This information manual was drafted by Michelle Harkess CNC with assistance from the multidisciplinary transplant team.

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Heart and Lung Transplantation

Information Manual

for
Patients
Family and
Friends.

St Vincents Health Network. Sydney. 2014

Eighth Edition

DEDICATED TO OUR FUNDRAISERS, OUR TRANSPLANT RECIPIENTS AND ONGOING SUPPORTERS OF THE TRANSPLANT UNIT, THANK YOU ALL
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INTRODUCTION

This booklet has been designed to help you understand what is involved in heart and lung transplantation. Information supplied follows the transplant journey and includes your hospitalisation for transplant surgery. Various members of the transplant team will discuss this information with you and we encourage you to use every opportunity to ask questions. Our goal is to provide you with information that will help you decide on your treatment based on a good understanding of heart and lung transplant procedures and the risks and benefits.

The transplant program commenced at St Vincents Hospital in February 1984. The Heart and Lung Transplant Unit at St Vincent’s Hospital, Sydney is amongst the largest and most successful programmes in the world, performing on average 20 heart and 40 lung transplants per year. The transplant program at St Vincents is primarily an adult service although does extend service and expertise to adolescent and paediatric patients.

To date, the transplant unit has performed over 770 heart transplants, 79 heart-lung transplants, 470 bilateral lung transplants and 148 single lung transplants. The transplant program is funded by the State Government, however, relies heavily on donations from the community.


Heart and lung transplant recipients celebrating 25yrs of transplantation at St Vincents 23 February 2009
INFORMATION YOU MIGHT NEED

Accommodation

Limited patient/family shared accommodation is available near St Vincents at a cost of $30 per person, per night; the account is to be paid in full before departure. Bookings are essential and can be made through the accommodations officer (02) 8382 2114, Monday to Friday, 8am-4.30pm. Hotel accommodation is available to suit most budgets in Kings Cross, Potts Point, Surry Hills, Darlinghurst, Paddington and Sydney CBD.

Travel and Accommodation Assistance

You are responsible for the costs of your travel and accommodation. However, if you travel 100km or more to St Vincents you may be entitled to some reimbursement for these costs from IPTAAS (Isolated Patients Travel and Accommodation Scheme). The scheme also covers the cost for one family member or a carer if an escort is required. The social worker can help you with the forms if required.
Health Insurance/Medicare

The Transplant Unit is government funded (Medicare), therefore, your patient costs for the transplant admission are covered. You should not receive an invoice after the first admission; this also includes most transplant related investigations.

Making a Compliment or Complaint

Compliments or complaints are appreciated and provides feedback to improve our service. If you have any concerns regarding your care or treatment please contact your nurse, doctor, or department manager and complete a Patient Verbal Feedback Form. You can also contact the Patient Liaison Officer on telephone (02) 8382 2250.

Social Work Department

The social work department is located on level 4, De Lacy Building, phone (02) 8382 2213.

The transplant social worker is located on level 4, Xavier Building in the Heart Lung Clinic.

Hospital Car Parking

The Parksmart Car Parking Building is available at a cost. There are no fee discounts for patients or their families. Metered parking is available around the hospital campus.

Media and Public Relations

St Vincents Hospital has a high media profile and the transplant unit staff often participate in documentaries, newspaper story and various radio and television interviews to promote organ donation and transplantation. We are often asked if transplant recipients or patients on the waiting lists want to do television or radio interviews. Please know you are not obligated in any way to participate in media interviews. Your decision to participate or not, will have no impact on your transplant or treatment.
REASONS FOR HEART AND LUNG TRANSPLANT

Transplant Society of Australia and New Zealand Criteria

Heart Transplant Inclusion Criteria

• Irreversible cardiogenic shock
• Intractable symptomatic heart failure
• Need for permanent mechanical support
• Frequent discharge from internal defibrillator
• Intractable angina despite optimal medical therapy

Heart Transplant Exclusion Criteria

• Active malignancy
• Complicated diabetes
• Morbid obesity
• Uncontrolled infection
• Inability to comply with complex medical therapy
• Active substance use – cigarettes, alcohol and drugs
• Irreversible damage of other organ systems that prevent rehabilitation after transplant
• Acute medical conditions – may be reconsidered at a later stage when resolved.

Lung Inclusion Criteria

• Respiratory failure despite optimal medical therapy, interventional and surgical treatment and/or;
• Poor quality of life, potentially with intractable symptoms and repeat hospital admissions.

Lung Exclusion Criteria

• Active malignancy
• Irreversible dysfunction of organs or other body systems – combined organ transplant may be considered.
• Non-curable chronic infection
• Documented non-adherence or inability to comply with complex medical therapy or follow up.
• Substance addiction that is either active or within the last 6 months – cigarettes, alcohol and drugs.

The above criteria are determined with specific tests and investigations with set parameters that will determine your suitability.

REFERRAL AND ASSESSMENT FOR HEART AND LUNG TRANSPLANT

Heart or lung transplant is usually suggested by your treating specialist. It is necessary for you to come to St Vincent’s to see a transplant doctor who will decide if you should proceed with assessment, work up and meet the transplant team.
You need an appointment to see a transplant doctor at the Heart Lung Clinic and will need to bring your Medicare Card and referral letter. Your work up may take a few weeks or months to complete depending on the severity of your heart and/or lung condition or the complex nature of your medical history. It is important to know that not every patient referred to the transplant unit is suitable for transplant. And it may take many weeks to months before a final decision can be made. Your information must be shared and discussed with many members of the transplant team to determine if you can have a transplant. If you are not suitable the transplant doctor will discuss alternative options and notify your referring specialist.

**ADOLESCENT TRANSITION AT ST VINCENTS**

We collaborate closely with the NSW Children’s Hospitals and see adolescent patients for heart and lung transplant assessment from both Childrens Hospital Westmead and Sydney Childrens Hospital Randwick. The adolescent patients are aged between 13 years and 18 years of age when first referred for assessment or transition care. We recognise the need for specialised health care for the younger patients and try to provide an environment where the adolescent and their family feel welcome. We involve the patient and parents in the decisions and management both before and after transplant and collaborate with the paediatric teams. Most adolescents are 16 years or older when they require a transplant, however, St Vincents do transplant adolescents under 16 years of age when needed.

**How we transition adolescent patients to St Vincents**

- Pediatric staff attends outpatient appointments with the adolescent and their family.
- Adolescent and family meet transplant staff and tour the unit.
- Introduce the adult environment and discuss differences and expectations.
- Single room provided in ward areas for patients less than 16 years of age.
- Intensive care endeavour to provide a single room or separate area.
• Parents have relaxed visiting hours and are encouraged to be with their child.
• Parents can stay overnight with their child.
• Parents are welcome to be present for medical rounds.
• Paediatric staff may also be present for the transplant rounds.
• Parents or a friend can provide company or chaperone for tests and investigations.
• Bedside and room decorations, laptops and games are encouraged.

Adolescent patients follow the same transplant journey as the adults. This includes assessment and work up, active listing, transplant, and post operative recovery and outpatient care.

**TRANSPLANT WORK UP**

Transplant work up involves a complete medical history and health screen that will include the following:

<table>
<thead>
<tr>
<th>Blood tests (multiple required)</th>
<th>Tissue typing and PRA (multiple blood tests)</th>
</tr>
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<tbody>
<tr>
<td>Body scans</td>
<td>Lung Function Tests</td>
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<tr>
<td>Sleep study tests</td>
<td>Heart scans and heart catheter tests</td>
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<tr>
<td>Bone scan</td>
<td>Colonoscopy/gastroscopy as indicated</td>
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<tr>
<td>Dental x-ray and examination</td>
<td>Cancer screening (male &amp; female health)</td>
</tr>
<tr>
<td>Infection screening</td>
<td>Alcohol, cigarette and drug screening</td>
</tr>
<tr>
<td>Allied health consultations</td>
<td>Psychiatry and psychology consultations</td>
</tr>
<tr>
<td>Medical consultations</td>
<td>Nursing consultations</td>
</tr>
</tbody>
</table>

Be prepared to expect delays when completing the assessment and work up as it can take time for the team to be thorough. There are often delays with appointments and results for various tests or medical consultations.
COMMITMENT BY THE PATIENT AND FAMILY

Heart and lung transplantation requires commitment from “you and your family or care giver.”

All members of the transplant team expect you to do your best to participate with the transplant program.

This includes attending all work up appointments made by the transplant coordinator who will try to arrange times to suit you. We try to accommodate family, school and work commitments. However, this is not always possible and you must attend the clinic and tests required.

This expectation continues after transplant with the transplant rehabilitation program, your medications, clinic visits, gym attendance, support group and lifestyle modification.

You will be required to reside in metropolitan Sydney for up to three months after the transplant. This is to ensure you can attend your medical follow up and rehabilitation program. If you do not have friends or family in Sydney then you will need to arrange accommodation. Speak to the transplant social worker and transplant coordinators for options. We strongly recommended that a family member, friend or care giver be with you during the first months after transplant. This persons role is to supervise and support you with your complex drug regimen, rehabilitation program and clinic appointments.

PSYCHOLOGICAL CHALLENGES ASSOCIATED WITH TRANSPLANTATION

Serious illness and organ transplantation poses a range of threats and challenges for patients and their supports, including health uncertainty, disruption to life roles, loss of independence, illness symptoms, medication side-effects, and readjusting to life after transplant. Not surprisingly, these stressors can have a significant emotional impact on patients and their supports, and rates of anxiety, depression and adjustment difficulties are high.

The emotional well-being of our patients and their supports is a priority and key to optimising outcomes in terms of quality of life and longevity. The Consultation-Liaison Psychiatry team (Psychiatrists, Clinical Nurse
Consultant, Clinical Psychologist) work closely with the social worker and transplant team and are regularly involved in patient care to assist with coping strategies, anxiety, depression and delirium. The “Dealing with a Transplant” booklet has been specifically designed to accompany this manual and assist with coping with serious illness and the various stages of transplant.

**SMOKING, ALCOHOL AND OTHER SUBSTANCES**

We recognise the stress of living with a chronic illness, undergoing transplant and adjusting to a new lifestyle can trigger bad habits. This requires a non-judgemental supportive approach and potential treatment recommendations. This can include psychiatry, psychology or regular follow up with drug and alcohol counselling.

The transplant team ask that patients never start smoking again. Smoking is severely damaging to the transplanted heart and lungs and will decrease long-term survival. Smoking also increases the risks associated with anaesthesia at the time of transplant surgery. The team insist on your commitment not to misuse alcohol and/or drugs; if misuse and relapse is suspected we will request you undergo random drug and cotinine (nicotine) testing. This can mean three tests at monthly intervals and all must be negative. You will not be activated on the waiting list until this requirement is met. Furthermore, you will be taken off the active list if tested positive and referred to the psychologist/psychiatrist or for drug and alcohol counselling.

**TRANSPLANT REHABILITATION PROGRAM**

The transplant rehabilitation program an 8 week education, exercise and lifestyle program designed to prepare you for life after transplant. Many patients need to learn new skills after having lived with a chronic illness. Some patients had to stop working and put their lives on hold due to their illness. This program will assist you get back confidence to help you integrate back into the workforce or help you to participate in lifestyle activities that you never thought possible again.

You will attend regular gym glasses twice a week and education sessions from the transplant pharmacists, nursing staff, dietician, occupational therapist, psychologist, and social worker. You and your family or care
giver will receive information about medications, and various transplant related topics. The rehabilitation program is compulsory and your attendance will be monitored.

After three months most transplant patients are ready to resume a normal lifestyle. That includes returning to work, high school and university, volunteering or training to learn a new work skill or hobby. All patients are welcome to attend the rehab program both before and after transplant for life. Program dates, times and education topics are displayed at the Heart Lung Clinic, Gym and Level 10 wards.

**Physiotherapy and Transplant Gym – Xavier level 4**

You will meet the physiotherapist (physio) during transplant assessment. The physio will get you to perform the “6 Minute Walk Test (6MWT) to assess your exercise and activity tolerance. All patients on the waiting list are encouraged to use the gym to improve fitness for transplant.

**Transplant Gym**
**Location:** level 4 Xavier Building
**Hours:** 11am to 12pm
**Days:** Monday and Thursday

Regardless how many years it has been since your transplant or your age, the team expect you to attend the transplant gym if you are readmitted to hospital. The physio will assess your level of fitness and ability to maintain an active lifestyle. You are required to participate in any form of exercise set by the physio.

**MEETING THE MULTIDISCIPLINARY TRANSPLANT TEAM**

You are required to meet various members of the transplant team for dietary assessment, physiotherapy assessment, social work assessment and psychiatry assessment. All patients must also meet the transplant nurse during work up. The information you provide during assessment will assist with your care after transplant surgery.

