

Princess Alexandra Hospital

Patient Information

Queensland Liver Transplant Service



support

through

education

program

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Liver Transplant

STEP - Support Through Education Program

Princess Alexandra Hospital Campus Map

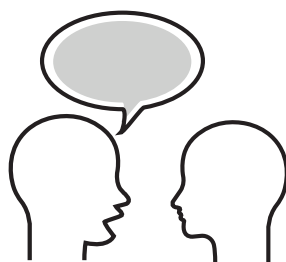
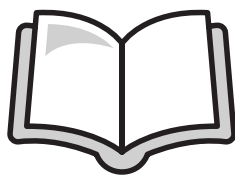


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| ● main hospital entries D4, E3, F5 | 31 ambulatory and renal transplant services (arts) B2 | P parking |
| ● emergency entry F2 | 33 building 33 B3 | 🚂 train station |
| 5 diamantina health care museum E2 | 37 specialised health services (shs) B2 | 🚌 bus stop |
| 7 geriatric and rehabilitation unit (garu) D3 | 55 metropolitan linen services (mls) C8 | 🚌 PA shuttle bus stops H4, F4, INSET A10 |
| 13 aquatic physiotherapy pool D6 | 57 central energy unit (ceu) C7 | 🚗 taxi rank |
| 15 executive building D6 | 61 general support services C6 | 🛒 shopping centre |
| 17 spinal injuries unit (siu) E6 | 63 maintenance services B5 | 📧 post office |
| 19 mental health services F6 | B2 burke street centre SEE INSET MAP | 🚶 pedestrian walkway access |
| R research wing D5 | TRI translational research institute 4B | 🚲 bike track |
| i campus map locations C5, E3, E5, F6 | D DSM Biologics (BPA) 3B | — pedestrian linkway |

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History

Professor Russell Strong and team performed the first Australian liver transplant in 1985. Since then, the Queensland Liver Transplant Service (QLTS) based at the Princess Alexandra Hospital (PAH) in Brisbane quickly became one of the major liver transplant programs in Australia and the world. With increasing numbers of patients referred to QLTS it was vital that patients were offered opportunity to manage in the best possible way, both before and after transplantation.

In 1998 the PAH *“Support Through Education” Program* (STEP) was started to provide information and support to PAH patients and their families, as they awaited liver transplantation and navigated the first few months after receiving a liver transplant. The STEP groups were run every few weeks at the hospital.

Patients and their families who take part in the *“Support Through Education” Program* (STEP) describe greater confidence in coping both before (pre) and after (post) transplant.

STEP is run by the PAH liver transplant multidisciplinary team. Patients and families who have already been through the liver transplant process sometimes take part in STEP as volunteers with the Liver Transplant Support Network. We regularly evaluate and change STEP to meet the needs of those involved.

During 2020 STEP moved online from face-to-face group programs held in PAH seminar rooms.

This now allow patients and families to access STEP from anywhere on a smartphone, laptop, tablet, iPad, iPod or desktop computer. The very popular end-of-year STEP lunch at a local café will continue.

We look forward to you taking part with STEP, trusting that you will find much helpful information and feel welcomed to the Queensland Liver Transplant Service.

QLTS
Queensland Liver
Transplant Service

Introduction to the Queensland Liver Transplant STEP: Support Through Education Program

The liver transplant process begins when patients are referred to the Hepatology Unit at Princess Alexandra Hospital (PAH) for assessment by a multidisciplinary treating team. The team includes specialist hepatologists, surgeons, anaesthetists, liver transplant coordinators, dieticians, social workers and mental health staff. Many other departments and hospital staff also contribute to health care services connected with assessment and treatment.

The evaluation and assessment process establishes whether liver transplantation is the right treatment for each individual patient, whilst enabling the team to provide support and information. This can be a stressful time for patients and their families giving rise to various questions such as: *What will happen to me? Can I cope?*

Taking part in the online STEP (*“Support Through Education” Program*) offers the opportunity to learn more whilst being supported by others in similar circumstances. This **STEP Booklet** in conjunction with the **Liver Transplant Evaluation and Assessment Booklet** and attendance at the **online STEP sessions** - provides information about organ donation, preparation for surgery, the transplant operation and what to expect at the recovery and return-home stages, diet and exercise, medications and the outpatient clinic reviews.

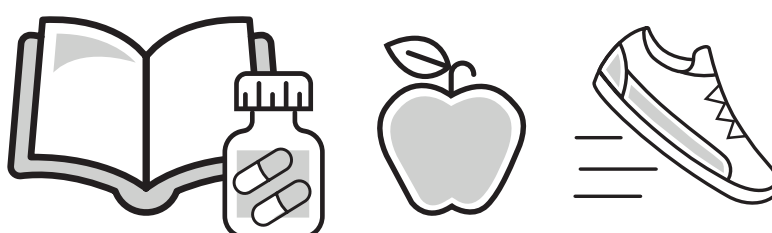
Liver transplantation is a complex, expensive and highly specialised treatment. Much of the world’s population do not have access to liver transplantation. In Australia, the cost of transplantation and medication, is government subsidised allowing availability and affordability for patients. The liver transplant program would however not exist without the generosity of organ donors and their families. Organ donation and its gift of life completely support the transplant program.

It is everyone’s responsibility to work towards achieving the best outcome. By gaining information and support, STEP participants can adapt their focus from the symptoms and effects of a chronic disease to active preparation for one of the most major life challenges.

Successful transplantation needs some lifestyle changes, clinical follow up and commitment to lifelong prescribed medication.

It is important that if listed for a liver transplant, you and your family are as ready as can be for transplantation and all its possibilities.

We wish you the very best.



Step 1

Waiting for the transplant



The time from acceptance onto the waiting list until a suitable donor organ becomes available, provides an opportunity for the patient to prepare for transplant surgery. The more prepared, fit and healthy the patient is at the time of the surgery, the greater are the chances of doing better afterwards.

There are many ways patients describe coping with the wait for a transplant. The patient's physical and mental well-being, life stage, outlook, experiences, family and employment situation; can all influence how they might cope. The good news is that patients often report coping much better than they thought they would. Making good choices, drawing upon one's strengths, taking one day at a time, and asking for help if needed; are key.

Top tips:

- Make sure you have a working mobile phone. It does not have to be top of the range but needs a strong ringtone, working voicemail, full charge and to be with you at all times.
- Confirm that your contact details on the hospital records are correct. Tell the liver transplant coordinators of any changes or if you need to be away from home for any length of time. It is also necessary to provide several other contact numbers for family, neighbour or others should there be any problem getting in contact with you.
- Increase your fitness by doing exercise and improving your diet. The dietician at the pre-liver transplant clinic provides assessment and review. A PAH physiotherapist can help with fitness or you can arrange a private physiotherapist for extra input. General practitioners have information about referral to a physiotherapist through the Chronic Disease Management Program.
- Plan for time away from home and/or work.
- Develop a plan to manage aspects such as bill payment, income support, home and garden maintenance, childcare, pet care, elder care and other care duties for which you might be responsible for.



