

Thinking about being a kidney donor?

If you have good general health and two well-functioning kidneys, you may be able to donate one of your kidneys to someone who needs a kidney. Someone who donates a kidney is called a kidney 'donor', and the person who receives the kidney is called a 'recipient'.

The donor may be related to the recipient, or they may be completely unrelated, such as a spouse, a partner, or a friend. The donor not only needs to be medically well, but they also need to be assessed as fit for surgery.

There are two types of living donor transplants in New Zealand:

- **Directed donor:** Directed donors are people who wish to donate to someone they know. They may be related, such as a parent, brother, sister, or cousin, or they may be unrelated, such as a spouse, a friend or a work colleague.
- Non-directed donor: Sometimes referred to as an 'altruistic donor', a non-directed donor wishes to donate a kidney to someone who needs a kidney, even though they don't know who will receive the kidney. Specialists will determine who will be a good match for the donor kidney from those patients already listed on the deceased donor waiting list, or on the kidney exchange programme. The donor and recipient will not get to know each other, as the donor's gift remains anonymous.

Deciding to donate

The way people decide to donate can vary from person to person. Some people make the decision instantly, with few concerns. Other people go through some soul-searching and will talk with close friends or family before deciding whether to donate or not. It is normal for many people to experience some hesitation and anxiety around donating a kidney.

People should not feel obligated to offer to donate. A potential kidney donor should have a genuine interest in donating without feeling pressured to donate.

Even if someone decides that they would like to donate, they are able to change their mind at any stage. For example, a change in personal circumstances during the course of donor evaluation might mean that the donor is no longer in a position to donate, or testing may need to be put on hold. A person who decides that they are unable to donate, for whatever reason, may also experience guilt.

The only "right" decision is one that the potential donor feels comfortable with. A person thinking about becoming a living donor should speak with their local transplant coordinator if they have any questions or concerns about their decision.

What if the potential recipient declines to accept my offer?

Just as a donor can decide at any point that they are unable to go through with donation, the potential recipient may also decide that they do not want you to donate to them. Often a recipient may care more for the health and wellbeing of those that they care about, than for their own wellbeing, and may not want to cause disruption, pain and risk, however small, to the potential donor.

What are the advantages of a living donor transplant?

For the person receiving the kidney, the advantages of a living donor transplant are:

- Having a transplant before the need for dialysis
- A shorter time on dialysis (this is especially important for children)
- The operation can be planned for a time that suits the potential donor
- A good success rate the transplanted kidney usually works straight away and usually lasts longer than a kidney from a deceased donor
- A longer life expectancy than when living on dialysis

Who can donate?

If a person is interested in knowing more about donating a kidney, and whether they might be suitable as a donor, they should contact their local transplant coordinator or hospital in the first instance. This service is free, as opposed to visiting your GP.

A link to New Zealand kidney transplant coordinators is found here: https://www.kidney.health.nz/for-patients/kidney-donation-and-transplantation/transplant-co-ordinators/

The transplant coordinator can answer any questions that the potential donor has, so that the donor can make an informed decision about being tested. This conversation is strictly confidential and is not shared with the potential recipient.

Potential donors should be over 18 years of age and in good health. There is no strict upper age limit, but there is less chance that an older person will pass the necessary medical tests to ensure that donation would be safe.

A health questionnaire will be completed before testing begins. The health questionnaire will include the potential donor's health history, both medical and surgical, as well as family health history. Medical reasons for not being able to donate might include:

- **High blood pressure** (both treated and untreated)
- Cancer
- Diabetes
- Kidney disease
- Heart disease
- Liver disease
- Being very overweight

- Mental health concerns
- Age

The donor evaluation

If there are no obvious risk factors identified in the health questionnaire, and the potential donor wishes to continue with the assessment, then the donor evaluation process can begin.

People thinking of giving a kidney who are over-weight, will be asked to lose weight before tests and assessments are started. If the potential donor is motivated to lose weight and would like some professional assistance this may be available from the hospital dietitian.

The donor evaluation is often likened to a full warrant of fitness for a motor vehicle. The testing is comprehensive and assesses the medical and surgical suitability of the donor. Should any test results be of concern, the transplant coordinator would let the potential donor know. Further investigations might be ordered, and workup put on hold until completed. For serious findings, the workup would stop altogether, and the donor declined as a potential kidney donor.

