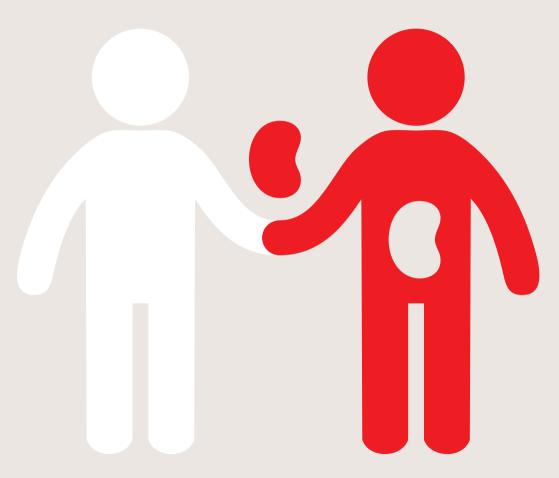
An Introduction to Kidney Donation by Living Donors





Acknowledgements:

This booklet was produced by Kidney Health Australia in collaboration with the Royal North Shore Hospital and the Victorian Renal Clinical Network. It has been supported by funding from the Joe White Bequest, and an unrestricted educational grant from Amgen Australia.





An Introduction to Kidney Donation by Living Donors © Kidney Health Australia 2017

Copyright:

This publication is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced without written permission from Kidney Health Australia. Requests and enquiries concerning reproduction and rights should be directed to Kidney Health Australia, PO Box 9993, Melbourne VIC 3001.

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.

Contents

What are the kidneys? What do healthy kidneys do? What happens when the kidneys don't work properly?	6
Kidney transplantation Who can have a kidney transplant?	9
Living kidney donors Living donor work-up tests Australian Paired Kidney Exchange (AKX) Programme What happens during a living kidney donor transplant? What are the risks to living kidney donors?	14
What support is available? Where can I get more information?	41
What does that word mean?	44

Kidney Health Australia acknowledges the valuable contribution provided by the reviewers of this resource:

Dr Marie Ludlow General Manager Clinical Directorate, Kidney Health Australia (Editor)

Dr Shilpa Jesudason Clinical Director, Kidney Health Australia

Dr Lisa Murphy General Manager Research, Kidney Health Australia

Mr Peter Carson, Living kidney donor

Ms Denise Fracchia, Dialysis/Transplant Coordinator, Western Health

Ms Alice Gleeson, Manager, Victorian Renal Clinical Network

Ms Cheryl Hyde, Nurse Manager Renal Services, Royal North Shore Hospital

Ms Orla Maney, Clinical Nurse Consultant, Monash Health

Dr Bill Mulley, Nephrologist, Monash Health

Dr Amanda Robertson, Head Nephrology Surgery, Melbourne Health

Dr Yvonne Shen, Nephrologist, Royal North Shore Hospital

Ms Amber Williamson, Living kidney donor recipient

Foreword



This booklet has been designed to provide you with information about what it means to be a living kidney donor.

If you are reading this for the first time it may be that you are thinking about being a living kidney donor, or asking someone to be a living kidney donor. The information provided in this booklet will help living

donors, transplant recipients, and their families and significant others to understand the planning, tests and procedures that are required for living kidney donation.

Being a living kidney donor is an immensely important decision and can be an emotional and life-transforming experience for both donor and recipient. It is normal to experience concerns and to have many questions. We hope this resource helps you explore these emotions and answers some of your questions.

Kidney Health Australia has many more resources available on living donation and other kidney health issues. Our fully qualified team of nurses and allied health professionals are only a phone call away, should you wish to speak to someone confidentially. Contact the Kidney Health Information Service on 1800 454 363 or khis@kidney.org.au.

Welcome to Australia's kidney community, and please keep in touch so that we can provide whatever assistance or guidance you may require. Kidney Health Australia is here to assist you throughout your journey.

