



TheAlfred

Information on

# Lung Transplant

A guide for prospective patients, their families and carers



The Alfred Hospital  
**Lung Transplant Service**

Level 5 Main Ward Block  
Phone: 9076 3600

## **INTRODUCTION**

Lung transplant is offered to patients who have severe lung disease for which other treatment options are no longer adequate. When this is first mentioned to you it may be a shock to think that you are sick enough for a transplant but it is important to think about this decision carefully and for us to have time to fully understand your medical and psychosocial situation. We feel that it is important for you to have a thorough understanding of the transplant process and to have realistic expectations of the outcome. We hope that this information book will help your understanding of lung transplant and to work with us towards a good outcome.

The Alfred Hospital commenced Lung Transplantation in 1990. Since then we have done over 890 lung transplants.

If you decide to consider transplantation you will be cared for by a small dedicated team of Physicians, Nurses and Allied Health staff. Once you have had a transplant you are looked after at the Alfred Hospital for life if you are Victorian, or by your state transplant service. To achieve the best outcome it is important that you establish good communication with the team so that we can support you in the best way possible.



## **MEETING THE TEAM**

Your first point of contact will be with a transplant doctor. This may be the first opportunity you have to ask questions about transplant and it can feel overwhelming. It is a good idea to bring a family member or friend for support and also so you have someone to talk it over with. You may also meet the social worker to give you some more time to ask questions and talk about how you feel. The social worker can also answer questions about some of the practical issues that may worry you.

Getting the timing right is often an important discussion. The two reasons for considering lung transplant are improving survival from lung disease and improving the quality of life for people with advanced lung disease. People have differing levels of tolerance for incapacity so the decision should take into account your feelings about your quality of life.

When you are ready to take the next step, which is to have a full assessment to determine your suitability for transplant, you may meet a Transplant Coordinator and Transplant Nurses.

## **THE ASSESSMENT FOR LUNG TRANSPLANT**

So that we can plan for the best treatment for you we need to have a thorough assessment of your overall health. So that we can do this most efficiently we usually admit you for two nights. There are three quite full days of tests and during this time you get the opportunity to meet all the members of the team. This is another opportunity for you to become more fully educated about the transplant process and to get some more detailed information of our expectations of your commitment to achieving the best possible outcome.

The medical assessment will look at your overall health such as your heart, kidneys, liver and bones so that any areas of concern can be addressed. The major concerns that would exclude the option of lung transplantation are if we find that you have any malignant disease or severe disease of other organs that cannot be improved with treatment.

## **(CONTINUED) THE ASSESSMENT FOR LUNG TRANSPLANT**

We will also want to get to know what sort of person you are, how you cope with stressful events and how we can best support you and your family through this time.

About two to four weeks following this assessment we will ask you to attend an out patient appointment so we can discuss with you what the team has recommended for you. This is a very good time to include all those people who are available to support you through your transplant.

**During your assessment, you will meet many members of the Transplant Team, including:**

### **RESPIRATORY PHYSICIANS**

You may not see your usual Physician during this stay but you will meet the Respiratory Registrar and Resident who will admit you to hospital and may do some of the blood tests. They are responsible for your medical care should you have any problems.

### **SOCIAL WORKER**

You will have time to have further discussions with the Social Worker about any psychological, social or family issues that are concerning you. It is important to achieving a good outcome from transplant to be as emotionally stable as possible and to have good family and social supports in place. If you need the support of our Consultant Psychiatrist we can make an appointment for you to see her also.

### **OCCUPATIONAL THERAPIST**

Occupational therapy assists you to maintain maximum quality of life by assisting you to maintain independence in the home and community. This is important while you are waiting and after the transplant as you return to suitable recreational and leisure activities, family responsibilities and employment.

### **PHYSIOTHERAPIST**

The Physiotherapist can help you to maintain or increase your level of physical activity and fitness during the waiting time. This will help your recovery after the transplant. While you are on the waiting list you are advised (and often expected) to attend an ongoing pulmonary

rehabilitation program, either at The Alfred or at a centre closer to home. The Physiotherapist will help you to arrange this.

### **DIETICIAN**

Prior to your transplant it is important to maintain good nutrition; this will support your recovery from surgery. Patients with lung disease face a variety of difficulties including poor appetite and weight loss, obesity, Diabetes management and high cholesterol. It is important that you stay within the healthy weight range, and the Dietician can support you to do this.

