

Queensland Kidney Transplant Service

Kidney Transplantation

What you need to know



**Queensland
Government**

Queensland Health
Queensland Kidney Transplant Service
Kidney Transplantation
What you need to know

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Introduction

Kidney transplantation provides an excellent treatment option for many, although not all, patients with kidney failure. A transplant will usually allow you to feel healthier and enjoy a better quality of life with freedom from dialysis and the related dietary and lifestyle restrictions. However, having a transplant is a serious undertaking and is sometimes very complicated.

The aim of this booklet is to provide information to people who are awaiting kidney transplantation. This will help you, and your family and friends, to develop a good understanding of what is involved in having a kidney transplant. The booklet explores the medical, social, emotional and practical views of transplantation from the work up, being placed on the transplant waiting list, the transplant operation and through to the post-transplant period.

Being informed about transplantation and knowing what to expect, will hopefully make it easier to cope with the changes that happen with kidney transplantation. It is a general guide only. You are likely to have your own questions that may be discussed with your own kidney team or by contacting the Kidney Transplant Unit.

The more you know about transplantation the better. Ask as many questions as you need and work through all the aspects of how you and your family will cope with each of the steps along the way.

A list of contacts is available at the back of the booklet and on the website.

QKTS

Queensland Kidney
Transplant Service

A history of kidney transplantation at the Princess Alexandra Hospital (PAH)

The Queensland Kidney Transplant Service (QKTS) is based at the PAH in Brisbane and covers The Queensland Children's Hospital. It is the only kidney transplant facility in Queensland. It is one of the longest established, and largest transplant units in Australia. We are proud of our success rate, which is among the best in the world.

As of 2024, more than 5067 kidney transplants have been performed through the Queensland Kidney Transplant Service since 1969 and nearly 2702 people in Queensland are living with a kidney transplant. The first living related kidney donation occurred in 1981 and our numbers of living donor transplants continue to increase. Another milestone occurred in 2008, with the successful undertaking of blood group incompatible (ABOi) transplants and involvement in the Australian and New Zealand Paired Kidney Exchange Program (ANZKX).

The Queensland Kidney Transplant Unit has made a major contribution to research including many international trials of new anti-rejection medications as well as better ways of using the immunosuppressant medications. Improved immunosuppressant medication has led to more transplants being offered to greater numbers of people, and greatly improved transplant outcomes.



“We would like to respectfully acknowledge the Traditional Owners of the land on which the PAH is located, the Jagera and Turrbul people”



Kidneys

Our kidneys perform a range of important functions that we need to survive and include:

- The removal of waste products by filtering the blood to make urine. We measure the blood creatinine and urea as markers for how well the kidneys are functioning. High numbers mean that the kidneys are not able to clear these waste products. There are many other toxins that we cannot measure, but the build up of these substances is what causes people with kidney failure to feel unwell. After a transplant we will monitor the creatinine as a measure of how well the new kidney is functioning
- Balancing salt and water: kidney's control the balance of the body chemicals, including sodium, potassium and phosphate and the body fluids
- Controlling blood pressure
- Red blood cell production: the kidneys produce Erythropoietin (EPO)-which stimulates the production of red blood cells
- Bone health: the kidneys produce active Vitamin D that controls calcium absorption and helps keep the bones strong.

There are many reasons why kidneys can fail. Failure can happen gradually as the result of long-term disease such as polycystic kidney disease, or be a sudden onset. Without treatment, kidney failure is a life-threatening condition.

A transplanted kidney should be able to help with most of these essential functions.

Sources of kidneys for transplantation

Deceased donor transplantation

Most kidney transplants come from people who have died in hospital, and whose families have consented to the organs being donated for the specific purpose of transplantation. This type of organ donation is known as deceased donor transplantation. Your doctor cannot tell you about the donor or where your kidney has come from.

The history of the donor is carefully checked and tests are done before the organ is transplanted to exclude illnesses in the donor that could be passed on, such as infections like hepatitis B and C and HIV.

The donor kidneys are removed in the operating theatre and are flushed with cold solution and placed on ice in an esky. The kidneys are then safely transported to the operating theatre at the Princess Alexandra Hospital. Sometimes, a lifeport box, is used, see picture below.

The kidney is continuously flushed with cold solution through its blood vessels, allowing a longer time between retrieval of the kidney and the transplant operation. Kidneys can survive for up to 30 hours on ice but all attempts are made to get the kidney transplanted as soon as possible.



Sources of kidneys for transplantation

Living kidney donation

A large number of kidneys are donated by family or friends to people with kidney failure or who are approaching kidney failure.

Providing the donor is in good health, with 2 functioning kidneys and no extra risks for developing future kidney failure, donating a kidney is a safe procedure. Safety data, mainly from Sweden and the USA, suggest that as long as the donor is carefully assessed, the risks related to the procedure are small. Generally, donors move from having a lower risk of future kidney failure to about the same risk as the general population.

The work up usually takes about 3 to 6 months and is a very detailed assessment by the ‘team’ that includes transplant coordinators, kidney specialists, surgeons, psychiatrists and social workers. The assessment looks closely at the risks both in the short and long term and a number of tests and medical visits are needed. It is very important that donors have regular medical follow-up for the rest of their lives to check their blood pressure and kidney function.

On average, kidneys from living donors last longer. More information is available in the “Becoming a Living Kidney Donor” fact sheet.

Improved immunosuppressive medication and treatments that remove blood group antibodies, now allow donors and recipients with incompatible blood groups to have very successful transplants. More than 50 of these transplants have now been performed successfully by the Queensland Kidney Transplant Service. More information is available in the “Blood Group Incompatible (ABOi) Kidney Transplants” fact sheet.

Some donor and recipient pairs remain ‘incompatible’ despite the best available technology. These patients may benefit from taking part in the Australian and New Zealand Paired Kidney Exchange Program (ANZKX). Patients may contact either their kidney specialist or the live kidney transplant assessment coordinators at PAH for additional details. More information is also available in the “Australian Paired Kidney Exchange” fact sheet.

Sources of kidneys for transplantation

Who can be a donor?

The first kidney transplants performed were from living related donors who were closely tissue matched. Now that better immunosuppression medication is available, the level of matching is less important, and transplantation of genetically unrelated living donors is very successful. This includes partners and friends, who may not be related by blood but share a close emotional link with the patient.

For the recipient, having a living kidney donor has many advantages. The waiting time for the transplant can be shorter and the transplant can sometimes be done before you need to start dialysis. The operation can be planned for a time that is suitable for the donor, recipient and transplant team. The quality of the kidney is known and there is a better chance that the kidney will work straight away.



Transplant options

What is the best option for me?

As your kidney function declines, your kidney specialist and the dialysis education nurse will start to discuss your options with you. This will include information about dialysis and possibly transplantation. Not all kidney failure patients will be suitable to have a transplant.

The assessment process is very important. It takes some time to consider the suitability of transplantation for **you** and if you are suitable, what type of transplant may be right for you. It will involve:

- Education about the transplantation procedure and medications
- Consideration of the likely problems that may occur following transplantation
- Discussion of risks and benefits
- Consideration of the likely success of transplantation.

A kidney transplant is a major operation and involves long term ‘heavy duty’ immunosuppressant medications to prevent rejection. You will need to be in good health going into a transplant. Major complications do sometimes occur, and it is important that you are strong enough to manage what can sometimes be a challenging time in the post-operative period.

The assessment, often called ‘the workup’ involves checking your medical and emotional state to be ready for the transplant.



Transplant options

It is also important to consider the timing of transplantation. If you are fit and well and have a suitable living donor it may be possible to have a transplant without starting dialysis.

There are benefits related to this, including, avoiding dialysis access creation such as a fistula or peritoneal dialysis Tenckhoff catheter insertion. Occasionally, depending on your blood group it may be possible to have a transplant from the deceased donor list before starting dialysis, but this does not happen very often and you should not delay starting dialysis if it is needed.

Some patients become very unwell as their kidneys fail and their general health and fitness is poor. Those patients may benefit from a period of time on dialysis to regain their health and fitness and go into a transplant in the best possible shape. For some, finding out that they have a serious medical condition that involves major changes to the way they live and work, is a very challenging time that needs many adjustments. Putting off your transplant until you are 'ready' is a very sensible approach in these situations. That way you can then focus on making your transplant a success rather than struggling with many complicated issues.

Once you and your kidney specialist have decided that transplantation is a good option for you, it will be possible to consider what donor choices are available for you. If you have a living donor, then their workup can begin. We strongly recommend that they have a different doctor to you so that they can get independent advice about their risk.

If you do not have a living donor or your donor is unsuitable, then the deceased donor list may be an option. Access to the list is the same regardless of where you live in Queensland. If you live in Northern NSW it is possible for you to choose to be transplanted at the PAH but you will go on the New South Wales (NSW) list and the kidney will be sent to Brisbane when it becomes available.

Transplant options

You will need to have many tests during the transplant work up phase and then repeated while you are on the transplant waiting list. These include:



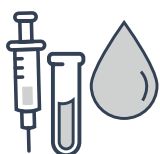
Heart tests. An echocardiogram is an ultrasound test of the heart which shows how well the heart muscle is pumping and if all the heart valves are working normally. This must be done once a year in all patients.

If you are over 60 years, have diabetes, have had kidney failure for a long time or have blood vessel disease, you will need to have a heart stress test. This will be repeated every 2 years.



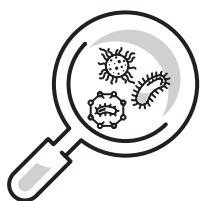
Blood vessel tests. If you are over 60 years, have diabetes, have had kidney failure for a long time or have blood vessel disease, you will need to have an ultrasound of the arteries in the abdomen, groin and in the neck.

HEP B & C

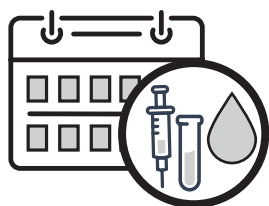


Blood tests for viruses. The tests for hepatitis B and C and HIV need to be repeated every year. You will need a test to see if you have ever had cytomegalovirus (CMV), Epstein-Barr virus (EBV - glandular fever), or Varicella virus (VZV - chicken pox).

VRE swab. Repeated every 6 months. VRE is a type of bacteria that is resistant to certain types of antibiotics.