Mikaela Stafrace

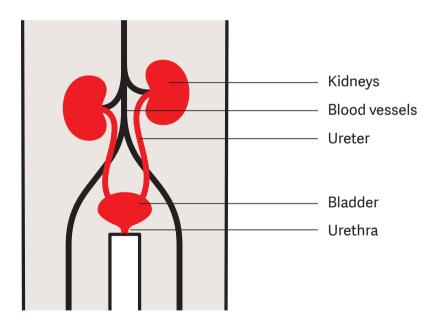
CEO Kidney Health Australia

What are kidneys?

Let's start your living kidney transplant journey at the beginning...

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), just under your ribs.

Your kidneys are part of the body's urinary system, and they connect to your bladder.

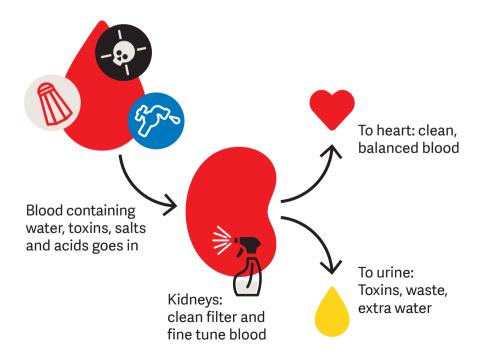


What do healthy kidneys do?

Kidneys are the unsung heroes of the body.

The kidneys play a number of important roles in the body such as:

- extracting excess water to make urine (wee)
- controlling your blood pressure
- filtering waste products and toxins from your blood into your urine
- helping make red blood cells
- keeping your blood chemicals and salts in balance
- keeping your bones healthy



What happens when the kidneys don't work properly?

Chronic kidney disease (also referred to as CKD) is called a 'silent disease' as there are often no warning symptoms. Sometimes people lose up to 90 per cent of their kidney function before getting any symptoms. The symptoms can be very mild, or you may simply feel unwell or 'not yourself'.

Symptoms of reduced kidney function:

- Holding on to fluid which leads to breathlessness and swelling
- Tiredness
- Headaches
- Poor memory and concentration
- Being irritable

- Sleep disturbances
- Feeling washed out
- Itchiness
- Nausea and loss of appetite
- Weight loss
- Changed sexual function

Treatment for end stage kidney disease

When the kidneys permanently stop working this is called end stage kidney disease.

There are 3 treatment options for people with end-stage kidney disease:

- Dialysis
- Transplant
- Supportive care

All 3 are important pathways a patient may decide to take in consultation with their kidney care team, and family.

Kidney transplantation

A kidney transplant involves removing a kidney from the **donor** and placing it in the body of the person with end stage kidney disease (the **recipient**). If a person is suitable for a kidney transplant, this is the most effective treatment for end stage kidney disease. Unfortunately a kidney transplant is not suitable for everyone, and potential recipients must be assessed first by their kidney specialist (**nephrologist**).

A kidney transplant is treatment for end stage kidney disease, but it is not a cure. A transplant offers a more active life, without needing dialysis. However, the transplanted kidney requires ongoing care. The transplant recipient will need to take medications to stop their body rejecting the donor kidney (anti-rejection medications) for as long as they have the transplanted kidney. There are also risks of infection and medication side-effects.

How long the transplanted kidney will work can depend on many factors. In Australia, around 4 in every 10 kidney transplants are still working 15 years later. Some people have had kidney transplants that have lasted more than 30 years.

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



RESOURCES

- Kidney Health Australia fact sheets (translated versions available): Kidney Transplants, Treatment Options
- Midney Health Australia booklets: An Introduction to Kidney Disease Treatment Options (translated versions available), An Introduction to Kidney Transplantation
- 🔞 Kidney Health Australia book: Living with Kidney Failure
- www.kidney.org.au > Your kidneys > Support > Kidney disease > Treatment
- (KHIS) 1800 454 363

Who can have a kidney transplant?

