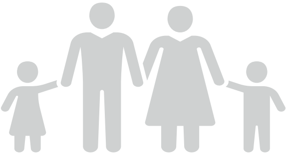
Metro South Health | Transplant Services
Princess Alexandra Hospital

patient information

Carers and support



Good social supports when having a transplant is vital.

The Transplant Services values the huge role of carers for family members and friends before and after having a transplant.

The hospital does not offer personal, private or unpaid carers to patients. The team does however offer full professional medical care when the patient is in hospital and attending the outpatient services.

If you do not have a support person either before or after the transplant, please speak with the social worker.

Some patients already have a home support package due to their medical care needs. Patients can ask for more supports post transplant from community organisations if needed. These supports could be through:

- **My Aged Care** (over 65 or over 50 for Aboriginal and Torres Strait Islander people)
  www.myagedcare.gov.au

- **Queensland Community Support Scheme** (under 65 or under 50 for Aboriginal and Torres Strait Islander people)
  www.qld.gov.au/community/getting-support-health-social-issue/community-home-care-services/queensland-community-support-scheme

- **National Disability Insurance Scheme (NDIS)**
  www.ndis.gov.au

There are a number of support services for patients and carers that might be useful.
Please visit:

- **Transplant Australia** - Carers
  https://transplant.org.au/living-with-your-transplant/support/carers/

- **Services Australia (Centrelink)** - Caring for someone
  www.servicesaustralia.gov.au/caring-for-someone

- **Queensland Government** - Support for carers
  www.qld.gov.au/community/support-for-carers/support-groups-for-carers

- **Kidney Health Australia** - Families and carers
  www.kidney.org.au/your-kidneys/living-with-kidney-disease/families-and-carers

Partnering with Consumers - 2.9 Where information for patients carers, families and consumers about health and health services is developed internally, the organisation involves consumers in its development and review. *Standard 2, 2nd edition*

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Queensland Government

What to expect as a carer

Before a transplant

Before a transplant, patients and their medical team are always working to take care of patient wellbeing. The aim is to support patients to be in the best condition they can for the surgery. Some patients have changes to their physical, emotional, and cognitive (thinking and mental processing) health while waiting for a transplant. This is due to the impact of their liver or kidney illness. This can be hard and distressing for patients, their carers, family and friends. The team are familiar with these situations and are always happy to offer support.

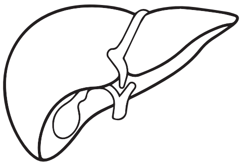
Carers can help by:

- Providing reassurance
- Identify any issues
- Give planning support
- Take care of day to day activities such as shopping, making food, home help and transport
- Providing emotional support
- Support with moving closer to the hospital if needed
- Just being present for the patient

Read more on the Queensland Kidney Transplant Services Website (QKTS) - Patient resources under Brochures and fact sheets
www.qld.gov.au/health/services/specialists/kidney-transplant/patient-resources

- Coping while waiting for the transplant
- Getting the call for the transplant

After a transplant – Liver

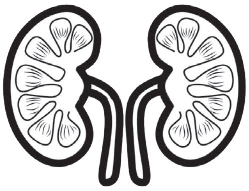


After a liver transplant, patients will be in the ward for around 7 to 10 days on average. During this time patients focus on breathing, walking, slowly eating and learning about their medicines. This is the best time to visit the patient in hospital.

Before going home from the ward, patients can leave the ward for a few hours on day leave. Their carer or other support person will need to be with them. Night leave can be offered, after which the patient attends the ward transplant clinic the next morning.

The main care needs start from the when day leave happens. The type of care needed will slowly change and be less over time as the patient gets better.

After a transplant – Kidney



The patient will be in the ward for at least 1 week after the transplant, between 5 to 7 days. During this time patients focus on breathing, walking, slowly eating and then learning about their medicines. This is the best time to visit the patient in hospital.

