



Centre of Research Excellence in
Pulmonary Fibrosis



**Lung
Foundation
Australia**

Living with Pulmonary Fibrosis

Treatments beyond medicines

Feeling your best with pulmonary fibrosis doesn't just mean taking tablets. There are a range of treatments beyond medicines that help you to get the most out of living with pulmonary fibrosis.



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Managing your lifestyle

Managing your condition starts with looking after yourself. Your whole self - not just your lungs.



BE PHYSICALLY ACTIVE

Moving more and sitting less is essential to living well with pulmonary fibrosis. Regular physical activity can help you manage your symptoms and maintain your strength, fitness and mental health so you can continue to enjoy the things that are important to you.

Try to do some sort of physical activity every day. This might be a walk every morning or afternoon, or it could be spending some time in the garden or on the golf course. Anything you enjoy that gets you up and about.

- Pulmonary rehabilitation programs can be a great way to start incorporating exercise into your everyday life. Check out the pulmonary rehabilitation section in this booklet and talk to your treating healthcare team about getting started.

If you're not sure how much physical activity is right for you, or what type of activity to do, speak with your treating healthcare team for some advice.



NUTRITION

Maintaining a healthy, balanced diet is an essential part of managing your pulmonary fibrosis. Don't despair though, if you love the occasional bit of chocolate or fish and chips, that's still fine. It's important you continue to eat the things you love - as long as they are in moderation.

Grapefruit juice can interact with certain medications. If you are a fan of the fruit, or drinks containing grapefruit juice, make sure you talk to your treating healthcare team first.

Lost your appetite?

If you take medication for your condition, or suffer from regular breathlessness, you might find that your appetite decreases and eating large meals is a bit tricky. If this sounds familiar, there are some things you can do to help you feel more like eating and ensure you find it pleasurable.



Try spacing out your meals or eating smaller, more-frequent meals or even just making your food look more appealing on the plate. Talk to your treating healthcare team for some hints and tips that might work for you. You could also speak with a dietician about taking high-protein supplements or vitamins that may help.

It's important that you try and maintain a healthy weight. That means not being too overweight or underweight. Being overweight can lead to breathlessness, while being underweight or not getting enough nutrients from your food might cause your strength and fitness to decrease.



SMOKING

For people with pulmonary fibrosis, quitting smoking is the most important thing you can do to look after your overall health and lung function. You will get more out of your treatment if you are able to quit smoking.

Help is available. Talk with your treating healthcare team to get the support you need to help you stop smoking.



AVOIDING INFECTION

Chest infections may lead to acute exacerbations and deterioration in your condition, so it is important that you try to avoid infections altogether. Make sure you regularly wash your hands and maintain physical distancing. Tell your family and friends they should not see you in person if they are feeling unwell and avoid people who have an active infection. If you feel an infection coming on, seek medical advice quickly.



Vaccinations can also help protect you from preventable lung infections. It is an important part of looking after yourself. There are very few reasons why a vaccination would not be suitable for you, but make sure you talk to your treating healthcare team first.

Vaccinations you should discuss with your GP include:

- The flu vaccination, ideally just before winter each year
- Pneumococcal pneumonia vaccination
- COVID-19 vaccination
- RSV vaccination
- Whooping-cough vaccination

If you are starting immunosuppressive medications, you may be required to have the Varicella (chicken pox) vaccine first, so make sure you speak with your treating healthcare team. If you are considering travelling, you may also need other vaccinations.

For more information about preparing for travel when you are living with pulmonary fibrosis, see our factsheet here.

Don't avoid your vaccinations, even if you have experienced flu-like symptoms after a previous vaccination. In most cases, this was probably either a normal reaction to the vaccination or a coincidence that you developed the flu soon after the vaccination.



KEEPING TRACK OF YOUR OWN HEALTH

Part of looking after yourself is keeping track of your health. You know your body best, so you will know when something has changed or isn't quite right. Some symptoms of pulmonary fibrosis will get worse over time while others may remain fairly constant. Changes in your symptoms may mean your condition is progressing, which is why it is important for you to keep track. You might find keeping a diary helps you to follow any changes in how you feel. Apps or other more high-tech devices, like smart watches or phones, can help track your activity levels over time.

