Kidney Health®
Australia

An Introduction to
Kidney Transplantation

Prevent, Detect, Support, Research.

Contents

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Disclaimer:
Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or other health professional's advice. All care is taken to ensure that the information contained in this booklet is accurate at the time of publication.

Foreword

An Introduction to Kidney Transplantation is designed specifically for people who are considering treatment options for kidney disease.

If you are reading this for the first time it may be that you have just received news that you need to consider kidney disease treatment options. You may also have had Chronic Kidney Disease (CKD) for some time and be ready to learn more, or you may be supporting a loved one in this situation.

An Introduction to Kidney Transplantation is designed to provide you with information about kidney transplantation as a kidney disease treatment option. Other booklets in this series cover home dialysis, haemodialysis, peritoneal dialysis, live kidney donation and comprehensive conservative care. We encourage you to read all the booklets so you can make an informed decision about your treatment.

Kidney Health Australia is here to support you throughout your journey. Our health professionals are only a phone call away should you wish to speak to someone confidentially.

Welcome to Australia's kidney community and please keep in touch so that we may be able to provide you with whatever support and assistance you require.

To receive monthly updates on the latest in the kidney community and managing your kidney health visit **kidney.org.au/subscribe**

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What are kidneys?

Most people are born with **two kidneys**, each growing to the size of your fist. Your kidneys are bean shaped and are positioned near the middle of your back, on either side of your backbone (spine). Your kidneys are part of the body's urinary system.

What do healthy kidneys do?

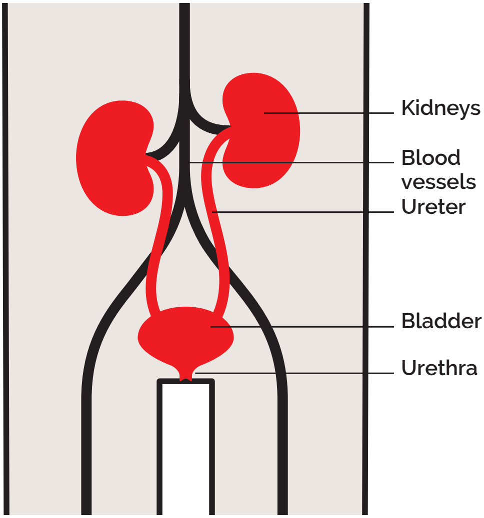
Kidneys are the unsung heroes of the body. The kidneys play a number of important roles in the body, such as:

- Extracting excess fluid to make urine (wee)
- Controlling blood pressure
- Filtering waste products from the blood
- Controlling body fluids
- Stimulating the production of red blood cells
- Controlling potassium, calcium and phosphorus levels
- Regulating vitamin D.

What happens when the kidneys don't work properly?

Sometimes kidney function can change quickly. For example, your kidneys may stop working properly because of a sudden loss of large amounts of blood (e.g. during surgery) or as a result of an accident, illness or infection.

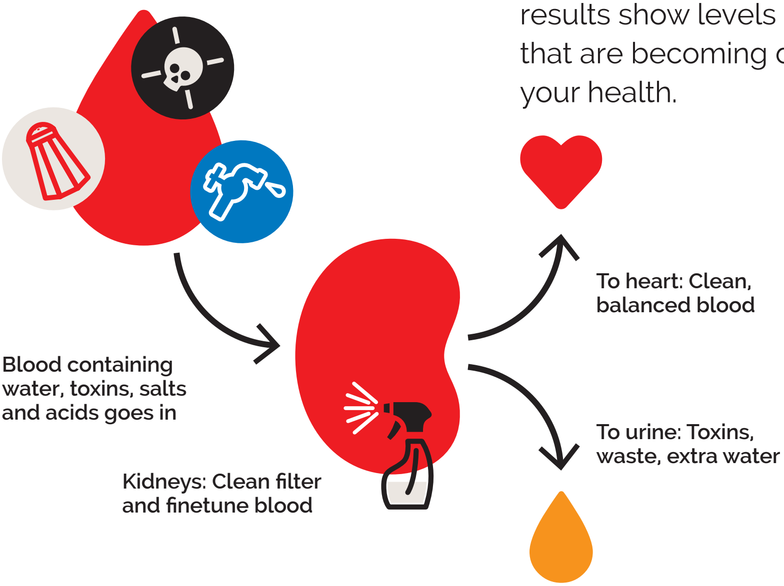
A sudden change in kidney function is called **acute kidney injury**. This is often temporary but can occasionally lead to lasting kidney damage. More often, kidney function worsens over a number of years – it is a chronic, or ongoing, condition. **Chronic kidney disease** (also referred to as CKD) is called a silent disease as there are often no warning signs. Sometimes people lose up to 90 per cent of their kidney function before getting any symptoms.



Symptoms you may experience

- Retention of fluid causing breathlessness and swelling
- Tiredness
- Headaches
- Poor memory and concentration
- Irritability
- Sleep disturbances
- Feeling washed out
- Itchiness
- Nausea and loss of appetite
- Weight loss
- Altered sexual function.

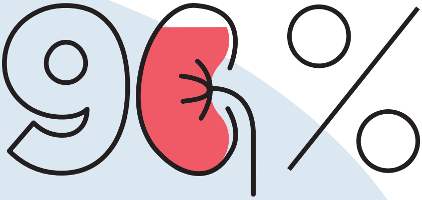
Dialysis is usually started when you no longer feel well enough to live your usual life, have excess fluid or swelling, or your blood results show levels of waste that are becoming dangerous to your health.



You are not alone

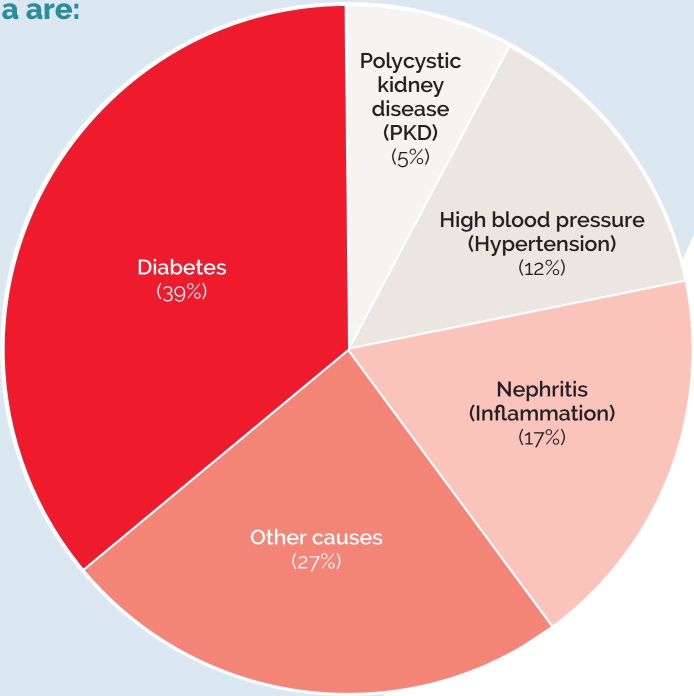
In Australia:

- Over 3,000 people start dialysis or receive a transplant every year
- There are currently over 27,000 people in Australia on dialysis or living with a transplant.



of kidney function can be lost without experiencing any symptoms

One of every 10 people has signs of kidney disease. The leading causes of kidney failure in Australia are:



Transplantation

A kidney transplant is treatment for kidney failure, but it is not a cure. A transplant offers a more active life, without needing dialysis. However, your new kidney will require ongoing care. You will need to take medications to stop your body rejecting the kidney (anti-rejection) for as long as you have the transplanted kidney.

If a kidney transplant stops working, dialysis treatment will be necessary again. Another transplant may also be possible.

