



ST VINCENT'S
HOSPITAL
SYDNEY

A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA



Information Manual

For Heart 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
Michelle Harkess CNC with assistance from
the multidisciplinary transplant team.

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Heart 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 book has been designed to help you understand what is involved in having a heart transplant. Information in this book follows the transplant journey, 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 transplant procedures, including the risks and benefits.

The transplant program commenced at St Vincent's 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 40 heart transplants per year. The transplant program at St Vincent's is primarily an adult service although it 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 (02) 8382 2114. Rooms cost \$30 per person, each night. The accommodation is a short steep walk from the hospital. If the hospital accommodation is not available our families from rural areas utilise Elizabeth Hunter Lodge at Waverly. For more information speak with the accommodation officer or your social worker.

We will provide 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 Vincent's 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 Vincent's 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 HEART TRANSPLANTATION

Transplant Society of Australia and New Zealand Eligibility Criteria

Heart Transplant Inclusion Criteria

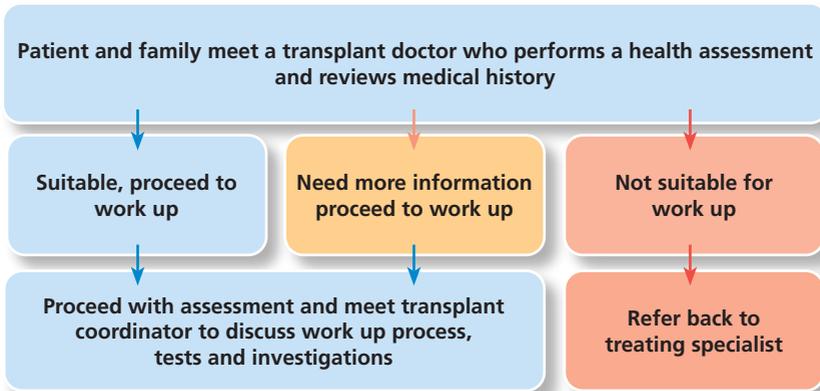
- Irreversible cardiogenic shock
- Intractable symptomatic heart failure
- Need for permanent mechanical support
- Frequent discharge from internal defibrillator
- Intractable angina despite optimal medical therapy

Heart Transplant Exclusion Criteria

- Active malignancy
- Complicated diabetes
- Body weight BMI >30
- Uncontrolled infection
- Inability to comply with complex medical therapy
- Active substance use – cigarettes (e-cigarettes) alcohol and drugs
- Inability to comply with medical therapy
- Irreversible damage of other organ systems that prevent rehabilitation after transplant
- Acute medical conditions – may be reconsidered at a later stage when resolved.

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

REFERRAL AND ASSESSMENT FOR HEART TRANSPLANTATION



Heart 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. Your GP or cardiologist must make a referral to St Vincent's before you can be reviewed for assessment.

You need an appointment to see a transplant doctor at the Heart Lung Clinic and will need to bring your Medicare Card. Your work up may take weeks or months to complete depending on the severity of your heart disease or the complex nature of your medical history. It is important to understand that not every patient referred to the St Vincent's 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 team to determine if you can have a transplant. If you are not suitable, the transplant doctor will discuss any alternative options and notify your referring specialist.

Adolescent Transition at St Vincent's

We collaborate closely with the NSW Children's Hospitals and review adolescent patients for heart transplant assessment from both Children's Hospital Westmead and Sydney Children's Hospital Randwick. The adolescent patients are generally aged between 16 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 Vincent's can consider adolescents under 16 years of age if required.

How we transition adolescent patients to St Vincent's

- 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.

Heart Health Website

Heart health website is designed to provide education and information about all things related to heart health. The website includes heart transplant information and videos, including links to the patient information manual and the dealing with transplant book.

For more information visit: www.svhhearthealth.com.au

Transplant Work Up

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

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 transplantation requires commitment from **“you and your family or care giver.”** All members of the transplant team expect you to do your best to participate with the transplant program.

This includes attending all work up appointments made by the transplant coordinator who will try to arrange times to suit you. We endeavour 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 and lifestyle modifications.

