Kidney Transplantation
The Social Matters
Introduction

This Queensland Kidney Transplant Service (QKTS) booklet aims to help patients and families plan for the personal and social aspects of kidney transplantation at the Princess Alexandra Hospital (PAH) in Brisbane. Having a kidney transplant is a major event for both patients and families. QKTS welcomes and cares for patients from throughout Queensland, New South Wales and beyond.

The information is for those who are waiting for a kidney transplant, but some sections are suited to both before and after transplantation.

The booklet is divided into 6 sections

- Travel
- Accommodation
- Money
- Care and Support
- Legal
- Social and Emotional

In each section there are “Key Facts” and suggestions about “What to Do” to become ready for the transplant.

Often when patients receive a deceased donor transplant, they describe how surprised and unprepared they were for this event. Everyone knows that being on the waiting list for a kidney transplant could mean a wait up to 3 years or more. But from the moment you are placed on the waiting list for a transplant, you need to start preparing for the fact you could receive your kidney anytime.

The transplant could happen within several months or even, weeks of being activated onto the waiting list. The wait can also be longer of course, and this can feel disheartening at times. Your Kidney Specialist can provide support and advice. Regardless of how long the wait for a transplant is, there is much you can do to plan and get ready.

Both living and deceased donor transplant recipients and their families should find the booklet helpful. A key difference experienced by the deceased donor transplant recipients, from that of the living donor recipients - is that they have no idea exactly when or if they will receive a transplant. Nor do they know their kidney donor or donor family.

It is very helpful for all patients and their families to make the best plans possible. These are then ready when needed.
Everyone’s transplant journey is very individual to them. Regardless of what happens, the one main thing patients tell us is that the more they learned and prepared, the easier it was to cope. We hope that the information here will place you in charge and help answer the many questions you might have.

**Travel**

**Key facts:**
- The Princess Alexandra Hospital (PAH) is the only hospital in Queensland that performs adult kidney transplants. Children and adolescents with kidney disease are cared for at the Queensland Children’s Hospital.
- When you receive the phone call to tell you that there is likely to be a kidney for transplant, you will need to travel to the PAH as soon as possible. This phone call can happen any time of the day or night. The doctor who calls you about the transplant, will let you know when you need to arrive at the PAH.
- The Queensland Ambulance Service does not routinely provide transport from either Brisbane or regional areas, for the purpose of travelling to the PAH for a transplant.
- People who live within the Brisbane, Redlands, Logan, West Moreton, Redcliffe, Caboolture, Gold Coast, Sunshine Coast, Toowoomba, Northern New South Wales or other near regional areas; usually travel by car to the PAH when called in for a transplant.
- Patients from more distant regional areas, such as those from Central, Central West, Western, North or Far North Queensland - will need to fly to Brisbane as soon as possible after being notified that a donor kidney is available for transplant. Patients and their carers would then need to travel to the PAH by taxi or train, or arrange to be picked up from the Brisbane Airport by a relative or friend. Travel time between the Brisbane Airport and PAH is about 15 minutes using the tunnels, 20 to 30 mins by surface road, or 45 to 90 mins by train, depending on the wait time between connections. The airport train, known as the “Air Train” does not run 24 hours.

**website:** airtrain.com.au/

Tickets can be bought online. **Taxi: $45 to $65**

**website:** taxifare.com.au/
Travel

Key facts:

- Travel subsidies for Queensland (QLD) residents whose local regional hospital is over 50 kilometres from the PAH, and who meet other specified criteria: are available through the QLD Government Patient Travel Support Scheme (PTSS).

- Subsidy applications and payments are managed by each patient’s individual local regional hospital. For example, Cairns residents needing a transplant are managed by the travel (PTSS) office at Cairns Hospital, Mackay residents by the travel (PTSS) office at Mackay Hospital. If you live in one area, and dialysis in another – it is the hospital or community health centre for the area in which you reside, which in the first instance receives and manages your PTSS application.

- Travel subsidies for New South Wales (NSW) patients who reside over 100 kilometres from the PAH, and who meet other IPTAAS criteria; are available through the NSW Government Isolated Patients Travel and Assistance Scheme (IPTAAS). NSW Patients who live under 100 kilometres from the PAH, are not eligible for any IPTAAS subsidies.

- The full cost of a return flight for the patient and a carer travelling from distant regional Queensland; is paid for by the patient’s local regional hospital under the PTSS if booked or organised by the regional hospital. If patients’ book and pay for their own flights, they will be subsidised at a set rate but will not automatically have the entire fare paid for. Local regional hospital travel offices can provide detailed advice regarding flight bookings, payments and subsidies.

- Patients whose local hospital is under 50 kilometres from the PAH, including Brisbane residents do not usually have access to any PTSS subsidies. Patients who have special support needs might in some circumstances be eligible for assistance. Generally, there is no financial refund for local Brisbane residents getting to and from transplant outpatient clinics at the PAH. These patients and families are responsible for costs associated with use of their, or a friend’s or relative’s car, public transport, taxis, and car parking in and around the PAH. This responsibility for local travel costs to and from the PAH, applies also, to patients who are from the further regional areas and who are staying in Brisbane in commercial accommodation, or with relatives within the Brisbane area. The PTSS does not pay for local travel or parking within Brisbane.
Travel

Key facts:

- Patients whose nearest local hospital is **over 50 kilometres** from the PAH, and attend the PAH for outpatient transplant treatment or clinic appointments; are eligible for either

  - A 30 cents/kilometre subsidy if using a private vehicle to get to and/or from the PAH
  
  - A return flight, train or bus fare for them and an approved carer, to get to the PAH at the beginning of treatment, and home again at the end of treatment.
  
  - A combination of the above – for instance, a patient might fly from Townsville when they receive the call to come to the PAH for the transplant, and then the family might choose to drive the patient home when discharged back to Townsville.

- After discharge from hospital, new transplant patients must attend the transplant clinic 7 days a week, for the first 2 to 4 weeks. This then reduces to 3 times a week for the last few weeks. It is not uncommon for new transplant patients to be attending regular transplant clinics for up to 8 to 10 weeks post-transplant. **6 to 8 weeks is the average time frame for attending Princess Alexandra Hospital kidney transplant clinics.**

- Organising travel to and from the daily transplant clinics, is the responsibility of the patient and family. Generally, the ambulance service does not bring patients to clinics. Patients are required to be at the hospital daily by 7am to have pre-clinic blood testing and are at the clinics until late morning. Travel arrangements to the clinics need to accommodate these times.