Tissue typing. This information blood test determines your Immune status (HLA). More on this is in the section on tissue matching.

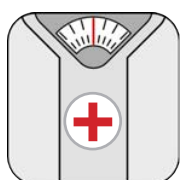


When you have been considered for transplant, you will need to provide a blood test every month which will be sent to the tissue typing lab. This blood sample is tested for any changes in your HLA antibody levels. This is important information when a donor kidney becomes available for matching. If the lab does not receive this blood within 60 days, you will not be considered for transplant.

There are many health issues that can increase the risk of problems after a transplant:



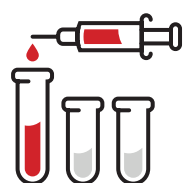
- **Diabetes** - this is related to many health problems, including blood vessel and heart disease and a higher risk of infections. Some of the immunosuppressant medications will increase your blood sugars and you will need more diabetic medication or possibly need to start insulin after the transplant.



- **Obesity** - being very overweight increases the technical difficulty of performing the transplant operation. There is also an increased risk of complications such as wound and chest infections. The transplant surgeons will carefully assess this at clinic to determine if it is possible to perform the transplant operation safely. They may give you a target weight.



- **Previous heart disease or stroke** - your history will need to be carefully reviewed to determine if a transplant operation is safe for you.



- **Blood vessel disease** - the surgeons must attach the new kidney onto blood vessels in the abdomen. In some patients these blood vessels are diseased or hardened. It is important that there is an area of vessel they can safely stitch into. The kidney uses blood that would have otherwise gone to your leg, and so if the blood flow to the leg is not very good, it may become worse after a transplant.
- **History of cancer** – we will need to go through the details of this with you and your treating doctor. In general terms the cancer needs to be ‘cured’.

It is important that all these tests are kept up to date.

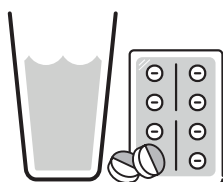
Transplant options



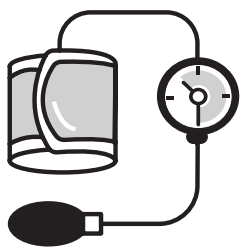
- **Active infection** - such as foot ulcers need to be healed before transplant, otherwise the immunosuppressant medications may make the infection more serious and difficult to treat.



- **Cigarette smoking or Vaping** - is associated with an increased risk of complications after transplant including pneumonia, wound complications and blood clots, and reduces the life span of kidney transplants. It also increases the risk of heart disease. You need to stop smoking or vaping for at least 3 months before being listed for transplant.



- **Non-adherence.** Transplantation is successful only because of medications that suppress the immune system. You need to take these medications, every day for the rest of your life. Missed tablets means an increased risk of rejection. Every year there are patients who reject their kidney and return to dialysis because they 'forgot' to take their medication or they ran out and did not refill their prescription. This is a tragic waste of a kidney that could have gone to someone else.



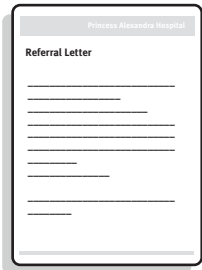
- **Low blood pressure** – some patients have very low blood pressure, and this can mean that a transplanted kidney will not recover after the stress of donation. Unless the blood pressure can be improved, this might prevent safe kidney transplantation.



- **Other serious diseases** that will impact on your survival or ability to have a successful transplant.
- **Patients who are generally frail** and have a **low level of fitness** often struggle greatly with the stress of a transplant.

Transplant options

What happens next



Your kidney specialist will send a referral as well as the results of various tests and investigations to the QKTS transplant team for review.

We will then ask you to come to the PAH Transplant Assessment clinic for review. You will meet the transplant assessment coordinator and nurses in outpatients and if you wish, have a look around the transplant ward. This way you can be familiar with practical issues like – how do I get to the PAH from the airport? Meeting some of the people who will be involved in your transplant and being a little more familiar with the surroundings when the time comes for the transplant does make it a little easier.

At clinic you will be assessed by one of the kidney specialists as well as a surgeon. This is a very detailed visit where we go through your medical, surgical and social history. We try to identify and explain specific issues that relate to you and your possibilities for transplantation as well as give you a general run through of the risks and benefits of transplantation. You will also see the social worker and pharmacist. This is a great opportunity to ask as many questions as you can think of. Write a list. Expect that the clinic assessment can take most of the day. Certain circumstances may need some individuals to have a psychiatric or anaesthetic review.

It is helpful if your support person comes with you. There is a lot of information to cover and it may help to have someone along to support you and ask questions relevant to their role as a ‘carer’.

Following clinic, some patients will then be activated on the waiting list or be booked for a live donor transplant. Some patients who are seen at clinic have health issues identified that need to be further investigated or treated. We may need you to come back for another visit. Some patients are assessed as not being suitable for transplantation based on a very high risk of the surgery, or likelihood that their health and quality of life is very likely to be worse following a transplant.

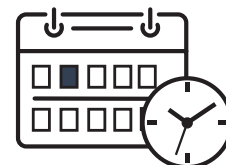
Transplant options

Activation on the deceased donor list

Once you become 'active' you will receive a letter in the mail to let you know that this has occurred. There are many important forms in the pack to review:

- Kidney Transplant Consent Form
- Fresh Blood and Blood Products Transfusion Consent Information
- Consent to Email Communication Form
- QKTS Contact Information Form
- Facsimile and Email Form
- Change of Address and Contact Details Form.

The call to come in for a transplant can come at any time now. The waiting time is variable – could be tomorrow – could be a couple of years, but you need to be ready.



1. Be sure the time is right

- Sometimes patients waiting for a kidney transplant have a change to their personal or family circumstances or general health after they become active on the list.
- This could mean that you are not so well placed to receive a transplant at this time and it might add distress or complicate your situation.
- If you think that you are not ready to be transplanted right now, please let either your local kidney specialist or the QKTS Coordinators know so we can discuss this further.
- If you are moved to the on hold list, this is okay. You do not miss out on any waiting time. Your waiting time starts from the day you start dialysis, not from when you are activated or reactivated on the list.

Transplant options

2. Be ready

- Have a plan for how you will get to the PAH and who will look after things at home while you are busy with the transplant.



3. Let us know if your contact details change and keep your phone on, always charged and with you at all times

- The call for the transplant can come at any time. It is often in the middle of the night but not always.
- We ring from a hospital phone. It will come up as **no caller ID** - Please answer

If you change your phone number – you must let us know

If we can not find you within 30 minutes, we will need to move on to the next person and you will miss out this time.



4. Provide other contacts for family or friends who will know how to find you quickly and let them know that we might call them if an offer comes up and we cannot find you



If you need to update your contacts or speak with us about being ready for a transplant please contact us on
(07) 3176 6963

Preparation for transplant

The wait for a deceased donor kidney is uncertain. Sometimes patients only wait a few weeks for their transplant while others wait for many years. It is important to be ready and stay ready during this time.

Patients having a living donor transplant will be given a date once the work-up is complete. Everything is done to keep to the scheduled date. However, sometimes things change, for example, you or your donor become unwell, or new information about your health comes to light.

Practical aspects

You and your family need to consider and make plans for your transplant and post-transplant stay. It can take up to 2 months and sometimes longer if complications happen. This is very important particularly if you live outside Brisbane. The social worker in your dialysis unit will be very helpful with some of these issues, that may include:

- How will you get to Brisbane? You can be called at any time day or night, on any day of the week, including public holidays.
- Have you registered for the patient travel subsidy scheme for travel and accommodation subsidy?
- Who will look after the children or the pets?
- Have you organised time off work, sick leave or recreational leave? Do you have the financial means to cover costs during the post transplant period?
- Who will be able to come to Brisbane after the transplant to be your support person?
- Special needs such as wheelchairs and diabetic testing equipment should be brought with you if possible.

Preparation for transplant

- You do not need to bring your PD machine if you use one.
- Learning difficulties, vision or hearing impairment: initially the learning curve can be steep. It is good if we know about any issues early, so we can help you in the post-transplant period.
- Your home and contents insurance should be up to date.
- Arrangements for the collection of mail, bill payments and access to money should be put in place.

If you can make plans for all these issues well in advance it may reduce some of the stress you feel at the time of your transplant.

Keeping fit and well

It is important that you are in good health at the time of your transplant. We would recommend:



- **Keeping healthy** for transplantation includes maintaining your dialysis schedule and being well dialysed. This means good fluid and blood pressure control and well controlled potassium and phosphate levels. Transplants may be cancelled or delayed for patients with high potassium levels or excess fluid. All infections must be reported, as it is very important that these are checked if necessary and treated quickly.

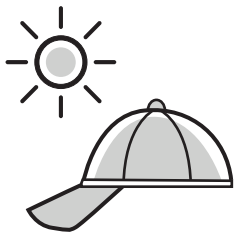


- **Maintaining target body weight.** Good diet and fluid control is essential when preparing for a transplant. Patients who are very obese may be excluded from transplantation because of their high risk of surgical complications like wound and chest infections.



- **Regular dental check-ups.** After the transplant you will be on medications that suppress your immune system and increase your risk of dental infections.

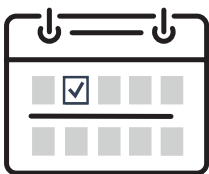
Preparation for transplant



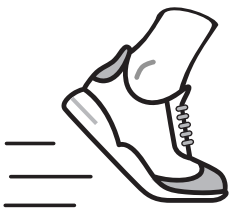
- **Regular skin checks.** Queensland has the highest rate of skin cancer in the world. The immunosuppressant medications will further increase your risk of skin cancers. Getting your skin checked and any suspicious 'spots' removed is a good idea. Also - protect yourself from any further sun damage.



- **Vaccinations.** Make sure all your vaccinations are up to date. It is recommended that you are vaccinated against Hepatitis B and Chicken pox (VZV). We recommend the flu vaccine every year (See vaccination fact sheet). We recommend you keep up to date with Covid-19 booster vaccinations.



- **Women need to make sure their cervical screening tests (PAP) and mammograms are up to date.**



- **Staying fit.** Having a transplant is sometimes hard work. Getting regular exercise and staying as fit as possible helps you recover faster from the transplant operation and gets you up and about much earlier. It also helps decrease your risk of developing diabetes after the transplant. Walk more! Use the stairs!



