

Heart Transplantation

PATIENT INFORMATION



TheAlfred

TRANSPLANT TEAM CONTACT NUMBERS

	Normal Hours	After Hours
TRANSPLANT CO-ORDINATOR	9076 3258	9076 2000
TRANSPLANT CLINIC NURSES	9076 3258	9076 2000
DIETICIAN	9076 3063	9076 2000
PHYSIOTHERAPIST	9076 3450	9076 2000
OCCUPATIONAL THERAPIST	9076 3526	9076 2000
SOCIAL WORKER/COUNSELLOR	9076 3026	9076 2000



CONTENTS	Page
Introduction	1
How the heart works	4
Assessment for transplant	5
The tests you will have	12
Being listed for a transplant	14
The waiting time	
Making a decision	
Recipient / donor matching	
The transplant operation	19
Orthotopic Heart Transplant	
Outpatients clinic visits	23
Medications	24
Types of rejection	26
Types of Rejection	
Detection of rejection	
Signs and symptoms of rejection	
Prevention Infection	29
Rehabilitation	31
Thanking the Donor family	36

INTRODUCTION

You have been given this booklet as you are going to be assessed for potential heart transplant. This booklet contains a lot of information and we would suggest that you take time to read the information and discuss with your family. If you have any questions please contact the Transplant Coordinators who will be happy to discuss things with you.

The Alfred Hospital Transplant Program commenced in 1989. Since then our team have performed more than 600 Heart Transplants.

We have a large team of Doctors, Nurses and Allied health professionals who continue to care for these patients.

The aim of this book is to give you and your family a clear understanding of the care you will receive prior to and after a heart transplant operation. It will provide you with information regarding what to expect during your assessment, whilst on the waiting list, through hospitalisation, on discharge home and your follow-up care.

This is in addition to education provided by members of the transplant team at the Alfred Hospital.

Normally, your first contact with the Alfred Hospital Transplant Program will be an appointment with the Cardiologist working with the Program.

The doctor will take a medical history, conduct a physical examination, discuss with you what is involved in having a heart transplant and answer any questions you may have. The cardiologist may also discuss other forms of heart failure treatment that may be considered for you

This is your opportunity to find out what is involved so that you can make an informed decision as to whether you wish to proceed with the formal assessment process. We recommend that you be accompanied by a family member or friend for this appointment. The timing of an assessment for transplant takes into account the severity of your illness and your quality of life. This is an individual decision. What also must be considered is the difficulty in finding suitable donor organs, taking into account your blood group, size and other matching factors. The individual and the medical team together must reach a decision about when to proceed to assessment.

HOME INOTROPES

When heart failure has progressed to a severe stage, inotropes may be required. An inotrope is a medication that helps a weak heart work better. This therapy is used to improve severe heart failure symptoms and can be used whilst a patient is awaiting a heart transplant. Once commenced and stabilized in hospital, inotropes may be continued at home. Inotropes are administered via a continuous infusion through a long term intravenous catheter placed under the skin into a major vein. This treatment is monitored by the Alfred's 'Hospital in the Home' program.

Inotrope therapy is not suitable for all patients. If your condition requires it, a senior member of the heart failure team will discuss this option with you.

VENTRICULAR ASSIST DEVICE PROGRAM

A ventricular assist device (VAD) is a mechanical pump that assists the weak heart to pump blood around the body. The VAD does not replace a person's heart. At surgery, the VAD is implanted into the chest and attached to the heart. The aim of the VAD is to improve the body organs' function, improve exercise performance, allow a patient to be discharged home and improve the quality of life.

The VAD can be used as a 'Bridge to Transplant'. This means it can help a patient survive until a donor heart becomes available for transplant. A VAD can also be used as 'Destination Therapy' which is an alternative to heart transplantation. Destination therapy offers long-term support for patients who are not suitable for heart transplantation. Destination therapy in Australia is currently only available as a clinical trial.

There are several types of VADs. A VAD may be used if one or both of the heart's chambers (ventricles) do not work properly. All VADs have the following parts:

- A tube that takes blood from the heart's chamber to the pump (inflow cannula)
- A pump that acts like a ventricle, pumping / pushing the blood out
- Another tube that returns the pumped blood to the artery leaving the heart (outflow cannula)
- A 'driveline' which connects the pump inside the patient to the power source and control unit outside the body
- The control unit monitors how the VAD is functioning, and gives an alert if the device is not working optimally
- The power source supplies the energy required to make the rotor inside the pump rotate



A VAD is not suitable for everyone. A senior member of the Heart Failure team will discuss with you whether this type of support meets your needs.

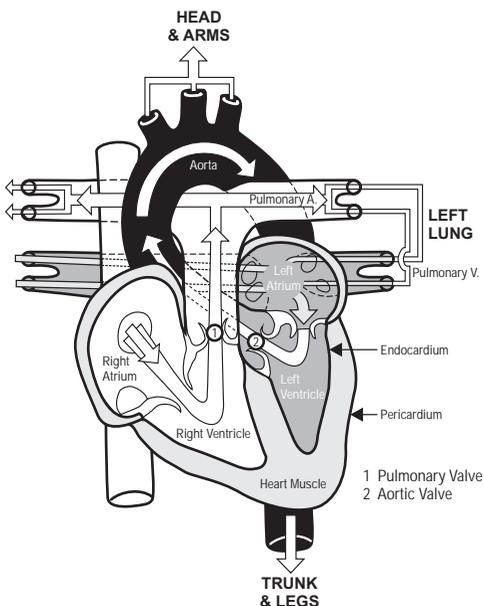
The Alfred Hospital has a comprehensive multidisciplinary team dedicated to caring for patients with heart failure who require the use of Ventricular Assist Devices. This team will provide extensive education for you and your loved ones about the device.

