



Understanding Idiopathic Pulmonary Fibrosis

Managing Progression in Idiopathic Pulmonary Fibrosis

Idiopathic Pulmonary Fibrosis (IPF) is a progressive illness, which means that it gets worse over time. Although anti-fibrotic medications can slow down progression, they don't cure the disease. You may have read that the average survival is three to five years, but it's important to remember that this is an average. Everyone is different, so no one can predict your individual experience or how quickly or slowly your IPF may progress.

What can you expect as IPF progresses?

Over time, your lungs will 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 hacking cough and discomfort in the chest.



Tiredness and weakness.



Loss of appetite and weight loss.



Frustration, stress and depressive feelings.

You might find that your symptoms get worse if you have a chest infection or go out in hot or cold weather. Keeping track of these symptoms and discussing them with your treating team is essential to make sure you get help when you need it.

Getting help with your IPF symptoms

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



Medication to help with symptoms, such as morphine for breathlessness.



Oxygen therapy can 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.



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



Advice from a dietitian if you are overweight or underweight.

Your treating doctor may refer you to a palliative care service, also known as supportive care, to help manage your symptoms. Your palliative care team may include doctors, nurses, social workers and other healthcare professionals who will work together with your treating doctors to provide you with the extra support you need.

Travelling with IPF for holidays may be difficult, but it isn't impossible. Discuss this with your healthcare team so they can help you make suitable travel plans.



You might find it helpful to connect with other people in your situation. Ask your treating team about:

- **Local support groups.**
- **Peer to peer connections through Lung Foundation Australia.**

Planning for the future

Although it is not an easy topic, it is a good idea to make arrangements for your future. This is known as advance care planning. It is important to make your wishes known so you get the care you want when you need it. Talk to your family and friends, or your treating team.

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 this topic with your family, don't be afraid to ask for help from your treating team. You might want to speak to a legal adviser about an advance care directive or appointing a medical treatment decision maker, so there are no uncertainties regarding your wishes for treatment.

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
- Lung Cancer and Respiratory Support Nurses
- Support groups
- Peer-to-peer connections
- Referral to pulmonary rehabilitation and Lungs in Action exercise programs
- Inspired Living Newsletter

External Links

- Centre of Research Excellence in Pulmonary Fibrosis
www.cre-pf.org.au
- Pulmonary Fibrosis Australasian Clinical Trials Network
www.pact.lungfoundation.com.au
- Pulmonary Fibrosis Foundation
www.pulmonaryfibrosis.org
- Canadian Pulmonary Fibrosis Foundation
www.cpff.ca

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

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Centre of Research Excellence in
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