### **TRANSPLANT CLINIC NURSES**

The nurses in the outpatient clinic will be closely involved in your day to day care once you leave hospital. They will be your main point of contact if you have any questions or concerns about your recovery. They will provide you with education about your medications and care at home and will schedule any tests that you require as you recover.

### **LUNG TRANSPLANT COORDINATOR**

You will meet the Lung Transplant Coordinator once you have made the decision to have the assessment. They will coordinate the booking of your assessment.

### **SURGEONS AND ANAESTHETISTS**

You may not meet a surgeon preoperatively but the surgical team is involved in discussions of your assessment and in advising the best surgical approach to help you.

An anaesthetist will meet you to explain how they will support you through the surgery and help to manage your pain post operatively. They will assess you to ensure your anaesthetic care is safe and effective.

### **LUNG TRANSPLANT ASSESSMENT**

When you are admitted for your three day inpatient assessment, you will undergo a series of tests to gain as much detailed information as possible about your lung disease, and your overall health and condition. All of this information will be vital in assessing your suitability for transplant, and identifying issues which may need to be addressed to ensure the best possible outcome for you.

## LUNG TRANSPLANT ASSESSMENT

The tests you will undertake will include:

- Echocardiogram
- Lung function testing
- Urine tests
- Blood tests
- Ventilation Perfusion Lung Scan
- DEXA bone scan
- Dental x-ray

There may be other tests required, depending on your condition and any other health issues you have. Ahead of your admission, you will be sent an information pack outlining the details and a schedule for your admission. If you have any enquiries regarding your assessment, you can discuss them with the Transplant Coordinator.

### KEY POINT

Not all potential cases will prove suitable for successful transplantation.

## AFTER YOUR ASSESSMENT

At the end of your admission for assessment, you will be given an appointment to attend the pre-transplant Outpatient Clinic to discuss the results of your assessment, and your suitability for listing for transplant, and any issues which may have come to light in the course of your assessment. Further tests may still be required.

## MAKING A DECISION

When you make a decision to go on the waiting list for a lung transplant, you are making a LIFETIME commitment to adhere to the medical regime prescribed by the transplant team. This includes, but is not limited to:

- Regular visits to the Transplant Outpatient Clinic as required
- Taking your medications as prescribed
- Attending education and information sessions
- Notifying us of any change in your condition
- Adhering to a regular exercise regime
- Adhering to the diet prescribed for you
- Not smoking EVER again



It is vital that you understand the importance of cooperating with the team in your treatment and ongoing management. Especially when you have recovered and just want to get on with leading a normal life, you may not see the need to attend clinic on a regular basis.

However this is essential in ensuring that your health and function are maintained and supported at an optimal level.

## BEING LISTED FOR A TRANSPLANT

If you are to be listed for transplant the Coordinators will spend time with you and your family discussing the logistics of contacting you, getting you to the hospital and explain the blood tests that you need to have done regularly while you are waiting. You need to stay in contact with the coordinators to let them know of any changes in your condition or time away from home on holiday or in hospital.

## HOW THE WAITING LIST WORKS

The Waiting List can be a complex thing to understand, and it would be easy to presume that it is a simple numbered list and that people are transplanted in order. In fact, it is a much more complex and involved list. People on the list are categorised first into blood groups (A, AB, B and O). They are then ordered in accordance to sizing measurements such as height. There may be instances where you will see someone who has been listed after you, be transplanted before you. This can be a challenging and upsetting occurrence, but it is important to remember that there are many factors involved, for example they may not have even been the same blood group as you, and that the ultimate goal of the Transplant Team is to see that all people on the list receive the most suitable organs, and are given the best possible survival outcome.

## RECIPIENT / DONOR MATCHING

Some of the factors taken in to account when matching donors and recipients are things such as:

- Blood group
- Size of recipient and donor
- Compatibility tests between donor and recipient blood
- How sick a person is. A patient whose condition is deteriorating will be given priority where possible

Although all precautions are taken and all the appropriate tests performed, there remains a minimal risk of the transmission of viruses from donated organs. The risk of transmission of Hepatitis C is approximately 1 in 4000, for Hepatitis B it is approximately 1 in 250,000 and for HIV it is 1 in 1,000,000. Other disease could also potentially be transmitted.

