

Lung transplant for Interstitial Lung Disease



Centre of Research Excellence in
Pulmonary Fibrosis



Lung
Foundation
Australia

What is a lung transplant?

A lung transplant is a complex surgical operation to replace one or both of your lungs with healthy donor lungs. A lung transplant has the potential to improve life expectancy and quality of life. If you have Interstitial Lung Disease (ILD), your doctor may discuss a lung transplant with you as a possible treatment option.

Why might I need a lung transplant?

Some ILDs cause your lung tissue to become thickened and scarred, known as fibrosis. Once your lung tissue becomes scarred, the damage cannot be reversed, and the more damage that occurs to your lungs, the harder it is for your lungs to function effectively. A lung transplant to replace damaged lungs may help you breathe easier and improve your everyday life. In certain ILDs, such as Idiopathic Pulmonary Fibrosis (IPF), referral to a lung transplant centre may be recommended early in the disease.

For people with ILD, a lung transplant can involve the replacement of either one or both lungs. There are pros and cons to receiving a single-lung or double-lung transplant, and for the timing of the transplant. Your doctor will discuss which option will suit you and your body best.

Where are lung transplants performed?



In 2021 **171 lung transplants** were performed in Australia.

In Australia, there are four centres that perform lung transplantation:



- The Alfred Program in Melbourne
- The Prince Charles Program in Brisbane
- The St Vincent's Program in Sydney
- The Fiona Stanley Program in Perth.

People from outside of these states will be referred to the closest program possible.

If you live too far away from the treating hospital or interstate, there are special arrangements that you will need to consider, such as costs for travel and accommodation, to allow you to be close to the treating centre before and after the surgery. This would usually be undertaken with the guidance of the transplant unit. They can also help connect you with services to support with reimbursement of some expenses if available to you.

What can you expect from a lung transplant?

It's important to know that complications associated with a lung transplant can be serious and sometimes fatal. Your transplant team will discuss all of the benefits and risks with you in detail so you can make an informed decision when considering if this treatment is for you.

Benefits

- Improved quality of life and increased life expectancy
 - Research shows that two in three people manage their day-to-day life with few limitations after three years.
 - Around 50% of people who have a transplant are alive after approximately six years.

Risks

- Surgical risks
- Transplant rejection
- Side effects from anti-rejection drugs
- Increased risk of infection
- Increased risk of other complications such as some cancers, hypertension, diabetes, kidney disease and gastrointestinal issues.

Who can receive a lung transplant?

If you and your doctor think a lung transplant may be a suitable treatment option for you, you will need to be referred to the lung transplant team to undergo a lung transplant assessment. As there are a number of factors that need to be considered before determining your suitability for a lung transplant, the assessment process will involve a comprehensive range of investigations. The assessment may discover health conditions or issues that will need to be addressed before determining whether you are suitable for a lung transplant. The whole process can often take many months to complete before being formally waitlisted for a lung transplant.

Eligibility assessment

- The stage of your disease and your chance of recovery post-surgery will be assessed.
- The transplant doctor/team will assess you for other health conditions that affect your suitability for a lung transplant, including:
 - **Absolute contraindications.** These factors mean you would not be suitable for a lung transplant and include:
 - Malignancy with high risk of recurrence or death from cancer
 - Untreatable issues with major organs other than your lungs
 - Some chronic infections (eg. active tuberculosis)
 - Repeated non-adherence with previous medical therapy without evidence of improvement
 - Lifestyle factors such as substance addiction, including any tobacco use, vaping, alcohol dependence and illicit drug use.
 - **There are some factors which may put you at a higher risk of poor outcomes following a lung transplant.** These factors may affect your suitability to receive a lung transplant and include:
 - Age over 70 years
 - Severe obesity or malnutrition
 - Severe or symptomatic osteoporosis
 - Severe coronary artery disease requiring bypass grafting at transplant
 - Significant cerebrovascular disease (conditions affecting blood flow and blood vessels in the brain)
 - Some chronic infections.
- You will need to undergo a series of tests known as the work-up process. Some of these tests may include:
 - Blood tests
 - High-resolution Computed Tomography (HRCT) scans or chest X-rays
 - Cardiac assessment, which may include a coronary artery angiogram (using X-ray imaging to view your heart's blood vessels)
 - 6-minute walk test, which checks your walking capacity and oxygen levels during exercise
 - Colonoscopy or gastroscopy
 - Sleep study.
- You will meet with a range of different healthcare professionals to assess your current health status and discuss the commitments involved in maintaining a healthy and active lifestyle post-transplant.

