

Queensland Liver Transplant Service



Liver Transplant Temporary Relocation Guide



Princess Alexandra Hospital Campus Map





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This information guide is useful for:

- Patients who have been referred to the Queensland Liver Transplant Service (QLTS) at the
 Princess Alexandra Hospital (PAH) in Brisbane for transplant assessment but who are not on the
 transplant waiting list, and their families.
- 2. Patients who have completed liver transplant assessment and who are on or have received advice that they are soon to be placed on the QLTS transplant waiting list; and their families.
- 3. Hospital and Health Services (HHS) throughout Queensland which manage the State's **Patient Travel Subsidy Scheme (PTSS).**





Key points

1. The Queensland Health **Patient Travel Subsidy Scheme** (PTSS) helps patients from regional and remote Queensland with a financial subsidy towards travel and accommodation costs. https://www.qld.gov.au/health/services/travel/subsidies



This includes patients who are at all stages of the transplant process, and their support person:

- Newly referred patients
- Patients who are undergoing a full transplant assessment
- Patients who are on the waiting list for a transplant
- Patients who have received a transplant and who attend transplant outpatient clinics or require hospital readmission as part of their ongoing review and management.
- 2. The PTSS is managed by the 16 regional Hospital and Health Services (HHS) throughout Queensland. Every resident in Queensland lives within a HHS. Therefore, patients and families need to discuss their particular situation with the Travel Officer in their HHS at their local regional hospital. The patient's local HHS Travel Office manages individual patient's PTSS payments and travel bookings, and in some instances, accommodation bookings.
- 3. The PTSS accommodation payment for regional patients moving to Brisbane to await and undergo liver transplantation, is usually calculated differently from stays of less than 3 months. The subsidy provided to (PTSS eligible) pre and post liver transplant patients is generally excellent and enables significant and fair long-term support to patients and families.
- 4. The PTSS does not pay any relocation costs, for example: storage of house contents or furniture removals. These costs are the patient or family's responsibility.
- 5. There is a good range of accommodation in the Brisbane area suitable for pre and post-transplant stays. There is no accommodation facility specifically for liver transplant patients/families. People choose where to stay, based upon individual needs and preferences.
- 6. Patients who live within a couple of hours driving time from PAH in Brisbane **do not usually need to stay in Brisbane until after their transplant.** They will need to stay near to the PAH upon discharge from the PAH Transplant Unit for between about 4 to 8 weeks after their transplant. The exact time depends upon individual medical situation and post-transplant health condition.
- 7. Patients who live **over 2 hours driving time from PAH need to temporarily move to Brisbane** for the pre transplant waiting period. They then stay in the Brisbane area for up to 12 weeks after the transplant.
- **8.** Parking at Princess Alexandra Hospital, 5 Day Parking Special and cost-saving information: https://metrosouth.health.qld.gov.au/princess-alexandra-hospital/getting-here/parking



About the Queensland Liver Transplant Service (QLTS)

QLTS was established by Professor Russell Strong and his team in 1985. QLTS is one of the most outstanding national and international liver transplant units.

It is the only liver transplant centre in Queensland and a privilege to be referred to.

Adults are transplanted at the Princess Alexandra Hospital, whilst children are transplanted at Queensland Children's Hospital. Organ Donation rates have increased in recent times and the number of patients referred for transplantation is also increasing.

No patient listed for transplant knows exactly how long they will wait for their transplant opportunity. The waiting time can range from days to a couple of years. DonateLife: https://donatelife.gov.au/about-us/donatelife-network/donatelife-queensland

Referral for liver transplantation



The success of liver transplantation as a therapy for a range of liver diseases has been well shown over time. This success has led to the steady increase in referrals.

QLTS provides people from Queensland and northern New South Wales who meet the established medical and psychosocial criteria for liver transplantation, with the opportunity for transplant. Not all patients referred for liver transplant assessment are accepted onto the waiting list. There are many liver diseases and abnormalities which can potentially be addressed by liver transplantation. The advent of multi - organ transplantation, for example: combinations of heart, lung, liver, kidney and bowel has widened the possible pool of transplant recipients.