You will be given a detailed questionnaire to complete as part of the workup process and the information provided will be used for discussion when meeting the multidisciplinary team and transplant nurse. This information is vital to help the team identify areas where you may need support or extra services during the rehabilitation stage after transplant.
# The Multidisciplinary Transplant Team

<table>
<thead>
<tr>
<th>Surgical transplant team</th>
<th>Dr Phillip Spratt (Director) Dr Paul Jansz Dr Emily Granger Dr Kumud Dhital Dr David Winlaw Dr Yishay Orr</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Assessment for active listing, transplant surgery, mechanical support surgery, cardiothoracic surgery, retrieval service and outpatient surgical follow up</td>
</tr>
<tr>
<td>Heart transplant team</td>
<td>Prof Anne Keogh, Prof Peter Macdonald Prof Christopher Hayward Dr Eugene Kotlyer</td>
</tr>
<tr>
<td></td>
<td>Assessment for active listing, heart failure and pulmonary hypertension management, drug trials, heart transplant management and research</td>
</tr>
<tr>
<td>Lung transplant team</td>
<td>Prof Allan Glanville Dr Monique Malouf Dr Marshal Plit Dr Adrian Havryk</td>
</tr>
<tr>
<td></td>
<td>Assessment for active listing, lung failure management, drug trials, lung transplant management and research</td>
</tr>
<tr>
<td>Transplant Coordinators</td>
<td>Sara Shaw Naomi Anderson Fleur Zani Elyn Montgomery Airlie Gilpin</td>
</tr>
<tr>
<td>Heart Lung Clinic</td>
<td>Assessment, education, transplantation coordination, outpatient care, data entry and biopsy procedures</td>
</tr>
<tr>
<td>Transplant Clinical Nurse Consultant</td>
<td>Michelle Harkess</td>
</tr>
<tr>
<td></td>
<td>Assessment, education, inpatient transplant care coordinator, outpatient clinic, transplant coordination, data management and research</td>
</tr>
<tr>
<td>Mechanical Circulatory Device Clinical Nurse Consultant</td>
<td>Desiree Robson</td>
</tr>
<tr>
<td></td>
<td>Assessment, education, inpatient care, outpatient care, clinical coordination and technical maintenance and support</td>
</tr>
<tr>
<td>Social Worker</td>
<td>Melveta James</td>
</tr>
<tr>
<td></td>
<td>Assessment, social assistance, travel, accommodation, finance, legal assistance, support group</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>Fay Burrows Lili Carlos</td>
</tr>
<tr>
<td></td>
<td>Education and medicines information after transplant</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>Darryl Wallington-Beddoe</td>
</tr>
<tr>
<td></td>
<td>Assessment, muscle and strength conditioning, rehabilitation program</td>
</tr>
<tr>
<td>Psychiatrist/Psychologist Clinical Nurse Consultant</td>
<td>Prof Kay Wilhelm Adam Finch Kerrie Cooper</td>
</tr>
<tr>
<td></td>
<td>Assessment, transition, chronic illness management, anxiety, depression and coping strategies</td>
</tr>
<tr>
<td>Dietitian</td>
<td>Clare Rawcliffe Sarah Cufer</td>
</tr>
<tr>
<td></td>
<td>Nutritional assessment and dietary recommendations, education and support</td>
</tr>
<tr>
<td>Nurse Unit Managers Clinical Areas</td>
<td>Nicole de Tullio (HLC) Raelene Kennedy (X105) Louise Fishburn (CCU) Nicola Mathews (ICU)</td>
</tr>
<tr>
<td></td>
<td>Patient satisfaction, complaints, nursing staff, bed allocation and patient admissions</td>
</tr>
</tbody>
</table>

**NOTE:**

The transplant unit work as a team and all your information will be shared in case conference. This is important because the decision to proceed with the transplant is a team decision. Regular case conferences are held to review the waiting lists and discuss your ongoing suitability for transplant. Your privacy and confidentiality will be respected.
TRANSPLANT ASSESSMENT COMPLETE

Following completion of the assessment and work up phase the transplant doctor will discuss with you and your family whether you should proceed to transplant. The results from your assessment will determine if you are suitable for transplant or not suitable for transplant.

**Not Suitable (ineligible) for Transplant**

The transplant team may conclude that, for a variety of reasons, transplant is not the best option for you. Some reasons for this include age related comorbidities, past history of cancer, other life threatening illness or infection. Sometimes you can be too sick to have a transplant. Whatever the reason, each case is looked at individually. The transplant doctor will explain the reasons to you and advise if you can be reconsidered for another assessment in the future.

**Heart and Lung Failure Treatments and Drug Trials**

You may be invited to participate in clinical drug trials that might help stabilise your condition and provide some symptom relief for a period of time; maybe months or years? If you are suitable for one of these trials the transplant doctor will discuss this with you. On occasion patients who are on the waiting list are invited to participate in drug trials to prolong survival until a suitable donor organ is available.
Other options may include synchronised pacemaker, internal defibrillator, heart valve surgery, bypass surgery and lung surgery. Then maximise medical therapy and consider home intravenous therapy, oxygen therapy and breathing machines for sleep, BiPAP and CPAP.

**End of Life and Palliative Care**

It’s important to be realistic about your future. You need to decide what is going to be best for you and your family. Your quality of life and wishes need to be discussed in the event that you are either not suitable for transplant or if a donor is not found in time. You should ensure you have an up to date will, consider an Enduring Power of Attorney and Advanced Health Care Directive.

You might be comfortable talking to your treating specialist who knows you and your family best about palliative care options. However, if you prefer, our social worker and transplant doctors can refer you to the appropriate services to discuss further.

**SUITABLE (ELIGIBLE) FOR TRANSPLANT**

Once accepted for transplant the final decision for activation on the waiting is up to you.

We will not activate you unless we have received your written consent for transplant. You have the choice to decide at anytime that transplant is not for you; this also applies to when you are on the waiting list. However, we ask that you make a firm commitment to your decision for active listing. The transplant team can also take you off the list or place you on hold at any time for medical reasons and these will be explained to you.

You are required to see the transplant doctors regularly while waiting for transplant. This is so we can monitor your health and assess your ongoing suitability for transplant. The team hold regular case conference meetings to review all candidates on the waiting list. Discussions will include your health when last seen in clinic, relevant social issues and if new tests and consultations are needed.

Often critical decisions are made by the team at case conference and patients can be removed from the list. This can be permanent or temporarily “on hold” until further investigation. The transplant doctors will notify and advise you if this happens and the reason why.
BRIDGING TO HEART TRANSPLANT WITH MECHANICAL SUPPORT

Patients suitable for transplant may need temporary mechanical support until a donor heart is available. Mechanical support can assist heart function or completely take over heart function depending on the device used. The goal of mechanical support is to minimize symptoms and improve quality of life while waiting for a donor heart. Mechanical support also enables patients to rehabilitate in preparation for the rigors of heart transplantation.

Mechanical Devices to Support the Heart

Left Ventricular Assist Device (LVAD)

A LVAD is a blood pump that is surgically implanted and sits inside your chest and is connected to your heart. The pump supports the left side of the heart and may not be suitable for patients with weakened right heart function. The LVAD pumps blood from the left ventricle (large heart chamber that receives oxygen rich blood from the lungs) to the aorta (big vessel that send blood to your body) and around the body; effectively taking over the role of the left ventricle. The pump provides a continuous flow of blood from the heart to the aorta and as a result you may not be able to feel a pulse. The LVAD is electrically driven and connects to an external wearable system (controller and power source) by a thin cable (driveline) that exits the skin though the abdomen. The power source can be two batteries or one battery and electricity from a wall or car outlet. Before going home patients and their carer will be given training on their LVADs and how to dress the driveline exit site.

Total Artificial Heart (TAH)

The TAH is a biventricular, pneumatic (air-driven) pulsatile pump that completely replaces the patient’s own heart. The TAH is surgically implanted into the chest after the failing heart is removed. Two drivelines that exit the skin through the abdomen connect the TAH to the external electrically powered driver. The driver provides compressed air that is needed to operate the TAH and can be powered by two batteries and electricity from a wall or car outlet. TAH is electrically powered and pneumatically driven. This means the pneumatic driver that shunts air in
and out the pump drivelines can be run on AC power adapter and battery. Because the TAH replaces the patients’ own heart and removes the problem of life threatening heart rates all pacemakers and defibrillators will be removed. Patients and their carers are educated on how to look after the TAH, trouble shoot alarms and do their exit site dressings before they go home.

Both the LVAD and TAH pumps allow patients to rehabilitate and get strong for transplant. Exercise tolerance, diet and nutrition will improve along with your overall health. Patients can go home to wait for transplant.

(Left) photo showing the LVAD (Right) photo showing the TAH. Permission provided by Heartware Ltd and SynCardia Systems Inc to reprint photos.
YOUR RESPONSIBILITIES WHILE ON THE ACTIVE WAITING LIST

While waiting for your transplant you must:

• have a monthly antibody test sent to Tissue Typing at Red Cross Blood Service.
• be contactable 24 hours a day, 7 days a week on telephone or mobile phone.
• notify the transplant coordinator if you are going on holiday.
• notify the transplant coordinator if you are admitted/discharged from a hospital.
• Notify the transplant coordinator if your body weight changes by more than 5kg.
• Have travel arrangements ready for transport to St Vincents for a transplant.

Antibody Blood Test

One important blood test performed during assessment and every month whilst on the waiting list, is called a” clotted tube.” This measures the amount of antibodies in your blood to other people’s blood.

Elevated levels of antibodies in the blood can be caused by a variety of factors. Some examples include past blood transfusions and previous transplants or pregnancy. High levels mean you might wait longer because you are more likely to not match potential donors and may put you at higher risk of rejection after the transplant. Antibody levels can increase or decrease over time.

You need to have a clotted tube blood test every month. It is imperative that this blood reaches the Red Cross before the 20th of each month. Therefore, we recommend you have the blood test before the 15th of each month. Failure to do this blood test may result in you not being able to have a transplant for that month. The request forms are available from the Heart Lung Clinic and you can go to your nearest pathology. Ensure the form and blood tubes are completed with your name, full date of birth and full date of collection.
Waiting list Priority

Priority will depend on determining who on the list is a potential match to the donor.

This is determined by:

<table>
<thead>
<tr>
<th>Heart Donation</th>
<th>Lung Donation</th>
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</thead>
<tbody>
<tr>
<td>Blood group and cross match</td>
<td>Blood group &amp; cross match</td>
</tr>
<tr>
<td>Weight</td>
<td>Lung size</td>
</tr>
<tr>
<td>Gender</td>
<td>Height &amp; Gender</td>
</tr>
<tr>
<td>Most critical in need</td>
<td>Most critical in need</td>
</tr>
</tbody>
</table>

Waiting list time can vary from 1 day to over 2 years. The length of time waiting will not increase your priority. The factors listed above will determine who can receive the transplant. The surgical and medical team must also decide if the donor heart or lungs offered will suit your medical condition. *Not all donor organs can function when transplanted into a person with a complex medical history.*

Organ Donation Information

The following information is to inform you about organ donation criteria to help you make an informed decision. National guidelines can be viewed in full in the “organ allocation protocols” section on the following website [www.tsanz.com.au](http://www.tsanz.com.au).

It’s important you understand that we don’t know when you will get a donor organ and we cannot guarantee that you will receive a transplant.

Organ Donation

Organ donors are people that have a catastrophic injury, illness or tumour that lead to bleeding and swelling of the brain. When the process called “brain death” occurs it is irreversible and the person is legally dead but
the heart is still beating. Strict testing to confirm brain death is performed by senior medical specialists. All donors will be in an intensive care unit on a ventilator to breath, needing oxygen and drugs to keep the organs working for transplant. Organ donation surgery will occur when the transplant teams are ready and the donor is transferred to the operating theatre.

**Donation after Cardiac Death (DCD)**

Organ donation can also occur when the heart stops. Again the donor has suffered a severe irreversible head injury or illness and will not survive without life support. Following a decision by the family and treating specialist a time will be made to withdraw life support and follow end of life care. Life support will be turned off and death will occur when the heart stops; rapid transfer to the operating theatre will occur within minutes and organ retrieval surgery will begin as quickly as possible. DCD donation is only suitable for liver, kidney and lung donation. While still relatively new in Australia our results are consistent with the international outcomes.

**Extended Criteria Donors (Marginal)**

Due to the lack of organs extended criteria donors are considered and used for heart and lung transplant with good outcomes. These donors are usually older, have a history of smoking, cancer or infection and have participated in high risk behaviour. These risks will be discussed with you in more detail by the transplant doctors. This will help you understand what happens if you receive an organ from a marginal donor.

*It’s important that you know the team will only proceed to organ retrieval and transplant after serious consideration following a thorough risk assessment with testing, investigations and donor optimisation.*

**Transmission of Infection**

Potential donors are assessed for high risk behaviours that can indicate if the donor has an increased risk of having HIV, Hep B and Hep C infection. The donor screening process will include multiple blood tests for diagnostic, serological and nucleic acid (NAT) testing. Donors identified as high risk are investigated to assess the time frame of exposure. It is these factors (timing of exposure and blood results) that determine whether or not to
proceed with organ retrieval. Not all positive results indicate active clinical infection; it can also indicate exposure from past infection or vaccination and immunity.

Screening is not 100% full proof no matter how accurate the test or how minor the risk.

This is why:

• You must start a course of Hep B vaccinations before going on the active waiting list
• We routinely screen for Hep B and Hep C up to 5 years after transplant
• We seek your consent to accept organs from a low risk donor with a history of Hepatitis B

The team do not accept organs for transplant from high risk donors that have clinical evidence of active HIV or Hepatitis infection or when we cannot reliably determine infection status.

Donor Cancer Risk Factors

National guidelines clearly state absolute contraindications for organ donation include:

• Any history of malignant melanoma.
• Any history of metastatic malignancy.

However, there are curable cancers that can be considered for transplant like prostate cancer, kidney and brain tumours or previously treated colon cancer greater 5 years that is completely eradicated. The team will seek expert opinion and consider the risk benefit ratio before proceeding with organ retrieval and transplant.

When you complete the heart consent form with the doctor you need to decide either “Yes” or “No” to accept organs from donors with the risk factors discussed. It is important you ask the doctor to explain the outcomes if you say “No.” The Risk versus Benefit.
If a donor becomes available that is a potential match for you, the transplant coordinator will contact you and ask if you would like to reconsider your previous decision and accept the donor organ for transplant.

**Communication with your Donor Family**

The staff cannot provide you with information about your donor unless there is a risk to your health. The Donatelife Coordinator (organise donation process) will tell the donor family what organs were successfully donated for transplant. Donor families and transplant recipients can communicate through letters and cards but it must remain anonymous and unidentifiable. We ask that all patients write a” Thank you” NOTE: or card to their donor family, this can be an emotional task, so do ask the team for advice. Either the social worker or nursing staff can forward your correspondence to the Donatelife Agency. All donor/recipient correspondence is read by staff to ensure it is unidentifiable for privacy and confidentiality. The best way to say “Thank You” to your donor family is to take care of your new heart or lungs and make the most of your second chance.
TIME FOR TRANSPLANT

When you receive the call to come in for transplant it is usually after hours and you will need to move quickly to arrive at the hospital and be ready in time for theatre. Keep your mobile phone with you until you go to theatre.

Consent for Transplant

If you are having a heart transplant you will need to sign the “Heart Transplant Consent Form” before you go on the waiting list. The consent form details the complications and risks and is explained further by the transplant doctor. Signing the consent form means you understand the risks and your commitment to transplant. At the time of transplant surgery you need to sign the “Consent Form” a second time reconfirming your agreement and also sign an additional “St Vincents Hospital Operation Consent Form.” Lung transplant candidates do not currently need to sign consent to be listed only the Operation Consent Form at the time of transplant.

Cancellation of Surgery

The transplant can be cancelled at anytime. It’s possible that you may have several false alarms without the transplant going ahead. This occurs when the donor organs are found to have deteriorated or the match between you and the donor is incompatible. These facts can only be ascertained in the last hours before the transplant goes ahead.