A kidney can be donated by living donors, such as family or friends, or deceased donors. To receive a kidney transplant from a deceased donor, you will first have to be added to the kidney transplant waiting list.

Having a transplant from a living kidney donor means you may have better outcomes. If you have a transplant from a living donor it usually means you will not have to wait as long for your transplant.

Talk to your health care team about whether a kidney transplant is a suitable option for you. Find out where your closest transplant hospital is.

Who can have a kidney transplant?

When exploring the available treatment options for kidney failure, you should discuss with your doctor if kidney transplantation is an option. It is important to understand that a kidney transplant is not suitable for everyone, as the risks of the operation or the medications may make your health worse.

Factors affecting your suitability for a kidney transplant include:

Physical Health

- Your general health, apart from kidney failure
- Agreement with the idea of transplantation and acceptance of the risks involved
- Self care, i.e. taking medications regularly, eating a healthy diet, stopping smoking
- Willingness to go through with the tests and the transplant surgery
- Willingness to take the anti-rejection medications.

Mental Health

- Your mental health
- Family and carer support
- Self care - following health advice, taking care/ responsibility for your health.

Most metropolitan cities have a hospital that performs kidney transplants. If you live in a regional or rural area of Australia or in a city that does not have a transplant hospital you will need to travel to the closest transplant hospital for your evaluation and tests, and for the transplant procedure itself. Your **health care team** will be able to discuss these travel arrangements with you.

Are kidney transplants successful?

Kidney transplants are very successful. On average, 95 per cent of transplants are working one year later. If the transplant works well for the first year, the chances are good that it will function very well for many years.

How long your transplanted kidney will work can depend on many factors. In Australia, around four in every ten kidney transplants are still working 15 years later. Some people have had kidney transplants that have lasted more than 30 years.

Success rates are higher with living donor kidneys than for deceased donor kidneys.

Percentage of people alive after five years who received a kidney from a:

Living donor

Deceased donor

Percentage of transplanted kidneys working after five years from a:

Living donor

Deceased donor

Kidney donors

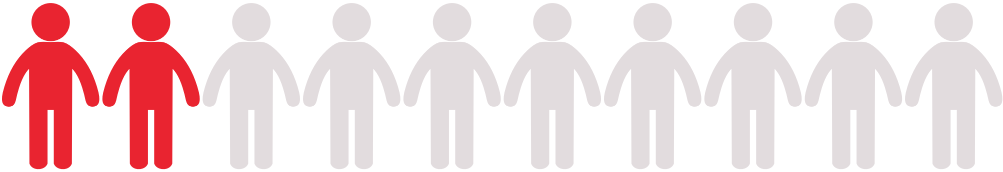
Kidneys for transplantation come from either living donors or deceased donors.

Living donors are usually donors known to the recipient, often a relative (parent, grandparent, spouse or sibling) donating one of their kidneys. Deceased donors are donors who have died in hospital, and their family agrees with their nomination to be an organ donor.

Talk about kidney transplantation with your family and friends. Discuss the options of receiving a kidney from a living or deceased donor.

The surgery and pre-surgical care for you will be similar whether your transplanted kidney is from a living or deceased donor. It is recommended that you discuss your situation with your health care team, to make sure you understand your options.

For every 10 kidney transplants performed in Australia:



two
involve kidneys from
living kidney donors

eight
involve kidneys from
deceased kidney donors

Living kidney donors

Living donors are usually relatives (parents, brothers, sisters, or adult children) of the person who needs the kidney transplant. If circumstances are suitable, people who are not related to you, such as your partner or friend, may also donate a kidney.

The tests to determine whether a living donor will be a compatible donor for you are very complex and can take a long time. New techniques mean that transplants can often now be done in situations that were previously difficult. For example, if your potential living donor is not from a compatible blood group there are now ways to deal with this.

The main benefit of having a living donor is timing. It can sometimes take years before a kidney becomes available from a deceased donor.

Having a living donor may mean you can have a transplant before you even need to start dialysis. This is called a **pre-emptive transplantation**. Having a living donor also means that the transplant surgery can be organised and planned. This means that the time between when the kidney is removed from your donor and transplanted into you (called the **cold ischaemia time**) is shorter. A shorter cold ischaemia time improves your chances of a successful transplant surgery and contributes to longer kidney transplant survival.

Hospital admission and surgery can also be planned ahead of time, allowing you and your donor time to prepare for the surgery and recovery. Another advantage of having a living kidney donor is that transplant success rates are higher with living donor kidneys than with deceased donor kidneys.

Deceased kidney donors

Deceased donors are people who die with organs that are suitable for transplantation. In Australia, most donations occur when a person is declared brain dead. This is called Donation after Brain Death (DBD). Brain death occurs when the brain is so badly damaged that it permanently stops functioning. This is usually because of bleeding in the brain, a stroke, or severe head injury.

Another method of organ donation is known as Donation after Circulatory Death (DCD). Potential DCD donors are patients in the Intensive Care Unit (ICU) who have suffered irreversible brain injury and may be near death, but do not meet formal brain death criteria.

These patients have no chance of survival without ongoing **artificial ventilation** or life support. In these cases, the family has decided to stop care. When the patient's heart stops beating, the organs are then removed in the operating room.

Any person is around 10 times more likely to need an organ transplant than to become a deceased organ donor.

These organs have had some loss of oxygen after the heart stops beating. This may make kidneys from this type of donor slow to start working.

Deceased donors may have recorded their decision to be an organ donor on the **Organ Donor Register**. Their family may make this decision after the person has died. This is a very special gift and the donor and their family are treated with the greatest respect throughout the decision and the surgery.

Unfortunately, the number or donors is outweighed by the number of people waiting for a transplant. Organ donation requires special conditions and is only possible in less than 1 out of every 100 deaths that occur in hospital.

The kidney transplant process

Assessment to have a kidney transplant

Before you can be placed on the kidney transplant waiting list you will need to undergo many tests. These tests are to make sure that both your body and mind are healthy enough for you to have the kidney transplant surgery and take the medications after surgery. These tests are often called the transplant work-up.

Medical tests that are used to assess your health before a transplant include:

- Assessment of your overall health, including your weight
- Blood tests
- Dental check
- Cancer screening (Pap smear, prostate, bowel)
- X-rays and other tests of your heart and lungs
- Tests involving your arteries, veins and bladder.

Living donor assessment

If you have someone who wants to be your living kidney donor they will probably go through a similar work-up at the same time as you. They will also have tests to make sure their kidney is healthy enough to be donated. There will also be tests to check if the kidney from your living donor is compatible or matched with you. More information on how kidneys are matched can be found on **Page 20**.

The process of assessment for both you and any potential living kidney donors can take between six months and a year depending on any issues that are faced.

Transplant waiting list

When you have been evaluated as being suitable for a kidney transplant your name will be placed on the **transplant waiting list** to receive a kidney from a deceased donor. You will be referred to as being active on the transplant waiting list.

You will only be activated on the transplant waiting list for a deceased donor once you have started dialysis. This does not mean you still can't look into having a transplant from a living donor. If you have started dialysis you can go on the transplant waiting list while you are waiting to see if you have a compatible living kidney donor.

If your health gets worse while you are waiting for a kidney, you may be temporarily taken off the active list. This is because your health is an important factor for a safe surgery. Once you are well you will be active on the waiting list again.

The kidney transplant waiting list is not just a queue where you slowly work your way to the front. Each time a deceased donor kidney becomes available a recipient is chosen taking into account a number of factors. A computer generates a score for these various factors, and the recipient with the highest score will be offered the kidney. See **Page 16** for more information about how deceased donor kidneys are matched and allocated.

Your waiting time is based on the day you started dialysis, regardless of when you were officially placed on the waiting list. If you come off the waiting list for any reason the same 'dialysis start' date is used when you become active on the list again. This means that you do not lose your accumulated waiting time.