Processes and help with costs

The following table highlights the **4 Main Steps** involved with the referral, assessment and treatment process – with brief overview of subsidies. Further information is found underneath the table.

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







Step 1. Referral



Step	What happens	Immediate outcome	Longer term outcome	Cost/PTSS/HHS implications
1. Referral	The patient is referred to the Gastroenterology and Hepatology Department at PAH from the regional hospital, patient's general practitioner or specialist. Patients are seen as inpatients or outpatients at this stage, depending upon their medical condition.	The patient is seen by a medical specialist usually at the PAH Burke Outpatient preliver Transplant Clinic. Sometimes the patient is already an inpatient at the PAH or another Brisbane Hospital at the time of the referral, so is seen as an inpatient at this point.	Decisions are made by the specialist about whether the patient is to proceed with a full pre - liver transplant assessment. If so, the patient proceeds to Step 2.	PTSS subsidies assist with accommodation and travel costs including mileage and public transport. Patients apply for PTSS help through their local regional hospital. Patients and families staying overnight in a commercial accommodation facility, should check directly with the facility what PTSS documentation they need.

Step 2. Assessment



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Step	What happens	Immediate outcome	Longer term outcome	Cost/PTSS/HHS implications
2. Assessment	The assessment usually takes place at the Princess Alexandra Hospital (PAH) on an outpatient basis. The patient therefore is not usually admitted to hospital for these procedures. Some of the tests and investigations can be done at hospitals near where the patient lives. Others must be done at the PAH. Patients from the more distant regions need to stay in the Brisbane area during this assessment period. This enables them to take part in all their assessments, investigations and treatments— whilst an outpatient. Sometimes as per Step 1, another Brisbane hospital might be involved at this workup stage, particularly if the patient is being managed and referred for transplant consideration by a specialist at one of these hospitals.	The patient is guided through the assessment process by the liver transplant nurse coordinators. Many investigations occur at this stage, often over several days. The patient and family from the more distant regions will need to stay in accommodation near to the PAH — either with family and friends or in commercial accommodation facilities.	Once the assessment stage is completed, and results of investigations are known, decisions are made by the specialist about whether the patient meets the criteria for presentation to the Liver Transplant Assessment Committee. Refer Step 3 below.	PTSS subsidies assist with accommodation and travel costs including mileage and public transport. Patients apply for PTSS help through their local regional hospital. If patients and families are staying in commercial accommodation, they are advised to discuss documentation and arrangements with their regional HHS travel office. https://www.qld. gov.au/health/ services/travel/ subsidies/about

Step 3. Case presentation



Step	What happens	Immediate outcome	Longer term outcome	Cost PTSS/HHS implications
3. Case presentation	At the end of the assessment as per Step 2, if the patient meets the criteria for case presentation then the patient's case is presented at the Liver Transplant Committee Assessment Meeting. Presentation of the patient's case could either be very soon after Step 2, or it could be planned for several months away – depending on the individual medical circumstances. The patient does not attend these case presentations.	One of 4 main patient outcomes from the QLTS Assessment Meeting occur: 1. Acceptance and placement onto the liver transplant waiting list 2. Acceptance, but delay of placement, onto the liver transplant waiting list 3. Delay of an overall decision about acceptance onto the liver transplant waiting list pending further actions and investigations 4. Non-acceptance onto the liver transplant waiting list.	Refer to Step 4	Nil

