

## Short of Breath: Understanding when your loved one is struggling

***DISCLAIMER: Please note I am not a medical professional. I spent 8 years as caregiver for my mom (2 years pre- and 6 years post diagnosis of IPF), until her passing in 2009. I have since been a PF Advocate for Patients & Families, as well as Founder and Support Group Leader of the Breathe Support Network of Groups. Information provided is from personal experience, combined with years of learning through interaction with patients, other caregivers, & healthcare professionals in the field of PF/IPF.***

Many of us are caring for someone who is living with PF, but we can't fully understand what is happening to their bodies or how it makes them feel because we don't live with the disease inside of us. I try to give everyone a refresher course every now and then to help them to be enlightened caregivers.

While we don't know what our loved ones are truly going through and can't "sympathize" with them, there are things we can do to help give us a little idea so we can "empathize" with them.

One strategy is the "straw test." This has been a very popular and easy way to gain a tiny bit of knowledge. If you take a small straw (coffee shop sized - not soft drink size) and put it in your mouth, plug your nose and walk around, go up and down stairs if you have them, walk briskly for even one minute... only breathing through this tiny straw, this will give you a small idea of what your loved one means when they say they are "short of breath."

The first time I did the straw test, I was sitting. I felt anxious. I used my finger pulse oximeter to check my saturation and found it to be normal, however I did notice an elevation in my heart rate - from the anxiety. Not being able to breathe is worse than any pain. It is truly the most frightening experience.

It's important to realize that as PF progresses, our loved one's lungs are turning to a stone like substance and "stones don't expand." Their lungs don't expand when they take a breath in like our healthy lungs do. They can't take a deep breath like you or me. This means they take a lot of little shallow breaths. Take a minute and try to breathe only in short shallow breaths. Now try it while walking around. You may likely feel like you aren't getting enough air. (Photo of an end stage lung with PF – photo credit: Intermune.)



The other thing happening in their lungs as fibrosis spreads is that the lungs aren't doing the vital gas exchange - removing carbon dioxide (Co<sub>2</sub>) from their blood and replacing it with oxygen (o<sub>2</sub>).

When this happens, not only do they not have enough o<sub>2</sub> in their blood, but they also have too much Co<sub>2</sub>, which causes them the same symptoms as carbon monoxide poisoning - and yes,

Co2 retention can get so bad that it can be fatal. (FYI... this is the natural progression of the disease process. Eventually, their lungs won't be able to rid the blood of Co2.)

Their brain, heart, and other organs, their tissues, and their muscles are all deprived of oxygen.

Over time:

- they may start having problems with short term memory loss and cognitive function (these are both irreversible)
- their heart has to work harder to take up the load from the loss of lung function (which causes the heart to break down and start to develop other problems)
- they may develop pulmonary hypertension (high blood pressure of the lungs - another irreversible and incurable and highly UNtreatable lung disease when secondary to PF)
- their muscles become fatigued to the point that just walking across the room feels like they are climbing a mountain

These are the outward symptoms they feel and that we, as loved ones, need to learn to recognize.

Can your loved one:

- finish a sentence without having to take a breath?
- go up and down the stairs normally?
- take a shower and still brush their teeth or eat breakfast when they get out?

Are their lips or nail bed taking on a bluish tinge? If they are, this is a sign of more extreme low oxygen saturation and they may need quick medical attention.

Low oxygen saturation can make them dizzy and disoriented, and they can fall and hurt themselves or have such low saturation that they lose consciousness. We have had cases of patients in our PF community who had low saturation, fell, and hurt themselves badly or desaturated while driving and wrecked their car. Some have even passed away from their injuries.

There are so many ways our loved ones bodies are stressed with this disease. Add to it the anxiety they feel when they can't catch their breath. When one is short of breath, they feel extreme anxiety. That anxiety leads to quicker, shallower breathing, a faster heart rate, and more shortness of breath. It's an endless circle. Remember, they are already breathing shallower because "stones don't expand."

