



The Prince of Wales Hospital
& Community Health Service

Kidney Transplants

Information for patients



Health
South Eastern Sydney
Local Health District

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Introduction

Welcome to the East Coast kidney transplant program. We are here to support you. The East Coast transplant program is made up of Prince of Wales, St. George, Wollongong, Sydney Children's and St Vincent's hospitals. All kidney transplant for the East Coast kidney transplant program take place at Prince of Wales hospital in Randwick.

Our 'transplant' team includes doctors, nurses, social workers, pharmacists and a dietician. Our team will explain what kidney transplant options are available, what is involved in a kidney transplant and can help you decide what option is best for you. You can talk to the Transplant Coordinator at St George Hospital on 02 9113 4205.

The information in this booklet explains

- the benefits and risks of a kidney transplant
- the different types of kidney donors
- what will happen at each step along the way, and
- how to look after yourself after a transplant.

Making a decision

What are the benefits of a kidney transplant?

There are many reasons why some people decide to have a kidney transplant.

It is important to realise that a kidney transplant is not a cure for kidney disease, but that it is another form of treatment.

If you decide to go ahead with a kidney transplant there are a range of potential benefits, although we cannot guarantee this will be the case for you.

If your kidney transplant is successful you will

- avoid the need for dialysis
- improve your quality of life
- improve your blood count and energy level
- improve your bone strength, growth, and appetite, and
- have fewer dietary restrictions.

If you have end stage kidney disease a kidney transplant is likely to prolong your life compared to staying on dialysis.

What are the alternatives to having a kidney transplant?

If you or your transplant team decide that a kidney transplant is not the best option for you right now, you will continue with your current dialysis routine. If you are offered a kidney transplant but say no, you can change your mind in the future.

What are the risks of having a kidney transplant?

A kidney transplant is not always the best option. It is very important that you are aware of, and understand what risks are involved in having a kidney transplant. Some of the risks are described below. You will need to talk to the transplant team about what options are available for you. They can also answer any questions or concerns you may have.

The following are the main risks with having a kidney transplant.

1. You may need to have blood transfusions. You will be asked to sign a consent form giving us permission to give you a blood transfusion if it is necessary. In most cases, a person with kidney failure will have a low blood count and will not be able to donate their own blood for use during surgery. The risks of receiving blood transfusions include infection, allergic reactions, and side effects from the preservatives added to the blood.
2. You may have problems with how well your wound heals. You may have fluid leaking from your wound. Most of the time we are able to stop this with bandages. A small number of patients can suffer bleeding, infection, urine leakage or a hernia which may require an additional operation. You may have some pain where your wound is, but this usually decreases within a few weeks. If the pain lasts longer than this you will be given more medicines. You may also find you have no feeling in the area around your scar.
3. After your transplant you will need to take medicines to prevent your immune system rejecting the kidney. You will need to take these medicines for as long as you have this kidney. These medicines may cause serious and potentially life threatening complications. The most serious complications include infections, certain types of cancers, kidney failure, and damage to your nervous system. We will closely monitor your medicines. These

medicines may also cause side effects, including:

- increase your blood pressure
- increase the chance of developing diabetes
- increase your cholesterol levels
- weaken your bones
- affect your bone marrow, and
- have some cosmetic side effects such as facial swelling, acne, excess hair growth or hair loss.

More serious complications occur in less than 10% of our patients.

These include, but are not limited to:

- failure of the transplant to work properly
 - recurrent disease in the transplanted kidney
 - infections such as pneumonia
 - transmission of a disease from the organ donor
 - blood clots in large veins
 - damage to nerves, blood vessels, intestines, or reproductive organs
 - multi-organ failure
 - heart attack
 - stroke
 - cancer
 - death
4. It is possible that either an infection or a cancer was present in the donor and was not diagnosed before transplant. There have been very rare reports of this occurring. It is important to know that all donor organs, even those from living donors, can transmit infections such as human immunodeficiency virus (HIV), hepatitis B virus (HBV), hepatitis C (HCV) or malaria. Potential donors are extensively screened for these diseases and all donors' health histories are reviewed prior to being accepted as donors to reduce the risks of a disease being transmitted. Even with these precautions, serious infections or an unknown cancer can be transmitted to the organ recipients. These risks are common for

all organ transplants.

