I'm Short of Breath When I Walk but Not When I Sit Down?

DISCLAIMER: Please note I am not a medical professional. I spent 6 years as caregiver for my mom, until her passing in 2009. I have since been a PF Advocate for Patients & Families, as well as moderator & owner of the Breathe Support Network of Groups. Information provided is from personal experience, combined with years of learning through interaction with patients, other caregivers, & medical professionals in the field of PF/IPF. I am not being paid by any organization and do not endorse any specific brand of equipment mentioned in this document.

This could also be sub-titled "*My oxygen saturation is fine when I sit, but goes down when I walk around*."

This is a common occurrence for those who are living with PF/IPF and is one not often explained when they are diagnosed. Also, quite often, patient's oxygen saturation is taken while they are seated rather than while they are actively moving around (like walking), which is misleading for those with PF/IPF.

What is oxygen saturation?

Oxygen saturation is a measure of how much oxygen is in your blood. This measure is taken with a pulse oximeter. You may have seen these at the doctor's office and you may even have one at home. If you do not have one at home, and you have been diagnosed with lung disease, this is a handy tool to use to monitor your saturation levels to ensure you are saturating well enough, either with or without supplemental oxygen.

These devices are not expensive. A pulse oximeter in the $20 - $30 (USD) range should be sufficient. When you buy one, take it to the doctor's office with you at your next appointment to compare with theirs and ensure it is measuring properly. *NOTE: Pulse oximeters can be up to +/- 3% off. This means a reading of 90% could be 87% - 93%.*

Normal oxygen saturation for a healthy person is 95% - 100% (at sea level).[1] In the earlier progression of the disease, many will find their saturation remains close to normal, however when they are up moving around or sleeping, they become short of breath (SOB). This is a normal occurrence with PF/IPF, albeit an unhealthy one.

Using your pulse oximeter to check your oxygen saturation at various times, during various activities, and especially if you are feeling short of breath, is one way to monitor your need for supplemental oxygen. You may require an increased flow if you are currently using supplemental oxygen. It is not necessary to check it all the time. Don't become dependent on your oximeter. Use it as a tool.

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[1] Mayo Clinic - https://www.mayoclinic.org/symptoms/hypoxemia/basics/definition/sym-20050930

When checking saturation while active, take the reading **while you are doing the activity**. For instance, while walking. For those with PF/IPF, it is common for saturation to normalize once activity is stopped. Earlier in disease progression, it will normalize within seconds. Waiting to check saturation until after activity has been stopped gives an unreal reading of saturation levels during activity. Additionally, the longer an activity goes on or the more strenuous it becomes, the more saturation may drop.

When checking saturation, make note of the date and time, activity and duration, both oxygen saturation and heart rate, and how you are feeling (short of breath, chest pain, etc). This is all good information to share with your medical professional when advocating for supplemental oxygen or a higher liter flow.

Activity vs. at rest vs. sleeping and how it affects oxygen saturation.

For someone with PF/IPF, their oxygen saturation may appear different depending on their activity level. Early in the disease process, oxygen saturation may stay at or above 90% when just sitting, watching TV, reading a book, or some similar activity. However, when sleeping or up moving around (even just upper body movement), saturation may drop. This makes knowing when oxygen is needed a bit more misleading.

Eventually, as fibrosis progresses through the lungs, PF/IPF patients will need oxygen full time. It is important they start using it as soon as they need it. For instance, if saturation is falling below 90% while sleeping, patients should start using supplemental oxygen during sleep. If they wake up tired or with a headache, it is possible their saturation is low during sleep. Be aware these symptoms can also be due to sleep apnea. It is important to talk with the doctor about these symptoms so appropriate tests can be ordered to confirm the correct diagnosis.

How do I or my loved ones recognize when I am short of breath?

If you need to stop talking mid-sentence to take a breath, you are short of breath. Normally, we experience this during heavy cardio activity. Those with PF/IPF will find they experience this much or all the time, even when just sitting and having a conversation. This is something your loved ones may recognize in you before you notice it yourself, as you may have become conditioned to think of this as normal.

Low oxygen saturation can also cause problems with brain function and patients often don't realize their saturation is low. They believe if they "feel" fine, then everything is normal. It is common for patients to forget to turn their oxygen delivery system on and "think" they are using oxygen, only to find out later that they have been without.

What can I do about my shortness of breath?

When you were diagnosed, one of the tests that should have been done is called a "6 minute walk" (6mw) test. If this was not done, you should contact your doctor and request the test.

The 6mw test is really a combination of 2 tests used to determine your need for supplemental oxygen with activity and the distance you can walk over a specific period of time. During this test, your oxygen saturation will be monitored, which will indicate your need for supplemental oxygen and at what liter flow to maintain 90% oxygen saturation. This part of the test is called "Walk Oximetry."