Donor organs are usually offered by immediate family members of a person who has suffered irreversible brain damage and cardiac death, who have absolutely no chance of recovery from their injuries the condition which caused their death, and several senior Doctors not connected to the Transplant Unit will sign off on each case first.

### KEY POINT

The anonymity of the donor and the recipient is maintained at all times. You are not permitted to know who your donor was, nor are you permitted to contact the donor family directly.

We do encourage that you anonymously contact the donor family if you wish to extend your gratitude, and this can be done through the Lung Transplant Social Worker.

## THE WAITING TIME

Waiting time for a transplant varies greatly and it is impossible to give you a firm estimate. Factors such as your blood type and size will have an impact on your waiting time, for example, more common blood groups may encounter a longer wait, as there are more people of that blood type on the waiting list.

You should discuss this with the Respiratory Physician assessing you to discuss a realistic estimate of your waiting time.

While you are waiting for a transplant, you will be monitored approximately every six weeks in the pre-transplant Outpatient Clinic. This clinic runs on a Thursday afternoon on Level 5 of the Main Ward Block at the Alfred Hospital. This clinic allows you to meet and talk with the Transplant Coordinators, become familiar with the Doctors, and to allow the team to keep an eye on your health and your medical needs, to ensure that you are managed and kept as well as possible while awaiting your transplant.

We recommend that in this time, you also maintain contact with your GP and other Specialist Physicians as they will continue to be your primary carers until the time of transplant.

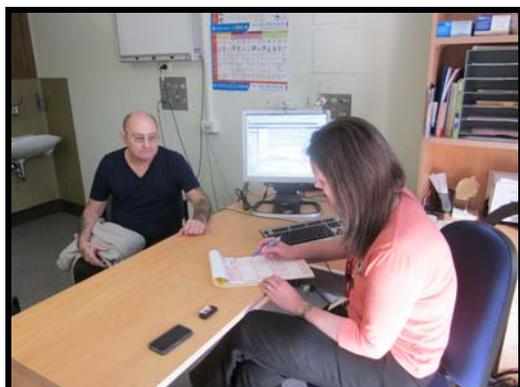
### KEY POINT

Monthly blood tests are required while you are waiting also, and this is a vitally important issue. We need to ensure that there is fresh blood available to cross match with any potential donors to check for compatibility in the event that organs become available which we believe might be suitable for you.



## PRE-TRANSPLANT EDUCATION AND INFORMATION SESSIONS

The Transplant Nurses and Coordinators arrange monthly education classes for people awaiting transplant. They will further discuss with you the classes you are advised to attend.



## CONTACTING YOU IN THE EVENT THAT TRANSPLANT MAY TAKE PLACE

It is important that we are able to contact you at all times, in the event that donor organs become available for you. We ask that you provide us with:

- All phone numbers for you
- Phone numbers of carers
- Updates on any changes in contact information

If organs become available and we believe that they are best suited to you, the Transplant Coordinator on call will phone you to advise of this, and to instruct you of what to do next. They will discuss with you the timing and manner of you attending the Hospital for preparation.

### KEY POINT

It is important that you discuss your action plan with your family and/or carers, so that you are as organised as possible when you are called to come in for your transplant.

When the Coordinator makes their initial contact to alert you to a potential donor being available, it is still relatively early in a long and complex process. The final matching may not yet have been completed between yourself and the potential donor, and the organs will not yet have been fully assessed by a member of the Transplant Team, therefore it is possible that the transplant may not go ahead.

Unfortunately, because of the time constraints involved with a transplant, it is often necessary to begin preparing you for theatre before this information is all available. Some people go through the difficult experience of a 'false start' so it is important to understand that it can happen and to be prepared for such an event. You will not be anaesthetised until we know that the organs are satisfactory and that the transplant is going to proceed.

### KEY POINT

If you are a country or interstate patient, the Social Worker will discuss arrangements for accommodation for you and your family at the time of your assessment. A plan will be put in to place ahead of your transplant.

## PREPARING FOR THEATRE

Preparation for theatre takes around two hours but can be much quicker if necessary. On arrival in the Ward, the medical staff will meet with you and will take a history and the Doctor will examine you. Blood will be taken, your chest shaved if necessary, and you will shower. You will then be given some medication before being transferred to the operating theatre.

A member of the Transplant Team may accompany you in to the operating theatre if you wish. Your family/carers may stay with you until you go in to theatre, before being directed to the waiting area, or they may return home for a few hours to wait.



