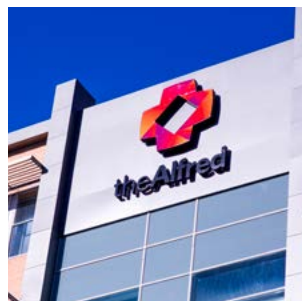
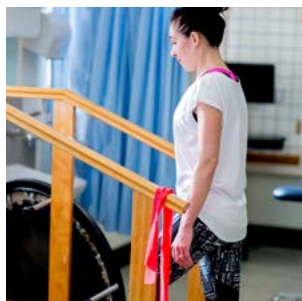
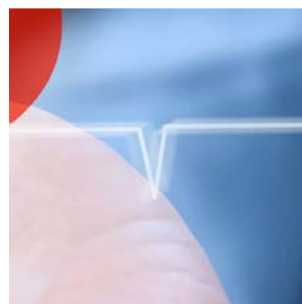
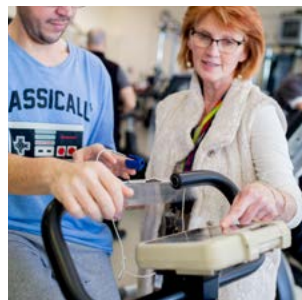
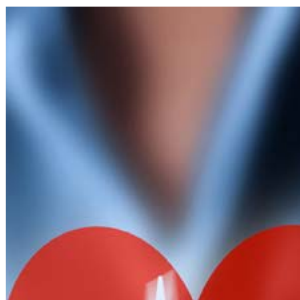




theAlfred
Part of AlfredHealth

**The Alfred
Heart Transplant Service**

Life After Heart Transplant



Contents

After your heart transplant	1	Things to know	10
Who to contact	1	Avoid infection	10
Clinic appointments	1	Vaccines	11
Blood tests	2	Your stitches/wounds	13
Cardiac Biopsies	3	Be sun smart	13
Rejection	4	Protect your bones	14
Types of rejection	5	Cancer screening	14
Making changes to your medications	6	Social media	15
Your gym visits	6	Your sexual health	15
Your education sessions	7	Alcohol	16
Prescriptions	7	Dental hygiene	16
Take your medications	8	Smoking	16
Keep well hydrated	9	Driving	16
Check your temperature daily	9	Travel	17
Check your blood sugar	9	Thanking the donor family	18
Check your weight	9	When to call	19

After your heart transplant

You have received the ultimate gift of life – an organ donation. The long-term management of your health and new heart is a life-long commitment, and we are here to help you through the next steps of this incredible journey.

Who to contact

Medical Emergencies: 000

Heart Transplant Reception: 03 9076 3258

Monday – Friday 8am - 4pm

Heart Transplant Nurse: 0407 203 444

Monday – Friday 8am - 4pm

t.clinicnurse@alfred.org.au

On Call Heart Failure Registrar via switchboard:

03 9076 2000 (after hours if you are unwell)



Clinic appointments

- In the first year after your heart transplant, your clinic is on a Friday morning– you will receive a phone call or text with the time before your appointment. After one year, your clinic appointments will change to Monday afternoon.
- On arrival, please check in with reception. You may need to see multiple members of the team (doctor, nurse, dietitian, physiotherapist, pharmacist, social worker or psychologist) and so your clinic appointment may take a few hours.
- Before you leave, please return to the reception to make your next appointment. Never leave clinic without another appointment booked in.
- **Always bring your medication list with you** to keep track of any changes, as well as your medications and dosette box to pack with the pharmacist.
- **Make sure you have enough scripts to last until your next clinic appointment.**

You have received the ultimate gift of life – an organ donation

Blood tests

- You will need to have a blood test taken at the Alfred **before every** clinic appointment to check your anti-rejection drug levels.
 - If you are having a biopsy the week of your clinic appointment, we will take your blood at the biopsy.
 - Otherwise, please have your blood test a few days before your clinic appointment. **If you have a blood test done locally, it will need to be 1-2 weeks before clinic to allow results to come through in time.**
- Pathology at the Alfred is open Monday to Friday from 8am (on the ground floor near the Main Ward Block lifts).
 - It is not open on public holidays or weekends..
 - You can book an appointment for your blood test through the Patient Portal to avoid waiting in line.



What time to have your blood test

To check the anti-rejection medication levels, the blood test must be taken before you take your morning tablets.