Kidneys can be donated by a Living Donor or a Deceased Donor.

For every 10 kidney transplants performed in Australia:



three

involve kidneys from living kidney donors

seven

involve kidneys from deceased kidney donors

In Australia the average waiting time for a kidney transplant from a deceased donor is 3 ½ years. Some people have to wait longer depending on their blood type and antibodies.

Living kidney transplantation often has better success rates and reduces the time the recipient will have to wait for a kidney transplant. A person with end stage kidney disease can be given the option of transplantation if they are considered to be medically suitable by the kidney transplant team.

Unfortunately a transplant is not suitable for everyone, as the risks are sometimes too high. The transplant team may decide that the risks of the operation or the medications may make their health worse.

Factors affecting a person's suitability for a kidney transplant include:

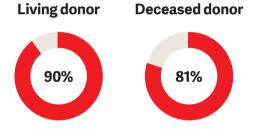
- Agree with the idea of transplantation and acceptance of the risks involved
- General health, apart from kidney failure especially the health of heart, lungs and blood vessels, and previous illnesses including cancer and infections.
- Willing to go through with the tests and the transplant surgery
- Willing and able to take the anti-rejection medications.

Are kidney transplants successful?

Kidney transplants in Australia have a high success rate. 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.

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

Percentage of tranplanted kidneys working after five years from a:



Living kidney donors

Living donors can be:

- Related: a relative (for example a parent, grandparent, brother, sister, or adult children), related by blood to the recipient
- Unrelated but known to the recipient: partner, non-blood relative or friend of the recipient
- Non-directed kidney donation (altruistic): This is where someone anonymously donates a kidney to a recipient on the transplant waiting list. In this situation the living donor has no say in who receives their kidney.

Transplant compatibility

The tests to determine whether a living donor will be a compatible donor for the recipient are simple blood tests. New techniques mean that transplants can often now be done in situations that were previously difficult. For example, if your recipient is not from a compatible blood group there are now ways to deal with this, depending on the individual situation.

Sometimes a donor and their potential recipient are not compatible. This donor-recipient pair may be suitable for the Australian Paired Kidney Exchange Programme (see page 28).

Timing of living donor transplants

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 the recipient can have a transplant sooner, and possibly even before they need to start dialysis. This is called a **pre-emptive transplant**.

Having a living donor also means that the transplant surgery can be organised and planned around the donors' and recipients' lives. Hospital admission and surgery can be planned ahead of time, allowing both the donor and the recipient time to prepare for the surgery and recovery, which also improves transplant success rates.

Planning for the surgery also means that the time between when the kidney is removed from the donor and transplanted into the recipient (called the **cold ischaemic time**) is shorter. A shorter cold ischaemic time improves the chances of a successful transplant surgery and contributes to longer kidney transplant survival.



RESOURCES

- Kidney Health Australia fact sheets: Deciding to be a live donor, Live kidney donation, Organ and tissue donation and transplantation, Non-directed living kidney donation
- 🌭 Kidney Health Information Service (KHIS) 1800 454 363
- For more information about organ and tissue donation, visit the DonateLife website at www.donatelife.gov.au
- For more information about the Australian Paired Kidney Exchange Programme visit www.donatelife.gov.au/about-us/kidney-exchange-programme

Living donor work-up tests

The assessment of a potential living kidney donor is extensive and will take between 3 and 12 months. The aim is to make sure the potential donor is medically and psychologically suitable to give one kidney.

The work-up tests will involve a number of health professionals, including:

- general practitioner (GP)
- transplant coordinator
- nephrologist
- surgeon
- psychologist/psychiatrist
- social worker
- and possibly more.

These health professionals all form part of your **health care team**. The members of your health care team will change depending on your needs and circumstances

Who can be a living kidney donor?

Not everyone is able to be a living kidney donor, as donors must be healthy and able to undergo surgery with a general anaesthetic. A donor must also be well enough to be able to live with one kidney after the donation.

