



St Vincent's Hospital Heart & Lung Clinic

Heart and/or Lung Transplant listing information for patients, family, carers and friends

This booklet has information for patients, family, friends and carers on:

- Your roles and responsibilities for being on the transplant list
- What to expect when you are put on a transplant list
- What to do when you are called in for transplant
- Information about carers
- Coming to hospital
- Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)
- Accommodation options
- Hospital parking
- The Intensive Care Unit

We are here to help you and your family, friends and carers throughout the transplant process.

Please contact us if you have any questions.

The last page of this booklet has our contact details.



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1. How long is the wait for a transplant?

Unfortunately we don't know how long you have to wait to receive your transplant. The wait could be as little as a day, several months or even years. There are many factors involved in finding the right donor for you. You and your donor need to be compatible in:

- Blood group
- Matching your blood with donor blood
- Height
- Weight
- Lung measurements (for those receiving a lung transplant)

If you have any questions on the above please talk to one of the Transplant Coordinators or your Transplant Doctor.

2. What are my roles and responsibilities when on the waiting list for a transplant?

You need to come for regular medical appointments at the Heart Lung Clinic.

- We will tell you when to come to appointments.
- At the appointment you will see the Transplant Doctor.
- At the end of each appointment you should ask when to come for your next appointment.
- During your visits you will meet all the members of the Transplant Team. This is so you can get to know them, and so they can know about your condition and needs. After your transplant the team will care for you.
- You might have to repeat your history and condition at each visit. This is so we can check if anything has changed since your last review.

You need monthly blood tests

- This is a blood test to match you against potential donors. You can go to any pathology service to do this blood test.
- You need to have this test done **on a Monday or Tuesday before the 20th of each month.**
- **It is very important that you have your blood taken monthly. If you don't get your blood tested each month you might miss out on a potential transplant.**
- The Transplant Coordinator will give you some Tissue typing forms to take to the pathology service.
- If you have run out of Tissue typing forms please call the Transplant Coordinators as they can send more to you.



Planning ahead

Information on Planning ahead can be found on the St Vincent's Hospital website <http://svhs.org.au/home/patients-and-visitors/being-involved-in-your-care/who-will-speak-for-me> or www.planningaheadtools.com.au or phone 1300 887 529. The website provides information on preparing a will, making a power of attorney and appointing an enduring guardian. If you would like to discuss this further please see the Transplant Social Worker.

You need to have a carer

By now, we will have asked you to find a carer for your recovery after your transplant. Most often a carer is someone known to you – a family member or friend. We understand that finding an available carer may have been hard. We know that this is also a very stressful and demanding time for your family, friends and carer.

3. Information about carers

Why do I need a carer?

Some of the reasons you need a carer are:

- We want you to have as much support around you as possible.
- Transplant is a very busy time and may be overwhelming for you, your family, carer and friends.
- Transplant can be a very emotional time and it's important you have people around you for psychological and practical support.
- You will have to come to hospital many times after transplant, particularly in the first three months.
- Your carer can help with carrying bags, transport, and collecting your medicine.

What does the carer have to do?

- Your carer comes with you to and from doctor appointments. At appointments we give you a lot of information. You may be very tired and so not remember all the information we give you. Your carer can help you remember the information.
- Your carer can tell us of any changes in your condition or treatment which you may have forgotten.
- Your carer should help you with transport. You will need to come to appointments in different locations.