- **All new transplant patients are advised not to drive during the first 4 to 6 weeks post-transplant.** This is for medical reasons and because drivers are generally, not covered by their car insurance during the immediate post-surgical period.
Travel

Key facts:

- The Princess Alexandra Hospital does not provide taxi vouchers to patients or families to attend transplant clinic appointments. If a patient already has a current Queensland Department of Transport taxi subsidy card, which was issued before the transplant, they are welcome to use this taxi subsidy card to get to and from the transplant clinics.

Having a taxi subsidy card before a transplant, demonstrates the patient’s *permanent inability to drive or use public transport for reasons of disability, medical incapacity or frailty, or of severe visual impairment*. If at the time of transplant, a patient does not already have a taxi subsidy card yet believes that they meet the criteria: - permanent inability to drive or use public transport for reasons of disability, medical incapacity or frailty, or of severe visual impairment, they can apply for a taxi subsidy card.

The application for the taxi subsidy card generally takes a couple of months to be processed. Therefore, this taxi subsidy application straight after transplant would not help with the costs of attending the daily post-transplant clinic. If the taxi subsidy card is approved, then the taxi subsidy card could assist with future transport needs and costs.

Unless the criteria as explained above can be met, there is little point in post-transplant patients applying for a taxi subsidy card. The post-transplant situation does not create a permanent inability to drive or use public transport – rather it is generally a brief post-surgical period during which driving is not allowed.

- There are several accessible and comfortable public transport, train and bus options near to the Princess Alexandra Hospital. Patients are however advised not to rely on public transport during the immediate couple of weeks after the transplant, due to discomfort which can arise when walking long distances and altered bladder function.

In the longer term, public transport can be a very useful way to get around and increase independence. Transport costs can be reduced by using a Translink Go Card.

The PAH is about 12 minutes from the CBD, 10 minutes from Southbank, 12 minutes from Garden City Shopping Centre, and 12 minutes from Carindale Shopping Centre by public transport. *The Translink Park ‘n Ride* is an excellent travel service, enabling free car parking at certain suburban areas, combined with affordable and direct bus or train travel to the PAH. The nearest train stations to PAH are Dutton Park, Park Road and Buranda. The Translink Go Card is easily available from many retail outlets, including at the PAH newsagency.
Travel

Key facts:

- There are 2 commercial, user pays car park facilities within easy access of the PAH. Both are privately run and operated.


**PA Parking:** located opposite the PAH on Ipswich Rd, and accessible from Wolseley Street, one street behind Ipswich Road. Phone (07) 3391 7884

**Metro Car Park:** located within the PAH grounds, and accessible directly from Ipswich Road and from O’Keefe Street. Phone: (07) 3217 3000

There is street parking in the area around the hospital. Pay in advance @ parking meter – cash or EFTPOS, Credit or Debit Card

There is a courtesy shuttle bus at the PAH:
- **7.30 am and 5.30 pm** - Monday to Friday, *not on public holidays*
  Ipswich road to main entrance
- **5.30pm to 11.30pm** 7 days per week
  Main entrance to Hospital car parks, bus and train stations
What to do:

From the time you are placed on the waiting list for a kidney transplant, start making a travel plan relevant to your situation.

1. Patients living in regional areas are advised to contact their regional hospital patient travel office and advise that they are on the kidney transplant waiting list at the PAH. Seek advice about what PTSS or IPTAAS paperwork you need to complete in advance to access the subsidies. Ask how the scheme works for your local regional hospital, there can be some minor variations between regions around the State.

If you will be relying on a commercial flight, that is QANTAS, Virgin, Tiger or Jetstar to get you and your carer escort to Brisbane – ask your local hospital travel office when on the waiting list what to expect when you receive the phone call to come to Brisbane? Ask who will be organising the flight?

Find out who you need to contact and what you will be expected to do. Be sure of this and have a complete plan.


If you are planning to travel to the hospital by car from a regional area – work out how you will get to the PAH, either using Google maps on your phone, or paper maps ready if unfamiliar with the roads. Know where PAH is. Contact the RACQ or Live Traffic for latest road and travel conditions. RACQ (Qld):
(NSW): website: livetraffic.com/desktop.html

Work out with your friends and family who will drive you to Brisbane, or if you plan to drive yourself – have a car parking plan worked out. This could involve parking at one of the commercial facilities or arranging for someone to collect your car. If your family member is booking into one of the local accommodation facilities, free car parking is usually available at the facility.
What to do:

2. If there is no-one available to drive you to the PAH when you are called in for a transplant – have a few other plans ready. This could involve public transport, taxi, private transport company or a share ride service such as Uber. If you are a non-taxi subsidy card holder, and plan to use a taxi make sure you have money saved and accessible or have an EFTPOS or Credit Card ready to pay. If you need to work out the cost, contact the taxi companies in advance and get a quote on the cost. This way there will be no surprises about the cost and you can be completely calm and organised. Or, register with one of the share - ride services and the fare will be automatically paid by your credit or debit card or PayPal.

3. The above taxi information is relevant also to patients travelling from regional hospitals. Check in advance, whether your regional hospital provides a taxi voucher to get from the Brisbane airport to the PAH – or whether you will be paying for this yourself.

4. If you think you might already meet the criteria for a taxi subsidy card that is having permanent inability to drive or use public transport for reasons of disability, medical incapacity or frailty, or of severe visual impairment – apply now whilst on the waiting list for a kidney transplant. If you are on dialysis and meet the taxi subsidy card criteria, the card could be very helpful to you anyway.

5. All regional patients are advised to have a good understanding of the subsidy Queensland PTSS or the New South Wales IPTAAS schemes. The Scheme is there to help you. Check the websites, in addition to discussing your circumstances directly with your regional travel office well in advance of your transplant. Queensland PTSS: website: qld.gov.au/health/services/travel/subsidies New South Wales IPTAAS: website: enable.health.nsw.gov.au/services/iptaas

6. Fact sheets put together by the PAH Social Workers are available. These provide plenty of down-to-earth and easy-to-read information about the steps and processes which occur before and after your transplant, in relation to travel and accommodation bookings, subsidies, getting back home, and more.