## ANAESTHESIA

Time permitting; the Anaesthetist will see you in the ward before your transplant. Otherwise, you will see them in theatre. They will discuss with you the various procedures you may undergo before your anaesthetic,

### **ANAESTHESIA (continued)**

some aspects of the general anaesthetic and may also discuss aspects of post operative care and the management of post-operative pain. Procedures which may be done by the Anaesthetist before the general anaesthetic include placement of an:

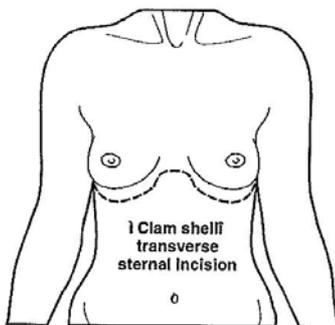
- **Intravenous drip in a neck or chest vein to give fluids or medicine**
- **Arterial line (a tube in an arm artery to measure blood pressure)**
- **Central venous line**
- **Epidural (a tube next to the spinal cord to give pain relieving medicine)**

The anaesthetist may also prescribe other medications depending on your needs.

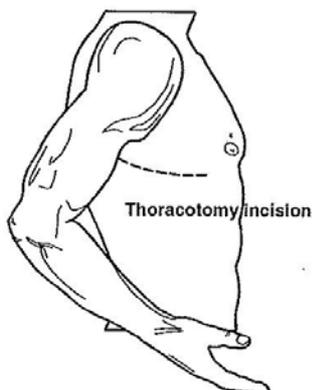
### **THE TRANSPLANT SURGERY**

The operation will generally take between five and 12 hours. When it is finished, one of the Transplant Team will usually visit your family if they are waiting in the Hospital, or will ring them at home to let them know the details of your operation.

Double Lung Transplant



Single Lung Transplant



Depending on whether you are to have a double or single lung transplant, your wounds and incisions may be of varied sizes. As you can see from the above diagrams, a double lung transplant requires a much larger incision. You should not have any scars from your incisions which will be noticeable when dressed, and this is often surprising to many people. After your lung or lungs are removed (one at a time for double lung transplants), the donor lungs are then placed in to your chest and the surgeons ensure that they are working satisfactorily before closing your incisions and preparing you to be moved to Intensive Care. Once your lung or lungs are removed, they are sent for pathological examination which may offer further information regarding your illness which led to you requiring the transplant.

### **POST-OPERATIVE RECOVERY**

#### **INTENSIVE CARE**

It is not uncommon for patients to have little, or clouded, memories of their initial time in ICU post-transplant. This is due to the heavy medications administered, and the fact that their bodies have undergone a major surgical procedure. For many family members the idea of ICU can be very overwhelming and some mistakenly associate ICU with there being a problem. While a person immediately post transplant will be in a critical condition, they are taken to ICU as a matter of course to ensure they receive the close monitoring and attention required to ensure that they have a successful recovery.

Family members will be able to visit you in ICU, usually within about an hour of hour return from theatre. Visiting hours are flexible in ICU, however they should discuss with the nurse caring for you the most convenient time for them to visit. The support of family is very important at this time but other visitors are restricted as patients tire very easily.

Upon arrival in ICU post-transplant, you will still be heavily sedated; though will slowly wake up within a few hours.

## **INTENSIVE CARE (CONTINUED)**

Initially you will have a number of tubes and attachments connected to you which will include things such as:

- **Heart monitor**
- **Intravenous lines and arterial line**
- **Urinary catheter**
- **Wound drains and dressing**
- **Epidural**
- **Breathing tube with extra oxygen**

This is to breathe for you until you are awake and strong enough to take over, and the time this tube is in place varies from patient to patient

Your pain relief will be monitored by the nursing and medical team, and it is important to notify them if your pain relief is not adequate. Your fluid intake and output will be monitored closely.

## **POST-OPERATIVE PHYSIOTHERAPY AND EXERCISE**

The Physiotherapist will visit you daily after surgery. As soon as you are able, they will assist you in moving out of bed (usually within the first few days) and then taking short walks, and commencing Physiotherapy to help you recover as quickly as possible.

Your full cooperation is essential to aid the expansion of your lungs and to avoid possible chest infections. Adequate pain relief is paramount to effective Physiotherapy. If you are finding that you are limited by pain, discuss this with your Physiotherapist, Nurse or Doctor as soon as possible.