Step 1

Waiting for the transplant



Make plans for the post- transplant time frame. Plan for discharge from hospital:

- Arrange a transport plan for regular outpatient clinic visits. Patients are unable to drive for at least 4 to 6 weeks after the transplant surgery. Transport options include family and friends, taxi and other commercial rideshare services or community transport, if available. If from a near regional area such as Gold Coast, Sunshine Coast, Bribie Island or Caboolture, Toowoomba, Tweed Heads or Lismore; plan where you wish to stay and make arrangements with your regional hospital patient travel office regarding accommodation and transport subsidies.
- Keep doing whatever works well for you and causes no harm.
- Maintain as much usual and normal day to day activity as possible.
- Get daily rest, eat well and exercise. Keep connected with family and friends. Check that finances are in order. Call the social worker any time for information and planning or referral to relevant support services.
- Stay Calm. Ideas include meditation apps and websites, essential scented aroma oils and listening to favourite music, playlist, podcasts or audiobooks. Headphones or earbuds are useful on wards and outpatient areas. Writing a paper or electronic journal can help document how you are. Take control and create a pleasing environment. Atmosphere greatly influences feeling and mood.
- Pack a few clothes and items ready for hospital. Have loose and comfortable clothing ready for day pass and overnight pass from the Transplant Unit. There is a Target store and Vinnies outlet across the road from the hospital if anything is needed.
- Go to Head to Health – an excellent website with many mental health and support resources <https://headtohealth.gov.au/>
- Have a list handy of absolutely everything else you need to collect or do when you get the phone call for the transplant.
- Get legal affairs in order. **This is part of Advance Care Planning.**
Even though the Queensland Liver Transplant Service achieves excellent results, not everyone on the waiting list will survive to transplant and not everyone who has a transplant will survive. And some patients who do survive, experience a much longer time than most in ICU or a hospital ward. The doctors will discuss the risks and benefits with each patient.

Step 1

Waiting for the transplant



Every adult over the age of 18 years especially when managing chronic or advanced disease is recommended to have:

- **Enduring Power of Attorney:** This allows a person to nominate whom they wish to make personal, health and financial decisions on their behalf if they lose capacity. The nominated friend, relative or legal agent can make decisions and act on the person's behalf. The same person or persons can manage both personal/health and financial matters, or different people or organisations can be nominated to carry out different aspects.
- **Will and Last Testament, known as a "Will":** All adults over 18 years old are advised to have a valid Will, in the event of their death. Whether or not a person has any money or assets is irrelevant.
- **Advance Health Directive or Metro South Statement of Choices:** These documents provide patients and their general practitioner or specialist opportunity to explore and document their preferences and wishes regarding future treatments.



Please note:

A Will and an Enduring Power of Attorney are 2 separate and different documents

- An Enduring Power of Attorney is relevant whilst alive
- A Will takes effect after death

We strongly advise that people seek legal advice regarding the completion of both their Will and the Enduring Power of Attorney.

Contact your own solicitor or the Queensland Law Society or the Public Trustee of Queensland or a Community Legal Centre for more information and assistance with your legal documents.

Find a Justice of the Peace (JP) to witness an Enduring Power of Attorney if you complete this without support of a solicitor

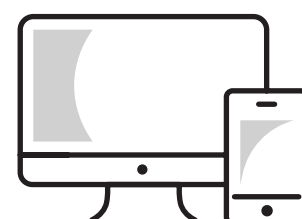
<https://www.qld.gov.au/law/legal-mediation-and-justice-of-the-peace/about-justice-of-the-peace>

Community Legal Service

<https://communitylegalqld.org.au/>

Queensland Law Society Find a Solicitor

https://www.qls.com.au/For_the_community/Find_a_solicitor



Step 1

Waiting for the transplant



Public Trustee Queensland

<https://www.pt.qld.gov.au/>

Advance Care Planning

<https://www.health.gov.au/health-topics/palliative-care/planning-your-palliative-care/advance-care-planning>

<https://www.advancecareplanning.org.au/#/>

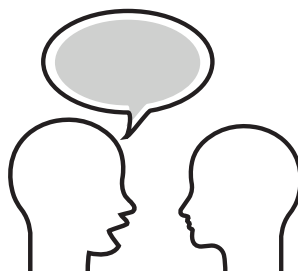
<https://www.advancecareplanning.org.au/resources/advance-care-planning-for-your-state-territory/qld>

<https://www.qld.gov.au/health/support/end-of-life/advance-care-planning/key-documents>

<https://metrosouth.health.qld.gov.au/acp/queensland-advance-care-planning-forms>

Organise money

<https://moneysmart.gov.au/>



Step 2 Carers



Whilst the focus is upon the potential transplant recipient, family members and other support people are valued and appreciated for the care and support they provide. Carers and supporters play a vital role.

Managing hospital appointments, employment, family and other commitments whilst maintaining one's own good health and well-being, can be challenging but is very important.

Plan for success. Carers can muster resources with these top tips:

- Eat super-healthily. Quick ideas:
 - Fresh or frozen vegetables for ease and nutrition
 - Fresh or tinned fruit, unsalted nuts and yoghurt
- Drink plenty of water - a cup every few hours
- No or minimal alcohol and soft drinks
- Regular sleep and regular exercise. Quick favourites include brisk walks, jog on the spot or around neighbourhood, skipping rope, gym equipment including weights such as dumbbells, stretch including stretch bands, dance, swim, exercise apps on phone or tablet
- Load books, podcasts, music and movies onto your tablet or smart phone – never be bored
- Focus on a hobby or interest – online, community or home based
- Keep in contact with friends and family
- Take set and regular time out. Do not skimp on this
- Take a few slow, deep breaths every so often
- Share the care responsibilities wherever possible
- Be proud about how well you managed previous challenging situations. Consider what worked in the past and tap into those strengths again. This can be amazingly helpful
- Seek counselling, support and information – team social worker, liver transplant coordinator, general practitioner for referral to a community-based psychologist or social worker, PAH pastoral care
- Visit Carers Queensland website: <https://carersqld.com.au/>
- Visit Head to Health website - mental health and support resources
<https://headtohealth.gov.au/>
- Visit Ask Izzy website - mental well-being, and everyday supports and resources
<https://askizzy.org.au/>

Step 3

The gift of a donor liver



The transplantation process depends not only upon the skill of medical and nursing staff and the compliance of patients and support of their families, but largely on the generosity of the families who have suddenly and tragically lost a loved one. This gift made by the donor and donor family is a precious and rare resource and is regarded as a privilege, and not by any means, a right.

The process by which donor organs become available to recipients is governed by both medical and legal criteria. In Queensland, this legislation is the Queensland Transplantation and Anatomy Act, 1979. DonateLife is the agency which manages organ donation in Queensland.