You will be required to reside in metropolitan Sydney for up to **three months** after the transplant. This is to ensure you can travel to attend your frequent follow up and rehabilitation program. If you do not have friends or family in metropolitan 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. The care giver's 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 pose 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 assessment 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 cessation** from smoking and substance use. If the transplant team recommend input and support from drug and alcohol or psychiatry, then failure to do this will be considered as **non-adherence** with the program.

For cigarette smoking, a minimum of three negative tests over the six month 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 and if relapse is suspected we will request you undergo random drug and cotinine (nicotine) testing.

Meeting the Multidisciplinary Team

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

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

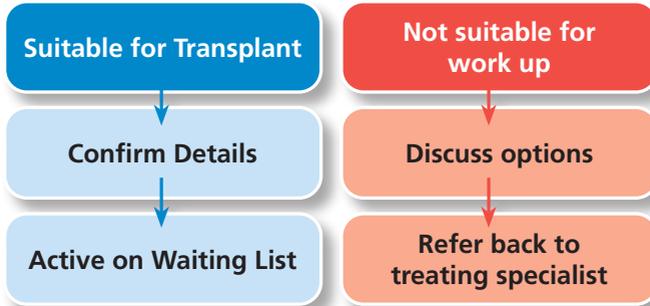
Cardiothoracic surgeons	Assessment for active listing, transplant surgery, mechanical support surgery, cardiothoracic surgery, organ retrieval surgery and outpatient surgical follow up.
Heart transplant doctors	Assessment for active listing, heart failure and pulmonary hypertension management, drug trials,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

NOTE:

The transplant program works as a team. All patient information is shared in case conferences. Regular case conferences are held to review the waiting lists and discuss your ongoing suitability for transplant. Patient privacy and confidentiality is paramount.

Transplant Assessment Complete

At completion of the assessment and work up your case will be presented at the weekly multidisciplinary team (MDT) meeting to discuss suitability. The results from your numerous investigation's and consultations will be reviewed by the MDT to determine if you are suitable for transplant. The outcome will be discussed with you and your family.



Not Suitable for Transplant

The transplant team may conclude that, for a variety of reasons, transplant is not the option for you. Some reasons for this include age related comorbidities, frailty, 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 end of life. 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 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

Once accepted for transplant the final decision for activation on the waiting is up to you. We will not activate you unless we have received your written consent for transplant. You have the choice to decide at any time that transplant is not for you. This also applies for 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 surgery. 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 conferences and patients can be removed from the list. This can be permanent or temporarily “on hold” until further investigation is completed. The transplant doctors will notify and advise you if this happens and the reasons why.

Bridging to Heart Transplantation with Mechanical Support

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

Mechanical Devices to Support the Heart

Left Ventricular Assist Device (LVAD)

A LVAD is a blood pump that is surgically implanted and sits inside your chest and is connected to your heart. The pump supports the left side of the heart and may not be suitable for patients with weakened right heart function. The LVAD pumps blood from the left ventricle (large heart chamber that receives oxygen rich blood from the lungs) to the aorta (big vessel that send blood to your body) and around the body; effectively taking over the role of the left ventricle. The pump provides a continuous flow of blood from the heart to the aorta and as a result you may not be able to feel a pulse. The LVAD is electrically driven and connects to an external wearable system (controller and power source)

by a thin cable (driveline) that exits the skin through the abdomen. The power source can be two batteries or one battery and electricity from a wall or car outlet. Before going home patients and their carer will be given training on their LVADs and how to dress the driveline exit site.



(Left) photo showing the LVAD (Right) photo showing the TAH.
Permission provided by Heartware Ltd and SynCardia Systems Inc to reprint photos.

Total Artificial Heart (TAH)

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

the TAH, trouble shoot alarms and do their exit site dressings before they go home.

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

Your Responsibilities while on the Active Waiting List

While waiting for your transplant you must:

- Have a monthly antibody test sent to Tissue Typing at Red Cross Blood Service.
- Be contactable 24 hours a day, 7 days a week on telephone or mobile phone.
- Notify the transplant coordinator if you are going on holiday.
- Notify the transplant coordinator if you are admitted 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 Vincent's for a transplant.

