ILD – Interstitial Lung Disease Defined

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.

Many are told by their doctor *"You have ILD."*

What does that statement really mean? This short document is meant to help guide you to questions to ask in finding answers to that **vague** diagnosis.

For a doctor to say *"You have ILD"* is akin to saying something equally as vague as *"You have cancer."* We all know what cancer is and we also know there are many types. Not all cancers are created equally. Some are more easily treated than others. Some come with a nearly certain death sentence (for instance cancers like ovarian and pancreatic).

It is important to know that ILD is an "umbrella" of diseases. Below is a list of many ILDs. *(From https://www.webmd.com/lung/interstitial-lung-disease#1)*

"Some of the types of interstitial lung disease include:

> **Interstitial pneumonia:** Bacteria, viruses, or fungi may infect the interstitium of the lung. A bacterium called *Mycoplasma pneumonia* is the most common cause.
>
> **Idiopathic pulmonary fibrosis** : A chronic, progressive form of fibrosis (scarring) of the interstitium. Its cause is unknown.
>
> **Nonspecific interstitial pneumonia:** Interstitial lung disease that's often present with autoimmune conditions (such as rheumatoid arthritis or scleroderma).
>
> **Hypersensitivity pneumonitis:** Interstitial lung disease caused by ongoing inhalation of dust, mold, or other irritants.
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> **Cryptogenic organizing pneumonia (COP):** A pneumonia-like interstitial lung disease but without an infection present. COP is also called bronchiolitis obliterans with organizing pneumonia (BOOP).
>
> **Acute interstitial pneumonitis:** A sudden, severe interstitial lung disease, often requiring life support.
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> **Desquamative interstitial pneumonitis:** An interstitial lung disease that's partially caused by smoking.
>
> **Sarcoidosis:** A condition causing interstitial lung disease along with swollen lymph nodes, and sometimes heart, skin, nerve, or eye involvement.
>
> **Asbestosis:** Interstitial lung disease caused by asbestos exposure."

What is the definition of an ILD? *(From https://www.mayoclinic.org/diseases-conditions/interstitial-lung-disease/symptoms-causes/syc-20353108)*

> "Interstitial (in-tur-STISH-ul) lung disease describes a large group of disorders, most of which cause progressive scarring of lung tissue. The scarring associated

with interstitial lung disease eventually affects your ability to breathe and get enough oxygen into your bloodstream.

Interstitial lung disease can be caused by long-term exposure to hazardous materials, such as asbestos. Some types of autoimmune diseases, such as rheumatoid arthritis, also can cause interstitial lung disease. In some cases, however, the causes remain unknown.

Once lung scarring occurs, it's generally irreversible. Medications may slow the damage of interstitial lung disease, but many people never regain full use of their lungs. Lung transplant is an option for some people who have interstitial lung disease."

Is every fibrotic lung disease progressive?

The short answer to that question is "no". *Pulmonary = lung and fibrosis = scarring*, so quite simply, *pulmonary fibrosis = lung scarring*. While most PF is progressive, sometimes it is not. For instance, when someone contracts pneumonia, they can have residual scarring of their lung tissue afterward, however it may not progress without another trigger. Many people contract pneumonia and get through it with no life limiting or life threatening damage to their lungs.

Unfortunately, many ILDs are pulmonary fibrosis of some type. Many of them are progressive. *(NOTE: There are over 200 types of PF.)*

If I am diagnosed with ILD, what should I do?

When your doctor says *"You have ILD"*, please do yourself the favor of beginning a dialogue with your doctor with the following questions:

- **Which ILD do I have?**
- **Is my ILD progressive?**
- **What is the treatment for my ILD?**
- **What is my prognosis?**

The answers to these questions are not the end of your research and learning. Once you have these answers, there is still much to be learned and follow up appointments to be made. This is just the beginning.

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Advocating to provide support for pulmonary fibrosis patients & families

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