Visit QKTS for Travel Subsidy Fact Sheets or go online to: website: qld.gov.au/health/services/travel/subsidies
What to do:

7. **For all information about public transport**, including about the Go Card, journey costs, and timetables in South East Queensland and throughout Brisbane, go to **website: translink.com.au/**
   or **phone: 13 12 30** any time day or night 7 days a week

8. **The Metro Car Park and the PA Car Park** can be contacted at any time for current rates, specials and opening times and more. **website: metrosouth.health.qld.gov.au/princess-alexandra-hospital/getting-here/parking**
Accommodation

Key facts:

- The Princess Alexandra Hospital neither owns nor provides accommodation facilities for outpatients and families.

- Transplant patients and their families from regional areas are likely to require accommodation anywhere between 2 to 12 weeks. It will be important to plan for this.

- Patients from areas such as the Gold Coast, Sunshine Coast or Toowoomba, generally need a shorter time staying in the accommodation facilities as they are more likely to do the last few weeks of transplant clinic visits as day trips. Once the clinic visits reduce to 2 to 3 times per week, this is when patients from these nearer regions usually return home and travel by car or community transport to the transplant clinics. Patients from the northern areas of the Gold Coast, or the outer northern regions such as Caboolture or Bribie Island often choose to stay nearby for only a couple of weeks if they have someone who can drive them to clinics daily after this time and if they are well enough to travel the distance.

- The Queensland Kidney Transplant Service Website contains information about accommodation and the subsidy schemes. The package has been designed to make it as easy as possible for patients and families to entirely organise their own accommodation, and to obtain the maximum subsidy to which they are entitled, through the Subsidy Schemes. [website: qld.gov.au/health/services/specialists/kidney-transplant](qld.gov.au/health/services/specialists/kidney-transplant)

- There are plenty of accommodation facilities within walking distance of the PAH. Accommodation is available for a few nights through to a few months.

- In addition, there are good accommodation available within a short driving or public transport distance. These include motels, hotels, apartments, hostels and quality caravan and mobile home villages.
Accommodation

Key facts:

- It is expected that patients and families take full responsibility for arranging and booking their accommodation. This enables you to discuss your individual and family needs with accommodation providers and stay where you are most comfortable. Special requirements, costs, arrival times and key collection can then be arranged directly with the management of the chosen facilities. It is recommended that quotes be obtained from several accommodation places, so that the most suitable choice can be made.

- Some, but not all, accommodation facilities offer “bulk billing”. This is relevant to patients who are eligible for the patient travel schemes. If a facility bulk bills, it will split the account and send the subsidised part to your local regional hospital for payment directly by that regional hospital and will provide you the patient with the other part of the account, which is the “gap” payment between the total cost and the subsidised component. This means you pay less upfront. If your accommodation is not bulk billed, you pay the full amount, and lodge a claim after you have returned home. This means that the subsidised component is paid to you directly.

- Transplant patients and families often prefer to stay right over the road from the hospital. This can be helpful during the early days after the transplant, but it is important to know that so long as you can comfortably and readily get to the PAH, you are able to stay a little further away if this suits your circumstances better – or if the nearby accommodation facilities are booked out.

- Accommodation rates are comparable to those of any motel or accommodation facility across the city. Accommodation costs are the responsibility of the patient or family.

- The subsidy schemes as explained in the Travel section above – can help with accommodation costs, to patients and families from regional areas. The cost is usually not completely covered but is heavily subsidised. Patients and families might have to contribute towards their accommodation expenses. It is vital to plan for this cost, and to consider how you and your family will manage the cost. Time on the waiting list enables this planning to occur.

- Application for the subsidy is the patient and family’s responsibility. The hospital travel offices can assist.
Accommodation

Key facts:

- The accommodation subsidy generally takes effect, from the day the patient is discharged from being an inpatient. If a Queensland patient does not have a Centrelink Health Care Card, they will need to pay for the first 4 nights of accommodation before the accommodation subsidy commences. A family member staying in accommodation during the time when the patient is hospitalised, is not automatically covered by the PTSS - but might be. Families must be prepared for this additional cost.

- Anyone can book into one of the accommodation facilities – the facilities are not restricted to patients and families from distant areas. Sometimes, patients who reside in outer Brisbane or near-Brisbane areas, such as Logan, Ipswich or Pine Rivers; choose to book and fully pay for accommodation near to the hospital for the first few nights or weeks after discharge from the ward. This often takes the pressure off daily or near daily travel and is a good investment in the patient and family’s well-being. Remember, it is not every day you get a transplant, so it is vital to do whatever is going to make things easier for you and your family. You and your family do not need more stress! Remember – unless your local hospital is over 50 kms from PAH – you are probably not eligible for the PTSS subsidy.

- It is fine to stay with friends or relatives in the Brisbane area, so long as you can easily get to all your outpatient appointments.
Accommodation

What to do:

From the time you are placed on the waiting list for a kidney transplant, start making an accommodation plan relevant to your situation. To do this:

1. Refer to the Accommodation and Subsidies Section including the fact sheets on the Queensland Kidney Transplant Service website:

   Check the following websites:
   - PTSS (Queensland residents):
   - IPTAAS (New South Wales residents):
     website: enable.health.nsw.gov.au/services/iptaas

   Contact the accommodation facilities of your choice, any time in advance, to obtain current information about costs or anything else you would like to know. You do not have to book in to make enquiries. Check websites, talk to the accommodation providers, ask for brochures to be sent and talk with others you know who might have stayed in Brisbane for additional ideas and hints. Being on the waiting list is an ideal time to put together as much information as possible to develop your plan.

2. For reduced rate accommodation and bookings across Brisbane, check the following web sites any time before or after your transplant to obtain further ideas about additional accommodation resources and costs. Getting ideas together is a great help.

   website: wotif.com.au
   website: booking.com.au
   website: needitnow.com.au
   website: travelmate.com.au


   If you need help with understanding anything, please make direct contact with the Princess Alexandra Hospital Travel Office  Phone: (07) 3176 5011
Accommodation

What to do:

4. Talk with your local regional hospital travel officers about how they can help you when you are staying in Brisbane. They might be able to provide an approximation of costs and subsidies to help you make an accommodation financial plan.