4. When should I contact the Transplant Coordinator?

You or your carer need to contact the Transplant Coordinator if:

- **You change carers:** If your carer changes please tell one of the Transplant Coordinators.
- **You are admitted to hospital, or leave hospital:**
 - If you are admitted to St Vincent's Hospital, tell the Transplant Coordinator.
 - If you are admitted to another hospital, ask a doctor to contact the On Call Transplant Registrar via St Vincent's Hospital switchboard).
- **Your health gets worse:** If your condition gets much worse, you must go to your local emergency department or General Practitioner. If they change your care or treatment please tell us.
- **Your weight changes:**
 - Putting on weight can be a sign of worsening heart failure (for patients listed for heart transplant).
 - Weight loss can be a sign of muscle loss.
- **You are not staying at home:** If are away from your usual town/city please tell the Transplant Coordinator. We need to know in case we have to arrange travel help for you on the night of transplant.
- **Your contact numbers change:** You must tell us if your home or mobile numbers change. We need your numbers so we can contact you for transplant. . You must be contactable 24 hours a day, every day.
- **You missed your monthly tissue typing bloods.**
- We aim to give you the best possible care. Please ask us any questions if you are not sure about anything.



5. What do I do when the Transplant Coordinator calls me about a potential transplant?

When the Transplant Coordinator calls you, they will give you some instructions. These include:

- **Food: You must not eat anything** from the time of the call, but you may have sips of water.
- **Packed bag: bring a packed bag** to hospital with your toiletries, current medications, pyjamas, phone charger and a change of clothing.
- **Travel:**
 - If you live in a **rural area** you might need to drive some distance as a plane may not be always available. We will try to arrange the best travel options for you.
 - If you live in **metropolitan Sydney**, someone should drive you to St Vincent's Hospital.
 - Whether you are flying or driving someone needs to **travel with you. If we have arranged a flight for you please only bring one person with you.**
 - If you are **flying and require oxygen** you must bring your **Clearance to Fly** documentation with you.
- **Getting a call overnight, on a weekend, or on public holiday:** If we call you during the night we will tell you to go to the St Vincent's Hospital Emergency Department. The Emergency Department is located on street level near the hospital entrance.
- **Getting a call in the daytime:** If we call you on a weekday we will tell you to come to the Heart & Lung Clinic which is on Level 4 at St Vincent's Hospital.



6. What do I do when I get to hospital?

When you arrive at the hospital you will go to the Emergency Department or the Heart & Lung Clinic.

- **Transplant team:** Members of the Transplant Team will see you including
 - Transplant Coordinator – who will arrange a blood test and chest x-ray
 - Transplant doctor – to check you are physically okay
 - Anaesthetist – to plan your anaesthetic
 - Transplant Surgeon – the surgeon will give you information and risks about surgery. They will check you understand it, and ask you to sign a consent form giving your permission for the surgery.
- **Admission to ward:** We will admit you to a hospital ward
- **Shower:** You will have a shower.
- **Family, friend, carer:** Your family, carer or friend can stay with you until you go to the Anaesthetic Bay. In some areas of the hospital, you can only have one or two people with you.
- **Anaesthetic bay:** You may be in the Anaesthetic Bay for some time (possibly hours) until the retrieval team tells the transplant surgeon that the organs are suitable to be used. If the organ/s are okay, then you will go to Theatre for your surgery.
- While you are in theatre your family/friends/carers can wait in the Intensive Care Unit waiting room. The Intensive Care Unit (ICU) is on level 5.

7. Could the transplant be cancelled?

- The transplant can be cancelled at any time. The transplant might be cancelled if
 - the donor organs are no longer usable
 - the matching between you and the donor is not compatible
- There might be several false alarms where you come for transplant and the transplant doesn't go ahead.

8. What does it mean if I'm a 'backup'?

- We might call you in as a 'backup'.
- This means that if another recipient's blood does not match the donor, then we can check if you are a match to the donor.
- When we call you we will tell you if you are a 'backup'.
- We might call to cancel at any time, even when you are on the way to hospital.



9. Does where I live affect my chances of transplant?

- Yes, in some cases where you live can affect your chance of transplant.
- There are rules around the timing of transplant.
- We will try very hard to get you to hospital in time. In some cases it might not be possible due to location or weather (e.g. fog, fire, flood). We then might choose another suitable recipient.