Not everyone who dies is able to be donate their organs. Less than 2 per cent of people die in a way to allow for donation of organs for transplant. To be eligible to become an organ donor, a person must have died in an Intensive Care Unit (ICU) and be supported on a mechanical ventilator. Medically, their organs must be working at the time of their death and be free of transmissible disease and cancer.

There are 2 pathways for organ donation after death has been determined. Donation after brain death (DBD) and donation after circulatory death (DCD).

Brain death occurs when a person's brain has been so badly damaged that it completely and permanently stops functioning. A DBD donor is a person who has died while on a ventilator in ICU with a beating heart. The deceased person will go to the operating theatre for the donation operation while still on the mechanical ventilator.

Circulatory death occurs when a person stops breathing and their heart stops beating. The opportunity for DCD donation can be considered when a person is in an ICU on a mechanical ventilator following a severe injury or illness from which they cannot recover. The doctors and family then agree it is in the person's best interests to remove the ventilator and any other life sustaining therapy. For a DCD donor, death is declared after withdrawal of the mechanical ventilator and circulation has stopped. The deceased patient will then go to the operating theatre for the donation operation.

When a donor liver becomes available the DonateLife donor coordinator will notify the liver team and the liver consultant on call. The consultant will decide the most suitable recipient by consideration of various criteria; mainly those of compatible blood group and matching size or weight between donor and recipient. The general health condition of the recipient is also considered.



Step 3

The gift of a donor liver

The consultant then contacts a patient on the liver transplant waiting list who has been selected to receive the donor liver. On some occasions, a second patient from the transplant waiting list is called in to standby, in case for medical or other reasons the first patient is unsuitable for that donor liver.

Meanwhile arrangements are made to take the donor to the operating theatre for organ retrieval surgery. The donor could be from any hospital in Queensland, Australia or New Zealand. The DonateLife donor coordinators organise surgeons, transport, and operating theatres and provide support to the donor's family. This support continues throughout the donation process and is followed up with a phone call the next day and at various intervals in the first year after the donation. Ongoing support is provided to donor families by the DonateLife Donor Family Support Coordinator for as long as they need it.

Every year around May or June, a special Service of Remembrance for donor families, transplant recipients and their families are held in all major Australian cities and in many regional cities Statewide.

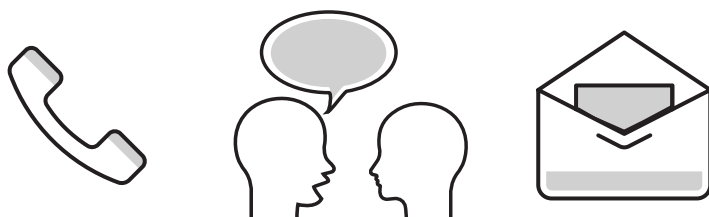
Check the DonateLife website for details. <https://donatelifegov.au/news-events/events>

Many transplant recipients and families write to their donor families anonymously, expressing their heartfelt thanks, for what is truly the "Gift of Life".

<https://www.donatelifegov.au/all-about-donation/support-for-donor-families/contact-between-donor-families-and-recipients>

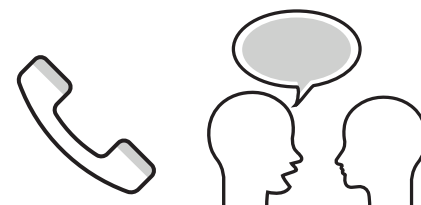
Information and brochures are available to assist with letter writing, and counselling is available to patients and families to help with any aspect of their transplant journey that may be causing distress or concern. It is often a good idea to discuss any worries you might have with the social worker, before receiving your liver transplant, to comfortably manage feelings you might be experiencing about the donation process or receiving a transplant.

For more information about donation and transplantation go to: <https://donatelifegov.au/>



Step 4

Admission for the transplant



This is often the time when good planning whilst on the waiting list, pays off. Patients and families have reported that staying calm and being organised is the best way to manage.

Receiving a phone call to say there is a possible liver available for transplant can result in a mix of feelings - excitement, anticipation or even fear. It is the phone call patients have been waiting for yet feel most nervous about.

It is important to have a transport plan to get to the PAH. A family member or another support person could bring the patient to hospital by car, taxi, uber or similar. An ambulance is not called to bring people in for liver transplant, unless the emergency is directly related.

Patients who have been offered a liver transplant need to make their way safely to hospital with pre- packed small bag of toiletries and medications and if possible, a support person. The patient is told at the time of the call where to go once at the PAH, this being at either the admission desk on the ground floor of the main building or the Emergency Department. After hours entry is through Emergency Department, which is located on the first floor via the Cornwall Street entrance.

This is not the time for a large family reunion, nor a time for relatives and friends to make phone calls to the Transplant Unit with general questions about the patient or to pass on their good wishes. One family member or friend is chosen as the contact person who can then be responsible for passing information to others.

The Transplant Unit staff will talk with the patient and family before the operation. If the transplant does go ahead, families usually wait away from the hospital. The surgeon will phone the contact person to discuss the outcome of the surgery.

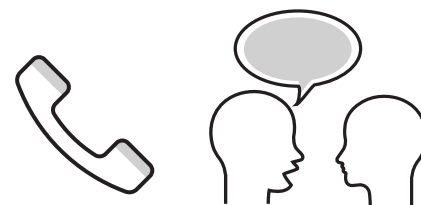
Being mindful that this is a stressful time for next of kin, consider the following:

- Patients need to be prepared from the moment they are placed onto the waiting list. The transplant can happen at any time from then onwards.
- Choose a family member or friend to be the point of contact for well-wishers.
- A regular group email or text message can be a useful way to communicate with friends and family.
- Use social media, like Facebook, Twitter, or family website or blog to update reports.

Be sure that the preferred privacy settings are in place.

Step 4

Admission for the transplant



The procedure from when you arrive on the transplant ward 4BT is similar to any pre-operative preparation. Normal investigations including blood tests, chest x-ray and assessment for fitness to have an anaesthetic are followed by nipple to knee shave, a surgical shower and an insertion of an intravenous line. In most cases you will have signed your consent forms for the transplant operation at the time you were listed for transplant.

While your operation is being organised, the donor retrieval operation is also being organised. At this stage there will still be some uncertainty around the donor suitability. The donor liver needs to be viewed by the other surgical team to confirm organ suitability. In some cases, the final decision may be delayed as a donor liver biopsy may be needed. When the OrganOx machine is used, the donor liver is monitored for 6 hours before a decision about suitability can be made. Occasionally patients are brought in as a “backup recipient”, in the event another pre-transplant patient’s surgery is unable to go ahead. All this is fully explained at the time.

The liver transplant operation will be cancelled in about 20 per cent of cases when the donor liver is not suitable. The ward staff will be called, if the donor liver is suitable and advised what time the liver transplant operation will start.