If you are receiving a second, third or even fourth transplant, your waiting time is based on the date that dialysis was re-started after your transplanted kidney failed.

The kidney transplant waiting list is not just a queue where you slowly work your way to the top. Your health care team can let you know if there are factors that may make your wait longer or shorter than average.

National and State allocation of deceased donor kidneys

There is a National Allocation Formula for allocating kidneys from deceased donors. This means a kidney may be sent interstate if that is where the recipient with the best match is.

If no one meets the criteria of the National Allocation Formula the State Allocation Formula is used. This means that the kidney is allocated to a recipient who lives in the same state as where the deceased donor is. In these cases, the kidneys are mostly allocated based on waiting time on dialysis.

Out of every 10 deceased donor kidneys, two are sent interstate and eight are allocated within the state.

Young children get priority for deceased donor kidneys. This is because dialysis impacts on their growth and education. As there are not many children waiting for a deceased donor kidney this policy has very little impact on the average waiting time. Overseas visitors are not eligible for an Australian transplant.

Unfortunately it may take months or even years of being active on the kidney transplant waiting list before you receive a kidney from a deceased donor. **Current average wait times are 2-3 years.**

Staying healthy while waiting for a kidney transplant

To give your transplant the best chance of success, it is important that you look after yourself while you are on the transplant waiting list.

You will also need to provide routine tissue typing and antibody blood tests every one to two months. This allows current samples to be used in the cross match tests. Small amounts of these samples are sent around Australia for donor matches in other states. If you do not do these blood tests, the laboratory will not be able to assess your compatibility with a donor and you may miss an opportunity. You will also have regular reviews where you can discuss any concerns about your transplant preparation.

Stay healthy while waiting for your kidney transplant by:

- Keeping to your regular dialysis schedule
- Following your recommended diet and fluid restrictions
- Taking your medications as prescribed
- Controlling your weight with diet and physical activity
- Visiting your dentist regularly to watch for any infections
- Protecting your skin, which will help to prevent skin cancer after your transplant
- Being a non-smoker
- Keeping your vaccinations up to date
- Avoiding blood transfusions if possible.

What happens when a deceased donor kidney becomes available?

When a kidney from a deceased donor becomes available for transplantation a number of laboratory tests are done. These tests include tissue typing and cross matching. The tests are done to work out who would be the best match for the kidneys.

Once the laboratory tests have been completed the organ donor coordinator will receive a list of potential recipients. They will then contact the Transplant Unit responsible for the first potential recipient on the list. If you are selected to receive a kidney from a deceased donor the hospital will contact you by telephone.

Pack a hospital bag so you are ready at any time. Include pyjamas, warm socks, toiletries, pen and paper, small amount of change, essential phone numbers, any necessary medical documents.

Make sure the hospital has your current telephone numbers as you may receive the phone call at any time – day or night. If you cannot be located and do not contact the hospital within a certain time (usually around 30 minutes), the kidney will need to be given to the next person on the waiting list. It is important that you are always prepared to answer your phone.

You will also need to be able to get to the hospital quickly as deceased donor kidneys are usually transplanted within 24 hours of their removal from the donor. This is to make sure that there is limited damage to the kidney from the loss of oxygen and blood supply. The kidney will be put on ice until it can be transplanted into your body.

Deciding whether to accept the kidney

Once you have received the phone call that there may be a kidney available for you, there may be further issues to think about. Your doctors will need to assess the compatibility, the safety, as well as the quality (likely survival) of the kidney that is being offered for donation.

Some of these issues may involve possible risks to your health. For example, if it is discovered that the donor had suffered from cancer or other infections.

In recent years there are more kidneys coming from elderly donors who may have had illnesses such as high blood pressure, diabetes or a history of smoking. In some cases, donors may have had a history of taking illicit drugs.

All these factors need to be taken into account by your doctors and by yourself. The quality of the kidney being offered may also influence the decision to go ahead with the transplant.

You may have to decide whether it's best to accept an immediately available, but less-than-ideal deceased donor kidney or take the chance and wait for a healthier one in the future.

Take some time to think about these issues before you receive your call that a kidney is available. Talk to your health care team and your family about your decisions.

How are kidneys matched and allocated?

Kidney donor and recipient matching can be divided into several areas. These areas include blood group matching, tissue type matching and cross matching. Soon, Australia will also be considering survival matching. This involves the assessment of how long a certain kidney is likely to last. It also involves allocating kidneys partly based on how long different recipients are likely to survive.

For these reasons, allocation and acceptance of a kidney offer needs to consider compatibility, your waiting time and the quality of the kidney being offered and its likely benefit to you.

A computer can manage some of these factors. Your doctors will also need to consider other issues and possibly discuss these with you if needed.

Each area of compatibility is important for donor and recipient matching for both living and deceased donors.

If you are receiving a kidney from a living donor it may be possible to get around some of these matching issues. For example, it may be possible to prepare your immune system so that you are able to receive a kidney that would have been incompatible.

It may also be possible for you and your living kidney donor to participate in the Australian Paired Kidney Exchange Program (see **Page 37**).

Donor and recipient matching

1. Blood group

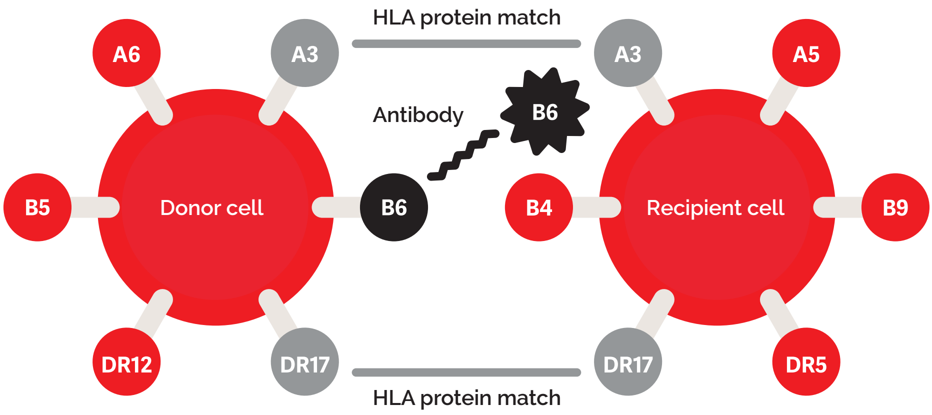
If your transplanted kidney comes from a deceased donor, the ordinary blood groups (A, B, AB, O) and red blood cells of the donor must be compatible with yours. This is similar to matching blood groups for a blood transfusion. We all have antibodies to blood groups different to ours.

If your transplanted kidney comes from a living donor it may be possible to have the transplant even if you and your donor are not from a compatible blood group. This is called an **ABO incompatible transplant**. Extra treatments will be needed to remove the antibodies before the transplant can go ahead. ABO incompatible live donor transplants are being performed in most Australian transplant units with excellent results.

2. Tissue type matching

Your immune system is designed to keep you safe from foreign invaders such as viruses and bacteria. Everyone has special proteins on their cells called **HLA proteins**. Your combination is unique to you and is recognised by your immune system so it will not attack your own cells.

Your immune system will recognise a combination of HLA proteins not belonging to you and will attack them. It will then develop antibodies against these HLA proteins. This is how your immune system defends your body against infections. This is also the underlying cause of your body rejecting a transplant and the reason you need to take anti-rejection medications.



If your body has produced antibodies against your potential kidney donor's HLA proteins, these are called **donor specific antibodies**. These antibodies may have developed because you have previously been exposed to other people's HLA proteins through a blood transfusion, through pregnancy, or from a previous transplant. Sometimes there is no clear reason found for the presence of these HLA antibodies.