Deep breathing exercises and strong effective huffing and coughing is very important and will aid a speedy recovery. Your level of Physio will be upgraded in line with your rate of recovery.

### **KEY POINT**

Ongoing exercise and Physiotherapy will be an important part of your ongoing management plan.



## **NUTRITION**

Whilst the breathing tube is in place, you will not be allowed to eat or drink anything; however you are expected to eat and drink normally once the tube is removed.

The Dietician will discuss your nutritional needs with you, and also food handling and hygiene issues.

## **TRANSFER TO WARD 5 EAST**

After leaving Intensive Care, you will be moved to the Respiratory Ward, 5 East. We advise you to keep visitors to a minimum initially, and that any person with an infection, cold, flu or other contagious illness must not visit you while they are unwell. At first, most of your care will be attended to by your Nurse; however as you become more mobile and feel well enough you will gradually be introduced to a program of self care. As you become more confident you can do more for yourself, and this will help you to feel more confident in managing your care when you leave hospital as well.

## **DISCHARGE FROM HOSPITAL**

You will be discharged from hospital when you are medically stable and when you have achieved independence with your self care, including administering your own medications. The average post-transplant hospital stay is between 2 to 4 weeks.

Upon discharge, you will be given an appointment to attend the Transplant Outpatient Clinic on level 5. In this clinic, you will be reviewed by one of the Doctors, and the Nurses will assist you in checking your dressings, taking bloods and other assistance as required.

### **LUNG TRANSPLANT CLINIC**

Initially, you will attend the Clinic at least once a week for review and these visits will become less frequent as your health stabilises and the Doctors are happy with your progress. The Clinic for newly transplanted patients (three months and less post-transplant) run on Monday and Friday mornings, and appointments will be made to fit in around your Physiotherapy program in the gym.

#### **KEY POINT**

As part of your rehabilitation program, you will attend the Transplant Gym sessions run on Monday, Wednesday and Friday mornings, as well as education sessions on Wednesday mornings. You will be given the schedule for Gym and Education before you are discharged from hospital.

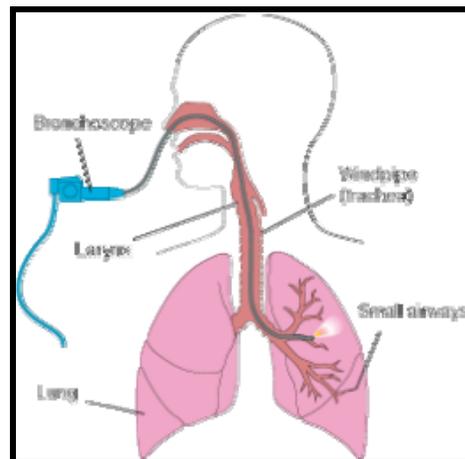
### **LUNG FUNCTION TESTING**

This will be performed regularly after your transplant, and is a way to keep an eye on your lungs, health and to map your progress. After three months post transplant, you will generally have a lung function at every clinic visit. You will also have a home meter, so that you can keep an eye on your lung function in between clinic appointments also. Any sudden, notable drops in lung function should be reported to the Transplant Clinic.



### **BRONCHOSCOPIES**

Bronchoscopies are performed regularly (up to seven times) within the first year post-transplant, and you will have one shortly after your discharge from hospital. Under light anaesthetic, a small flexible scope is inserted into your airways via the nose to look at the lungs and take biopsies to ensure they are healthy and functioning well. After the first year, you will not require routine Bronchoscopies however you may have them intermittently for monitoring or investigation.



### **BEING AWARE AND MANAGING POTENTIAL COMPLICATIONS**

#### **REJECTION**

Rejection occurs when the transplanted organ is attacked by your own immune system, and we endeavour to avoid this by managing you with immunosuppressant medicines. Sudden (acute) rejection is an occasional occurrence. This is treated by adjusting the immunosuppressant medication, and is closely monitored. There are instances where some patients develop a form of chronic rejection where their lung function will slowly deteriorate over time, however this too is managed with medication and close monitoring. Rejection is diagnosed via biopsy taken in a Bronchoscopy and measuring lung function.

#### **SIGNS AND SYMPTOMS OF REJECTION**

In most instances rejection is detected on biopsy before any signs or symptoms appear but some patients may experience changes in their wellbeing, such as feeling generally tired and unwell, a high temperature, rapid weight gain within 24-48 hours, nausea and loss of appetite.