Conditions that may prevent you from being a donor include:



Kidney damage, reduced kidney function, or an increased risk of developing reduced kidney function in the future



Structural issues such as complex blood supply to your kidney



Diabetes, or an increased risk of developing diabetes in the future



High blood pressure



Heart, stroke or lung problems



Being overweight or underweight



Smoking



Other conditions such as cancer, chronic infections, other chronic illnesses or psychological issues.

Step-by-step to being a living kidney donor

The first steps in becoming a living kidney donor are:

- Contact the transplant hospital that is providing treatment for your potential recipient and ask to speak to a transplant coordinator about being a living donor.
- The transplant coordinator will provide you with a list of tests that your GP can perform or arrange.
- Visit your GP and arrange for the work-up tests (see the next page for a sample list of tests that you may need).
- You can also talk to your GP about some of the conditions that may prevent you from being a living donor.
- Attend an education session and meet other members of your health care team such as a social worker, psychologist or psychiatrist.
- The final step is to meet the transplant team (nephrologists, surgeons) for a review and decision about donation.

The transplant coordinator will be your key contact during the work-up process and will help to coordinate the tests. They will also support you with any questions or concerns that you have.

During the work-up process you may find out that you have a health problem that you did not know about. If this happens you will receive support and referral to a specialist.

Sample living kidney donor work-up tests

You will need initial bloods tests, urine tests and scans to make sure you are healthy. This list is a guide only, as each renal unit will have an agreed procedure. Additional tests may be needed, depending on individual circumstances.

This may seem like a lot of tests, but this is a very important part of making sure living kidney donation is going to be safe for you.

Initial tests:

- Bloods tests to check blood group, general health, heart health, diabetes, liver and kidney function
- Urine tests
- Blood tests to check for infections

Stage 2 tests:

- Repeated blood and urine tests to double-check for kidney disease or diabetes
- Specialised tissue type and cross match testing to assess matching between donor and recipient

Stage 3 tests:

- Chest x-ray and lung function tests
- Heart function tests
- Kidney ultrasound and other scans of kidney anatomy and function
- Pap smear and mammogram test (to screen for cervical and breast cancer in females)
- Prostate test (to screen for prostate cancer in males)
- Bowel cancer screening (for people with risk factors, usually if aged over 50 years)
- Tissue typing and cross matching (again)



Quinnie enjoys a cuddle from her grandfather who is also her living kidney donor. Image courtesy of Geelong Advertiser.

Education for living kidney donors

It is important that all potential living kidney donors are making an informed decision. To do this, you will need to understand the possible risks and benefits of being a living kidnev donor.

You will be expected to attend an education workshop on living kidney donation hosted by a renal unit. You will also be provided with written information about living kidney donation. Your transplant coordinator can provide a lot of answers and you can also do your own research. You will also talk frequently with your doctors and surgeon, and will have many opportunities to ask questions.



Some people find it helpful to talk to someone who has been a living kidney donor. Kidney Health Australia can connect you with someone who has been through this experience. Call 1800 454 363 for more information. You can also watch the videos 'Living Kidney Donation: What you need to know' with your family and friends (see resources on page 23).

These are some questions to think about:

- Why do you want/not want to donate a kidney?
- What do you think about organ donation in general?
- What effect could donation have on your relationship with your relative or friend?
- Do you expect some sort of reward or emotional 'pay-back' for donating?
- Do you feel you can make an informed choice about being a living kidney donor? Do you need more time or information?
- How would you feel if the kidney transplant is not successful or does not go as smoothly as everyone would like?
- Are there other people who could be donors?
 If so, how will the donor be chosen?
- Do you have a 'support network' family and friends to help you through the donation experience?
- Will your current job/home situation allow you to have time off for testing, surgery and recovery?
- How will you feel if the tests show you are not able to donate?
- Are you healthy enough to donate? Would you be willing to make changes (such as losing weight) to be able to donate?



