

Getting the Air You Need

Oxygen provision is a crucial component of treatment for PF patients – it is life-saving. There are many providers and many options when it comes to equipment choices and patients often must be their own advocates when it comes to finding the best equipment for their needs. University of California San Francisco Interstitial Lung Disease Program nurse Sally McLaughlin suggested that getting the best service involves learning the government guidelines for coverage and gathering as much information as possible from a nurse or pulmonary rehabilitation specialist. There are resources available to assist patients in understanding the options. Please find below excerpts from the pamphlet “Living Well with Supplemental Oxygen” on the UCSF Interstitial Lung Disease Program website. The entire booklet can be found at www.ucsfhealth.org/ild.

Some pointers from UCSF Interstitial Lung Disease nurse Sally McLaughlin on key oxygen provision issues:

“In my experience, doctors tend to leave the choice of equipment up to the nurses. This is fine because it takes a lot of time in terms of thought and advocacy to get equipment that meets the patients’ lifestyle needs – equipment that the patient CAN and WILL use. Pulmonary rehabilitation programs are very good resources for recommending equipment for patients to meet their lifestyle needs and oxygen needs... so are some oxygen suppliers – especially their respiratory therapists. Patients need to learn about the different kinds of oxygen equipment available today that will meet their needs and keep them active, and make sure they get it. In truth, suppliers are reimbursed the same amount whatever equipment they offer.

People with ILD are dealing with some challenges regarding their oxygen equipment because their oxygen needs may be low at first, but tend to increase over time:

1. Liquid systems tend to deliver higher flows for longer periods of time, but there is a trend amongst oxygen supply companies to no longer offer liquid systems because they are labor-intensive and therefore more costly.
2. Because of Medicare guidelines, it’s harder to switch oxygen suppliers after the first year. So, when patients with ILD start to need higher flows (greater than 5 liters per minute) and their current company doesn’t provide high flow equipment or liquid oxygen, which would serve them better, they are unable to switch to a new company that can meet their needs - they’re locked in, because Medicare will not pay another company until the patient’s 60 month rental cycle is over. Patients with ILD need to start out with a company that offers a variety of equipment.
3. Health care providers, including oxygen suppliers, don’t always understand that people with ILD may be sufficiently saturated while at rest, but as soon as they start walking, their requirement can shoot up. It is important that whoever is assessing the oxygen needs of the patient performs a walk test. Patients need to understand this and ask to be tested while ambulating.
4. The new portable oxygen concentrators are terrific for travel and other situations – they really keep people mobile – but there currently only two on the market that will go up to 3 liters continuously - the Invacare Solo with also goes to 5 liters per minute pulsed dose, and the SeQual Eclipse that which also goes to 6 liters per minute pulsed dose. All the other units on the market only deliver pulsed dose oxygen from 3 – 5 liters per minute. So it’s important for ILD patients to invest in a portable oxygen concentrator that will meet their higher flow needs. New equipment is coming out all the time, though, and I hope that we will see ones that delivers higher flows.”

Living Well with Supplemental Oxygen

Courtesy of UCSF Interstitial Lung Disease Program

The following information represents selected material from the UCSF Oxygen brochure.

For a complete copy please go to www.ucsfhealth.org/ild.

The Need for Supplemental Oxygen



Why Did My Doctor Prescribe Oxygen For Me?

Every body needs oxygen! In fact, every tissue and every cell in the body needs a constant supply of oxygen to work properly. The way oxygen gets into our cells and tissues involves the lungs – the lungs allow us to breathe in oxygen from the air, and pass the oxygen into the bloodstream through millions of tiny air sacs, called alveoli. Hemoglobin in the red blood cells then picks up the oxygen and carries it off to the tissues and cells of the body.

Interstitial lung disease can cause inflammation and/or scarring in the part of the lung tissue where oxygen passes into the bloodstream – the alveoli. This inflammation and scarring make it difficult for oxygen to move into the bloodstream. Therefore, the amount of oxygen in the blood drops, resulting in not enough oxygen to keep the tissues and cells functioning properly. Not enough oxygen in the bloodstream is called hypoxemia.

How Did My Doctor Determine That I Need Supplemental Oxygen?

The amount of oxygen in the bloodstream can be easily measured two ways:

Oximetry

This is the method most often used to measure the amount of oxygen in the blood. A small clip-on device shines a light through your finger or earlobe and measures the amount of light absorbed by the oxygen carrying hemoglobin in the red blood cells. By calculating the amount of light absorption, the device can measure the percent of hemoglobin that is carrying oxygen – the oxygen saturation of the blood (or O₂ sat). Normally, the oxygen saturation of the blood is around 95 – 100%.