5. After having a transplant, you may experience depression, Post-Traumatic Stress Disorder (PTSD), generalized anxiety, anxiety about being dependent on others and feelings of guilt. These problems may interfere with your relationships with your family or friends and may require treatment with medicines. Having a kidney transplant may cause problems returning to work, obtaining future employment, and getting insurance. These problems may require treatment with medicines or counselling.

There may also be other rare or unforeseen problems that could occur.

Types of kidney donors

Research and our experience tells us that we will get the best results when a kidney is received from a living person.

If you are considered a suitable candidate for a kidney transplant operation, you will be placed on a national waiting list to receive a kidney from someone that has died. The average waiting time is between 3-5 years. How long you will need to wait will depend on your blood group and the type of donor you are prepared to accept. The Australian Organ Matching System (AOMS), under contract with the federal government, decides who gets a kidney when it becomes available. It may take many years before a suitable organ becomes available and is influenced by the ability to match your tissue with the donor, how long you have been waiting and antibody levels in your blood. Children may be a priority.

Many people that die have some diseases that could affect the kidneys, such as smoking, high blood pressure, infection, diabetes, or old age. The damage to the kidneys may be minor and can occasionally be fixed. Some organs may have vascular anomalies or very small blood vessels that could increase the potential for problems at the time of transplantation.

If you do not want to accept the additional risks associated with the use of a kidney that shows signs of disease or damage, you should let your doctors know. This decision could mean that you will have to wait substantially longer to receive a kidney transplant.

While you are on the waiting list, your body functions may deteriorate due to the effects of kidney failure or other diseases. Your transplant team will organise for you to have tests regularly to monitor how kidney failure is affecting your body. They will also organise an annual medical review to determine whether you are still suitable for a kidney transplant. It is possible that you may die before a kidney transplant is performed if the risk of having a transplant is considered too high, or a kidney transplant is no longer considered a suitable option for you.

What type of donor are you prepared to accept?

The quality of the donor organ can have a significant effect on the outcomes of a kidney transplant. The risks and benefits of the different types of donors are described below. You should discuss this information with your kidney doctor

1) Living donor kidney

yes no

A kidney from a living donor, who has two functioning kidneys and no medical evidence of kidney disease. In some cases, one of the kidneys may have multiple blood vessels, a urinary collecting system different to normal, history of a kidney stone, history of mild high blood pressure, history of potential exposure to an infectious disease or a medical condition that could potentially increase the risk of kidney transplantation.

2) Standard criteria deceased (SCD) donor kidney

yes no

A kidney from a donor of less than 60 years of age, who was declared dead based on a lack of brain function. These kidneys usually function better and last longer than kidneys donated by Expanded Criteria Deceased donors (see below). By accepting only kidneys from SCD donors you will most likely have to **wait longer**, than if you are prepared to accept a kidney of slightly lesser quality.

3) Expanded criteria deceased (ECD) donor kidney

yes no

A kidney from a donor aged over 60 years; or over 50 years with a history of high blood pressure, death due to stroke, or poorer kidney function at the time of death; who was declared dead based on a lack of brain function. These kidneys have almost twice the risk of transplant failure compared to an SCD donor. Approximately 30% of donor kidneys are in this category. By accepting one of these kidneys you may receive a transplant **sooner**, but the kidney may not function as well, or last as long, as a kidney from a younger donor.

