants designed for oxygen users.
- Don't store tanks in closets, in direct sunlight, or next to heat sources.
- Ensure that stationary concentrators are well ventilated with no items stored on top.
- Contact your electrical company and fire department to let them know you use supplemental oxygen. It's important they're aware of your need for oxygen in case of a power outage.
- Keep smoke detectors and fire extinguishers in your home.
- Don't use cracked or broken tanks.
- Secure oxygen tanks to prevent them from falling and becoming projectiles.

### Ensuring the right amount of oxygen

Your healthcare provider may ask you to periodically monitor your oxygen levels using a pulse oximeter. Ask him or her what your target oxygen level should be. If your healthcare provider asks you to, you can adjust the flow of oxygen depending on what you're doing to keep your oxygen level in a recommended range. It's very important to alert your healthcare provider of changes in your oxygen saturations or an increase in oxygen needs.



### Maintaining oxygen equipment

Ask your supplemental oxygen supplier for instructions for cleaning and maintaining your specific equipment. Some basics you may need to consider:

- Change the nasal cannula and long tubing for the stationary system regularly according to guidelines from your oxygen company.
- Regularly clean the filter if your oxygen concentrator requires one.
- If you're using a humidifier, wash it regularly. Fill it only with distilled water, not tap water.
- Clean face masks regularly.
- Ask your supplemental oxygen supplier to schedule a yearly servicing for your concentrator.



### BOOST YOUR OXYGEN IQ

Oxygen isn't flammable and doesn't explode on its own – but it will make a fire burn faster. Always keep oxygen away from sparks, sources of flames, and flammable items.



### More PFF oxygen resources

The PFF offers additional resources for learning about and using supplemental oxygen:

- Check out oxygen-related webinars (visit [pulmonaryfibrosis.org/webinars](https://pulmonaryfibrosis.org/webinars)).
- Several patient and caregiver sessions at PFF Summits cover supplemental oxygen issues. Find slides from these presentations at [pulmonaryfibrosis.org/summitarchive](https://pulmonaryfibrosis.org/summitarchive).

# MEDICARE AND SUPPLEMENTAL OXYGEN

Here are answers to frequently asked questions about Medicare and supplemental oxygen.

## How is supplemental oxygen covered by Medicare?

Oxygen equipment and accessories are covered through Medicare Part B on a five-year cycle. If you have original Medicare Part B and a medical need for oxygen, you'll rent your equipment from a supplier for 36 months. The supplier must then continue to provide the equipment, oxygen tank refills, and accessories like tubing and filters for an additional 24 months after the end of the initial 36-month rental period. Your supplier also must service and repair the equipment throughout the whole five-year cycle.

## What if I have a Medicare Advantage Plan?

Medicare Advantage Plans must cover supplemental oxygen. If you have one of these plans, review its benefits to understand how supplemental oxygen coverage works.

## Can my supplier decide to stop providing equipment and services in the middle of the five-year cycle?

Under Medicare guidelines, your supplier is obligated to continue providing your equipment and services for the length of the five-year cycle, except under a few circumstances (for example, in emergency situations).

If your supplier refuses to provide equipment or services, get their intentions in writing, then file a complaint at 1-800-MEDICARE (1-800-633-4227).

## Can my supplier change the type of oxygen system I'm receiving during the five-year Medicare contract?

Your oxygen supplier cannot change the type of oxygen system you receive – or the number of tanks you receive – unless your healthcare provider orders the change.

## What happens if my oxygen needs change during the five-year Medicare contract?

Keep up with recommended medical appointments and be sure to talk with your healthcare provider if you notice a change in your oxygen needs. If your needs change, you should be retested and your healthcare provider will change the Certificate of Medical Necessity as needed. The supplier is required to provide the equipment and service that meet your current medical needs.

## What happens at the end of a five-year cycle?

At the end of the five-year cycle, your supplier is no longer required to provide your oxygen equipment and service. You may choose to remain with the same supplier or switch to a different one. Your healthcare provider will need to complete a new Certificate of Medical Necessity.

Remember: before you enter into a Medicare contract with an oxygen supplier, ask your healthcare provider to make sure the equipment offered by the supplier is correct for you.

## What happens if I move in the middle of the five-year cycle?

If you move during the initial 36-month rental period, you can ask your current supplier to help you find a supplier in your new area. You can also use Medicare's supplier directory, found at [medicare.gov/supplier](https://www.medicare.gov/supplier), to identify a new supplier.

If you move after the initial 36-month rental period, your current supplier generally has a responsibility to make sure you have a supplier in the new area.

## Who owns the equipment when the five-year cycle ends?

The oxygen supplier owns the equipment both during and at the end of the five-year cycle.

## Can I decide which brand of oxygen equipment I receive?

You can ask for a specific brand, but a supplier is only required to provide you with the type of system prescribed by your healthcare professional, not a specific brand. Before you enter into a Medicare contract with an oxygen company, ask your healthcare provider to make sure the equipment offered by the oxygen supplier is correct for you, as different companies may offer different choices.

## If I have original Medicare, what will my costs be?

You're responsible for 20% of the Medicare-approved amount. A Medicare supplemental insurance plan (also known as a Medigap plan) may be able to help with the 20% coinsurance.

