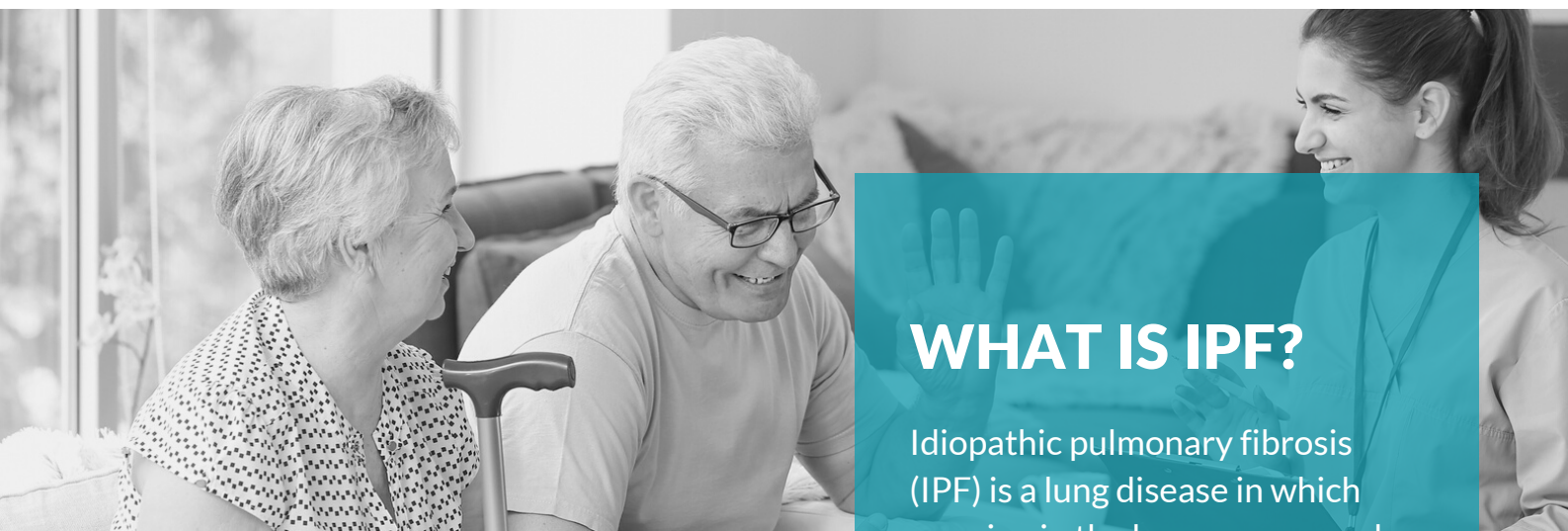




A guide to help you with your new diagnosis



WHAT IS IPF?

Idiopathic pulmonary fibrosis (IPF) is a lung disease in which scarring in the lungs occurs and the cause is unknown. It is part of a larger group of lung diseases characterized by thickening of the walls of the air sacs known as alveoli. As the disease progresses, the air sacs gradually become replaced by fibrotic tissue or scar tissue. As the scar tissue becomes thicker, it leads to stiffness in the lungs, making it difficult to breathe.

QUICK FACTS:

- IPF impacts 5,000,000 patients globally each year
- More than 132,000 US citizens have IPF
- More than 50,000 new cases are diagnosed each year

The Beginning of Your IPF Journey

A new diagnosis can be overwhelming and frightening. You may be looking for information and answers. You may be looking to get a jump start on treatment options. You may also be looking for others who know what you're going through.

What's Next?

You have options. Knowing what comes next can help you and your health care provider determine the next best steps in your course of treatment. The following are the options you should begin to consider as you move forward on your treatment path:

- Medical Treatment
- Pulmonary Rehabilitation/Oxygen Management
- Lung Transplantation
- Palliative Care
- Support for Patients and Care Partners

Medical Treatment

Pirfenidone (Esbriet®, Pirfenex®, Pirespa®) and Nintedanib (OFEV®) are two drugs, taken by mouth, approved to treat IPF in many countries around the world. These drugs help to slow the progression of mild-to-moderate IPF.

Several organizations have more information on Pirfenidone and Nintedanib as well as other medications that help to treat symptoms of IPF including the Pulmonary Fibrosis Foundation and the American Lung Association.

Pulmonary Rehabilitation/Oxygen Management

Pulmonary rehabilitation is a program of education and exercise that helps you manage your breathing problem, increase your stamina, and decrease your breathlessness. You will be educated on taking charge of your breathing--learning how to pace your breathing with your activities, how to take your medicines, and even how to talk to your health care provider.

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Oxygen is prescribed when oxygen levels go below about 88%. Your doctor may choose to measure your oxygen level in different circumstances: while sitting, while walking in the hallway or on a treadmill, and during sleep. If your oxygen level drops below about 88%, your doctor may prescribe supplemental oxygen to prevent your oxygen level from dropping further.

Lung Transplantation

Early evaluation for lung transplant is important because the process involves a series of appointments to provide the patient with information about transplantation and to determine if they are an appropriate candidate.

More than 15% of all lung transplants in the United States performed in Pennsylvania hospitals.

Palliative Care

Palliative care—also referred to as supportive care—is a medical treatment focused on relieving and preventing symptoms that are bothersome or distressing. Palliative care also helps you address advanced care planning, which allows you and your loved one to decide your goals of care as your disease progresses.

It is important to understand that you can also receive “curative care” at the same time. Curative care refers to participating in research studies, being evaluated for lung transplantation, and considering new medications. This is distinct from hospice care, which is treatment administered in the last months of life.



Transplant Centers within the state include:

- Penn Lung Transplant Center: www.pennmedicine.org
- UPMC Lung Transplant Program: www.upmc.com
- Temple Health Lung Transplant Program: www.templehealth.org

Support for Patients and Care Partners

Support groups can offer additional care and connection with those who share your journey and who can relate to what you're going through. In addition to helping put you at ease, talking with others who are in the same situation can help you to learn new information or ask questions you hadn't thought about. In addition to receiving additional information about IPF, studies have shown that participation in support groups helps patients and care partners feel less isolated and improves the outlook on their condition.

In addition to in-person support groups, many online communities exist where patients can connect virtually.

In affiliation with the Wescoe Foundation for Pulmonary Fibrosis.

Resources:

- Wescoe Foundation for Pulmonary Fibrosis: wescoefoundationforpulmonaryfibrosis.org/PA
- IPF Patient and Caregiver Support Network: paipfsupportnetwork.org
- Pulmonary Fibrosis Foundation: pulmonaryfibrosis.org
- American Lung Association: lung.org
- American Thoracic Society: thoracic.org
- CHEST Foundation: thoracic.org

PFF Care Center Network:

- Temple Health Lung Center: <https://www.templehealth.org/services/lung>
- University of Pennsylvania Pulmonary, Allergy, and Critical Care Division: <https://www.pennmedicine.org/>
- Jane and Leonard Korman Respiratory Institute at Thomas Jefferson University: <https://hospitals.jefferson.edu/departments-and-services/jane-and-leonard-korman-respiratory-institute/>
- Penn State Health Milton S. Hershey Medical Center, Division of Pulmonary, Allergy and Critical Care Medicine: <https://hmc.pennstatehealth.org/pulmonary>
- The Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease at UPMC: <https://www.upmc.com/>

Support Groups and Online Communities:

- PF Warriors: <https://pfwarriors.com/>
- Responsum for PF: <https://responsumhealth.com/pulmonary-fibrosis/>