Monthly 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 service. **Ensure the form and blood tubes are completed with your name, full date of birth and full date of collection.**

Waiting list Priority

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

This is determined by:

Heart Donation

- Blood group
- Weight/Height
- Gender
- Cross matching process
- Most critical in need

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 offered will suit your medical condition. **Not all donor organs can function when transplanted into a person with a complex medical history.**

Organ Donation Information

The following information is to inform you about organ donation criteria to help you make an informed decision. National guidelines can be viewed in full at the following website www.tsanz.com.au

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

Pathways to Organ Donation

Brain Death Donation (BDD)

Organ donors are people that have a catastrophic 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 has died while still on machines to maintain organ function. Strict testing to confirm brain death is performed by senior medical specialists and brain scans. All donors will be in an intensive care unit connected to a machine to breath, 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 a patient's 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 treating specialist, 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 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, should you be offered a transplant from an ECD donor.

Organ Care System (OCS)

The Organ Care System (OCS) referred to as heart-in-a-box is a special machine that can assess and recondition DCD heart. The purpose of the machine is to improve function of the heart before transplant and to allow transport over greater distances. The heart is 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. Upon arrival at St Vincent's the heart will undergo a thorough final assessment and if it has reconditioned to standard criteria for donation, the heart transplant will go ahead. The OCS is also a requirement for heart donation after circulatory death retrieval surgery.

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.” This is Risk versus Benefit.**

If a donor becomes available that is a potential match for you, the transplant coordinator 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 donor unless there is a risk to your health. The Donateliflife 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 Donateliflife Agency. All donor/recipient correspondence is read by staff to ensure it is unidentifiable for privacy and confidentiality. The best way to say “Thank You” to your donor family is to take care of your new heart or lungs and make the most of your second chance.

Time for Transplant

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

Consent for Transplant

You will need to sign the "Heart Transplant Consent Form" before you go on the waiting list. The consent form details the complications and risks and is further explained 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 Vincent's Hospital Operation Consent Form."

Cancellation of Surgery

The transplant can be cancelled at anytime. It's possible that you may have several false alarms without the transplant going ahead. This occurs when the donor organs are found to have deteriorated or the match between you and the donor is incompatible. These facts can only be ascertained in the last hours before the transplant goes ahead. The transplant coordinator, transplant doctor or surgeon will explain to you why. The transplant coordinator will make a follow up call once you are discharged home.

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 notified of the possibility of a transplant. You must commence fasting and make your way promptly to the hospital.
- Keep your mobile phone with you until you arrive at SVHS

Arrival

- Upon arrival at the hospital you will go to either the emergency, level 10, or Heart Lung Clinic depending on the time of day and hospital bed status.
- You will be rapidly prepared for surgery; this includes chest xray, bloods, shave, shower, gown and premedication with anti-rejection drugs.

Theatre

- You will be transferred to theatre at a designated time. Your family can go with you to theatre reception then they can wait in the ICU waiting room.
- 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

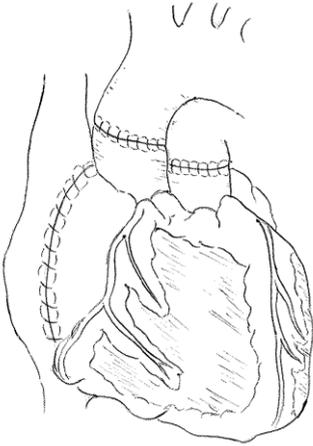
The intensive care unit (ICU) has a waiting room for family and friends and is located on the same level as the operating suites. Alternatively, family and friends can wait in the lounge area on level 10. Depending on the time of day or night those waiting may prefer to go down to the hospital café, local café or restaurant to pass time. Waiting times can vary. There are many reasons why there are delays. Please note that in some cases it can be up to 12 hours before your family see you. The ICU or transplant team will do their best to communicate with your family and friends if there are any delays. Staff will call family and friends to go into intensive care when the operation is completed.