Antibodies mean your immune system remembers this exposure and is ready to attack cells with similar HLA-proteins on them. The cross match test also checks for this.

HLA proteins and antibodies

You have a combination of A, B and DR HLA proteins inherited from your parents. When you are exposed to other HLA proteins your immune system attacks them. Your body then develops antibodies against these HLA proteins. If you have already have antibodies against a donor cell HLA protein (B6 in the diagram above) then your body may attack those donor cells and reject the donor kidney.

When you are tissue typed, a blood test is taken to determine your HLA proteins and antibodies. This is usually one of the first steps in your transplant work-up. Your HLA proteins and antibodies can also change over time, so these tests will be repeated every one to two months.

You will share some HLA proteins with other people and the more you share the more likely your body is to accept their kidney. How similar your tissue typing is with someone else's refers to your 'HLA-match'. This is usually given as a number out of six as there were six groups of proteins identified many years ago that were found to be important.

For many people, HLA-matching is less important than it was a few decades ago. This is because the anti-rejection medications have improved. We also understand more about tissue typing than we used to, and this has led to longer survival of transplanted kidneys.

Most kidney transplants that are performed do not have a high level of HLA protein matching and still have excellent results. Many people would wait a long time or never get transplanted if they waited for a very good HLA-match.

What is more important is whether you already have anti-HLA antibodies in your blood against any foreign HLA proteins in the potential transplant kidney.

3. Cross match

In the cross match test, your blood cells are added to blood cells taken from the donor. A positive reaction means that there is a high likelihood of severe rejection of the donor kidney. In the case of a deceased donor, the transplant will not go ahead if there is a positive cross match.

What happens during a kidney transplant?

Before surgery

You will be admitted to the hospital where the transplant surgery will take place. You will have a physical examination, and you may need to have a dialysis session. If you have any active infections or other significant medical problems the transplant surgery may need to be cancelled.

You will be given anti-rejection medications before and after the surgery to control your immune system and stop your body from rejecting the new kidney.

During surgery

Surgery for a kidney transplant takes about two to three hours. A cut is made in your lower abdomen, on the right or left side. The new kidney is placed in your pelvis. The renal **artery** and **vein** of the transplant kidney are connected to an artery and vein in your pelvis (usually the iliac artery and vein that lead down towards the leg). The **ureter** of the transplanted kidney is connected to your bladder so urine can flow.

Many people are surprised to learn that their own failed kidneys are not removed. They are left in your body to continue to provide whatever amount of function they may still have. Sometimes it may be necessary to remove your failed kidneys if they are very large (for example, if you have **polycystic kidney disease**). If this is needed, your failed kidneys will be removed in a separate surgical procedure before your transplant surgery.

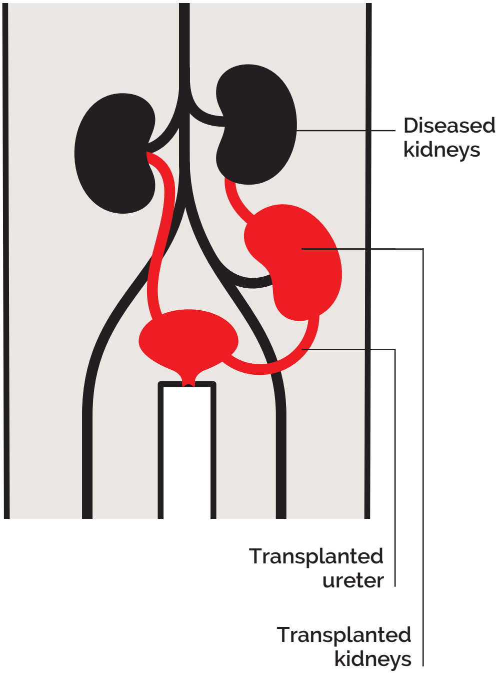
After surgery

After the transplant surgery it is normal to feel some pain around your wound. You will be given medication to help with this.

Your transplanted kidney may start to make urine immediately, or you may need dialysis for a few days. If you need dialysis it does not mean that your transplanted kidney will not work. It just may need a bit of time to recover from the transplant procedure.

A **catheter** will be placed in your bladder for around five days to drain your urine into a bag. This helps your health care team to check that your kidney is working well. Often there are tubes from your wound draining away extra fluid. These are usually removed after a few days.

Kidney transplant anatomy



You will have blood tests every day to check the function of your transplanted kidney, to measure medication levels and to detect any problems early so they can be treated quickly.

The blood tests for **creatinine** and **eGFR** measure how well your kidney is working. These may already be familiar to you. In many cases your creatinine and eGFR will go back to what they were before you first got kidney disease.

The amount of fluid you take in is important. The nurses may be asking you regularly how much you have had to drink. If your new kidney is working well, the amount of fluid you are able to drink will increase.

It is important to do coughing, breathing and leg exercises while you are restricted to bed rest.

This helps to:

- **Reduce the risk of a chest infection**
- **Reduce the chance of clots in your legs**
- **Keep your airways clear**
- **Encourage good blood flow.**

A physiotherapist may assist you with an exercise plan. You will probably be able to sit out of bed on the first day after your surgery. You should be able to go for a walk within a couple of days.

Reducing the risk of an infection is very important. For this reason, you may be looked after in a separate room or ward of the hospital, your visitor numbers may be limited, and you may not be allowed to receive flowers from visitors.

The length of time that you will need to stay in hospital after the transplant surgery will depend on how well your body responds to the new kidney and whether you have any complications. Most people are in hospital between six and ten days. You may feel better immediately after your surgery or you may take longer to adjust.

Going home with a successful transplant

Caring for yourself after your kidney transplant is very important. The first few months after a kidney transplant are the most unstable, it is important that you look after yourself following **instructions from your doctor** and report any changes in your health to your **health care team** as soon as possible.

You will have regular check-ups to monitor the function of your new kidney. These will be daily at first, then weekly, then monthly.

At these visits your wound will be assessed to make sure it is healing well, and you will be checked for any signs of rejection of the transplanted kidney. Slow wound healing can be caused by some medications, diabetes and obesity. If you are at increased risk of slow wound healing, you may be monitored more closely.

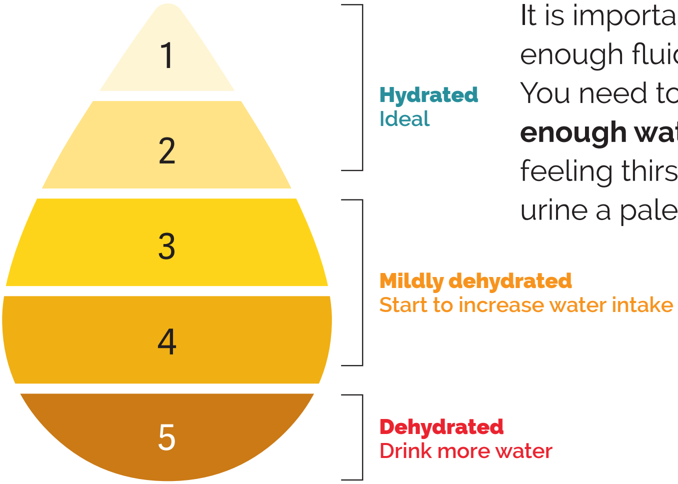
You will need to think about where you will stay after you are discharged from hospital. If you live a long distance from the transplant unit you will need to find short-term accommodation close to the hospital. Travel and accommodation assistance schemes are available to help with this, including the **Kidney Health Australia** Transplant House accommodation in Adelaide, Melbourne and Perth. Refer to **kidney.org.au/ways-we-help/transplant-house-program**. (see **What Support is Available** on **Page 44**).

Think about where you will stay after you are discharged from hospital. If you need to arrange accommodation it is best to do this sooner rather than later.