You can change your mind about being a living donor right up to the moment of the operation. However, it is important to think through the issues carefully before confirming your intention to be a living kidney donor, as changing your mind at a later stage may cause you and your intended recipient anxiety.



RESOURCES

- Kidney Health Australia fact sheets: Deciding to be a living kidney donor, Live Kidney Donation, Life With A Single Kidney.
- Queensland Health videos 'Living Kidney Donation:
 What you need to know' at www.kidney.org.au
 Your kidneys > Support > Organ donation >
 Living kidney donation
- Making a Decision about Living Organ and Tissue Donation published by the National Health and Medical Research Council, available to download at www.nhmrc.gov.au/guidelines-publications/e70
- If you would like more information about organ and tissue donation, visit the DonateLife website at www.donatelife.gov.au

Donor and recipient matching

Your immune system is designed to keep you safe from foreign invaders such as viruses and bacteria. It does this by recognising proteins different to your own on the virus or bacteria. It will attack them and develop antibodies against these proteins.

This is how your immune system defends you against infections. It is also the reason that rejection can occur after a transplant, as the proteins on the donor's cells are usually different to those of the recipient. The donor's cells are recognised as being different and attacked - this is rejection.

To reduce this risk, kidney donor and recipient matching is carried out. The technology for this is always improving and it can be very complicated.

Matching can be divided into 3 broad areas:

- blood group matching
- tissue type matching
- cross matching.

Each of these is important to assess the risk of rejection between a donor and a recipient.

Blood group matching

Ideally, both you and your intended transplant recipient should be of the same blood group.

However, living kidney donor transplants can often go ahead even if you and your intended recipient are not from matching blood groups, as long as the antibody levels are not too high. This is called an **ABO incompatible transplant**.

Extra treatments will be needed for your intended recipient to remove the blood group antibodies before the transplant can go ahead. ABO incompatible live donor transplants are being performed in many Australian transplant units with excellent results.

Tissue type and cross matching

Tissue typing is done by taking a blood sample from you and your intended recipient and comparing the proteins on both of your cells. There is some detailed laboratory work needed at this stage.

HLA Matching: The proteins which are most important for rejection are called HLA-proteins. The more HLA-proteins that are the same between you and your intended recipient the lower the risk of rejection.

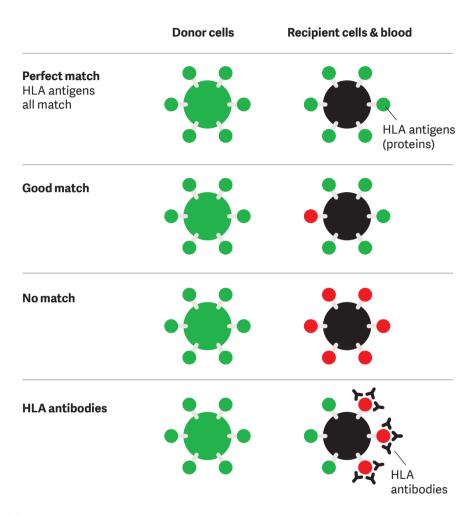
If you are related to the recipient there is a higher chance that you will have HLA-proteins in common, but sometimes there can be none that match even between siblings. Also, it is possible to be well matched with someone who is not related to you.

Sometimes there may not be a tissue type match between you and your recipient. The transplant can still go ahead if your recipient does not have antibodies against the HLA-proteins which are different.

This is assessed by a special test called the cross-match. If the cross match is positive, often a straightforward transplant cannot occur.

HLA Antibodies: Sometimes the recipient makes antibodies against HLA antigens (proteins). The anti HLA antibodies can attack the kidney and cause rejection. So if the level of these antibodies are too high, the donor and recipient may not be suitable for a transplant.

If the antibody levels are too high it may be possible to enter the Australian Paired Kidney Exchange (AKX) Programme instead (see page 28).