Testing evaluates not only the health of the donor, but also whether the donor is likely to be able to live well with one kidney for the rest of their days. Should the transplant team be unsure as to whether a potential donor be at future risk if they were reduced to a single kidney, the team will err on the side of caution to protect the donor. It is the transplant team's decision as to whether a donor is able progress to donating, even if the donor is highly motivated to donate.

Although the cost of the testing is 'free', the donor may need to take time off work to attend daytime clinic appointments or complete tests. The cost of time of work, or paying for parking or childcare, is borne by the potential donor.

Tests include:

BLOOD AND URINE TESTS

CHEST X-RAY

24 HOUR BLOOD PRESSURE MONITORING

ECG

An ECG is a recording of heart electrical activity. Electrodes, pads with wires linking them to a recorder, are put on the chest, arms and legs. These electrodes pick up the electrical signal from the heart, transfer it to the recorder and a graph is printed out. It is a painless test.

CANCER SCREENING

An acceptable prostate (PSA blood test) for men over 50, acceptable mammogram within two years for women over 45, and acceptable cervical smear within last three years is required.

TISSUE TYPING/CROSSMATCHING

The bloods taken for tissue typing and crossmatching are collected at the same time and sent for testing in Auckland.

PSYCHOSOCIAL EVALUATION

A clinical psychologist meets the potential donor to talk about informed consent, their reasons for donating and the decision-making process, the adequacy of support (financial and social), their psychological health, and the donor/recipient relationship.

CT ANGIOGRAM SCAN

During this scan, a special fluid (an iodine-based contrast medium) is injected into the blood stream through a vein in the arm. The scan shows the position and shape of the kidneys, the kidney arteries and veins as well as the tubes (ureters) connecting the kidneys to the bladder. It can also identify any scarring to the kidney or kidney stones. The potential donor does not need to be admitted to hospital for this scan.

The transplanting hospital team will review the scan (usually the following month) to see if there are any medical or surgical reasons why donating a kidney would not be advisable.

OTHER INVESTIGATIONS AS REQUIRED

Depending on the results of various tests, other radiology tests may be requested, such as a split function test that examines the function of one kidney versus the other as a percentage, an Isotope test that examines real time filtration of kidneys, or an abdominal ultrasound.

Should the donor's health history identify any pre-existing conditions, other tests may also be ordered, such as a lung function test for someone with a history of asthma or smoking.

What if our blood group or crossmatch is not compatible?

Donors and recipients do not have to have the same blood group, although it is preferable. As long as the recipient's blood has acceptably low levels of antibodies to the donor's blood, a direct donation can still take place. A donor who has an 'O' blood group can donate to an A, B, or O blood group recipient. Donors with 'O' blood group are often referred to as 'universal donors' for this reason.

Another test that is done to determine whether a donor can donate directly to a recipient is the crossmatch / tissue type (blood) test. A test date is arranged by the transplant coordinator and samples of blood are collected from the donor and recipient and sent to NZ Blood in Auckland.

Tissue typing is a blood test that examines the special pattern of antigens (called tissue type) that are present in everyone's cells and tissues. The antigens of a prospective donor and recipient are tested for compatibility prior to transplantation.

A crossmatch uses the serum (the clear liquid in blood) of the potential recipient and mixes it with white blood cells of a potential donor. A negative crossmatch allows for a direct donation, as it demonstrates an absence of antibodies to the donor's blood. A positive cross match is when antibodies in the recipient's serum damage the donor's white blood cells. In this case, the potential donor would be unable to donate directly to this recipient. However, the donor could still complete their workup, and both the donor and recipient could progress as a pair into the kidney exchange programme. In this programme, donor and recipient pairs are matched from within Australia and New Zealand to other donors and recipients also waiting for a match.

You can learn more about the Australia and New Zealand Kidney Exchange (ANZKX) programme at:

paired-kidney-exhange-donor-inf-copy-2.pdf (kidneys.co.nz)

Referring to the transplanting hospital

Once the donor's tests are complete, their nephrologist will write a referral letter to the transplanting hospital. This is attached to the donor's complete file of test reports. Where the referring centre is

not the transplanting hospital, the file will then be scanned to the transplanting centre. A team at the transplanting hospital will then meet to review and make a decision as to whether it is safe for the potential donor to donate a kidney.