4) Donation after circulatory death (DCD) donor kidney

yes no

A kidney from a donor, who was declared dead based on a lack of a heartbeat. All organs require oxygen to survive. When a donor is declared dead without a heartbeat, the kidney may be damaged due to a lack of oxygen prior to recovery and preservation. These

kidneys are less likely to function immediately and may have a greater risk of rejection. However, the long term outcome is not inferior to organs donated by a brain death donor.

5) Dual adult donor kidneys

yes no

When the kidney function of a deceased donor is less than 80% of normal, or a biopsy of the kidneys shows evidence of chronic kidney disease, then it might be possible to achieve improved results by using both kidneys in a single patient. The transplant operation takes about 2 hours longer and the risk of surgical complication may be higher. The surgeon reviewing will determine if you would be suitable for this type of transplant.

6) Pediatric donor kidney

yes no

A kidney from a donor less than 6 years of age, who was declared dead based on a lack of brain function. The smaller size of the kidney, blood vessels, and ureter increase the risks of surgical complications with these kidneys. If there is no rejection the kidneys may grow to adult size in approximately 3 months. If the donor is less than 2 years old, both kidneys are transplanted with the aorta and vena cava. The risk of reoperation with these kidneys is higher. The long-term success rate is similar to those achieved with a SCD donor. To improve the chance of success with these kidneys, we usually recommend that the recipient's weight should be less than 80 kg, there is no evidence of tissue antibodies, or a condition that could increase the chance of blood clotting.

7) High risk donor kidney

yes no

Patients with the following criteria are considered at high risk for a transmission of viral disease, including HIV and hepatitis:

1. Men who have had sex with another man in the previous 5 years
2. Persons who report non-medical injection of drugs in the previous 5 years
3. Men and women who have engaged in sex in exchange for money or drugs in the previous 5 years
4. Persons who have had sex in the previous 12 months with any person above or with a person known or a suspected HIV-infection, and
5. Prison inmates.

The risk of transmission of a viral disease from a donor in this category is not known, but estimates range from 1/300 to 1/10,000. Occasionally transplantations with an organ from a donor of this type may have a lower risk of death than remaining on the waiting list. You will only be offered an organ of this type once we have talked to you about the risks.

Potential living donors

If you know of someone who is interested in obtaining information about being a living donor, ask them to contact the living donor team on 02 9113 4205. The living donor team will evaluate whether it is possible for your potential kidney donor to donate a kidney to you. Living donor kidney transplants offer the benefit of shorter waiting times and better long-term outcomes and the ability to have a transplant before the need for dialysis.

What is involved in getting a kidney transplant?

Step 1: Getting on the transplant waiting list

- First, you need to be on dialysis unless you have a living donor available.
- You will need to have many tests completed to help us assess your suitability to have a transplant. The criteria for medical suitability follow the guidelines determined by the Australian Transplantation Society (www.donatelife.gov.au/clinical-and-ethical-guidelines-organ-transplantation-deceased-donors)
- You will have an appointment to meet your potential transplant team.
- A special blood test will be conducted that will tell us your genetic makeup and help us to match your tissue type with a potential kidney donor.

Step 2: Waiting, Waiting, Waiting

Once all of your medical and social information has been collected and the transplant team has approved for you to have a kidney transplant, you will be placed on the waiting list.

While you are on the waiting list it is important that you let us know of any changes to your contact details (telephone, address, email). You can expect to wait at least 3 – 5 years.

If during this time you are having significant new health or social problems (eg have been admitted to hospital/surgery) or are experiencing old health problems that are getting worse, you will be placed “**on hold**”. While you are on hold, you will not be called for a kidney transplant until the problem is resolved and your doctor has informed the transplant team you are well enough again for a transplant. While you are on hold you will continue accruing waiting time, so **you won’t lose your position on the list.**

Step 3: When you get the phone call telling you of a potential donor

- You will be asked about your current health, recent blood transfusions and asked to come to the hospital to be seen by a doctor who will make sure that you are healthy enough for surgery.
- **Do not eat or drink anything from the time you are called.**
- **Bring all the medicines you are currently taking with you when you come to Prince of Wales hospital.**
- Sometimes even if you are called for a transplant the surgery may not go ahead. If this happens, it is likely your turn will come again relatively soon.
- When you are in surgery your relatives can ring the renal ward at Prince of Wales hospital on 9382 4611 to check if you are back in the ward and when you will be able to have visitors.