- The test must be taken as close to 12 hours after your night time dose as possible.
- For example, if you take your night time dose at 8pm, do not take your tacrolimus in the morning and have your blood test at around 8am.

Bring your morning anti-rejection medications with you and take them straight after your blood test.

Cardiac Biopsies

- Cardiac biopsies are done to detect rejection and are performed regularly following your transplant.
- Biopsies are done on Monday or Thursday. If your biopsy falls on a Monday, you do not need to attend gym that day.
- The biopsy is performed under local anesthetic, usually through a vein in the side of the neck. The procedure takes about 30 minutes .
- You will need to remain in the clinic area and put pressure on the side of your neck for about 15 minutes after the biopsy to ensure the bleeding has stopped.
- **If you are prescribed blood thinners other than aspirin, please let us know well in advance of your biopsy.**
- Biopsies are usually scheduled as follows:
 - Weekly for 6 weeks
 - Fortnightly for 6 weeks
 - Monthly for 3 months
 - Second monthly for 6 months
 - In the first year, you will usually have about 15 or 16 biopsies.



Day of biopsy

- On the day of your biopsy present to admissions on Level 1 of the Main Ward Block with your Medicare card.
- After you have been admitted, go to the Transplant Clinic to meet the transplant nurse.
- The transplant nurse will
 - Take your blood pressure and heart rate
 - Record your weight
 - Take some blood, including immunosuppressant levels
 - Make sure you don't take your tacrolimus or everolimus until AFTER your blood test
- You will then have an ECG, followed by your biopsy in the Heart Centre.
- After the biopsy, you will be taken back to the transplant nurse to monitor the biopsy site and recover for about 15 minutes.
- Before you go home, you need to have a chest x-ray at The Alfred Centre.

Rejection

- The normal function of the immune system is to protect the body against infections and cancers by recognizing foreign matter and removing it. This is known as the immune response.
- Unfortunately, the immune system also recognizes the transplanted organ as foreign and may try to harm it as well. This is called rejection.
- Anti-rejection medication is used to prevent this from happening.
- The risk of rejection is highest in the first few months after transplantation, and reduces over time. However, it is important to remember that the risk of rejection is always there and therefore, it is essential to take medications as prescribed, for life.
- Rejection is a common occurrence and many of our patients will experience an episode of rejection at some stage. It is usually always treatable.



Grades of rejection

Grade	Description	Action
0	No rejection	No adjustment to medications. Can continue with gym as usual.
1R	Small amount of rejection	Doctors may or may not change medications. Can continue with gym as usual.
2R	Moderate rejection	Doctors may change your immunosuppressant medication. You may need to come to clinic for 3 days in a row for an intravenous prednisolone infusion. In some cases you may need to be admitted to hospital. You will have a repeat biopsy the following week. No gym or strenuous activity until the next clear biopsy.
3R	Severe rejection	This will require a hospital admission for closer monitoring and immunosuppression medications. You will have a repeat biopsy the following week. No gym or strenuous activity until the next clear biopsy.

Types of rejection

Hyper-acute rejection

- Hyper-acute rejection can happen in the first few hours after transplantation. It occurs because the body has previously been exposed to the same or similar antigens found in the donor organ. This may be due to previous blood transfusions, pregnancy or prior transplantation.
- This type of rejection is very rare.

Acute rejection

- Acute rejection occurs when T cell lymphocytes (a type of white blood cell) attack the heart.
- Acute rejection can occur within days of transplantation and is most common within the first 6 months. However there is always a risk of acute rejection at any stage after transplant.

Antibody mediated rejection

- Antibody mediated rejection occurs when the immune system develops antibodies directed against the donor heart antigens.
- This form of rejection may require specialized blood tests and biopsy samples for testing and treatment.

Chronic rejection

- Cardiac allograft vasculopathy is also known as chronic rejection. It usually does not occur until several years post-transplant.
- It involves progressive and diffuse narrowing throughout the entire length of the coronary arteries (the arteries that supply the heart muscle with blood).
- Overtime this type of rejection may result in a deterioration of heart function through silent heart attacks, and can eventually cause failure of the organ.
- Angiograms or cardiac CT are used to diagnose this form of rejection and should be performed every few years.
- Cholesterol management is also important to prevent this process from occurring.



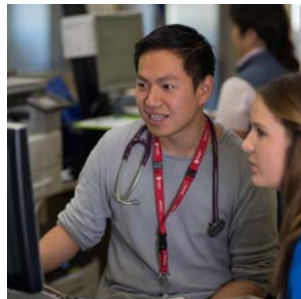
Making changes to your medications

After we get your blood test results, we will contact you by telephone if there are any changes to make to your medications.