HOW THE HEART WORKS

Most people evaluated for heart transplantation have heart failure. Usually this has been long standing, but sometimes the diagnosis has been made recently. Heart failure develops when the pumping chambers of the heart contract poorly, and do not supply adequate circulation to the vital organs. Frequently, heart failure is caused by blockages in the coronary arteries which can lead to heart attacks in the past. At other times cardiomyopathy, a weakness of the heart muscle, develops as a result of a viral infection and damaged valves or other toxins. Prior to considering heart transplantation as an option, your condition will be treated with every possible means to make the heart work better.

This usually involves medications, but may include bypass surgery, valve replacement, implantable defibrillator or pacemaker insertion. Some people may benefit from using intravenous medication infusion with drugs that support the heart function (inotropes).

Mechanical heart (Ventricular Assist Device) insertion may also be considered. To better understand your heart condition, a brief review of the cardiovascular system is important.



The heart is divided into four chambers. Blood enters the heart at the right atrium and passes through the tricuspid valve into the right ventricle. The tricuspid valve keeps blood moving in a forward direction and prevents backflow of blood during contraction. From the right ventricle, blood is pumped through the pulmonary valve and pulmonary arteries into the lungs.

In the lungs, blood releases carbon dioxide, a waste product, and picks up oxygen. Blood then returns to the heart via the pulmonary veins into the left atrium. Blood crosses the mitral valve and enters the left ventricle, which is the main pumping chamber of the heart. From the left ventricle, blood is pumped across the aortic valve into the aorta. Blood is then distributed to remote regions of the body

by the arteries. The coronary arteries are the first side-branches of the aorta. They lie on the surface of the heart, and supply blood to the heart muscle. The right coronary artery provides blood to the right side of the heart and the bottom of the heart. The left coronary artery originates as the left main trunk, and supplies blood to the front wall of the heart via the left anterior descending artery, and the left lateral wall of the heart via the circumflex artery.

The heart rate is controlled by nerves which regulate the heart's internal pacemaker, the sinus node. The sinus node rhythmically discharges electrical impulses. These impulses spread through the heart via the heart's electrical system. This allows sequential contraction of the atria and the ventricles.

ASSESSMENT FOR TRANSPLANT



The very significant risk of undergoing heart transplantation necessitates a detailed evaluation. This is required to see firstly that a transplant is a feasible option and second, to make sure that your condition is severe enough to require transplantation and justify the substantial risk. You will undergo a large number of tests which look at not only your heart condition, but will also determine whether you have other conditions which would exclude you from being suitable for transplantation.

When all your tests are completed, the transplant team will decide on your suitability for transplantation. Not all people are suitable for organ transplantation. Continued smoking or significant alcohol intake, for example, will prevent you being considered for transplantation. If there is any other disease present, for example kidney disease or severe osteoporosis, you may not be suitable for transplantation.

You will be given an appointment to attend the Transplant Clinic where all the treatment options are discussed with you. We strongly recommend that you be accompanied by a family member or friend for this appointment. During your assessment, you will meet many members of the team including:



SURGEONS AND ANAESTHETISTS

The surgical team will help assess your suitability for transplant and discuss issues relating to the operative technique. The anaesthetist will assess you to ensure your anaesthetic care is safe and effective. He will support you through the surgery and help with post operative pain management.

PHYSICIANS (Cardiologists)

They are responsible for your assessment and ongoing care after the transplant. If you are admitted for assessment, they will be responsible for your care.

SOCIAL WORKER/COUNSELLOR - Psychosocial Evaluation

Thoughtful consideration of psychological issues is important to successful transplant surgery. A social worker will assess you and your family to determine the stresses facing you. Emotional stability and a supportive environment are important factors in achieving a successful recovery from the transplant operation. Your family play an important role throughout the transplant process and support from family and other important people in your life is essential. If we understand these important relationships in your life we are better able to assist you.

The information you give us during this assessment provides a basis for us to understand your strengths and how you cope with stressful events.

The social worker's role is generally a supportive one. The goal is to assist you and your family to achieve optimum functioning through the transplant process and if necessary to help you with appropriate lifestyle changes. He/She will also be able to assist and advise with practical difficulties of being away from home and work, such as finance, travel and accommodation.

At times of crisis, counselling is offered and can support you through difficult periods.

If you have had significant emotional difficulties in the past or have needed psychiatric treatment we will arrange a meeting with our consultant psychiatrist who can provide further assistance.

OCCUPATIONAL THERAPIST

Occupational Therapy assists you to maintain maximum quality of life by addressing your ability to cope with daily living activities both at home and in the community. Through the provision of equipment and/or use of energy conservation techniques, the Occupational Therapist will assist you in maintaining independence in these activities. Being on a transplant waiting list, coping with change and reducing levels of independence can be extremely stressful. The Occupational Therapist is able to assist you to develop stress management techniques and relaxation skills.