Symptoms you should watch out for if they get worse:



More breathlessness than usual, especially when doing mild physical activity



A cough that doesn't go away



Tiredness and generally feeling unwell



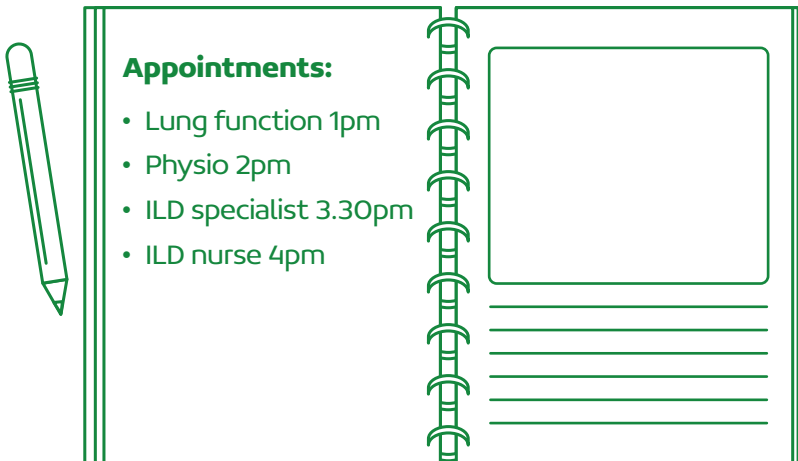
Gradual, unintended weight loss

Talk to your treating healthcare team if you experience any of these changes. Your healthcare team can provide advice about what you should expect at each stage of your condition and what you can do to manage it.



CO-ORDINATING YOUR CARE

If you have other conditions (known as co-morbidities) as well as pulmonary fibrosis, you might find you have multiple doctors' appointments at a range of times and days. If you are able, try co-ordinating your appointments so you can reduce your travel time and so your appointments intrude less on your everyday life.





WHAT IS OXYGEN THERAPY?

Oxygen therapy helps deliver extra oxygen to your lungs. Your doctor will determine if oxygen therapy will help you with your everyday life. Just like a normal medication, your doctor will need to write you a prescription that tells you what kind of oxygen device you need and how often you need it. Ultimately, the goal is to make sure that your quality of life is improved and your lifestyle is less affected by breathlessness from pulmonary fibrosis.



WHO CAN OXYGEN THERAPY HELP?

If you feel breathless either when you are at home or when you are out doing activities, oxygen therapy might help if you have low oxygen levels. When you see your doctor, they will do some checks to see if oxygen therapy is right for you.

- Incorporating oxygen therapy into your life may require some adjustment. Generally, people who try it find that it makes their life more enjoyable as it lets them do more for themselves. This can sometimes make you feel stronger and better.
- Oxygen can make exercise easier and you can use it while doing pulmonary rehabilitation.



WHAT ARE THE BENEFITS OF OXYGEN THERAPY?

Oxygen therapy affects different people in different ways, but generally for patients with low oxygen levels at rest, it may:

- Improve breathlessness
- Improve energy levels and help you stay active, alert and keep you moving
- Improve quality of life
- Let you do more in daily life including keeping up with your hobbies, getting to appointments and going out with friends and family.

Pulmonary rehabilitation



WHAT IS PULMONARY REHABILITATION?

Pulmonary rehabilitation can help everyone with pulmonary fibrosis, especially if you have symptoms such as breathlessness, fatigue or low levels of physical activity.

Pulmonary rehabilitation is a program of supervised exercise, education and support that is specifically tailored for you and aims to improve your physical condition, quality of life and mental wellbeing.

The programs usually last for eight weeks and you'll need to attend twice a week. You might find that it is like having your own personal trainer. The program is usually run in a group setting in a hospital outpatient department (face-to-face, or virtually), so you will likely be meeting with others with similar conditions.

Before starting pulmonary rehabilitation, you will undergo a thorough assessment to work out what exercises will best suit you. Depending on what your treating healthcare team recommends, pulmonary rehabilitation will include both endurance and strength training designed especially for you. Endurance training consists of walking on a treadmill or cycling on an exercise bike. Strength training includes arm and leg exercises with or without weights.



WHAT ARE THE BENEFITS OF PULMONARY REHABILITATION?

- Taking part in pulmonary rehabilitation can help improve your exercise capacity and quality of life by reducing your breathlessness and fatigue. It also aims to improve your activity levels and your muscle strength.
- Pulmonary rehabilitation can improve your confidence about exercise, especially because it can be difficult to exercise when you are limited by breathlessness. You will learn how to exercise safely and feel in control. These programs also provide a great opportunity to meet other people with a similar condition so you can learn from each other.



MAINTAINING THE BENEFITS AFTER PULMONARY REHABILITATION

Once you have completed pulmonary rehabilitation and experienced the benefits of exercise, it is important to continue exercising to help maintain your physical fitness and lung health.

Exercise tips

- Stay active – sit less, do more
- Walking every day is the best exercise – try bouts of at least 30 minutes, or two 15-minute walks, or three 10-minute walks [most days]
- Choose an exercise that you like to do – aerobic exercises include walking, swimming and cycling
- Strength exercises [3 days per week] include using hand weights, body weight or using Theraband
- When you finish pulmonary rehabilitation, the team can design a maintenance exercise program for you to continue.

