



ST VINCENT'S  
HOSPITAL  
SYDNEY

A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA



# *Information Manual*

For Lung Transplant Recipients

HEART · AND · LUNG · TRANSPLANT · UNIT

Printing of this manual has been supported by  
an educational grant from



This information manual was drafted by  
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the multidisciplinary transplant team.

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# Lung Transplantation

## Information Manual

for

Patients

Family and

Friends.

St Vincents Health Network. Sydney. 2019

Eighth Edition

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





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*Heart and lung transplant recipients celebrating 30yrs of transplantation at St Vincents  
Photo by Andrew Quilty Photography*

## 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 including the admission 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 including 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 45 heart and 60 lung transplants per year. The transplant program at St Vincents is primarily an adult service although does extend service and expertise to adolescent patients.

To date, the transplant unit has performed over 1000 heart transplants, 90 heart-lung transplants and 1000 lung transplants. The transplant program is funded by the State Government, however, relies heavily on donations from the community.

*Statistics sourced from the Australian & New Cardiothoracic Organ Transplant Registry Twenty 2ND Annual Report 1984-2018.*

# GENERAL INFORMATION

## Accommodation

We have limited accommodation at St Vincent's Hospital for patients and relatives from rural and remote areas. To book accommodation you can ring the Accommodation Officer at the Social Work Department on 8382 2114. Rooms cost \$30 per person, each night. The accommodation is a short steep walk from the hospital. The hospital accommodation fills up quickly and if we don't have any rooms sometimes our families from rural areas also utilise patients and relative's accommodation at War Memorial Hospital, Elizabeth Hunter Lodge. For more information speak with the accommodation officer or your social worker.

We can also give you a list of other options (local lodges, hotels and motels). "You will need to book these yourself."

## 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 will not receive an invoice after the 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.

## Social Work Department

The social work department is located on level 4, De Lacy Building, phone (02) 8382 2213. The transplant social workers are 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 team often participate in documentaries, newspaper radio and television to promote organ donation and transplantation. We are often asked if transplant recipients or patients on the waiting lists will 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 LUNG TRANSPLANTATION**

### **Transplant Society of Australia and New Zealand Eligibility Criteria**

#### **Lung Inclusion Criteria**

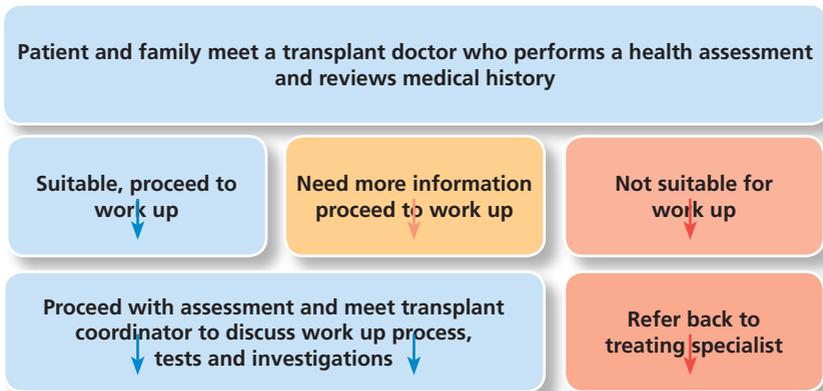
- Progressive respiratory failure despite optimal medical therapy, interventional and surgical treatment and/or;
- Poor quality of life, potentially with intractable symptoms and repeat hospital admissions.

#### **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 medical up.
- Substance addiction that is either active or within the last 6 months – cigarettes, alcohol and drugs.
- Uncorrected atherosclerotic disease with end-organ dysfunction including coronary artery disease not amenable to revascularisation
- Body Mass Index BMI >35 is an absolute contraindication and BMI >30 is a relative contraindication
- Absence of an adequate and reliable social support system
- Severely limited mobility with poor rehabilitation potential

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

# REFERRAL AND ASSESSMENT FOR 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 transplant work up/assessment

You need an appointment to see a transplant doctor at the Heart Lung Clinic and will need to bring your Medicare Card and copy of your referral letter. Your work up may take a few weeks or months to complete depending on the severity of your heart and/or lung disease or the complex nature of your medical history. It is important to know that not every patient referred to the transplant unit is accepted for transplant. And it may take weeks or months before a final decision can be made. Your information must be shared and discussed with numerous members of the multidisciplinary 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 review adolescent patients for heart and lung transplant assessment from both Children's 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 may transplant adolescents under 16 years of age when needed.

### How we transition adolescent patients to St Vincents

- Paediatric staff attends outpatient appointments with the adolescent and their family.
- Adolescent and family meet transplant staff
- 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 are welcome to be present for medical rounds.
- Paediatric staff may also be present for the transplant rounds.
- Parents or relatives 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 postoperative recovery and outpatient care.

### Transplant Work Up

Blood tests (multiple required)	Tissue typing and PRA (multiple blood tests)
Body scans	Lung Function Tests
Sleep study tests	Heart scans and heart catheter tests
Bone Scan	Colonoscopy/gastroscopy as indicated
Dental x-ray and examination	Cancer screening (male & female health)
Infection screening	Alcohol, cigarette and drug screening
Allied health consultations	Psychiatry consultations
Medical consultations	Nursing consultations

**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 transplant require 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 and lifestyle modification.

You will be required to reside in local 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 workers 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. Patients **must demonstrate six months abstinence and cessation** from smoking and substance use. If the transplant team advise support from drug and alcohol or psychiatry then failure to do this will be considered as non-adherence with the program.

For smoking, three negative tests over a six month time period is required. 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. 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.

## 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 classes 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:** 10.30am to 12pm

**Days:** Monday and Thursday

## **Meeting the Multidisciplinary Team**

You are required to meet various members of the transplant team for assessment and receive education. All patients are required to meet the nursing and allied health staff during work up. The information provided during work up will assist with your care after transplant surgery.

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

## **Frailty Assessment**

The Occupational Therapist will usually see you for a Frailty assessment as a part of your transplant work-up. This is to assess your physical strength, appetite, endurance, cognition and mood in relation to your activities of daily living and quality of life. The Occupational Therapist may also have recommendations of ways to improve these factors with a view to maximising your quality of life and independence within your activities of daily living.