Following surgery, the Occupational Therapist can assist you in returning to suitable employment, recreational and leisure interests.



PHYSIOTHERAPIST

Physiotherapy aims to maintain/increase your level of physical activity and overall fitness in the 'waiting time' prior to your transplant. This will help you in your recovery phase post-operatively. An individual exercise program will be designed for you to specifically cater for your needs. This program includes stretches, various strengthening and aerobic exercise - all carried out in a monitored environment. The Alfred Hospital Physiotherapy Department runs classes three times per week. The Physiotherapist can otherwise refer you to an exercise program closer to your home. Other specific problems may also be discussed with the Physiotherapist. The Physiotherapist will discuss postoperative care (chest physiotherapy and mobility/ exercise) with you.

DIETITIAN

Prior to your transplant, it is important to maintain good nutrition to maximise your health and aid recovery. The Dietitian is available to assist you with your eating program or any problems you may have, for example:

- A poor appetite and/or you are losing weight.
- Excessive weight.
- High cholesterol.

Any queries or questions regarding the adequacy of your eating pattern.

Your Dietitian will contact you during your assessment or in the Outpatient Assessment Clinic.

NURSING STAFF

Nursing staff in the outpatient clinic will be involved in your care both prior to and after your transplant. They will participate in your education regarding the transplant process, in particular, rejection, infection and relevant medication and also assist clinically during your outpatient clinic visits after your surgery. The transplant nurse is available to help with any queries you may have both before and after your transplant.





TRANSPLANT COORDINATOR

The Coordinator will meet you when the decision has been made that you are to be listed for a transplant. He/she will explain to you how you will be contacted when donor organs become available, will discuss transport to the hospital and will explain the need for regular blood tests while you are on the waiting list and will advise you how to do this. The Coordinator must be advised of any change in your condition, location or admission to hospital. A coordinator is on call 24 hours a day, 7 days a week and can be contacted via the hospital switchboard.

TRANSPLANT REHABILITATION COORDINATOR

The Rehabilitation Coordinator is responsible for organising your involvement in the 8 week post transplant education program. The education classes are designed to teach you how to monitor your body for signs of Rejection and Infection after your transplant and the lifestyle changes that you will need to adhere to for a successful outcome. In addition to this program, a support group is available for all partners or care givers of transplant patients.

INFORMATION FOR INTERSTATE AND COUNTRY 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 and your family in arranging accommodation if required.

PASTORAL CARE

Chaplains, as members of the hospital team, are available to support patients, relatives and staff. Pastoral ministry enables people to share their stories, express their needs, if any and work with the chaplain to find the spiritual resource for addressing those needs. Specific denominational ministry is available on request as is after hours ministry. Please ask a nurse if you would like to see a chaplain.

THE TESTS YOU WILL HAVE DURING YOUR ASSESSMENT

ECHOCARDIOGRAM

Ultrasound of the heart measures size of heart chambers and thickness of heart muscle, it also detects blood clots in the heart and function of the heart valves.

GATED BLOOD POOL SCAN

This assesses the heart's pumping ability

CARDIAC MRI - with this test the cardiologist can

- examine the size of the heart chambers and the thickness of the heart wall
- determine the extent of cardiac muscle damage and effect on heart function caused by heart attack or progressive heart disease
- detect the plaque build up in the heart vessels
- assess recovery following treatment
- evaluate heart anatomy function, valve function and vascular blood flow in congenital heart disease.

LUNG FUNCTION AND EXERCISE TEST (VO₂ MAX)

This test assesses your cardiovascular fitness

24 HOUR HOLTER MONITOR

This portable monitoring device is used to document any irregular heart beats.

24 HOUR URINE TEST

This test assesses your kidney function

DEXA SCAN

Measures your bone density to diagnose osteoporosis

RIGHT HEART CATHETERIZATION

This is used to measure the pressure in the right side of the heart. This will help the cardiologists determine what type of heart transplant operation you require.



DOBUTAMINE THALLIUM HEART STRESS TEST

This test involves having a small intravenous injection of Dobutamine, a medicine which stresses your heart as if you were performing exercise. Following this, a series of scans will be performed to assess the heart's response to stress. The initial part of your test will take approximately 1-1.5 hours. You will probably need to have a follow up scan to assess how the heart responds to a period of rest. This is done 3-4 hours later and takes about 45 mins.

O.P.G. (Orthopantomogram) - dental Xray

This assists the dentist in checking your dental health.

BEING LISTED FOR A TRANSPLANT

THE WAITING TIME

Waiting time for transplant varies greatly and it is impossible to give you an estimate. Waiting time is influenced by your blood group, size and blood compatibility. You should discuss this with the cardiologist assessing you for a realistic estimate. You will be reviewed regularly in the Transplant Outpatient Clinic whilst you are waiting and we advise you to maintain contact with your own General Practitioner and specialist. If there is any change in your condition or you go into hospital during this time, you need to inform the Transplant Coordinator. Transplant education sessions will be conducted on a monthly basis for updating and reinforcing information while you are waiting for your operation. Monthly blood tests are also required while you are on the waiting list to ensure fresh blood is available to cross match with the donor for compatibility. You will be asked to sign consent forms for the following

- The anaesthetic and the transplant operation.
- Consent for cardiac biopsies after the transplant.
- Consent for tissues removed during the operation being used for medical research or used in other patients, e.g. heart valves.
- Consent that you are aware of the risks of contracting disease from donor tissue and blood.