Please be available via phone at **all** times to allow us to do this.

Make sure your phone number is correct on the Alfred's computer system before you leave hospital.

Alfred staff will call from a 'private number' so make sure you answer these calls.



Your gym visits

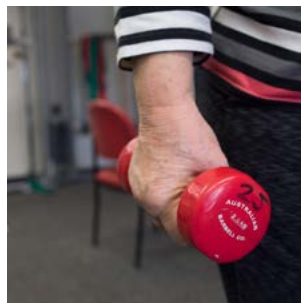
Gym is on Monday, Wednesday and Friday for a minimum of 8-12 weeks after you have been discharged from hospital.

You may be given a time to attend gym. On your clinic day, please make sure you allow enough time to attend your clinic appointment as well as gym. Do not attend gym on the same day as a biopsy.

Ensure you are wearing appropriate exercise shoes and clothing (and well-fitting wire-free support for women i.e. singlet with shelf bra or a crop top).

Remember to bring a full water bottle and **always** have breakfast on gym mornings!

If you are diabetic, make sure you bring your blood sugar monitor and some jelly beans in case of low blood sugar readings.



Remember to bring a full water bottle and always have breakfast on gym mornings!

Your education sessions

Education is at 10am on a Tuesday or Wednesday.

There are about eight different sessions on a range of topics – you and your carer must attend each session at least once.

You will be given a schedule of upcoming education sessions on discharge from hospital.

Prescriptions

You need to keep track of your medications and repeats.

Before you come to clinic, please check your supply of medications and scripts you have at home.

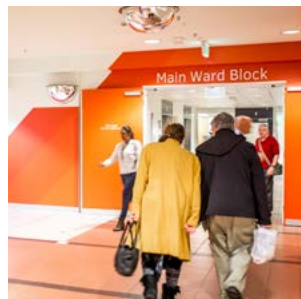
Prescriptions will be provided at your clinic appointment, so remember to ask your doctor.

Please ensure you have enough medication to last until your next clinic appointment.

Getting prescriptions between appointments can be difficult and may not be possible, **so please be organised.**

The transplant nurses can help you get a script for medications that can only come from the Alfred, (e.g. immunosuppression, antivirals, antifungals and magnesium, calcium, vitamin D), but need at least 1 weeks' notice before a script will be ready to be collected.

If you require scripts for other medications in between your clinic appointments, please obtain these from your GP.



Take your medications

Take your medications as you are instructed by your doctor, nurse and pharmacist.

Please do not miss doses or adjust the dose of your medication unless advised by the transplant team.

Medications that are twice daily should be taken 12 hours apart.

What to do if you miss a dose of your anti-rejection medication

- If you take the medications once daily, take the medication as soon as you remember.
- If you take the medications **twice daily**
 - If it's within 6 hours of the due dose, take the medication as soon as possible.
 - If it's more than 6 hours late, skip a dose and take the next dose as usual.
- If in doubt, contact the heart transplant nurse for advice.

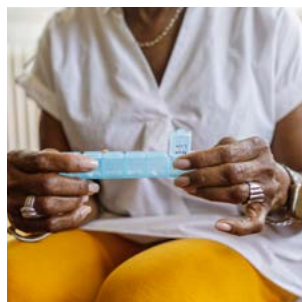
If you think you have unpleasant side effects from your medication, please discuss this with the transplant doctor or pharmacist, but do not stop or change the doses.

Never run out of medication.

It is extremely important that you do not take any new medications prescribed by another doctor or you buy over the counter, unless it has been approved by the transplant team.

Store your medications in a cool dry place.

Please bring your medication list to every clinic appointment.

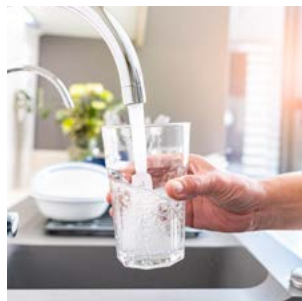


Keep well hydrated

Aim to drink 1.5-2 litres of fluids every day (unless your transplant doctor has told you otherwise). Some people may need more or less, but your doctor will discuss this with you.

Try to make sure you mostly drink water (or sugar free cordial) but all liquids count!

Limit caffeinated drinks (coffee, tea, coke, energy drinks etc.) to three or four per day, as these can cause dehydration, can affect your kidneys and your heart.