Fluids and medications are commenced about 2 hours before leaving the ward for the operating theatre. These medications including antibiotics, anti-fungal and anti-viral medications are to assist in protecting you from infections and transmission of viruses from the donor.

There are 3 different anti-rejection or immunosuppressive drugs, which are given at this time to stop the recipient’s immune system from attacking the new liver as soon as blood supply is established. Some of these medications need to be taken lifelong.

The patient leaves the ward to go to theatre, and from there will go to the Intensive Care Unit for 24 to 48 hours, on average. The family are told not to wait in the hospital for the length of the operation, as there could be many hours involved and there is nothing that the family can do for the patient at that stage. Over the years, families have reported that they have found comfort by returning home and waiting for the hospital to call, or to book into one of the accommodation facilities across the road from the hospital, where they can comfortably rest, read, watch television and wait for the call. This is when a mobile phone is important.

When stable enough, the patient will return to the Transplant Unit for recovery and education before going home. The inpatient stay is usually 7 to 14 days, depending on the pre-operative condition of the recipient. There are however a number of factors that can lead to a longer stay in hospital. Some patients may need 3 to 4 months in hospital post-operatively, and whilst these situations are uncommon, the fact that they are not unknown, suggests that you and your family need to be prepared for absolutely any event.

Step 5

The transplant operation

The liver transplant operation can take between 6 to 14 hours and is split into 2 parts. Because the new liver is placed into the same place as the old one, the right upper corner of the abdomen it is necessary to remove the old liver first. This is often difficult due to previous surgery, scarring, bleeding problems and the location of a major blood vessel.

Then the new liver has to be put in and connected. There are joins or anastomoses between donor and recipient hepatic artery, portal vein and bile duct. Major problems including leaks and blockages, can occur in these three areas.

Drains are inserted into the lower abdomen below the wound to drain away extra fluid which slows healing. They are removed when the drainage reduces in the following days. Patients who have large volumes of fluid in the abdomen before transplant may take longer to reduce the fluid and need the drains to stay in longer or have a bag placed over the drain site to collect the fluid.

A tube or stent may be placed in the bile duct across the join to maintain the bile flow and prevent a narrowing or stricture blocking the drainage of bile out of the liver. If a stent has been inserted, an abdominal X ray will be taken about 6 weeks post-transplant to check if the stent has passed via the bowel into the toilet. If the stent is still present, an endoscopy will be organised to remove it.

Every individual experiences and responds to pain differently. It is normal to have pain after an operation. The goal is to provide enough pain relief so that the liver transplant recipient can move, breathe deeply and cough. It is important not to be over-sedated or too drowsy. Always let the nursing staff know if pain is not relieved. The most common method of pain relief used today is the 'Patient Controlled Analgesia' (PCA) machine. The pain-relieving medication is administered via a pump connected to the patient's IV line. The patient presses a button to deliver a pre-set amount of pain relief. The patient can push the button as much as needed to achieve relief. The machine will lock out requests within 5 minutes to prevent overdose. It is important that only the patient, and not relatives or staff, presses the button. If pain continues, tell the nurse who will arrange a review by a doctor.



Step 6

The Intensive Care experience

All patients who have a liver transplant are transferred to the Intensive Care Unit (ICU). This happens immediately after the transplant operation.

One of the main reasons for needing to be in ICU is to help with breathing. After the long operation and the large incision, the patient is often too tired or sore to breathe as deeply as they need to. The breathing tube is connected to a mechanical ventilator. Because this tube passes through the vocal cords to the entry of the lungs, it is not possible to speak. Most people find the tube a little uncomfortable, but it is removed as soon as the patient is awake and fully breathing for themselves. Once the tube is removed the throat may be sore and the voice husky.

Due to the high level of monitoring and care needed by patients, one on one nursing support is provided. There is an extremely high level of bedside technology and constant medical supervision.

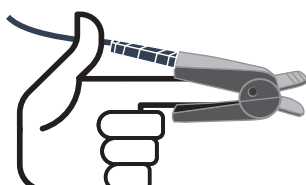
While the breathing tube is in place, the physiotherapist provides regular support, to ensure that the:

- Lungs remain clear and fully expanded.
- Limbs are moving. This movement helps to prevent blood clots

What else is being monitored?

It is important to monitor the patient closely after the operation and to do this there are many lines coming from the patient to equipment or drainage. Some of these are:

- ECG or heart leads on the chest to monitor the heart continually
- A probe on a finger to monitor oxygen concentration
- An arterial line to measure blood pressure
- A Swan Ganz catheter in the neck to measure blood volume
- Many surgical drains in the abdomen around the wound
- T tube to drain bile
- Indwelling catheter in bladder to drain and measure urine



Step 6

The Intensive Care experience

Do patients need compression stockings?

Yes. To prevent clots in the legs, compression stockings are worn until the transplant patient is up and walking around for most of the day.

Is it possible for a patient to walk in ICU?

Before discharge from Intensive Care, the physiotherapist will assist the patients with deep breathing and supported coughing. The physio will sometimes be able to take the patient for their first post-operative walk on a walking frame. This depends upon the condition of the patient.

Every situation is individually assessed.

Is there much noise in ICU?

As can be imagined, the machines and constant activity can result in the ICU feeling quite noisy. Staff do their best to create the calmest and most peaceful environment for the patient and family, but the machine alarms and beeps can add to the sound level.

Staff will explain to visitors what the alarms and noise means, to help make the experience as comfortable as possible.

Can patients and families see the ICU before the transplant?

ICU offers all future patients and families the opportunity to visit the ICU to see the equipment and surroundings. If interested, please ask one of the liver transplant coordinators organise a suitable time.

Can the family visit?

Visiting is restricted to immediate family and close friends. The child friendly policy ensure that children are allowed to visit. It is generally suggested that no more than 2 people visit the bedside at any one time. **There is no visiting before 11 am** as this is a very busy time during which the ICU doctors conduct their rounds and when routine tests are performed.



Step 6

The Intensive Care experience

Can the family stay overnight in ICU?

Unfortunately, visitors are unable to stay overnight in ICU. There is 1 shared public waiting room.

During business hours, there is a hospital volunteer in the waiting room who can help with any family questions.

Accommodation facilities are available across the road, in nearby suburbs and the city.

Guide to Accommodation near the PAH:

<https://metrosouth.health.qld.gov.au/sites/default/files/pah-accommodation-guide.pdf>

The Patient Travel Office can provide full information about subsidies available to eligible patients' and their carers. For further information go to:

<https://metrosouth.health.qld.gov.au/patients-and-visitors/leaving-hospital/travel-assistance>

How long is the liver transplant patient in ICU?

Most post-liver transplant patients are in ICU for no more than 24 to 48 hours. They are then transferred to the Transplant Unit Ward 4BT which is on the 4th floor.