Stand By

You may be called in as a “stand-by” or “back up” in cases where matching of the donor to the recipient is uncertain. You are required to come in and prepare for theatre until the final cross match is known. We recognise that this is a very stressful time and we try to avoid this happening.
What happens from the time of the call?

**THE CALL**
- You will be contacted by the transplant coordinator and informed of the possibility of a transplant. You must commence fasting and make your way to the hospital.
- Keep your mobile phone with you until you go into surgery.

**ARRIVAL**
- Upon arrival at the hospital you will go to either the emergency department, ward, heart lung clinic or day surgery depending on the time and bed status.
- You will be rapidly prepared for surgery; this includes chest xray, bloods, shave, shower, gown and premedication with antirejection drugs.

**THEATRE**
- You will be transferred to theatre at a designated time. Your family can go and see you off and wait in the ICU waiting room.
- You will be taken into anaesthetic bay and commence preparation for transfer into the operating theatre for surgery.

Family and Friends Waiting Room

The hardest part is for those who are waiting not knowing if you are going to be ok. The intensive care unit (ICU) has a waiting room for family and friends and is located on the same level as operating suits, level 5 Xavier Building. Alternatively family and friend can wait in the lounge area on level 10. Depending on the time of day or night those waiting may prefer to go down stairs to the hospital café, local café or restaurant to pass time. Waiting times can vary depending on delays but have been known to take from 4 hours up to 10 hours. Staff will call family and friends to go into intensive care when the operation is over.
ORTHOTOPIC HEART TRANSPLANT

Both heart and lung transplant operations can take from 4 hours up to 10 hours to complete. Transplant surgery as a rule requires the use of cardiopulmonary bypass and can be technically complicated. This will depend on your medical condition, any previous heart or lung surgery and the donor organs. As with any surgery there are associated risks that can include bleeding, stroke, wound infection, kidney dysfunction, heart rate problems and early graft dysfunction. The transplant doctors will discuss the risks and complications in more detail with you. It is important to ask questions to help you understand what they are explaining. You might need the doctors to repeat things and this is ok. We want you to understand the risks and benefits before you consent to transplant.

Orthotopic Heart Transplant
Surgical Wounds Following Transplant

Illustrations by: Dr Yuji Kawanishi, Department of Cardiothoracic Surgery, St Vincents Hospital.

Median sternotomy wound for heart transplant.
LIFE EXPECTANCY AFTER HEART TRANSPLANT

The transplant doctor will have explained to you that heart transplant is not without considerable risks. Current survival rates in Australia are as follows:

- One year after transplant 95% of patients are alive.
- Five years after transplant approximately 75% of patients are alive.
- Ten years after transplant about 60% of patients are alive.
- Twenty years after transplant 35% patients are still alive.

Life Expectancy after Lung Transplant

Lung transplant surgery carries with it major risks and these will be explained to you by the transplant doctor at assessment. The current survival rates in Australia are as follows:

- One year after transplant approximately 90% of patients are alive.
• Five years after transplant about 60% of patients are alive.
• Ten years after transplant approximately 40% of patients are still alive.
• Fifteen years after transplant about 35% of patients are still alive.

Long Term Survival

Long term survival after heart or lung transplant is largely dependent on you. On how well you manage your medications, your follow up and maintaining your health and fitness with lifestyle modification. The longest surviving patient transplanted at St Vincents is still alive after 27 years. You must maintain contact with the transplant team for life; heart recipients once a year and lung recipients twice a year to monitor graft function, prevent graft loss and screen for complications associated with taking antirejection drugs.

AFTER TRANSPLANT SURGERY

Intensive Care Unit (ICU) level 5

Following your surgery you will be transferred from theatres to the intensive care unit (ICU). When you are stable staff will speak with your family and they will be allowed to see you, at this time you will still be sedated and asleep. You will be very drowsy when you wake and will have the breathing tube in place. You will get regular intravenous pain relief and will remain in ICU until your new heart and/or lungs are recovered from the large operation. Sometimes problems occur as a result of your new transplant that means a longer stay in ICU. Family and friends can visit but must follow the visiting times unless otherwise arranged with the ICU manager.
### ICU Equipment

<table>
<thead>
<tr>
<th>ICU Equipment</th>
<th>Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ventilator</td>
<td>Machine that delivers oxygen &amp; assists your breathing</td>
</tr>
<tr>
<td>Breathing tube</td>
<td>Tube to connect you to the ventilator for breathing</td>
</tr>
<tr>
<td>Central Venous Line</td>
<td>Intravenous line to give multiple drugs</td>
</tr>
<tr>
<td>Chest tubes</td>
<td>Drain air &amp; fluid from the lungs &amp; around the heart</td>
</tr>
<tr>
<td>Pacing box</td>
<td>Paces the heart at a set beat rate</td>
</tr>
<tr>
<td>Indwelling catheter</td>
<td>Drains urine from the bladder</td>
</tr>
</tbody>
</table>

### Pain following Transplant Surgery

The level of pain differs between patients, the type of transplant and the involvement with the sternum or chest bone. Following surgery you will feel some pain usually associated with the surgical wound and the chest drains. While in ICU the nurse will give you intravenous and oral medications for pain. The pain team will monitor you regularly while you need intravenous pain relief and you will be switched to tablets as quickly as possible. The teams will ensure you receive enough pain medication to perform your physio and coughing and breathing exercises without becoming too drowsy.

### Post-Operative Wards level 10

When you no longer require intensive care you will go to the ward. The ward environment is very different from ICU, it can be busy and noisy and you might move to different bed spaces often.

The medical and surgical transplant doctors will see you daily. The ward routine starts early with nursing staff measuring your daily weight, vital signs and giving you medication. The rest of your day will include physiotherapy and education.

Education will commence with learning your medications, this will be done by the transplant nurse (CNC) and pharmacist using your treatment book. Nursing staff will encourage you to self medicate while they supervise, it’s vital that you and your carer know your medications before discharge from hospital. The physio will be exercising you twice daily, the dietitian will provide information about healthy eating and the transplant nurse
will educate on rejection and infection. Social support will come from pastoral care services, social worker, psychiatry and psychology services. Before you leave you will be asked to complete a short education quiz to complete your education.

Recovery Time

Transplant patients total length of stay can vary between 7-14 days depending on the post operative complications that can extend your stay. You will be encouraged to mobilise quickly to aid your recovery and participate in your education for discharge from hospital.

Isolation and Infection

If you have an infection that requires isolation you are nursed in a single room. If you get an infection whilst in hospital then you will be moved into a single room. Isolation occurs for organism called MRSA, VRE, ESBL, and some respiratory viruses. Staff will wear protective gown, gloves and mask, but your family and friends only need wash their hands when they come and go.

Activities and Exercise

During your hospital stay you will have two physio sessions daily, morning and afternoon. The physios will work through the considerations with you, to help you do the exercises. When the physios think you are ready; you’ll start the gym sessions in the rehabilitation program. You are safe to leave the ward to do this!

<table>
<thead>
<tr>
<th>Safe exercises to do</th>
<th>Things to consider when exercising</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing and coughing</td>
<td>Sternum precautions</td>
</tr>
<tr>
<td>Cardio: bike and treadmill</td>
<td>Wound discomfort</td>
</tr>
<tr>
<td>Arm and leg strengthening</td>
<td>Side effects from the new medications</td>
</tr>
<tr>
<td>Bed and chair exercises</td>
<td>General tiredness</td>
</tr>
<tr>
<td>Stair work</td>
<td>Change of breathing pattern</td>
</tr>
</tbody>
</table>
Routine Tests while in Hospital

While in hospital you need to have regular blood tests for drug levels, kidney and liver function and blood counts. You also need regular chest xrays to monitor for fluid, air or infection on your lungs and these tests are routinely done on Monday and Thursday. Other tests may include echocardiography, CT and MRI scans. Surveillance procedures for rejection happen on Tuesday and Thursday. Information about heart biopsy and bronchoscopy will be discussed separately in the heart transplant and lung transplant sections.

MONITORING YOUR HEALTH AFTER DISCHARGE FROM HOSPITAL

Treatment book

The blue treatment book is for you to record your medications and monitor your health. You must bring your treatment book to every clinic appointment and admission to hospital. You should keep track of results, tests and your daily health checks; blood pressure, pulse, temperature, weight and FEV1 (lung transplant only).

Blood Pressure (BP)

The early weeks after transplant your medications continue to change frequently. During this time you should monitor your blood pressure once daily. If you feel dizzy or have a headache check your blood pressure. High blood pressure is a side effect of some antirejection drugs. Normal blood pressure after transplant is less than 130/90. If your blood pressure goes above 140/90 and you feel unwell contact the team.

NOTE:

Adolescent patients should maintain a blood pressure less than 120/90. Normal blood pressure for younger patients is around 110/80. Contact the team straight away if your blood pressure exceeds 120/90 and you feel unwell with headaches or feel light headed and dizzy. This is important in the early months after transplant!
Pulse

Before you leave hospital you should know your normal heart rate. Knowing your normal heart rate is important so you can tell if it’s too fast or to slow. If you have palpitations or feel your heart racing check your pulse and contact the team if it’s a lot faster than normal. Again, if you feel unwell check your pulse if it’s very slow, contact the team. Too fast is over 120 beats/min and too slow is under 50 beats/min.

Temperature

Buy a thermometer and if you fell unwell you should take your temperature, if it is above 37.3 and/or you feel unwell you should contact the transplant team.

Weight

Monitor your weight daily in the early months after transplant. If you have had a heart transplant and you have a weight increase of 1-2kg over a day or two it may indicate rejection. Lung transplant patients should weigh themselves daily if they are still retaining fluid from surgery and are taking fluid pills, i.e. frusemide.

FEV1

Lung transplant patients do this measurement twice a day, morning and evening and record the best (highest) of three readings. This is a commitment to monitor the lung function for life.

*See the lung transplant section for more detail.*

THE IMMUNE SYSTEM

The immune system is the body’s defence system. Its function is to protect the body from bacteria viruses and other potential invaders. When an organ is transplanted from one person to another, the immune system regards it as an invader. Although the organs are matched for blood group, the body’s immune system is so sensitive that it recognises that the organ is not part of “you”. The presence of the new organ stimulates the immune system to attack and this is called rejection.
The immune system is made up of different types of white blood cells. A group of white blood cells — called lymphocytes — are divided into two groups, T cells and B cells. The T and B cells work together in many ways but it’s the T cells that are most commonly associated with cellular rejection and B Cells with antibody mediated rejection (AMR).

There is a fine balancing act in organ transplantation to prevent the T cells from attacking the new organ, while allowing other white blood cells to continue protecting the body against infections.

You will take drugs (antirejection) for the rest of your life to prevent rejection. It’s not possible to prevent rejection without weakening your immune system and its ability to fight infection. This will mean you are susceptible to get more infections than most people. You will be at greatest risk of infection when your dose is high during the first few months after transplant and if you are given large dose treatment for rejection.

**ANTIREJECTION MEDICATIONS ARE FOR LIFE.**

**HEART TRANSPLANTATION**

When you have an orthotopic heart transplant the old heart is surgically removed and the donor heart is sewn into place. Alternatively if you have a heterotopic heart transplant the donor heart is piggy backed onto your heart and sewn into place. The large vessels are reconnected for blood flow and circulation but the nervous system remains disconnected. This is called “denervation,” it is not possible for the surgeon to reconnect the nervous system during transplant surgery. The heart will beat and provide adequate circulation but the disconnection (denervation) mean there is no nerve connection to affect heart rate and volume change inside the transplanted heart.

Heart transplant recipients have almost near normal function but there are some differences in the transplanted heart.

- Heart transplant recipients generally don’t experience angina pain (chest pain) if there is a narrowing of the coronary arteries.
- Heart transplant recipients may have a normal resting heart rate of 90-100 beats per minute.
- Heart rate is normally slow to respond to the demands of exercise.
• Patients can feel dizzy or light headed if they change position too quickly.

All patients are different but the general advice is a slow warm up to allow the heart rate to increase and slow cool down following exercise to allow the heart rate to return to normal. Another suggestion to prevent being lightheaded when standing is to do ankle rotations or leg pumps to promote circulation and change position slowly.

**Heart Transplant Rejection**

It can be common with heart rejection not to notice any signs or symptoms. Some people are surprised when told they have rejection because they feel well. Then other patients can be very sick and unwell with rejection.

**Symptoms of heart rejection:**

<table>
<thead>
<tr>
<th>Shortness of breath</th>
<th>Fatigue &amp; tiredness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swollen ankles</td>
<td>Increased weight</td>
</tr>
<tr>
<td>Light headed &amp; dizzy</td>
<td>Decreased exercise tolerance</td>
</tr>
<tr>
<td>Heart palpitations</td>
<td>Loss of appetite</td>
</tr>
</tbody>
</table>

In patients experiencing rejection there is often evidence of reduced heart function on ECG, ECHO and heart biopsy (Endomyocardial Biopsy).

**Heart Biopsy (Endomyocardial Biopsy – EMBX)**

The heart biopsy is initially performed weekly for the first month and will decrease with time. After a year there is usually no need to do biopsies unless symptoms of rejection occur. Many patients liken the biopsy procedure to the Right Heart Catheter they had before the transplant, except quicker.

You are asked to lie on an X-ray table and turn your head to the left. A sterile cloth is then placed over your neck and face. Some local anaesthetic is injected into the skin. The doctor then threads a small wire down a vein in your neck, under X-ray guidance, and takes small samples of the inside
of your heart. This procedure is usually relatively painless and takes 15 minutes. The main complication of heart biopsy procedure is bleeding from the puncture site; this is controlled by applying pressure and sitting in an upright position for an hour or so. The specimens are sent to the laboratory for inspection by a pathologist and result will be available the same evening or next morning. If rejection is there the appropriate treatment will be commenced. The team may also request echocardiography to determine if the rejection has affected cardiac function.

**Grades of Heart Rejection**

<table>
<thead>
<tr>
<th>Rejection Grade</th>
<th>Level of Rejection</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 0</td>
<td>No rejection</td>
<td>No treatment required</td>
</tr>
<tr>
<td>Grade 1a</td>
<td>Mild rejection</td>
<td>No treatment required</td>
</tr>
<tr>
<td>Grade 1b</td>
<td>Mild to moderate rejection</td>
<td>No treatment required</td>
</tr>
<tr>
<td>Grade 3a</td>
<td>Moderate rejection</td>
<td>Requires treatment</td>
</tr>
<tr>
<td>Grade 3b</td>
<td>Moderate to severe rejection</td>
<td>Requires treatment</td>
</tr>
<tr>
<td>Grade 4</td>
<td>Severe Rejection</td>
<td>Requires treatment</td>
</tr>
</tbody>
</table>

Mild and moderate rejection (grade 1a to 3a) is the most common forms of rejection. Rejection decreases in severity and frequency with time. However, you will always be at risk of rejection because your immune system is always actively working to protect you.