## TRAVELING WITH OXYGEN

### Air travel and PF

Whether you're at sea level or high in the mountains, the atmosphere is made of 20% oxygen and 80% nitrogen. But at higher elevations, there is simply less air – the atmospheric pressure is lower – so there is less oxygen for you to breathe.

Since commercial airplane cabins are usually pressurized to an elevation equivalent to about 1,500-2,500 meters (about 5,000-8,000 feet), passengers are breathing less oxygen while in flight. Many people with PF can safely travel by air, but for some, air travel can be dangerous. If you have PF, it's important that you discuss your travel plans with your healthcare provider weeks or months before planned travel, even if you don't normally use oxygen at home.

### Determining your ability to travel by air

To determine whether you should travel by air, your healthcare provider may order tests including:

- Pulse oximeter to check your oxygen level
- Six-minute walk testing
- Pulmonary function testing
- Arterial blood gas measurement to check your oxygen and carbon dioxide levels
- Echocardiography
- High-altitude simulation test (HAST) measuring your oxygen level while you breathe air with a reduced oxygen level (15% oxygen instead of 20%)

Based on these test results, your healthcare provider will determine whether you need oxygen while in flight. You'll then need enough time to notify the airline, have your doctor fill out paperwork for the airline, and coordinate with an oxygen supplier. If your oxygen requirements are too high or you have other medical conditions, your healthcare provider may advise you to not travel by air, since your oxygen levels may drop dangerously low in flight.

### Airline requirements for oxygen

In the United States, airlines are required to allow battery-powered portable oxygen concentrators (POCs) that have been approved by the Federal Aviation Administration (FAA). Most airlines require you to bring your own POC, but not all POCs are allowed by all airlines. Each airline maintains a list of which POCs they will allow on board. Airlines won't allow you to bring filled oxygen tanks (green cylinders) or liquid oxygen onto the plane.

Your healthcare provider must complete paperwork ahead of time that instructs the airline on how and when you should use oxygen. Your healthcare provider can also help arrange for a short-term POC rental from an oxygen supply company.



### BOOST YOUR OXYGEN IQ

A small number of airlines will provide you with oxygen on board rather than requiring you to bring your own. There's usually a charge to use an airline's oxygen. Check with your airline for details.



## Checklist for air travel with oxygen

- ✓ Prepare weeks or months ahead of time. See your healthcare provider and notify the airline as early as possible. While some airlines only need 48 hours advance notice, it's advisable to prepare at least a month in advance.
- ✓ Be aware of the airline's specific policies for which oxygen concentrators are allowed, what paperwork is required before you travel, and what documentation you need to have with you when you travel. Contact your airline for further information.
- ✓ Be sure to bring enough batteries – and make sure they're fully charged. The FAA requires you to have battery life equal to 150% of your expected travel time. Remember to factor in time for traveling to the airport, waiting to board, layovers, deplaning and picking up baggage, and traveling from the airport to your destination after arrival. The plane may or may not have an electrical outlet available if your batteries run out. Always "plug in" while waiting for your flight.
- ✓ Ask your healthcare provider if you should monitor your oxygen level in flight with a portable pulse oximeter.
- ✓ If you're traveling outside the United States, different regulations may apply. Contact your airline for guidance, and remember to bring the correct electrical plug adapter for the country you're visiting.



### Planning for battery time

**When planning battery life for a flight, be sure to include your total travel time. Here's an example:**

Travel time to airport .....	1 hour
Checking in, going through security, waiting to board .....	2 hours
Flight .....	2 hours+ 1 hour*
Deplaning, picking up baggage.....	30 minutes
Travel time after arrival to your destination .....	1 hour

**Minimum battery time  
needed for this trip: ..... 7.5 hours**

\*The FAA requires battery life equal to 150% of your expected flight time. For this example, a two-hour flight, the FAA would require battery life of three hours for the flight itself.

### Traveling to high elevations

If your destination is at an elevation above sea level, you may suffer from breathlessness with small degrees of exertion or even while resting. Your healthcare provider may advise you to not travel to destinations at high elevation.

### Traveling by car

Inform your oxygen supplier of your travel plans and your oxygen needs at your destination. The 12V DC outlet power source charger in your vehicle can charge your portable oxygen concentrator.

### Oxygen at your destination

Your healthcare provider may determine that your portable oxygen concentrator is sufficient for your travel needs. If you need an additional oxygen delivery device while away from home, your oxygen supplier may be able to coordinate with a supplier at your destination to provide the equipment you need. Be sure to plan ahead of time.

## HAVE QUESTIONS ABOUT SUPPLEMENTAL OXYGEN THAT AREN'T ANSWERED IN THIS GUIDE?

The PFF Oxygen Information Line provides information and resources to individuals using supplemental oxygen and to their caregivers. The Oxygen Information Line is staffed by trained representatives who can help you understand how to access oxygen, how to use it safely, and what to do if you have a problem.



Call the PFF Oxygen Information Line Monday to Friday between 9:00 a.m. and 5:00 p.m. CT at 844.825.5733.

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Please note that any information contained in this guide is for informational and/or educational purposes only. It is not intended to be a substitute for professional medical advice. Always consult your personal physician or healthcare provider with any questions you may have regarding your specific medical condition.

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# Pulmonary Fibrosis

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