Living with your new kidney

You should be able to return to normal **activities and work** within three to six months of your transplant. You will need to allow time for your wound to heal and for your stomach muscles to get strong again. Regular exercise is an important part of staying healthy. It is recommended that you start regular exercise under the guidance of your health care team.

It is recommended that you **do not drive a car** until six weeks after your transplant. You should also avoid any **heavy lifting** for six weeks.



Check the colour of your urine regularly. If the colour is too dark drink some water. If the colour is unusual, red or the urine is frothy speak to your health care team.

You will need to **manage your medications** carefully. It is important that you take your medications exactly as prescribed by your doctor. Support from your pharmacist as well as a **webster pack** might be needed as there will be a large number of medications needed at specific times of the day.

It is important your kidney has enough fluid to work properly. You need to make sure you **drink enough water** or fluids to stop you feeling thirsty, and to keep your urine a pale yellow colour.

More tips on staying healthy

Avoid infections

- Wash your hands well
- Keep your vaccinations up to date
- Limit contact with people with colds or viruses (especially small children)
- Treat scratches.

Reduce your risk of skin cancer

- Follow the **slip, slop, slap, seek, slide** advice provided by the Cancer Council of Australia (slip on a shirt, slop on sunscreen, slap on a heat, seek shade, and slide on sunglasses)
- Have regular checks for other cancers such as bowel cancer, breast cancer (women) and prostate cancer (men).

Be a non-smoker

- Having a transplant increases your risk of having health problems caused by smoking
- This includes lung cancer, stroke, and heart attack
- Your chances of a long-term, successful transplant may be reduced if you smoke.

Let your health care team know if you get sick

- If your illness is treated quickly your risk of damaging your transplant is reduced.

Stay at a healthy weight

- Your anti-rejection medications may increase your appetite
- Talk to your doctor or **renal dietitian** about how to stay at a healthy weight.

Practice good food safety to avoid food poisoning

- Wash your hands well before preparing food or eating
- Keep cooking utensils, chopping boards, and knives separate for raw and cooked meats
- Cook foods thoroughly – no pink left in cooked meats such as mince, sausages and chicken
- Avoid eating foods that have a higher risk of food poisoning – soft cheeses (such as brie and camembert), pate, salami, and raw seafood.

Sexuality and fertility after a transplant

Sexual activity will not harm your transplanted kidney. It does not increase your risk of infection. It is recommended that you wait about four weeks after your transplant before having sexual intercourse.

As your health improves after your kidney transplant your fertility may increase. This is true for both men and women. Contraception options should be considered and discussed with your doctor.

If you are a woman and would like to have a baby it is suggested that you wait at least 1-2 years after your transplant before trying to get pregnant. This allows time for you to become stable on your anti-rejection medication.

It is important to discuss pregnancy with your doctor, before you start trying for a baby, as some of your medications may need to be changed or even stopped before pregnancy. You will be carefully monitored to make pregnancy safer for you and your baby.

People deal with a transplant in different ways. Your emotions affect your health so it is important to talk about your thoughts and feelings with your family, friends and health care team.

Speak to your doctor if you are thinking about becoming pregnant after your kidney transplant.

Many transplant centres also hold information workshops for people with a kidney transplant. These can add to the discussions that you have with your health care team.

Emotional well-being

Having a transplant should have a positive effect on your life. However it is still a major life event. You may have mood swings and feel stressed or depressed as you adjust to your transplant, and as your body responds to your anti-rejection medications. It is not unusual to have these feelings. The earlier you talk to someone the quicker you can get support.

You may also:

- Have to come to terms with having another person's organ inside you. Some people worry that they may develop the donor's personality but this is not possible
- Have conflicting feelings about receiving a kidney from a deceased donor. You may feel relief and happiness at having a new kidney, but upset because the donor's family and friends are grieving
- Be overwhelmed by feelings of being **normal** again
- Find that your relationships change as your family and friends adjust to you becoming more active
- Experience a roller-coaster of emotions about the possibility of rejection. You may feel anxious about attending medical appointments and then relief after being told that your transplant kidney is functioning well
- Be overwhelmed at the thought of taking many medications with their possible side effects
- Feel guilty about your transplant because there are other people still on dialysis.

Many people who receive a deceased donor kidney may wonder who the kidney came from. This information is not released, however, Donate Life have a program where donor families and recipients can write anonymous letters to each other. There are also annual services that involve both donors and transplant recipients. See **Resources** on **Page 43**.

Transplant rejection

You must take anti-rejection medications for as long as your transplanted kidney is working. These medications partially block the activity of your body's immune system. This prevents your body from attacking your transplanted kidney.

There are many different medications which are used to prevent rejection. For each of your medications find out:

- When and how to take them
- What to do if you miss a doses
- Possible dietary restrictions
- Interactions with other medications
- What side effects you may experience
- How to store your medications. Your pharmacist is a good resource for information. A **webster pack** may also be helpful.

In the early period after your transplant, you may have some rejection episodes. These may only be picked up by your regular blood tests. These episodes can usually be managed with changes to your medications.

Some rejection episodes may require extra treatments such as plasma exchange (to remove antibodies in your blood) or special infusions.

Most rejection episodes can be managed successfully. However, rejection can take place at any time after your transplant so it is very important that you follow any medical instructions and receive regular monitoring.

Types of rejection episodes

Hyperacute rejection

This can occur minutes or hours after the transplant. This type of rejection is very rare. It is untreatable and the kidney is removed immediately.

Acute rejection

Acute rejection appears as an inflammation in the kidney. This usually needs quick diagnosis and action. It usually occurs in the early weeks following a transplant. This is why you will have frequent blood tests in the first weeks after your transplant. Mild acute rejection is very common in the first year after a kidney transplant.

Acute rejection sometimes causes pain and fever but usually has no symptoms. An increasing eGFR or creatinine is usually the first sign of acute rejection. A **biopsy** of the kidney transplant is often used to diagnosis rejection and to decide on the best treatment.

Chronic rejection

Chronic rejection refers to a gradual process, which leads to scarring and damage in the transplanted kidney. This usually occurs over several years and can be very difficult to treat. Often this is due to **anti-HLA antibodies** that are present (see **Page 22**). During this time the kidney is gradually losing its function and may eventually fail, leading to the need for dialysis and another kidney transplant.

Anti-rejection medication side effects

Anti-rejection medications have a number of possible side effects. These side effects are usually able to be managed by changing the dose of your medications.

Some of the most common side effects include:

- Increased risk of infections
- Puffiness of your face and stomach
- Unwanted hair growth or hair loss
- Increased appetite and weight gain
- Mood swings
- Increased risk of high blood pressure, diabetes and cancer (particularly skin cancer)
- Pimples
- Muscle weakness and shakiness in your hands
- Stomach problems such as indigestion and diarrhea.

If you become worried about any possible side effects, you should discuss them with your health care team.

If you need treatment from other health professionals (such as a dentist), let them know that you have had a kidney transplant.

- **Check with your nephrologist before taking any medication prescribed by another health professional**
- **Check before taking any medication that you can purchase over-the-counter from the supermarket or chemist, as these may affect your anti-rejection medications**
- **Do not stop taking your medication unless you are told to do so by your health care team.**

The live kidney donation process

Kidney transplants from live donors now make up around two out of every ten kidney transplants in Australia each year.

To be a living kidney donor, the potential donor must have normal kidney function, overall good health, and be emotionally suitable for living donation.

The evaluation process includes blood tests and other investigations, as well as a psychological assessment.

Medical assessment

If someone is considering being a living kidney donor they will need a thorough medical check by a doctor. These tests will check that donating a kidney will be safe for the donor both in the short term and the long term. The transplantation team will also decide whether the donor is fit for surgery and has a suitable kidney to donate.