## The Multidisciplinary Transplant Team

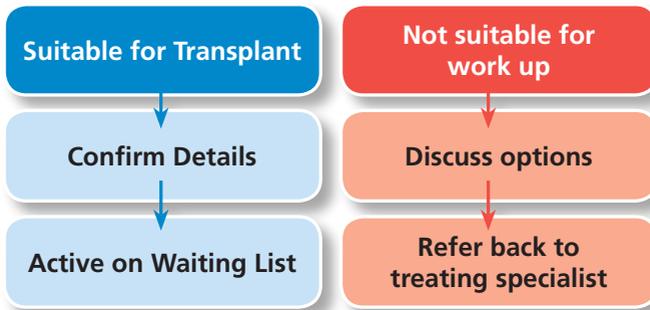
<b>Cardiothoracic surgeons</b>	Assessment for active listing, transplant surgery, mechanical support surgery, cardiothoracic surgery, organ retrieval surgery and outpatient surgical follow up.
<b>Heart transplant doctors</b>	Assessment for active listing, heart failure and pulmonary hypertension management, drug trials, heart transplant patient management and research.
<b>Lung transplant doctors</b>	Assessment for active listing, lung failure management, drug trials, lung transplant patient management and research.
<b>Transplant Coordinators</b>	Assessment and work up, education, transplantation coordination, outpatient care and support
<b>Cardiothoracic surgeons</b>	Assessment for active listing, transplant surgery, mechanical support surgery, cardiothoracic surgery, organ retrieval surgery and outpatient surgical follow up.
<b>Heart transplant doctors</b>	Assessment for active listing, heart failure and pulmonary hypertension management, drug trials, heart transplant patient management and research.
<b>Lung transplant doctors</b>	Assessment for active listing, lung failure management, drug trials, lung transplant patient management and research.
<b>Transplant Coordinators</b>	Assessment and work up, education, transplantation coordination, outpatient care and support
<b>Transplant Clinical Nurse Consultant</b>	Assessment and work up, education, inpatient transplant clinical coordination, outpatient clinic, transplant coordination, data management and research.
<b>Mechanical Circulatory Support Clinical Nurse Consultant</b>	Assessment and work up, education, inpatient care, outpatient care, clinical coordination and technical maintenance and support
<b>Social Workers</b>	Assessment, social assistance, travel, accommodation, finance, legal assistance, support group
<b>Pharmacists</b>	Education and medicines information after transplant.
<b>Physiotherapists Occupational therapists</b>	Assessment, muscle and strength conditioning, rehabilitation program
<b>Psychiatrist/Psychologist Clinical Nurse Consultant</b>	Assessment, transition, chronic illness management, delirium, anxiety, depression and coping strategies
<b>Dietician</b>	Nutritional assessment and dietary recommendations, education and support.

### NOTE:

The transplant program work as a team and all patient information is 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 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 and frail to have a transplant. Whatever the reason, each case is looked at individually. The transplant doctor will explain the reasons to you and your family.

### Supportive and Palliative Care

It's important to be realistic about your survival. You need to decide what is going to 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, 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 and supportive care options. However, if you prefer, our social worker and transplant doctors can refer you to the appropriate services to discuss further.

### Suitable for Transplant

If 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 your health can be monitored and to 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.

## **Your Responsibilities while on the Active Waiting List**

While waiting for your transplant you must:

- Have a monthly antibody blood 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 or 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." The monthly sample is used to match you to potential organ donors.

It is imperative that this blood test 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 labelled with your name, full date of birth and full date of collection.**

## Waiting list Priority

Priority will depend on who is a potential match to the donor. This is determined by:

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.**

### Lung Donation

- Blood group & cross match
- Lung size
- Height & Gender
- Most critical in need

## 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 at the following website [www.tsanz.com.au](http://www.tsanz.com.au)

Organ donation rates are increasing however, 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.

### Pathways to Organ Donation

#### Brain Death Donation (BDD)

Organ donors are people that receive a fatal head injury, illness or tumour that leads to bleeding and swelling of the brain. When the process called "brain death" occurs it is irreversible and the person is legally deceased while on machines to maintain organ function. Strict testing to confirm brain death is performed by senior medical specialists. All donors will be in an intensive care unit on a ventilator, needing oxygen and drugs to maintain organ function for transplant. Organ donation surgery will occur when the transplant teams are ready and the organ donor is transferred to the operating theatre.

#### Donation after Circulatory Death (DCD)

Organ donation can also occur when circulation has ceased. The potential donor has suffered a severe irreversible head injury or illness and will not survive without life support. Following a decision by the

family and doctors, end of life care will be provided and a time will be agreed for when to turn off life support. When death occurs; a rapid transfer to the operating theatre will occur and organ retrieval surgery will begin.

### Extended Criteria Donors (ECD)

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

### Organ Care System (OCS)

The Organ Care System (OCS) referred to as heart in a box or lungs in a box. The OCS is a special machine that can assess and recondition ECD heart or lungs. The purpose of the machine is to improve function of the heart or lungs before transplant and to allow transportation over longer distances. The organs are supplied with warm blood containing oxygen rich nutrients to provide protection from cold ischemia. The heart in a box allows the heart to beat continuously during transport and the lungs in a box allow the lungs to be ventilated during transport. Upon arrival the St Vincents the organs will undergo a thorough final assessment and if they have reconditioned to a standard criteria for donation the transplant will go ahead.

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

### Transmission of Infection

Potential donors are assessed for increased risk behaviours that may indicate if a donor has an increased risk of **HIV, Hepatitis B and Hepatitis C infection**. The donor screening process will include multiple blood tests for diagnostic, serological and nucleic acid (NAT) testing. Donors identified as increased risk are investigated to assess the time frame of exposure. Examples of a potential risk includes intravenous drug use, unprotected sex and incarceration. 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. Hepatitis B and Hepatitis C is easily treated and curable with the current treatments available.