Step 4. Treatment pathways



Step	What happens	Immediate outcome	Longer term outcome	Cost PTSS/HHS implications
4. Treatment pathways	If accepted for transplant: If accepted for placement on the waiting list for a liver transplant, the longer - distance regional patients must temporarily move to within a 2 hour driving radius of Brisbane. If already living within 2 hours driving distance of Brisbane — simply stay put, no need to move. Being near the PAH is vital. The majority of patients listed for transplant choose to move to an area near PAH. If patients choose to live further away but still within the 2 hour radius, they need to have an excellent transport plan for getting to the PAH before and after the transplant.	If accepted for transplant: If in reasonable health, the newly accepted regional patient usually returns home for a few weeks to prepare for their temporary move to the Brisbane area. If too unwell to return home, patient begins their wait for liver transplant in Brisbane. Fast fact: The waiting time for a transplant is always unknown. A donor liver could be several days or 1 to 2 years away.	If accepted for transplant: The patient waits for a transplant, which happens when a donor organ becomes available. If transplanted, the patient is hospitalised for 7 to 10 days, on average after the transplant and attends daily or neardaily liver transplant clinic for several weeks. The patient then continues attending weekly clinic appointments for 3 months or so, after the time of the transplant. All patients must be ready and able to attend the PAH for up to 3 months post-transplant. The length of time for which patients and their carers need to stay near the hospital during the post- transplant and discharge timeframe, is determined by how far their home region is from the PAH, and their post-transplant medical condition. Continues on page 10.	If accepted for transplant: Long term financial support is available for PTSS eligible patients. For full details, please refer to the information below this table.

Step 4. Treatment pathways



Step	What happens	Immediate outcome	Longer term outcome	Cost PTSS/HHS implications
4. Treatment pathways			If accepted for transplant: Patients from North Queensland for example, usually stay in the Brisbane area for 3 months post-transplant. Patients who live within a few hours drive of Brisbane generally, stay in the Brisbane area for 4 to 8 weeks after their transplant.	

Step 4. Treatment pathways



Step	What happens	Immediate outcome	Longer term outcome	Cost/PTSS/HHS implications	
4. Treatment pathways	If accepted for transplant awaiting further tests or treatments:	If accepted for transplant pending further tests or treatments:	If accepted for transplant awaiting further tests or treatments:	If accepted for transplant awaiting further tests or treatments:	
	The patient is not placed on the waiting list yet until further investigations or treatments occur for example, dental work. The results of these tests or treatments could determine if the patients will be listed, or not.	The specialist will decide whether to discharge the patient to their home region for the time being, or request they stay nearby. If not accepted for transplant:	Once the outcome of	Once the outcome of the additional investigations or treatments is known, a decision will be made by the specialist as Once the as described document is a to help eligible with transposance accommodation. This enables proceed to obtain the up investigation treatments.	Regular PTSS support as described in this document is available to help eligible patients with transport and accommodation costs. This enables patients to obtain the follow up investigations and treatments.
	If not accepted for transplant:	The patient is patient is listed	If not accepted for transplant:		
If the patient is not accepted onto the liver transplant waiting list, the patient is told and arrangements made for follow up care. ongoing outpatient management or is referred back to the referring doctor. In some situations, this might involve referral to palliative care support services.	If not accepted for transplant: The patient does not attend the pre- transplant clinics in the long term – as per previous column.	Regular PTSS support is available to enable eligible regional patients to return to their home regions for follow up treatment and care.			

Other possible outcomes

- The patient improves after a while and does not need a transplant, so is removed either permanently or for a short time from the liver transplant waiting list.
- The patient deteriorates and becomes too sick for transplant surgery. Inpatient care at a
 hospital, specialised palliative care unit or community supported palliative care at home,
 would be offered.
- The patient dies whilst waiting for a donor liver.









Summary of steps

Step 1

- In order to attend a clinic review by a PAH hepatologist, regional patients need to travel and sometimes stay near the hospital. The PAH prefers that a support person be with them. Often the patient cannot drive at that stage, or is having difficulties with mobility, fatigue, itch or memory. These are symptoms of liver deterioration. At this stage of the process, PTSS might need to help with arrangement and subsidy of transport to the PAH and overnight accommodation of the patient support person.
- Overnight accommodation is generally needed if the patient's home region is more than several hours away.