MAKING A DECISION

When you make a decision to go on the waiting list for a heart transplant, you are making a lifetime commitment to adhere to the medical regime prescribed by the transplant team.

This includes:

- Regular visits to the Transplant Outpatients Clinic
- Taking your medications as prescribed
- Attending ongoing education and information sessions
- Notifying the clinic of any change in your condition
- Adhering to a regular exercise regime
- Adhering to the diet prescribed for you.

RECIPIENT/DONOR MATCHING

The matching of donor organs is a complicated process which takes into account:

- Blood group
- Recipient/donor size (some recipients require a larger donor heart to compensate for high lung pressures)
- Whether or not you have had Cytomegalovirus (C.M.V.)
- 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 transmission of viruses from donated organs.

Donor organs may be offered to the Alfred transplant programme from a number of hospitals in Australia and New Zealand. All donor organ referrals come through the Victorian State Donor Coordinator Network (Donate Life).

Donor organs are usually offered by immediate family members of a person, previously healthy, who suffers complete irreversible brain damage (brain death) from one of many causes which may include head injury sustained from a stroke, motor vehicle accident or work injury.

NOTIFICATION OF TRANSPLANT

The Coordinator will contact you when suitable donor organs are offered. At this stage, often the final matching has not been completed, nor has a member of the transplant team assessed the organs, therefore, it is possible that the operation will not go ahead. Unfortunately, because of the time constraints, 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 often happens and to be prepared for such an event. You will not be anaesthetised until we know the organs are satisfactory.

When the Coordinator calls you, he/she will discuss travel to the hospital and remind you that you should have nothing to eat or drink. He/she will advise you where you will be met when you come to the hospital, which will normally be in the Emergency Department. Here you will have a chest x-ray and be taken to Ward 3CTC to prepare for theatre.

Preparation for theatre takes approximately 2 hours but can be much quicker if necessary. On arrival in the Ward, you will meet a nurse and Hospital Medical Officer. They will take a history and the doctor will examine you. Some blood will be taken, you will be clipped and then have a shower.

You will be given some medication before being transferred to the operating theatre.

A member of the transplant team may accompany you into the operating theatre if you wish. Your family may stay with you until you go to theatre, then will be directed to the waiting area or they may go home for a few hours to wait.

The social worker will arrange accommodation for family of country and interstate patients.

OPERATING THEATRE

ANAESTHESIA

Time permitting, the Anaesthetist will see you in the ward pre operatively, otherwise, you will see him/her in theatre. The anaesthetist will discuss the various procedures you may undergo before your anaesthetic, 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 Infusion**

Local anaesthetic will be put into the skin before the intravenous cannula is inserted into a large vein, usually your arm.

- **Insertion of an Arterial Line**

This cannula is usually placed into the artery on the front of the wrist under local anaesthesia. It is used to monitor blood pressure and to withdraw blood for the many blood tests that will be required.

- **Insertion of a Central Venous Line**

These lines are usually placed into a vein on the side of the neck under local anaesthesia. These lines are used to monitor the performance of your heart.

The anaesthetist may also prescribe medication that includes:

- Antacid to neutralise the acid in the stomach so that vomiting is less of a risk.
- Anti nausea medication.
- Sedation.

If you have concerns about any of this information, it is possible for arrangements to be made for you to meet one of the anaesthetists to discuss them.

OPERATIVE PROCEDURE

The operation will generally take between five and eight hours. When it is finished, the Surgeon will visit your family if they are waiting in the hospital, or ring them at home to let them know the details of the operation.

If a member of the surgical team does not contact your family, please make an appointment with the Nurse Manager or Nurse in Charge to see the Surgeon.

THE TRANSPLANT OPERATION

The transplant operation takes between six and eight hours. The first part of the operation is to be prepared by a cardiac anaesthetist in the operating theatre. The transplant surgeon will then establish you onto the heart lung machine so that your old heart can be removed and the donor heart implanted. This type of heart transplant is called an orthotopic transplant and is the most common type of heart transplant performed at The Alfred. When the surgeon has completed the transplant operation the cardiac anaesthetist will transfer you to the intensive care unit.



POSTOPERATIVE RECOVERY

INTENSIVE CARE

After the operation, you will be taken to the Intensive Care Unit. Family members will be able to visit you there, usually within about an hour of your return from theatre.

Visiting hours are flexible in ICU, however you should discuss with the nurse caring for your relative the most convenient time to visit. The support of family is very important at this time but other visitors are restricted as patients tire very easily. Within a few hours of your return, you will slowly wake up. You will feel the tube in your throat and you may feel thirsty.

