

Living with
Pulmonary Fibrosis

How can palliative care help you?



Centre of Research Excellence in
Pulmonary Fibrosis



Lung
Foundation
Australia

This factsheet is intended for people living with Pulmonary Fibrosis (PF) and their carers. Please bear in mind that it will not be relevant to all types of PF.

The idea of needing or receiving palliative care may be confronting, particularly when you are newly diagnosed. Decisions relating to if, when and how to engage with palliative care are personal and can be difficult. However, it may be useful to know that there are known benefits of involving palliative care early. This resource contains information, which along with advice from your treating healthcare team, will help you make choices which are the best for you and your situation.

Palliative care is a broad term used to describe the multidisciplinary approach to the care of people who have a life-limiting, incurable disease, including some types of PF. Some people with PF may benefit from palliative care because it focuses not just on your lung health but on you as a whole person, including physical, mental, emotional and social aspects.



Palliative care is about living as well as possible with your condition, it is not only about end-of-life care.

The goal of palliative care is to reduce your symptoms at any stage of living with PF and improve your quality of life. Palliative care is also about giving you more control over your end-of-life care decisions.

Starting palliative care

Palliative care can be started as early as you would like. It can even be started as soon as you are diagnosed alongside usual treatments for your condition. Palliative care can be provided to people of any age and at any stage in their disease. As your disease progresses, the type of palliative care you receive will change to suit your needs at the time. You don't have to wait for your treating healthcare team to suggest it, you can discuss the role of palliative care with them at any time.

To access specialist palliative care services, start by talking to your treating healthcare team or contacting the palliative care peak body in your state for more information.

You can receive palliative care in a range of settings, including your home, an aged care facility, in hospital, outpatient clinic or a palliative care unit. The palliative care team will work together with your treating healthcare team, including your GP and specialist respiratory team, to make sure you receive the best possible care.

Your palliative care team

With palliative care, you will engage with a whole team of healthcare professionals who will help optimise the care you receive, reduce your suffering and provide support to both you and your family. The members of your team will vary depending on what kind of support you need, but they may include:



Your dedicated team can also give you support over the telephone or via telehealth, or may visit you at home. They can help you with a variety of things along the way, including access to resources if you need them, such as wheelchairs or moving beds. Palliative care also supports carers and your loved ones in their caring role.

Components of palliative care

Palliative care can be separated into three key components: symptom care, end-of-life discussions and end-of-life care.



Symptom care aims to improve your quality of life by helping you to manage your symptoms. These may include:

- Breathlessness
- Cough
- Fatigue
- Anxiety
- Depression
- Loss of muscle strength.

Along with your treating healthcare team, the palliative care team helps manage worsened or new symptoms which may cause distress, such as:



Breathlessness

Your palliative care team may suggest a variety of treatments to help manage your breathlessness including physiotherapy and pulmonary rehabilitation where you will be taught breathing and relaxation exercises. There are also some medicines available that may help.

Your palliative care team can develop or update your breathlessness plan, which is individualised to help you and your carer during a breathlessness crisis.



Cough

Although cough can be difficult to treat, there are several options that your palliative care team may try such as a linctus or lozenges. Your palliative care team will talk to you about pharmacological treatment options and any side effects they may have.



Anxiety and depression

Your team may include a psychologist or psychiatrist who can help you cope with your condition and manage any feelings causing you distress.



End-of-life discussions give you the opportunity to talk about the future and the type of care you want towards the end of your life.

You can also talk about how and where you want to die and give instructions about whether or not you want to be resuscitated. Although it may be hard, you should make sure you openly discuss your decisions with both your treating healthcare team and your family and friends so that when the time comes, they can support the decisions which respect your values and preferences.

You can also record your decisions in official documentation as part of advance care planning. This may include an advance care directive, an enduring power of attorney, and a statement of choices which can cover, for example, your preferences for organ and tissue donation. The plan will be a written record of your preferences for your future care. You can record your goals, the outcomes you want and give direction about your care and treatments. You can also appoint a substitute decision maker for times when you can't make the decisions for yourself. Your treating healthcare team or palliative care team can help you with the advance care planning process.



Starting end-of-life discussions

Starting these conversations can feel difficult. Think about who you want to have the conversation with and choose a quiet setting where you will not be interrupted.

Although people may try to protect their loved ones by avoiding this topic, talking about these things can bring a sense of peace, shared understanding and help to relieve stress and worry about what the other person is thinking and feeling. Take your time and remember you don't need to talk about everything all at once.



End-of-life care aims to prevent or relieve suffering as much as possible while fulfilling the wishes you have expressed in your end-of-life discussions.

It is carried out in the last few weeks of life to help ensure you are as comfortable as possible and you receive care, dignity and respect.

Palliative care is about minimising your symptoms and living well with PF. It will help support you and your family through future care discussions and allow you to live your life as comfortably as possible.

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Information and
Support Team



Peer-to-peer connections



Lung disease
information resources



Referral to pulmonary
rehabilitation and Lungs in
Action exercise programs



Education webinars



E-newsletter



Support groups

EXTERNAL LINKS

Palliative Care Australia State
based members

palliativecare.org.au/members

Palliative Care Australia

palliativecare.org.au

Donate Life

donatelife.gov.au

Advance Care Planning Australia

advancecareplanning.org.au

My Values

myvalues.org.au

Pulmonary Fibrosis Foundation

pulmonaryfibrosis.org

Canadian Pulmonary Fibrosis
Foundation

cpff.ca

This resource was developed based on the 2020 'Understanding Palliative Care and Advance Care Planning' webinar by A/Prof Nicole Goh, Respiratory and Sleep Physician.

Produced in collaboration with:



Centre of Research Excellence in
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Freecall 1800 654 301

enquiries@lungfoundation.com.au

lungfoundation.com.au

PO Box 1949 Milton, QLD 4064



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