Step 2

- Most patients undergo their full assessment as an outpatient. They need to attend the hospital over several days. Patients from regional areas often choose to stay nearby. The patients are given a list of appointments, tests and treatments they need to get done. Some of these tests happen at their regional hospitals either before or after they are in Brisbane, but a number of the booked appointments can only be done at the PAH in Brisbane.
- If a patient is transferred for the assessment as an inpatient from a regional hospital to the PAH or is admitted to the hospital from an outpatient clinic or the Emergency Department, this suggests the patient is sicker or has particular treatment needs.

Step 2

- As psychosocial and emotional support is important for the successful long-term outcome of the treatment process, the family and patient's support system are assessed during the early stage. It is therefore essential that at least 1 family member accompany the patient during this stage. Patients might not be at their best, hence having family support is vital to the patient. It is important for the family to spend time with their loved one, given that long term outcome is often uncertain. Families and friends report they find it useful to take part with the assessment activities, so they know what is happening, and can obtain the information they need to support the patient.
- At this stage, patients are invited to complete the Social Work Intake Assessment Questionnaire.
- Unless they have family or friends in Brisbane to stay with, patients usually stay in nearby commercial accommodation whilst their assessments and tests are conducted. Patients and their carers choose where they wish to stay.

Step 3

- After the tests and procedures are finished, the patient returns to their home, unless they need ongoing care in Brisbane or need to be immediately or urgently listed for a transplant.
- If the results from the assessment show that the patient meets criteria for presentation to the Queensland Liver Transplant Assessment Committee, then a decision is made by the specialist as to how soon this presentation needs to be. The patient's case might be presented for consideration at the next Assessment Meeting. Or the presentation might be delayed due to the patient's stable or improved medical condition, or if waiting on further test results. The medical staff and liver transplant coordinators keep the patients well informed.

Step 4

- If a patient from a long distant region is **accepted** onto the waiting list, several things can happen:
 - 1. The patient is told they are being listed soon and need to remain in Brisbane until the time of their transplant and for up to 3 months afterwards. Details are provided to the patient to help them plan.

or

2. The patient is told they will be listed for transplant, but that they can return home for a short while to organise things before booking long term temporary accommodation back in Brisbane.

Step 4

New South Wales

Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) - Enable NSW https://www.enable.health.nsw.gov.au/home?a=261962 www.iptaas.health.nsw.gov.au

Victoria

Victorian Patient Transport Assistance Scheme (VPTAS) - health.vic https://ww2.health.vic.gov.au/hospitals-and-health-services/rural-healh/vptas-how-to-apply

Northern Territory

Patient Assistance Travel Scheme - NT.GOV.AU

https://nt.gov.au/wellbeing/health-subsidies-support-and-home-visits/patient-assistance-travel-scheme

Western Australia

WACHS: The Patient Assisted Travel Scheme (PATS) (health.wa.gov.au) www.wacountry.health.wa.gov.au/index.php?id=pats

Tasmania

Patient Travel Assistance Scheme (PTAS) | Hospitals (dhhs.tas.gov.au) https://www.dhhs.tas.gov.gov.au/hospital.ptas

South Australia

PATS | SA Health

https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/services/regional+health+services/patient+assistance+transport+scheme/patient+assistance+transport+scheme

- If the patient is not accepted for the transplant waiting list, they could be referred back to their regional hospital or referring doctor for ongoing management, or they might be transferred to one of the other outpatient clinics at the PAH for medical management. The doctor will discuss the best options with each patient.
- If the patient is delayed or if the decision is postponed, the patient would either return home or remain in Brisbane until further investigations are done.