Check your temperature daily

It is best to do this in the morning before having your medication (and always before having paracetamol)

If you have a temperature of 37.5 or higher, contact the heart transplant team immediately. Go to the Emergency Department for medical review if you are clearly unwell.

Check your blood sugar levels

Some people may develop diabetes and require insulin injections after transplant. If you need to monitor your blood sugar levels, you will see a diabetes nurse for education before you leave hospital.

Check your blood sugar levels as advised by the endocrine doctors or the diabetes nurse educator and record it in the book you are given. Bring this book to clinic for review.

Send through your blood sugar levels to the diabetes nurses once a week. The diabetes nurses will monitor your blood sugars and contact you if any changes need to be made.

You will need to see an endocrinology doctor regularly. We will help set this up for you.



Check your weight

Check your weight every day and keep a record to bring to your clinic appointments.

It is best to weigh yourself first thing in the morning, before breakfast and after you have been to the toilet.

If your weight increases by 2kg in 24-48 hours, please contact the transplant nurse.

Things to know

Avoid infection

Hand washing is one of the best ways to protect yourself from getting infections. This is because many germs are shared on people's hands.

Use soap and warm running water when you wash your hands. It should take about 20-30 seconds. It is ok to use anti-bacterial hand gel when you are out instead.

Always wash your hands before:

- eating or preparing food
- touching your face (particularly eyes, nose and mouth).

Always wash your hands after:

- going to the toilet
- touching animals
- handling garbage
- touching raw meat
- gardening.

Avoid sick people and make sure family and friends know not to visit if they are unwell. This is particularly important if someone has an obvious chest infection.

If someone you live with is unwell:

- avoid close contact (less than one metre)
- avoid having the sick person prepare food for you
- be extra diligent with hand washing.

Avoid crowded places, such as public transport, for the first weeks after transplant.

Don't use public swimming pools for 3 months after transplant.

Tattoos and body piercings are not advised following transplant due to the increased risk of infection.

Avoid the following as **fungal spores** can cause serious lung infections:

- building sites with current excavation, earth or soil works
- cleaning mouldy bathrooms or other mouldy areas such as damp buildings / dirty air conditioning
- always wear a mask and gloves when gardening or using mulch, compost or potting mix.



Pets & animals

- Always wash your hands after handling pets or pet food/ toys/ bedding.
- If you have a cat, ask someone else to clean out the kitty litter tray if possible, or wear gloves and a mask as you can get serious infections from cat waste.
- Avoid birds as much as possible. This includes their droppings and cleaning out their cages.
- It is best to rehome pet birds or keep them outside and avoid close contact with them as you can get serious infections from birds.



Vaccines

Some vaccines are 'live' and must be avoided – they are dangerous after heart transplant.

This is a list of live vaccines, you **must not** have:

- Measles, Mumps, Rubella (MMR) vaccine
- Chicken Pox (Varicella) vaccine
- Shingles (Zoster) vaccine
- Tuberculosis (BCG) vaccine
- Yellow Fever vaccine
- Salmonella typhii (Typh-vax oral) Vaccine
- Oral Polio (sabin)

If you are unsure if a vaccine is 'live', please discuss this with the heart transplant team.



Live vaccines for close contacts

We recommend that the people you live with and other close contacts have all the recommended vaccines including live vaccines.

Please discuss with the heart transplant team as there are specific recommendations for live vaccines:

MMR and Varicella:

- If a rash develops in the person who had the vaccine they should cover the area (if possible) and avoid close contact with the transplant recipient until the rash is fully crusted over.
- Good hand hygiene should be practised.

- If the rash cannot be covered, the vaccine recipient and the transplant recipient may need to live in separate households before the rash is fully crusted over.

Rotavirus vaccine:

- This vaccine is given to all newborns.
- As rotavirus can then be detected in the baby's waste products, we recommend that a person who has had a transplant:
 - avoid nappy changing for at least two weeks
 - always practice good hand hygiene.

We also ask that any child who has been vaccinated with rotavirus vaccine not be brought into the transplant clinic area for at least two weeks after each dose.

Household and other close contacts can safely receive travel vaccines such as yellow fever and oral typhoid, if required.

Flu shot

The yearly flu shot is vital, helping protect you against influenza viruses during the winter months.

In the first year after transplantation, you should have two flu vaccinations 4-6 weeks apart to boost your immunity. After that, you should have 1 flu vaccination each year, unless advised otherwise.