5. If the accommodation facility you book into does not bulk bill or you choose to pay the cost outright and seek later subsidy, work out a plan to pay the entire accommodation account yourself (cash, credit or debit card). When due to return home after your treatment finishes, complete the PTSS paperwork so you can claim the subsidy from your local regional hospital. This is by far the easiest way to claim the accommodation subsidy and provides your ultimate flexibility with regards where to stay. Your long-term accommodation costs are identical, whether bulk billed or not. Full details available on the Queensland Kidney Transplant Service website.

6. If from a regional area and staying with friends or relatives in Brisbane, you can submit a PTSS application form at the end of your stay, to claim a PTSS subsidy. Travel officers can provide further information. Also check:
   website: qld.gov.au/health/services/travel/subsidies/ptss-subsidies#about-accommodation

7. Talk with the travel officer from your local regional hospital, telling them that you are on the waiting list for a transplant. The travel officer might have further information to help process your future subsidy claim. Ask the travel officer whether your regional local hospital provides financial subsidy for the family member’s accommodation, whilst the patient is still in hospital.

8. RACQ and NRMA members can access these motoring organisations’ accommodation information and booking service. This can be of assistance both during the planning stages and at the time of, the transplant.

   RACQ accommodation booking service:

   NRMA accommodation booking service:
Money

Key facts:

1. The PAH Transplant Unit is in a public hospital ward. If admitted as a public patient for a transplant, all inpatient and outpatient treatment costs are covered. No cost to the patients. Patients who elect to nominate they are privately insured, can talk with the PAH Patient Options Officers or their private health fund, about any costs they are likely to incur. Note that there is a cost for in-room television.

2. The pricing of your transplant medication is the same as it was for medication you were on before the transplant. If you already have a Centrelink Health Care Card you will continue to receive Pharmaceutical Benefit Scheme (PBS) listed medications at a cheaper cost. If you do not have a Centrelink Health Care Card, your costs for medication will be charged in the same way as before the transplant. Make sure that you fully understand the Pharmaceutical Benefit Scheme (PBS) Safety Net Scheme and have a Safety Net Card in place. This will ensure that you can access reduced cost prescriptions, if you reach the safety limit within that calendar year.

PBS Information:

3. If you are on a Disability Support Payment (DSP) or your Carer receives a Carer Payment or Allowance from Centrelink at the time of your transplant, these will continue until your usual Centrelink review date. You do not need to automatically notify Centrelink at the time of your transplant, that you have had a transplant. You do need to tell them of any changes to your income or circumstances. Centrelink will work out a plan with you. The plan might be to continue your and your Carer’s income support in the same way. If your work or income circumstances or your care requirements change any time after the transplant, for instance you return to part or full-time work because your health improves after the transplant, or your carer no longer needs to provide the level of care as before your transplant and returns to part or full-time work – then you will need at that time to tell Centrelink of the changed circumstance, so your payments can be adjusted accordingly.

4. There is no special Centrelink “Transplant Payment” or “Carers Transplant Support Payment” at the time after a transplant. Patients who are employed and who take leave of absence for the transplant and post-transplant period; and who have a job to return to, might be entitled to Centrelink Sickness Allowance.
Money

This is a short-term income payment to people who meet all the following criteria:

- a. Are temporarily ill or undergoing medical treatment and unable to do their work
- b. Have no income support through their work for the duration of their time off
- c. Have a job to return to
- d. Meet the household income and assets test

5. There is no short-term Centrelink Carers Payment specifically for Carers who are not already in receipt of a Carers Payment or Allowance at the time of transplant, and who might offer to provide support during the first few weeks after a transplant, for instance, by staying over the road or bringing patients to hospital. Centrelink Carer Payments and Allowances are designed for more enduring and complex care situations. The Centrelink Carer Payments and Allowances are not designed for short term, under 6 months or so, post-surgical care and support even though the care and support are very valued by patients, hospital staff, and the community. website: https://www.servicesaustralia.gov.au/individuals/centrelink

6. Some patients have an income protection, superannuation or disability policy, which can be activated in response to a transplant.

7. **There are costs which patients attending PAH might face. These include:**
   - Public transport, community transport, such as CODI, Transit Care or STAR transport or taxis to and from outpatient clinics
   - Transit Care: website: transitcare.com.au/
   - CODI and STAR: website: starcommunityservices.org.au/
   - Car parking fees
   - Café food and drinks
   - Accommodation and travel costs for regional patients staying in Brisbane
   - Mobile phone and data use

8. There are ATM’s in the hospital foyer near gift shop and newsagency, ground floor blue lifts and at Buranda Village across the road. All cards accepted.

9. There is a Commonwealth Bank Branch and other ATM’s at Buranda Village.

10. Princess Alexandra Hospital staff are unable to assist directly with patients’ money and bill payments.
Money

What to do:

From the time you are placed on the waiting list for a kidney transplant, start making a transplant financial plan suited to your situation. To do this:

1. If you have private health insurance, check with your private health insurance company whether you are likely to pay additional costs, gap payments. Also check whether there is anything your private health insurance might help with, such as accommodation or travel expenses in relation to medical treatments.

2. Check if you can claim any expenses associated with transplantation and medical treatments, via your taxation. An accountant, taxation return officer or the Australian Taxation Office can tell you.

3. Whilst on the transplant waiting list, or if you plan to become a short-term transplant patient carer and you are currently employed or self-employed - and think you will be unable to work for a period of time: - check in advance what financial entitlements you might be able to access. This could involve talking with your workplace, insurance or superannuation organisation and with Centrelink. Having an appointment with any of these organisations can ensure your issues are well understood and you receive the correct information. There might be a way you meet eligibility requirements for a payment. It is highly recommended to research as much as possible; so that you have a strong idea as to what you might be eligible for. Paperwork can be completed in advance, as much as possible. If applying for a Centrelink payment, ask your ward or clinic doctor in the days after the transplant, for a Centrelink Medical Certificate. Any of the transplant unit doctors can assist. The Certificate can be for up to 13 weeks. Lodge this with your local Centrelink office, or at Centrelink Stones Corner, 5 mins from PAH on corner of Logan Rd and Cornwall St.


   Fax: Centrelink: 1300 786 102

4. Consider whether you need the bedside television on at the hospital, as this can be expensive. Some patients bring their own device like phone, portable DVD player, tablet, iPad, notebook. There is a free - to - air television in many patient waiting areas near the ward and in the hospital foyer and cafeteria.