Relocation and financial assistance

- The way PTSS Guidelines are presently structured, is that patients who are eligible for PTSS can receive financial help up to \$60 per night staying in a commercial facility, and their approved support person can also receive up to \$60 per night. So, for 2 people, a total of \$120 per night maximum. If staying with family and friends, a \$10 per night (total) subsidy is applicable. Long term stays of over 3 months are calculated differently, as seen in the points below.
- Because pre and post liver transplant patients often stay in Brisbane for quite a few months,
 the subsidy payments might be worked out differently by the patient's HHS. The subsidy
 amount provided is up to the patient's regional Hospital and Health Service (HHS) to decide.
 This decision by the regional HHS occurs because whilst the PTSS scheme is a state-wide
 scheme, it is managed at the local regional HHS level. Therefore, every regional HHS manages
 the PTSS Guidelines according to local needs.
- More recently, the regional HHS's have been supporting transplant patients and families at
 the equivalent rate of the single commercial rate up to \$420 per week. This enables patient
 and families to receive a significant contribution to their rental payment. There are many rental
 options which provide flexibility and choice for patients and families. For more information:

Accommodation Guide

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

Real Estate Rentals

https://www.realestate.com.au/rent/

• When a patient, or family on patient's behalf know they are being referred for transplant assessment or is to be definitely listed for a transplant and is seeking PTSS support - they should tell their regional HHS Travel Office. The Travel Officers will then be able to tell the patient and family about what documentation is needed. Specific subsidy amounts and payment arrangements can be worked out. These arrangements continue until the patient is discharged back to their home region – usually about 12 weeks post-transplant.





Brisbane accommodation information

- Metro South HHS maintains an Accommodation Guide. The PAH does not make recommendations regarding facilities in which to stay, but rather provides a list of some known accommodation facilities. It is important that patients and families check facilities and make decisions about accommodation with which they are comfortable.
- Short and long stay available. Ask about long stay weekly, monthly or 3 to 6 monthly rates. Explain the need for a longer term, minimum 3 months stay.
- Patients and families are encouraged to go to property websites such as:
 www.realestate.com.au or www.domain.com.au for a complete overview and comparison of suitable accommodation.
- Local real estate agents can be contacted for help. The PAH Social Worker can provide documentation if needed, to a real estate agent confirming that a patient has moved to Brisbane for medical treatment.
- Patients, who are tenants of the Department of Housing, are asked to discuss moving plans with their local Housing office to get the best help.
- Church and non-government or community organisations can sometimes help with housing choices.

Accommodation options

- Many accommodation choices exist. Patients and families have stayed in apartments, hotels, townhouses, duplexes, freestanding houses, Air BnB, granny-flats, share houses, mobile homes, cabins and high-quality tents in environments with suitable camping infrastructure.
 Supported Accommodation helps patients with specific care needs. https://www.sapa.org.au/
- Some patients and families choose to stay in the city or near the PAH in one of the inner suburbs such as Buranda, Stones Corner, Woolloongabba, Kangaroo Point or South Brisbane. Others prefer to be further out in suburbs or areas where they have family or personal connection. Through the transplant process, it is important to stay somewhere safe, comfortable, affordable, and close to the PAH.

PTSS support: patients from nearby regions

- Nearby regional areas would include the Gold Coast, Sunshine Coast, Bribie Island, Caboolture, Toowoomba, Beaudesert, Northern Rivers (NSW) and other areas of similar distance.
- Patients who reside in these areas, generally do not need to move before the transplant, but need to be prepared to stay near the PAH for up to 2 months post-transplant. The exact time frame recommended to stay nearby, is determined by individual medical needs.
- PTSS is generally offered at the regular rate for the time-frame which the near-regional patient needs to stay in Brisbane, at the \$60 or \$120 per night formula, as they meet the PTSS criteria and are classified as short stay, as compared with the patients who stay for an unknown number of months before there transplant and then for up to 12 weeks after their transplant.
- It is important to note that if near- regional patients become unwell during the wait for the transplant, they might need to move short term to Brisbane or be admitted as inpatients.