Step 4: After you have the kidney transplant surgery

- You will probably be in the hospital for 7 – 10 days. During this time the members of your transplant team will visit you. The transplant pharmacist will review your new medicines. The transplant dietitian will explain what changes you can make to your diet. The transplant nurses will explain how to care for yourself at home and answer any questions you have before you go home from hospital.

Step 6: After you go home

You will need to attend the Outpatient Kidney Transplant Clinic. Initially the visits will be a minimum of three times a week for at least the first month.

What happens during surgery?

After we give you some anaesthetic to make you unconscious, the skin and muscles in the lower part of your abdomen will be cut. A new kidney is attached to the blood vessels near the bladder. The ureter is usually connected to the bladder over a small plastic tube to help this connection heal. This plastic tube, also known as a stent, is removed at a later date by placing an instrument into the bladder called a cystoscope. Another tube, called a drain, is often placed around the kidney to remove fluids that can collect in the space created by the operation. A bladder catheter will also be used for at least the first 5 days after the operation. The kidney for transplantation may come from a healthy living person or a deceased donor. In most cases, it is not necessary to remove the failed kidneys. However, if your kidneys are enlarged, infected, or limit the ability to connect the blood vessels of the new kidney, we may need to remove one of your kidneys before or at the time of the transplant. If the blood vessels are diseased, vascular reconstruction might be necessary. The surgeon may also remove your **PD** catheter at the time of surgery if the catheter cannot be safely used after your surgery, or if it is expected that your transplanted kidney will begin to work quickly. The surgeon may conduct additional procedures such as repairing a hernia or your bowel if necessary. We may also need to put a tube in a vein in your neck to give you your medicines and to monitor the amount of fluid you have in your body.

Medicines

Your immune system is your body's natural defence system working to protect your body from infection. You will need to take medicines to keep your immune system working at a lower level to help prevent the transplanted kidney from being damaged or rejected by your immune system. You will need to take medicines to prevent your body rejecting your new kidney for your whole life. All medicines that lower your immune system, including your transplant medicines, increase your risk of developing certain infections and cancers, which can be life threatening.

You will be taking a combination of a few of the following medicines. We will adjust what medicines you need to take to minimise any side effects. Potential side effects of each are listed below:

1. **Tacrolimus (Prograf):** Approximately 10% increase in diabetes, high blood pressure, headache, hand and feet tingling, tremors, hair loss, problems with how well your transplanted kidney works.
2. **Cyclosporine (Neoral):** Headaches, tremors, swollen gums, acne, increased hair growth, tingling in hands and feet, problems with how well your transplanted kidney works, high blood pressure, approximately 5% increase in diabetes, increased cholesterol levels and gout.
3. **Prednisone:** Include weight gain, high blood pressure, indigestion, nervousness, acne, skin rash, swelling of face, feet and ankles, approximately 10% increase in diabetes, mood changes, slower wound healing, bone thinning, bruising and increased cholesterol levels.
4. **Mycophenolate (Cellcept):** Include nausea, vomiting, diarrhoea and low white blood cell count.
5. **Sirolimus (Rapamune):** Increased cholesterol levels, low iron levels and swelling.

Other types of medicines you may need to take after your transplant include blood pressure pills, cholesterol-lowering pills, antiviral and antibiotics to prevent or fight infection, iron to help increase your haemoglobin, stool softeners to help prevent constipation and additional medicines to prevent your body rejecting your new kidney(s).

After your transplant

How long can I expect my kidney transplant to work?