There are other things going on in their body as well that are not as easy to recognize. Every part of the body needs proper oxygen saturation so who knows what else is going on with their other organs that may cause problems as time goes on.

It is so important to learn what your loved one is living with. If you've ever had pneumonia or something that causes a bad cough and you were left feeling as if you couldn't breathe - and

you panicked - then you got just a little glimpse into their world 24x7. (I have personally been through this and it is truly awful. But I had the knowledge that I was going to get better.)

If you have asthma and have ever had an asthma attack and your throat started to close up on you - then you got just a little glimpse into their world 24x7.

The other problem our loved ones have with breathing is when they need to bend over to do something or raise their arms up over their head (for instance in the shower trying to wash their hair) this makes breathing more difficult. This happens because these actions cause the diaphragm to push up into their lungs, causing even more shortness of breath. Remember, the lungs are turning to a stone like substance so when the diaphragm pushes up into the lungs, it is pushing into a more solid object. Not one that is soft and pliable.

Regarding showering: your loved one will find that showering is actually one of the most difficult things to do. This is because showering usually entails warm to hot water, which raises the humidity in the room, making the air heavier and harder to breathe. If that bathroom is not well ventilated with good fans or open windows and doors, this further exacerbates the problem.

When showering, it's important for them to:

- have good ventilation
- turn down water temperature so as to not make the air too humid (and many enjoy - or used to enjoy - their hot showers, so now they've had to give that up)
- have a shower chair to sit on with their shower nozzle on a flexi-hose that is placed on the shower wall at the appropriate level for them to use while seated
- Have a nice terry cloth towel and slippers to put on after with which to dry off as an alternative to towel drying - which causes them to have to use their arms, making them more short of breath and tired

So, caregivers, when your loved one says "I'm short of breath" or "I can't catch my breath" or "I am so tired and can't make it across the room" or the many other things they may say when they are not able to breathe properly... this is not them being lazy or weak. This is the disease taking its toll on their bodies. They may also get to the point where they find they sit down and fall asleep. Their bodies are just so incredibly fatigued: being deprived of good o<sub>2</sub> and overrun with Co<sub>2</sub>.

Your loved one also may not tell you these things. They are trying to be strong or brave. They don't want to be a burden. They want to feel "worthwhile" and not being able to do the things they used to do is a very emotional thing for them to come to grips with. They FEEL their bodies being overtaken with this disease.

Be their partner. Learn to recognize the signs that things are getting harder for them. Offer to do things for them. Let them know that you are there to help them. That you are happy to

help them. It's hard for them to give up these things. Some may say "no, I can do this." But reassure them that you will jump in when they are ready for you to do so.

It's hard to find the happy medium of not jumping in and helping when it's not wanted. I made this mistake with my mom early on as her caregiver. So, every now and then I just reminded her that I was there to help. If I asked if she wanted me to carry her oxygen tanks and she said no, then I let her do it. But I still offered again next time. Finally, she started saying yes. She needed that time to adjust to the changes in her life and be accepting of help. She was fiercely independent.

Learn as much as you can about oxygen. There are some excellent articles on our website for you to reference. Please check them out. You can find them at the link below. Ask questions in our support group. There is always someone here who has learned this and understands it and can talk to you.

Your loved one is living with this disease IN them, but you are living with it too. You both need to learn how to best #LIVEwithPF and that comes with you learning how to help them manage it. That begins with you having some understanding of what is happening and compassion for what they are experiencing - even though you can't "feel" it yourself.

[www.BreatheSupport.org/articles/oxygen](http://www.BreatheSupport.org/articles/oxygen) <-- This will take you directly to the oxygen section. I would encourage you all to read ALL the articles in all our article categories. And of course, always ask questions here in the groups and read what others are posting.

#caregiving #compassion #empathy #LIVEwithPF #BREATHE #BreatheSupport

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