The time in ICU is dependent on a range of factors, including:

- How sick the patient was before the surgery?
- Whether there are any post-operative complications?
- How quickly the patient is waking up and breathing on their own?

The patient will never be discharged from ICU until the medical team believes that the patient is ready for the transfer to the Transplant Unit. For further information:

<https://metrosouth.health.qld.gov.au/intensive-care-unit>



Step 7

The Transplant Unit



Our knowledge and understanding of transplantation, illness and recovery has grown over the years through dedicated and organised research. For example, we know that unless patients move very early after an operation, they are at risk of the life-threatening complications of pneumonia and/or clots in the legs and lungs. We also know that hospital are breeding grounds for ‘Super Bugs’ and that extended stays in hospital increase the risk of becoming infected. This can also be life threatening and very costly in terms of expensive drugs and increased length of stay in hospital.

The main goal and work of the staff in the transplant unit in their post- operative cares is to help the new transplant recipient recover quickly from the operation and to learn their medications to enable them to return home as quickly as possible.

The patient arrives in the Transplant Unit, Ward 4BT from as early as day 1 or 2 after transplant - or as late as several months afterwards if there have been complications. The patient’s pre-operative condition, fitness and disease can influence this timeframe. Transfer to the Transplant Unit is the cue to move from the acute to the recovery and rehabilitation phase. The inpatient stay on the Transplant Unit is usually about 7 to 14 days

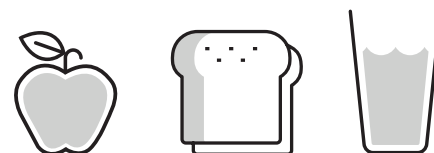
The patient can suffer from confusion and hallucinations particularly if they were encephalopathic before their transplant. The medications used in transplantation can occasionally cause confusion and hallucinations which is distressing for both the patient and their family. With the right care, treatment and support, the symptoms improve with time.

While the patient is initially tired and possibly experiencing pain or discomfort, it is important they gradually begin doing things for themselves for example reaching for water, tissues, feeding themselves, moving up and down and side to side in the bed and walking longer distances. It is not unusual to feel even more tired and sore after starting an activity, but it is important to continue. Eventually this discomfort eases.



Step 7

The Transplant Unit



A similar challenge occurs with eating, as intake must slowly increase to supply the nutrients and energy needed to improve and aid healing. Although appetite may not have returned it is important to follow all suggestions of the treating team with regards eating and drinking.

Use all the tactics at your disposal:

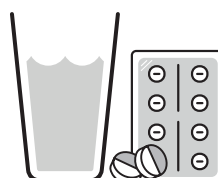
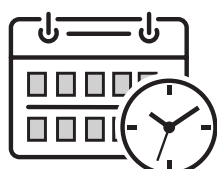
- Eat small frequent amounts until your stomach can tolerate larger volumes
- Eat high quality and healthy foods, rather than empty calories
- Arrange for family to bring in food you enjoy. Check with transplant staff if there are any restrictions.

It is also very important to drink water to protect your kidneys from the medications used for immunosuppression. Generally, a person needs to drink 2 to 3 litres of water a day and this should continue after discharge and be ongoing. Of note, when it is hot and humid you should increase your water intake. Please seek advice from the treating team.

Patients will need to learn about their medications so that they can manage them at home. More on medications in Step 10 - Medication for life.

Some strategies for success include:

- Plan rest periods **after** activities
- Eat, drink and move around as advised
- Limit numbers of visitors to reduce tiring
- Involve visitors in education process.



Step 8

Exercise is for life



Regular exercise is key to a healthy liver. People who do regular physical activity, generally stay healthier and have less problems than those who don't. Keeping active is important while preparing for and recovering from your transplant. Exercise decreases stress on the liver, increases energy levels and helps to prevent weight gain. Other benefits include better sleep, mood, fitness and quality of life.

So, what can you do? You can prepare for your surgery by starting to do regular exercise. Exercise uses the large muscles of your body, raises your heart rate, and increases the rate of your breathing. Common forms of exercise are walking, swimming, cycling, aerobics and dancing. Housework, gardening and home maintenance are also great. Walking is the cheapest and safest form of exercise and is good to start before and continue after your surgery. When you begin your walking program you should start with a 5 to 10 minute walk at a slow pace and slowly build your speed and distance. Gentle strengthening exercises with light weights can also improve your muscle and bone strength.

The exercise you do should be light to moderate, if you are breathless and unable to talk you are working too hard. If you would like to return to heavier activity, that is heavy weights, running or team sports please speak to your doctor first.



Step 8

Exercise is for life

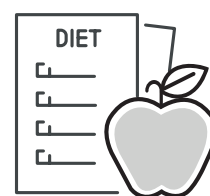
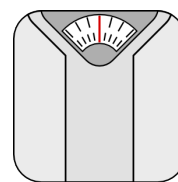


Guidelines for safe walking

- Wait at least 1 hour after meals before walking
- Wear loose, comfortable clothing and well-cushioned flat soled shoes
- Don't exercise in extreme heat and humidity
- Ensure that you drink water before, during and after exercise
- It is okay to rest before, during or after you walk
- Walk on flat ground first and then build up to hills as your fitness gets better
- Start slowly and gradually build up as things become easier. Be aware of your own symptoms, everyone is different
- If you suddenly find your walking or activity is harder for no reason, it may be a good idea to see your doctor for a check-up
- Don't walk if you have a fever or a bad cold
- Don't hold your breath while exercising. Walk at a speed where you can easily speak in full sentences without becoming breathless
- It is a good idea to walk with someone to make your exercise more fun. Remember, walk at your pace, not anyone else's pace!

If you become extremely short of breath, tired, dizzy or have chest pain, stop immediately to rest until the symptoms pass. Get medical attention if they continue.





Step 9 Nutrition

The right fuel for the best results

The liver has many roles in the body, one of which is to help to store and utilise the energy from the food we eat. When the liver is not working properly, your body struggles to store and use the energy from our food in the usual way, and you may also find that you can't eat as well as normal, due to feeling unwell or having symptoms like reduced appetite, nausea, vomiting or stress. Chronic liver disease is often linked with weight loss - including both loss of body fat and muscle mass - and this can lead to reduced strength, make you feel more tired and decrease your ability to go about your daily life and activities. With weight loss and poor eating, you are at risk of malnutrition, where your body is not getting the nutrients it needs and can start to break down fat stores and body muscle to use for energy. This can lead to further nutritional problems, and more complications before and after transplant. So, good nutrition both before and after a liver transplant is vital!

Some things to consider in your diet:

Eat enough protein: To try and prevent muscle loss, a high protein, high energy diet is recommended. As protein provides the building blocks for your muscles, this will ensure that your body has enough protein and energy from your food, so it doesn't need to break down proteins from your muscles to keep working. Your dietitian will let you know if you would benefit from nutrition supplements.