The tube is connected to a ventilator, the machine that does the work of breathing for you until you are awake and strong enough to take over. Often this will come out some time in the first few days but some patients will require support for a longer period. While the tube is in place, you will not be able to talk, eat or drink. From time to time, the nurse will apply suction to the tube to remove secretions. This is uncomfortable and makes you cough but only lasts for a few seconds. After the tube is removed, you will be given an oxygen mask to wear. Your throat may be sore and your voice a bit hoarse. This is common but gets better in a few days. You will be connected to a heart monitor. There will also be several intravenous lines going into your shoulder and arms and an arterial line into your wrist.



These allow staff to give you fluid and medications and are also used to monitor your blood pressure. The monitor is very sensitive and will pick up vibrations caused by body movement. Do not be concerned if you hear any alarms from the attached machinery.

One of the drugs given through these IV lines will be for pain control. If you are experiencing a lot of pain, let the nurse caring for you know so that she can adjust the dose to make you more comfortable.

You will have a urinary catheter placed into your bladder while you are asleep in theatre to measure urine output. You may sometimes feel that you wish to pass urine but this is just the irritation caused by the catheter. This will normally remain in place for two to three days.

The wound will be covered with a dressing and below it there will be several drain tubes. These will usually come out over the first week. Under the dressing there will be some temporary pacemaker wires. These allow the staff to connect you to a pacemaker box should your heart rate need to be increased temporarily. The wires will be removed at 10 to 14 days postoperatively.

It is very common for people to have nightmares and unreal sensations in the Intensive Care Unit and early post transplant period. These will reverse completely with re-establishment of a normal sleep pattern. Be reassured you are not going mad! Please let the staff know what you are experiencing.

Medication may be required if these sensations are causing a lot of distress.

PHYSIOTHERAPY

The Physiotherapist will visit you daily after surgery. Your full cooperation is essential to aid expansion of your lungs and to avoid possible chest infection. Adequate pain relief is paramount to effective physiotherapy. If 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. As part of your routine care, the nurse will change your position onto your side for short periods. This is important in aiding the lungs to expand fully.

You will begin arm and leg exercises from the first day to gradually increase your mobility.

It is most important that you repeat the breathing and limb exercises hourly when the physiotherapist is not around. Within a few days, you will be sitting out of bed and beginning short walks. These activities are gradually upgraded until you start a more active rehabilitation program in the gymnasium.

NUTRITION

Whilst the breathing tube is in place, you will not be allowed anything to eat or drink. For the first 24 hours after surgery, you will only be allowed ice to suck or sips of water. You may feel thirsty but drinking large amounts of fluid may make you feel nauseated. A strict record of your fluid intake and output is important.

During recovery from your operation, you may usually eat any foods you can tolerate. This will prevent weight loss, promote healing and protect against infection. You may, if you wish, have some foods brought in from home. Prior to your discharge, your Dietitian will help you plan healthy eating at home. He/she will also be available during rehabilitation sessions and outpatient clinic visits. The Dietitian will discuss healthy eating, your ideal body weight, blood fats (cholesterol and triglycerides) and the effect of the medication on your diet.

TRANSFER TO WARDS

You will be transferred from ICU to Ward 3CTC which is the Cardiothoracic Surgical Ward. Visiting hours are flexible in most wards.

We advise you to keep visitors to a minimum and prohibit anyone with an infection from visiting you. You will need a “rest period” during the day so your family need to understand this and allow you to rest.



At first, most of your care will be attended to by your Nurse. As you become more mobile and feel well enough, you will gradually be introduced to a program of self care. Your Nurse will teach such tasks as charting your own fluid intake and output; taking your medications and recording your weight. As you become more confident, you can begin to do them for yourself This will help you feel more confident when you leave hospital.

DISCHARGE

You will be discharged from hospital when you are medically stable and when you have achieved independence with your self care including your medications. The average hospital stay is around 2 to 4 weeks.



OUTPATIENT CLINIC VISITS

After discharge from hospital, you will have an appointment made to visit the transplant outpatient clinic in Ward 3F. Initially, this will be three times per week and then these visits will decrease as your condition stabilises

The transplant clinic nursing staff will perform your blood tests, any wound dressings or Intravenous medication required and make appointments for your regular biopsies and also for various tests that need to be performed to monitor your progress.

The clinic nurses can be contacted by telephone for any queries you may have after your discharge.

MEDICATION

All transplant patients require the administration of numerous medications to prevent rejection and maintain good health. It is important that you understand the effect of each drug and its possible side effects.

The normal function of the immune system is to protect the body against infections and cancers. It does this by recognising the organisms that cause infection as foreign, releasing chemical signals that bring other white blood cells to the area and then destroying them. This is known as the “immune response”. Unfortunately, your immune system also recognises your transplanted organ or tissue as not belonging to you and may try to destroy it as well. This is called **rejection**. The purpose of anti-rejection medication is to prevent this from happening. The time at which you are at highest risk for this happening is in the first few months after transplantation, with the risk reducing over time. However the risk of developing rejection always remains. Rejection may be acute (quick) or chronic (over a long period of time) and may be classified from mild to severe. It is essential that you always take your medication as prescribed, and on time, to reduce the chances of rejection developing.

Immunosuppression therapy protects your new organ from rejection, and missed doses of these drugs may expose you to the risk of rejection of your transplanted organ. It is important to continue regular blood tests to monitor both transplant function and the levels of immunosuppressive drugs in the blood. Rejection is usually always treatable. You may require a short stay in hospital for a biopsy and intravenous medication, and your current medication regime may require dose adjustment. At times an alternative medication may be introduced.