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

- Tests are not performed for all known diseases
- It is not possible to know everything about an individual donor
- False positives and false negative tests results are possible
- Transplant surgery carries risks, but often not performing the transplant carries a higher risk of death than the risk of an infection from a donor organ

**This is why:**

- You may be required to start a course of Hepatitis B vaccinations before going on the active waiting list
- We seek your consent to accept organs from an increased risk donor with a potential history of Hepatitis B, Hepatitis C or HIV

Donor Cancer Risk Factors

National guidelines clearly state absolute contraindications for organ donation include:

- Any history of melanoma
- Any history of metastatic malignancy
- Any history of blood malignancy

However, there are curable cancers that can be considered as low risk for transplant. The team will seek expert opinion and consider the risk benefit ratio before proceeding with organ retrieval and transplant.

When you complete the consent form for heart transplant 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 or transplant doctor may 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 organ 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 Donatelif e 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 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 promptly to arrive at the hospital and be ready in time for theatre. Keep your mobile phone with you until ready for theatre.

## **Consent for Transplant**

You will need to sign the “Lung and Heart-Lung Transplant Consent Form” before you go on the waiting list. The consent form details the complications and risks that will be explained to you in more detail 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.”

## **Cancellation of Surgery**

The transplant can be cancelled at any time. 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 decision is made. 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 there is a possibility of a transplant. You must commence fasting and make your way promptly to the hospital.
- Keep your mobile phone with you until you go to surgery.

### Arrival

- Upon arrival at the hospital you will go to either the emergency department, ward or heart lung clinic depending on the time and hospital 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 or level 10 waiting area
- You will be taken into the anaesthetic bay and commence preparation for transfer into the operating theatre for surgery.

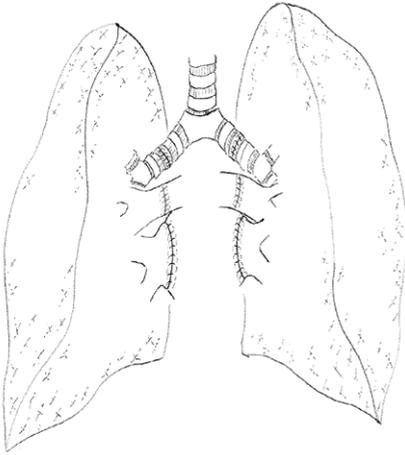
## Waiting Room for Family and Friends

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 friends 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 up to 12 hours. Staff will call family and friends to go into intensive care when the operation is over.

## Transplant Surgery

Lung transplant operation can take from 6 hours up to 12 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 death, bleeding, stroke, wound infection, kidney dysfunction, heart rate problems and early lung 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.

## Single and Bilateral Lung Transplant



### Illustrations by:

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## Surgical Wounds Following Transplant



*Left picture: bilateral thoracotomy wound for single and double lung transplant, right picture: clamshell sternotomy wound for double lung transplant.*

## **Survival after Lung Transplant**

Transplant surgery comes with major risks, these have been included on the Transplant Consent Forms and will be explained in more detail by the lung transplant doctors for listing.

Long term survival after heart or lung transplant is largely dependent on you. On how well you manage your medications, your follow up and maintain your health and fitness with lifestyle modification. The longest surviving patient transplanted at St Vincents is still alive and well after 30 years. You must maintain contact with the transplant team for life three monthly to monitor organ function, to prevent organ loss and screen for complications associated with taking antirejection drugs.

### **Death After Lung Transplant: Request for a Post Mortem**

At any time after transplant (months or years) if your death is sudden, unexpected or associated with a complicated illness it is important to confirm the cause. Confirming cause of death is by post mortem.

The transplant doctor will approach your family to request consent for post mortem. Having information about your cause of death and condition of your 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 may lessen your family's distress during their grief if they know your wishes.

## **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	Use
Ventilator	Machine that delivers oxygen & assists your breathing
Breathing tube	Tube to connect you to the ventilator for breathing
Central Venous Line	Intravenous line to give multiple drugs
Chest drains	Drain air & fluid from the lungs & around the heart
Pacing box	Paces the heart at a set beat rate
Indwelling catheter	Drains urine from the bladder

## Pain Management after 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, education and investigations.

Education will commence with learning your medications, this will be done by the transplant nurse 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, and psychiatry and psychology services. Before you leave you will be asked to complete a short quiz to complete your education.

## Clam Shell Wound Precautions:

After lung transplant: The majority of lung transplants are now typically done via a surgical thoracotomy incision where possible. If this is the case, there are no restrictions on movement. However,

occasionally some lung transplants are completed via a 'clam shell' incision. This means that the surgeon will need to cut through the sternum (breastbone) horizontally to access the lungs. As a result, the following restrictions would be in place for up to 6 weeks:

- DO NOT lift more than 5kg
- DO NOT lift your elbows over your shoulders i.e. over 90 degrees
- DO NOT push or pull with your arms e.g. pushing up from a chair/ pulling up on a rail/ use your arms to get out of bed
- Try to avoid bending your chest at breast level
- Keep your shoulders and hips facing the same direction.

You will have ongoing education from your Occupational Therapist and Physiotherapist around managing everyday activities with these restrictions.

## Recovery Time

Transplant patient's length of stay can vary between 10-14 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 organisms 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 visit.

## 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

Safe exercises to do	Things to consider when exercising
Breathing and coughing	Sternum precautions
Cardio: bike and walking	Wound discomfort
Arm and leg strengthening	Side effects from the new medications
Bed and chair exercises	General tiredness
Stair work	Change of breathing pattern

## Routine Tests 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 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.

### 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.

**NB:** 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 too 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

If you feel unwell you should take your temperature, if it is above 37.5 and/or you feel unwell you should contact the transplant team.

### Weight

You should weigh yourself daily, if you are still retaining fluid from surgery and taking fluid pills.

## FEV1

You must measure your lung function twice a day, morning and evening and record the best (highest) of three readings. This is a commitment to monitor your lung function for life.

## **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 components of the 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**

## 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 provide you with a spirometer and 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 72 hours 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**

Feeling breathless	Tightness in chest when breathing
Drop in lung function (FEV1)	Temperature
Decreased exercise tolerance	Cough

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

### **Bronchoscopy (bronch)**

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.

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.