Eat regularly: A healthy liver plays an essential role in storing energy or glycogen in the body to use at a later time so we don't need to rely on constant eating. However, a liver with cirrhosis is unable to do this well. This means the liver needs a constant supply of energy from our food as it cannot rely on stored energy supplies. Therefore, it is important to eat regularly, aiming to eat every 2 to 3 hours as well as consuming an energy-rich snack before bed.

Not too much salt: As liver cirrhosis progresses, extra fluid can build up around your stomach which is ascites and in the feet and legs called oedema. If this occurs, it becomes important to follow a diet low in salt or sodium. This is because salt acts like a sponge in your body and retains fluid, therefore reducing salt in your diet can reduce the amount of fluid that stays in your body. Reducing salt in the diet is important and safe for everyone, but it is especially important if you have cirrhosis and start to get fluid building up in your body.

Are you overweight? All patients with liver disease are at risk of losing muscle. This is regardless of their body size and of whether they have intentionally lost weight, or not. Therefore, it is important to focus on eating a high protein, balanced diet while minimising foods that provide minimal nutrition, for example takeaway foods, sweets, biscuits, soft drinks, pastries. You can also speak with your dietitian for further information.



Step 9 Nutrition

Long term nutritional considerations post liver transplant

Eating well after a liver transplant is essential to keep you, and your new liver healthy in the long-term! We know that it is common for people to gain weight after their transplant, and this can lead to damage to the liver as well as increase the risk of other diseases such as obesity, diabetes, heart disease and kidney disease. Therefore, it is important to keep physically active and follow a healthy diet and lifestyle for life-long health after your transplant.

A Mediterranean style diet has been shown to have positive benefits in a number of different conditions and is considered to be a healthy diet and lifestyle to follow after a liver transplant.

Some strategies include:

1. Basing your meals on the Mediterranean Diet:
 - Include lots of non-starchy salad and vegetables at main meals
 - Include wholegrain breads and cereals
 - Include healthy fats, such as extra virgin olive oil, avocado, unsalted nuts
 - Include legumes, such as lentils, chickpeas, beans
 - Include 2 to 3 pieces of fruit per day
 - Include moderate amounts of fish and chicken
 - Limit red and processed meats to once a week
2. Avoiding sugar-sweetened drinks
3. Avoiding added sugar and salt from packaged foods
4. Avoiding saturated fats
5. Planning meals ahead of time
6. Measuring out portions!

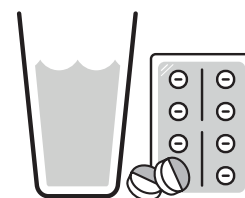


Your Dietitian will speak to you about healthy weight, healthy eating

- Including a Mediterranean Diet and
- Physical activity after your transplant

Step 10

Medication for life



Following your liver transplant, you will take a lot of new medicines. These are vital to the success of the transplant and will become an important part of your life. It is important that you have a good understanding of your medicines including how to take them properly and what side effects to expect.

Anti-rejection medicines

The most important group of medicines following a liver transplant are those that suppress your immune system, otherwise known as ‘immunosuppressant’ or ‘anti-rejection’ medicines. Without these you would reject your liver within a few days.

Our immune system protects the body against infection. It does this by recognising foreign material such as bacteria or viruses which cause infection and releasing a variety of chemicals and white blood cells to destroy them. However following a liver transplant your immune system will recognise your new liver as foreign and will respond to destroy it. This is called ‘rejection’.

We use anti-rejection medicines to prevent your body rejecting your new liver. It is important that you never stop taking your anti-rejection medicines, even for a short time



You will be at risk of losing your liver due to rejection or shortening the life of it. If, for any reason you cannot take your anti-rejection medicine for example, you are vomiting or you have left your medicine at home or run out of tablets, contact the transplant unit or your clinic area as soon as possible.

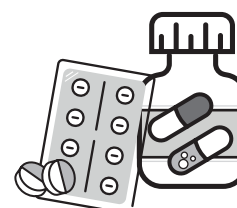


Key questions which many people ask include:

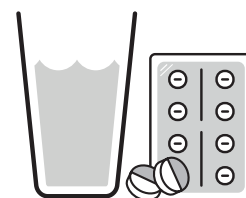
1. What medications do I need to take after my liver transplant?

You will be taking a combination of anti-rejection medicines. The most commonly used anti-rejection medicines are:

- Tacrolimus (Prograf®) regular release or Tacrolimus (Advograft®) controlled release **or** Cyclosporin (Neoral®)
- Azathioprine **or** Mycophenolate
- Prednisolone



Step 10 Medication for life



Other anti-rejection medicine which may be used include:

- Everolimus

In addition to these immunosuppressive medications you may also need medications to prevent infections. These include antibiotics to prevent bacterial infections, antivirals to prevent viral infections and antifungals to prevent fungal infections.

2. How long do I take the medications for, and what happens if I forget a dose?

Having a liver transplant means you that you will need to take medications life-long. Following your transplant the pharmacist will provide you with a dosette box which allows you to set out your medications for the week. This process helps you with managing and remembering to take your medications every day.



The success of your liver transplant relies on you taking your medication at the same time each day, exactly as it is prescribed.



Do not double up on dose

If you forget to take a dose, take it as soon as you remember unless it is time for your next dose.

If you have missed a dose **you must inform your clinic nurse or doctor** as this may affect your blood levels.



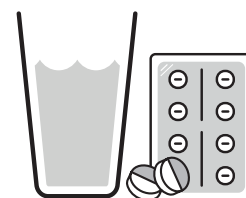
If you regularly forget to take your medication or alter your prescribed medications without discussing with your transplant team, you are at a very high risk of damaging your liver transplant. Sometimes the damage can be irreversible and your life will be at risk.

If you are experiencing discomfort or side effects from medication, we would encourage you to discuss these with your liver transplant team. Good communication is vital between you and the team.



Step 10

Medication for life



3. What are the main side effects of the medications?

The anti-rejection medications can cause a variety of side effects that the team will work to minimize. It is really important to alert the doctors to any side-effects you are experiencing, as alteration of dosage or medication might be possible.

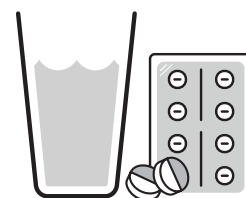
Possible side effects can include:



- Diabetes
- High blood pressure
- High cholesterol
- Tremor, tingling of the fingers and toes, burning sensation
- Headache, blurred vision
- Nausea, vomiting, diarrhoea
- Hair loss or hair growth
- Impaired kidney function
- Vomiting or diarrhoea
- Low white cell count
- Low haemoglobin
- Low platelet count are cells that help blood to clot
- Abdominal pain
- Mood swings
- Nervousness, restlessness, trouble sleeping
- Increased appetite, which can lead to weight gain
- Acne or other skin problems
- Facial or body hair
- Slower healing of wounds
- Thin skin and easy bruising
- Osteoporosis or weak bones - you will be on medication to limit this
- Cataracts - you should report any changes in vision
- Loss of potassium
- Fluid retention
- Increase in blood pressure
- Upset stomach or gut irritation
- Increase in blood sugar levels - you may need to start additional medication to control this

Step 10

Medication for life



4. What if I want to take other medications, over-the-counter vitamins, other supplements or herbal medications after my transplant?