Arterial Blood Gas Study

Blood is drawn out of an artery (usually in the wrist) using a needle and syringe. The blood is then sent through an analyzer to measure the amount of oxygen gas dissolved in the blood. This result is called the arterial oxygen pressure (paO₂), and is normally 80 – 100 mm Hg. When the O₂ sat falls below 89%, or the paO₂ falls below 60 mm Hg - whether at rest, with activity, or during sleep – the tissues are not getting enough oxygen, and supplemental oxygen is needed to correct the hypoxemia. Your healthcare provider can determine your supplemental oxygen needs by testing you while you are at rest and while walking, and can also order an overnight oximetry study to test your oxygen saturation at night.

When/How Much Do I Have To Wear My Oxygen?

The body needs enough oxygen to keep the blood adequately saturated so that cells and tissues get enough oxygen to function properly. Furthermore, cells and tissues can neither “save up” nor “catch up” on oxygen – they need a constant supply. When the oxygen saturation falls below 89%, or the arterial oxygen pressure falls below 60 mmHg – whether at rest, with activity, or during sleep – then supplemental oxygen is needed. Your health care provider will write a prescription for when and how much you should wear your oxygen, based on the results of your testing. The prescription should specify the appropriate oxygen flow rate or setting (as liters per minute [lpm or l/min] of oxygen) that will keep your saturations ≥ 90%, when you should wear your oxygen (i.e., with activity, overnight, or continuously), and should specify a type of equipment that will accommodate your lifestyle needs.

Why Would I Need to Wear Oxygen When I’m Sleeping?

Oxygen levels in the blood are lower for everyone during sleep, due to a mildly reduced level of breathing. Also, some alveoli drop out of use during sleep. If your waking oxygen saturation is greater than around 94% on room air, it is unlikely that your saturation during sleep will be below 88%. If there is a question about your oxygen levels while you are sleeping, however, an overnight pulse oximetry test can be ordered by your physician.

How Do I Know That I'm Using the Right Amount of Supplemental Oxygen?

The way to tell for sure if you are using the right amount of supplemental oxygen is to measure your oxygen saturation while using your oxygen. Your provider or a respiratory therapist from the oxygen supplier should test your oxygen saturation on oxygen while you are at rest, while walking, and, if indicated, while you are asleep. As long as your saturation is in the 90's you are getting the right amount of supplemental oxygen.

Should I Buy My Own Finger Oximeter to Test My Oxygen Saturations?

Some people feel more comfortable testing their oxygen saturation periodically throughout the day or with various activities, to make sure they are 90% saturated or more. Others learn how much oxygen they need at various activity levels to keep them saturated in the 90's through pulmonary rehabilitation programs. Still others are comfortable with periodic testing at their provider's office. Finger oximeters are available on the internet, through medical supply companies, and even in sporting goods stores. They can be expensive and have not been adequately tested for accuracy. You and your provider can determine together if a finger oximeter is necessary for you.

How Important Is Wearing My Oxygen As Prescribed?

When a person isn't getting enough oxygen, all organs of the body can be affected, especially the brain, heart, and kidneys. Wearing supplemental oxygen keeps these organs, and many others, healthy. There is evidence that, for people who are hypoxemic, supplemental oxygen improves quality of life and survival.

Will I Feel Better When I Use My Oxygen?

Supplemental oxygen can help relieve your symptoms. You may feel relief from shortness of breath, fatigue, dizziness and depression. You may be more alert, sleep better, and be in a better mood. You may be able to do more activities, including travelling and travelling to high altitudes.

But there are other reasons for symptoms such as shortness of breath besides lack of oxygen. In these cases, supplemental oxygen may not relieve shortness of breath. However, if tests show that you are not getting enough oxygen, it is still important that you wear your oxygen.

Does My Need for Supplemental Oxygen Mean That I Don't Have Long To Live?

People live for years using supplemental oxygen.

Will I Always Need to Use Supplemental Oxygen?

That depends on the reason oxygen was prescribed. If your lung or heart condition improves, and your blood oxygen levels return to normal ranges without supplemental oxygen, then you don't need it anymore.

Can I Become "Dependent On" or "Addicted To" Oxygen?

There is no such thing as becoming "dependent on" or "addicted to" supplemental oxygen – everybody needs a constant supply of oxygen to live. If there is not enough oxygen in your bloodstream to supply your tissues and cells with oxygen, then you need supplemental oxygen to keep your organs and tissues healthy.

Are There Any Side Effects From Using Oxygen?

It is important to wear your oxygen as your provider ordered it. If you start to experience headaches, confusion, or increased sleepiness after you start to wear oxygen, you might be getting too much. Oxygen settings of 4 liters per minute or above can cause dryness and bleeding of the lining of the nose. A humidifier attached to your oxygen equipment, or certain ointments can help prevent or remedy this.

Will I Be Able to Go Out and About With My Oxygen Equipment?

Our goal is to have you continue as many of your usual activities as you can. With that in mind, your healthcare provider, your oxygen supply company and you should work together to get oxygen equipment that will allow you to do these things. Choosing the right type of equipment for you and your lifestyle is very important - the right ambulatory oxygen equipment can play a major role in improving quality of life.