### International Grading of Lung Rejection

	Rejection Grade	Airway Inflammation Grade
Nil	A0	B0
Minimal	A1	B1
Mild	A2	B2
Moderate	A3	B3
Severe	A4	B4

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.

### Treatment for Lung Rejection

There are various treatment options for rejection. However, most patients will only require high dose steroid therapy with intravenous methylprednisolone and/or oral prednisolone. Treatment can be given either in the Heart Lung Clinic or on the ward. It will depend on the severity of your symptoms, lung function, oxygen levels 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 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 lifelong 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, reflux, and burping caused by stomach acids. GORD must be treated promptly to prevent damage to the new transplanted lungs. Investigations can include 24 hour pH probe to monitor the severity of stomach acids and a short stay laparoscopic procedure to tighten the stomach valve preventing reflux. Please report reflux symptoms promptly to the team and follow these simple strategies.

### **Strategies to reduce risk of reflux**

- Prop up the head of the bed by 15-30 degrees to prevent risk of silent reflux at night
- Ensure you have arranged a foam wedge prior to discharge home
- Eating smaller meals more frequently
- Maintain a healthy weight
- Avoid food that make reflux worse

Foods that may make reflux worse include;

- peppermint
- alcohol
- chocolate
- tomato
- citrus
- high fat meals
- carbonated or caffeinated drinks

**Do not delay reporting symptoms of reflux to the transplant team.**

**EARLY DETECTION ALLOWS TREATMENT  
TO REVENT LUNG INJURY.**

## **Infections After Transplant**

Transplant recipients are 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 respiratory infections because they risk lung dysfunction. Lung recipients can have more severe illness and longer recovery. Therefore, you 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 Flu 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.

## **Other Infections After Transplant**

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 any time 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.

Patient CMV Status	Donor CMV Status	Risk for CMV Activation
Negative	Negative	Low
Positive	Positive	Medium
Negative	Positive	High (CMV Mismatch)

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 (PJP)**

Pneumocystis Jiroveci (formerly carinii) is an organism that can cause serious chest infections 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 Enterococci (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.

## **Symptoms of Infection**

Cough & sputum	Feeling breathless
Fevers	Drop in lung function (FEV1)
Shakes & shivers	Temperature >37.5
Sore throat	Nausea/Vomiting/Diarrhoea
Runy nose	Pain or burning when passing urine

# 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. During this time, you should avoid soaking your wounds (bath or swimming pool), as this can soften the scar tissue. Make sure you pat dry your wounds, and avoid rubbing the wound area, as this may also affect healing. 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 patients 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 animal 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 maintain bird aviaries. 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 new 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 transplant 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 more 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.

## **Medications to Prevent Rejection (immunosuppression, anti-rejection medications)**

It is important with all anti-rejection 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 (24hrs) you must call the transplant team.*

### **TACROLIMUS (PROGRAF®)**

Tacrolimus is the chemical name and Prograf® is the brand name. It prevents the production of substances that promote T-cells multiplying and stimulating attack of the transplanted organ.

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

Tacrolimus is available in 0.5 mg, 1 mg and 5 mg capsules. Be sure to check the strength on the box and foil carefully. 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 a day.

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.

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

## Tacrolimus Levels

The dose of tacrolimus is decided by checking a tacrolimus trough 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 not be accurate 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	Tremor
Nausea, vomiting	Sleeping difficulties
Diarrhoea	Loss of appetite
Pins and needles	Increased sugar and potassium levels in the blood

## MYCOPHENOLATE MOFETIL

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 is taken twice a day. 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 at least 2 hours apart from magnesium supplements (e.g. Magmin®, Mag-Sup®), antacids (e.g. Mylanta®), cholestyramine (Questran®). **MYCOPHENOLATE SODIUM (MYFORTIC®)**

Myfortic® is mycophenolate in a different formulation. Myfortic® is taken twice a day and is available in 180 mg 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	Nausea, vomiting
Stomach pain	Decreased white cell count

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

## CICLOSPORIN (NEORAL®)

Ciclosporin is the chemical name, and the brand name is Neoral®. Ciclosporin prevents the production of substances that promote T-cells multiplying and stimulating attack of the transplanted organ.

Ciclosporin 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.

Ciclosporin may be taken with food or on an empty stomach. It is important to get into the routine of taking ciclosporin at the same time in the same way twice a day (twelve hours apart). Note: cystic fibrosis transplant recipient must take creon with ciclosporin to aid with absorption.

Ciclosporin 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 pill box to organise your medication.

## Ciclosporin Liquid Formulation

Ciclosporin 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.

To prepare your dose, add the ciclosporin to a glass or crockery cup only. Ciclosporin 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 the cup around 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 ciclosporin 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 ciclosporin remaining in one bottle should not be tipped into a new bottle, as this can ruin the quality of the new bottle.

## Ciclosporin

The dose of ciclosporin for lung transplant patients is decided by checking a ciclosporin C2 level. A C2 level is a blood test that measures the amount of ciclosporin 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 CICLOSPORIN AND HAVE A C2 LEVEL TAKEN EXACTLY 2 HOURS LATER.**

Tell the nurse or doctor if the C2 level was taken late as this may affect the accuracy of the level and the dose prescribed for you.

## Potential side-effects of ciclosporin

Side-effects can occur during early treatment when the dose is high. As the dose is decreased, sideeffects may lessen or disappear. Not all side-effects occur in all patients taking ciclosporin.

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

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

Azathioprine is the chemical name. There are several brand names available. Azathioprine is available in 50mg and 25mg tablets and is taken once daily at night.

## Potential side effects of azathioprine

Diarrhoea	Increased skin sensitivity to sunlight
Nausea	Decreased white cell counts
Vomiting	Effects on liver function

Azathioprine can interact with some medicines used for gout — particularly with allopurinol (Progout®, Zyloprim®). **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 brand name. You may also hear this medication referred to as "RAD". Everolimus prevents T cells and B cells that are responsible for rejection from multiplying.