What does the operation look like?

There are two types of operations to remove a kidney:

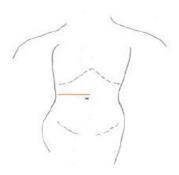
- a laparoscopic nephrectomy (also called keyhole surgery)
- an open nephrectomy (rare)

During the **laparoscopic nephrectomy**, the surgeon inflates the abdomen with gas after making 3 or 4 small incisions in the abdomen to allow the insertion of surgical instruments. A small (8-10cm) incision is made in the lower in the abdomen to allow removal of the kidney. The advantages of this surgery are quicker recovery time, less abdominal pain as fewer muscles are cut, and less trauma to the internal organs.

However, it is important to be aware that there is always the possibility that an open nephrectomy might be needed once the laparoscopic surgery has begun due to unforeseen complications. Therefore, even if a laparoscopic procedure is planned, the surgeon will ask the potential donor to consent to the operation being changed to an open procedure if this should become necessary during the course of the operation.

For an **open nephrectomy**, the surgeon makes an incision about 25cm long horizontally below the ribs, and cuts through the abdominal muscles.

What would I look like after surgery?



Right Open Nephrectomy



Left Laparoscopic Nephrectomy

After the operation

Potential donors will be admitted into hospital the day before, or the day of the operation, depending on the hospital.

Once the surgery is completed, the donor will be taken to the recovery room where their condition will be monitored as they start to wake up from the anaesthesia. Once fully awake and stable, the donor will be transferred to a ward.

The donor will be given medications to help manage the pain associated with surgery. Everyone has a unique pain tolerance, so the donor should ensure they keep their nurse informed about the level of pain they are experiencing. Their nurse will also instruct them on coughing and deep breathing exercises to prevent pneumonia and will help the donor to get out of bed several times a day to prevent blood clots from forming in their legs.

The donor will have a thin tube in a vein in their neck, a catheter in their bladder, and an IV line (a drip) in their arm. The IV drip will be used to give the donor both fluids and medications.

Donors can expect to be in hospital for 3-5 days after a laparoscopic nephrectomy and 5 to 7 days after an open nephrectomy. Donors will be discharged when the transplanting hospital surgeon and nephrologist considers that it is safe for the donor to go home. This can vary for each person.

Depending on where the donor usually lives, the donor may be asked to come back to outpatient clinic 2-3 weeks after the operation, and again at week 6. Should a working donor require more time off work at the 6-week clinic appointment, their doctor can provide a medical certificate.

Working donors are entitled to up to 12 weeks donor compensation, and medical certificates should be scanned to the Ministry of Health/Manatū Hauora at claimsmanagement@health.govt.nz

Most kidney donors recover reasonably quickly after the surgery and are able to go back to work and other activities within six weeks. The length of time off work depends on the type of work the donor does, as well as the type of operation they've had. Kidney donors should avoid strenuous activities such as heavy lifting, digging, and playing golf, for a minimum of six weeks, but can aim to be back doing their usual activities of daily living by 3 months after the operation.

The donor can expect to be offered long-term follow up, with an annual check at their renal unit or GP practice. This is important to ensure that the donor and their remaining kidney are in good health.

Is it safe?

People can safely donate an organ if they have successfully completed medical tests and checks to make sure that this type of surgery is acceptable for them.

There is a risk with any surgery. That's why live organ donors have thorough health assessments prior to surgery, and are carefully monitored after surgery.

Are there risks for the potential donor?

The kidney team will discuss all health risks with the potential donor. The risks of donation are similar to those involved with any major surgery, such as bleeding and infection. Death resulting from kidney donation is extremely rare.

0800 KIDNEY / 0800 543 639 www.kidneys.co.nz



The long-term health risks associated with kidney donation are very low. Only people in very good health are accepted as kidney donors. For this reason, most people do not have any change in their long-term health outcomes after donation. A very small number of people, however, may go on to develop kidney failure themselves in the future. This risk will be discussed with all potential donors as part of the assessment process.