Staying in Brisbane after discharge to home region

Sometimes patients and families from more distant regional areas choose to stay in Brisbane, after being given clearance by the treating team to return to their home region. There could be many reasons for this. Family members might have new responsibilities or commitments in the Brisbane area. Children might be settled in schools with families preferring to wait until the end of a school term before returning home. Once medical clearance is given, the PTSS support is discontinued and any ongoing accommodation costs become the patient's and family's full and immediate responsibility.



Long term care

- The QLTS oversees the lifetime care of liver transplant patients with the patient's general practitioner and/or regional Hepatologist. If a patient moves interstate or overseas, they can be referred to another liver transplant unit for ongoing management. For the first 12 months post-transplant, patients are reviewed fortnightly or monthly in clinic at the Princess Alexandra Hospital either in person or via telehealth. The clinics are held on Monday mornings. Appointment details are provided to patients. After the first post-transplant year, clinic visits reduce to 3 monthly or according to need.
- Over time, the number of clinic visits generally reduces to once or twice a year. Blood test
 results are continually monitored by the QLTS coordinators and medical staff. If a review is
 needed, the patient might be recalled to the PAH as either an inpatient or an outpatient for
 further testing or treatment. The PTSS implications are similar to those of step 1 or 2. Often
 a support person is needed as the patient is unwell or needing emotional or mental health
 support.
- If the regional patient dies during any of the 4 steps of assessment and treatment, the PTSS subsidy relating to a deceased person as outlined in the PTSS Guidelines applies.

Waiting times

- Transplantation depends 100 per cent on organ donation. Some patients wait longer than others to be offered a transplant. Donor organs are matched with a recipient based on factors including blood type, weight of the recipient or donor, how long a patient has been waiting, and the sickest patient at the time of the donor organ offer. National clinical and ethical guidelines are in place.
- Patients with Advanced Liver Disease often experience anxiety as they wait for a transplant and can become more ill. There are no guarantees regarding donation and transplantation.
- Other factors which influence organ donation and transplantation include:
 - 1. Medical indicators for transplantation.
 - 2. The known success of transplantation at QLTS and increased rates of referral
 - 3. Increasing population shift toward Queensland

Impact of moving on patients and families

- Patients from regional Queensland need to move to the Brisbane area for possibly significant
 periods of time. This move is a requirement of being on the QLTS waiting list. Sometimes entire
 families move which can involve organising housing, employment transfers and new schooling
 or care arrangements for children. Whilst all this can be challenging, patients and families
 generally find ways to make it work successfully.
- Patient eligibility for Centrelink support including rental allowance and carer payments, varies according to each individual situation. It is important to contact Centrelink for advice. https://www.servicesaustralia.gov.au/individuals/centrelink. Some patients pay the mortgage with rental payments received by renting out their homes whilst away and waiting for the transplant, adding finance from other income sources to top up the mortgage repayment. It is a personal choice as to how families manage the temporary move to Brisbane. Patients generally don't need to sell their main residence whilst awaiting transplantation.
- PTSS subsidy is recognised as a critical component enabling patients to remain near the hospital both during the pre- and post-transplant stages. The majority of patients do return to their home regions once transplanted.
- There being only one liver transplant unit in Queensland, Queensland Health and Metro South HHS has a responsibility, to ensure that post-liver transplant recipients can access any assessment and treatment at all stages of the treatment process.
- De-centralisation of PTSS funding, places the responsibility for management and provision of PTSS subsidy, entirely upon each individual Regional HHS. Goodwill, sensibility and correct interpretation of PTSS Guidelines have supported the optimal management of Queensland's regional and remote liver transplant patients, since liver transplantation commenced.

Conclusion

Gratitude is expressed to regional HHS's which continue to support Queenslanders with advanced liver disease through the provision of the right subsidies which acknowledge market rental rates and the patients' movement requirement. This support throughout the treatment process enables patients to access a world class medical service and contribute in turn to their personal, family and community wellbeing. The significant help from families and carers is also deeply acknowledged and appreciated.









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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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