Preparation for transplant

Remain informed



Ask questions and seek out as much information as you can about your kidney disease and how transplantation might affect you and your family. The Transplant Unit regularly run education seminars and it is important that you attend one of these. For patients in remote regions you may be able to 'link in' via video conferencing from your kidney unit.

It can be very helpful to speak to other families who have experienced transplantation. Remember however, that the experience of transplantation is different for each person or family, and that whilst information from other transplant recipients and their families can be extremely helpful, your experience may be different, and you need to be prepared for any range of situations.

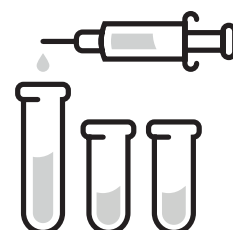


Tissue matching

Kidney matching between donor and recipient

It is important to check that patients will receive a compatible kidney from their donor. This is done by blood tests to check for:

- Blood group compatibility
- Tissue type ('HLA') matching
- Tissue type ('HLA') antibodies.



The compatibility of blood groups for transplantation is the same as for a blood transfusion. People of the same blood group can give to each other. Donors who are blood group O can give to anyone.

Recipient blood type	Donor blood type
A	A or O
B	B or O
AB	A B AB O
O	O

The tissue typing laboratory checks the tissue type ('HLA') of the donor and recipient. Each person is born with 6 major HLA types. HLA matching is a bonus, but with the immunosuppressant medication now available, it is not necessary to have a close match with your donor.

Some patients develop 'antibodies' to other people's tissue type ('HLA'). It can happen after a blood transfusion, a previous kidney transplant or during pregnancy. This is called being 'sensitised'. The tissue typing lab looks for tissue type antibodies against a potential donor's cells. This is called the cross match. If tissue type antibodies are present, then the transplant will usually not go ahead because the risk of rejection is too high.

Tissue matching

When patients are sensitised, they are more likely to have a positive cross match and they will need to find a donor who is more closely tissue matched. This is also why we recommend that, if possible, you receive immunosuppressant medication if you need a blood transfusion. If you do need a blood transfusion or have an old kidney transplant removed, it is very important that somebody tells us so that we can retest your antibodies.



It is now possible with the use of special technology to transplant the kidneys of patients who do not share the same blood group or who have a weakly positive cross match. Because the treatment needs to start in the weeks before the transplant, these techniques are only available for living donor pairs. Another option is the Australian and New Zealand Paired Kidney Exchange. If this applies to you, we will discuss the options when you come to the Transplant Assessment Clinic.

Deceased donor transplants - who gets the kidney?

Once the cross match has been done, the laboratory computer comes up with a list of compatible recipients. If there are any patients who have a very good HLA match, they are listed first. This is a bonus. If there are no good matches, the kidney goes to the person who has been waiting the longest. This will vary depending on blood group. The longest waiting time is for blood group 'O' recipients.

The allocation of kidneys is absolutely independent of factors such as where you live or dialyse.

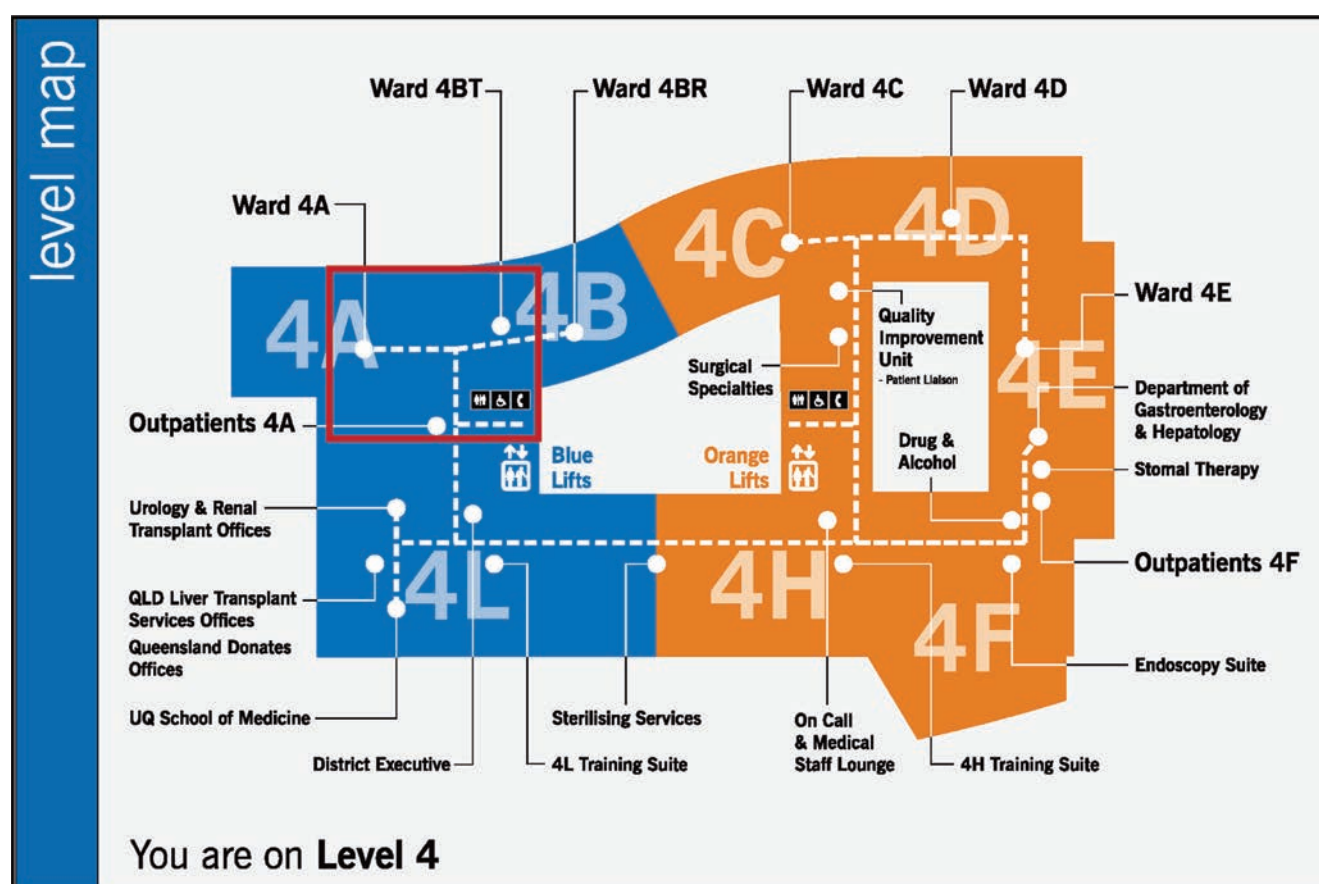
For further information on tissue typing please speak to your kidney specialist.

The transplant

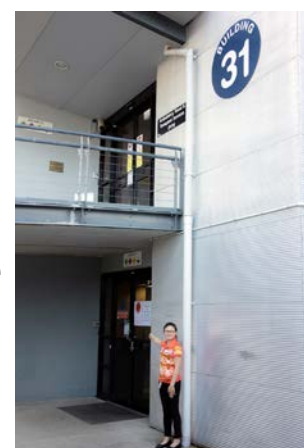
The Transplant Unit and outpatient areas



The PAH Transplant Unit 4BT is a 14 - bed ward, located just around the corner from the blue lifts, 4th floor, main building, building 1 of the Princess Alexandra Hospital. Each of the rooms on the ward has its own en-suite bathroom, and either 1 or 2 beds. There is a phone and television provided for each bed, and there are fees related to the use of these.



There is a small outpatients area, 4A outpatients, near the ward where transplant patients are reviewed daily for the first few weeks after their discharge from the ward. After the first few weeks, patients attend their outpatient appointments in the Ambulatory Renal Transplant Service Building 31 located just off Cornwall St. The same building where the transplant assessment clinic is held.



The transplant

The transplant team

The team of dedicated health professionals who work together to provide the highest quality care for both the transplant recipient and the family includes:

- Transplant assessment coordinators who ensure all assessments and work-up tests are completed, coordinate transplant clinics and are often the initial point of contact for patients needing information about transplantation.
- Physicians who provide medical care to maximise the function of your new kidney, adjust your medications and treat rejection or other medical conditions that may arise.
- Social workers and psychiatrists who together care for the psychological and social impact of the transplant on you and your family. The social worker may also be able to provide practical help with accommodation, travel and financial matters.
- Surgeons who perform the transplant and provide surgical care.
- Nursing staff who provide specialist nursing care and education for long-term kidney care.
- Physiotherapists who help with deep breathing and exercise after transplant, necessary to help prevent some of the complications of surgery
- Dietitians who help with adjusting your diet post-transplant.
- Pharmacists who provide education and help with medications.



The transplant

For patients on the deceased donor list, when you get a call offering you a kidney transplant, carefully listen to the instructions given to you. Some people will be asked to go directly to Admissions, or to the Emergency Department (ED).

A general anaesthetic is needed for the transplant operation



Do not have anything to eat or drink after you get the call unless you are told it is all right to do so.

Many people feel both anxious and excited at this time and find it difficult to think clearly about what to pack. It is a good idea to have a list prepared and maybe even a bag packed. Here is a checklist of items that you may wish to bring with you:



- Current medications or list
- Your diabetes monitoring equipment
- Warm loose fitting pyjamas and dressing gown
- Toiletries including soap, a toothbrush, toothpaste, hair shampoo and slippers, enclosed for safety
- Books and magazines to read.



Remember that for those patients who live outside Brisbane, it is likely that you will be in Brisbane for about 8 weeks, so it is important that you bring clothes to wear when you are out of hospital. A support person can bring the additional items down in the first week after the transplant.

The transplant

Arriving in the ward

The Transplant Unit, 4BT is on the 4th floor of the main building. Use the blue lifts.

The medical and nursing staff will meet you, check that you are medically fit for the operation and get you ready for theatre.



It is often a time of intense activity as your blood pressure, pulse, temperature, urine and weight will be checked. The doctors will talk to you about the transplant and any risks or issues that you have and go through the consent form which, you will need to sign.

Blood tests, a chest x-ray and an ECG, a tracing of your heartbeat, will be taken, followed by a shave, shower and you will be asked to change into a hospital gown. The doctors examine you to make sure that you are fit for surgery.