A number of tests are needed to make sure that the living donor is suitable to donate their kidney to you. These may include:

- Tissue typing
- Blood group
- Testing the recipient for anti-HLA antibodies
- Blood tests and scans to check their kidneys are functioning well and to make sure there are no signs of kidney damage
- Tests to find any viruses that may lead to an infection
- Tests for heart disease, diabetes, lung problems and cancer.

During these tests donors may find out that they have a health problem that they did not know about. If this happens they will receive support and referral to a specialist.

Psychological assessment

A psychological assessment is performed to make sure the living kidney donor is certain about donating and making a voluntary and informed choice.

Living kidney donors must be fully aware of the risks to their own health. The transplant team helps the donor to weigh up the risks and benefits and understand the medical procedure. This is called informed consent.

A psychological assessment also helps to make sure that the donor:

- Is comfortable with the idea of donation
- Is not being forced or paid for the donation
- Has a good understanding of the physical and emotional outcomes of kidney donation.

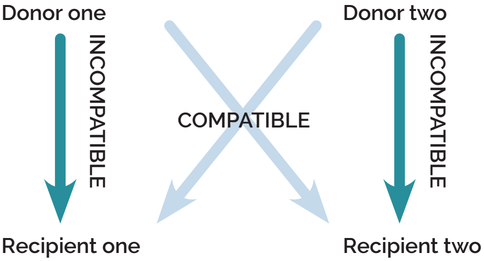
The living kidney donor can change their decision to donate at any time; right up to the time that the surgery takes place.

Not everyone is able to be a living kidney donor. Some conditions that may prevent someone from being a living kidney donor include:

- **Having cancer (or a history of cancer), hepatitis or AIDS**
- **Having diabetes, or having an increased risk of developing diabetes**
- **Having heart or lung problems (including high blood pressure)**
- **Being overweight**
- **Being a smoker**
- **Psychological concerns.**

Australian Paired Kidney Exchange Program (AKX Program)

If you have a living kidney donor that is not matched or may not be compatible for you it may be possible to enrol in the AKX Program. The AKX Program identifies matches between transplant recipients and living donors.



A computer program searches the entire database of registered recipient and living kidney donor pairs. The program looks for combinations where the donor in an incompatible pair can be matched to a recipient in another pair. If the computer finds a compatible match, two or more transplants can occur by swapping the living kidney donors.

More than 170 transplants have been successfully performed in Australia as part of the AKX program.

What happens during a living kidney donor transplant?

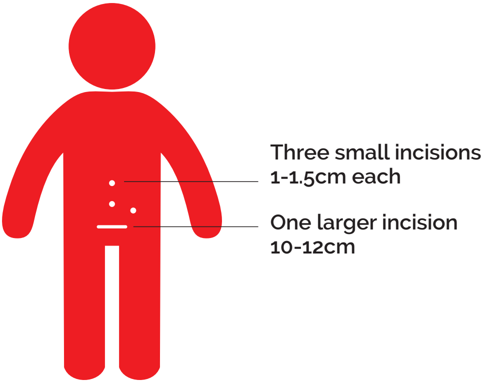
Before surgery

In the week before surgery, you and your living kidney donor will be re-tested to make sure you are both healthy and emotionally ready for the surgery. Another serum cross match test is done. The day before surgery, you and your donor go to hospital. You (the kidney recipient) may have a dialysis session or other special treatments.

During surgery

There are two ways of removing the kidney from a living donor; **laparoscopic nephrectomy** or **open nephrectomy**. The transplant team will discuss these procedures in detail with your living kidney donor. Most live donation procedures now occur through laparoscopy.

The procedure for transplanting the living donor's kidney into your body is the same as the procedure for a deceased donor kidney (see **Page 24**).

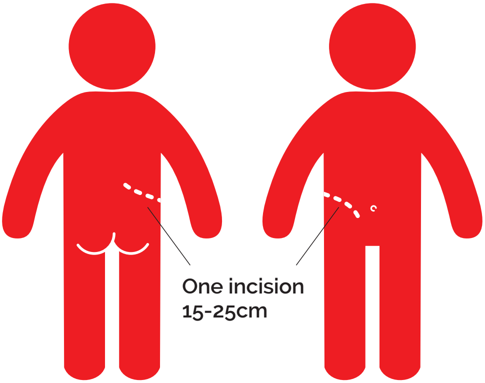


Laparoscopic nephrectomy

This is also called **keyhole surgery**. The surgeon inserts special instruments into the living donor's abdomen through three small cuts (also called incisions). A thin tube with a video camera on the tip (called a laparoscope) is inserted into the donor's abdomen. This allows the surgeon to see inside the living donor's body.

The kidney is collected in one of two ways:

- Endo catch – a drawstring bag is used to catch the kidney and draw it out of their body through a small cut about 10–12cm long
- Handport – the surgeon's hand is used to remove the kidney.



Open nephrectomy

The surgeon makes a cut about 15–25cm long on the side or front of the living donor's abdomen. The cut is along the bottom of their lower rib to a point just above their belly button. The cut will be on their left or right side depending on which kidney is being donated. The vessels connecting the kidney to its blood supply are clamped and cut. Their ureter (which is connected to their bladder) is disconnected.

After surgery

After the transplant surgery your living kidney donor will:

- Feel pain around their wound
- Be in hospital between four and ten days
- Need up to six weeks' recovery time at home
- Be unable to drive a car for six weeks minimum
- Need to avoid any heavy lifting for six weeks minimum.

It is important to follow all recovery instructions from your doctor to reduce the risk of infection and support the healing process.

Living donors who have laproscopic (keyhole) surgery often recover quicker than livening donors who have an open nephrectomy. Everyone's experience is different so it is important to talk about recovery with the health care team, family and friends.

What are the risks to living kidney donors?

Physical risks

Being a living kidney donor means having major surgery. This always carries a risk of serious complications, including death.

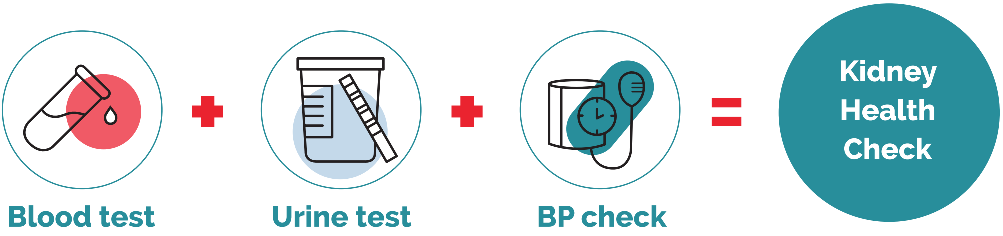
Complications that may occur during surgery include:

- Punctured lung (pneumothorax)
- Lung infection (pneumonia)
- Nerve damage
- Blood clots (thromboembolism)
- Bowel perforation
- Bleeding
- Death (very rare).

The transplant surgeon will talk to your living kidney donor about these risks in detail.

Living kidney donors are unlikely to develop kidney problems in the future. The removal of one kidney triggers the other kidney to increase in size and function. The remaining kidney can provide up to 75 per cent of normal kidney function rather than the expected 50 per cent. Any decline in overall kidney function is usually mild. This has no impact on the life span of your living kidney donor.

However, living kidney donors may be at increased risk of kidney disease if their remaining kidney is injured or a disease develops unexpectedly. There is also a small risk of increased blood pressure and protein in their urine as they get older.



A **kidney health check** is recommended for all living kidney donors.

Emotional risks

Most living kidney donors say they feel very satisfied with the donation experience. Even if the transplant is not successful, many donors say they feel positive about their decision.

There is a small chance for living kidney donors to experience mixed feelings after the donation. These feelings may be more likely if the transplant surgery has not gone as well as expected.