Family members should also have the flu shot each year.

Be aware, vaccination guidelines can change overtime.

Please speak to the transplant team about any other vaccinations you should have after your transplant.



Your stitches/wounds

Your wounds must be reviewed by the heart transplant nurses weekly at your clinic visit until the stitches are removed and/ or your wound is completely healed. Keep any dressings clean and dry.

If you have complex wounds that require more frequent dressings, a plan should be made before you leave hospital for who will attend to these and how often they need to be changed.

Report any unusual opening, heat, pain, redness, drainage, ooze or pus from your wounds to the heart transplant team immediately.



Be sun smart

Many drugs increase your sensitivity to the sun, which increases your risk of sunburn (and skin cancer) after heart transplant.

There can still be risk of sun damage even if it is not sunny so always:

- **SLIP** on a collared shirt
- **SLOP** on some sunscreen
- **SLAP** on a hat
- **SEEK** shade between 11am and 3pm
- **SLIDE** on some sunglasses

Hands, noses, ears, heads and necks are particularly at risk.

You will need to see a dermatology doctor to monitor your skin at least once per year. Your heart transplant team will help set this up for you or you can do this locally.

Report any new or suspicious spots or moles to your heart transplant team immediately.



Protect your bones

Some transplant medications can impact on your bone health and increase the risk of osteoporosis. In order to keep your bones healthy and strong, make sure you are:

- getting 30 minutes of cardiovascular exercise daily e.g. walking, stationary bike
- strength training 3 x week e.g. squats, step up, dumbbells
- eating 3-5 serves of dairy daily (or alternatives - our dietitian can advise) e.g. 1 cup of milk/ milk alternative, 2 slices of cheese (40g), $\frac{3}{4}$ cup (a 200g tub) of yoghurt.

You may need to be seen by an endocrinology doctor to monitor your bones. You will need special blood tests and a DEXA (bone density) scan every two to five years, before you see the endocrinology doctor. Your heart transplant team will help set this up for you.



Cancer Screening

Anti-rejection medications can increase the risk of cancers including skin cancer, lymphoma and solid organ tumours. It is important to undergo regular cancer screening and be vigilant if you experience any new symptoms such as bleeding from the bowel, breast or testicular lumps or swollen lymph nodes, as cancers can spread rapidly.

- Women should have mammograms every 2 years (age > 50) and cervical screening every 5 years (age > 25)
- Men should have a PSA (prostate specific antigen) blood test every 2 years (age >50)
- Bowel cancer screening (faecal occult blood test) should be performed every 2 years (age >50)

This information is based on the Department of Health guidelines and may change overtime.



Social media

Your transplant is a day of hope and happiness for you and your family, and many patients want to share their journey on social media. However, it's important to remember there is a donor family that has lost a loved one and is going through a very distressing time. We must protect their privacy and the dignity of their gift. Sharing details about your transplant on social media can jeopardise this.

It is important that you do not:

- post details of your transplant, particularly the exact date, on social media. As per the Human Tissue Act 1982, it is a requirement to protect the identity of the organ donor.
- post photographs or details of the team looking after you.

Anything you post on social media is permanent and can easily be shared with people you don't know. It's important for transplant recipients to be considerate about what they post.



Your sexual health

There is a very small chance of getting blood borne infections (Hepatitis B, Hepatitis C & HIV) from your donor after transplant.

Everyone will have a three-month blood test after transplant to check this. Please use condoms to protect your partner until then.

Women are strongly advised against becoming pregnant.

- Pregnancy can affect your heart transplant and drop your heart function.
- Anti-rejection medications can cause birth defects.

Your new medications can cause birth defects by affecting the eggs in females and the sperm in males. Anyone considering pregnancy or fertility investigations / treatments (eg: IVF) **must** discuss this with one of the heart transplant doctors well in advance.

We advise long-term contraception. Please discuss options with your transplant doctor.

Alcohol

Responsible consumption of alcohol is important following transplantation. Alcohol can affect your liver and impact your medications.

We recommend avoiding alcohol in the first three months after heart transplant.



Dental hygiene

You must have regular 6 monthly dental check ups after transplantation in order to maintain good oral hygiene.

You may need a dose of antibiotics prior to undergoing dental procedures as a precaution.

Smoking

You should **never smoke** after a heart transplant and should avoid being in areas where people are smoking.

Smoke exposure may lead to damage of your transplanted organ and we feel is not fully respecting the precious gift of organ donation.