Some patients are from out of town. The carer may need to organise a place for them to stay and the patient once leaves the ward. Most carers would be aware of Patient Travel and Subsidy Scheme (PTSS). It is best to liaise with their closest public hospital patient travel officer.

Outpatient clinics

The first 3 months after the transplant are very important. After leaving the ward, the patient attends the Princess Alexandra Hospital transplant outpatient clinic. Attendance is daily or near daily for a few weeks.

The kidney outpatient clinic will then be 3 times a week then 2 times a week. Patients then go back to their own kidney unit.

The liver outpatient clinic appointments continue during the ongoing months. Initially once a week, once a fortnight, then monthly.

There can be tests and investigations in between clinic appointments. The team is making sure that patients are healing from the surgery and taking care of their medicines.

The carer will need to help the patient arrive at the hospital by 7am for clinic. This support is especially important during the first few weeks.

Patients who are from out of town are likely to stay in local accommodation close to the hospital.

Patients should not drive up to 4 to 6 weeks post transplant. Carers can support with transport to and from the hospital.

This could involve:

- Driving the patient
- Organising community transport
- Support with using public transport

Some patients will need support with walking in the early weeks. Wheelchairs for use within the hospital grounds are on hand at the main entrance. Mobility aids can be hired from chemists if needed. However most patients can move around independently without aids, after going home from hospital.

Daily living activities

Carers help with daily activities such as shopping (online or at the store) cooking and cleaning. The patient is usually able to shower, dress, eat and walk by the time they leave the hospital. Although light support may be needed initially depending on each person.

Carers should also support and encourage light activity and exercise. The team will advise recommended activity levels for each patient.

Patients should not attend large public venues such as sporting events for the first few weeks after their transplant. This is due to the risk of infection because of lowered immunity.

Monitoring

Part of the carers role is to check the patient's general wellness and alert the team to any concerns. The treating team will advise the carer what to look out for. However please feel free to call us at any time to talk over any concerns. If the carer sees any of the following signs of sickness worsening, please tell the team.

- Feeling weak all over
- Cognitive impairment - confusion, vagueness or just "not themselves"
- Low interest in food
- Limited physical energy or strength
- A lot of pain.

Sometimes patients need to go back to surgery in the early days or weeks. Some patients have needed to stay in hospital for a few weeks after the transplant. Inpatient or outpatient rehabilitation may be needed. Every situation is different and it is important to be prepared for anything.

The medicines can have a huge impact for some patients. Especially in the first few days or weeks after the transplant. Patients can become mentally affected, seeing and imagining things, paranoia, inappropriately over-confident, or emotional. Carers are in the best position to advise the team for help or advice. If needed, staff can provide professional assessment, support and advice.

Ongoing care

The full healing from a transplant generally takes the better part of a year. However most patients will no longer need the formal support of a carer after 2 to 3 months

Financial considerations for carers

Carers sometimes qualify for either a Centrelink Carers Payment or Carers Allowance. Carers of pre- and post-transplant patients do not automatically get these payments. There are no specific “transplant” carer payments from Centrelink.

Read more on the Centrelink website. www.servicesaustralia.gov.au/caring-for-someone

Carers who are on Job Seeker or are in employment can ask for a medical certificate from the doctor in the outpatient clinic if medical evidence is needed to show they are currently caring for the patient.

Carers might need to take time away from work and other commitments during the first few weeks and months after the transplant. Remote work arrangements may be possible for carers so they can continue their employment. It is encouraged that carers talk with their employers.

Practical arrangements

Share the care responsibilities with family members or friends. Some carers share the time by splitting up days and weeks or daytime and overnight care responsibilities.

Time out

It is important for carers to have time out for themselves. This could be:

- A coffee or meal
- Having a rest
- Reading a book or listening to a podcast
- Watching a favourite TV show
- Going to a shopping centre or watching a movie
- Getting some exercise
- Visit other family and friends.

Support people are important in transplantation. The maintenance of their good health and wellbeing is as important as that of the patient’s health and wellbeing.