Information for family, carers and friends about the day/night of transplant

10. Information about the Intensive Care Unit (ICU) for family, carers and friends

- **Patients who have a transplant will be admitted to the Cardiothoracic ICU after surgery.**
- **Location:** The Intensive Care Unit (ICU) is on Level 5 of St Vincent's Public Hospital.
 - If you come in the main hospital entrance (level 3), take the main hospital lifts to Level 5.
 - When you exit the lift, you will see directions to the ICU displayed on the corridor wall.
- **Intercom:** There are two intercoms near the main entrance to the ICU. These intercoms ring the reception desk in the ICU.
- **Please call the intercom (labelled North) to tell the staff you are in the waiting room so that they can contact you as needed.**
- **Visiting hours:** ICU visiting times are between 11am-1pm and 3pm-8pm every day. These can be changed in exceptional circumstances to suit your needs.
- **Visiting the patient:**
 - We will tell you when you can visit the patient.
 - We will open the entrance doors which are located on your left.
 - Only two people can visit the patient at a time. This is because space is limited.
 - The ICU is a very busy place, with lots of noisy equipment around the beds. There are alarms to monitor the patient and also to alert the ICU nurse and team of any changes in the patient's condition.
- **Contact details:** Please update the nurse with your contact details in case they need to contact you once you leave the hospital.
- **Updates on patient progress:** We ask you to nominate one person to call ICU for updates on the patient.
- **Social Worker:** The Transplant Social worker will contact the family, carer or friends to provide support and discuss accommodation options. If you need urgent help from the Social Worker please tell the Transplant Coordinator and/or the ICU staff.
- **Pastoral Care:** If you wish to see Pastoral care please ask the ICU nurse at the bedside and they will arrange for someone to meet with you.
- **ICU can be an overwhelming and frightening place. The ICU team are happy to give you updates and explain tests. Please ask them any questions.**
- **Transfer to ward:** We will move the patient to ward Xavier 10 South when the patient is ready. Xavier 10 South is on level 10. To get there; take the main lifts to level 10. When you come out of the lift, turn right.
- **Leaving the ward:** after leaving the ward, the patient may go to rehabilitation (in the hospital)



11. Accommodation

- **St Vincent's Hospital has accommodation available for rural, isolated and interstate patients and their relatives.**
- The accommodation has basic shared facilities with shared kitchen and shared bathrooms. We provide linen.
- **Accommodation is \$30 per night per person. Unfortunately** there are no parking facilities.
- **St Vincent's Hospital accommodation is only available for patients and relatives who live in rural and isolated areas.**
- The Transplant Social Worker can help arrange accommodation for relatives who live outside the metropolitan area. They can also help relatives who live within the Metropolitan area with accommodation options if they wish to stay close.



Other options are:

| Accommodation | Location | Contact and booking |
|--|-------------------------------------|--|
| Elizabeth Hunter Lodge | Waverley near Bondi Junction | Ph: (02) 9369 0307 email: ehunterlodge@wmhw.org.au |
| Arts Hotel | 21 Oxford Street Paddington | Ph: (02) 9361 0211 – Quote St Vincent's Hospital when booking to get the special rate. Limited parking available. |
| The Macleay Serviced Apartments Hotel | 28 Macleay Street Potts Point | Ph: (02) 9357 7755 Quote St Vincent's Hospital when booking to get the special rate. Parking available. |
| IBIS Budget Sydney East | 191-201 William Street East Sydney | Ph: (02) 9326 0300 Quote St Vincent's Hospital when booking to get the special rate. Parking available. |
| Morgans of Sydney | 304 Victoria Street Darlinghurst. | Ph: (02) 8354 3444 Fully self-contained units (no laundry facilities). |
| Quest Potts Point | 15 Springfield Avenue, Potts Point. | Ph: (02) 8988 6999 Quote St Vincent's Hospital when booking to get the special rate. |
| The Maisonette Hotel | 31 Challis Avenue, Potts Point. | Ph: (02) 9357 3878 Book online and enter the code: STVINCENTS in the comments to receive a discount of 10% upon check in. If making a reservation by telephone, mention that the booking has been referred by St Vincent's Hospital to receive a 10% discount. |
| Pullman Sydney Hyde Park | 36 College Street Sydney. | Ph: (02) 9961 8400 - Quote St Vincent's Hospital when booking to get the special rate. |
| Meriton Serviced Apartments | 97 Grafton Street, Bondi Junction | Ph: (02) 8305 7600 |