**Treatment for Heart Rejection**

There are various treatment options for rejection. However, most patients will only require high dose steroid therapy with intravenous methylprednisolone and/or oral prednisone. Treatment can be given in either the Heart Lung Clinic or on the ward. It will depend on the severity of your symptoms, cardiac function, how unwell you feel and grade of rejection.
Treatment:

- High dose (500-1000mg) intravenous methylprednisolone once daily for three days.
- Reducing dose oral prednisolone twice daily over 1-2 weeks until back to baseline dose.

The heart transplant team may make adjustments to your antirejection medications. If unresponsive to steroid therapy alternatives may include a more powerful intravenous medication called ATG or total radiation therapy. The team can also target antibodies with intravenous medications and aphaeresis (wash the antibody from the blood). The transplant team will discuss these treatments with you in detail if needed.

Cardiac Allograft Vasculopathy (CAV)

Cardiac allograft vasculopathy can occur early or late after transplant. This condition results in the narrowing of the coronary arteries that supply blood to the heart. CAV can affect the large main vessels, the small diffuse vessels or both. Cardiac allograft vasculopathy is graded as CAV 0-3 depending on the degree of vessel disease. The severity of CAV can also be evident on echocardiography as a wall motion abnormality and ventricular dysfunction. Many patients have some form of CAV and manage to lead a full and active life. Treatment for CAV is varied and will depend on the speed of development and time post transplant. Because the heart is denervated 50% of patients do not feel angina or heart attack pain. This is why it’s important to attend every transplant clinic for routine heart biopsy, echocardiography, angiography and dobutamine stress echocardiography to monitor for the presence of CAV. All patients must report within 24 hours to the team if they feel unwell and think something is wrong with their heart.
LUNG TRANSPLANTATION

When you have a lung transplant the surgeon will remove each lung separately one at a time and transplant the new lungs one at a time. The surgeon will reconnect the large airways and large blood vessels but cannot reconnect the nervous system during transplant surgery. This is called “denervation,” the denervated lungs have normal mechanics and perform oxygen and carbon dioxide exchange as normal. Most patients achieve near normal lung function with time following rehabilitation after surgery. But there are differences in the transplanted lungs.

- Transplanted lungs don’t have feeling or sensation below the suture line.
- Clearance of secretions is slower than normal as the cilia (tiny hair lining the airways) beat slowly.
- The cough strength is sometimes weakened.

Coughing and deep breathing exercises are important to prevent infections due to the loss of sensation and to prevent secretions building up.

Lung Function (FEV1)

Monitoring lung function is important because it’s a simple way to detect a problem, i.e. rejection or infection. The transplant nurse will provided you with a spirometer and give instruction on its use and how to record your measurements while you are in hospital. Measuring the trend in FEV1 readings provide an accurate picture of how your transplanted lungs are functioning when you are at home.

Measuring your lung function is for life and is a small task to honour your commitment to transplantation, the team and your donor.

Tips for Measuring Your Lung Function

Before starting it’s a good idea to do your coughing and breathing exercises. If the wound is still uncomfortable you can wait until after your pain relief.
• Measure lung function twice daily
• Measure at the same time in the morning and evening (not late at night)
• Measure in the same position – sitting or standing (preferably standing)
• Measure three blows and record the highest or best of the three.

If you notice a sudden and significant fall in your lung function (i.e., 10–20% drop in your measurement) or if you notice a slow, steady decline in your lung function over a 24 hour period, you must inform the team. You may not feel any symptoms of lung rejection and the only indication that something is wrong will be a drop in your lung function (FEV1).

**Important: you must not measure your lung function for 48hrs after you have a bronchoscopy and biopsy.**

**EARLY DETECTION WILL PREVENT GRAFT LOSS!**

**Lung Transplant Rejection**

Rejection is a part of transplantation. Although all precaution is taken to prevent it, rejection still happens to almost everyone. You must take your medications as prescribed, follow recommended lifestyle changes and attend all scheduled follow up to reduce the risk of rejection.

**Symptoms of lung rejection**

<table>
<thead>
<tr>
<th>Feeling breathless</th>
<th>Tightness in chest when breathing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drop in lung function (FEV1)</td>
<td>Temperature</td>
</tr>
<tr>
<td>Decreased exercise tolerance</td>
<td>Cough</td>
</tr>
</tbody>
</table>

Patients with rejection often have evidence on chest xray, and change in chest/breath sounds, lung function (LOOP) and oxygen levels.
**Bronchoscopy**

If you have symptoms for rejection or a chest infection the team may decide to do a bronchoscopy. A bronchoscopy is a procedure where the physician inserts a tube with light and camera into your lungs to visualise your airways. Bronchoscopy is a “day only” procedure with a premedication, under light sedation in the operating theatre and requires fasting from midnight. You will also need to remain fasting for three hours after the procedure before you will be allowed to eat and drink again. Two types of bronchoscopy are performed after lung transplant.

**Bronchoscopy and Wash**

The bronch usually takes around 30 minutes. It is done regularly to check the healing of the stitches holding the airways together (anastomosis) and to clear secretions. The lungs will be washed (with saline) and samples taken at this time to test for organisms or infection. The Look-See bronch is performed a few times after the transplant.

**Bronchoscopy and Biopsy**

Bronch and biopsy is performed at regular intervals from approximately 3 weeks to assess your lungs for evidence of rejection and infection. This bronch takes about 30 minutes and involves a small instrument to obtain tissue samples or biopsies from your lung/s. The samples are sent to the laboratory and examined by a pathologist. Results are usually obtained the same afternoon and

the grade of rejection will be described to you in the following way; minimal, mild, moderate and severe. You will also hear the team use terms to describe the grade; it’s useful to learn the grades so you understand what they mean. See table: International Grading of Lung Rejection.
Minimal and mild rejection is common during the initial months following lung transplant and will decrease in frequency with time. All rejection is potentially serious and will be treated quickly to prevent lung injury and graft loss.

**Grades of Lung Rejection**

<table>
<thead>
<tr>
<th>Rejection Grade</th>
<th>Airway Inflammation Grade</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>A0</td>
</tr>
<tr>
<td>Minimal</td>
<td>A1</td>
</tr>
<tr>
<td>Mild</td>
<td>A2</td>
</tr>
<tr>
<td>Moderate</td>
<td>A3</td>
</tr>
<tr>
<td>Severe</td>
<td>A4</td>
</tr>
</tbody>
</table>

The lung transplant team may make adjustments to your antirejection medications. If you are unresponsive to steroid therapy alternatives may include targeting donor antibodies with intravenous medications and aphaeresis. The transplant team will discuss these treatments with you in detail if needed.
Antibody Mediated Rejection (AMR)

Antibody mediated rejection is a different type of rejection that may not respond to steroid treatment. If this rejection is suspected a luminex test (blood test) is sent to the Tissue Typing Laboratory. The luminex test will tell if your immune system has developed antibodies to your donor called “Donor Specific Antibodies” (DSA). The luminex will report if you are positive or negative. If tested positive the next stage of testing will commence to see if the antibody is donor specific. Not all antibodies are targeted at your donor lungs. Antibodies are graded using a scale called Mean Florescent Intensity (MFI) that gives a number indicating mild, moderate or severe level of antibodies. Donor Specific Antibodies with a moderate or severe level of MFI will need treatment.

Treatment for Antibody Mediated Rejection

Treatment for this type of rejection is intensive and can require a hospital admission for up to two weeks to complete. Patients need a large Vascular Catheter (VAS Cath) inserted in the neck vein for treatment. Treatment includes plasmapheresis, this procedure requires being connected to a large machine similar to dialysis. Plasmapheresis circulates your blood in the machine (centrifuge) and removes antibodies from your blood. You will be given new antibodies from donor plasma (albumin) that is transfused into the machine. Each treatment takes about 2.5hrs from start to finish and most patients need five treatments. A repeat luminex test is done mid course to determine if treatment is working. The final stage will involve administering a drug called Rituximab to prevent more antibodies being produced. Monitoring is life long with luminex testing periodically throughout the year.

Obliterative Bronchiolitis (OB)

Chronic rejection damages the small airways. This condition can occur after one or two years and causes fibrosing damage to small airways that result in loss of lung function (FEV1). OB is graded as BOS 0-4 and measured as a percent in drop of FEV1 from baseline over a specific period of time. Many patients have some form of BOS and continue to lead an active and productive life for many years.

Some risk factors related to the onset of BOS include acute rejection episodes, respiratory infections (bacterial, fungal, viral) and gastroesophageal reflux disease (GORD). If diagnosed early damage can be stopped but not reversed, when lung damage is permanent, loss of
lung function is irreversible. This is why it’s vital that a drop in home FEV1 that does not return to baseline within 24 hours must be reported to the team.

**Gastroesophageal Reflux Disease (GORD)**

Common symptoms of GORD include heartburn and reflux caused by stomach acids regurgitating up the oesophagus from the stomach. GORD must be treated promptly to prevent damage to the transplanted lungs from the stomach acids. Treatment includes diet modification, weight loss, eating smaller meals and medications to reduce stomach acids. To prevent silent reflux at night it is advised to prop the head of the bed by 30 degrees. Further investigations can include 24 hour pH probe to monitor the severity of stomach acids and a short stay laparoscopic procedure to the stomach and oesophagus to tighten the stomach valve preventing reflux. **Do not delay reporting symptoms of reflux to the transplant team.**

**EARLY DETECTION ALLOWS TREATMENT TO PREVENT LUNG INJURY**
RESPIRATORY INFECTIONS AND LUNG TRANSPLANT

The transplanted lung is susceptible to infections. These infections can be acquired from the donor, the environment or the patient if previously colonised with an organism. Lung transplants will be at greater risk from lung infections because they risk graft dysfunction. Lung recipients can have more severe illness and longer recovery. Lung transplant recipient must not ignore cold and flu symptoms! Report symptoms early and provide a sputum sample and have a nasopharyngeal swab (NPS) to detect the infection responsible.

**Bacterial Pneumonia**

Chest infection can occur in the early post operative period. Symptoms of pneumonia can include a cough with or without sputum, shortness of breath and fever. Sputum samples will assist diagnosis of pneumonia and treatment. Pneumonia can be successfully treated with antibiotics.

**Pseudomonas**

Is a species of bacteria that is a serious complication for Cystic Fibrosis and transplantation. Infection with pseudomonas is diagnosed by bronchoscopy and sputum samples. It is likely that antibiotics will not totally eradicate pseudomonas from the lungs once established. It is also common for patients with pseudomonas pre transplant to redevelop the infection post transplant.

**Respiratory Syncytial Virus (RSV)**

Is one of the most common causes of lower respiratory illness in infants and young children. Lung transplant patients are highly susceptible to RSV and can have severe illness. We often see a secondary bacterial pneumonia associated with the virus. RSV is seasonal in autumn or winter and can mimic colds and flu. Infection requires hospitalisation and isolation for intravenous drug therapy and steroids for up to one week.

**Other Respiratory Viruses (Influenza, H1N1 and hMPV)**

Influenza, H1N1 (Swine Flu) and hMPV (Human Metapneumovirus Virus) are common in the autumn and winter seasons. These viruses can cause
serious illness and will require hospitalisation and isolation; you will need immediate treatment similar to RSV.

**INFECTIONS AND HEART AND LUNG TRANSPLANTATION**

When the immune system is weakened you are susceptible to infections. All methods for prevention are followed and early treatment is initiated. The following are infections that can cause serious illness for both heart and lung transplant patients.

**Aspergillus**

Is a fungal infection that is transmitted by inhalation of fungal spores. Aspergillus is often seen as a lesion or cavity on chest xray and can be cultured in sputum samples or bronchoscopy washings. Aspergillus and fungal infections are not isolated to the lungs and can occur anywhere in the body. If aspergillus is diagnosed treatment usually requires long term antifungal therapy as most forms of fungus take a long time (months) to eradicate.

- Patients receive inhaled Amphotericin nebulisers while still in hospital following transplant to prevent aspergillus.

**Cytomegalovirus (CMV)**

CMV stands for “cytomegalovirus”. CMV is a viral infection that comes from the herpes virus family. CMV will lay dormant in the immune system and can reactivate at anytime like a cold sore. Most of the general population have been exposed to CMV but have a normal immune system and do not get sick. However, because of the antirejection drugs and weak immune system CMV can be life threatening if left untreated. It is important that you know your CMV status and your donor CMV status as this will indicate your risk for CMV activation.
<table>
<thead>
<tr>
<th>Patient CMV Status</th>
<th>Donor CMV Status</th>
<th>Risk for CMV Activation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative</td>
<td>Negative</td>
<td>Low</td>
</tr>
<tr>
<td>Positive</td>
<td>Positive</td>
<td>Medium</td>
</tr>
<tr>
<td>Negative</td>
<td>Positive</td>
<td>High (CMV Mismatch)</td>
</tr>
</tbody>
</table>

Patients at highest risk for CMV activation are those who are positive from previous exposure and patients that are CMV mismatched with their donor. High risk patients receive preventative intravenous ganciclovir followed by oral valganciclovir. CMV is diagnosed by blood test (CMV PCR) that reports the level of virus. CMV commonly reactivates in the lungs or bowel and often produces the following symptoms: fever, diarrhoea, nausea, vomiting, stomach pain, loss of appetite, cough, shortness of breath, and lethargy. All at risk recipients will take prescribed Valganciclovir for 3-12 months.

**Epstein Barr Virus (EBV)**

EBV is a virus that is in the same viral family as CMV, herpes and zoster. EBV is generally harmless in the general population. However, after transplant EBV has been associated with cancer and is a risk factor that will be monitored. Risk is the same as CMV, in that your risk is calculated on your EBV status and donor EBV status. You may require the antiviral medication valaciclovir.

**Herpes Simplex Virus (HSV)**

HSV oral cold sores and ulcers can appear any time and usually start on the lip and can spread inside the mouth to your gums, tongue and throat. Severe episodes can result in loss of appetite and difficulty eating from ulceration to the mouth, throat and stomach. The spread of HSV can be very rapid and painful because of the weak immune system. You must report cold sores and ulcers for early antiviral treatment.