If the donor is fit and well, they can lead an active, normal life with only one kidney. Studies have shown that one kidney is all a person needs to keep the body healthy. After recovering from surgery, a donor can work, drive, exercise and participate in sports, though certain very physical contact sports are not recommended. A donor can continue in all types of occupations. Female kidney donors can have children with no increased concerns.

What if the donated kidney does not work?

We know that one year following a transplant operation, about 9 out of 10 kidneys transplanted from a living donor will be working well. Most of these continue to work well for at least 8 to 10 years. Many people who have been transplanted still have a kidney that is working well after 20 years.

What we cannot tell a potential donor is whether their potential recipient will be the one person out of 10 whose kidney is not going to work well. Unfortunately, some kidneys are lost through rejection, infection, or blood supply problems.

Before donating a kidney, it is important that the potential donor considers what their feelings would be if the transplanted kidney did not work.

Can I donate a kidney or part of my liver to a person living in New Zealand, if I am living overseas?

Yes, subject to approval from the transplanting hospital. Once the donor has successfully completed the required medical checks, their information will be sent to the transplanting hospital who will decide whether they are medically and surgically fit to donate.

The transplanting hospital will then arrange a date for surgery, and the recipient's hospital will arrange travel to New Zealand for the donor, along with accommodation.

Kidney transplants are carried out at Auckland, Wellington, and Christchurch hospitals. Liver transplants are only carried out at Auckland Hospital.

The recipient who is receiving the organ, must be eligible for transplant surgery within the New Zealand health system in order for the donor to be eligible for compensation for loss of income.

For more information about eligibility for New Zealand health services: <u>Guide to eligibility</u> for public health services — Te Whatu Ora - Health New Zealand



If I donate a kidney, then need a kidney later, will I be prioritised on the waiting list for a transplant?

Kidneys are allocated according to the National Kidney Allocation Scheme. Should you develop end stage kidney disease as a former kidney donor, and meet deceased donor waiting list criteria, you may receive priority on this list when a suitable match comes up. Your specialist can discuss this with you before you donate.

Financial matters

The costs of the tests and the surgery will be met by the hospital.

In New Zealand, it is not legal to offer kidneys for sale, or to advertise to buy a kidney.

Potential donors should discuss any financial matters with the social worker who works with the kidney team, or their transplant coordinator.

There may be assistance with any loss of income or extra childcare costs the potential donor has because of the operation. (Refer to Ministry of Health website: compensation for live donors)

https://www.health.govt.nz/system/files/documents/publications/compensation-for-live-organ-donor-information-pack-19-nov-19.pdf

In general, medical insurance companies do not deny cover for subsequent unrelated conditions to people who have previously donated a kidney. Potential donors who have any concerns about future entitlement to private health insurance should discuss these with their insurance company.

Key points to note

- You have the right not to be a kidney donor
- You can stop the workup process at any stage
- The transplant coordinator, nephrologist, kidney surgeon, psychologist and social worker are your team they are always willing to answer your questions and provide support
- The process from deciding to be a donor to the transplant operation can take about a year
- Living with one kidney should not interfere with your everyday activities

Further information

There are three transplant units in New Zealand and each has their own information booklet with information relevant to their region.

- Auckland City Hospital (includes Northland, Waitemata, Auckland, Counties Manukau, Waikato, Tarawhiti, Bay of Plenty, Lakes, and Taranaki DHBs)
 Contact: 0800 736 258 or ADHBARTGRenalTransplantCoord@adhb.govt.nz
- Wellington Hospital (includes Nelson/Marlborough, Capital and Coast, Hutt, Wairarapa, Whanganui, MidCentral, Hawkes Bay DHBs)
 Contact: 04 806 0532 or kidneys@ccdhb.org.nz

0800 KIDNEY / 0800 543 639 www.kidneys.co.nz



 Christchurch Hospital (includes Canterbury, South Canterbury, West Coast, Otago and Southland DHBs)

Contact: 03 364 1041 or kidney@cdhb.health.nz

For further information on being a live kidney donor you can contact the kidney transplant coordinator through the kidney department at your nearest hospital. A link to your nearest transplant coordinator is attached here: https://www.kidney.health.nz/for-patients/kidney-donation-and-transplantation/transplant-co-ordinators/