A variety of new, as well as tried and true immunosuppressive medications have been developed over many years, to become very specific in their actions in preventing rejection.

As with all medications, there are things you need to be aware of such as drug interactions and side effects. Before you take any new medications (including over the counter and naturopath medications) or alter your current medication, you must consult with your transplant doctor first. This is vitally important as any changes may seriously harm the health of your transplanted organ. You may be on as many as three different immunosuppressive medications in the early phase after your transplant, or as little as one in the long term. These will be prescribed on an individual basis, taking into consideration current medical concerns such as poor kidney function, blood counts, hypertension and previous rejection episodes.

The nursing staff and Pharmacist will help with self medication before your discharge from hospital and the transplant clinic nursing staff will again ensure a thorough knowledge of these drugs.

MEDICATION COSTS

While you are in hospital your medication is free. When you are discharged from hospital you will be given one months supply of medication which will cost between \$50 to \$300 dollars depending whether you have a Health Care Card. You should ask your Pharmacist about the Safety Net. Once your family reaches the safety net threshold, you can apply for a safety net card and your PBS medicines will be cheaper or free for the rest of the year. Please bring your Health Care Card and Medicare Card to the hospital when you are admitted.

REJECTION

The human body has a built in defence mechanism called the immune system. The immune system helps the body to destroy germs, such as bacteria and viruses, and helps to fight other diseases such as cancer. Lymphocytes are important components of the immune system. They are the white blood cells which are subdivided into B cell lymphocytes and T cell lymphocytes. The B cell lymphocytes make antibodies which kill germs. The T cell lymphocytes directly destroy foreign invaders. Unfortunately, the immune system views the transplanted organs the same way as harmful diseases, and attempts to destroy the organ as a foreign substance. Rejection occurs when the transplanted organ is attacked by the immune system. Without detection and intervention, the transplanted organ will be damaged and subsequently destroyed.

Following your transplant, you will be given three drugs to suppress the immune system to prevent you from rejecting your new organ. This will also make you more prone to infection so particular care is taken to prevent and treat infection.

Rejection is a common occurrence and it is anticipated that in the majority of patients, at least one rejection episode will occur. This will be treated by either increasing your doses of immuno- suppressive drugs or using additional drugs. You should reduce your exercise level for a short time while you are being treated for rejection.

TYPES OF REJECTION

A. HYPERACUTE REJECTION

This type of rejection occurs rarely. It is an immediate rejection that happens within the first several hours after transplantation. It occurs because the body has previously been exposed to the same or similar antigens (or stimulants) found in the donor organ. Antigens are proteins that stimulate lymphocytes to become active. Previous exposure to these antigens may have occurred through blood transfusion, pregnancy, or previous organ transplant.

The body's immune system reacts swiftly and strongly in hyperacute rejection. Because the immune system remembers the previous exposure, an instantaneous, sometimes overwhelming response occurs to the new organ, and failure can occur within a few hours.

Hyperacute rejection occurs rarely, because transplant recipients undergo testing to determine if they have preformed antibodies which place them at risk for this problem. This test is called a PRA (panel of reactive antibodies) test. We also do a cross match at the time of transplant.

B. ACUTE REJECTION

Acute rejection usually does not occur for several days after transplantation. Acute rejection does not occur immediately, because it takes time for the recipient's lymphocytes to realise that the transplanted organ is foreign, in order to mount a defence against it.

Drugs called immunosuppressives help to overcome acute rejection by blocking the immune system's reaction to the transplanted organ. Without immunosuppressive medications, transplanted organs would probably fail within 2 to 4 weeks as a result of acute rejection.

The chances of acute rejection are greatest during the first 6 months post-transplant. Most transplant recipients experience one or more episodes of acute rejection during this time. The chance of acute rejection diminishes with time and remains very low after the first year because of immunosuppressive medications and tolerance to the transplanted organ.

C. CHRONIC REJECTION

CORONARY ARTERY DISEASE (Heart Transplant) Coronary artery disease, a type of rejection, is sometimes called chronic rejection. It usually does not occur until several years after transplant. The coronary arteries develop progressive and diffuse narrowing throughout their entire length. The diagnosis is made by coronary angiogram or intravascular ultrasound. The mechanism of this problem is not fully understood, although considerable research is directed to prevention and treatment of this problem. Coronary artery disease may result in slow deterioration of organ function as a result of silent heart attacks, and eventually may cause failure of the transplanted organ.

DETECTION OF REJECTION

Rejection is diagnosed by taking a biopsy of some tissue from the heart and examining it under a microscope in the laboratory. These biopsies are performed on a regular basis following your transplant to detect early rejection.

The result of these biopsies will help the cardiologists to prescribe the right doses of immunosuppressive medication for you.

You will have around 12 biopsies in the first year after your transplant.

CARDIAC BIOPSY

This is performed under local anaesthetic through a vein in the side of the neck. The procedure is performed under x-ray control and takes about 10 to 30 minutes. They will be performed weekly for 6 weeks following transplant then less frequently throughout the first year, depending on the amount of rejection you experience.