A sudden drop in lung function, increased sputum production and chest tightness may also be indicators of possible rejection, however may also be a more simple infection. It is important that if you are concerned about new symptoms or a change in your level of function, that you contact the Clinic and speak to a Nurse and arrange an appointment to be reviewed.

### **INFECTION**

Infections are something all people can encounter; however transplant recipients are more susceptible to picking up bugs due to low immune systems in light of their medication. It is important that you avoid people you know to have an active infection (cold, flu, gastro) until they have recovered and are no longer contagious.

#### **KEY POINT**

Experienced Transplant Doctors and Nurses will follow up your health and treatment indefinitely.

### **PREVENTION OF INFECTION**

It is important to be alert but not alarmed by the idea of infection. Use of common sense and good hygiene practice will be helpful in preventing infection, and simple practices such as good hand washing, use of antibacterial gel, and good personal hygiene will be of benefit. You are encouraged to lead a normal lifestyle, although caution should be exercised.

### **VACCINATIONS**

Prior to your transplant you will need to have up to date annual flu vaccinations, Pneumovax (every five years), Polio boosters, Hep B vaccination, and all of these can be arranged through your GP. Following your transplant you will need to have two flu vaccines each year (six weeks apart). However, you must not have any vaccination containing a 'live virus' such as Measles, Mumps or Rubella. You should also avoid contact with anyone who has recently been vaccinated with the 'live' Polio Sabin or Typhoid vaccine for 10 days.

### **MALIGNANCIES**

Transplant recipients are more susceptible to malignant tumours and cancers than the general population. This is due to the immunosuppressant medication.

Skin cancers are the most common cancers in transplant patients, and therefore it is vital that you practice good skin care such as wearing sunscreen when exposed to the sun. In the event that any form of cancer is suspected or identified, the Respiratory Physicians will act quickly to investigate and ensure that the appropriate treatment is commenced as quickly as possible.

### **DIABETES**

Some patients may have Diabetes prior to transplant, whereas others can develop it post-transplant as a side effect of some medications. We have an Endocrinologist attached to the Unit who will be able to manage the care of any transplant patient suffering from Diabetes.

### **KIDNEY FUNCTION**

Staying hydrated is important in keeping you kidneys healthy, however many of your new medications can put strain on your kidneys. We have a Renal Physician attached to the Unit who you can see to manage any kidney problems, and to review you if required to ensure good kidney health and function.

### **COMMON SENSE ITEMS TO PROTECT YOUR HEALTH AND AVOID COMPLICATIONS:**

- Maintain good dental hygiene
- Discuss any potential surgeries or day procedures with the Transplant Team before proceeding
- Do not expose yourself to obvious, unnecessary sources of potential infection (eg, tattoos / piercings)
- Female patients should have routine pap smears and breast exams annually
- Avoid contact with people who are ill with infective illnesses (cold, flu, gastro, etc...)
- Be aware of any changes in your health and wellbeing, and discuss them with the Transplant Team and your local Doctor
- Take care of your skin with good sunscreen use and skin cancer risk awareness

## **MEDICATIONS**

Following your transplant there will be a number of medications you will be required to take to prevent rejections and maintain good health. It is important that you understand the effect of each drug and its potential side effects, and our Pharmacist and the Respiratory Physicians or Nurses will be able to discuss these with you in detail. Never under any circumstances stop taking any medication without specific instructions from a member of the Transplant Team. It is important that you do not miss a dose of medication if at all possible. If you realise you have missed a dose, you make take it if it is no more than six hours overdue, but do not double your dose. The use of any 'over the counter' medications (cold and flu tablets, herbal products etc...) must be discussed with a member of the Transplant Team before you take them. Likewise, if your GP wishes to prescribe you a new medication, please ask that they discuss this with a member of the Transplant Team.

It is important that you bring an up-to-date list of your medications with you to every Clinic and Hospital appointment.

## **MEDICATION COSTS**

While you are in hospital your medication is free. When you are discharged from hospital you will be given one month's supply of medication which will cost anywhere between \$50-\$300 depending on whether you hold a Pension or Health Care Card. You will be responsible for the ongoing costs for your medications.



## **REHABILITATION AND GETTING BACK TO NORMAL LIFE**

### **OPERATIVE WOUND**

By the time you are discharged from hospital, this should be healing well. However, it can take a number of months for the bones to heal completely, and it is normal to have some minor aches, pains or discomfort in your chest and surrounding areas. These aches and pains will gradually diminish as you heal. If the wound becomes discoloured or produces discharge, you should contact the Clinic.