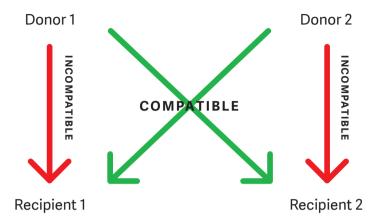
For more information about tissue typing, please talk to your transplant unit. It can get very complicated, so it is best to ask the transplant coordinators or doctors to talk you through your own individual circumstances.

Australian Paired Kidney Exchange Programme (AKX Programme)

If you have a living kidney donor that is not match for you it may be possible to enrol in the AKX Programme. The AKX Programme 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 Programme.





www.donatelife.gov.auAbout us > Kidney exchange programme

Donor surgeon assessment

Having a kidney removed to donate for transplantation is a major procedure. The donor surgeon will be responsible for this operation. Your donor surgeon will have a detailed consultation with you to inform you of the procedure and the short and long term risks.

Your surgeon will recommend to you:

- any extra tests that may be needed
- how you can prepare for your surgery
- what to expect during your recovery from surgery
- how to reduce your risks in surgery

You can expect two or more visits to you donor surgeon before the surgery and at least one after your surgery.

You are welcome to bring a family member or friend to your appointments with your donor surgeon, but is preferred that you do not bring the potential recipient of your kidney.

See 'What are the risks to living kidney donors?' on page 37 for more information about the possible physical and emotional risks of being a living kidney donor.



RESOURCES

- Kidney Health Australia fact sheets: Deciding to be a live donor, Live kidney donation, Non-directed living kidney donation
- Kidney Health Information Service (KHIS) 1800 454 363

Psychological assessment for living kidney donors

A psychological assessment is performed to make sure that you are certain about donating your kidney, and that you are making a voluntary and informed choice.

All living kidney donors must be fully aware of the risks to their own health. The transplant team will help you to understand the risks, benefits and details of the medical procedure. This is called an informed decision.

A psychological assessment also helps to make sure that you:

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

What happens during a living kidney donor transplant?

Before surgery

In the week before surgery, you and the transplant recipient will be re-tested to make sure you are both healthy and emotionally ready for the surgery. Another cross match test is done. The day before surgery, you and your recipient go to hospital.

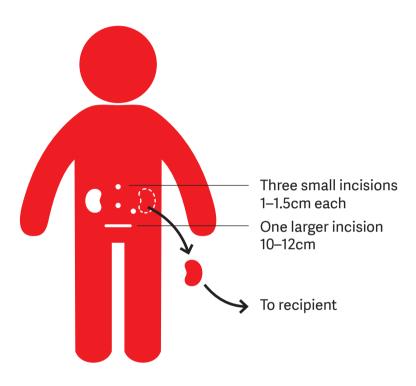
During surgery

There are two ways of removing your kidney; *laparoscopic* nephrectomy or open nephrectomy. The transplant team will discuss these procedures in detail with you.

Laparoscopic nephrectomy (also known as keyhole surgery) This is the most common way of removing a kidney for living donation. Compared to an open nephrectomy, a laparoscopic nephrectomy has a quicker recovery and less pain.

The operation is performed under **general anaesthetic**. Between 3 and 5 small cuts are made in your abdomen to place 'ports'. Instruments and a camera (called a laparoscope) are placed in these ports so that the surgeon can see the kidney and remove it from the surrounding organs. The blood vessels to and from your kidney and your ureter are then stapled and divided. The kidney is then removed through a larger cut before it is cooled and washed of your blood in a bowl of ice on a back table.