Many medicines, including 'over the counter' medicines, herbal and complimentary medicines have the possibility to damage your new liver or interact with your transplant medicines. Taking these could lead to rejection of your liver or increase the chance of side effects from your transplant medicines.



It is important that any doctor, pharmacist or dentist who is treating you knows that you have had a liver transplant and which medicines you are on.



Please make a habit of always letting them know.

All livers are precious, but donor livers are more sensitive to injury than healthy, non-transplanted livers. The advice from the Queensland Liver Transplant Service is that you should check with your doctors before taking absolutely anything which is not prescribed. It is a good idea to bring into clinic a sample of what you wish to take to discuss its safety **before** starting therapy.

Do not drink grapefruit juice. All other citrus drinks are fine.

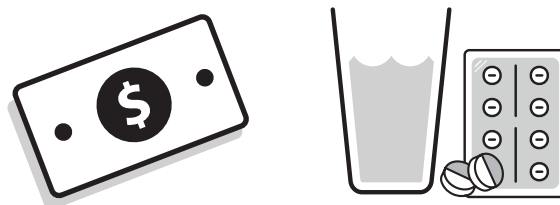


Do not eat grapefruit nor drink grapefruit juice

As this increases the absorption of Tacrolimus and Cyclosporin and increases the risk of side effects.

Step 10

Medication for life



5. How much do the medications cost, and where do I obtain them from?

Normal PBS prices apply for all item prescribed following a liver transplant.

More information on fees and patient contributions can be found at the PBS website:

<https://www.pbs.gov.au/info/healthpro/explanatory-notes/front/fee>

Before you are discharged from the ward after your liver transplant you will spend time with a pharmacist who will discuss a lot of information including where you can get access to ongoing supplies of your medications. Most of your scripts for your transplant medications will be provided by your hospital specialist. Over time as your tablets become more stable your general practitioner will be able to prescribe your regular medicines allowing you to access them from your local community pharmacy.



Drug trials

Progress in our understanding and use of medications following liver transplant has been thanks to previous patients participation in approved clinical trials.

You may be offered the opportunity to take part in a clinical trial whilst under the care of the Liver Transplant Team. Participation is entirely optional, and individuals will be asked to consent to being included **only** after all the details of the clinical trial are explained.

Your participation or otherwise, will in no way affect your treatment as a liver transplant patient, as it is a purely personal choice.



Step 11

Leaving hospital, attending clinics and other details

By the time of discharge from the Transplant Unit Ward 4BT patients are regaining their well-being, strength and independence with care needs and daily living activities. Most drains and drips have been removed. Despite patients and their support people often describing that they feel a little nervous about how they will manage everything in the first few days and weeks, most do extremely well. The treating team is close by to assess and respond quickly to any concerns.

Key points:

1. **Discharge planning commences soon after the patient returns to the ward from ICU.** The time frame for discharge can vary quite considerably depending upon the patient's medical situation and recovery. The treating team monitor patients very closely and provide regular updates to the patient and their chosen support people.
2. **When discharge is looking likely the patient is provided with a day pass so they can have a few hours off the ward with their support person.** If all is well an overnight pass is then provided the following day so the patient can stay out of the hospital overnight for the first time since the transplant.
3. **The patient returns to outpatient clinic the following morning** with their support person or carer for the beginning of regular post-transplant outpatient appointments.

The outpatient clinic staff provide detailed information about the frequency and process of the outpatient appointments. During the first few weeks the appointments are daily or near-daily, sometimes including weekends. The appointments reduce over time to 1 to 3 times each week. By the fourth month after the transplant, outpatient clinic appointments are usually 1 to 2 times monthly.

4. **During the first few weeks after discharge,** the patient attends the outpatient clinic near the Transplant Unit, Ward 4BT on the 4th floor near the blue lifts. In the weeks afterwards, the patient commences attending the Monday morning outpatient clinics held in the PAH Specialty Outpatients Clinic located in Building 15 from the main Hospital, on level 2. The Transplant Unit and W4BT outpatient clinic support the management of transplant patients who need review outside Building 15 and Burke Street clinic times.

Step 11

Leaving hospital, attending clinics and other details

5. **The support person or carer is very important during the first few weeks, helping with such things as:**
 - Transport to the PAH and support for the patient to attend clinics. Patients cannot drive for the first 4 to 6 weeks after their surgery.
 - Meal and food management, online or in-store shopping, meal deliveries, cooking
 - Alerting staff to any concerns
 - Assisting with medication, if this arrangement is in place
 - Supporting with activities to help the patient recover and rehabilitate, for example exercise such as going for walks; and maintaining social connections.
6. **Patients who live in the Brisbane area** are discharged directly to their home or to that of their locally- based support person. Patients who live in near- regional areas need to stay nearby and accessible to the PAH for about 6 to 8 weeks. Patients from more distant regional areas usually start their temporary relocation to Brisbane before the transplant. The distant regional patients stay in Brisbane for 12 weeks after their transplant. During these times a support person is required.
7. **All new liver transplant patients** attend the Monday morning Outpatient Liver Transplant Clinic located in Building 15 from the main Hospital, on level 2 during the first 12 months after their transplant.
8. **From the second year after their transplants** onwards, patients attend the Wednesday morning clinics either at Burke St or by Telehealth.

Burke Street Clinic

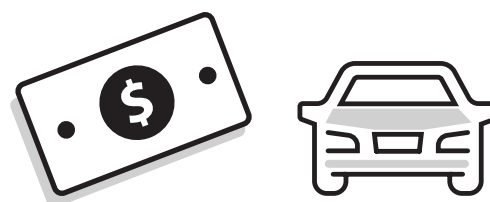
<https://metrosouth.health.qld.gov.au/burke-street-centre>

Telehealth Clinics

<https://www.health.qld.gov.au/telehealth>

Maps of PAH including Building 15 and Burke Street

<https://campuses.uq.edu.au/files/11202/76-pa-hospital-map.pdf>



Step 11

Leaving hospital, attending clinics and other details

- 9. Accommodation and subsidies:** Information about accommodation facilities near the PAH and regional patient subsidies to help with accommodation cost is available from their Regional Hospital, the PAH Travel Office and from the Queensland Liver Transplant Service social worker.

Accommodation

<https://metrosouth.health.qld.gov.au/sites/default/files/pah-accommodation-guide.pdf>

Queensland Subsidies

<https://www.qld.gov.au/health/services/travel/subsidies>

New South Wales Subsidies

<https://www.health.nsw.gov.au/transport/Pages/iptaas.aspx>

- 10. Carer payments:** It is recommended that all questions regarding Centrelink Carer Payment and Carer Allowance be addressed to Centrelink. There is clear criteria to be met in relation to the degree of the patient's disability, the nature of the care needs and the time for which care is likely to be needed.