Everolimus is available in 0.25 mg, 0.5 mg, 0.75 mg, and 1 mg tablets. It is usually taken twice a day. If you are also taking ciclosporin they should both 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 trough 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

Swelling/fluid retention	Increased cholesterol
Delayed wound healing	Decreased white cell counts
Acne	Nausea, vomiting, stomach pain

## 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 corticosteroid 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

Increased appetite	Weight gain
Mood changes	Round face and fat around your stomach
Loss of muscle bulk	Fluid retention
Acne	Thinning of the bones (osteoporosis)
Thinning of the skin and stomach lining	Increased blood sugar levels (diabetes)

Some 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 side-effects experienced varies between individuals.

### **ANTI-THYMOCYTE GLOBULIN (ATGAM®, THYMOGLOBULINE®)**

Anti-thymocyte globulin is a powerful drug which reduces the number of T-cells circulating in the body. It is used to treat steroid resistant rejection and it can also be used to prevent rejection. It is sometimes used 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 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 prevent complications of having a suppressed immune system, including to prevent and treat infections, or to reduce or prevent side effects from your anti-rejection medications. You should continue to take these medications even when you are feeling well.

### **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®, Septrin Forte®, Resprim Forte®)**

This antibiotic helps to prevent pneumocystis jirovecii pneumonia (PJP), 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, ganciclovir is usually given via a drip twice a day for 14-21 days. Treatment is usually commenced in hospital but may continue as an outpatient or at home.

## **VALGANCICLOVIR**

Valganciclovir is the oral version of ganciclovir and is used to prevent CMV infection. It is usually taken once a day with food for at least 6 months, depending on your CMV status.

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

## **NYSTATIN**

Nystatin is given as mouth drops to prevent thrush in the mouth, which may be caused by antibiotics and high doses of immunosuppressant medications. 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 a day 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 a day. The capsules are best taken with food, or you may be asked to take it with an orange juice.

If you are taking medicines that neutralise or reduce stomach acid, such as ranitidine, or antacids like Mylanta®, it is important that you take them at least 2 hours after itraconazole. This is to ensure that itraconazole is properly absorbed.

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

## Antihypertensives

Antihypertensive medications lower blood pressure. Patients taking tacrolimus or ciclosporin may have an increase in 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 medicines most commonly given to control blood pressure include diltiazem (Cardizem®), irbesartan (Avapro®, Karvea®), and hydralazine (Alphapress®).

## Anti-Reflux, Anti-Ulcer Drugs

These medicines suppress production of stomach acid and help to prevent reflux, and the development of stomach ulcers that may be caused by stress and/or prednisolone. These include ranitidine (Zantac®), pantoprazole (Somac®) and rabeprazole (Pariet®).

## 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)

Contact the transplant team before starting any new medication. Many prescription, over-the-counter (not requiring a prescription) and herbal medications can interact with your anti-rejection medication and either make it less effective and increase the risk of rejection, 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.

Trials of new medicines 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 an extended 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. A community nurse will be sought where possible but most cases require more administrations than community nurses can accommodate. You will receive an intravenous (IV) PICC line and will be taught how to prepare and administer your IV medications. You will be taught how to administer your medications using either Baxter® bottles, Sapphire® infusion pump or other intravenous administration techniques. All equipment (lines, syringes, fluids) will be provided from the ward or Heart Lung Clinic (HLC) and can be restocked from clinic.

Either you or a family member, are required to demonstrate a clean and safe technique when preparing IV medication and managing the PICC line.

Picture below showing a Sapphire Infusion Pump and Baxter Infusor Bottle:



## Prescriptions

It is important to make sure you have enough supply of medications until your next clinic appointment. 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 require a prescription for anti-rejection or hospital-only medication you can email the prescription line on [hltxscriptline@svha.org.au](mailto:hltxscriptline@svha.org.au) regarding the prescriptions you require.

You must provide the following information:

- Your full name
- Medical record number (MRN)
- Address
- Telephone number
- Medication name
- Medication dose & frequency

## Blood Tests

It is important to make sure you can get your bloods taken when required by the team. This will ensure appropriate and timely treatment. The transplant team will inform you when these need to be taken.

If this is outside of your normal clinic visits and you cannot attend St Vincents Hospital, then your doctor may give you a blood request form to have completed at your closest pathology centre. In this case, you must email the Heart Lung Clinic nurses at [svhs.hlcreresults@svha.org.au](mailto:svhs.hlcreresults@svha.org.au) and tell us:

Your name, MRN number (medical record number) and Transplant type

- Pathology Centre where you had your bloods collected
- Date you had your bloods collected
- Tests requested (listed on the request form)
- The reason why you had bloods taken:
  - To check drug levels
  - To check kidney function or white cell count
  - To check CMV levels
  - Or any other reason

## The Heart Lung Clinic (HLC)

The Heart Lung Clinic is located on Xavier level 4 in the main building. You will be already familiar with the HLC from when you were 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 from 8.00am. HLC is open Monday to Friday at 8.00 a.m.– 4.00 p.m.

Week Day	Lung Transplant
Monday	Blood tests, drug levels, chest xray, spirometry. Transplant rehabilitation
Tuesday	See doctor
Wednesday	Day off
Thursday	Blood tests, drug levels, chest xray, spirometry. Transplant rehabilitation
Friday	See doctor

### Heart Lung Transplant Clinic Routine.

**NB:** tests and investigations are for inpatients and most outpatients on the days indicated. 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 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 (8.00 a.m. to 4.00 p.m.)

Contact one of the nurses in Heart Lung Clinic by phoning (02) 8382 3158 or (02) 8382 4115 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)**

Phone the hospital on (02) 8382 1111 and ask for the,

- Transplant Coordinator or
- Lung Transplant Registrar

They are always available and can provide direction 24/7 if you become unwell. If you leave a message, speak slowly when 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 NOT WELL.**

## **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
- Minimum of 30mins a day
- Try walking, cycling, swimming, gym class, group exercise, team sports, DVD, phone Apps.