12. Parking and public transport

- **We are unable to cover parking costs.**
- **Parksmart** manage the St Vincent's Hospital car park.
 - Hours of operation: Mon-Thurs 6.30am -11.30pm. Fri-Sat 6.30am – 1.30am. Sundays 06.30am – Midnight.
 - The entrance is accessible from Victoria Street.
 - Hourly rates apply.
 - Maximum cost \$50 per day.
 - Night rates available with entry after 4pm and exit before close.
- You can ask the **Parksmart** attendant or phone (02) 8382 3896 to ask for a weekly rate if you expect to use the carpark for a lengthy period.
- There are metered car spaces in the area around St Vincent's Hospital
- There are several disabled car spaces located near the hospital. They are located on Boundary Street, Forbes Street, Surrey Street, Womerah Avenue and Victoria Street.
- St Vincent's Hospital is very accessible by public transport. There are bus stops on Burton St and Oxford St. These are close to the hospital.
- The 440 bus from Central station stops at Taylor Square. This is a 10 minute walk to the hospital. The bus stop returning to Central Station is on Oxford Street.
- The 311 bus from Central stops at Darlinghurst Road. To go back to Central you can get the bus from Burton Street.
- The closest train station to St Vincent's Hospital is Kings Cross which is a 10 minute walk to the hospital.

13. Travel and Accommodation assistance

- You are responsible for travel and accommodation costs. If you travel 100km or more to St Vincent's Hospital you might be able to get some travel and accommodation costs back. This is available through the Isolated Patients Travel and Accommodation Scheme (IPTAAS). The scheme also covers the cost of one family member or carer if escort is required.
- You can get an IPTAAS forms from the Heart Lung Clinic front desk. Or via the IPTAAS website <http://www.enable.health.nsw.gov.au/services/iptaas> . If you need help filling these out please ask the Transplant Doctor or the Transplant Social Worker. After each of your appointments the forms must be signed by the treating transplant doctor.



14. Important contact numbers

| Department | Hours | Phone |
|---|--|---|
| St Vincent's Heart & Lung Clinic: Transplant Coordinators | Monday to Friday 7.30am – 4.00pm | Tel: (02) 8382 3158 Fax (02) 8382 2505 |
| | Monday to Friday 4.30pm to 8.30am and Weekends and public holidays | Call the St Vincent's Hospital switchboard on Tel: (02) 8382 1111 and ask for the On call Transplant Coordinator |
| St Vincent's Heart & Lung Clinic: Transplant Social Worker | Monday to Friday 8.30am – 4.30pm | Tel: (02) 8382 3294 or Call the St Vincent's Hospital switchboard on Tel: (02) 8382 1111 and ask for the Transplant Social Worker |
| St Vincent's Heart & Lung Clinic: Appointments | Monday to Friday 7.30am – 4.00pm | Tel: (02) 8382 3150 |
| St Vincent's Hospital Intensive Care Unit: Cardiothoracic Unit | 24 hours/day | Tel: (02) 8382 2036 or Call the St Vincent's Hospital switchboard on Tel: (02) 8382 1111 And ask for ICU Cardiothoracic Unit |
| Ward – Xavier 10 South | | Tel: (02) 8382 2585 |
| Ward – Xavier 10 North | | Tel: (02) 8382 2256 |
| Ward - Rehabilitation | | Tel: (02) 8382 9514 |

Acknowledgements:

References

Related Policies/Procedures – [Transport or Transfer for Potential Recipients to St Vincent's Hospital for Heart and/or Lung Transplant policy](#)

This brochure was developed in partnership with consumers.

Developer information e.g. Clinic / ward / service

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