Some of the healthcare professionals that may be involved in your work-up assessment include:



Respiratory physician - To discuss the short and long term management that you will need to follow after receiving a lung transplant



Dietician - To assess your health and diet and help you prepare for any long term lifestyle changes



Physiotherapist - To discuss your fitness requirements and help get you started with pulmonary rehabilitation, which can help monitor your progression pre-transplant and help improve your post-transplant outcomes



Social worker - To explore and connect you with the appropriate support systems before and after your surgery



Cardiothoracic surgeons - The surgical specialists who perform your surgery

Waiting list registration

- After your work-up, a multidisciplinary team discussion will determine if you are a candidate for a lung transplant. If you are a candidate, you will then be registered on the lung-transplant waitlist. It's important to understand that you can be removed from the waiting list if your circumstances change.
- If you live too far away from the transplant centre or interstate, you may need to move closer while you are awaiting the transplant and remain there for three months or longer after the surgery.

Once you are on the list, the wait for a lung transplant can vary from days to many months. You will need to undergo regular monitoring by your healthcare team to ensure you maintain your health and strength during this time.

Maintaining your health and maximising your condition

It is important that you continue to look after your health whilst you are waiting for a lung transplant. This will help to maximise your current condition and give you the best chance of transplant success. There are a number of ways that you can do this including:

- Continue taking the medications prescribed by your doctor
- Keep up to date with your vaccinations
- Make sure you attend your scheduled medical reviews to stay in touch with your healthcare team and monitor your condition
- Participate in a pulmonary rehabilitation program and continue to maintain your fitness to improve exercise tolerance, reduce breathlessness, and improve quality of life
- Continue to manage other health conditions and follow the medical advice given to you to maintain your health. It is important to seek medical advice if new conditions arise
- Look after your mental health and wellness
 - Accessing a counsellor or psychologist can help you manage any stressors and emotions associated with the lung transplant journey
 - Access peer support groups to connect to others who know what you are going through.

To connect with peer support services, contact Lung Foundation Australia's Information and Support Centre on **1800 654 301** (option 3), or visit lungfoundation.com.au/PeerSupport.

What happens next?

When there is a possibility that a suitable donor lung has become available, you will receive a call notifying you of the next steps. Usually, you will need to make your way to the hospital straight away, where you will be prepared for the surgery. It is important to note that this does not always guarantee that lung transplantation will proceed, as suitability assessments on donor lungs will continue up until donation occurs.

During the surgery

- Lung transplants are performed by a team of specialists that include surgeons, anaesthetists, nursing staff and staff in intensive care.
- The time you will be in surgery varies, but it's usually between four and eight hours.

Post-surgery

- You will spend several days in the Intensive Care Unit (ICU) immediately after the surgery. Be prepared for a lot of medical equipment to be involved including a ventilator, drainage tubes, a urinary catheter and medications.
- As your condition improves, the equipment will be removed and you will move out of the ICU to focus on your recovery.

Recovery

- A whole team of healthcare professionals will be involved in your recovery.
- You will participate in physiotherapy programs (particularly to improve your upper and lower body strength) and you will need to be taking medications, including immunosuppressants and steroids aimed at reducing the risk of rejection.
- Before you can go home, you will need to satisfy certain requirements set out by your healthcare team. When you get home, you will continue to undergo frequent monitoring, especially during the first three months. This will include outpatient physiotherapy, clinical visits, bronchoscopies and blood monitoring.

Long-term life adjustments

- After receiving a lung transplant, you will need to make some changes to your life to ensure you achieve the best-possible results for you and the donor family.
- You will need to take immunosuppressants to prevent rejection for the rest of your life, along with some other medications and therapies.
- You will need to maintain your fitness through regular exercise and keep a healthy diet.
- It will be important to look after your mental health and seek support from family, friends and healthcare professionals when you need it.
- You will need to attend regular medical reviews and bronchoscopies to monitor your lung transplant. Monitoring of your health will be a life-long commitment to ensure you have the best outcomes following your lung transplant.

If you think a lung transplant may be an option for you, make sure you talk to your healthcare team. Your specialist doctor can provide guidance on whether transplantation is an option and whether you should be referred to your local lung transplant unit for further discussion and evaluation. Lung Transplant Centres in Australia are willing to review all referred patients, including, where there might be any uncertainty about suitability for transplantation.

LUNG FOUNDATION AUSTRALIA SERVICES



Information and Support Team



Lung disease information resources



Education webinars



Support groups



Peer-to-peer connections



Referral to pulmonary rehabilitation and Lungs in Action exercise programs



E-newsletter

EXTERNAL LINKS

Transplant Australia

www.transplant.org.au

Lungitude Foundation

www.lungitude.com.au

Donate life

www.donatelife.gov.au

We thank the individuals who contributed to the content and expert review of this fact sheet, in particular Dr Jeremy Wrobel, Respiratory and Lung Transplant Physician; John Price, patient and consumer advocate; and Dr John Mackintosh, Respiratory and Lung Transplant Physician.

Proudly sponsored by



**Boehringer
Ingelheim**



**Centre of Research Excellence in
Pulmonary Fibrosis**

Freecall 1800 654 301

enquiries@lungfoundation.com.au

lungfoundation.com.au

PO Box 1949 Milton, QLD 4064



**Lung
Foundation
Australia**