An intravenous line or drip will be inserted where your anti-rejection medications will be given before surgery. In some cases, a short dialysis may also be necessary.

It is important to know that sometimes the transplant operation may be cancelled. This may be because a problem with your health is found or that the donor kidney is unsuitable. This can be disappointing; however, it is very important that no unnecessary risks are taken that might seriously threaten your health or the chances of a successful transplant. If your transplant operation is cancelled, you will be able to return home when all the necessary medical details are attended to. You do not lose any 'waiting time' benefit.

Sometimes delays happen and this can be very frustrating, but it is critical that everything that needs to be sorted out and corrected, is done before the transplant operation goes ahead.

The transplant

Visitors and phone calls

Support from family and friends is an important part of helping you get through this emotional time. When you are first admitted, there is a great deal to be done in a very short amount of time. Therefore, while members of your family are welcome to stay and comfort you during this time, we ask that the numbers be limited to 1 or 2, so that staff can provide the best service.



While you are in the operating theatre, a nominated family member can ask general questions about your condition and progress, by calling the hospital switchboard on (07) 3176 2111.

For privacy reasons, only limited information will be provided. It is a good idea for 1 person to contact the hospital and then pass the information on to other family members. After a day or so, and when you are well enough, calls can be put through to the patient's bedside phone.

The operation

The operation usually takes 3 to 4 hours, but you will be away from the ward for much longer than that, usually 7 to 8 hours. Everything needs to be checked before you leave the operating theatre and return to the ward.

Once the pre-operative checks are finished and the anti-rejection medications have been started, you will be taken to the operating theatre. The operation is performed under a general anaesthetic. During the operation, a special intravenous drip called a central venous line (CVL) will be inserted. This is placed into a large vein in the neck and is used for giving fluid and medications. It is usually removed on day 4 after the transplant.

In addition, a catheter, a soft silicon tube is inserted into the bladder - its function is to drain urine from the bladder. This is to check how much urine the kidney is making. The catheter can irritate the lining of the bladder, sometimes giving the feeling that the bladder is not emptying and may be a little uncomfortable. The catheter usually comes out a few days after the operation.

The operation is performed through a cut in the lower abdomen just above the groin. The kidney has 2 main blood vessels, an artery where blood travels into the kidney before it is filtered, and a vein for returning filtered blood back into the circulation. Usually, the new kidney artery is joined onto the artery that provides the blood supply down the patient's leg. The kidney vein is joined to the main vein in the pelvis that carries blood from the leg.

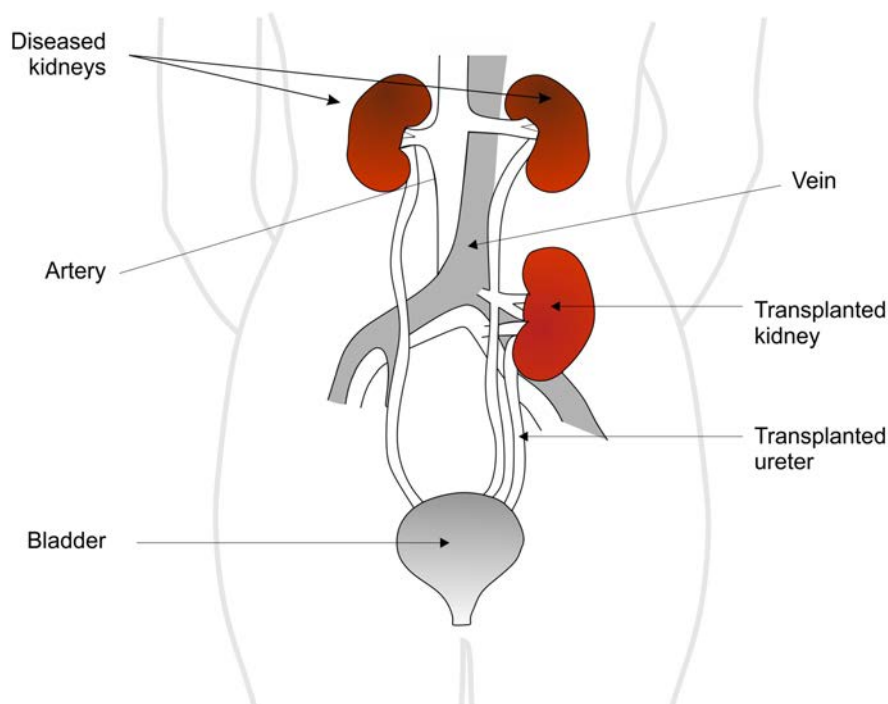
After the blood vessels have been joined, the ureter, that is the tube that carries the urine from the kidney to the bladder, is then joined to the bladder. A stent is a small plastic tube that is placed inside the ureter between the transplanted kidney and the bladder to help with this part of the operation. The stent reduces the chance of the ureter becoming blocked or urine leaking from the join between the ureter and the bladder. The stent is removed about 3 to 6 weeks after the surgery. This involves a second minor procedure using a telescope that is inserted into the bladder called a cystoscopy.

The operation

In male patients it may sometimes be necessary to divide the vas deferens, a tube draining the sperm from the testicle, on the side of the operation to enable the kidney to be positioned correctly. This results in a vasectomy on the affected side. The vas deferens on the side opposite of the transplant, however, is not affected and so fertility is usually preserved. It is important to tell the surgeon if you have had any damage or disease of the testicles.

Small plastic tubes or drains are inserted into the wound to ensure that blood or serum will not collect around the kidney. The muscles and skin are then closed over the kidney and the patient is transferred to the recovery area. The drains are removed a couple of days after the surgery. Your own kidneys are not removed.

You will be very carefully checked in the post-operative period. Keeping your blood pressure stable is very important to help the new kidney to work. You will be given intravenous fluids for 2 to 4 days and frequent blood tests are done to check your progress. The urinary catheter is usually left in the bladder for 4 days. Occasionally longer periods are required if the kidney continues to produce very large volumes of urine or in males with prostate enlargement. The drains are also left in for about this period of time.



After the operation

Pain relief is given intravenously for the first couple of days using a patient controlled analgesia (PCA) pump. After that, oral medication is usually enough to keep you comfortable.

You are usually up and about by the day after and starting to eat and drink.



About 80 percent of kidneys from deceased donors and 98 percent from live donors work immediately. In patients with delayed kidney transplant function, dialysis, either haemodialysis or peritoneal dialysis may be needed. The transplanted kidney has a great capacity for healing itself and almost always recovers well. This can range from a few days to a couple of weeks. You will be closely checked during this time and will probably need to have a transplant biopsy if the kidney does not work straight away.

During your stay in the ward you may feel excited, anxious, emotional, and in need of sleep, or all these things:

- You will have many nursing reviews
- Trips to x-ray
- Visitors
- Noisy neighbours
- Effects from the new immunosuppressive medications
- Receive information from many people from many ward rounds
- Learn fluid and medication needs
- It may seem a little overwhelming at times.

Always ask questions if you do not understand. No question is too silly. Your questions not only help you, but also help us to understand you and alter the care specific to your needs.

After the operation

On average, you will leave hospital on day 5 to 7 after the operation. This is a guide only and some patients will need longer to be ready to manage as an outpatient. The drains, catheter and central line are usually all out by this time. Occasionally, one or other of the tubes needs to stay in for a little longer. You will have learned all your medications and be able to drink the amount of fluid necessary to keep the kidney functioning well. You should be up and about and your pain well controlled.

The staff will continually ask you about whether your bowels are working! It is important that this is sorted out before you leave hospital.

Constipation is common after any operation, but is particularly important after a transplant because if your bowel is not working well, the transplant medications may not be as well absorbed.



After the operation

Outpatients

The next stage is 4A outpatients. You will be reviewed every day for the first few weeks post-transplant, including weekends and public holidays. Each visit takes 3 to 4 hours. The purpose of this visit is to check how the kidney is working and pick up any problems as early as possible so that they can be sorted out and treated quickly. We also check the wound, check your blood pressure, adjust your medications and follow up any other problems that occur.



This stage of the transplant is often the most difficult for you. Even if the kidney is working magnificently and you are feeling better than before the transplant, there are daily blood tests, and hours of waiting around for results and doctors' visits. You will often feel tired. You have just had a major operation! The medications are all new and some will have side-effects that you need to get used to. There may be stress felt if your new kidney is slow to function or blood tests are 'not quite right'.

You may need readmission or a kidney biopsy. This is where being as fit as possible pre-transplant will be an advantage. In addition, the doctors and nurses are always happy to listen to your concerns and frustrations. They are busy, but the psychological support post-transplant is very important. Remember to ask as many questions as you need.

At 2 to 4 weeks post-transplant your outpatient appointments will move to Building 31, Ambulatory Renal Transplant Services.

The visits will decrease to 3 times a week. We will continue to monitor the transplant function and adjust your medications. Some tablets will be stopped and others reduced. The urinary stent and Tenckhoff catheter, if you have one, will be removed.

After the operation

Outpatients

If you are normally looked after by a different hospital, plans to return home may now be made. On average, patients return to their usual kidney specialist at 2 months. Sometimes patients who have a more complicated time after the transplant need to stay at PAH for a longer period.

The first few months following a transplant are absolutely critical. This is when the risk of both rejection and infection is the highest. Problems can generally be sorted out with a good outcome, but getting through this period can be challenging, especially if you are away from home.

When you return home, we will send a report of your transplant to your doctors, kidney specialist and general practitioner (GP), so that they know all the events that have occurred. The nurses in outpatients will help you arrange this transition of care.

Patients who are 'high risk' for rejection or other complications, may need to come back to PAH on and off for follow up. This allows us to help your kidney specialist in giving you the best possible care and the best chance for a long term successful transplant.

We are happy to see you at any time if there are specific transplant issues that you would like to discuss.