5. Make sure you are on the best landline and mobile phone plan or bundle, relevant to your situation. Check that you have a reliable message bank and voicemail system on your phone, in case messages need to be left for you from the hospital. This is absolutely vital.
Money

What to do:

6. Organise well in advance for as many home bills to be deducted automatically, either fortnightly, monthly or on a specific date. This includes electricity, rates, water, telephone and rental. Regular, planned, small payments have taken the stress away for many dialysis and transplant patients and their Carers. There is also no worry about making payments whilst you might be in hospital or unexpectedly away from home for any length of time. This payment can be arranged through Centrelink or as direct debit through your bank or credit union.

7. If you already experience financial stress, organise to see a financial counsellor as soon as possible. Do not wait until you are in hospital to do this. Lifeline and Salvation Army provide excellent financial counselling services, can review your situation entirely, provide help and will act on your behalf. The private sector also provides financial support services.

8. Try to save at least a dollar a day towards your transplant time. That $300, $600 or $900 saved, can make a big difference. Consider having a few dollars a week transferred automatically to an account you can easily access when the transplant happens. Develop a “Transplant Financial Plan”.

9. Make further saving and financial plans by going to Money Smart:
   website: moneysmart.gov.au

10. Patients living in Ipswich, Logan and Redlands areas can contact their community transport schemes in advance, to help establish travel costs to help with their travel plan.

11. Consider ways to save money when attending outpatients after your transplant:
   - Check with the car parks what their best weekly or monthly parking rate is, as these rates could be cheaper than daily rates
   - Bring your own food and drinks to outpatient clinics
   - Bring your own mug for cheaper hot drinks from hospital café’s Starbucks, The Coffee Cart, Catalyst Café @ TRI or Brew on Two
   - Bring a book or magazine, kindle, iPad or tablet, smartphone, or portable DVD player
   - Bring your own portable Wi-Fi.
**Money**

**What to do:**

12. Plan well in advance for costs associated with accommodation and travel.

Talk with your pharmacist about the PBS Safety Net Card and make sure you have this in place. For further information:


13. Talk in advance with your employer about what arrangements are likely to be made for you to receive sick, family or annual leave. Learn about your entitlements and how to access these. Generally, employers are very helpful when assisting employees through transplantation. The PAH can provide information about organ donation and transplantation to employers at any time, upon request.

website: [moneysmart.gov.au/](https://moneysmart.gov.au/)
Carers and support

Key facts:

• If you are on the public deceased donor waiting list for a kidney transplant, receiving the phone call asking you to come to the PAH for a transplant, causes a chain of events and rush of activity.

• Whilst you knew that you were on the waiting list – to go ahead with a transplant means having to drop everything, travel to the hospital as soon as possible, which for some people could involve a journey of several hundred or thousand kilometres and undergo a major operation. It is a big undertaking. All in one day or night, and with minutes or several hours of warning. It then means starting on a range of new and powerful medications some of which will suppress and affect your immune system and your body. It will hopefully mean being off dialysis for a very long time, and a chance for improved health. Despite high hopes for the future and feeling like “hitting the jackpot” and “… a dream come true” there are uncertainties built into all of this, and many new things to consider:

  • How will it feel being in hospital?
  • Who will help me?
  • How can I quickly tie up the loose ends at home to manage in Brisbane for the next few months?
  • Will my travel, accommodation or money plan work for me?

• Working out in advance who might be your care and support person, will take a load off your mind. The PAH strongly recommends that you ask a friend or relative to help you through.

• The most important time to have a Carer is during the first 2 to 4 weeks. Ideally, a carer can stay with or near you for the first 4 to 6 weeks after you are discharged.

• The carer will be able to assist with accommodation and transport plans, luggage, phone calls to family and friends, and if you are from a regional area – will be able to assist as you settle into the accommodation facility when you are discharged from PAH to start attending the outpatient transplant clinics. Patients are often discharged 5 to 6 days after their transplant operation, and it is the presence of a carer which can make all the difference to patients.
Carers and support

Key facts:

- The carer goes with the patient to the outpatient transplant clinics during the first few weeks. Also, the carer helps with shopping and cooking or with organising a food delivery system such as Meals on Wheels or Lite ‘n Easy. There are supermarkets close to the PAH. Meals on Wheels: website: qmow.org/

- The carer therefore provides support and reassurance to the patient who is:
  - Physically recovering from a significant operation
  - Dealing with the new medications, sometimes which affect the patient’s emotions and sense of self
  - Taking in the fact that a donor family made a momentous decision, at a time of enormous personal grief

- These factors combine to reinforce why a carer plays such an important role in the post-transplant recovery period. If the patient already had a Centrelink designated /paid carer, the pre-existing care needs can continue being attended to.

- There can be more than 1 carer over time. The carer does not have to be at the patient’s side every hour and minute of the day.

- The carer does not have to perform medical procedures, but might assist with overseeing medications or with alerting the transplant unit if the patient seems unwell.

- The carer does not have to be at the hospital at the time of the transplant – rather their role starts during the week you are in hospital, and especially when you are discharged.

- Many people who offer to provide that care during those first few weeks describe the honour they felt, being able to help and be part of the healing and rehabilitation process. Family members have been known to travel from across the state, country and world to be part of the patient’s post-transplant recovery.

- Queensland Health does not provide paid carers to transplant outpatients.

- Patients and families are welcome to organise and pay for a private carer if this arrangement works well for them.
Carers and support

What to do:

From the time you are placed on the waiting list for a kidney transplant, start making a transplant care and support plan relevant to your situation

1. Talk openly with your family and friends to establish who might be able to participate in the care role after a transplant. Explain that the care role is important and encourage them to seek information from the PAH if that would help them to understand what is involved.

2. Understand that it might be possible to finalise a plan until the actual transplant occurs – as a long period of time could pass between when listed for transplant and when the transplant happens. We understand that people’s circumstances can change over time, so it is natural that your plans also might change over time.

3. It is not often in your life that you need the type of post-operative care being described here – and typically, the care role need only last a few weeks. Therefore, even if you unsure about involving someone in the care arrangements remember it is only for a short time in the scheme of things, and that people often are very happy to help when and where they can.