**Pneumocystis Carinii Pneumonia (PCP)**

Pneumocystis Jiroveci (formerly carinii) is an organism that can cause serious chest infection in transplant patients. Symptoms include
shortness of breath, tightness in chest, temperature, cough and sputum. You must report cold and flu symptoms to receive prompt treatment. All transplant patients take Bactrim DS twice a week to prevent this type of chest infection. You should never stop taking this medication. If you are allergic to Bactrim you will receive an alternative medication.

**Methicillin Resistant Staphylococcus Aureus (MRSA)**

Methicillin Resistant Staphylococcus Aureus (MRSA) is an organism, which is resistant to a wide range of antibiotics. MRSA can cause various degrees of infection, especially if you have a lowered immune system (e.g., after a transplant). MRSA can be cultured on skin, in wounds, sputum, blood cultures, and urine. MRSA is usually treated with a drug called Vancomycin. If you acquire MRSA or have previously had MRSA you will be placed in a single room. While in hospital you must shower daily using the green antiseptic soap. Staff will wear protective clothing and all visitors must wash their hands on arrival and when leaving your room.

**Vancomycin Resistant Enterococcus (VRE)**

Enterococcus is a bacterium that usually lives in the bowel and is treated with the drug vancomycin. Sometimes the bacteria develop resistance to vancomycin and then vancomycin can’t destroy the infection, this is called VRE. VRE is generally harmless but can cause infections in the blood, urine and wounds. It is routinely tested by rectal swab and if you have the bacteria you will be placed in a single room. Staff will wear protective clothing and all visitors must wash their hands on arrival and when leaving your room. While in hospital you must shower daily using the green antiseptic soap.

At St Vincents Vaalia yoghurt is used as a treatment for VRE in the bowel. All patients will receive one Vaalia yoghurt daily with breakfast. It is recommended you continue daily Vaalia products when discharged from hospital until you have a negative rectal swab.
SYMPTOMS OF INFECTION

- Cough +/- sputum
- Fevers
- Shakes and shivers
- Sore throat
- Runny nose
- Temperature >37.3°C
- Breathlessness
- Drop in lung function (if lung transplant patient)
- Nausea
- Vomiting
- Diarrhea

HOW TO AVOID INFECTIONS

Hand Washing

The easiest way to prevent infection is to wash your hands! You should wash your hands for food preparation, before eating, handling raw meats, after going to the toilet, after changing nappies, after cleaning rubbish or removing garbage, after using a tissue or handkerchief and after petting animals.

Personal Hygiene

You should shower or bath daily to cleanse your body to prevent infections and body odour. This is very important while you still have healing surgical wounds from the operation. You should use the blue/green hospital antiseptic soap until your wounds are completely healed. You must also never share towels to prevent cross contamination.

Open Wounds and Cuts

Clean with an antiseptic solution and cover all cuts and wounds daily. If cuts become red, painful and develop pus see your GP for antibiotics.

Dental Hygiene

You should brush and floss your teeth twice a day and don’t forget to clean your tongue. Change your toothbrush every two months and keep your dental appointments twice a year. Poor dental hygiene can cause
infections in your blood and infection on your heart valves. You will also need antibiotic cover for major dental work.

Children

Transplant patient can catch zoster or chicken pox from children infected with chicken pox. If you are exposed to chicken pox, and have not had it previously, speak to the transplant team immediately.

House Hold Pets

If you have a dog or cat around the house keep them clean and minimise pet hair by regular grooming. Litter trays must also be kept clean. These are common-sense issues that most people apply for good pet care, regardless of whether they have had a transplant or not.

One pet of concern are birds. Birds tend to carry diseases that are potentially harmful in transplant recipients. You will need to discuss this with the transplant physician if you keep birds. They are generally not recommended inside the house.

Dusts

Certain types of dusts can be harmful to transplant patients particularly dusts that carry moulds and fungi. An example is dust from exposure to building debris or stagnant soils. This means you should take precautions with tasks like sanding old paintwork, working in enclosed dusty areas and exposure to high levels of outside dust and soils. Wear a good quality protection mask in these situations. If gardening wet the soil so that dust is minimised and wear a mask and gloves when handling potting mixes. No precautions are needed for normal day-to-day activities.

Normal Socialising

The aim of the transplant is for you to return to a normal life. This means socialising with friends, family and meeting new people. We encourage you to do this as soon as you feel well enough. Exposure to infection happens every day and unless told otherwise by the transplant team, your
immune system is strong enough to endure most normal activities. Going to the movies, catching the bus, attending a party — all of these things are fine.

If family have a cough or cold it is a good idea to avoid them if possible, but within reason, you don’t need to move out of the house. Use common sense and remind family and friends of cough etiquette and hand washing. Talk to the transplant physician or nurse should you have any questions.

Reduce the risk of infection by maintaining your hygiene and reporting symptoms early. You were transplanted to have a normal life - enjoy it!

**MEDICATIONS USED IN TRANSPLANT**

Once you are on the ward, the nurses will start teaching you about your medications. As the nurse administers the drugs, their purpose will be explained. You will receive a treatment booklet that lists your drug regime. The pharmacists and nurse will teach you how to use this booklet so you can take responsibility early for your medications.

As you become more confident, the nurse and pharmacist will discuss your medication in more detail and you will be encouraged to self-administer your medications under nursing supervision. By the time you are ready for discharge, you will be getting confident with your medications and their role in your continued well-being.

**NOTE:**

Before we outline the commonly used medications, it is important to remember that all medications have two different names.

- Chemical name: will never change
- Brand name: can have many names

This can be confusing, so it is important to become familiar with both names. There is a section in your treatment booklet where we can record both names for you to learn.
ANTIREJECTION MEDICATIONS USED IN TRANSPLANTATION

It is important with all antirejection medications that you take the dose prescribed for you and not change the amount unless instructed by the transplant doctor. It is also important to take your antirejection medication at the same time and in the same way each day to minimise variability.

If for some reason you do not take a dose at the usual time, take it as soon as you are able to, unless the time is closer to when the next dose is due. In this case, do not take the late dose, wait and take the next dose on time. Do not double your dose to make up for the missed one. If you are unwell and miss up to three doses you need to call the transplant team.

CYCLOSPORIN (Neoral®)

Cyclosporin is the chemical name, the brand name is Neoral®. Its main effect is on the immune system’s T Cells. Cyclosporin inactivates certain T Cells, preventing the production of substances which stimulate an attack of the transplanted organ.

Cyclosporin is usually taken twice a day and is administered in capsule form. Capsules come in

100 mg, 50 mg, 25 mg and 10 mg strengths. Be sure to check the strength on the box and foil carefully. It is also available as a drinkable solution.

Cyclosporin may be taken with food or on an empty stomach. It is important to get into the routine of taking Cyclosporin at the same time in the same way twice each day (twelve hours apart). This will give you the best levels in the blood.

If you have a lung transplant for Cystic Fibrosis, you will be required to take Cyclosporin three times per day. This is because you may have difficulty absorbing the drug. You will also need to take 2 or 3 pancreatic enzyme capsules with your Cyclosporin doses as the drug is in an oily formulation.

Cyclosporin capsules should be kept in the foil wrapper until just prior to taking the dose. Their effectiveness may be diminished if out of the foil for any length of time. It is important to remember this if you use a dosette box or pill box to organise your medication.
Cyclosporin Liquid Formulation

Cyclosporin liquid should be diluted in orange or apple juice. To maintain a steady level in the blood, it is a good idea to get into the habit of using a similar type of juice.

Add the Cyclosporin to a glass or crockery cup only. Cyclosporin cannot be mixed in plastic or paper. Add about ¼ cup of juice, mix with a metal spoon and drink immediately. Add some more juice, swirl around cup to make sure that the whole dose has been taken, and drink. The cup should be washed after each use in hot soapy water. The oral syringe should be wiped clean and not washed.

Each bottle of Cyclosporin should be stored in a cool, dry place. DO NOT STORE IN THE FRIDGE. Each bottle can be used for up to two months after opening. Each dose should be measured accurately with the oral syringe provided. Any Cyclosporin remaining in one bottle should not be tipped into a new bottle, as this can ruin the quality of the new bottle.

Cyclosporin Levels (Heart transplant patients only)

The dose of Cyclosporin for heart transplant patients is decided by checking a Cyclosporin level. This is a blood test that is done every Monday and Thursday for the first month. This test is done when the cyclosporin level in the blood is at its lowest. That is, just before your morning dose. It is important NOT TO TAKE YOUR CYCLOSPORIN UNTIL AFTER YOUR BLOOD TEST ON MONDAYS AND FRIDAYS. If you accidentally take it before your blood test, tell the doctor or nurse, as the level will come back as too high and may affect the dose we prescribe for you.

C2 Levels (Lung transplant patients only)

The dose of Cyclosporin for lung transplant patients is decided with C2 levels. A C2 level is a blood test that measures the amount of Cyclosporin in your blood 2 hours after you have taken your morning dose. This test is done every Monday and Thursday for the first month after transplant. It is important that you TAKE YOUR CYCLOSPORIN AND HAVE A C2 LEVEL TAKEN EXACTLY 2 HOURS LATER. Tell the nurse or doctor if the C2 level was taken late as this will affect the level and dose prescribed for you.

Potential side-effects of Cyclosporin
Side-effects can occur during early treatment when the dose is high. As the dose is decreased to a maintenance dose, side-effects may lessen or disappear. Not all side-effects occur in all patients taking Cyclosporin.

- Changes in kidney and liver function
- High blood pressure (hypertension)
- Headache
- Tremor or shaking
- Nausea
- Increased potassium, sugar and cholesterol levels in the blood
- Decreased magnesium levels in the blood
- Increased hair growth
- Increased gum growth

**TACROLIMUS (PROGRAF®)**

Tacrolimus is the chemical name and Prograf® is the brand name. It inactivates certain T-cells and prevents the production of substances that stimulate attack of the transplanted organ.

Tacrolimus is usually taken twice daily. To ensure stable blood levels it is very important to get into the routine of taking Tacrolimus in the same way twice each day, twelve hours apart.

Tacrolimus is available in 0.5 mg, 1 mg and 5 mg capsules. Your pharmacist or nurse will instruct you on how to take your tacrolimus should your dose not be able to be taken by using whole capsules, for example, if your dose is 0.6 mg twice daily.

Tacrolimus capsules should be kept in the foil blisters until it is time to take them. It is important to remember this if you use a dosette or pill box to organise your medication. Use all the capsules within 12 months of opening the aluminium wrapper. Do not let anyone else handle the capsules.

**NOTE:**

Tacrolimus is also available in a modified release formulation (called Prograf XL®) intended for once-daily dosing. This is NOT the same as the twice-daily dose. Prograf ® and Prograf XL® are not interchangeable.
Tacrolimus Levels

The dose of Tacrolimus is decided by checking a Tacrolimus level. This is a blood test done every Monday and Thursday for the first month after transplant. The blood test is taken when the level of Tacrolimus is at its lowest — that is, just before your morning dose. It is important NOT TO TAKE YOUR TACROLIMUS UNTIL AFTER YOUR BLOOD TEST ON MONDAYS AND THURSDAYS. If you accidentally take it before your blood test, tell the doctor or nurse, as the resulting level will come back too high and may affect the dose we prescribe for you.

Potential side effects of Tacrolimus

Some patients may experience side effects, particularly if the blood level of Tacrolimus is high. Not all side effects occur in all patients taking Tacrolimus.

- Changes in kidney and liver function
- High blood pressure (hypertension)
- Headache
- Sleeping difficulties
- Nausea, vomiting
- Diarrhoea
- Loss of appetite
- Tremor
- Pins and needles
- Increased sugar and potassium levels in the blood

Mycophenolate prevents rejection by suppressing the production of T and B cells. It is available in 250 mg capsules and 500 mg tablets. It is also available as a suspension.

Mycophenolate Mofetil is used as part of a triple therapy regime, often in combination with either:

- Cyclosporin and prednisolone
• Tacrolimus and prednisolone

Mycophenolate is taken twice daily. Swallow the tablets and capsules whole. DO NOT HALVE or CRUSH TABLETS. It is best to take doses 12 hours apart to maintain good blood levels. Mycophenolate can be taken with or without food.

Keep your capsules or tablets in the blister pack until it is time to take them. Do not let anyone else handle them. It is important that mycophenolate not be taken at the same time as certain other medications as they may interfere with the body’s ability to absorb mycophenolate. Mycophenolate should be taken 2 hours apart from magnesium supplements (e.g. Magmin®, Mag-Sup®), antacids (e.g. Mylanta®), cholestyramine (Questran®).

**MYCOPHENOLATE SODIUM (Myfortic®)**

Myfortic contains the same active ingredient as Cellcept (mycophenolate mofetil) but in a different formulation. You may be taking this medication as part of a trial. Myfortic is taken twice a day and is available in 180mg and 360 mg tablets.

Myfortic tablets are specially coated to try to reduce side effect such as nausea and indigestion. DO NOT BREAK or CRUSH TABLETS. It is still important to avoid taking magnesium supplements and antacids within 2 hours of taking Myfortic.

**Mycophenolate Levels**

Occasionally your doctor will check the level of mycophenolate by taking a blood sample. This test is done when the blood level is at its lowest, which is just before your morning dose. This will allow the doctor to ensure that you are receiving the correct dose. Your doctor will notify you when a level needs to be done.

**Potential side effects of Mycophenolate**

- Diarrhoea
- Stomach pain
• Nausea, vomiting
• Decreased white cell count

Mycophenolate has been associated with possible birth defects. Please discuss with your transplant physician if considering a family.

**AZATHIOPRINE (IMURAN®, AZAMUN®, AZAHEXAL®)**

Azathioprine is the chemical name. There are several brand names available. Azathioprine is an antirejection drug usually used in combination with cyclosporin and prednisolone, or tacrolimus and prednisolone. Azathioprine is available in 50mg and 25mg tablets and is taken once daily at night.

**Potential side effects of Azathioprine**

• Diarrhoea
• Nausea, vomiting
• Increased skin sensitivity to sunlight
• Increased liver counts
• Decreased white cell counts

Azathioprine can interact with some drugs — particularly with allopurinol (Progout®, Zyloprim®) which is used for gout. It is therefore VERY important to check with the transplant doctors before starting to take allopurinol if you are also taking Azathioprine.