## Healthy Eating

### Nutrition Immediately Post Transplant

Nutrition can play an important role in your recovery from a transplant. For the first few months after a transplant you will be recovering from the stress of surgery. It is important for you to maintain your weight and consume enough energy and protein to help your body heal. To help meet your energy and protein needs the following foods should be included in your diet;

- Lean meats including poultry, beef, lamb, pork
- Eggs
- Fish (canned or fresh)
- Dairy products including milk, cheese, yoghurt
- Legumes including chickpeas, beans, lentils
- Meat alternatives including tofu, vegetarian sausage
- Nuts and seeds
- Healthy fats including olive oil, vegetable oil, margarine
- Peanut butter
- Avocado

If you are not eating and drinking enough to optimise your recovery, your dietitian can provide further suggestions on ways to help increase your energy and protein intake. Your dietitian may prescribe nutritional supplements drinks to help boost your intake and support your recovery. After your transplant your appetite may be slow to return but with time, this should return to normal. You may also experience taste changes such as a metallic or bitter taste and/or dry mouth or no taste. Speak with your dietitian if you are experiencing poor appetite or taste changes after your transplant. Some suggestions to help with taste changes include; Keep your mouth clean and brush your teeth twice a day

- Use plastic cutlery if having a metallic taste
- Rinse your mouth out with your sodium bicarbonate mouthwash (or alcohol free mouthwash) throughout the day and before eating
- Add extra flavour to your foods e.g. herbs, spices, lemon juice
- Try using a straw to help avoid the taste buds
- Try sucking on hard lollies such as mints, eucalyptus or sweet & sour lollies to remove unpleasant tastes and increase your saliva production

## Food Safety & Hygiene

After a transplant you will need to take antirejection medication for the rest of your life which increases your risk of food-borne illness. Some foods are considered “high risk” of causing foodborne illness and consumption of these foods should generally be avoided. These include;

- Raw eggs
- Rare or undercooked meats, fish or chicken
- Cold deli meats and chicken
- Soft cheeses including brie, blue-vein, camembert and soft serve ice cream
- Unpasteurised milk or dairy products e.g. raw goats milk
- Pre-prepared or pre-packaged salads

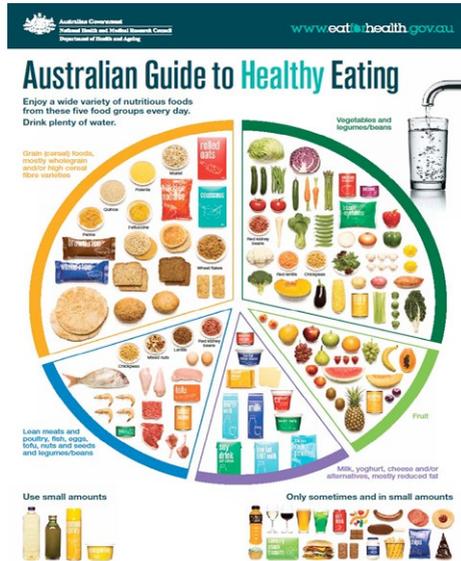
Your dietitian can provide more advice on food safety after your transplant. It is also important that you remember to use safe food practices including food handling, storage and temperature control.

- Always wash your hands with soap and dry well before handling and/or eating foods
- Use separate chopping boards and utensils for raw and undercooked foods
- Wash all fruits and vegetables well before eating. Rub gently using a vegetable brush or clean cloth where appropriate
- Keep raw and cook foods separate in your fridge
- Avoid buying or using damaged cans or bloated packages
- Never eat foods past the ‘use by’ date
- Reheat food thoroughly until piping hot and never reheat more than once
- Foods not eaten immediately should be refrigerated
- Do not keep left over for longer than 24 hours
- Keep hot food >60 degrees Celsius and cold food cold <5 degrees Celsius
- Defrost all foods in the fridge or microwave, not on the kitchen bench
- Keep your refrigerator clean

Your dietitian will review food safety and hygiene guidelines with you after your transplant. If you have immediate concerns or questions please ask to speak with your dietitian.

## Nutrition Long Term

It is important to continue to maintain a healthy weight and eat a variety of nutritious foods. The 'Australian Dietary Guidelines' provide up-to-date advice about the kinds of foods and drinks that we need



Source: National Health and Medical Research Council.

regularly for health and well-being. For detailed information serving sizes or meal advice please go to [www.eatforhealth.gov.au](http://www.eatforhealth.gov.au) or speak your dietitian.

In the long term, antirejection medications may cause a variety of potential side effects including;

- Excess weight gain
- Thinning of the bones (osteoporosis)
- High blood fats (hyperlipidaemia)
- High blood pressure (hypertension)

If any of the above apply to you, it is important to speak with your dietitian as dietary changes may help.

## Alcohol

During the first three months after transplant you are advised to avoid alcohol. From three months onwards (unless you are specifically told to avoid alcohol) it's considered acceptable to consume alcohol within the recommended amounts. For both men and women drinking no more

than two standard drinks on any day reduces your lifetime risk of harm from alcohol-related disease or injury. 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.rms.nsw.gov.au](http://www.rms.nsw.gov.au)

The transplant team as a rule do not directly communicate to the NSW RMS – Roads & Maritime Services. 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 may request you be assessed by the occupational therapist. They can provide you with a letter for the RMS if required.

As a rule you should be allowed to drive a car again after **approximately 8 weeks following your transplant**. However, this can be delayed if complications prolong your recovery that can affect your ability to concentrate and 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 and social worker to help you transition back to the workforce.

## **Resuming Relationships and Intimacy**

When you have recovered from surgery some of the issues you will need to consider are relationships, 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 intimacy. This will allow your chest wounds to heal and mend. Of course, you can be intimate with your partner however 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 some men and women. Many of our patients have successfully become parents. We recommend that females prevent pregnancy after transplant for a minimum of **two years** as there is high risk of rejection. Before considering family planning and pregnancy, you must first consider your own health to have a baby.

Things you and your doctor must consider are:

- Lung function
- Antirejection medications and levels
- Kidney function
- Blood pressure
- Overall general health

There is 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 sexually transmitted 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 protection 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.