Public information about Carer support - no connection with the PAH

- Mable: website: mable.com.au/find-home-care/?utm_medium=cpc&utm_source=google&utm_campaign=1349336072&utm_content=325974624238&utm_term=%2Bfind%20%2Bcarers&gclid=EAIaQobChMl142--piN4AIYBaqWCh2oxQx7EAAYASAAEgLG3PD_BwE

4. If the Carer or potential Carer is concerned about implications for them with time off work or being away from other family commitments, they have – they can discuss concerns with the transplant unit social worker in advance. Phone: (07) 3176 2610.

5. If you are on the waiting list for a kidney transplant, and are concerned by not having a suitable Carer – please discuss this with your dialysis unit social worker or phone the PAH transplant unit social worker. Phone: (07) 3176 2610
Legal matters

Key facts:

- All adults over 18 are recommended to have a current Will, an Enduring Power of Attorney and an Advanced Health Care Directive. These legal documents hold special relevance to people with chronic health conditions and who are on surgical waiting lists, such as the kidney transplant waiting list at PAH.

- A Will enables people to clearly identify how, in the event of their death; they would like their estate, property and other assets to be managed and distributed and/or how they would like the welfare of their dependents managed. No matter how simple your situation or how rich or poor a Will is always helpful.


- An Enduring Power of Attorney (EPoA) enables an adult to decide in advance which person or organisation they would like to manage and be responsible for their financial and/or health matters, if they lose ability to make or carry out decisions either temporarily or permanently. Such loss of capacity can happen because of illness, surgery, or during rehabilitation. For information:


  Public Trustee Queensland


- An **Advance Health Directive** enables a person to choose in advance, the degree of treatment and assistance, they would want in certain medical situations. It is essential for a doctor, often a general practitioner to go through the Advanced Health Directive with the patient, to ensure full understanding of the information and of the decisions they might make on their own behalf. A new and easier alternative to the Advance Health Directive is to complete a Metro South “Statement of Choices” Form with your doctor. It can be printed out from:

  **Google: Metro South Statement of Choices Form**

Legal matters

Key facts:

- The PAH Transplant Social Workers are unable to directly assist as Witness to Wills, Enduring Powers of Attorney, or Advanced Health Directives. Information however, can be provided.

- There is Justice of the Peace (JP) available to witness documents, on the ground floor area near the PAH Information Desk on Wednesday afternoons and Saturday mornings.
  

Find a community JP in Queensland:


- Ensure your wishes are fully upheld. Place yourself in charge of your legal situation. Never wait until the time of your transplant to organise legal documents. **Take your time and use the time whilst waiting for the transplant to get things in order.**
Legal matters

What to do:

From the time you are placed on the waiting list for a kidney transplant, start making a legal plan relevant to your situation.

1. Seek legal advice from a solicitor, the Public Trust, or a JP whenever such legal documents are being considered. All these processes and documents are private, personal and legally binding. It is recommended that a copy of all your legal documents including the Enduring Power of Attorney, the Statement of Choices or the Advance Health Care Directive; be uploaded to your Medical Record. Queensland Health Administration Officers can help. Copies can also be sent to: Office of Advance Care Planning
   PO Box 2274
   Runcorn Qld 4113
   Phone: 1300 007 227   Fax: 1300 008 227
   Email: acp@health.qld.gov.au
   The night of your transplant is not the best time at all to be sorting out legal matters. Ensure everything is completed in advance, and as soon as possible. All documents can be changed at any time by you, so long as you have legal Capacity or mental ability to do so.

2. Consider the following:

   • Contact your family solicitor, or a solicitor recommended by a friend or relative.

   • Will Kits, Enduring Powers of Attorney Forms and Advanced Health Directive Forms can be purchased from newsagents and Australia Post Offices. EPOA Forms and information are available on the Queensland Government website.

     Advance Care Planning Forms and information are available on the Advance Care Planning website.

   • Queensland Law Society
     Phone: (07) 3842 5842
     For referrals to at least three solicitors who can assist with your specific legal matter Select ‘You and Your Solicitor’, ‘Area’ and ‘Area of Law Required’ – go to:
     website: qls.com.au/for_the_community/find_a_solicitor
Legal matters

What to do:

- Public Trustee of Queensland
  Phone: (07) 3213 9288 or 1300 360 044 - Wills
  Phone: 1300 351 591 - Enduring Powers of Attorney

- Legal Aid Queensland
  Phone: 1300 651 188
  website: www.legalaid.qld.gov.au/Home

- Caxton Legal Centre Inc.
  Phone: (07) 3254 1811
  Monday Tuesday and Thursday between 6pm and 7.30pm
  - Walk in service – no appointment necessary
  - 28 Heal St, New Farm – free service – donations accepted
  website: caxton.org.au/

Wills

Enduring Power of Attorney


Advance Care Planning

Justice of the Peace

Social, psychological and emotional well being

Key facts:

- It is vital to be well prepared as early as possible given that there is no way of knowing exactly when you will be called in for your transplant. Every small piece of planning helps.

- If you are not already a PAH dialysis patient, the PAH could be a place you don’t know very well.

- If you are from a distant regional area, being away from home could be either quite stressful – or it could be viewed as an unscheduled break which you hope to make the most of.

- Counselling and support services are available to all patients and their families, any time before or after a transplant. Telephone or in-person appointments can be made to suit your schedule.

- It is quite normal to experience a range of emotions before and after your transplant.

- Transplantation aims to bring a new sense of physical and emotional well-being, and can greatly improve quality of life. It can also bring new issues which need adjustment. Kidney transplants do not come with a guarantee, and life which had become predictable on dialysis may seem less predictable in the first instance, after a transplant. Sometimes the new kidney takes a while to start working, and dialysis is needed for a while after the transplant. The treating team keep you well informed and be available for ongoing support.

- Whilst hopeful things will be better after a transplant, patients are sometimes very anxious that their transplant might reject or that they might feel worse than when on dialysis. There could be fears about returning to dialysis. Sometime, patients report that they feel emotional, even quite teary, especially in the first few days after a transplant. These feelings can be one of several side effects of the new medication. Some patients worry that the new kidney feels strange, even alien to their body. Being away from home can be very distressing for some patients. It is not uncommon to be dealing with many different feelings, often it seems all at once.