To learn more about exercise and pulmonary fibrosis, access the resource here.



Lung transplant



WHAT IS A LUNG TRANSPLANT?

A lung transplant is a complex surgical procedure that involves replacing one or both of your lungs with those from a donor (someone who has died and agreed to donate their organs).



WHO CAN A LUNG TRANSPLANT HELP?

There are very strict criteria associated with receiving a donor lung and only some people will be suitable. Generally, someone with pulmonary fibrosis must be at the end stages of the disease or their quality of life must be significantly impaired before they receive a lung transplant (although the assessment process may start many years earlier). There are also a range of other medical criteria associated with your emotional health and the health of your other organs that are important to consider before you receive a lung transplant. If you would like more information on a lung transplant as a treatment for pulmonary fibrosis, make sure you talk to your treating healthcare team.



There are a series of steps you will need to go through to receive a lung transplant:

1. Transplant evaluation

You will be assessed to see if you fulfill the criteria and are physically and emotionally healthy enough for a transplant.



2. Join the waiting list

Your name will be added to the list for when a suitable donor becomes available. You will be required to see the transplant doctors regularly while waiting for a transplant to make sure that you remain suitable for the operation.



3. Waiting list priority

Your priority for a transplant depends on your match to the donor and how unwell you are. Waiting times can vary from 1 day to over 2 years.

Unfortunately, there are just not enough donor lungs in Australia for everyone who needs them. Only around 150 patients receive a lung transplant every year in Australia.



WHAT ARE THE BENEFITS OF LUNG TRANSPLANTATION?

A lung transplant can extend your life. Of the people who receive a lung transplant, most people will continue to manage their day to day life with few limitations and around 50% of people are alive after approximately 7-8 years.

For more information on lung transplant and pulmonary fibrosis, access the resource here.

Palliative care



WHAT IS PALLIATIVE CARE?

For some people with pulmonary fibrosis, your treating team may recommend a referral to a palliative care service. Palliative care is often misunderstood. Some people mistakenly think of it as pain relief at the end of life or as care in a hospice for people who are dying, but it actually offers much more than that. Often, palliative care can begin shortly after you are diagnosed and be a part of your ongoing long-term care. Ultimately, the aim of palliative care is to help relieve symptoms and provide support to you and your family so that you can go on living your best-possible life, while living with pulmonary fibrosis.

Palliative care is made up of three components and includes:

SYMPTOMATIC CARE

Symptomatic care is designed to help manage the symptoms of your disease. It can include a wide range of things depending on your individual needs, such as learning new strategies to relieve breathlessness through to organising help with household tasks, support for mental health or adjustments to your medical care.

FUTURE-CARE DISCUSSIONS

Future-care discussions allow you to talk openly about the future and plan the type of care you want (this is sometimes called advanced healthcare planning). If you are frightened or have questions about what will happen as your disease progresses, you can discuss this with your team. It's important that you openly discuss your options and thoughts with both your treating healthcare team and your friends and family.

END-OF-LIFE-CARE

End-of-life-care which helps to relieve suffering in patients with advance illness.



WHO CAN PALLIATIVE CARE HELP?

Many people with pulmonary fibrosis will benefit from palliative care – in fact, it is generally recommended that everyone with some sort of life-limiting disease is offered palliative care.



WHAT ARE THE BENEFITS OF PALLIATIVE CARE?

Palliative care can reduce the symptom burden you may be experiencing, improve your quality of life, reduce depression and give you more control over your end-of-life care. It can also benefit your carers by supporting them.

To learn more about how palliative care can help you, access the resource [here](#).



Alternative therapies

Some people with pulmonary fibrosis are interested in alternative and natural therapies to help their condition or reduce their symptoms. Most of these therapies haven't been scientifically studied before, so we don't know much about how they affect pulmonary fibrosis and if they make a difference or not.



Some types of alternative therapies can interfere with the other medications your doctor has prescribed for you, making them either ineffective or sometimes even toxic. It is essential to talk to your treating healthcare team before you start any type of alternative therapy.

Valuing your wellbeing and mental health

Your health is important, and it is more than just your lungs. Looking after your overall wellbeing, including your mental health, is an essential part of managing pulmonary fibrosis and living your best life.



SLEEP

Some people with pulmonary fibrosis struggle to get a good night's sleep. Try setting yourself up for a restful night by:

- Having regular bed and wake-up times
- Trying to do some exercise during the day
- Making sure your bedroom is dark so you are not disturbed
- Ensuring your room temperature, pillows and mattress are comfortable for you
- Having a regular bed-time ritual
- Trying some relaxation techniques
 - Try apps such as Calm or Mindset, or access our Mindfulness and Self-compassion video series developed for people living with a lung condition [here](#).

If you wake up feeling unrefreshed and/or experience snoring, gasping, choking or morning headaches, talk to your treating healthcare team as they might be able to help.