SIGNS AND SYMPTOMS OF REJECTION

In most instances, rejection is detected by biopsy before any signs or symptoms appear but some patients may experience changes in their wellbeing, for example:

- Feeling more tired than usual.
- Shortness of breath and decreased exercise capacity.
- Weight gain (particularly more than 2 kg in 24 to 48 hours).
- Temperature more than 37.5°C.
- Abdominal discomfort or pain.
- Fast or irregular pulse rate.
- Nausea and/or loss of appetite.

Any of these symptoms should be reported immediately to the transplant outpatient clinic on 9076 3258. Out of hours, contact the hospital switchboard on 9206 2000 for the Heart Transplant Registrar.

SIGNS AND SYMPTOMS OF INFECTION

- Fever - temperature more than 37.5°C
- Sore throat
- Night sweats
- Shaking associated with feeling unwell
- Coughing, either a dry or productive cough
- Burning sensation when passing urine
- Shortness of breath
- Persistent headaches

Any of these symptoms should be reported immediately to the transplant outpatient clinic on 9076 3258 or out of hours contact hospital switchboard on 9076 2000 for the cardiology registrar on call.

PREVENTION OF INFECTION

Do not become obsessed by infection, but use common sense every day. Good hand washing, cleanliness and personal hygiene are the keys to preventing infection. During the post transplant hospital stage, visitors will be asked to wash their hands thoroughly before visiting. Visitors who have a cold or other signs of infection should avoid visiting until they are healthy. After hospital discharge, avoid crowded environments and anyone who has a cold or active infection. Don't use public transport for six weeks after your operation and then try to use it at non peak times. You are encouraged to lead a normal lifestyle, although caution should be exercised in some areas, e.g.

- Don't eat shared finger food (e.g. bowls of nuts or chips) or share eating utensils or cups and glasses.
- Wear gloves when gardening.
- Wash your hands after handling pets, don't let pets sleep on your bed and wear gloves when cleaning bird cages and cat litter.
- Don't use a public swimming pool for 3 months after your operation.

VACCINATIONS

Prior to your transplant you should have:

- an annual flu vaccination
- the Pneumovax vaccine which only needs to be given every 5 years this is to protect you from contracting meningococcal pneumonia
- Hepatitis B vaccination

These can all be arranged by your local doctor.

Following transplant you must still have an annual flu vaccination but you will need two vaccinations 6 weeks apart. Because you are immunosuppressed you will not achieve immunity with one dose of the vaccine.

After your transplant you must not have any vaccination that is made from a "live" virus, e.g. Measles, Mumps, Rubella, B.C.G., Yellow fever vaccine, Polio Sabin (oral), Typhoid (Typh-Vax oral)

BODY PIERCING AND TATTOOING

These are not advised following transplant due to the increased risk of infection.

DENTAL HYGIENE

You must have regular 6 monthly dental check ups after transplant and maintain good dental hygiene.

PAP SMEARS & BREAST EXAMINATION

All female transplant recipients should have annual gynaecological check ups, breast examination and pap smears.

MALIGNANCIES

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

Skin cancers are the most common tumour in transplant patients. Sun exposure is the major risk factor. Always wear a sunscreen preparation on exposed areas when outdoors in bright sunlight. Wear a broad-brimmed hat and protective clothing to avoid this problem. Skin cancer should be excised by a Dermatologist when detected.

If any form of cancer is suspected or identified the Physicians will act quickly to investigate

REHABILITATION

On discharge from hospital, you should be independent in managing your personal care.

THE WOUND

The wound is securely fastened at the time of surgery and by discharge it will be healing well. However, it takes 2 to 3 months for complete healing of the bone and wound and as you begin to do more, you may feel unusual aches and pains in the muscles of the chest and in the shoulders, neck and back. These pains will gradually diminish but may need pain relieving tablets in the early days. You will be prescribed these before you leave hospital.

No special treatment should be needed for your chest wound. This may be washed with unperfumed soap and water as usual. If the wound becomes discoloured or discharges, you should contact the transplant clinic.

CONCENTRATION AND MEMORY

Patients frequently notice difficulty with their memory and concentration in the weeks following surgery. This slowly improves and over a period of two to three months should return to normal.

TIREDNESS

This is common after all forms of surgery. You should increase your activity slowly, avoiding sudden bursts of activity such as running or climbing stairs quickly. As a general rule, physical activity is good for your heart and lungs and the recovery of muscle strength.

MOODS

It is common to have mood swings after major surgery and these can be most pronounced around the time of discharge. The drugs, particularly Prednisolone, can also have an effect on mood. If they persist or you feel they are effecting your recovery, please talk to the Clinic Nurses, your doctor or your Social Worker.



EXERCISE

The Physiotherapist will give you guidelines for exercise for when you return home. You will continue to attend physiotherapy three times a week following discharge, until you have reached a good level of fitness. You will be given a program to follow at home. You should keep the following guidelines in mind:

- Avoid extreme temperatures.
- Do not begin to exercise if feeling unwell or you are having an episode of rejection.
- Begin exercise when you are rested.
- Cease exercise if you feel dizzy, light headed, faint, cold sweat, nausea or chest pain. Lie down and check with your doctor.
- Always warm-up and cool-down by walking slowly for 5 minutes and stretching your muscles. Your Physiotherapist will advise you on appropriate levels of strength, endurance and flexibility for a safe return to sport, work and leisure interests.