Vaccines	Before Transplant	After Transplant
Hepatitis A	Yes, if seronegative	Yes, if seronegative
Hepatitis B (accelerated schedule before transplant)	Yes, depending on serological status	Yes, depending on serological status
Influenza Vaccine	Yes - annually	Yes - annually 2 doses first year after transplant, then 1 dose every year after that
Pneumococcal Conjugate Vaccine (13vPCV)	Yes	Yes
Pneumococcal polysaccharide vaccine (23vPPV)	Yes ( $\geq$ 8 weeks after 13vPCV)	Yes ( $\geq$ 8 weeks after 13vPCV)
Inactivated Poliovirus (IPV)	Yes, if no booster in past 10 years	Yes, if no booster in past 10 years
Diphtheria-tetanus-pertussis (DTpa)	Yes if not been given previously	Yes if not been given previously
Meningococcal B vaccine & Quadrivalent Meningococcal Conjugate Vaccine	Yes	Yes
Human Papillomavirus Vaccine (9vHPV)	Yes	Yes
Varicella Vaccine (live)	Yes (at least one month before transplant)	<b>No - contraindicated after transplant</b>
MMR vaccine (live)	Yes (at least one month before transplant)	<b>No - contraindicated after transplant</b>

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 full lung function and investigations for transplant lung 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 Cancers

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**

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 50 sunscreen a hat, sun glasses and proper T Shirt when out in the sun and when swimming.

## **Post Transplant Lymphoproliferative 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.

## INFORMATIVE 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](http://www.ahlta.com.au)
- Australian Transplant Games – [www.australiantransplantgames.com](http://www.australiantransplantgames.com)
- Donatelife - [www.donatelife.gov.au](http://www.donatelife.gov.au)
- Transplant Australia - [www.transplant.org.au](http://www.transplant.org.au)
- Transplant Society of Australia and New Zealand - [www.tsanz.com.au](http://www.tsanz.com.au)

### **Making a Donation to the Transplant Program**

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 speak with the nurse unit manager at Heart Lung Clinic for more information.

## 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 notes 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 be there to support you...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.**



## Glossary

<b>Acute</b>	Term meaning to have a sudden onset.
<b>Antibody</b>	Part of the immune system to protect the body from foreign objects and help fight infections.
<b>Antigen</b>	Part of the immune system that is triggered to produce an antibody.
<b>Antiviral</b>	Medication to prevent or treat a range of virus.
<b>Bacteria</b>	An organism that can cause serious bacterial illness.
<b>Biopsy</b>	Procedure performed to take tissue samples.
<b>Bronchoscopy</b>	Procedure to look inside the lungs for infection and take tissue samples
<b>B Cells</b>	Part of the immune system that can cause antibody mediated rejection.
<b>CAT Scan</b>	Computerised xray machine to capture multiple images of the body to look for cancers and abnormalities.
<b>Chronic</b>	Term meaning to happen over a long period of time.
<b>CMV</b>	Cytomegalovirus is a virus that can cause serious illness after transplant and is treated with ganciclovir.
<b>Compliance</b>	Is following medical advice and taking medications as prescribed.
<b>Coronary Angiogram</b>	Procedure that injects a dye into the body through the groin blood vessel to view the blood vessels around the heart.
<b>Creatine</b>	A waste product excreted by the kidneys that is an indicator of kidney function.
<b>Cross Match</b>	Process used to match donors and recipients by blood test.
<b>CXR</b>	Radiological test to view areas of the body for air spaces, fluid spaces and masses.
<b>Cytotoxic</b>	Term used to describe hazardous medications used to prevent rejection or treat viruses.
<b>Diabetes mellitis</b>	A condition that causes abnormal blood glucose levels and may need insulin.
<b>ECG</b>	Electrocardiogram is a test to look at the heart's electrical system.
<b>Electrolytes</b>	Minerals in the body that help maintain normal organ function. i.e potassium, sodium, calcium, magnesium.
<b>ECHO</b>	Echocardiography is a ultrasound of the heart to view the valves, chambers and strength strength and motion.
<b>Fluid retention</b>	Excess build up of sodium and water in the body that causes swelling or odema.
<b>Fungus</b>	Organism that can cause a fungal illness.
<b>Graft</b>	Is the transplanted heart or lungs
<b>Heart Biopsy</b>	Procedure used to test for heart rejection via puncture in the large neck vein.
<b>Hypertension</b>	Medical term meaning high blood pressure

<b>Immune System</b>	System in the body made up of cells, proteins and tissue to protect the body from invasion by infections and foreign bodies.
<b>Immunosuppression medication</b>	Medications to lower the immune system to allow the body to accept a transplanted organ and prevent rejection.
<b>Isolation</b>	Used when infectious patients are nursed in a single room.
<b>LOOP</b>	Flow volume loop – lung function test.
<b>Lung Function</b>	Test to measure how well the lungs work.
<b>Noncompliance</b>	Refusing medication or not following medical advice.
<b>Oedema</b>	Is swelling that can appear in various parts of the body due to illness.
<b>Osteoporosis</b>	Condition that causes brittle bones and discomfort.
<b>Pacemaker</b>	Small device inserted under the skin to control heart rate.
<b>Prophylaxis</b>	Term meaning to prevent illness or disease with medication.
<b>Rejection</b>	Immune system process that causes poor function of the transplanted heart or lungs.
<b>Right Heart Catheter</b>	Procedure used to measure heart pressures via puncture in the large neck vein.
<b>Six Minute Walk Test</b>	Test to calculate the distant walked in six minutes.
<b>Sputum</b>	Thick secretions that build up in the lungs because of infection.
<b>T Cells</b>	Part of the immune system that can cause rejection.
<b>Tissue Typing</b>	A blood test that looks at the inherited cells from parents to aid matching with organ donors.
<b>Transfusion</b>	Blood transfusion for anaemia or large blood loss.
<b>Vaccination</b>	A technique to protect (vaccinate) the body from community acquired virus and illness.
<b>Virus</b>	Organism that can cause serious viral illness.



**ST VINCENT'S  
HOSPITAL**  
SYDNEY

**Consent for Lung  
or Heart-Lung Transplant**

MRN		SURNAME	
GIVEN NAME(S)			
DOB	SEX	AMO	WARD/CLINIC

(Please enter information or affix Patient Information Label)

This lung/heart-lung transplant consent form is an addition to the transplant information manual and will confirm your decision to accept the responsibility of a transplant and ensure you understand the known risks and potential benefits.