DEPRESSION, ANXIETY AND FEELING FLAT OR LOW

Feeling flat or low in mood are common in people with pulmonary fibrosis. Experiencing a range of negative emotions is a normal and natural response for people living with a chronic disease. These feelings tend to ebb and flow over time and generally only last a few hours or a few days at a time. When this happens, try to be kind to yourself and find ways to help lift your mood.

If you are suffering from feelings of depression, anxiety or feel flat and low for more than two weeks, it is important to talk to your treating healthcare team. Negative feelings that don't go away and have an impact on your everyday life can be managed in a variety of ways. Managing this does not necessarily mean taking tablets. You might want to consider treatments such as relaxation techniques, support groups or talking to a psychologist to give you some support and strategies to cope. Remember, however you are feeling, you are not alone and don't have to suffer in silence.



TIREDNESS AND FATIGUE

People with pulmonary fibrosis often suffer from tiredness and/or fatigue, so it is important that you understand your own body and how it varies from a good day to a bad one. Everyone is different, so you need to know what you are capable of and pace yourself to account for it. Allowing yourself to rest when you feel fatigue is important.

- You might want to consider pacing your activities. Rather than trying to do a lot in one day, stretch it out over a few days with plenty of breaks in between.
- Listen to your body. Resting when you feel tired will help you recover your energy faster and allow you to achieve more than if you just 'push through'.

If you think that you are feeling more tired or more breathless than usual, make sure you talk to your treating healthcare team. It could be the start of a flare up (acute exacerbation) or deterioration in your illness.



LOOKING AFTER YOUR RELATIONSHIPS¹

Some people find it challenging when their family or friends don't understand their disease – they may even make comments like “you don't look sick”. If you can, try not to take these comments to heart and just let them slide past you. Remember that it is important to maintain your relationships with your friends and family. You might find it hard, particularly in the beginning as you all come to grips with the disease, but you will feel better about yourself if they stay in your life.

If you have a partner, you might be wondering how pulmonary fibrosis will affect your relationship and your sex life, particularly if you experience breathlessness. The most important thing is to make sure you have an honest conversation with your partner about your concerns. Together, and perhaps with the help of your treating healthcare team, you should be able to come up with a plan on how to maintain your sex life and your relationship.



MAINTAINING YOUR IDENTITY

You are not your disease. You are not defined by it and it should not define what you do. You may need to make some changes to your life and activities, but you should continue to do the things you love (even if you now need to do them a bit differently). If your disease impacts your ability to work or to do your favourite things, it can be a blow to your sense of identity. Try focusing on the things you can still do and build your sense of purpose and identity that way.

Make sure you get advice from your treating healthcare team on ways you can continue living your life the way you want. They can help you set manageable goals to help you feel more like yourself.

¹Reference - Action for pulmonary fibrosis. Sex and living with pulmonary fibrosis. Available at <https://www.actionpf.org/information-support/sex-and-living-with-pulmonary-fibrosis>



Centre of Research Excellence in
Pulmonary Fibrosis

Funded in 2017 by the Australian National Health and Medical Research Council, the Centre of Research Excellence in Pulmonary Fibrosis (CRE-PF) aims to build research capacity in the area of pulmonary fibrosis. The CRE-PF enables a nationally coordinated, clinically focused research program to address the urgent need for more effective, personalised approaches to identify and better manage fibrotic lung disease, as well as to educate the public and train future generations of researchers in pulmonary fibrosis.

For more information on CRE-PF, visit cre-pf.org.au.



**Lung
Foundation
Australia**

For more than 30 years, Lung Foundation Australia has walked alongside people living with lung disease and lung cancer, helping them navigate some of life's hardest moments with care, knowledge and hope.

We provide trusted support through our nurses, peer support programs and social workers. We fund research that leads to better treatments. We speak out for people who need lung health to be taken seriously.

Everything we do helps protect the gift of breath, so that more Australians can breathe easier, live well and feel less alone.

Lung Foundation Australia collaborates with the CRE-PF, working together to drive patient and clinician involvement in pulmonary fibrosis research and trials via the Pulmonary Fibrosis Australasian Clinical Trials (PACT) Network and the Australasian Interstitial Lung Disease Registry.

For more information on PACT, visit pactnetwork.com.au.

EXTERNAL LINKS

Pulmonary Fibrosis Foundation
www.pulmonaryfibrosis.org

Centre of Research Excellence in Pulmonary Fibrosis
www.cre-pf.org.au/

Canadian Pulmonary Fibrosis Foundation
www.cpff.ca

CONNECT WITH LUNG FOUNDATION AUSTRALIA

Contact us to find out more and access additional information and resources and to connect with support services and guidance:

Lung Health Helpline (Freecall) 1800 654 301

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