Walk Oximetry is used to determine supplemental oxygen liter flow needs at every minute and post 2 minute rest with an additional SpO2 check and blood pressure monitoring.

The following is a link to the guidelines for the 6mw test per the American Thoracic Society. https://www.thoracic.org/statements/resources/pfet/sixminute.pdf

It is the opinion of many that these guidelines need to be rewritten as they don't adequately reflect a person's normal day-to-day activity. For that reason, patients should advocate for themselves to ensure their 6mw test fits their needs.

Patients should walk at their normal pace for this test. Because we don't live life on a flat surface, if using stairs or slopes is the norm for your lifestyle, you may suggest during the 6mw test, that you also walk the stairs or a slope.

During the test, oxygen saturation will be monitored. It should be monitored WHILE activity is happening, not after activity has stopped. If it drops below 90%, the patient should be given supplemental oxygen. After the test is over, the doctor should know if the patient needs supplemental oxygen, and if so, what liter flow is needed to maintain normal activity with an oxygen saturation no lower than 90%.

NOTE: The goal is for supplemental oxygen to work <u>for</u> the patient, NOT the other way around. This means the patient should be tested to find an oxygen flow that will help them maintain a relatively normal life style. If the tech performing your test tries to slow you down to maintain your oxygen saturation, advocate for yourself and maintain your normal pace.

What are the effects of oxygen saturation lower than 90%?

When your oxygen saturation is falling below 90%, it is not always wise or as simple as "slowing down". This is a mistake a lot of people make. They think if they slow their walking, they can go without needing oxygen longer. While this may work for the short term, you will not be successful making this a permanent solution. It is important to

maintain a normal lifestyle as long as possible. Not only is this healthy for you emotionally, it is healthier for you physically. A body that is strong in every other way will handle this disease better than one with weak muscles and a weak heart.

As oxygen saturation falls below 90%, **over time** irreversible damage is done to the heart, brain, and other organs.

- Patients experience muscle fatigue. Muscle fatigue can be so extreme as to make one think they are nearing the end, when what they really need is supplemental oxygen or a higher liter flow of supplemental oxygen.
- Tissue damage can occur due to insufficient blood flow to the extremities.
- Hands and feet may become colder.
- Brain cell death begins to occur. Two things quickly (and permanently) affected are short term memory and cognitive ability. Short term memory loss is often mistaken for early signs of dementia/Alzheimer's.
- Heart rate increases and over time, the heart becomes weak. The heart and lungs work together. When the lungs are compromised, the heart picks up the load. It is important to keep the heart as healthy as possible. Even the best heart will suffer damage due to PF/IPF over time.
- Pulmonary Hypertension (PH) is another side effect of ongoing low oxygen saturation. PH is high blood pressure of the lungs and is another incurable lung disease. PH is best staved off by keeping oxygen saturation from dipping below 90%. PH secondary to PF/IPF may be treatable with medications. PH takes an even bigger toll on the heart as well.

What makes 90% oxygen saturation the magic number?

Oxygen deprivation actually starts around 94% saturation. Oxygen saturation lower than 90% is considered unhealthy. However, insurance companies typically do not pay for supplemental oxygen until a patient's saturation is 88% or less on a 6mw test. This is an unhealthy prospect for patients due to the effects on the body.

To fully understand how this works, this analogy may prove helpful.

Imagine you are standing near the edge of a cliff having your picture taken. There is a distance of 10 feet between the photographer and the edge of the cliff. You can back up 10 feet and everything is fine. If you back up any further, you fall off the cliff. [2]

When looking at oxygen saturation, if your saturation is between 90% and 100%, everything is fine. When it drops below 90%, there are many effects on the body.

This means that the differences between 90% and 100% are slight, but the differences below 90% can become extreme.

[2] Dr. Noah Greenspan, DPT, CCS, EMT-B, Board Certified Clinical Specialist in Cardiovascular and Pulmonary Physical Therapy.

Most of this is “over time”. It doesn’t mean that if your saturation drops below 90% you will have immediate brain cell death or your heart will become irreparably damaged. However, if this decrease in saturation continues, over time you may likely experience damage to your body. *NOTE: Heart rate is where you will see an immediate change with lower saturation. As saturation goes down, heart rate goes up.*

Where do I go from here?

Now that you understand some of why you are short of breath, it is important for you to be proactive about your healthcare needs. If your doctor has not checked this or you think your disease has worsened, it is up to you to bring this up with the doctor. Every “body” needs the right amount of oxygen and if it doesn’t get that, it suffers.

It is also important to know there are many other reasons which can cause shortness of breath. Please see the related article titled “***What Causes Shortness of Breath***” to learn more about this problem.

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