Medications after transplant operation

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

Anti-rejection medicines

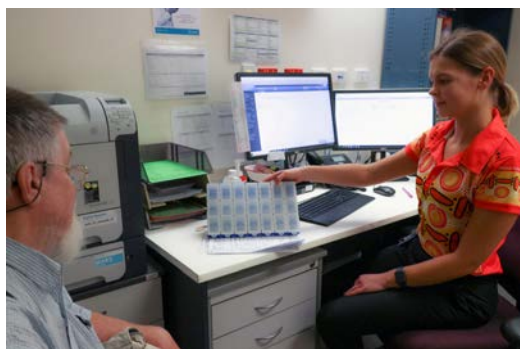
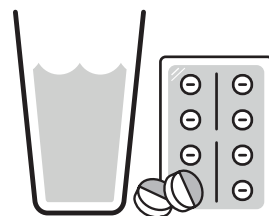
The most important group of medicines following a kidney transplant are those that suppress your immune system otherwise known as 'immunosuppressant' or 'anti-rejection' medicines. Without these your body would reject your kidney within a few days.

Our immune system protects the body against infection. It does this by recognising foreign material such as bacteria or viruses which cause infection. Your body releases a variety of chemicals and white blood cells to destroy them.

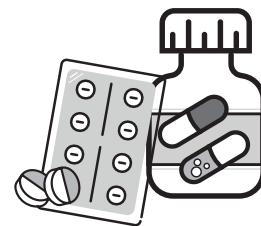
However, following a kidney transplant, your immune system will recognise your new kidney as being foreign, and will respond to destroy it, this is called 'rejection'. Therefore, we use anti-rejection medicines to prevent rejection of the kidney.

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

- Calcineurin inhibitors
 - Tacrolimus
 - Ciclosporin
- Anti-metabolites
 - Mycophenolate mofetil
 - Mycophenolate sodium
 - Azathioprine
- Corticosteroids
 - Prednisolone
- mTOR inhibitors
 - Sirolimus
 - Everolimus



Medications after transplant operation



Tacrolimus (Prograf® or Advagraf® XL)

Action

Tacrolimus helps to prevent rejection of your kidney by stopping white cells or T-cells from becoming active in your blood and attacking your transplanted kidney.

Dose

Tacrolimus needs to be taken twice a day, about 12 hours apart, at the same time each day.

The level of drug in your blood is tested regularly to make sure we are giving you enough to prevent you rejecting your kidney but not too much to cause toxicity.

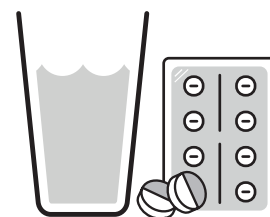
Due to this, your dose of tacrolimus changes regularly according to your blood levels.

You will start having blood levels taken every morning once you are discharged from the ward. You will be asked not to take your tacrolimus until after your morning blood test. The result of the tacrolimus level will not be known until late in the afternoon therefore you will be called each afternoon to be given your dose. After a few months, your levels should even out and change less often.

Food can also have an effect on the absorption of your tacrolimus. It can be taken with or without food but we advise that you keep it consistent, that is either always take it with food, or always take it on an empty stomach.



Medications after transplant operation



Tacrolimus (Prograf® or Advagraf® XL)

Possible side effects

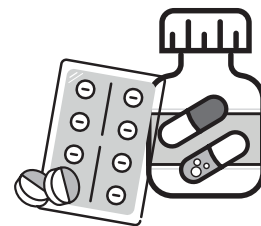
- Increase in blood sugar levels
- High blood pressure
- High cholesterol
- Tremor or shakes
- Tingling of the lips, fingers or toes
- Headache
- Blurred vision
- Hair thinning or loss

Tacrolimus can interact with a lot of other medications, including herbal and natural medications. Ensure you check with your transplant doctor or pharmacist before commencing any new medications.

Grapefruit juice can also increase the absorption of tacrolimus and increase the risk of side effects. **Do not eat or drink grapefruit** or grapefruit juice after your transplant.

Generic brands of tacrolimus are available. They may not be identical to Prograf® and you should not change brands unless you discuss this with your transplant doctor first. A long acting version of Prograf® called Advagraf® is also available. This is not the same as Prograf® and they cannot be interchanged.

Medications after transplant operation



Mycophenolate

There are 2 different formulations of mycophenolate available: mycophenolate mofetil and mycophenolate sodium. You will be prescribed one of these brands however they are not the same. Do not swap to another brand unless told by your doctor.

Action

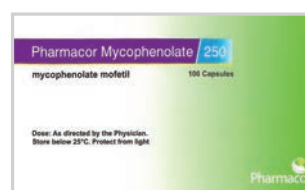
Mycophenolate helps to prevent rejection of your kidney by acting on the bone marrow to decrease the production of white blood cells that can attack transplanted organs.

Dose

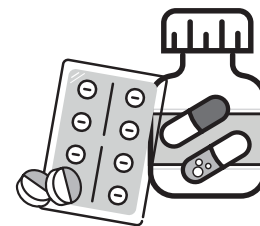
Mycophenolate is taken twice a day, about 12 hours apart, at the same time each day. It should be taken with food and swallowed whole.

Possible side effects

- Nausea, vomiting, diarrhoea
- Low white cell count
- Low haemoglobin
- Abdominal pain



Medications after transplant operation



Prednisolone

Action

Prednisolone decreases the body's inflammatory response and helps to prevent rejection of your kidney.

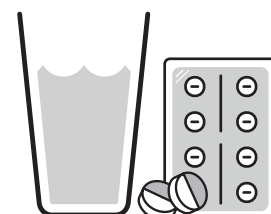
Dose

Your initial dose is based on your weight and height and will be slowly reduced over time, to reduce the risk of side effects. Prednisolone is available as 1mg and 5mg tablets. You will take this in the morning, preferably with food.

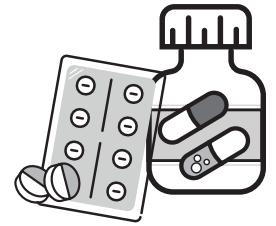


Possible side effects

- Increased appetite, which can lead to weight gain
- Increase in blood sugar levels
- Mood swings, nervousness, irritation or trouble sleeping
- Acne
- Thin skin and easy bruising
- Hot flushes
- Osteoporosis
- Cataracts
- Fluid retention
- Stomach upset or reflux



Medications after transplant operation information



Immunosuppression doses are slowly decreased in the weeks and months following the transplant to reach your maintenance level of immunosuppression. Sometimes your immunosuppression regime may need to be changed or reduced. However this should always be done under the direction of your kidney specialist. **You must never stop** your immunosuppressants **at any time**. Stopping your medicines will result in rejection, even years after your transplant, resulting in a return to dialysis.

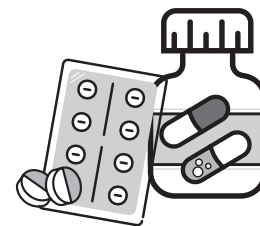
If you do develop side effects from your medication, you should contact your doctor as soon as possible. Please do not stop any of your medications without discussing with your kidney specialist. There are many alternatives available for the medications we use and it may be possible to find a combination that is more suitable for you.

Please note: If you are diabetic you may find that your diabetes becomes more difficult to control in the early period after the transplant. Some patients who do not have diabetes may develop diabetes after transplant as a result of prednisolone. This is more likely to happen if they already have an increased risk of diabetes because they are overweight or have a family history.

You will be on a number of other medications following a kidney transplant. As you will be immunosuppressed, you will need to take some medications to prevent infections. You will also need to take some other medications to limit the side effects of the anti-rejection medications.

After your transplant, you will have many changes made to your medication regime. Your new medication regime is vital to the success of your transplant, and will become an essential part of your life. You may no longer need to take many of the medications that you were taking before your transplant, but there will be a whole new set of medications to learn. This can seem to be overwhelming in the beginning, but the staff of the transplant unit will help you to learn about your tablets.

Medications after transplant operation information



A pharmacist will complete an education session with you before your discharge from hospital. During this session, they will provide you with information about all your new medications and teach you how to pack a weekly dosette box.

Drug interactions

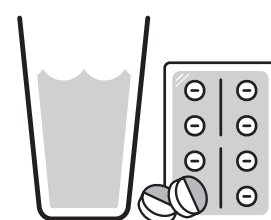
Many medicines can damage your new kidney or interact with your transplant medicines. This could lead to rejection of your kidney or increase the chance of side effects from your transplant medicines. This includes prescription medicines, ‘over the counter’ medicines, herbal and natural medicines. It is important that any doctor, pharmacist or dentist who is treating you knows that you have had a kidney transplant and which medicines you are on. No herbal or natural medicines should be taken unless discussed with your transplant doctor and the pharmacist.

How long will you need to take medication?

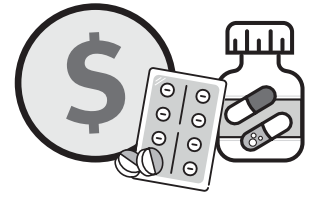
You will need to take anti-rejection medication for the life of your new kidney. Never stop taking your tablets even for a short time. If you do there is a high risk of rejection and you will be at risk of losing your kidney entirely or at least reducing its function. If you have missed a dose you must inform your clinic nurse or doctor as this may affect your blood levels.

What should I do if I miss a dose?

If you forget to take a dose, take it as soon as you remember unless it is time for your next dose. Do not double up on dose.



Cost and access to medication



Normal PBS prices apply:

- Non- concession patients pay \$30.60
- Concession patients pay \$7.70

Please note: These prices are subject to change each year

The PBS Safety Net threshold applies, ask your pharmacist for more information. Scripts can be organised through your specialist or general practitioner and supplies can be obtained from your local hospital or community pharmacy. Note: some medications are only available from your local Queensland Health pharmacy.



Possible problems

The transplant kidney will be able to fulfil all the usual functions of the kidney. You will feel better because the toxins are being removed. Anaemia, if you have suffered from this, will improve. It takes a few weeks after the transplant, usually you will not need to take Erythropoietin (EPO) any longer.



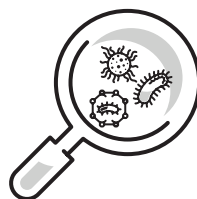
Salt and water balance

The new kidney takes a few days to weeks to settle in and maintain the correct salt and fluid balance. It is common to have oedema or swelling after the transplant and it gets better over a couple of weeks. Some kidneys cannot concentrate urine early on and patients pass many litres of urine. If so, it is important that you drink lots to keep up with the kidney. Dehydration can cause the creatinine to go up.

You will be weighed every day and for the first couple of weeks, the urine you pass will be measured. The doctors will give you a target amount of fluid to drink, usually about 3 litres but sometimes more. It is a big change from dialysis where you are constantly trying to limit the intake of fluids and run 'dry'.