Transplant Surgery

Both heart and lung transplant operations 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 graft dysfunction. The transplant doctors will discuss the risks and complications in more detail with you. It is important to ask questions to help you understand

what they are explaining to you. **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.

Orthopic Heart Transplant



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Surgical Wounds Following Transplant



Median sternotomy wound for heart transplant.

Survival after Heart Transplant

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

Long term survival after heart transplant is largely dependent on you. This means how well you manage your medications, your attendance at follow up appointments and living a healthy life style. The longest surviving patient transplanted at St Vincent's remains alive and well after 30 years. You must maintain contact with the transplant team for life. Review with the heart transplant doctors for heart recipients is 6 monthly to monitor heart function, to prevent decreased heart function and screen for complications associated with taking lifelong antirejection drugs.

Death After Heart 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 the 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 heart 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 your mouth. You will get regular pain relief via a drip in your arm. You will remain in ICU until your new heart is 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 Following Transplant Surgery

The level of pain differs between patients, the type of transplant and the involvement with the sternum or chest bone. Following surgery you will feel some pain usually associated with the surgical wound and the chest drains. While in ICU the nurse will give you pain relief via a drip in your arm 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 new medications, this will be done by the transplant nurse and pharmacist using your blue treatment book. Nursing staff will supervise you to self-medicate. It is important that you and your carer know your medications before discharge from hospital. The physiotherapist will exercise with you twice daily, the dietitian will provide information about healthy eating, the occupational therapist about sternal wound precautions and the transplant nurse will educate on rejection and infection. Social support will come from pastoral care services, social worker, and psychiatry services. Before you leave hospital you will be asked to complete a short quiz to complete your education.

Recovery Time

Transplant patient's length of stay is approximately 14 days depending on any post operative complications. You will be encouraged to mobilise quickly to aid your recovery and participate in your education for discharge from hospital.

Sternal Precautions

After Heart Transplant: The surgical incision for a heart transplant is typically via a sternotomy, which means through the breastbone. As the pectoral major muscle is attached down the full length of the sternum, engaging it against resistance may cause delays in the healing process. As such, the following restrictions are enforced for up to 3 months post transplant. If you have had any open heart surgery previously, this is likely to be longer.

For 6 weeks:

- DO NOT lift more than 2kg
- 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
- DO NOT reach backwards or put your arms behind your back

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

Activities and Exercise

During your hospital stay you will have morning and afternoon physiotherapy sessions. The physiotherapist will work through the routine with you, to help you do the exercises. When the physiotherapist thinks 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 x-rays to monitor for fluid, air or infection on your lungs and these tests are routinely done on Monday and Thursday. Other tests may include Echo, CT and MRI scans. Surveillance procedures for rejection happen on Monday and Thursday. Information about heart biopsy will be discussed in the rejection section.

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 and weight.

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 take your temperature, if it is above 37.5 you should contact the transplant team.

Weight

Monitor your weight daily in the early months after transplant. If you

have a weight increase of 1-2kg over a day or two it may indicate rejection.

The Immune System

The immune system is the body's defence system. Its function is to protect the body from viruses, cancer 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 can recognise that the heart is not part of "you". The presence of the new heart stimulates the immune system to attack and this process 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 heart, 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 infections more 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 treatment for rejection.

ANTIREJECTION MEDICATIONS ARE FOR LIFE

HEART TRANSPLANTATION

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

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

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

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

Heart Transplant Rejection

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

Symptoms of Heart Rejection

Shortness of breath	Fatigue & tiredness
Swollen ankles	Increased Weight
Light headed & dizzy	Decreased exercise tolerance
Heart palpitations	Loss of appetite

When patients experience rejection there is often evidence of reduced heart function on ECG and ECHO, rejection is diagnosed with heart biopsy (Endomyocardial Biopsy).

Heart Biopsy (Endomyocardial Biopsy – EMBX)

The heart biopsy is initially performed weekly for the first month and

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

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

International Grades of Heart Rejection

New Grade	Old Grade	Interpretation	Outcome
0	0	No rejection	No treatment required
1R	1a, 1b, 2	Mild rejection	No treatment required
2R	3a, 3b	Moderate rejection	Requires Treatment
3R	4	Moderate rejection	Requires Treatment

The two grading's are provided to help prevent any confusion of your results.