Living Donor Transplants:

	Working kidneys
By end of first year	98.5%
By 5 years	92%
By 10 years	70%

Deceased Donor Transplants:

	Working kidneys
By end of first year	94%
By 5 years	85%
By 10 years	55%

What happens if my kidney transplant stops working?

When a transplant stops working well in the first year after the surgery, it is usually because of problems with blood flow or the ureter (the tube connecting the kidney to the bladder) or your immune system recognises that the transplanted kidney is not your own and tries to get rid of it. The medicines you will be taking will try to prevent your immune system from doing this.

However, sometimes even when you do everything right, your body may try to reject your transplanted kidney. When this happens, you may have a biopsy performed on your transplanted kidney and you will be given medicines to fight the rejection. If these medicines are not successful, you may have to return to having dialysis treatment.

Medicines

You play a very important role in helping your kidney transplant be a success. It is very important that you take your medicines **exactly** as we tell you. If you have any questions or concerns about any of the medicines you are taking or are experiencing side effects, call the renal department on 02 9113 2622 and speak to a kidney doctor.

Do not make changes to your medicines without talking to the transplant doctors or nurses first.

It is important you let your transplant team know about **all** the prescribed and non-prescribed medicines and any other other tablets, vitamins or herbal products you are taking to look after your health.

Most of the medicines you will need to take after having a transplant can be brought from your local pharmacy with a prescription. However, there are some prescription medicines that you will need to get from the hospital pharmacy. The hospital pharmacist will explain more about this.

The Pharmaceutical Benefits Scheme (PBS) Safety Net reduces the cost of prescription medicines for individuals and families once the PBS Safety Net threshold has been reached. Your pharmacist will also explain how this works. Information is also available online at www.humanservices.gov.au/customer/services/medicare/pharmaceutical-benefits-scheme-pbs-safety-net

Blood tests

You will be asked to regularly have blood tests. It is important you follow the schedule we give you.

Clinic visits

After your transplant you will need to regularly attend the transplant clinic at your hospital. If you need to cancel or reschedule your appointment please contact the clinic. At your clinic appointment you will have the opportunity to review your medicines, blood tests, diet and ask any questions you have.

Returning to work

It is expected that once you have had your kidney transplant, you will be able to return to the activities you did before starting dialysis, including work. Once everything is going well, it is expected that you will no longer be eligible for a disability pension due to kidney failure. This usually happens within 3 months. It is recommended that you won't return to work for at least 3 months after surgery. Your surgeon will let you know when you are able to drive a car. It is likely to be within 2-4 weeks.

Participating in research

All the hospitals that form part of the East Coast Renal Services conduct research about kidney health and transplants. You may be invited to participate in a study we are conducting. You are free to choose if you would like to be involved. If you choose not to participate in a research study, your care will not be compromised nor will the attitude of the staff towards you change in any way.

Data collection

Some data may also be used to provide information to the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). You may have already given consent to be part of this registry. Living kidney donors are also included in this registry. The ANZDATA database remains confidential and is only used to provide annual statistics on dialysis and transplantation within Australia and New Zealand. The identity of those involved is not made available. Participating in this registry is voluntary. The information provided by the ANZDATA database helps us better understand what will improve the quality of the kidney transplant program. Information collected, in addition to that mentioned above, will consist of medical tests performed prior to transplantation, the exact type of surgery performed, and progress of the donor after transplantation.

Contact Numbers

The main point of contact for you at Prince of Wales hospital will be the Renal Clinic in the Kidney Care Centre. Some handy contact numbers are as follows:

Renal Clinic Reception: 9382 4442

Renal Clinic Nurse: 9382 4426

Transplant Coordinator: 9382 4443

Two weeks after the transplant you will return to the clinic at St George hospital. Contact numbers at St George are as follows”

4West Renal clinic: 9113 4530

Transplant coordinator: 9113 4205

After Hours

If you become unwell between 3.30pm - 7am you can speak to the Renal Registrar by calling the main hospital switch board on 9113 1111 and asking them to page the Renal Registrar.