If you were not passing urine before the transplant, the bladder can contract and only have a volume of 100ml. That means a lot of trips to the toilet if you are making 4 litres of urine a day! Also, you will pass urine day and night, therefore, you may expect a fair number of trips to the toilet overnight. Do not be alarmed. The good news is that this gets better fairly quickly and after a couple of weeks toilet trips settle down.

Possible problems



Rejection

This is the term used to describe the reaction of the immune system against the transplant. This causes deterioration in the kidney function.

Acute rejection is a type of rejection that occurs in the early period following transplantation, although it can happen at any time if you stop or miss your medications. It refers to a very rapid reaction of the immune system against the transplanted kidney. Usually it is discovered because the blood test shows a rise in the level of creatinine, a measure of kidney function. This is why you come to clinic so often. Most patients with rejection do not notice any physical changes or symptoms. If rejection is suspected, many tests are usually performed to confirm this and exclude other reasons that cause decreased kidney function. Scans of the kidney, as well as a biopsy, may be needed.

The biopsy is done using a needle with a local anaesthetic. The correct position in the kidney is identified by ultrasound. A small piece of the kidney is removed and is examined under a microscope. About 10 to 20 percent of patients will experience an acute rejection episode following their transplant. However, with treatment, over 90 percent of these can be overcome to allow continued function of the kidney. The treatment for acute rejection involves additional medications or plasma exchange for short periods of time.

High dose steroids are usually used for a first rejection episode, particularly if it is only mild.

Possible problems

Other medications and treatments for rejection are:

Plasma exchange is used when the rejection is caused by antibodies to HLA, it is possible to remove them with plasma exchange. This process is similar in some ways to haemodialysis. Blood is passed through a filter and the liquid portion which contains the damaging antibodies, the plasma, is removed and replaced with fresh plasma from the blood bank, protein and salt solutions that do not contain the harmful antibodies. Plasma exchange is usually given as a course over several weeks.

Anti-lymphocytic medications are prepared from animals and specifically destroy the lymphocytes that cause rejection. They are usually reserved for severe or recurrent rejection. ATG, Thymoglobulin and ATGAM can be used and are given intravenously for 7 to 14 days. The patient is usually admitted to hospital for the first few doses, although later it can be given as an outpatient. If you need this therapy, the doctors will go through the risks and benefits of these medications in more detail.

Chronic immunological damage or chronic rejection happens later and usually is not noticeable for several years following the transplant. It is a slower process and the reason why it happens in some patients is not well understood but may relate to having too little immunosuppression. You may need a biopsy to diagnose this and/or a change in your medications to treat it. Unfortunately, chronic rejection can be difficult to treat and it can lead eventually to loss of the kidney.

Possible problems

Infection

Because the immune system is suppressed to prevent rejection, transplant patients are more likely to get infections. You will be given medications in the early post-transplant period to try and decrease the infection risk. These medications include:

- Resprim which is taken lifelong to prevent a bacterial infection called pneumocystis.
- Valganciclovir or valaciclovir which is taken to prevent viral infections. The duration and dose is dependent on each individual patient but is usually temporary, anywhere from between 1 to 6 months.
- Amphotericin lozenges are taken for 1 month to prevent a fungal mouth infection called candida.

The increase in risk includes common viral infections that can just take longer to get better, but also unusual infections that are only seen in immuno-suppressed patients.

In the early post-operative period, you will be checked for wound infections, urine infections and chest infections.

It is important to use common sense and act quickly – if you have a temperature or a symptom of infection, it is important to seek help early.



Possible problems



Viral infections

We check before the transplant to see if you and the donor have had common viruses that include:

- Cytomegalovirus (CMV)
- Epstein-Barr virus (EBV) - glandular fever virus
- Varicella virus (VZV) - chicken pox.

Once you have had these viruses they will stay in the system and can become 're-activated' once you start on the immunosuppressive medications. The risk is highest in the early post transplant period when the medication doses are highest.

BK Virus

BK Virus is another virus that most people have as a child and does not cause any problems unless you take immunosuppressant medications. It also stays silent in the kidney and can become reactivated post transplant. BK does not cause any symptoms, but can cause kidney damage and is an increasingly common cause of transplant failure. It can be checked by blood tests and you will be routinely screened for BK after your transplant for the first 2 years when it is most likely to cause a problem.

CMV

CMV is most likely to cause problems early post-transplant so you will routinely take valganciclovir for 3 to 6 months to prevent CMV. If you have never had CMV and your donor has, you are in a high risk group for CMV. The most likely time that it will happen is after you stop the valganciclovir. The symptoms of CMV can be variable and they include general flu-like symptoms like lethargy, diarrhoea, cough and fever.

Possible problems

The doctors will often notice a drop in the white blood cell count or a change in the liver function tests. You will then be retreated with valganciclovir and the symptoms generally resolve. In more severe cases you will need to be admitted to hospital and treated with intravenous medicine.

EBV

If you have not had glandular fever and your donor has, the virus can be transmitted with the kidney. This generally does not cause a problem, but occasionally it causes a type of white blood cell cancer or lymphoma called post transplant lymphoproliferative disorder (PTLD). The risk to you if you are in this group is less than 1 percent. If you develop PTLD this is a serious complication, and you will need a decrease in your immunosuppression and chemotherapy or radiotherapy.

Chicken Pox

Shingles is a reactivation of the chicken pox virus and is more common post transplant. If you develop shingles it is important to seek medical advice so that treatment can be started as early as possible to decrease the severity of this painful condition.



Before your transplant, talk to your general practitioner about whether you should have the chicken pox or shingles vaccine, because it is not safe to have it after your transplant.

Other rare and unusual infections are increased in transplant recipients. **The key is to be aware of the increase in risk and be on the lookout for anything unusual. If you have a fever or symptoms of infection, seek medical help early.**



Dental prophylaxis is recommended, and it is advised that you are given a dose of antibiotics before any invasive dental work.



You should have the flu vaccine each year.

Possible problems

Diabetes

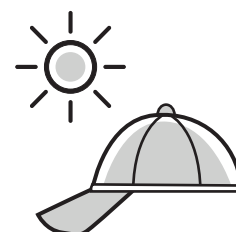
Diabetes is one of the most common post-transplant complications and it occurs in up to 25 percent of patients. You will be more at risk of becoming diabetic if you are overweight and/or have a family history of diabetes. Some of the immunosuppressant medications will promote high blood glucose levels or blood sugar, therefore the risk is highest in the first few weeks following the transplant when the doses of the medications are highest.



If your glucose level is high, you will be taught how to monitor the levels by using a finger prick blood test. If you develop diabetes, you will probably need medication and Insulin is often used in this period. Many patients will remain diabetic, even when the immunosuppressant medications are decreased.

Cancer

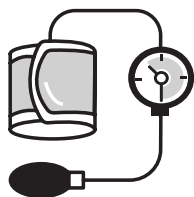
There is an increased risk of cancer developing after a transplant. In Queensland, skin cancer is a problem and transplant patients must take extra precautions in protecting their skin from the sun, before transplantation.



Regular checking of any skin lesions or spots is necessary, as treatment, either freezing or removal, may be needed. In addition to skin cancers, there is also a slight increase in white cell cancers or lymphoma compared to the general population. Other cancers including cervical cancer may also be more common, therefore female recipients must continue with cervical cancer screening.

Most of the common cancers, like lung cancer, breast and bowel cancer are a little bit more common than usual in transplant patients. Standard recommendations for screening for breast and colon cancer apply. If in doubt – check it out.

Possible problems



Hypertension

High blood pressure can continue to be a problem even with a successful transplant, so continued treatment with medications may be necessary. There is evidence that transplants last longer in patients with good blood pressure control.



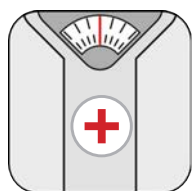
Heart Disease

Like all patients with kidney disease, the risk of heart disease is increased and it will be important to reduce these risk factors. They include smoking, high blood pressure, high cholesterol and diabetes.



Osteoporosis

In some patients, weakening of the bones or osteoporosis can occur. With the use of newer immunosuppressants, this is less common than in the past. Occasionally, severe arthritis or avascular necrosis, that mainly affects the hips, can be a problem and surgery may be necessary. It is recommended that you have a bone density scan before or soon after your transplant and then every 2 years after transplantation. If there is evidence of osteoporosis, then you may be given additional therapy to control or reverse this.



Weight gain

Once you have a transplant, there is greater freedom to enjoy the foods that may have been restricted before your transplant. You will feel better and your appetite will improve. This is a good thing up to a point! It is important that you enjoy a nutritious diet and regular physical activity as weight gain following a kidney transplant is common. The average weight gain in the first year after a transplant is about 6 to 10kg. It is worth remembering that being overweight increases your risk of diabetes and that it is always easier to put it on than take it off!

How successful are kidney transplants?

Kidney transplantation is a highly successful and well accepted treatment for kidney failure. Whilst not a cure, a kidney transplant generally allows a person to return to regular life, with a greater sense of well-being. It allows a life free from dialysis and the dietary, fluid, time and mobility restrictions related to it. In addition, it usually improves the various problems related with kidney failure, such as anaemia, infertility, fatigue, bone disease and in children; growth.

Currently, recipients of deceased donor kidneys have a 95 percent chance of having a functioning kidney after 1 year. Recipients of living related or unrelated kidneys have a slightly better chance with 97 to 98 percent having functional kidneys. The reasons that patients lose their kidney transplants in this first year are:

- **Technical factors.** Occasionally deceased donor and live donor transplant patients lose their kidney because of a surgical problem. It is usually due to blockage or thrombosis of the blood vessels. If this happens the kidney will not survive, and it will need to be removed. Problems that happen with the ureter, for example blockage or leakage can generally be repaired. However occasionally this also can cause loss of a kidney.
- **Rejection.** About 1 percent of patients lose the kidney due to acute rejection early after transplant.
- **Recurrent disease.** A small percentage of patients also develop the same disease in the transplanted kidney that damaged their own native kidneys. Sometimes if this happens, specific treatment can be undertaken. Some diseases are more likely to return than others. Atypical Haemolytic Uraemic Syndrome (aHUS) and Focal Segmental Glomerulosclerosis (FSGS) have a higher than average risk of recurrence, may be up to 50 percent risk and may happen quickly after the transplant.