### **MENTAL FUNCTIONING**

It is normal for patients to find that they have some difficulty with concentration and memory in the first weeks post-transplant. This will slowly improve as you recover. Tiredness is common after any surgery, particularly such a major operation as a transplant. It is important to remain physically active, but you should increase your activity slowly to begin with. You may also find your mood effected as you recover, and this is normal. Medications can affect your mood, particularly steroids such as Prednisolone, and you may experience mood swings which should settle. If you are struggling with your mood, please discuss this with a member of the Transplant Team, particularly the Social Worker.

### **EXERCISE**

For the first 12 weeks after your discharge, you will be attending the Transplant Gym three times per week. The Physiotherapist will also be able to provide you with instructions on exercises you can do at home to aid in your recovery. Your exercise program will change as you recover, and the Physiotherapist will guide you through this.

### **ONGOING EXERCISE AND FITNESS**

Ongoing exercise and fitness beyond the initial 12 week rehabilitation period are a major component to healthy recovery after transplant and you are encouraged to return to sport and physical leisure activities when able. If you have any questions about what exercise is suitable for you to undertake, or how to go about this, please discuss with the Physiotherapist.

### **DAILY ACTIVITIES**

Everyone differs in terms of the speed of their recovery, but it is important to get back to normal activities as soon as you feel able to do so. You can recommence light daily tasks (such as preparing food, washing dishes) as soon as you are home, and you should gradually introduce more tasks to your daily routine. Heavy lifting should be avoided for the first few months while your bones heal, as should the use of any vibrating machinery such as power tools or vacuum cleaners. Leisure activities can be recommenced as soon as you feel well enough.

### **SEXUAL ACTIVITY & PREGNANCY**

There are no physical restrictions on sexual activity, and sex can be resumed as soon as you feel able post-discharge. It is vital that female patients avoid pregnancy by using appropriate contraception, as pregnancy is very strongly advised against in transplant patients due to the very high risk of mortality for mother and baby. During the first six months post-transplant we advise that all patients use condoms to avoid the minimal risk that there may be transmission of newly acquired Hepatitis or HIV.

### **DRIVING**

Driving can be considered from roughly six-eight weeks post-discharge. You will be screened by the Occupational Therapist to ensure it is safe for you to resume driving.

### **SMOKING**

Smoking is detrimental to your overall health and well being, but especially your lungs. It is therefore absolutely forbidden.



### **RETURN TO WORK**

Return to work goals are usually addressed around four-six months post-transplant. The Occupational Therapist can assist you in establishing goals, and assessing your ability to return to work. Returning to work or re-training for a new role can be very helpful in assisting you to resuming a normal life post-transplant.

### **THANKING THE DONOR FAMILY**

This is something many transplant recipients or their families wish to do. In light of strict privacy measures and the need to maintain anonymity, there are guidelines which must be followed to protect everyone. You can discuss this with the Social Worker who will be able to assist you in passing on your letter. However, some patients prefer not to undertake this, and it is a personal and individual decision.



### **ACCOMMODATION INFORMATION FOR COUNTRY & INTERSTATE PATIENTS**

As our Unit caters to patients from Interstate and Regional Victoria, there are a number of accommodation resources available. The Social Worker is able to assist you in arranging accommodation if required. Please arrange to speak with the Social Worker about this issue as early as possible, to ensure a plan is in place ahead of your transplant.

### **THE BIG PICTURE**

A lung transplant is a complex treatment for end-stage lung disease, and will always carry risks as well as benefits.

Although our lung transplant team will try their hardest to work with you and your family to get the best from this therapy for as many years as possible, exactly how long each transplant will last is not possible to predict.



# The ALFRED TRANSPLANT FAMILY

## History

The Alfred Transplant Family is officially known as Heart and Lung Transplant Trust (Victoria) Inc. ('HLTTV'). It was originally formed in 1994 as the 'Family Fund', and was incorporated as HLTTV in 1998. Our vision is for a bright and active future for all those involved with or in need of a heart or lung transplant. We actively encourage organ donation and support the Alfred Hospital Melbourne, the Transplant Team, patients, recipients, their families and carers, throughout the journey.