- Deceased donor transplant recipients and their families, sometimes report being anxious, sad or bereft for their unknown and grieving donor family who lost a loved one. In turn they might feel guilty that they are celebrating the “new” kidney and “being off dialysis”, during a time of the donor family’s loss and mourning. It can be distressing knowing that receipt of the transplant kidney, has come about because of somebody else’s sudden death. Patients often wonder about where their kidney came from, and what life their donor lived. Working through these mixed feelings can be very challenging.
Social, psychological and emotional well being

Key facts:

- It is important to remember however, that the death has happened, and that many donor families report that the opportunity to donate the organs and/or tissue of their loved one was a positive benefit to arise from their family member’s unexpected death. The donor did not die for you. Their death happened. After which organ donation was possible. Many donor families have reported comfort from the knowledge that the donation honours the memory of their deceased loved one.

- Recipients are strongly encouraged to consider writing a Thankyou Letter or Card to their donor family. Not only does it acknowledge the gift of life provided by the donor, but it can help process your feelings about donation and transplantation and can help you move forward. Donor families generally treasure thank you cards and letters from transplant recipients, and sometimes they reply back.

- There is more information available from the outpatient staff and social workers in transplant Outpatient areas. Please also visit the Donate Life Website:


Transplantation can be an excellent long-term treatment. If, however the transplant is unsuccessful, as it is in a small number of cases each year; you will return to dialysis. This can be very disappointing and result in feelings of grief and sadness. The doctors will discuss the situation in detail with you and your family to help ensure that you fully understand the circumstances and have opportunity for as much support as you feel you need. Each patient situation is different. The doctors will discuss your future treatment options with you. Support for you and your family is available at any time. Let the team know if you wish to speak with a Social Worker.

- Moving from dialysis to having a transplant can bring about anxiety for some transplant recipients. Being discharged from hospital after the transplant is something most patients look forward to, but it can also cause patients to feel a bit anxious. You will be well supported by staff and will find the transplant clinics excellent. Monitoring of the transplanted kidney by hospital staff at the clinics provides reassurance and security for patients. However, these frequent visits to the hospital may also be frustrating for recipients at a time when so much time is spent at the hospital. The weeks do pass. Patients are encouraged to live their lives as normally as possible with the new kidney, heeding all medical recommendation.
**Social, psychological and emotional well being**

**What to do:**

From the time you are placed on the waiting list for a kidney transplant through to after you receive a transplant, continue planning for the social, emotional and practical aspects relevant to your situation.

**10 top tips**

1. **Talk to professionals:** Talk about transplants with your Nephrologist, Dialysis Nurses and other staff who look after you, so that you can get an idea about what to expect and of details relevant to your situation.

2. **Read, watch and listen:** Read any books or articles about transplants, to get an overview about what to expect, and to learn about other peoples’ experiences. The Queensland Kidney Transplant Service website provides a lot of information and support to help plan for a transplant.

3. **Kidney Transplant seminar:** Attend a Kidney Transplant Seminar, presented 3 times each year at the PAH or ask your dialysis unit to participate in the Seminar video-link. The seminars are featured on the Queensland Kidney Transplant Service website.

4. **Talk to transplant patients:** Recent transplant recipients can be a helpful source of information and advice. Most people are happy to share their experience with you, but it is important to remember and respect that everyone’s experience is personal to them, and that no two transplant experiences are exactly the same. What goes for one will not necessarily go for another. However, there are likely to be features common to all transplant recipients and their families.

5. **Make lists and plans:** Patients need to be aware of what arrangements will have to be attended to when they come into hospital for the transplant and post-transplant period. This is especially important for patients who are on the deceased donor waiting list. After being called and told that there is the possibility of a kidney transplant, the patient needs to be at the PAH within a matter of hours. Your operation is unscheduled, unlike those receiving a planned live donor transplant. Matters to consider include childcare, pet care, cancellation of newspaper delivery, mail collection or holding services, notifying an employer, notifying relatives, closing the house for a while. Make a list now of all the things you would need to attend to, should you be having your transplant tonight. Fill in the Pre-Transplant Checklist, available on the Queensland Kidney Transplant Service Website. Know in advance who is most likely going to assist or be available to help sort out at the time, or shortly afterwards. Be prepared.
Social, psychological and emotional well being

10 top tips

6. Keep a lookout for the “New - Transplant Breakfast Support” Groups, held from time to time during the year. **Posters advertise the Groups**, which aim to provide relaxed support and education for new transplant patient and their families in the café over a coffee, fruit compote, muffin or croissant.

7. Seek counselling and support from the transplant unit, if you or a family member have any concerns whatsoever. The Social Worker is available by appointment to provide any further information or counselling which you or your family might need any stage of the transplant journey. Some patients are a long way from their homes during the time of their transplant, and might be on their own if a family member or friend is not able to stay long. Sometimes patients experience complications or disappointments associated with their transplants or have been worried about family or personal issues, unrelated to the transplant.

Everyone in the Transplant Unit is there to help, and will provide whatever professional support possible, to help you and the family through the transplant time. You do not need to feel alone or that there is something wrong with you. Simply ask for help by talking to the staff caring for you, or phoning or emailing the social worker for an appointment.

A transplant is a big change. If there are any matters with which you would like support, or you wish to discuss, please make an appointment with one of the social workers. It does not matter how long before or after the transplant this occurs. Referrals can also be arranged to other mental health practitioners such as a psychologist or psychiatrist. Never feel ashamed to seek help.

8. Obtain the brochure produced by Donate Life about writing a letter to the donor family. Most patients receive a copy in the social work kit provided after the transplant, or copies are available from outpatient clinics. It is very helpful. Write and send the letter when you are ready, but perhaps don’t leave it too long.

Social, psychological and emotional well being

10 top tips

9. Consider the future: One of the issues that patients find helpful to consider is how they are going to spend their time and live their best life. Returning to work or retraining can usually happen 3 months or so after transplant. With the time constraints of dialysis gone, work may be easier to maintain. There are many resources within the community, regardless of where you live, to assist with long term job seeking, training programs and courses that can be undertaken for either enjoyment or for general learning. Centrelink have fully trained Disability Support Officers, who can assess the patient’s specific needs. Many patients have gone on to learn new activities, commence university, TAFE or volunteer work. Much of the groundwork and planning can occur whilst on the waiting list for a transplant.