How successful are kidney transplants?

- **If you have one of these diseases** then it is important to discuss the risks of recurrence either with your kidney specialist or the transplant unit. Other diseases such as IgA nephropathy often do return but usually this is a slow process and typically it does not cause a problem until more than 10 years out from transplant.
- **Death.** About 1 to 2 percent of patients die in the period following transplantation. This is due to either a heart attack or stroke or as a complication of a particularly severe infection. Obviously, this risk is higher for older patients, and those with known heart or vascular disease.

If the transplant fails, patients return to dialysis. The transplanted kidney is often removed so that the immunosuppressant medications may be discontinued.

Whilst most kidney transplants are successful and recipients and their families report a much improved quality of life; transplants can be also difficult for some recipients.

The first few months after the transplant can be 'hard work'. Some problems can be expected and discussed before the transplant. These include problems like increased risk of wound infections in patients who are obese.



How successful are kidney transplants?

After 1 year

After 1 year, there continues to be a small number of patients who lose their kidneys. Reasons for this happening are usually:

- **Acute rejection** that usually happens because patients are not on enough immunosuppressant medications. This can happen if patients 'forget' to take their tablets or run out and do not refill their prescription. It can also happen if they are not able to take their medication through illness. In addition, if patients have severe vomiting or diarrhoea the medications may not be absorbed properly. It is important that you seek medical help quickly if you think this may be happening.
- **Chronic rejection** is the most common cause of kidney failure and happens over several years and is the reason why it is so important not to miss your transplant immunosuppressant medication. Also:
 - Avoid smoking.
 - The treatment of high blood pressure.
 - High cholesterol levels are also important to avoid as they may cause the decline in kidney function.

Return of your original kidney disease can sometime occur and may result in the loss of the kidney after a few years, although this only happens with a few kidney diseases such as IgA nephropathy and other types of glomerulonephritis.



Transplant recipients have a higher risk of dying from heart attacks and strokes than the general population, although this risk is lower than for patients on dialysis. In the later years after transplantation the risk of dying from cancer increases, especially the risk of skin cancers.

How successful are kidney transplants?

Non adherence

This term is used where patients do not follow the medical advice of the transplant treating team. Usually this involves not taking the medications that have been prescribed, but also includes not attending follow-up appointments. This is one major reason for patients losing their kidney after leaving hospital. Non-adherence can result in several problems, although acute and chronic rejection is the most common. It is a problem in adolescent and young adult patients.

Taking medication is not negotiable. Patients who are prepared to accept a donor kidney, as a means of treatment for their kidney failure must accept that taking medication is essential. Not only does medication improve your chances of a successful transplant outcome, but it is also a significant mark of respect to your donor, whether live or deceased.

Your doctors will only prescribe what you absolutely need, therefore, it is really important to take what has been prescribed. It is essential that you talk openly with the treating team, so that if major side effects are being experienced, other medication may be prescribed, where possible. If a transplant is lost from non-adherence, it may not be possible to re-list you for another transplant.

Overall, if a kidney is functioning at 1 year, a transplant recipient would have a 70 percent chance that it will still be functioning after 10 years. Kidneys do eventually 'wear out', but there are recipients with grafts that have been functioning 20, 30, 40 years or longer.

Patients can have more than 1 kidney transplant in their lifetime. Occasionally a patient may have up to 4 transplants when they have had kidney failure from childhood. The first transplant is usually the easiest and every effort should be made to make it last as long as possible.

The people who remember to take their tablets all the time are the ones who stay off dialysis the longest!

Research studies



You may be asked to take part in a research trial when you come for your transplant. Trials are done to try and improve the health of transplant patients and learn about new therapies. All the current treatments we use now are based on research done in the past. Studies may involve learning about what causes infections like BK virus to be a problem after transplant or testing new medications that may have fewer side-effects. The studies are approved by the Transplant Unit and a Research Ethics committee. The details will be discussed with you in detail and often you will be sent a copy of a study when you join the transplant list.

Carefully consider if you would like to be involved. The doctors and nurses will discuss the pros and cons, and you and your family will have the opportunity to ask questions about what is involved.

Involvement is completely voluntary and your care is **not** altered by whatever you decide. You can be withdrawn from the study at any time either because you wish to stop your involvement or because your doctors think it is in your best interests to withdraw from the study. Your privacy is always respected and no personal details are ever made public.

ANZDATA

Australia and New Zealand dialysis and transplant registry collects information about patients and their treatments for kidney failure. It has been collecting national data since 1963 and is an important way for us to compare our results with other units and to make sure that we are providing the best quality care possible to our patients.

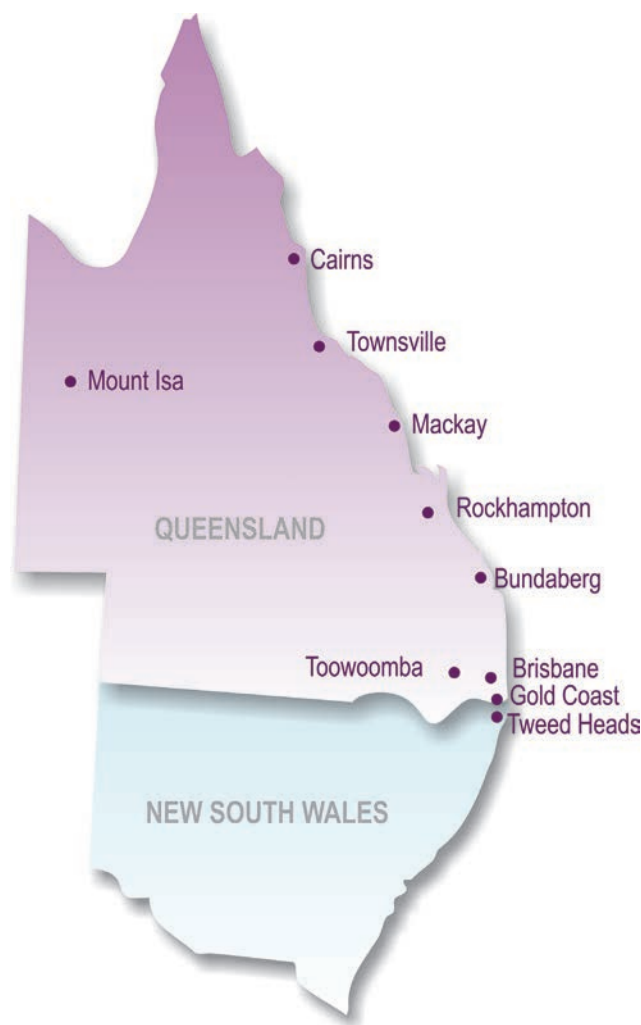
Further information see web address: www.anzdata.org.au/anzdata/

Practical considerations

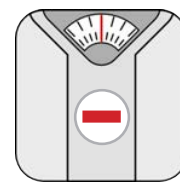
Patients from regional or interstate areas will need to arrange to have this 2 month period in Brisbane. It is a good idea where possible, to arrange for a family member or friend to stay with you, especially during the initial 2 to 4 weeks, after you are discharged from the ward. This is to help with daily living activities, including transport, shopping, meal preparation and washing.

After 2 months, many patients may be referred back to their own kidney specialist. Patients are usually fit to return to work after this time. In a very small percentage of cases serious complications may arise that will need lengthy hospitalisation, up to 3 months or more.

A successful kidney transplant will keep the patient well for many years. Therefore, the patient and family will need to be prepared to make a financial and emotional commitment during this early period to ensure the best possible outcome. While you were on dialysis you would have been given guidelines for looking after yourself and for maintaining your health. After your transplant you will be provided with a **Kidney Transplant Patient Folder** with relevant information.



Practical considerations



Diet

In the short term, recovering from your operation and getting back on your feet is the main priority. Once everything has settled down and your transplant is working well, getting back into a healthy lifestyle, with a balanced diet is important.

Some of the long term dietary challenges that may develop following a kidney transplant may include:

- Excessive body weight gain
- High blood cholesterol levels
- High blood glucose or sugar levels

To help in the management of dietary issues, remember that a healthy lifestyle can be achieved in many ways.

- Try getting involved with some regular exercise, like going for a walk!
- Enjoy a wide variety of nutritious foods
- Eat plenty of vegetables, fruits and wholegrains
- Eat a variety of healthy protein sources including fish and seafood, lean meat and poultry, legumes, tofu, nuts and seeds
- Choose reduced fat dairy such as unflavoured milk, yoghurt and cheese
- Choose water over sugar sweetened beverages such as fruit juices, cordials, soft drinks, sports drinks, energy drinks and flavoured milks
- Take-aways and eating out should be a special treat rather than an everyday occurrence
- Limit your intake of refined sugars and added salt
- Use herbs and spices to flavour foods instead of adding salt
- If you drink alcohol, do so in moderation
- Drink plenty of water every day: check with your doctor if you are unsure of your recommended amount
- Care for your food: prepare and store safely.

Practical considerations

Fluids



You will still have to watch your fluid intake after your transplant. The goal is to keep up with the set fluid target given to you by your doctor and not drink too much **or** too little. Both can be equally dangerous to your new kidney. It will also be necessary for you to spread your fluid intake evenly over the day.

This will include having at least 1 or 2 drinks overnight in the early period after the operation. During the first few months following the transplant you may pass a lot of urine during the night. On hot days or if you are exercising, you will need more fluids.

Exercise



It is hoped that all patients receiving a transplant can restart a normal and active lifestyle. Although body contact sports are not recommended, participation in sporting activities is encouraged and it is suggested that some form of regular exercise is part of your normal routine. Walking is ideal and 3 or 4, half-hour walks at a brisk pace per week should be undertaken, if possible.

Dehydration should be avoided during all forms of exercise. This would include avoiding the middle of the day in summer months and having ready access to water or other fluids during, or immediately after exercise.

Practical considerations



Fertility and pregnancy after a kidney transplant

Key points

- Fertility, the ability to fall pregnant, improves quickly after transplantation
- Some common transplant medications are not safe in pregnancy - this means it is important to use effective contraception after your transplant
- Many patients can have a successful pregnancy after transplantation - the outcomes are better if pregnancy is planned, so that your medications can be adjusted to medications that are safe in pregnancy
- Talk to your kidney specialist for more information.