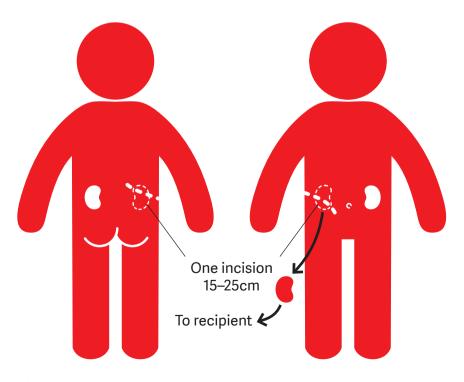
Laparoscopic nephrectomy



Open nephrectomy

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

Open nephrectomies are rarely performed now as the donor has more pain and is slower to return to normal activities compared with laparoscopic donor surgery. An open nephrectomy is occasionally required if the laparoscopic technique does not work.





RESOURCES

The procedure for transplanting your kidney into the transplant recipient is described in detail in the booklet 'An Introduction to Kidney Transplantation'.



REMEMBER

Talk to your health care team about the differences between laparoscopic and open nephrectomy. Call the Kidney Health Information Service 1800 454 363 if you have any questions or would like more information.

After surgery

The operation to remove your kidney will take between 2 and 3 hours. You will then be taken to the Recovery Room where you will wake up, before being transferred to the Ward. You will feel some pain around your wound and you will be given medication for this.

Most donors are able to sit out of bed the next morning to have breakfast. You will then have your catheter, drain and IV drip removed as soon as possible.

The length of time that you will need to stay in hospital may be around 4 to 7 days.

You will then need up to 6 weeks of recovery time before returning to work. It is recommended that you do not drive a car until 2 to 4 weeks after the surgery. You should also avoid any heavy lifting for 6 weeks.

Living donors who have laparoscopic (keyhole) surgery often recover quicker than living donors who have an open nephrectomy. Everyone's experience is different so it is important to talk about recovery with your health care team.

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. The risk of death is approximately 1 in 3000. This is similar to the risk of death from having a gall bladder removed.

Complications that may occur during surgery include:

- Chest infection (pneumonia is rare)
- Urinary tract infection
- Bleeding
- Blood clots
- Damage to other organs

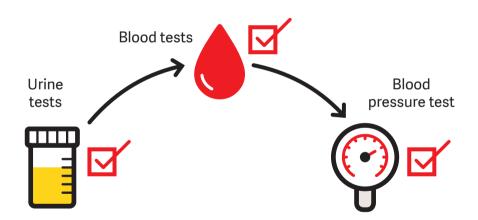
Your donor surgeon will talk to you about these risks in detail.

To be accepted as a living kidney donor you need to be very healthy. This is so that the risk of kidney donation to your future health is minimal.

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 and make up for the loss of one kidney. Your remaining kidney can provide up to 75 per cent of normal kidney function rather than the expected 50 per cent.

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

It is recommended that you return to your transplant unit for a follow-up 3 and 6 months after your surgery. Follow-up with your GP is then recommended every year after that. This will include a general health review, blood pressure measurement, and blood and urine tests to assess the health of your remaining kidney.





RESOURCES

(ii) Kidney Health Australia fact sheet: How to look after your kidneys, Life with a single kidney

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 you may experience mixed feelings after the donation. These feelings may be more likely if the transplant surgery has not gone as well as expected.

It is also common for living kidney donors to experience depression and anxiety after surgery. This is normal, and happens after many different types of surgery.

Your transplant coordinator, a social worker, or the nurses or doctors at your renal unit are the best place to ask for help. Social workers are employed in renal units to provide professional counselling to you and your 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.



CALL TO ACTION

If you find yourself feeling low, please ask for help. Beyondblue (<u>beyondblue.org.au</u> or call 1300 22 4636) provide a confidential telephone information and advice helpline.

Financial risks

Being a living kidney donor can impact your finances. During the work-up assessment, transplant and recovery process you will have a lot of appointments and will need to take time off work. After the surgery it is recommended that you have around 6 weeks of recovery time at home. See Financial Assistance on page 42 for more information on this topic.



Amber with her dad and living kidney donor.

What support is available?

There is support available for living kidney donors and transplant recipients. Your hospital will also have staff available to help. This may include an accommodation officer, a patient liaison officer, and a social worker, as well as the transplant coordinators.