An assessment tool is applied and scored. One of the criteria is that the care needs extend past 6 months. The experience of the Queensland Liver Transplant Service is that most patients enjoy a good recovery and are fully independent of post-surgical care by 3 months after their transplant. Therefore, liver transplant patients don't always meet the criteria for Centrelink Carer payments.

If someone is already receiving a carer payment or allowance at the time of the patient's transplant, this will continue for the time being. Please visit the Centrelink Carer's information page for further information:

<https://www.servicesaustralia.gov.au/individuals/services/centrelink/carers-payment>

Phone: 132 717



Step 11

Leaving hospital, attending clinics and other details

11. Return to work and Centrelink income support: Patients who already receive Centrelink income support whilst waiting for the liver transplant will continue to receive income support in the months after the transplant. If you already report your income and circumstances to Centrelink, it is important to continue doing so as per usual. This way any changes to your income or employment circumstances can be noted and the relevant income support adjustments made.

The amount and type of income support provided for pre and post - liver transplant patients and their carers is based upon assessable income and assets a medical assessment and sometimes other criteria. Disability payments are not automatically provided due to having had a transplant. The patient's situation is assessed using the standard Centrelink assessment tools, criteria and requirement of evidence.

For full information regarding Centrelink services, please visit:

<https://www.servicesaustralia.gov.au/individuals/centrelink>

Centrelink Service Centre - 5 minutes by car from PAH

Corner of Logan Road and Cornwall Street

Stones Corner Qld 4120

Monday to Friday

8.30 am to 4.30 pm



Step 12

Life after transplantation



After the transplant you will receive your personal copy of the *Queensland Liver Transplant Service Shared Care Booklet*. Included is information about employment, re-training, travel, volunteer and other meaningful activities.

Many patients describe transplantation as an opportunity to review their life, because of the second chance transplantation has provided.

Patients vary in their readiness to start activities of day to day living. There is no set time when to start work or similar activity although many patients comment that 3 to 6 months after the transplant is often when they are feeling settled and stronger. The individual transplant experience, past medical history and reason for needing a transplant; can all impact the recovery. It is generally a gradual but forward-moving process. The key however is making the most of the transplant opportunity in whatever way is meaningful and useful to you, your family, your situation and your hopes.

Counselling and support appointments, office, ward, clinic or telehealth are available to help with any matters that individuals, couples and families might be facing both during the pre and post-transplant phases. These can range from practical concerns, right through to personal, relationship or family issues; or dealing with lifestyle or ongoing illness issues. Referrals can also be arranged to external practitioners and agencies. The important thing is to ask for help as we do not always know when you might need extra support.

We express genuine and heartfelt appreciation to former liver transplant patients who over the years have chosen to participate with the STEP (*Support Through Education Program*) on a voluntary basis, sharing their experiences and stories with those waiting transplant and navigating the early stages of transplantation. The volunteer former patients and families make up what has become known since 2002 as the Liver Transplant Support Network. This informal network provides an important component of support to newer patients especially through the support program (STEP).

With a move towards online delivery of STEP, we will continue offering established liver transplant patients and families the opportunity to join the **Liver Transplant Support Network**; thereby enabling them to participate in STEP when they wish to and from wherever they are.

Step 12

Life after transplantation



Liver Transplant Support Network members are always welcome to join the end of year lunch STEP program. The **Liver Transplant Support Network** is recognised by the Metro South Princess Alexandra Hospital Volunteer Department. Please contact the Social Workers for more information.

Many post-transplant patients, dialysis patients, living organ donors and organ donor families join together to participate in the National or World Transplant Games. This worldwide sports movement hosts some of the most exciting events you can be part of. Many thousands of people compete or cheer others on, confirming the value of life whilst expressing heartfelt appreciation to the organ donors and their families.

For more information go to: <https://transplant.org.au/>

And remember that attending the Annual DonateLife Service of Remembrance and writing a thank you letter to your liver donor family are two further ways you and your family can extend heartfelt thanks to the people who made the selfless decision to gift their loved ones organs on what was likely the toughest day of their life.

For further information, please visit:

<https://donatelife.gov.au/about-us/donatelife-network/donatelife-queensland>



In conclusion

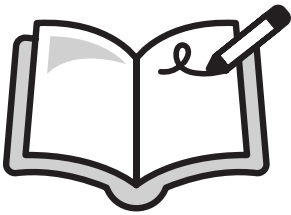
We hope that this booklet provides useful information whilst you are on the waiting list for a liver transplant. It provides an overview of some of the topics covered by the Liver Transplant STEP (*Support Through Education Program*) including those which patients and families most commonly ask about.

We wish you well with the transplant journey. It can be a mixed time, giving rise to many thoughts, feelings, hopes and reflections. Whichever direction things take for you and your family, we hope that the support you receive can be of great help.

Key search words - Google or similar

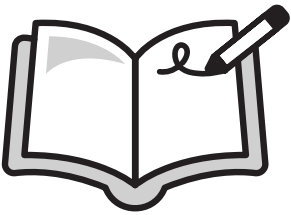
- DonateLife
- Office of the Adult Guardian Queensland
- Public Trustee Queensland
- Queensland Law Society
- Advance Care Planning Australia
- Private Meal Deliveries Brisbane
- Relaxation Centre
- Meals on Wheels
- Transplant Australia
- Head to Health
- Ask Izzy
- Relationships Australia
- Patient Travel Scheme Queensland (or other state)
- Metro South Accommodation Guide
- Money Smart
- Centrelink





Notes

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Notes

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Coronavirus (COVID-19) Safety updates



All patients and families are advised to check the latest COVID-19 updates with their treating practitioners at the Princess Alexandra Hospital.

Information is available on the following websites:

Metro South

<https://metrosouth.health.qld.gov.au/covid-19>

Queensland Health

<https://www.qld.gov.au/health/conditions/health-alerts/coronavirus-covid-19>

Australian Government

https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert?gclid=EAlaIQobChMIgcrMr4y66glVBQ4rCh3uXgdsEAAYASAAEgIJTfD_BwEAAustralian Government Health

For further information contact:

Princess Alexandra Hospital

Liver Transplant Recipient Coordinators

Phone: (07) 3176 7481

Email: livertxcoord_qlts@health.qld.gov.au



If you have any further questions, please ring the Princess Alexandra Hospital, Liver Transplant Recipient Coordinators office on (07) 3176 7481 or switchboard (07) 3176 2111 and ask to speak to the Recipient Transplant Coordinator on call during office hours.

Once again, do not hesitate to talk to the staff about any concerns you or your family may have. We are here to help you in your journey through assessment and transplant.



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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