



Understanding Pulmonary Fibrosis

Managing Progression in Pulmonary Fibrosis

Pulmonary Fibrosis (PF) may be a progressive illness, which means that it gets worse over time. This can be seen in people with idiopathic pulmonary fibrosis or other types of Interstitial Lung Disease (ILD). Although there is no cure for PF, there are various treatment options and management strategies to help stop or slow the progression of the condition and manage symptoms. Everyone is different, so no one can predict your individual experience or how quickly or slowly your PF may progress.

How can you tell if your disease has progressed?

Noticing your symptoms worsen is one of the key warning signs that your disease has progressed.

Your doctor will monitor your lung function (breathing tests) to look for sustained changes or worsened fibrosis, and they may confirm this with a high-resolution computed tomography scan (HRCT).

What can you expect as PF progresses?

Over time, your lungs may become more scarred, which makes it harder for them to work properly. As this happens, you may start to experience symptoms including:



Increasing breathlessness during everyday activities



Dry cough and discomfort in the chest



Tiredness and weakness



Loss of appetite and weight loss



Frustration, stress and depressive feelings



Decreased exercise capacity.

It is important to note that symptoms can vary according to changes in weather or during times of poor air quality such as bushfire season. These variations are common and may be transient, and are not necessarily indicative of progressive disease.

Getting help with your PF symptoms

There are a range of supportive treatments and pathways available to help you achieve the best possible quality of life:



There are now medications available that may slow the progression of the fibrosis. Depending on the type of PF these medications may include anti-fibrotics or immunosuppressants to reduce inflammation



Supervised exercise programs to help manage your breathlessness and to get stronger. These programs are called pulmonary rehabilitation



Oxygen therapy to help if your blood-oxygen level falls significantly when you are active or resting



Therapies to manage anxious feelings, frustration or low mood, which may include relaxation techniques, psychological counselling or medication



Advice from a dietitian if you are overweight or underweight



Clinical trials are essential for finding new treatment options for PF. Ask your treating specialist about PF clinical trials, or visit the **Pulmonary Fibrosis Australasian Clinical Trials (PACT) Network** for information about current trials



Lung transplantation may be a treatment option for some people with PF, but not suitable for others. Your specialist doctor will provide guidance on whether transplantation is an option for you



Your treating doctor may refer you to a palliative care service, also known as supportive care, to help manage your symptoms



Talk to your healthcare team so they can help you make suitable plans for how to keep doing things that are important to you. For example, travelling for holidays may be difficult with PF but it is generally possible with some help planning and preparing.



You might find it helpful to connect with other people in your situation. Lung Foundation Australia offers:

- Local support groups
- Online support groups
- Peer-to-peer connections.

Planning for the future

Although not an easy topic to think about or discuss, it is a good idea to make arrangements for your future so that your wishes are known. This will ensure you get the care you want when you need it. Such arrangements are known as advance care planning. Talk to your family and friends, or your treating team about your wishes.

Questions that you might want to discuss include:

- What can be done to help me if I become more breathless?

- What can be done to reduce any symptoms I might experience?
- Where can I find support for myself and my family or friends?
- What is palliative care?
- Where would I like to be cared for towards the end of my life?
- Do I want resuscitation if my heart or lungs stop working?

If you find it difficult to talk about these topics with your family, don't be afraid to ask for help from your treating physician or healthcare team. You might want to speak to a legal advisor about an Advanced Care Directive, Power of Attorney and appointing a medical treatment decision maker (Enduring guardian), so there are no uncertainties regarding your wishes for treatment.

Palliative care can be an important part of planning for the future with PF. It is about living as well as possible with your condition, and not only about end-of-life care. A palliative care team may include doctors, nurses, social workers and other healthcare professionals who work together with your treating doctors, and your General Practitioner (GP), to provide extra support when needed. You can read more about this in the **How can palliative care help you?** booklet.

Care at the end of life

It is common to experience more symptoms towards the end of life, but it doesn't mean that you will be distressed or suffering. Care can be provided to manage symptoms and ensure comfort in a variety of settings, including a hospital, hospice, nursing home or at home. You can work with your family, carers and healthcare team to choose the most suitable option.



FURTHER INFORMATION AND SUPPORT

Contact Lung Foundation Australia for more information, to access our support services and join our mailing list for regular updates and latest news.

Lung Foundation Australia Services

- Information and Support Team
- Lung disease information resources
- Education webinars
- Support groups
- Peer-to-peer connections

External Links

- Centre of Research Excellence in Pulmonary Fibrosis: cre-pf.org.au
- Pulmonary Fibrosis Australasian Clinical Trials (PACT) Network: pact.lungfoundation.com.au
- Pulmonary Fibrosis Foundation: pulmonaryfibrosis.org

We thank the individuals who contributed to the content and expert review of this fact sheet, in particular A/Prof Yet Khor, Respiratory and Sleep Physician.

Lungfoundation.com.au | Freecall 1800 654 301 | enquiries@lungfoundation.com.au

Note to reader: This information is intended as a general guide only and is not intended or implied to be a substitute for professional medical advice or treatment. While all care is taken to ensure accuracy at the time of publication, Lung Foundation Australia, the Centre of Research Excellence in Pulmonary Fibrosis and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided. Always consult with your doctor about matters that affect your health.