10. And remember - make the best choices you can: you are in charge of choosing how to respond to your situation and how best to live your life. There are many ways to move forward and the team of doctors, nurses and allied health staff can all assist you identify which way is best for you.

More resources

There is a lot of information in this booklet. The Social Workers can be contacted any time for further assistance:

- Studying and retraining
- Getting back to the workforce
- Mental Health and wellbeing
- Coping
- Becoming less stressed
- Counselling and support
- Grief and bereavement
- Legal matters
- Accommodation
- Housing
- Caring for someone
- Money matters
- Domestic violence support

And much more...
Social, psychological and emotional well being

More resources

Ask Izzy
A useful website: food, money, public toilets, accommodation, emergency housing, legal, and more.
website: askizzy.org.au/

Life Options – to help people with kidney disease.
website: lifeoptions.org/

Lifeline - for personal and financial counselling
Phone: 13 11 14  24 hours
website: lifeline.org.au/

Kidney Health Australia (KHA)
Since 1968 is the lead National not- for- profit organization focussing on the improvement of kidney health outcomes and the quality of life for people with kidney and urinary tract diseases; their families and carers.  KHA is always developing initiatives to help reduce the incidence of kidney disease in the Australian community and to support kidney patients and their families.
website: kidney.org.au/

Transplant Australia

Kidney Support Network
Phone: 1800 358 797
The Queensland support association for people with kidney disease, and their families.
For full details website: ksn.org.au/

Home and Community Care
Excellent information about supported care housing options, local respite centres, community care agencies such as Blue Care, Anglicare and Ozcare; and other sources of help at home:
website: myagedcare.gov.au/

Brisbane Relaxation Centre
Excellent courses and activities to assist with skill building and with coping better in everyday life. Informative, interesting and affordable.  Highly recommended.
Phone: (07) 3856 3733
website: relaxationcentreqld.org/

Best and Smart Money Advice
Tools and ideas – for savings, retirement, budget planners:
website: moneysmart.gov.au/
Social, psychological and emotional well being

Meal delivery - sample only

**Meals on Wheels**
Phone: 1300 90 97 90
[website: qmow.org/](http://qmow.org/)

**Gourmet Meals**
Phone: 1300 112 112

**Lite N Easy**
Phone: 13 15 12

**Diet Factory**
Phone: 1800 065 255

**Jenny Craig**
Phone: 1300 858 198

More resources

**Help at Home for People in the Community**

**Help with Disabilities**

**Help for Depression and Mental Health**
[website: BeyondBlue.org.au](http://BeyondBlue.org.au)

**Relationship Support**

**Salvation Army**
[website: salvos.org.au](http://salvos.org.au)
Social, psychological and emotional well being

More resources

St Vincent de Paul
Phone: (07) 3010 1096 Brisbane Metro only
website: vinnies.org.au

Volunteering
website: volunteeringqld.org.au

TAFE and Learning New Skills
TAFE website: tafeqld.edu.au/
Open Learning
website: openlearning.com/?utm_source=google&utm_medium=cpc&utm_campaign=ol_au&gclid=EAIaIQobChMIwonttKmN4AlIVSYqPCh1KCAPIEAAYAiAEGLdIPD_Bw

For information about any of the following, and relevant Application Forms: Google these key words

Travel to and from the Brisbane Airport:
Google: Air Train Brisbane

Half price Taxi Card:
Google: Taxi Card Queensland

Accommodation and Road Conditions:
Google: RACQ
Phone: (07) 3361 2802

Patient Travel and Accommodation:
Google: PTSS Queensland

Patient Travel and Accommodation New South Wales:
Google: IPTAAS NSW

Public Transport in Brisbane and South-East Queensland:
Google: Translink
Phone: 13 12 30

Public Transport in Brisbane and South-East Queensland
Google: Translink
Phone: 13 12 30

All information provided in this booklet, was accurate at time of writing
Social, psychological and emotional well being

For information about any of the following, and relevant Application Forms: Google these key words

**Taxis in Brisbane:**
Google: Yellow Cabs Brisbane  
Phone: 131 924  
Black and White Cabs Brisbane  
Phone: 131 008

**PBS Safety Net Scheme to Help with Pharmacy Costs**  
Google: PBS Safety Net Medicare

**Centrelink Eligibility or Any Other Centrelink issue:**  
Google: Centrelink or go to website: www.servicesaustralia.gov.au

**Princess Alexandra Hospital phone numbers:**

**Social Worker (Transplant)**  
Phone: (07) 3176 7180

**Social Worker (Renal)**  
Phone: (07) 3176 6397

**PA Hospital Social Work Department**  
Phone: (07) 3176 2610

**Princess Alexandra Hospital main switchboard**  
Phone: (07) 3176 2111

**Kidney Transplant Coordinators**  
Phone: (07) 3176 7769 or (07) 3176 7397

**4BT Outpatients**  
Phone: (07) 3176 5133

**Ambulatory Renal Transplant Services (ARTS)**  
Phone: (07) 3176 2615

**PAH Metro South Travel Office**  
Phone: (07) 3176 5011

*All information provided in this booklet, was accurate at time of writing*
Conclusion

It is 50 years since the first kidney transplant at the Princess Alexandra Hospital (1969).

Princess Alexandra Hospital Kidney transplant patients, continue receiving excellent care and expertise from a world class transplant team. From going onto the waiting list, to being called in for the transplant, to getting through that first week or two on the ward, to moving through the transplant clinics, and then to eventually moving towards a dialysis free and transplanted life – you, the patient – are partnering with the team to meet the opportunities and challenges of each stage.

Transplantation represents a big change for patients and their families. The PAH aims to support you every step of the way. We know that the more patients and families can do to learn, plan and prepare – the more they will cope with everything that happens, no matter what.

It might seem easier not to think too much about transplantation until it happens. Especially when busy managing dialysis, medical appointments and day to day life. However, the overwhelming feedback we receive each year from patients and families who have travelled the transplant road is that the more they think about and plan for the transplant – the better they got through everything.

Waiting for a kidney transplant is the best time to plan. Planning for travel and accommodation; organising legal, money and employment matters; considering how best to develop a support plan with family and friends; and addressing any other concerns.

We hope that the information provided will assist you with this and look forward to meeting with or hearing from you. We are here to help at any time.
Notes
Contact us:

Queensland Kidney Transplant Service
Social Work Department

Phone: (07) 3176 2610

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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