Mild and moderate rejection (grade 1R to 2R) is the most common forms of rejection. Rejection decreases in severity and frequency with time. However, you will always be at risk of rejection because your immune system is always actively working to protect you.

Treatment for Heart Rejection

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

Treatment:

- High dose (500-1000mg) intravenous methylprednisolone once daily for three days.

- Reducing dose oral prednisolone twice daily over 1-2 weeks until back to baseline dose.

The heart transplant team may make adjustments to your antirejection medications. If unresponsive to steroid therapy, alternatives may include a more powerful intravenous medication called ATG or total radiation therapy.

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 heart. Antibodies are graded using a scale called Mean Florescent Intensity (MFI) that gives a number indicating mild, moderate or severe level of antibodies. Donor Specific Antibodies with a moderate or severe level of MFI will need treatment.

Treatment for Antibody Mediated Rejection

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

Cardiac Allograft Vasculopathy (CAV)

Cardiac allograft vasculopathy can occur early or late after transplant. This condition results in the narrowing of the coronary arteries that supply blood to the heart. CAV can affect the large main vessels, the small diffuse vessels or both. Cardiac allograft vasculopathy is graded as CAV 0-3 depending on the degree of vessel disease. The severity of CAV can also be evident on echocardiography as a wall motion abnormality and ventricular dysfunction. Many patients have some

form of CAV and manage to lead a full and active life. Treatment for CAV is varied and will depend on the speed of development and time post transplant. Because the heart is denervated 50% of patients do not feel angina or heart attack pain. This is why it's important to attend every transplant clinic for routine heart biopsy, echocardiography, angiography and dobutamine stress echocardiography to monitor for the presence of CAV. All patients must report within 24 hours to the team if they feel unwell and think something is wrong with their heart.

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. Transplant recipients 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.

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. We also see it in the heart transplant population. We often see a secondary bacterial pneumonia associated with the virus. RSV is seasonal in autumn or winter and can mimic colds and flu. Treatment for RSV is oral antibiotics.

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 may 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 anytime like a cold sore. Most of the general population have been exposed to CMV but have a normal immune system and do not get sick. However, because of the antirejection drugs and weak immune system CMV can be life threatening if left untreated. It is important that you know your CMV status and your donor CMV status as this will indicate your risk for CMV activation.

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

Methicillin Resistant Staphylococcus Aureus (MRSA)

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

Vancomycin Resistant 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	Breathless
Fevers	Drop in lung function (FEV1)
Shakes & shivers	Temperature >37.5
Sore throat	Nausea/Vomiting
Runy nose	Diarrhoea

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 hospital antiseptic soap until your wounds are healed. You must never share towels to prevent cross contamination.

Open Wounds and Cuts

Clean with an antiseptic solution and cover wounds daily. If wounds 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 virus 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 can carry diseases that are potentially harmful in transplant recipients. You will need to discuss this with the transplant physician if you maintain bird aviaries.

Dusts

Certain types of dusts can be harmful to transplant patients particularly dusts that carry moulds and fungi. An example of dust is 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 members 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® AND ADVAGRAF® XL)

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).

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 heart transplant patients is decided by checking a ciclosporin trough level. This is a blood test that is done every Monday and Thursday for the first month. This test is done when the ciclosporin level in the blood is at its lowest. That is, just before your morning dose. It is important **NOT TO TAKE YOUR CICLOSPORIN 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 level may come back inaccurately high and may affect the dose we prescribe for you.

Potential side-effects of ciclosporin

Side-effects can occur during early treatment when the dose is high. As the dose is decreased, side-effects 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 band 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

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.

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)

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.

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 to leave a message 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

Transplant Rehabilitation Program

The transplant rehabilitation program is 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.

Transplant Gym

Location: level 4 Xavier Building

Hours: 10.30am to 12pm

Days: Monday and Thursday

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 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.

The clinic team will also be monitoring your blood results sent to St Vincent's from external collection pathology labs.