**EVEROLIMUS (CERTICAN®)**

Everolimus is the chemical name and Certican is the band name. You may also hear this medication referred to as “RAD”. Everolimus prevents T cells and B cells multiplying that are responsible for rejection.

Everolimus is available in 0.25 mg, 0.5 mg and 0.75 mg tablets. It is usually taken twice a day. If you are also taking cyclosporin they should be taken at the same time. The tablets may be taken with food or on an empty
stomach but it is important to keep taking everolimus at the same time and in the same way.

**Everolimus Levels**

The dose of Everolimus is decided by checking an Everolimus level. This is done when the blood level of everolimus is at its lowest, which is just before your morning dose. The doctors will notify you when a level needs to be done. On that day do not take your everolimus dose until AFTER the blood test.

**Potential side effects of Everolimus**

- Nausea, vomiting
- Stomach pain
- Delayed wound healing
- Increased blood pressure
- Increased cholesterol
- Decreased white cell counts

**SIROLIMUS (Rapamune®)**

Sirolimus prevents the multiplication of T cells and B cells which are responsible for rejection. It may be given in combination with cyclosporin and prednisolone or tacrolimus and prednisolone.

Sirolimus is available as 1mg tablets and as a syrup. It is taken once daily usually in the middle of the day. *Cyclosporin may interfere with the absorption of sirolimus, therefore sirolimus must be taken at least 4 hours apart from cyclosporin.* Sirolimus does not need to be separated from tacrolimus.

**Sirolimus Levels**

Occasionally your doctor will check the level of sirolimus by taking a blood sample. This test is done when the blood level of sirolimus is at its lowest, which is just before your dose. This will allow the doctor to ensure that
you are receiving the correct dose. Your doctor will notify you when a level needs to be done.

**Potential side effects of Sirolimus:**

- Delayed wound healing
- Swelling/fluid retention
- Acne
- High cholesterol

Advise your doctor if you notice any unusual:

- Bruising or bleeding
- Coughing, wheezing and difficulty breathing.

**CORTICOSTEROIDS (Prednisolone & Methylprednisolone)**

Prednisolone suppresses the immune system and helps to control and reverse rejection. Prednisolone blocks the immune response by decreasing the number of T Cells, B Cells and inflammatory cells from reaching the transplanted organ.

Prednisolone is a steroid and is very similar to a hormone produced by the body called “Cortisone”. Prednisolone is not the same type of steroid as “anabolic steroids.” Prednisolone is in tablet form and should be taken with food or after food. The intravenous form is called Methylprednisolone and may be used during periods of rejection where it is given in a high dose via a drip over 3 days, followed by an oral dose slowly decreasing over time (known as a taper or wean).

**Side Effects of Prednisolone**

Many side effects of Prednisolone are dose-related. This means that they will be more noticeable in the initial period after transplant. Other side effects may occur when Prednisolone has been taken for a long period of time. The severity of side-effects varies between individuals.

- Increased appetite, which may result in weight gain
• Fluid retention
• Mood changes
• Increased blood sugar levels — Diabetes
• Acne
• Loss of muscle bulk
• Thinning of the bones – osteoporosis
• Thinning of the skin and stomach lining
• Your face may become rounder and you may notice fat around your stomach

ANTITHYMOCYTE GLOBULIN (ATGAM®)

ATGAM® is a powerful drug used to treat steroid resistant rejection and it can also be used to prevent rejection. It is sometimes used in place of cyclosporin in the immediate post-operative period for patients with poor kidney function.

BASILIXIMAB (SIMULECT®)

Basiliximab is a long-acting anti-rejection drug which stops T cells from multiplying. It is sometimes used instead of cyclosporin in the immediate post-operative period in patients with poor kidney function. It is given as an intravenous injection at the time of transplant and again four days later to prevent rejection.

OTHER MEDICATIONS USED IN TRANSPLANT

Most other medications used in transplant are to reduce or prevent side effects from your antirejection medications, or to prevent and treat infections. You should continue to take these even if you are feeling well.

Antihypertensives

Antihypertensive drugs lower blood pressure. Patients taking Cyclosporin and Tacrolimus often have an increase in their blood pressure. If this
occurs a variety of medications can be used. You may have heard of or taken these medications prior to your transplant.

Some of the drugs most commonly given to control blood pressure include Diltiazem (Cardizem®), Irbesartan (Avapro®, Karvea®), Ramipril (Tritace®), and Hydralazine (Alphapress®).

**Anti-Ulcer, Anti-Reflux Drugs**

Medicines that suppress production of stomach acid and help to prevent the development of stomach ulcers and reflux that may be caused by stress and/or Prednisolone. These include Ranitidine (Zantac®), Omeprazole (Losec®) Pantoprazole (Somac®) and Rabeprazole (Pariet®).

Some lung transplant recipients can develop problems with stomach emptying as a result of the surgery. You may need to modify your diet and commence additional medications. Should this become a problem, the transplant physician will discuss this with you.

**Antibiotics**

Antibiotics are required to prevent and treat infections after a transplant. The listed antibiotics are some of the most commonly used antibiotics following transplant.

**SULFAMETHOXAZOLE & TRIMETHOPRIM (Bactrim DS®, Seprin Forte®)**

This is an antibiotic which helps to prevent pneumocystis carinii pneumonia (PCP), which can be a serious chest infection in transplant patients. It is usually given twice a week for life.

**GANCICLOVIR**

Ganciclovir is an anti-viral medicine given either to prevent or treat cytomegalovirus (CMV) infection. When being given to prevent CMV infection, it is given three times per week in a drip until your IV line is removed. You will then need to take valganciclovir tablets.
For treatment of CMV infection, Ganciclovir is usually given via a drip twice a day for 14-21 days. Treatment is usually commenced in hospital but can continue as an outpatient or at home.

**VALGANCICLOVIR (VALCYTE®)**

Valganciclovir is the oral version of ganciclovir and is used to prevent CMV infection. It is usually taken once or twice a day with food for between 3 and 6 months, or for life depending on your CMV status. If you are a lung transplant recipient and a CMV mismatch you will need to take this medication for life.

In some cases, valganciclovir can also be used to treat a CMV infection if it is less severe.

**NYSTATIN (Nilstat®)**

Given as mouth drops to prevent thrush in the mouth, which may be caused by antibiotics and high doses of immunosuppressant drugs. One dropper full is swished around the mouth then swallowed after each meal and before bed time, after brushing your teeth. It is usually stopped at discharge from hospital.

**NEBULISED AMPHOTERICIN (FUNGIZONE®)**

Nebulised amphotericin is given twice daily after transplant to help prevent the development of fungal infections in the lungs. It is usually stopped at discharge from hospital.

**ITRACONAZOLE (SPORANOX®)**

Itraconazole is available in either capsule or syrup form and can be used to prevent or treat fungal infections. It is usually taken twice daily. The capsules are best taken with food. If you are taking medicines that neutralise or suppress production of stomach acid, such as ranitidine, omeprazole, pantoprazole, rabeprazole, or antacids like Mylanta®, it is important that you take them at least 2 hours after itraconazole. This is because sufficient stomach acid is required to ensure that itraconazole is properly absorbed. Acidic beverages such as Coca-cola® and Pepsi® may
affect the absorption of itraconazole, it is therefore important to limit the amount of these drinks unless otherwise advised by your doctor.

If you are taking the liquid, it should be taken on an empty stomach, at least 1 hour before food.

**VANCOMYCIN**

Vancomycin is an antibiotic which is given intravenously to treat some infections including MRSA. It is given via a 2 hour drip once or twice a day, or as a continuous 24 hour infusion. If you require vancomycin as an outpatient it may be prepared in infusor bottles to allow for easy administration.

Vancomycin requires blood level monitoring to ensure that safe and effective levels are achieved. To help with this monitoring we ask that you keep a record of the time that you administer your vancomycin and advise your doctor of these times when you are seen in clinic for blood level monitoring.

**Cholesterol Lowering Agents**

After your transplant it may become difficult to control your cholesterol by diet alone. Some antirejection medicines can increase cholesterol levels. Medications are often necessary to lower your cholesterol. All heart transplant recipients are commenced on Pravastatin (Pravachol®) which prevents the body making cholesterol. It should be taken at night. Sometimes pravastatin may affect your muscles so it is important to let your doctor know if you develop any unusual muscle pain, tenderness or weakness.

**Information About Over the Counter Medications (OTC)**

Never start any new medication without contacting the transplant doctors. Many prescription, over-the-counter (not requiring a prescription) and herbal medications can interact with your anti-rejection medication and thereby prevent it from working or put you at an increased risk of suffering from side effects.

Below are some examples of medications that should be avoided:
• Cough and cold syrups
• Oral medications for blocked sinuses e.g., Sudafed®
• Anti-inflammatory pain killers e.g. Ibuprofen (Nurofen®, Brufen®), Diclofenac (Voltaren®), Indomethacin (Indocid®), Celecoxib (Celebrex®)
• Herbal medications, such as St. Johns Wort (Hypericum perforatum), Echinacea

As well as medications, some foods can interact with antirejection medications. In particular, it is important to avoid eating grapefruit or drinking grapefruit juice.

Please NOTE:

There are many different types of medications that may need to be given during your recovery. The medications described above are the most commonly prescribed medications.

Trials of new drugs are often being undertaken at St Vincent’s Hospital. Should you be included in one of these trials, this will be fully explained to you at the time. If commenced on any new drug it will be discussed with you individually.

HOME INTRAVENOUS THERAPY

It is sometimes necessary to have a prolonged course of intravenous antibiotic therapy. This does not mean you have to remain in hospital, in fact if you are well we prefer you go home to finish your antibiotic therapy. Community nurse will be sought where possible but most cases require more administrations than the community nurse can accommodate. You will receive an intravenous access line (either CVC or PICC line) and will be taught how to prepare and administer your intravenous medications. You will be taught how to administer your medications using either Baxter® bottles, Gemstar® infusion pump or other intravenous administration techniques. All equipment (lines, syringes, fluids) will be provided from the ward and can be restocked from the Heart Lung Clinic following discharge.
Either you or a family member are required to demonstrate a safe technique preparing the medication and managing the intravenous line to nursing staff before you will be allowed to do it at home.

*Pictures below show Gemstar Pump and Baxter Infuser Bottle.*

**PRESCRIPTIONS**

Please ensure you have a list of required medications so that you can have a script written by the doctor at your doctor’s visit. If you do not have a clinic visit or require only a script for medication you can use the prescription line to leave a message regarding the prescriptions you require.

You must provide the following information:

- Medication name
- Medication dosage
- Medication frequency
- Your full name
- Medical record number (MRN)
- Address
- Telephone number
Alternatively you can send an email and provide the information above to hltxscriptline@stvincents.com.au

**THE HEART LUNG CLINIC (HLC)**

The Heart Lung Clinic is located on Xavier level 4 in the main building. You are probably already familiar with the HLC from when you were being assessed for transplant. The HLC has many heart and lung specialist doctors that hold clinics from Monday to Friday both morning and afternoon.

The triage and treatment room are run by nursing staff who are also transplant coordinators.

All follow up for transplant is attended in the HLC after discharge. Intensive follow-up of your condition is required after transplant and often readmission to hospital is common. The HLC can attend your dressings, intravenous medications, treatment for rejection, education, heart monitoring, all day drug monitoring, some invasive procedures, and doctor appointments etc.

You should report to the Heart Lung Clinic on your transplant day (some transplant clinics are different see table) from 8.30am. HLC is open Monday to Friday at 8.30 a.m.—4.00 p.m.
Heart Lung Transplant Routine

NOTE:
Tests and investigations are for inpatients and most outpatients on the days indicated.

<table>
<thead>
<tr>
<th>Week Day</th>
<th>Heart Transplant</th>
<th>Lung Transplant</th>
<th>VAD Patients</th>
<th>Transplant Rehab</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
<td>Blood tests, drug levels, chest xray.</td>
<td>Blood tests, drug levels, chest xray, lung function, bronchoscopy as required</td>
<td>Blood tests, CXR, RHC as needed, Gym</td>
<td>See doctors, Gym 11am-12pm</td>
</tr>
<tr>
<td>Tuesday</td>
<td>See doctors, Heart biopsy as required</td>
<td>See doctors</td>
<td>See doctors</td>
<td>Transplant education 12.12pm – 1.30pm</td>
</tr>
<tr>
<td>Wednesday</td>
<td>Day off unless dressing or IV drip</td>
<td>Day off unless dressing or IV drip required</td>
<td>Blood tests, CXR, RHC as needed</td>
<td>See doctors</td>
</tr>
<tr>
<td>Thursday</td>
<td>See doctors, blood tests, drug levels, chest xray, gym, heart biopsy as required</td>
<td>Blood tests, drug levels, chest xray, lung function, gym, bronchoscopy as required</td>
<td></td>
<td>Gym 11am – 12pm, Support Group &amp; education 12.15pm – 1.30pm</td>
</tr>
<tr>
<td>Friday</td>
<td>Day off unless IV drip</td>
<td>See doctors</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

After three months, your visits will decrease in frequency. Remember that no one person is the same. Do not compare your recovery rate to others.

Reporting a Problem

Regardless of whether you are in the hospital accommodation or at home, if there is an emergency, you or your family should call an ambulance by dialling “000”. You will be taken to the nearest hospital by the ambulance.
They may not take you to St Vincent’s Hospital unless it is closest. The attending hospital will stabilise your condition.

If you are experiencing any **symptoms of infection or rejection** you should contact one of the following numbers:

**Monday to Friday (8.30 a.m. to 4.00 p.m.)**

Contact one of the nurses in Heart Lung Clinic by phoning (02) 8382 3150 or (02) 8382 3158

We strongly advise if you are concerned about anything that you contact the Heart Lung Clinic during work hours rather than wait until late at night or the weekend. This will assist the team to streamline any interventions you may need or admission if required.

**After Hours (weekends, holidays and night) 24 hours a day:**

Phone the hospital on (02) 8382 1111 and ask for the Transplant Coordinator.

They are always available and can offer advice around the clock and will contact the doctors to discuss your case if required. If you leave a message speak slowly leaving your name and contact phone number. If your call has not been returned within 30 minutes call switch and try again.

