

Chest or Back Pain: Should I be Concerned

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.

The first and most important piece of information in this document is:

If you are having new or worsening chest pain that has not yet been diagnosed, please call 911 and seek emergency medical treatment.

Chest and/or back pain is a very common problem for people with lung disease and one that is important to understand. There are many reasons as to why one may feel pain in their chest or back. Some of those reasons are quite benign. Some are emergent medical situations and can prove critical or even fatal if not evaluated right away.

My doctor said I can't be having lung pain. Is this true?

The short answer to this is... your doctor is correct. The lungs do not have pain receptors and therefore people do not feel "lung pain". However, this is a "simple" answer to a more complex situation.

"Lung pain" can be felt in the chest or in the back.

There are many reasons a patient may be feeling what they perceive as "lung pain".

Allergies/Post Nasal Drip – This is another cause of cough, and for many with PF/IPF, they find since their diagnosis that allergies and/or post nasal drip have become more problematic. You should consult with your pulmonologist or a good allergist to talk about ways to control this problem. Post nasal drip can also be a sign of a sinus infection and may need to be treated.

Costochondritis – This is inflammation of the cartilage that connects the ribs to the breast bone. It can cause chest and breast pain and make the chest or breasts tender to the touch.

Esophageal Motility and Hypersensitivity – Motility problems with the esophagus can cause spasms and can be mistaken for heart attack symptoms.

GERD (acid reflux) – This is a large cause of cough as well as chest or back pain in many people. If you know you have GERD, you should be doing what you can to control it. If you don't know if you have it, because you have PF/IPF, you should be evaluated for it. Talk to your doctor about being tested. GERD can seriously exacerbate PF/IPF. Reflux backs up the esophagus and can spill over into the lungs, causing additional damage to the lung tissue. This is true of both acid and alkaline reflux.

Heart Attack/Cardiac Event – These of course cause pain in the chest and/or back and can cause pain in other parts of the body. The left arm, neck, shoulders, and jaw. This is especially critical for women to know because many women do not experience the classic heart attack symptoms that men do. Heart attacks are frequently overlooked in women for this reason. With a cardiac event, every second counts. Over time, more and more damage can be done to the heart so acting quickly is important. Those with PF/IPF are at increased risk of a cardiac event because the heart is being overworked.

High Blood Pressure – Blood pressure can often be a problem for those with PF/IPF due to the fact the heart is working extra hard to maintain. It would be prudent to get a good, easy to use, blood pressure cuff for home use. The wrist cuffs are easy for someone to use on their own and are fairly accurate. Do take it to your doctor's office to check it against theirs to make sure that 1) it is reading correctly and 2) you are putting it on correctly. If these are not put on properly, they will not return a true reading.



Lung Cancer – PF/IPF patients are at an increased risk of being diagnosed with lung cancer. It is important to rule this in or out. Treating lung cancer can be tricky in someone with PF/IPF because many cancer treatments are a known cause of lung fibrosis and can easily exacerbate existing fibrosis, causing the fibrosis to spread and worsen quickly.

Muscle soreness & cracked or broken ribs from cough – Patients with lung disease may cough a great deal. This cough can cause muscle pain and even cracked or broken ribs (as well as anxiety, turning blue, vomiting, and even passing out). The pain can become quite severe. The best way to minimize this is to minimize cough. If you have the “PF cough”, talk to your doctor about ways to suppress the cough. (The “PF cough” is often dry and non-productive. A wet productive cough may be a sign of a respiratory infection and should be checked out by a doctor. That being said, pneumonia can cause a dry non-productive cough because the mucus in the lungs isn't breaking up easily. Don't ignore a new cough or a worsening in an existing cough.)

Pleurisy – This is inflammation of the pleura (the sac around the lungs) and may have no cause or may be due to an infection like pneumonia. While the lungs themselves do not have pain receptors, the pleura does. The pain from this can be excruciating. Pleurisy can be treated with anti-inflammatory medication as well as antibiotics when caused by an infection.

Pneumonia – PF/IPF patients are at high risk of this infection. The common cold or the flu (influenza type) can easily cause pneumonia as well. Pneumonia can be accompanied by a wet productive cough or a non-productive cough. It may or may not involve a fever. A worsening of shortness of breath is often a problem for those who are developing or have pneumonia. Patients should seek medical attention immediately. Pneumonia can become critical or fatal quickly in someone with lung disease.

Pneumothorax – This is a collapsed lung. PF/IPF patients are at increased risk of this and should seek medical attention immediately. Some with PF/IPF experience recurrent pneumothorax. There are treatments to help with this, such as pleurodesis.

Pulmonary Embolism – A pulmonary embolism is a blood clot that has made its way to the lung/s. These typically break off from a clot in the deep veins of the leg. Deep vein thrombosis (DVT) can be caused by various factors such as genetic blood disorders, being overweight, smoking, and even just maintaining a sedentary lifestyle. For patients with PF/IPF, especially if advanced, they do not move around as much, which increases their risk of clotting and PE's. Additionally, for some reason, PF/IPF patients seem to be more prone to these events. This is important for you (as patients and caregivers) to know, as many medical professionals who may be evaluating a PF/IPF patient in clinic may not know this is a risk factor. PE's are often overlooked in PF/IPF patients who do not have other recognizable risk factors. First line testing for this is often a blood test called a D-Dimer. This gives an indication if there may be clotting somewhere in the body. If the D-Dimer registers there may be clotting, then a lung "CT with contrast" should be ordered. However, it is important to note that the *D-Dimer can be WRONG!* It has been my experience in the PF/IPF support community that this happens quite often. The D-Dimer does NOT register there may be clotting, the patient is sent home, then later presents with the same or worsening symptoms, and finally a lung CT with contrast is ordered and the PE is found in the lung/s. *It is important that patients and caregivers advocate for the scan regardless of the D-Dimer results.* Even a small PE in the lung/s can prove fatal. The lungs are already at a diminished capacity and often do not have the ability to fight something like a clot. Intervention needs to happen immediately. Typically, fast acting blood thinners will be started (usually Lovenox injections – which are short acting but fast acting). Oral blood thinners (like Coumadin/Warfarin) will then be started. It takes about 3 days for Coumadin/Warfarin to start working so it may take a week or two to get the blood to a therapeutic level. The blood doesn't actually become "thinner", it just becomes more slippery, so it doesn't clot as quickly. Clotting factors will be monitored to ensure it doesn't become "too thin". However, it is also important to note that patients may continue to clot while on these medications. It's not a guarantee that unwanted clotting won't occur. I can't stress

enough here... If you are having symptoms of a PE, do not let them send you home without doing the lung CT with contrast.

Regardless of what you “think” may be the cause of your chest and/or back pain, DO NOT attempt to self diagnose. Seek medical attention immediately, even if that means calling an aid car/ambulance. An aid car/ambulance is actually your safest alternative in this circumstance because if you are having an emergent event, you may have a problem on the way to the hospital that requires professional intervention. Your caregiver may not be able to give this intervention (unless he/she is a medical professional and has equipment with them). If you are driving, you could easily lose consciousness and cause an accident, injuring yourself or others (or worse).

This document is not all inclusive. There may be other reasons for your chest or back pain. Please consult your medical professional to get an accurate and complete diagnosis and talk about treatment options.

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