Some living kidney donors experience depression and anxiety after surgery. This is normal after many different types of surgery. Your donor's health care team can suggest ways of helping to manage this.

beyondblue (beyondblue.org.au or call 1300 22 4636) provide a confidential telephone information and advice helpline if you are feeling anxious or depressed.

Combined kidney and pancreas transplantation

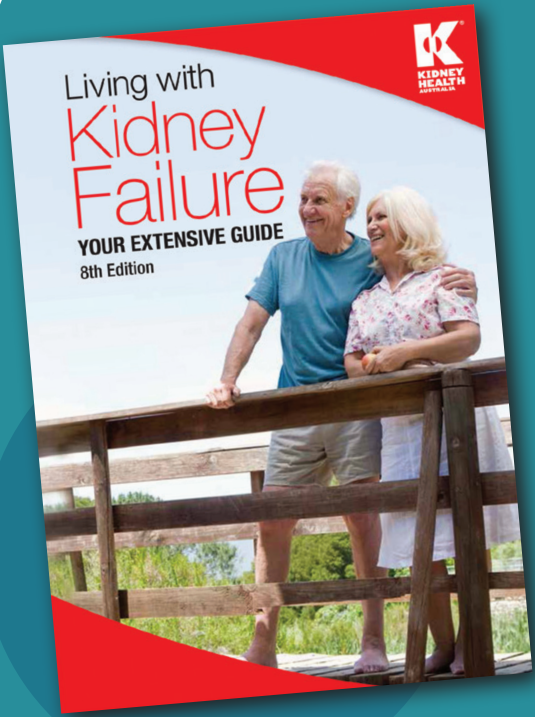
If you have developed kidney failure due to the complications of type 1 diabetes it may be possible for you to be considered for a combined kidney and pancreas transplant.

If you are medically and emotionally suitable for a kidney transplant you may also be suitable for a combined kidney and pancreas transplant if you:

- Have type 1 diabetes and are dependent on insulin
- Are a healthy weight range
- Are ideally aged less than 50 years
- Have no history of heart disease.

A number of extra tests will be performed to check what impact diabetes has had on your blood vessels, eyes, nerves and kidneys. These tests are needed to make sure that the benefits of the transplant surgery are greater than any risks.

Outcomes of combined kidney and pancreas transplants vary from person to person. If you would like to consider a combined kidney and pancreas transplant your health care team can discuss this with you.



Resources

Kidney Health Australia factsheets
kidney.org.au/resources/factsheets-and-photosheets

Kidney Health Australia book: **Living with Kidney Failure**.

An Introduction to kidney donation for live donors booklet.

My Kidneys My Choice Decision Aid available at **kidney.org.au/your-kidneys/treatment/my-kidneys-my-choice**

Kidney Helpline 1800 454 363
kidney.helpline@kidney.org.au

Clinical Guidelines for Organ Transplantation from Deceased Donors **tsanz.com.au**

Australian Organ Donor Register
donatelife.gov.au
02 6289 1555 or **1800 020 103**

donatelife.gov.au/ANZKX/information-patients for information on kidney transplants.

donatelife.gov.au/resources/donor-families/donor-family-support-services

What support is available?

There is support available for you if you are considering a kidney transplant or living with a transplant. Your hospital will also have staff available to help. This may include an accommodation officer, a patient liaison officer, and a social work department.

Financial assistance

If chronic kidney disease is causing you and your family financial hardship, there is a range of assistance available.

Start by speaking with the patient liaison officer or the social work department at your hospital.

Financial support from the Australian government can help you cover dialysis costs, travel costs, and carer support costs. To find out exactly what you're eligible for, please speak to your social worker or health care team.

For remote and rural patients – you may be able to recoup travel and accommodation costs for medical treatment far away from home. This is called the Patient Assistance Transport Scheme (PATS), and the amount of assistance varies per state. For more information, you can view the Guide to Patient Assistance Transport Schemes compiled by the National Rural Health Alliance **ruralhealth.org.au/sites/default/files/publications/nrha-guide-pats-2019.pdf**

For patients requiring carers – you may be eligible for carer assistance. To find out, call **Services Australia** on **132 717**. You can also refer to the **Department of Human Services** website.

There is also support available for living kidney donors. If your living kidney donor is employed they might be eligible for the **Supporting Leave for Living Organ Donors Programme**. This scheme provides reimbursement to their employer for up to 9 weeks of leave (based on a 38 hour week) of leave, at an amount up to the National Minimum Wage. For more information or to register see the **Department of Health** page **health.gov.au/initiatives-and-programs/supporting-livingorgan-donors-program**

Transport assistance

If you live in a rural or regional area you may be eligible for financial support from your state government to help with the costs of traveling to and from your transplant hospital.

Accommodation assistance

If you live in a rural or regional area you may need to find short-term accommodation close to your transplant hospital. You may be eligible to stay in the **Kidney Health Australia** Transplant House accommodation in Adelaide, Perth and Melbourne. This accommodation is available to patients travelling to the city from regional and rural areas undergoing a kidney transplant or for operation recovery. Some hospitals have an accommodation liaison officer to help patients and their families to find suitable accommodation close to the hospital. Hospitals that do not have an accommodation officer, the patient liaison officer or social work department are there to help.

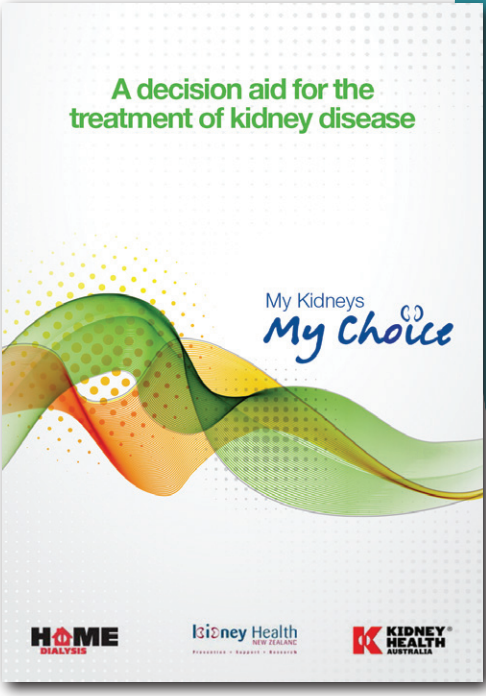
Travelling after a transplant

Traveling for work or pleasure within Australia and even overseas is possible after receiving a kidney transplant. However, you will require special attention to make sure that both you and your transplanted kidney stay healthy.

How do I make the choice?

The choice between a kidney transplant, dialysis and comprehensive conservative care depends on factors such as your age, health and lifestyle.

Education is the first step to choosing what type of treatment you will have. Take advantage of the nurses and social workers who offer group and individual education sessions. Use booklets (like this one), good quality websites, videos, and consider talking to other people in the same position. Your health care team can offer advice on any possible reasons why a particular treatment may not be possible due to current or previous health issues.



My Kidneys, My Choice is a useful decision aid that will help you to make your choice. It contains a check-list of issues that you should consider when making your choice. The decision aid is available from **kidney.org.au/your-kidneys/treatment/my-kidneys-my-choice**

Resources

Kidney Health Australia factsheets (translated versions available): **kidney.org.au/resources/factsheets-and-photosheets**

Kidney Health Australia booklets:
An Introduction to Haemodialysis,
An Introduction to Peritoneal Dialysis,
An Introduction to Home Dialysis,
An Introduction to Comprehensive Conservative Care for Kidney Failure,
An Introduction to Kidney Failure Treatment Options (translated versions available),
An Introduction to Kidney Donation for Living Donors
kidney.org.au/resources/books-and-publications

kidney.org.au/your-kidneys/living-with-kidney-disease/managing-money-work-and-travel

More information on accommodation assistance is available at **kidney.org.au/ways-we-help/transplant-house-program**

More information on transport assistance is available at **kidney.org.au/get-involved/advocacy/our-patient-charter**

Kidney Health Australia has a factsheet that provides details and useful tips about traveling with a kidney transplant available here **kidney.org.au/resources/factsheets-and-photosheets**

Kidney Helpline 1800 454 363
kidney.helpline@kidney.org.au

What if I am struggling to cope?