Please do not contact the transplant team after hours for non-urgent matters such as clinic appointments or blood results “unless instructed otherwise.” This can wait until clinic opens. **The transplant team need their rest as well.**

**However, do not hesitate to phone any time of the day or night if you are unwell.**
RESUMING NORMAL LIFESTYLE ACTIVITIES

Exercise for a Healthy Life

Exercise and activity is important to maintain your health. Daily exercise can help increase energy and reduce stress that will aid sleep and maintain your emotional and psychological health. Other benefits include weight control, prevent osteoporosis, improve diabetes and improve overall fitness and strength. Find something you enjoy doing and do it every day. Walking for 45 minutes a day is recommended for all patients of all age groups.

Many recipients can achieve good levels of fitness and some have been able to attain athlete ability. When our fitness has declined we often lack motivation to start again. Involve your family and friends to join in and start exercising to improve fitness and health.

Aim to:

- Exercise daily.
- At light to moderate intensity
- From 30mins building up to 60mins a day
- Try walking, cycling, swimming, gym class, group exercise, team sports, wii fit, DVD.
Healthy Eating

After your transplant it is important to eat a sensible well balanced diet. The ‘Healthy Living Pyramid’ below gives a guide how we should all lead a healthy lifestyle.
Some of the main considerations after transplant are:

- Aim to keep your weight within the ‘acceptable weight for height’ range. Prednisolone can increase your appetite, but if you exercise regularly and eat sensibly you can achieve your goals.
- Check your calcium intake is adequate. The best sources of calcium are dairy foods (low fat are best for most of us) and tinned fish with the bones ie. salmon and sardines.
- Practice safe food handling. You are more at risk of food poisoning when you are taking antirejection drugs. Refer to www.foodsafety.asn.au for more information.
- If your blood cholesterol is high or you are on cholesterol-lowering medications, switch from saturated to unsaturated fats/oils, and follow other heart-healthy eating guidelines. The Heart Foundation website www.heartfoundation.org.au is a reliable and useful source of information.
- Go easy on salt, particularly if your blood pressure is high, or you have fluid retention or are on a fluid restriction. Choose fresh foods where possible, or processed foods that are low in salt. Minimise salt added in cooking and at the table. www.saltmatters.org is a very useful website for salt skippers.

Enjoy all foods in moderation and get the balance right. Talk to your dietitian if you need further help or have specific dietary needs.

**NOTE:**

This information is only a general guideline to healthy eating and you may have different nutritional requirements at different times post transplant. However, it’s important to eat healthy, improve nutrition and maintain a healthy weight to help your recovery, compliment your drug therapy and maintain good health long term. The dietitian will provide more information should you have a specific dietary requirement.

**Alcohol**

During the first months after transplant you are advised to avoid alcohol while close monitoring is required for drug levels and kidney and liver function. However, from three months (unless you are specifically told
to avoid alcohol) it’s considered acceptable to consume in recommended amounts. The recommended amounts for men and women refer to two “standard” drinks per day.

A ‘standard drink’ is 10 grams of alcohol. Drink serving sizes in pubs and restaurants are often more than one standard drink. The label on an alcoholic drink container tells you the number of standard drinks in the container.

**How much is in a standard drink?**

<table>
<thead>
<tr>
<th>Drink Type</th>
<th>Standard Drink</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can/Stubbie - low-strength beer</td>
<td>0.8</td>
</tr>
<tr>
<td>Can/Stubbie - mid-strength beer</td>
<td>1</td>
</tr>
<tr>
<td>Can/Stubbie - full-strength beer</td>
<td>1.4</td>
</tr>
<tr>
<td>100ml wine (13.5% alcohol)</td>
<td></td>
</tr>
<tr>
<td>30ml nip spirits</td>
<td></td>
</tr>
<tr>
<td>Can spirits (approx 5% alcohol)</td>
<td>1.2 to 1.7</td>
</tr>
<tr>
<td>Can spirits (approx 7% alcohol)</td>
<td>1.6 to 2.4</td>
</tr>
</tbody>
</table>

**Driving after Transplant Surgery**

Most patients want to start driving as soon as possible after their transplant. But the rules are very clear and set out to protect you, the transplant patient, the transplant doctors and the general public. The guidelines clearly outline the responsibilities of drivers, health professionals and the licensing authorities. For more information on assessing fitness to drive you can visit the website: [www.austroads.com.au](http://www.austroads.com.au)

The transplant team as a rule do not directly communicate to the NSW RTA - Diver License Authority. However, the team are bound by law to report patients that are considered a risk despite having received counselling and advice not to drive. The transplant doctor will inform you when it is safe to drive again and can provide you with a letter for the RTA if you have a conditional license.
As a rule you should be allowed to drive a car again after **approximately six weeks following your transplant**. However, this can be delayed if complications prolong your recovery that can affect your ability to drive safely. If you doubt your own ability to drive a car safely, don’t do it.

**Returning to Work**

Even before the transplant you should be thinking about what might be required to return work. When the time comes for preparation to begin it may be easier than you think? You must talk to the transplant team first to confirm you are fit to return to work. There may be certain areas of your job you are unable to perform until after a specific time point. It may be that you can no longer return to the same type of work. We can enlist the help of an occupational therapist, workforce officer and social worker to help you transition back to the workforce.

**Resuming Relationships and Sexual Intimacy**

When you have recovered from your surgery some of the issues you will need to consider are sexual intimacy, birth control and pregnancy. This is equally important for both men and women.

It is important to know all patients are advised to wait up to 6-8 weeks after transplant surgery before recommencing vigorous physical activity. This will allow your chest wounds to heal and mend. Of course you can be intimate with your partner but not in a way that can cause injury to healing chest wounds.

**Pregnancy**

Many women worry about pregnancy and their ability to start a family after transplant. However, fertility and libido can return quickly for men and women. Many of our patients have successfully become parents. We recommend that females avoid pregnancy after transplant for a minimum of one year **(two years for lung transplant recipients)** as there is high risk of rejection. Before considering pregnancy you must first consider your health to have a baby.

Things you and your doctor must consider are:

- Transplant graft function – heart or lung.
- Antirejection medications and levels
• Kidney function
• Blood pressure
• Overall general health

There is also concern for men and women about the possibility of birth defects caused by the drugs you are taking. Therefore, we strongly encourage you to discuss family planning and pregnancy with your transplant doctor, gynaecologist and obstetrician.

Before embarking on a sexual relationship, in order to prevent unplanned pregnancies or potential serious infections we encourage you to discuss birth control options with your transplant doctor. Condoms, diaphragms and spermicidal jellies are safe to use and some contraceptive pills, but you must clarify the brand with the transplant doctor. Remember to follow safe sexual health practices and use a condom to reduce the risk of sexually transmitted infections.

**Travelling after Transplant**

Many people want to take a holiday after they have been given clearance by the transplant team. This is both welcomed and encouraged. If you wish to travel, especially overseas or to a remote area, you need to plan ahead.

• Ensure that you have enough supply of medications to last the duration of your holiday; plus carry extra in case some are lost.
• NEVER travel with a depleted stock of drugs; this is both irresponsible and dangerous.
• If travelling overseas, put medications in your luggage and spare stock in your hand luggage in case your bag is lost!
• Carry identification at all times with details of your medical history and a contact numbers for St Vincent’s.
• You should try gain travel insurance that covers you for illness associated with your transplant. Overseas medical treatment can be very costly. Most travel insurance companies are reluctant to cover transplant recipients. You will need to shop around.
Vaccinations

Vaccinations are still important after transplant to prevent infections. However, not all vaccines are safe for transplant patients. You are encouraged to have all necessary vaccines before transplant. You must NOT receive a **LIVE VACCINE after transplant**; these are contraindicated for transplant patients. Once you have a transplant you can only receive the inactive (dead) form of vaccine.

<table>
<thead>
<tr>
<th>Vaccines</th>
<th>Before Transplant</th>
<th>After Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis A</td>
<td>Yes if seronegative</td>
<td>Yes if seronegative</td>
</tr>
<tr>
<td>Hepatitis B (accelerated schedule before transplant)</td>
<td>Yes depending on serological status</td>
<td>Yes depending on serological status</td>
</tr>
<tr>
<td>Influenza Vaccine &amp; Pneumococcal vaccine (23vPPV)</td>
<td>Yes - annually</td>
<td>Yes - annually</td>
</tr>
<tr>
<td>Inactivated Poliovirus (IPV)</td>
<td>Yes, if no booster in past 10 years</td>
<td>Yes, if no booster in past 10 years</td>
</tr>
<tr>
<td>Diptheria-tetanus-pertussis (dTpa)</td>
<td>Yes if not been given previously</td>
<td>Yes if not been given previously</td>
</tr>
<tr>
<td>Vaccination</td>
<td>Offered</td>
<td>Contraindicated after transplant</td>
</tr>
<tr>
<td>-------------------------------------------------</td>
<td>---------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>Meningococcal C conjugate (MenCCV) &amp; Meningococcal Polysaccharide Vaccine (4vMenPV)</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Varicella Vaccine</td>
<td>Yes</td>
<td>No – contraindicated after transplant</td>
</tr>
<tr>
<td>MMR vaccine.</td>
<td>Yes</td>
<td>No - contraindicated after transplant</td>
</tr>
<tr>
<td>HPV Vaccine</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>


If you need vaccinations for international travel you must seek expert opinion first and request information about the **inactivated form of Vaccines**. The following live vaccinations are contraindicated in patients with an impaired immunity.

- Smallpox (vaccinia virus).
- Tuberculosis (BCG).
- Oral typhoid vaccines
- Yellow fever vaccine.

**LONG TERM HEALTH AFTER TRANSPLANT**

It is important that you maintain lifelong contact with the transplant team. If you move interstate we will refer you to the local transplant service in your area. Regardless of where you chose to live; you **must** have your annual health checks!

You will receive a long term follow up schedule and it is your responsibility to ensure you have each of the tests or investigations listed at the time point indicated. You are required to have specific heart or lung investigations for transplant graft function. However, you also need tests for health problems associated with long term antirejection medications. Your GP can refer you to the appropriate radiology centre or specialist in your area for tests. Make sure results are sent to St Vincents or bring them with you for your annual follow up appointment.
Cancer Screening

Transplant patients have a high risk of certain types of cancer because of suppression of the immune system. It is vital that men’s health and women’s health routine screening tests are not forgotten! Early detection is the key for early treatment.

Cervical and Breast Cancer

Women should have annual pap smears and gynaecological examinations and report any unusual menstrual bleeding patterns. Monthly self breast examination is also important to check for lumps and bumps and should be done about one week after having a period. Mammograms must also be included in routine screening.

Bowel Cancer

Some patients are at greater risk following transplant especially those with a family history and medical history of inflammatory bowel disease. Patients with risk factors should have annual faecal occult blood tests and colonoscopy. All patients must report any sign of blood in their stool or bleeding from the anal and rectal area.

Prostate Cancer

Men should have regular PSA blood test and internal prostate examination. If the prostate is enlarged and the PSA is elevated it may indicate cancer. Men’s health screening is very important do not forget.

Skin Cancers (Melanoma)

You must see a dermatologist annually to assess your skin for cancers. We recommend that you do your own skin self assessment at the same time each month. If you notice a change in size and appearance of any mole or freckle go see your dermatologist immediately. You must wear SPF 30 sunscreen, hat, sun glasses and proper T Shirt when out in the sun and when swimming.
Post Transplant proliferative Disease (PTLD)

PTLD is associated with the Epstein Barr Virus (EBV) and mostly causes B Cell lymphoma. PTLD can occur in the first year after transplant and this is why it’s important you attend all follow up for early detection. You should also know your EBV status and if you don’t ask your transplant doctor or nurse.

Osteoporosis

Patients are at risk for developing osteoporosis from long term steroid therapy. Osteoporosis leads to brittle bones and fractures commonly in the spine and ribs and may cause joint problems. Most patients will take Calcium and Vitamin D to prevent bone loss. Bone Mineral Density (BMD) scan is done as part of your work up and should be repeated annually after transplant. You may need to take medications if you have more risk factors.

Diabetes

It is common to have diabetes during the first year of transplant particularly when medication is at high doses. Prednisolone and Tacrolimus can contribute to high blood sugar levels. Most patients find with time that their diabetes improves and people previously not diabetic will also see an improvement.

Diabetes is managed with a good diet, oral medications and insulin. If you develop diabetes you need to see the diabetes doctor and educator.

Ophthalmology

You should see an ophthalmologist every year because you take Prednisolone and other medications that can cause problems with your eye sight and blur your vision.

SUDDEN AND UNEXPECTED DEATH AFTER TRANSPLANT (POST MORTEM/AUTOPTSY)

You have every chance to live a long and healthy life after your transplant. However, life does come to an end for all of us. If your death is sudden,
unexpected or associated with a complicated illness it is important to confirm the cause. Identifying cause of death is by post mortem.

The transplant doctor or post mortem coordinator will approach your family to request consent for post mortem. Having information about your cause of death and condition of your heart or lungs will not only be beneficial for your family and the transplant team but future generations of transplant patients. We ask that you talk to your family about consenting for post mortem, as you would for organ donation. This will lessen your family’s stress during their grief if they know your wishes.

INTERNET AND WEBSITES

There are multiple internet websites that have good and bad information about transplantation.

The websites below have national and international information that is suitable for transplant recipients and transplant professionals.

- Australian Heart Lung Transplant Association:  
  www.ahlta.com.au
- Australian Transplant Games:  
  www.australiantransplantgames.com
- Donatelifes:  
  www.donatelifegov.au
- Transplant Australia:  
  www.transplant.org.au
- Transplant Society of Australia and New Zealand:  
  www.tsanz.com.au
- Australia & New Zealand Cardiothoracic Transplant registry:  
  www.anzcotr.org.au
- International Society for Heart & Lung Transplantation:  
  www.ishlt.org
Maintaining Communication

After transplant all recipients must maintain lifelong following up with the transplant unit. The transplant unit will also endeavour to update our recipients as often as possible with new information or activities. If you have an email address the transplant nurse will add this to the database and on occasion you will receive emails from the following address. svhtransplantpatients@stvincents.com.au

Do not reply to emails from this address or send emails to this address, if you have an enquiry contact the Heart Lung Clinic.

MAKING A DONATION

The transplant program is funded by the state government however, relies heavily on donations from the community. Should you wish to make a donation to the transplant unit you can make a donation to the Harry Windor Trust Fund that goes directly to the unit for equipment or to the Mary Stringer Trust Fund, which is for patient assistance.

SUMMARY

It is important to read this booklet often because it will help you to understand transplantation. You will need to refer to it on many occasions. Always keep it handy.

Remember the signs and symptoms of infection and rejection and report these promptly. The sooner you receive treatment the better your outcome. Never forget your annual follow up appointments.