Patients email the team when a blood test has been taken, this will ensure the team know to check for your results. Only have blood tests when instructed by the transplant team. The patient email address is:

svhs.hlcreresults@svha.org.au

Please provide your – Name, medical record number, contact number, why you are having bloods taken and what pathology service you’ve had bloods taken.

That is so we can follow up on your results.

Heart Lung Transplant Clinic Routine.

HLC is open Monday to Friday at 8.00 a.m.–4.00 p.m.

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

After three months, your visits will decrease in frequency to monthly. 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.)

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

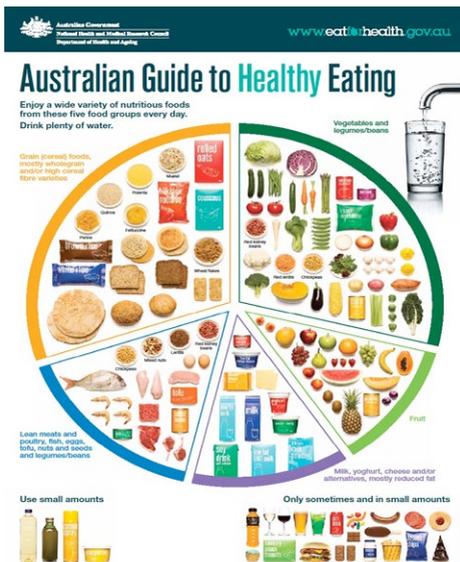
Your dietitian can provide more advice on food safety after your transplant. It is also important that you remember to use safe food practices including food handling, storage and temperature control.

- 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 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

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 but not in a way that can cause injury to healing chest wounds.

Pregnancy

Many women worry about pregnancy and their ability to start a family

after transplant. However, fertility and libido can return quickly for some men and women. Many of our patients have successfully become parents. **We recommend that women prevent pregnancy after transplant for a minimum of one year as there is high risk of heart rejection.**

Before considering pregnancy, you must first consider your 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 serious infections we encourage you to discuss birth control options with your transplant doctor. Condoms, diaphragms and spermicidal jellies are safe to use and some contraceptive pills, but you must clarify the brand with the transplant doctor. **Remember to follow safe sexual health practices and use 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 (13xPCV)	Yes	Yes
Pneumococcal polysaccharide vaccine (23vPPV)	Yes (≥ 8 weeks after 13vPCV)	Yes (≥ 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)	No - contraindicated after transplant
MMR vaccine (live)	Yes (at least one month before transplant)	No - contraindicated after transplant

Australian Technical Advisory Group on Immunisation (ATAGI). Australian Immunisation Handbook, Australian Government Department of Health, Canberra, 2018, immunisationhandbook.health.gov.au.

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

with an impaired immunity.

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

LONG TERM HEALTH AFTER TRANSPLANT

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

You will receive a long term follow up schedule and it is your responsibility to ensure you have each of the tests or investigations listed at the time point indicated. You are required to have specific investigations for heart 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 the suppressed 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. Testicular cancer is also a risk, it is recommended that men do a regular self examination of the testes.

Skin Cancers

You must see a dermatologist annually to assess your skin for cancers. We recommend that you do your own skin check 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, 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 a 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 vision.

INTERNET AND WEBSITES

There are multiple internet websites that have good and bad information about transplantation. The websites below have national and international information that is suitable for transplant recipients and transplant professionals.

- Australian Heart Lung Transplant Association - www.ahlta.com.au
- Donatelife - www.donatelife.gov.au
- Transplant Australia - www.transplant.org.au
- Transplant Society of Australia and New Zealand - www.tsanz.com.au
- Australia & New Zealand Cardiothoracic Transplant registry - www.anzcotr.org.au

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 make a donation to the Harry Windsor Trust Fund that goes directly for high cost equipment or to the Mary Stringer Trust Fund, which is for patient assistance. Speak to the nurse unit manager of Heart Lung Clinic if you wish to make a donation.

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 do their job...now you must do yours!!

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



Glossary

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

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



**ST VINCENT'S
HOSPITAL**
SYDNEY

**Consent
for Heart Transplant**

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

(Please enter information or affix Patient Information Label)

I am consenting for a heart transplant.