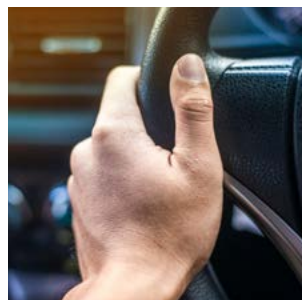


Driving

You will not be able to drive for **at least twelve weeks** after heart transplant. At that point you will need to talk to one of the heart transplant doctors and physiotherapist to ensure that you are fit to resume driving. An eye test or other specialist opinions may be required to complete the assessment.

Please be aware that you may take longer to get your license back, so please ensure you have made the appropriate arrangements to travel to and from the hospital in that period.

If you have not been medically cleared for driving, your insurance will not be valid.



Travel

There are some important issues to consider before travelling after your heart transplant and planning ahead is essential.

- Take care in considering your destination including the sanitary conditions and access to healthcare. Be aware of the closest hospital and closest transplant units should you become unwell.
- Ensure you have a letter from your Doctor with your medical history, current medications and contact details for the Alfred transplant unit.
- Ensure you pack more medications than you need for the trip (pack in an airtight container and carry some in your hand luggage and some in your suitcase in case either is lost).
- Discuss vaccinations with your Doctor before travelling. We can refer you to the Alfred Travel Clinic to facilitate this.
- Take a basic medical kit including a thermometer and first aid supplies.
- It is important to have travel insurance – you may need to shop around to find a company that will cover transplant recipients.



Thanking the donor family

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

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

You can tell the donor family about your:

- age
- gender
- immediate or extended family (no names)
- course of illness and need for a transplant
- impact of the transplant on yourself and your family

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

- Names - just sign as "transplant recipient" or "recipient"
- Address or city name

The timing of the letter is left very much up to you, but most often letters are sent 3-6 months after your transplant.

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

When your letter or card is ready, forward it to the transplant coordinator who will pass it on to the Donor family. The transplant coordinator will read the letter to ensure that it does not include any identifying details.



When to call

Signs of infection

- Fever over 37.5 degrees, sweats, chills or body aches.
- Cough, sore throat, runny nose.
- New, severe or increasing shortness of breath.
- Vomiting that lasts for more than 12 hours or if you are unable to keep medications down.
- New diarrhoea lasting longer than 12 hours.
- Burning sensation when passing urine.
- Redness around or drainage from any wounds.
- Persistent, severe or sudden headache (with no relief from regular strength paracetamol).
- If symptoms are mild, you can seek advice from your GP in the first instance.

Signs of rejection

- Weight gain of more than 2kg in 24-48 hours.
- New, severe or increasing shortness of breath.
- New swelling around abdomen or ankles.
- Fast or irregular heart beat/palpitations.
- Severe unexplained tiredness or reduced exercise capacity.
- Nausea/loss of appetite.
- Abdominal pain or discomfort.

Who to contact

Medical Emergencies:

000

Heart Transplant Nurses:

0407 203 444

t.clinicnurse@alfred.org.au

Mon – Fri 8am – 4pm

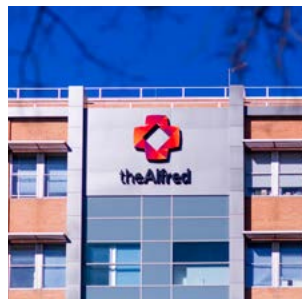
On call Heart Failure Registrar:

03 9076 2000

(after hours if you are unwell)

You should also notify us (call or email)

- If you or any family members have been exposed to chickenpox, shingles, measles, mumps, or any other significant viral infection, like gastro or the flu.
- If you miss any doses of anti-rejection medications.
- Before starting any new medications (including those that you can buy at the supermarket/ petrol station or pharmacy without a prescription).
- Before stopping any medications or changing the dosage of any current medications.
- Before having dental work done (you may need a prescription for antibiotics to take before the dental visit).
- Before you have any procedure that requires sedation or anesthetic (either at the Alfred or at another hospital).
- If you are admitted to another hospital you must let the transplant team know. The hospital you are admitted to should contact and discuss your care with the transplant team at the Alfred.



The heart transplant team are very happy to give advice on any of the topics discussed here.

Everyone is different and will have different needs after heart transplant – this information is very general.

Please also note that not everything you read on google/ social media is accurate – if you want specific advice please talk to the heart transplant team.



Developed and reviewed by our consumers

The Alfred

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Booklet proudly sponsored by Astellas