We provide peer-based support for people who are waiting for, or have had, heart and/or lung transplants, and their carers. HLTTV works to identify the needs of the transplant community and the transplant services at The Alfred, and meet those needs through fundraising and the provision of practical assistance.

HLTTV is entirely volunteer run, and relies on membership fees and donations for all its activities. All volunteers are transplant recipients or their carers – HLTTV is run by patients, for patients. HLTTV is recognised as a health promotion charity and all donations to us over \$2 are tax-deductible.

## What help have we given the transplant clinic?

Some examples of the work of HLTTV are:

- Provision of exercise equipment to The Alfred gym
- Paying for refurbishment of the transplant clinic consulting rooms
- Purchase of additional IT equipment for The Alfred
- Provision of a 'quiet room' for families on the heart transplant ward

## What else do we do?

- [www.hlttv.org.au](http://www.hlttv.org.au) is our website, and our primary online presence. The website contains a lot of useful information for pre and post transplant patients and generates enquiries from around the world. We are also on Facebook and Twitter.
- '[The Circulator](#)' is our quarterly newsletter and keeps members up to date with current trends in medication, clinic happenings, activities with and by other transplant interest-groups, and any interstate news of interest.
- [Fitness Grants](#) are available to post transplant members to help maintain their fitness and wellbeing. Each Fitness Grant has an application and review process, with HLTTV reimbursing costs up to a \$150 maximum. Contact HLTTV to find out more.
- [Easter and Christmas Barbecues](#) are held every year to allow members to get together, share their transplant journeys and support each other. Keep an eye on the website, Facebook, or The Circulator for dates and locations. We also have other ad-hoc events from time to time.
- [Accommodation Program](#) HLTTV runs a subsidised accommodation program to help transplant recipients who are either from rural Victoria or interstate. Transplant recipients generally require daily post-operative outpatient treatment for 3 months following their transplant surgery. For many people, finding adequate, affordable accommodation in close proximity to The Alfred is extremely difficult. Contact HLTTV or speak to your transplant clinic social worker to find out more.

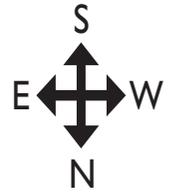
## How do I join?

Membership of HLTTV is open to people on the waiting list, post-transplant, their carers, or anyone who wants to support and keep up with the work of HLTTV. We have over 200 members from all over Australia, and always welcome new people into HLTTV and the heart and lung transplant community. Membership for pre-transplant patients is free. Visit our website [www.hlttv.org.au](http://www.hlttv.org.au) or pick up a form at the clinic.

# CAR PARKING & PUBLIC TRANSPORT GUIDE TO THE ALFRED



The Alfred



**40 School Zone**

**Moubray Street** 2 hour metered parking (both sides of Moubray Street)

Prahran Railway Station (Greville Street - 500metres)

Freemasons Homes

Moubray Lane\*

Fairfield House

Vision Australia

Engineering

Alfred Lane\*

Staff Parking

Staff Parking

WBRC Bunker

South Block William Buckland Radiotherapy Centre

Boiler Building

OLD BAKER BUILDING

CHILD CARE CENTRE

**NO RIGHT TURN IN OR OUT OF ALFRED LANE\***

THE ALFRED CENTRE Stage 2

UNDERGROUND\* VISITOR PARKING

Psychiatric Unit

Tynan Eyre MRI Unit

Centre Block

Main Ward Block

Monash University

Entrance Café

PATIENT PICK UP/DROP OFF ZONE

THE ALFRED CENTRE

MacFarlane Burnet Centre

Monash University & Ian Potter Library

AMREP Seminar Room

Baker Heart Research Institute

East Block

Philip Block

Café Courtyard

Out Patients (2<sup>nd</sup> Floor)

Main Entrance

Emergency/Trauma

Transit Lounge

Intensive Care

Annex

TAXI RANK

PATIENT PICK UP/DROP OFF ZONE

Helipad

Commercial Road

Bus 246

Punt Road

Bus 216, 219, 220

Tram 72

St. Kilda Road

Tram: 3, 5, 6, 16, 64, 67

Chevron

**Melway 58 B5**  
NOT TO SCALE  
\* New street names

\* x16 UNDERGROUND DISABLED PARKING BAYS (Visitors Rates Apply)



To find out more about changes in car parking arrangements at The Alfred visit The Alfred website at [www.alfred.org.au](http://www.alfred.org.au) or call (03) 9076 2000