Donors go through a rigorous screening process to ensure that their organs are appropriate to be transplanted, however because of the shortage of organ donors, I may be offered a 'extended criteria' or less than ideal organ (e.g. coming from a donor who is older) only after the transplant team have considered the risks and benefits specific to my case.

I am aware that my chance of being alive at 1 year after a heart transplant is 87%; at 2 years 85%, at 5 years is 80% and at 20 years is 50%.

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

I understand the following complications may occur:

- Dying in the first year. 1 in 8 chance
- The new heart failing to function (primary graft failure) and need for circulation support machines (ECMO or balloon pump). 1 in 4
- If ECMO is required, I have an increased risk of death. 1 in 5
- Stroke or disabling brain damage. 1 in 20
- Bleeding from the operation, or needing a repeat operation. 1 in 10
- Needing a blood transfusion. 1 in 2
- Rejection of the new heart. 2 in 3
- Severe infection of the breast bone. 1 in 20
- Need for a pacemaker or defibrillator for the new heart. 1 in 10
- Infection of any type. 1 in 2
- Rejection of the new heart. 2 in 3
- Severe infection of the breast bone. 1 in 20
- Need for dialysis in the early transplant period. 3 in 20
- Risk of kidney failure within a decade. 1 in 10
- Risk of cancer within 3 decades 1 in 4

**(Statistics sourced from Australia & New Zealand Cardiothoracic Transplant Organ Registry Annual Report 2015).*

I agree to cooperate with medical advice and recognise the need to take my medications for life or my heart will fail. Yes No

I am willing to accept the option of receiving a 'extended criteria' donor heart which has been successfully reconditioned in a special machine referred to as the Heart-in-a-box. I understand these hearts may come from donors following either brain death or circulatory death. Yes No

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

I am willing to accept a donor heart from someone with a tumour which is generally not considered likely to reoccur. Yes No

I consent to the removal of my heart and any other tissues during the procedure which may be needed to diagnose and manage my condition. Yes No

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 St Vincent's Hospital Sydney Limited
 ABN 77 054 036 872

Updated March 2017

SV011*****



**ST VINCENT'S
HOSPITAL**
SYDNEY

Consent

for Heart Transplant

MRN		SURNAME	
OTHER NAMES			
DOB	SEX	AMO	WARD/CLINIC

(Please enter information or affix Patient Information Label)

I consent to the use of any unneeded tissue for research. I understand that my tissue will not be identified and that I will not receive any feedback on its use. Yes No

I consent to a post mortem if I die following the heart transplant. Yes No

I consent to my information being discussed in case conferences and being used in quality assurance programs and databases. Yes No

I consent to my information being used in scientific presentations, publications and in the Australian and New Zealand Cardiothoracic Organ Transplant Registry. I will not be able to be identified from such publications. Yes No

I understand that my clinical situation may change so that I am no longer eligible for transplant. After team discussion, I may be temporarily or permanently removed from the transplant waiting list. Yes No

I am being listed for a combined heart and kidney transplant and I have received information about kidney transplant from the renal physicians. Yes No

At Listing for Transplant:

Name of patient _____ Signature _____ Date _____

Transplant Coordinator _____ Signature _____ Date _____

Doctor (Physician) _____ Signature _____ Date _____

Doctor (Surgeon) _____ Signature _____ Date _____

At Time of Transplant:

(This is a re-acknowledgement of the above agreement and is separate from and in addition to the St Vincent's Hospital Operation Consent Form.)

Name of patient _____ Signature _____ Date _____

Doctor _____ Signature _____ Date _____

All statistics sourced from Australia & New Zealand Cardiothoracic Transplant Organ Registry Annual Report 2015.

NSW Health Policy Directives.

PD2010_002 Organ Donation and Transplantation: Managing Risks of Transmission of HIV, HCV and HBV.

PD2005_341 Human Tissue Use/Retention Including Organ Donation, Post Mortem Examination and Coronial Matters.

PD2005_406 Consent to Medical Treatment - Patient Information.

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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

Blood results 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