I am consenting for:

- Single lung transplant (Left  or Right  Lung)
- Bilateral lung transplant
- Heart/lung transplant

Depending on the type of transplant you require; single lung, double lung or heart-lung. The incision will involve either a single cut on one side of the chest, across the lower part of the chest from left to right or a cut down the middle of the breast bone as described in your transplant information manual.

I know that success cannot be guaranteed. As there is a relative shortage of organs, I may be offered an extended criteria organ (e.g. coming from a donor who is older, or from a donor who has smoked). I understand these lung/s may come from donation after brain death (DBD) or donation after circulatory death (DCD) donation.

I am aware that my chance of being alive at 1 year after lung transplantation is about 90% and at 5 years about 70%, at 10 years 50% and at 20 years 30%. Survival after heart-lung transplantation is very similar.

I will accept that I need to be on lifelong medications to stop my immune system rejecting the transplanted lung/s or heart-lungs block.

I understand the following complications may occur:

- Death within the first post-transplant year. 1 in 10
- Failure of the lung/s or heart-lung block to function adequately (primary graft failure) and need for support of my breathing and/or circulation with machines (ventilator/ECMO) for a period of time immediately after transplant. 1 in 4
- Risk of stroke. 1 in 50
- Bleeding from the operation, or needing a repeat operation. 1 in 20
- Severe infection of the breast bone (clam-shell and median sternotomy). 1 in 20
- Need for kidney machine support (dialysis) which may be temporary or long term. 1 in 20
- Risk of kidney failure within a decade. 1 in 20
- Infection of any type. 1 in 2
- Any rejection of the lung/s or heart-lung block requiring treatment. 2 in 3
- Needing a blood transfusion. 1 in 2
- Having a significant reaction to prescribed medications or anaesthetic agents. 1 in 10
- The risk of cancer within a decade (especially skin but also lymphoma and cervix). 1 in 6
- Prolonged ventilation support requiring a temporary tracheostomy (hole in wind pipe). 1 in 15
- Poor healing of the airway or bronchial join requiring further treatment or surgery. 1 in 50
- Injury to the nerves supplying the voice box, the diaphragm or the stomach. 1 in 20

I agree to co-operate with medical advice to look after my new lungs/heart-lungs and to take my medications. Yes No

I accept the option of receiving extended criteria lung/s which has/have been successfully reconditioned in a special machine referred to as 'Lungs in a Box'. Yes No

I am willing to accept a donor lung/s from a donor with a risk of Hepatitis B, Hepatitis C and HIV. I have been vaccinated for hepatitis B but there is a chance I can catch Hepatitis B, Hepatitis C and HIV. Yes No  
If I acquire one of these viruses I will need to take antiviral medications.

BINDING MARGIN - NO WRITING  
 St Vincent's Hospital Sydney Limited  
 ABN 77 054 038 872

Revised June 2018

**CONSENT FOR LUNG OR HEART-LUNG TRANSPLANT**

**P20.3**



**Consent for Lung  
or Heart-Lung Transplant**

MRN		SURNAME	
OTHER NAMES			
DOB	SEX	AMO	WARD/CLINIC

(Please enter information or affix Patient Information Label)

- I am willing to accept lungs from someone with a tumour which is generally not considered likely to reoccur. Yes No
- I have seen a transplant surgeon and have been fully informed of the surgical risks. Yes No
- I consent to the removal of my lung/s or heart-lung block and other tissues for the diagnosis or management of my condition. Yes No
- I consent to the use of any unneeded tissue for research. I understand that my tissue may be identified and that I will not receive any feedback on gene testing results. Yes No
- To aid in clinical insight and improvement in future outcomes, I consent to a post mortem examination in the event of my death following lung/s or heart-lung transplantation. Yes No
- I consent to my information being discussed in case conferences and data being used in quality assurance programs and databases held securely by the hospital. Yes No
- I consent to the use of that information in scientific presentations and publications. I will not be able to be identified from such publications. Yes No
- I consent to my de-identified information being transferred to the Australian and New Zealand Cardiothoracic Organ Transplant Registry. Yes No
- I am being listed for combined lung-liver transplant or combined lung-kidney transplant and I have received information about liver or kidney transplant from the liver physicians or kidney physicians. Yes No N/A

**At the Time of Listing for Transplant:**

Name of patient \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Name of witness \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Doctor (Physician or Surgeon) \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

**At the Time of Transplant Surgery:**

Name of patient \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Doctor \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

*Reference:*

*Australian and New Zealand Cardiothoracic Organ Transplant Registry Annual Report 2015.*

*Transplant Society Australia and New Zealand Clinical Guidelines for Organ Transplantation from Deceased Donors 2016.*

*NSW Health Policy Directives.*

*PD2013\_029 Organ Donation and Transplantation: Managing Risks of Transmission of HIV, HCV and HBV.*

*PD2016\_001 Human Tissue Use/Retention Including Organ Donation, Post Mortem Examination and Coronial Matters.*

*PD2005\_406 Consent to Medical Treatment - Patient Information.*

*GL2014\_008 Organ Donation After Circulatory Death: NSW Guidelines.*

# IN AN EMERGENCY DIAL 000 TO CALL AN AMBULANCE

## Clinic Hours Monday - Friday 8am - 4pm

### Heart Lung Transplant Unit

Clinic appointments 02 8382 3150

Clinic Nursing Staff 02 8382 3158

Transplant Nurse 02 8382 1111

Lung Transplant Reistrar 02 8382 1111

Clinic Fax 02 8382 2505

Lung Function appointments 02 8382 2353

Fax 02 8382 2944

Echocardiogram appointments 02 8382 2422

Transplant Gym 02 8382 3346

Outpatient Pharmacy 02 8382 2594

Prescriptions [hltxscripeline@svha.org.au](mailto:hltxscripeline@svha.org.au)

Blood results [svhs.hlcreresults@svha.org.au](mailto:svhs.hlcreresults@svha.org.au)

### Outside Clinic Hours - 24 hours

Phone 02 8382 1111 (St Vincents switch board)

Transplant Co-ordinator - for nursing and home  
IV therapy questions

Lung transplant registrar - for medical questions

Printing of this manual has been supported by  
an educational grant from