Information for female transplant recipients



What are my chances of getting pregnant?

Fertility is reduced in patients with severe kidney failure or who are receiving dialysis. Receiving a kidney transplant usually improves fertility rapidly, as well as increasing the chance of having a successful pregnancy. However, the chance of getting pregnant after a kidney transplant remains a little lower than the general population.

Are transplant medications safe in pregnancy?

Some of the tablets that you will be prescribed after a kidney transplant can cause problems in pregnancy. This means that it is really important to use effective contraception after your transplant, and to talk to your doctor early if you are thinking about pregnancy so that they can discuss the options for changing your medications with you. Never stop taking any of your medications without talking to your doctor, as this could result in rejection - which may damage your kidney and make it more complicated to have a pregnancy in the future.

Transplant medications in pregnancy

Usually safe to continue while pregnant

- Tacrolimus (Prograf)
- Ciclosporin (Neoral)
- Prednisolone
- Azathioprine (Imuran)
- Some blood pressure medications:
 - Labetalol
 - Methyldopa
 - Nifedipine

Not safe in pregnancy

- Mycophenolate (Myfortic or Cellcept)
- Sirolimus (Rapamycin)
- Everolimus (Certican)
- Valganciclovir (Valcyte)
- Cotrimoxazole (Bactrim/Resprim)
- Some blood pressure medications:
 - ACE-inhibitors
for example Perindopril or Ramipril
 - Angiotensin receptor blockers
for example Irbesartan or Candesartan

What contraception can I use after kidney transplantation?

Most forms of contraception are suitable after a transplant – the most effective are the ones that you cannot forget to use! Good options include:

- Mirena device – intrauterine device (IUD) containing levonorgestrel that is inserted into the womb by a doctor; effective for 5 years but can be removed if you want to become pregnant
- Implanon - a soft plastic stick containing Etonogestrel that is inserted under the skin by a doctor; effective for 3 years but can be removed if you want to become pregnant
- Progesterone depot intramuscular injection – effective, but needs to be repeated every 12 weeks.

The oral contraceptive pill is safe to use from 1 month after transplant, but has a failure rate of 0.3 to 9 percent per year depending on how regularly they are taken. Patients who have had a thrombosis, a blood clot in a leg, deep vein thrombosis, or lung, pulmonary embolus should avoid taking the oral contraceptive pill. Condoms provide additional protection from sexually transmitted infections as well as contraception, but have a high failure rate for pregnancy, 2 to 18 percent per year. Your kidney specialist can discuss which contraception options would be best suited to you, and refer you to a general practitioner or specialist if necessary.

When is it safe to get pregnant after a kidney transplant?

The risk of rejection and other problems is highest in the first 3 to 6 months after a transplant. It is best to wait until your transplant and general health are stable before trying to get pregnant. This is so that you have the best chance of having a successful pregnancy, and to minimise the risk of problems with your transplant during the pregnancy. The usual advice is



to wait at least 1 year after transplant, and 6 months after any treatment for rejection. It is also important to delay pregnancy if you have cytomegalovirus (CMV) infection, as this can affect the developing baby.

How successful are pregnancies in kidney transplant patients?

The chance of having a good outcome from pregnancy depends on how well your kidney transplant is functioning, as well as your general health. In kidney transplant patients with good kidney function, the possibility of a successful pregnancy is similar to the general population. However, the chance of experiencing problems during pregnancy is higher if you have a transplant, including an increased risk of:

- Early miscarriage
- High blood pressure during pregnancy
- Pre-eclampsia
- Having a baby that is born early, or has a low birth weight
- Needing a caesarean section to deliver the baby
- Getting urinary infections during pregnancy.

The risk of some problems in pregnancy can be reduced – for instance by taking a low dose of aspirin during pregnancy.

Your kidney specialist can discuss your personal risk factors with you, and may refer you to a pregnancy specialist or obstetric physician for further advice and counselling. Sadly, there are a small number of kidney transplant patients who would be at high risk of having a bad outcome from a pregnancy. This may mean that they are at high risk of developing other health problems during pregnancy, or that the chance of a successful pregnancy would be extremely low. In this situation your medical team may advise you against getting pregnant.

Will pregnancy affect my kidney transplant?

If your kidney transplant is functioning well, pregnancy does not seem to reduce transplant survival compared to other kidney transplant patients. However, your transplant kidney does have to work harder during pregnancy, and some patients may experience a fall in their kidney function after pregnancy, which may be permanent. The chance of this happening is increased if your transplant function is reduced. This is if your creatinine results are high, you have high blood pressure, or there is an increased level of protein in your urine.

Information for male transplant recipients

Is it safe for my partner to get pregnant if I have had a transplant?



Men who have had a kidney transplant usually experience an improvement in sexual function. Sperm counts and libido increase, and the chance of experiencing erectile dysfunction goes down. If you continue to experience problems with achieving or maintaining an erection – let your kidney specialist know – there are treatment options for example Viagra (Sildenafil) that are usually very effective.

Some of the medications you may be prescribed after a transplant can affect your sperm, so it is important for male transplant patients and their partners to use effective contraception after transplantation:

- Valganciclovir or Valcyte – you will usually take this for the first 3 to 6 months after transplant, and should use contraception until you have stopped taking it for at least 90 days.
- Sirolimus or Rapamycin and Everolimus or Certican – these medications can reduce your sperm count. If you are thinking about starting a family, talk to your kidney specialist about the risks and benefits of changing to an alternative medication.
- Mycophenolate or Myfortic and Cellcept – there is a very small chance that this medication could affect sperm, so some patients choose to switch to another medication if their partner is intending to get pregnant. However, this risk must be balanced against the increased chance of experiencing rejection if you change medications. For most transplant patients, it is likely to be better to continue to take Mycophenolate – discuss with your kidney specialist.

Aboriginal and Torres Strait Islander Health Care Worker - Kidney and Transplant Services

Supporting patients, families and/or carers whilst being treated by Queensland Kidney Transplant Services and Metro South Integrated Kidney and Transplant Service.

Princess Alexandra Hospital (PAH)– Kidney Department

The Metro South Integrated Kidney and Transplant Service is a part of the Division of Medicine and provides kidney specialist services in a number of locations including:

- Kidney transplantation throughout Queensland and Northern NSW
- Dialysis services to PAH, QEII, Logan and Redland Hospitals
- Darling Downs and inpatients needing care at PAH, cardiac services and liver transplantation.

Our services include:

- Ambulatory Kidney Services - Multidisciplinary CKD clinic
- Kidney Transplant Clinics and Dialysis Access Surgery Coordination
- Peritoneal Dialysis, Home Haemodialysis, In-Centre Haemodialysis Units, including High-Dependency Haemodialysis.
- 2 satellite Haemodialysis Units at Redland and Logan
- Inpatient Kidney Ward, 4BR and Kidney Transplant Ward, 4BT.

Aboriginal and Torres Strait Islander Health Care Worker

The Health Care Worker helps with correct kidney care support to patients and their families by:

- Working with patients, carers and staff to deliver culturally appropriate care plans.
- Helping with the patient's journey right through to discharge planning to reduce the stress and anxiety for patients.
- Attending pre-transplant assessment clinics with patients.
- Supporting the correct service delivery and identifying opportunities for improvement.
- Helping with extra support services to reduce stress.

Aboriginal and Torres Strait Islander Health Care Worker - Kidney and Transplant Services

- Improving the health education of patients and their families
- Talking with health providers, Health Workers and Aboriginal and Torres Strait Islander medical services.
- Taking part in multi-disciplinary team meetings for patients along with weekly meetings, discharge planning and case conferences.
- Ensuring services are culturally respectful and safe.
- Helping communication between patients, their families and hospital staff.

How to contact the Kidney Health Care Worker

All referrals should be made by phone or email to:



Brett Mooney

Aboriginal and Torres Strait Islander Health Care Worker - Kidney

Email: brett.mooney@health.qld.gov.au

Mobile: 0436 859 954

Purpose of the role

The Health Worker is a valued and respected member of the Kidney team. The role is to support and encourage Aboriginal and Torres Strait Islander peoples to access culturally appropriate Kidney Health Services across Queensland. Through clinical yarning and collaboration, the Health Worker supports a culturally safe environment for all patients (mob) and staff.



Further information

Below are important contact details and external organisations you may wish to contact for further information.

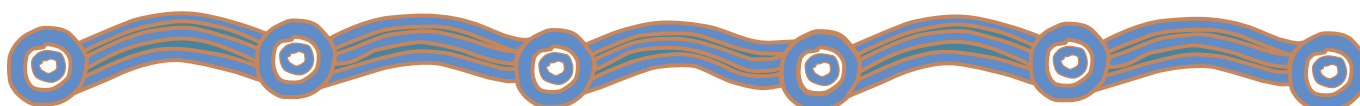
- Queensland Kidney Transplant Service
www.qld.gov.au/health/services/specialists/kidney-transplant
- Kidney Health Australia
Free call: 1800 682 531
www.kidney.org.au
- Kidney Support Network
Free call: 1800 358 797
www.ksn.org.au
- Medicare Australia
www.medicareaustralia.gov.au/public/services/scripts/pbs.jsp



Important contact details

To discuss anything you have read or heard, we encourage you to contact

- Queensland Kidney Transplant Service Coordinators
Phone: (07) 3176 6963
- Social Work for Transplant
Phone: (07) 3176 7180
- Aboriginal and Torres Strait Islander Liaison Service
Phone: (07) 3176 7073
website: <http://paweb.sth.health.qld.gov.au/clinicalsupport/atsi>
- Aboriginal and Torres Strait Islander Health Care Worker - Kidney and Transplant Services. More information please go to page 64.
Mobile: 0436 859 954
- Ambulatory Renal Transplant Services, Building 31
Phone: (07) 3176 2615
- 4BT Outpatients
Phone: (07) 3176 5133
- Transplant Ward
Phone: (07) 3176 2646
- PAH Travel Office
Phone: (07) 3176 5011
- Princess Alexandra Hospital
Phone: (07) 3176 2111



Important names and phone numbers



Name: _____

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Date created: June 2023
Review date: June 2026
Brochure no. PIB1070/v1

Princess Alexandra Hospital Campus Map



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



Queensland
Government