If you have any questions, do not hesitate to ask. Always make NOTE:s and write questions down to ask the team. Be responsible and get involved in your care, take charge. Your health is important, the transplant team will always to their job...now you must do yours!!

Organ donation saves lives and we hope you will help raise awareness and promote organ donation to save many more.
APPENDICIES

Heart Transplant Follow Up Schedule

<table>
<thead>
<tr>
<th>Weeks 0 – 4</th>
<th>Weeks 5-11</th>
<th>Months 3-6</th>
<th>Months 7-11</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bloods:</strong> twice weekly UEC/FBC/LFT/CMP/Gluc.</td>
<td><strong>Bloods:</strong> weekly UEC/FBC/LFT/Gluc</td>
<td><strong>Bloods:</strong> monthly UEC/FBC/LFT/Gluc Cholesterol &amp; lipids at 3 &amp; 6 months.</td>
<td><strong>Bloods:</strong> monthly UEC/FBC/LFT/Gluc Cholesterol &amp; lipids at 9 months</td>
</tr>
<tr>
<td><strong>Cholesterol &amp; lipids</strong> week 4</td>
<td><strong>Cholesterol &amp; lipids</strong></td>
<td><strong>Cholesterol &amp; lipids</strong> at 3 &amp; 6 months.</td>
<td><strong>Cholesterol &amp; lipids</strong> at 9 months</td>
</tr>
<tr>
<td><strong>Drug levels:</strong> weekly</td>
<td><strong>Drug levels:</strong> weekly</td>
<td><strong>Drug level:</strong> monthly</td>
<td><strong>Drug levels:</strong> monthly</td>
</tr>
<tr>
<td><strong>Heart biopsy:</strong> weekly</td>
<td><strong>Heart biopsy:</strong> weeks 6, 8, 10.</td>
<td><strong>Heart biopsy:</strong> monthly.</td>
<td><strong>Heart biopsy:</strong> 9 months</td>
</tr>
<tr>
<td><strong>Chest Xray:</strong> weekly</td>
<td><strong>Chest Xray:</strong> weekly</td>
<td><strong>Chest Xray:</strong> monthly</td>
<td><strong>Chest Xray:</strong> monthly</td>
</tr>
</tbody>
</table>
Annual Tests after 1st year

- Blood tests: UEC/FBC/LFT/Gluc, drug levels, cholesterol & lipids
- Chest Xray
- Stress Echo
- Bone Mineral Density scan
- Skin Check
- Angiogram: years 1, 5, 10, 15, 20
- Hepatitis B & Hepatitis C blood test: years 3 & 5
- Men’s & woman’s health screening

Lung Transplant Follow Up schedule

<table>
<thead>
<tr>
<th>Weeks 0-3</th>
<th>Weeks 4-12</th>
<th>Months 4-11</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bloods:</strong></td>
<td><strong>Bloods:</strong></td>
<td><strong>Bloods:</strong></td>
</tr>
<tr>
<td>twice weekly</td>
<td>twice weekly</td>
<td>monthly</td>
</tr>
<tr>
<td>UEC/FBC/LFT/CMP/Gluc</td>
<td>UEC/FBC/LFT/CMP/Gluc</td>
<td></td>
</tr>
<tr>
<td><strong>Drug levels:</strong></td>
<td><strong>Drug levels:</strong></td>
<td><strong>Drug levels:</strong></td>
</tr>
<tr>
<td>twice weekly</td>
<td>weekly</td>
<td>monthly</td>
</tr>
<tr>
<td><strong>Chest Xray:</strong></td>
<td><strong>Chest Xray:</strong></td>
<td><strong>Chest xray:</strong></td>
</tr>
<tr>
<td>twice weekly</td>
<td>weekly</td>
<td>monthly</td>
</tr>
<tr>
<td><strong>Bronchoscopy:</strong></td>
<td><strong>Bronchoscopy:</strong></td>
<td><strong>Bronchoscopy:</strong></td>
</tr>
<tr>
<td>weeks 1 &amp; 3.</td>
<td>weeks 6, 9 &amp; 12.</td>
<td>as required.</td>
</tr>
<tr>
<td><strong>LOOP:</strong></td>
<td><strong>LOOP:</strong></td>
<td><strong>LOOP:</strong></td>
</tr>
<tr>
<td>twice weekly if outpatient.</td>
<td>weekly</td>
<td>monthly</td>
</tr>
</tbody>
</table>

Annual Tests after 1st year

- Blood tests: UEC/FBC/LFT/Gluc, drug levels, cholesterol & lipids
- Full Lung Function
- Chest Xray
- Bone Mineral Density scan
- Skin check
- Hepatitis B & Hepatitis C blood test: years 3 & 5
- Men’s & woman’s health screening.
- Angiogram for heart & lung transplant patients at: years 2 & 10

**Glossary**

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute</td>
<td>Term meaning to have a sudden onset.</td>
</tr>
<tr>
<td>Antibody</td>
<td>Part of the immune system to protect the body from foreign objects and help fight infections.</td>
</tr>
<tr>
<td>Antigen</td>
<td>Part of the immune system that is triggered to produce an antibody.</td>
</tr>
<tr>
<td>Antiviral</td>
<td>Medication to prevent or treat a range of virus.</td>
</tr>
<tr>
<td>Bacteria</td>
<td>An organism that can cause serious bacterial illness.</td>
</tr>
<tr>
<td>Biopsy</td>
<td>Procedure performed to take tissue samples.</td>
</tr>
<tr>
<td>Bronchoscopy</td>
<td>Procedure to look inside the lungs for infection and take tissue samples.</td>
</tr>
<tr>
<td>B Cells</td>
<td>Part of the immune system that can cause antibody mediated rejection.</td>
</tr>
<tr>
<td>CAT Scan</td>
<td>Computerised xray machine to capture multiple images of the body to look for cancers and abnormalities.</td>
</tr>
<tr>
<td>Chronic</td>
<td>Term meaning to happen over a long period of time.</td>
</tr>
<tr>
<td>CMV</td>
<td>Cytomegalovirus is a virus that can cause serious illness after transplant and is treated with ganciclovir.</td>
</tr>
<tr>
<td>Compliance</td>
<td>Is following medical advice and taking medications as prescribed.</td>
</tr>
<tr>
<td>Coronary Angiogram</td>
<td>Procedure that injects a dye into the body through the groin blood vessel to view the blood vessels around the heart.</td>
</tr>
<tr>
<td>Creatinine</td>
<td>A waste product excreted by the kidneys that is an indicator of kidney function.</td>
</tr>
<tr>
<td>Cross match</td>
<td>Process used to match donors and recipients by blood test.</td>
</tr>
<tr>
<td>CXR</td>
<td>Radiological test to view areas of the body for air spaces, fluid spaces and masses.</td>
</tr>
<tr>
<td>Cytotoxic</td>
<td>Term used to describe hazardous medications used to prevent rejection or treat viruses.</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>A condition that causes abnormal blood glucose levels and may need insulin.</td>
</tr>
<tr>
<td><strong>ECG</strong></td>
<td>Electrocardiogram is a test to look at the heart’s electrical system.</td>
</tr>
<tr>
<td><strong>Electrolytes</strong></td>
<td>Minerals in the body that help maintain normal organ function. i.e potassium, sodium, calcium, magnesium.</td>
</tr>
<tr>
<td><strong>ECHO</strong></td>
<td>Echocardiography is a ultrasound of the heart to view the valves, chambers and strength strength and motion.</td>
</tr>
<tr>
<td><strong>Fluid retention</strong></td>
<td>Excess build up of sodium and water in the body that causes swelling or odema.</td>
</tr>
<tr>
<td><strong>Fungus</strong></td>
<td>Organism that can cause a fungal illness.</td>
</tr>
<tr>
<td><strong>Gated Heart Pool Scan</strong></td>
<td>Heart scan that uses a dye to view how well the heart is pumping.</td>
</tr>
<tr>
<td><strong>Graft</strong></td>
<td>The transplanted heart or lungs.</td>
</tr>
<tr>
<td><strong>Heart Biopsy</strong></td>
<td>Procedure used to test for heart rejection via puncture in the large neck vein.</td>
</tr>
<tr>
<td><strong>Hypertension</strong></td>
<td>Medical term meaning high blood pressure.</td>
</tr>
<tr>
<td><strong>Immune System</strong></td>
<td>System in the body made up of cells, proteins and tissue to protect the body from invasion by infections and foreign bodies.</td>
</tr>
<tr>
<td><strong>Immunosuppression medication</strong></td>
<td>Medications to lower the immune system to allow the body to accept a transplanted organ and prevent rejection.</td>
</tr>
<tr>
<td><strong>Isolation</strong></td>
<td>Used when infectious patients are nursed in a single room.</td>
</tr>
<tr>
<td><strong>LOOP</strong></td>
<td>Flow volume loop – lung function test.</td>
</tr>
<tr>
<td><strong>Lung Function</strong></td>
<td>Test to measure how well the lungs work.</td>
</tr>
<tr>
<td><strong>Noncompliance</strong></td>
<td>Refusing medication or not following medical advice.</td>
</tr>
<tr>
<td><strong>Oedema</strong></td>
<td>Is swelling that can appear in various parts of the body due to illness.</td>
</tr>
<tr>
<td><strong>Osteoporosis</strong></td>
<td>Condition that causes brittle bones and discomfort.</td>
</tr>
<tr>
<td><strong>Pacemaker</strong></td>
<td>Small device inserted under the skin to control heart rate.</td>
</tr>
<tr>
<td><strong>Prophylaxis</strong></td>
<td>Term meaning to prevent illness or disease with medication.</td>
</tr>
<tr>
<td><strong>Rejection</strong></td>
<td>Immune system process that causes poor function of the transplanted heart or lungs.</td>
</tr>
<tr>
<td><strong>Right Heart Catheter</strong></td>
<td>Procedure used to measure heart pressures via puncture in the large neck vein.</td>
</tr>
<tr>
<td><strong>Six Minute Walk Test</strong></td>
<td>Test to calculate the distant walked in six minutes.</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-----------------------------------------------------</td>
</tr>
<tr>
<td><strong>Sputum</strong></td>
<td>Thick secretions that build up in the lungs because of infection.</td>
</tr>
<tr>
<td><strong>T Cells</strong></td>
<td>Part of the immune system that can cause rejection.</td>
</tr>
<tr>
<td><strong>Tissue Typing</strong></td>
<td>A blood test that looks at the inherited cells from parents to aid matching with organ donors.</td>
</tr>
<tr>
<td><strong>Transfusion</strong></td>
<td>Blood transfusion for anaemia or large blood loss.</td>
</tr>
<tr>
<td><strong>Vaccination</strong></td>
<td>A technique to protect (vaccinate) the body from community acquired virus and illness.</td>
</tr>
<tr>
<td><strong>Virus</strong></td>
<td>Organism that can cause serious viral illness.</td>
</tr>
</tbody>
</table>
Contact Telephone Numbers

Heart Lung Clinic

*Business hours only*  
**Phone:** (02) 8382 3150 or (02) 8382 3158

Transplant Nurse Consultant

*Business hours only*  
**Phone:** (02) 8382 1111 (ask to page)

Transplant Co-ordinator  
**Phone:** (02) 8382 1111 (ask to page)

Transplant Physician  
**Phone:** (02) 8382 1111 (ask to page)
The heart transplant consent form is an addition to the transplant information manual and will confirm your decision to accept the responsibility of transplant and ensure you understand the risks and benefits.

I am consenting for a heart transplant. I know that success cannot be guaranteed. Because of the shortage of organ donors, I may be offered a 'marginal' or less than perfect organ, e.g. coming from a donor who is older, or from a smoker.

I am aware that my chance of being alive at 1 year after a heart transplant is 87%, and at 10 years 62% and at 20 years 36%.

I will accept I will be on lifelong medications to stop my immune system rejecting the new heart.

I understand the following complications may occur:

- Dying in the first year 1 in 8 chance
- The new heart failing to function and need for support of my circulation with machines (ECMO or balloon pump) 1 in 100
- Stroke or disabling brain damage 5 in 100
- Bleeding from the operation, or needing a repeat operation 1 in 10
- Severe infection of the breast bone 1 in 20
- Need for a pacemaker or defibrillator for the new heart 1 in 10
- Infection of any type 1 in 2
- Rejection of the new heart 1 in 3
- Needing a blood transfusion, or having a reaction to anaesthetic 1 in 2
- Risk of kidney failure within a decade 1 in 10
- Risk of cancer (including cancer of white blood cells, skin cancer) 1 in 3

*(Statistics sourced from Australia & New Zealand Cardiothoracic Transplant Organ Registry Annual Report 2010)*

I agree to cooperate with medical advice to look after my new heart and to take my medications.

Yes No

I have been offered the option of taking a donor heart from someone that is hepatitis B positive. I have been vaccinated for hepatitis B but there is still a chance of catching hepatitis. I consent to accepting a donor who is hepatitis B positive.

Yes No

I have been offered the option of taking a donor heart from someone with a tumour which is generally not considered likely to reoccur. I consent to use of such a donor.

Yes No

I understand that the transplant involves the removal of my heart and other tissues which may be required for the diagnosis or management of my condition. I consent to this.

Yes No

I consent to the use of any unneeded tissue for research.

Yes No
I consent to my information being discussed in case conference and data (no name attached) being used in quality assurance programs and databases. Yes No

I have read the information provided and had the opportunity to ask questions and I am satisfied with the explanation and the answers to my questions.

At Listing for Transplant:

Name of patient __________________________ Signature _______________ Date ___________

Name of witness __________________________ Signature _______________ Date ___________

Doctor (Physician or Surgeon) __________________________ Signature _______________ Date ___________

At the time of Transplant:

(This is a re-acknowledgement of the above agreement and is separate from and in addition to the St Vincent’s Hospital operation consent form.)

Name of patient __________________________ Signature _______________ Date ___________

Name of witness __________________________ Signature _______________ Date ___________

Doctor __________________________ Signature _______________ Date ___________

Reference:
Transplant Society Australia and New Zealand Organ Allocation Protocols

NSW Health Policy Directives.
PD2010_002 Organ Donation and Transplantation: Managing Risks of Transmission of HIV, HCV and HBV.
PD2005_341 Human Tissue Use/Retention Including Organ Donation, Post Mortem Examination and Coronial Matters.
PD2005_406 Consent to Medical Treatment - Patient Information.
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[Logo of Astellas Transplant]