Post COVID-19 Interstitial Lung Disease

Pulmonary Fibrosis Foundation™

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I had COVID-19, and now my doctor says I have ILD. What does that mean?

Interstitial lung disease or "ILD" refers to inflammation and/or scarring in the lung tissue. In ILD, it is the walls of the air sacs of the lung, and the tissue and space around these air sacs, where the injury and damage occur. Some interstitial lung diseases don't include scar tissue. When an interstitial lung disease does include scar tissue in the lung, we call it pulmonary fibrosis (PF).

The word "pulmonary" means lung and the word "fibrosis" means scar tissue— similar to scars that form on the skin from an old injury or surgery. So, in its simplest sense, pulmonary fibrosis means scarring in the lungs. Over time, the scar tissue may build up and block the movement of oxygen from inside the tiny air sacs in the lungs into the bloodstream. Low oxygen levels (and the stiff scar tissue itself) can cause people who have pulmonary fibrosis to feel short of breath, particularly when walking and exercising.

What are symptoms of ILD after COVID-19?

People with ILD after COVID-19 can experience a bothersome cough and breathlessness during exercise and daily activities. While some people may have worsening symptoms over time, others can have gradual improvement in symptoms, and still others can have stable but persistent symptoms. Fatigue, depression, and anxiety are also commonly experienced by people living with ILD after COVID-19.

It is important to note that symptoms of shortness of breath or cough following COVID-19 infection do not mean that a person has ILD. Persistent symptoms should prompt a medical evaluation for the cause.

What causes ILD after COVID-19?

COVID-19 pneumonia causes inflammation in the lungs. Inflammation in some cases can be followed by development of fibrosis, or scarring, in the lungs. People with more severe disease during the acute phase of their COVID-19 infection, specifically those who develop acute respiratory distress syndrome (ARDS) and require mechanical ventilation, are at the highest risk for developing PF. In many cases, the lung damage from ARDS will fully resolve over time, but in other cases permanent lung damage can develop.

The ways in which less severe COVID-19 infection causes ILD and PF are not clear. Studies are ongoing to understand this as well as risk factors for development of ILD after COVID-19. These studies may show if ILD seen in patients who have had COVID-19 is inflammation that improves with time, if it is fibrosis that does not improve but is stable, or if it is disease that continues to worsen over time.

What makes ILD after COVID-19 different from other types of ILD?

Respiratory symptoms of ILD after COVID-19 may be similar to those from other types of ILD, including breathlessness and cough. People with ILD after COVID-19 may experience additional symptoms of Post-Acute Sequelae of COVID-19 (PASC) or "long COVID", including heart palpitations, chest pain, or difficulty thinking and concentrating. Survivors of critical illness related to COVID-19 who had lengthy hospital stays often have prolonged recoveries and ongoing symptoms called Post-Intensive Care Syndrome (PICS), which can result in physical symptoms, such as muscle weakness, as well as emotional and cognitive symptoms.

How is ILD diagnosed after COVID-19?

People who develop pneumonia from COVID-19 will often have chest imaging, such as a chest X-ray or CT scan (also known as CAT scan), as part of their medical evaluation. Abnormalities on chest imaging or persistent respiratory symptoms after recovery from acute COVID-19 infection can be clues that ILD may be present.

In addition to reviewing chest x-rays and CT scans, a doctor or other healthcare provider who suspects that a patient has ILD might perform pulmonary function tests and blood work. Pulmonary function tests measure how much air the lungs can hold. The more scar tissue the lungs have, the less air they will hold. A doctor will also use a special kind of X-ray of the chest, called a high-resolution computed tomography (HRCT) scan, which shows detailed images of the lung. Healthy lung tissue looks nearly black on a CT scan, while scar tissue and inflammation both appear grey or white. In some cases, a diagnosis of ILD can be made from these tests and in others, a lung biopsy may need to be performed. Patients may be monitored over time to evaluate if the scarring or inflammation progresses, stabilizes, or resolves.

How is ILD treated after COVID-19?

There are no guidelines or completed clinical trials available to help clinicians make treatment decisions. Sometimes monitoring a person's disease without medication is appropriate. When inflammation is present in the lung (which can be seen on a CT scan or lung biopsy), steroid medications (such as prednisone) are commonly used. The antifibrotic medications pirfenidone and nintedanib, which can be prescribed to treat other forms of PF, are being studied in clinical trials of ILD after COVID-19. We do not know if these medications are effective to treat ILD after COVID-19.

Pulmonary rehabilitation, supplemental oxygen, smoking cessation, routine vaccinations (such as influenza, COVID-19, and pneumonia vaccination), and disease management by a specialist skilled in treating patients who have ILD are all important parts of living with ILD.

Learn more about supplemental oxygen at **pulmonaryfibrosis.org/oxygen.**
Learn more about pulmonary rehabilitation at **pulmonaryfibrosis.org/pulmonaryrehab.**
Find suggestions for maintaining your health at **pulmonaryfibrosis.org/myhealth.**
Search for PFF Care Center Network medical centers at **pulmonaryfibrosis.org/medicalcare.**

What is my prognosis?

There is significant uncertainty regarding the prognosis of ILD after COVID-19. Studies show that most survivors of severe illness from COVID-19 experience gradual improvement or stability, although they may have ongoing lung function impairment if they developed PF. It is not yet clear whether ILD after COVID-19 will improve over time, persist and be permanent, or result in progressive PF. Studies are ongoing to understand the natural history and risk factors for development of ILD after COVID-19.

Are there experimental therapies?

You can search for research studies closest to you on our PFF Clinical Trial Finder at **trials.pulmonaryfibrosis.org**.

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