Accommodation assistance

If you live in a rural or regional area you may need to find short-term accommodation close to the transplant hospital. Kidney Health Australia has secure, comfortable quality accommodation where you can rest and recover from your donor surgery. Kidney Transplant Houses are currently available in Perth and Melbourne, and construction is underway in Adelaide. More information is available at kidney.org.au > your-kidneys > support > patient-and-carer-support > kidney-transplant-houses.

Some hospitals have an accommodation liaison officer to help patients and their families to find suitable accommodation close to the hospital. In hospitals that do not have an accommodation officer, the patient liaison officer or social work department will be able to help.

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 travelling to and from your transplant hospital. More information is available at **kidney.org.au** > your-kidneys > support > patient-and-carer-support > country-travel.

Financial assistance

Public hospital costs, including medical tests, are covered by the usual hospital payment arrangements. There is usually a six-week recovery period before you can return to work. You will also need to allow time to have medical tests before the operation and check-ups afterwards.

Living kidney donors can also seek assistance from the Australian Government Support for Living Organ Donors Program. This program is designed to help support people who may wish to be a living donor, but may be unable to do so due to a loss of income or the financial stress that living donation may cause.

This program provides a financial contribution (calculated for up to nine weeks of leave, based on a 38-hour week, at up to the National Minimum Wage) to employers to either replenish an employee's leave or contribute towards reimbursing an employer who has made a payment in place of income lost due to living organ donation.

From 1 July 2017, the program has been expanded to allow all living organ donors, whether they are employed or not, to claim reimbursement for some out-of-pocket expenses that are experienced due to the living organ donation process (up to \$1,000). Both employed and non-employed living kidney donors can apply for reimbursement for out-of-pocket expenses.

For more information or to register see the Department of Health website www.health.gov.au/internet/main/publishing.nsf/Content/Leave-for-living-organ-donors, call (02) 6289 5055 or email livingorgandonation@health.gov.au.

Where can I get more information?

If you are thinking about being a living kidney donor we encourage you to contact Kidney Health Australia's Kidney Health Information Service on **1800 454 363** or **khis@kidney.org.au** and we can assist with support and information.



RESOURCES

- Kidney Health Australia has a range of fact sheets on this topic. See the Patient & carer support page at kidney.org.au
- www.kidney.org.au
- Connect with us on Facebook, Instagram and Twitter
- Kidney Health Information Service 1800 454 363

What does that word mean?

A

ABO incompatible transplant

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

C

Chronic kidney disease

Progressive reduction in kidney function or kidney damage which is present for at least three months.

Cold ischaemia time

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

Compatible

When a donor's blood type is a good match to the recipient's blood type.

D

Deceased donor

Someone who donates an organ or tissue for transplantation after their death.

Donor

Someone who donates an organ or tissue for transplantation. Donors can be deceased (they donate after their death) or living (they donate while still alive).

Ε

End stage kidney disease

The stage of kidney disease when the kidneys have stopped working and treatment, such as dialysis or a transplant, is needed to sustain life. Also referred to as End Stage Kidney (Renal) Failure, kidney failure or stage 5 chronic kidney disease.

G

General anaesthesia

Medicine that makes you unconscious so that you do not feel pain during surgery.

Н

Health care team

The team of people involved in your care. This may include health professionals, family members, loved ones, and yourself.

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).

Living Donor

Someone who donates an organ or tissue for transplantation while they are still alive.

N

Nephrologist

A doctor who specialises in kidney function.

0

Open nephrectomy

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

P

Pre-emptive transplant

When someone receives a kidney transplant before beginning dialysis.

R

Recipient

The person who receives a transplant.

S

Social worker

Health professionals who are available to support and advise you and your family about daily stresses, lifestyle readjustments and practical issues associated with kidney disease.

Т

Transplant coordinator

A health professional who assists in organising the testing required for a transplant to go ahead.

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