It is normal to feel anger, despair, fear and other emotions during the journey of kidney disease diagnosis and treatment. These feelings usually improve with time. If the impact of kidney disease is overwhelming you, it is important that you talk to someone.

The nurses, social worker, doctor at your renal unit or your GP are the best place to start. Social workers are employed in renal units to provide professional counselling to patients and their family members. They are very familiar with the issues you are experiencing. There is no need to feel embarrassed or ashamed or to suffer in silence.

You can also see your GP who can arrange a referral to a psychologist or social worker in your community. These services can be accessed through Medicare.

If you find yourself feeling low, please ask for help.

Resources

Kidney Health Australia fact sheet **Depression and Chronic Kidney Disease** can be found at **kidney.org.au/resources/factsheets-and-photosheets**

Kidney Health Australia book **SANE Guide to Good Mental Health for People affected by Kidney Disease** can be purchased at **kidney.org.au/shop/books**

beyondblue
beyondblue.org.au or call **1300 22 4636** provides a confidential telephone information and advice helpline.

Lifeline
lifeline.org.au or call **13 11 14** provides 24 hour crisis support and suicide prevention services.

What does that word mean?

A

ABO incompatible transplant

A type of transplant where your donor's blood type and your blood type are not compatible. With this type of transplant you receive medical treatment before and after your kidney transplant to lower antibody levels in your blood and reduce the risk of antibodies rejecting the donor kidney.

Acute kidney injury

A loss of kidney function that happens quickly which may or may not be permanent.

Acute rejection

Where your body quickly begins to reject your transplanted kidney in the first few weeks after your transplant.

Altruistic donation

Where someone anonymously donates a kidney to a recipient on the transplant waiting list.

Anti-HLA antibodies

Antibodies that your body develops to prevent infections.

Anti-rejection medications

Medication to reduce the risk of your body rejecting your new kidney.

Artery

The large blood vessel that takes blood from the heart to other parts of the body.

Artificial ventilation

Where a special machine called a ventilator is used to allow you to breathe.

B

Blood group

Refers to the red blood cell groups (O, B, A or AB) that determine the compatibility for blood transfusion and kidney transplantation.

Biopsy

A small piece of tissue is removed for testing and examination under a microscope.

C

Catheter

A plastic tube that is used to take fluid in or out of your body.

Chronic kidney disease

A term used to describe kidney damage or reduced kidney function that lasts for more than 3 months.

Chronic rejection

Where your body gradually rejects your transplanted kidney in the months and years after your transplant.

Cold ischaemia time

The time between when the kidney is removed from your donor and transplanted into your body.

Compatibility

An assessment of whether your body will accept the transplanted kidney.

Creatinine

Waste that is produced by your muscles. It is usually removed from your blood by your kidneys and passes out in your urine. When your kidneys aren't working very well, the creatinine stays in your blood.

D

Diabetes

A chronic disease caused by problems with the production and/or action of insulin in the body which helps control blood sugar levels.

E

eGFR

Where a mathematical formula is used to estimate your glomerular filtration rate. (See **Glomerular Filtration Rate**).

G

Glomerular filtration rate (GFR)

The best measure of kidney function and helps to determine your stage of kidney disease. It shows how well your kidneys are cleaning your blood. Your GFR is usually worked out from your creatinine blood test. (See **eGFR**).

H

Haemodialysis

A treatment for kidney failure. Your blood is pumped through special tubing to a haemodialysis machine. The machine acts like a kidney, filtering waste products from your blood before returning it to your body.

Health care team

Living with kidney disease means you will have contact with a great many health professionals. The members of your health care team will change depending on your circumstances. Your health care team may include these health professionals; nephrologist, surgeon, nurse, transplant coordinator, GP, social worker, psychologist, dietitian, physiotherapist, pharmacist. Your health care team are here to help you – ask questions and keep them up to date with how you are feeling.

HLA (Human Leukocyte Antigen) proteins

Special proteins on your cells that are unique to you, and are responsible for controlling your immune system.

Hyperacute rejection

Rejection that occur minutes or hours after your transplant. This is very rare.

K

Keyhole surgery

Surgery that uses very small incisions and special instruments for the surgeon to see inside your body.

L

Laparoscopic nephrectomy

Where a kidney is removed from a donor using a number of small incisions rather than one large incision (compare **open nephrectomy**).

N

Nephrologist

A doctor who specialises in kidney function.

Non-directed kidney donation

Where someone anonymously donates a kidney to a recipient on the transplant waiting list.

Nephrectomy

Surgical removal of one or both kidneys.

O

Open nephrectomy

Where a kidney is removed from a donor using one large incision (compare **laparoscopic nephrectomy**).

Organ Donor Register

The Australian Organ Donor Register is the only national register for people to record their decision about becoming an organ and tissue donor for transplantation after death. Joining the register is voluntary and you can elect which organs and tissues you are willing to donate. For more information visit: **donatelife.gov.au/join-register**

P

Peritoneal dialysis

Treatment for kidney failure during which dialysis fluid is moved in and out of your peritoneal cavity to remove wastes and fluid from your blood..

Plasma exchange

A treatment for kidney rejection that removes antibodies in your blood.

Polycystic kidney disease

An inherited kidney disease that produces fluid-filled cysts in your kidneys.

Pre-emptive transplant

When someone receives a kidney transplant before starting dialysis.

R

Rejection

Where your immune system attacks your transplanted kidney.

T

Terminal illness

An illness that is expected to lead to death.

U

Urine
The name for excess fluid and waste products that are removed from your body by your kidneys. Commonly called wee.

V

Vein
A blood vessel that returns blood to your heart.

W

Webster pack
A blister pack of medications put together by your pharmacist to assist with your medication routine.

Where can I get more information?

This booklet contains information about kidney transplantation. Other booklets in this series cover live kidney donation, home dialysis, haemodialysis, peritoneal dialysis, and comprehensive conservative care. We encourage you to read all the booklets so you can make an informed decision about your treatment.

Resources

Visit **kidney.org.au**

If you want to read more, **Kidney Health Australia**'s publication **Living with Kidney Failure** provides comprehensive information about all aspects of living with kidney disease.

Connect with **Kidney Health Australia**:

- Community Newsletter **kidney.org.au/subscribe**
- Social groups - Kidney club
- Facebook, Instagram, Twitter.

Kidney Helpline

1800 454 363
kidney.helpline@kidney.org.au

Free health information service for anyone requiring assistance with managing their kidney health, understanding their kidney disease diagnosis or information on **Kidney Health Australia** support programs.

Kidney Health® Australia

www.kidney.org.au

As the peak body for kidney health in Australia, we strive to create a healthier community through increased awareness and early detection of kidney disease. We connect kidney patients to vital resources and services to help them manage their condition and improve their quality of life. We also support and foster advocacy and research to drive improvements in the diagnosis, management and eventual cure of kidney disease.

Our support services

- Educational resources on kidney health and kidney disease, covering diagnosis, treatment options and management
- Fact sheets, books and educational videos and apps about kidney disease
- A large range of self-management resources including recipe books and nutrition resources
- Renal unit locations guide
- Peer support programs
- Holiday dialysis bus
- Transplant housing
- Support groups
- Kidney Health Week – national kidney awareness week
- Community events and challenges
- Regular newsletters
- Guidelines, resources and education for Health Professionals.

Connect with us:
Freecall 1800 454 363
www.kidney.org.au

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