ACTIVITIES

Each person varies a great deal in their rate of recovery and you should use your discretion as to what you are capable of doing. If you are concerned about undertaking any activity, consult your Occupational Therapist or your Physiotherapist. In the first few days following discharge, you will probably tire very quickly and may need to limit visitors. You will benefit from a rest during the day. Light daily tasks should be commenced within the first week, e.g. folding light washing, making a cup of tea/ snack, washing dishes. Gradually introduce more tasks into your daily routine. You will need to be aware of your individual level of physical endurance and grade the introduction of tasks appropriately, which your Occupational Therapist can guide you with. Major restricting factors for participating in domestic tasks are usually muscle fatigue, poor endurance and lack of confidence. Due to the time required for the wound and bone to heal, you should avoid lifting heavy weights, for example anything heavier than a full kettle or moving furniture for two months after the transplant. Use of heavy vibrating machinery, e.g. vacuuming, lawn mowing, power tools, should be avoided for 3 months after surgery.

RETURN TO WORK

Return to work or vocational goals are usually addressed from 4 to 6 months post transplant. The Occupational Therapist can assist with establishing goals, assessing your ability to return to work and establishing a graded return to work program.

For those receiving Disability Support Pensions and other social welfare payments your entitlement can be reviewed randomly at any stage pre or post transplant by the Department of Social Security. This is undertaken in consultation with the treating staff. Reviewing your entitlements is based upon your medical and functional status. Recommendations may include; continuation of current payments, transfer to alternative benefits, referral to a vocationally based rehabilitation program. The Department of Social Security, Commonwealth Rehabilitation Service and Commonwealth Employment Service offer comprehensive assistance with retraining and return to work.

DRIVING

Return to driving is considered from six to eight weeks following discharge from hospital. At this stage, a screening assessment is conducted by the Occupational Therapist, addressing concentration, memory, physical endurance and visual acuity.

You will be required to notify your insurance company of the change in your medical status following transplant and they may require a doctors letter stating that you are safe to return to driving.

SEXUALACTIVITY AND PREGNANCY

There are no physical restrictions on sexual activity. They may be resumed after discharge from hospital. Women should avoid the risk of pregnancy by using an appropriate contraceptive method. Generally, pregnancy following transplantation is not advised. Please discuss this with your doctor.

During the first 3 months after surgery, we advise that all patients use condoms during intercourse to avoid the very small risk of the transmission of diseases. Although there has been no incidence of HIV transmission during transplantation in Australia, there have been some cases of Hepatitis transmission from the donor or from blood products to transplant recipients. We repeat blood testing routinely at 3 months after your Transplant.

If you are having any problems, please feel free to discuss these with the transplant staff.

SKIN CARE

Immunosuppression has the capacity to increase your sensitivity to the sun's rays. This in turn can cause increased skin damage and subsequent skin cancers. It is extremely important that you apply an SPF 30 sunscreen lotion whenever you are outside (winter or summer), wear a wide brimmed hat and do not expose your arms and legs unnecessarily to the sun.

SMOKING

Smoking is detrimental to the health of our heart and lungs, particularly in the case of newly transplanted organs. Smoking therefore is absolutely forbidden.

REHABILITATION PROGRAM

A comprehensive rehabilitation program has been designed for you. At the time you are discharged from hospital, you will be given a folder explaining the program content.

Rehabilitation sessions are conducted on one morning each week involving you and your family or close friends. The sessions cover an eight week course. Each session runs for one hour. The content covers medications, rejection and infection, nutrition, physiotherapy, occupational therapy and social and emotional issues. At the end of each seven week program, longer term patients are asked to return to share their experiences with you.

Your commitment to look after yourself after transplant is important for a successful outcome after surgery. Keeping this commitment will require that you do the following:

- Take all your medications as prescribed by the doctors.
- Keep all your medical appointments including clinic visits and biopsies.
- Call the transplant team about potential problems.
- Do not abuse your body by smoking, drinking or using non prescribed drugs.
- Adhere to dietary guidelines and restrictions as instructed by the dietitian.
- Adhere to exercise guidelines as prescribed by the doctors and physiotherapist.

THANKING THE DONOR FAMILY

During your recovery, you may wish to take time to write a short note of thanks to the donor family. Many donor families have found that receiving a letter from the recipients of their relative's organs is a great comfort.

If you do choose to write to the donor family, you need to be aware that guidelines exist that prevent identification of both the donor family and the recipients.

You can tell the donor family about your:

- Age
- Gender
- Immediate or extended family (no names)
- Course of illness and need for a transplant
- Impact of the transplant on yourself and your family.

Some information is confidential and should be avoided in your letter:

- Names, just signed "*Transplant Recipient*" or "*Recipient*".
- Addresses or city name

The timing of the letter is left very much up to you, but most often letters are sent 2-3 months after your transplant.

Some people find that they need to wait longer before they are ready to write and may write around the anniversary of their transplant.

When your letter or card is ready, forward it to the Transplant Co-ordinator who will forward it to the Donor family. The Transplant Co-ordinator will read the letter to ensure that it does not include any identifying details.

