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You’ll never do anything better than donate a kidney.
Donating a kidney will make a real difference to the life of a person with kidney disease.

A live kidney transplant is considered the best treatment for someone who has end stage kidney disease.

Donating a kidney is a big decision, so you need to have a good understanding of what live kidney donation is all about.

This booklet has been written for people who are thinking of donating a kidney. This booklet will give you general information to help you decide if you want to be a live kidney donor.

If you decide to donate, there is another booklet with more detailed information on the tests you need, the operation and life after donation. This second booklet is called *Live Kidney Donation – Information for donors about the tests, the operation and what life will be like after donation*.

It is available on health.govt.nz
Your kidneys clean your blood.

Your kidneys are found on either side of your spine, just below and partly under your ribs.

Your kidneys work as filters to remove water and waste from your blood.

You get rid of this waste when you pass urine (pee).

**How kidneys work**

1. Blood enters the kidneys through an artery from the heart.

2. Blood is cleaned by passing through millions of tiny blood filters called nephrons.

3. Waste material passes through the ureter and is stored in the bladder as urine.

4. Newly cleaned blood returns to the blood stream through the veins.
Kidney disease damages the kidneys so that the waste can't be properly removed from the body.

When this happens, the waste builds up in the body. If the damage becomes very bad, your kidneys don't recover.

This is called end-stage kidney disease.

Over time, this will make a person very sick, and without treatment, the person will die.

End stage kidney disease is sometimes called renal or kidney failure.

You might know someone with kidney disease.

This is where your kidneys are
What is live kidney donation?

Live kidney donation is when you give one of your healthy kidneys to a person whose kidneys don’t work.

People whose kidneys don’t work need dialysis (a treatment that cleans their blood) or a kidney transplant to stay alive.

Live kidney donation can give them a better and usually longer life.

The person who gives the kidney is called the donor.

The person who receives the kidney is called the recipient.

If you donate a kidney, you will need to have an operation.
Why is a live kidney transplant better than dialysis?

A live kidney transplant is a better treatment option than dialysis for many people with kidney disease.

If dialysis is done well, it can be very effective in treating kidney disease. However, a live kidney transplant will give the recipient a much more independent, active and usually longer life.

About 19 out of 20 live kidney transplants are working well 1 year after the operation. About 10 out of 20 live kidney transplants will still be working well after 15 years.

The best time for most people with kidney disease to get a live kidney transplant is just before they start dialysis.

This is called a pre-emptive transplant.

Without a kidney transplant, people on average only live for 4–5 years after they start dialysis, although some people can live for much longer.
You can live a healthy life on one kidney.
You can donate a kidney to a member of your family, a friend or, if you agree, your kidney will be used in the Kidney Exchange programme. For more information about the Kidney Exchange programme see page 19.

Donating to someone you know, like a family member or a friend, is called ‘directed’ donation. This is because you ‘direct’ that your kidney goes to a particular recipient.

Donating to someone you don’t know is called ‘non-directed’ donation. In this case, you cannot say who receives your kidney. The kidney is given to the highest placed person on the kidney transplant waiting list.
How safe is donating a kidney?

Most people have two kidneys but can lead a normal life with just one.

Kidneys will only be accepted from donors who have passed a number of very thorough medical tests. There can still be a small risk that the donor could have problems after they donate their kidney.

If you pass all the tests, you can donate one of your kidneys to another person.

When you have your operation, the surgeon will leave your best kidney in you. Your other kidney will be transplanted into your recipient.

Most donors do not have any change in their health after donating a kidney.

About 3 in 1000 donors will go on to develop end-stage kidney disease. This is considered to be low risk.

About 2 in 1000 people who do not donate a kidney will develop end-stage kidney disease. This is also considered low risk.

For comparison, about 50 in 1000 New Zealanders will develop bowel cancer at some point in their lives, and about 100 in 1000 New Zealand women will develop breast cancer. These are considered to be high risks.
About 3 in 1000 donors will go on to develop end-stage kidney disease.
Most female donors who become pregnant after donating a kidney can have normal pregnancies. However, if you do get pregnant you will need to tell your doctor and midwife that you have donated a kidney. There is a risk that you could get high blood pressure when you are pregnant so your midwife and doctor will need to monitor you more closely.
Can I donate a kidney?

To donate a kidney, you need to be:

- over 18 years old
- in good health with two healthy kidneys.

You can't donate a kidney if you have a medical condition like diabetes, cancer or poorly-controlled blood pressure, are very overweight or have serious mental health problems.
How do I get started if I decide to become a donor?

If you decide you want to be a kidney donor, you will need to get in touch with the renal (kidney) transplant co-ordinator at the nearest hospital that has a renal (kidney) specialist service.

The transplant co-ordinator is usually a nurse.

The co-ordinator’s job is to help potential donors like you go through the kidney donation process. The transplant co-ordinator can answer your questions.

Phone numbers for transplant co-ordinators in New Zealand are at the back of this booklet.

If you decide to donate your kidney, you will also deal with other doctors and nurses in the renal transplant team, including renal doctors and surgeons.

You will have your own team of doctors, nurses and co-ordinators who will look after you.

A different team will look after the recipient.
You will have your own team of doctors, nurses and co-ordinators who will look after you.
If you want to donate your kidney to someone you know, talk to that person.

Sometimes you might need a family meeting to talk about it.

Some transplant co-ordinators might be able to come and talk to your family at home. Not all co-ordinators do this, so ask your transplant co-ordinator if they are able to do this.

Your recipient might say no the first time you offer to donate a kidney to them.

Keep on talking to them and offering to donate a kidney even if the recipient is on dialysis and seems to be doing okay.

New Zealand research shows that some recipients later regretted that they said no to someone who offered them a kidney. The person didn’t offer again, and the recipient didn’t know how to talk about donation with them again.
Dad, I can see that dialysis is really hard on you. I still want to give you a kidney so you can stop dialysis and have a better life. Will you think about it again?
What will I need to do if I decide to donate my kidney?

You will need to have some tests to find out whether you are healthy enough to donate a kidney and whether you are compatible with your recipient.

These tests will include:

- blood tests
- heart, lung and kidney checks, and
- blood pressure tests.

You will need to be available on week days to complete most of these tests.

Some of these tests will be carried out at hospital, while others will be done at laboratories.

You won’t have to pay for these tests – they are free for people who want to be donors.
Some of these tests might show you have medical problems you didn’t know about. If this happens, you will be told immediately of any problems and offered appropriate treatment.

These problems could mean it could take longer for the renal transplant team to agree that you can donate your kidney. Sometimes these problems might stop you from donating.

This can happen at any time. For example, you may be near the end of your tests and find out you can’t donate.

All of these tests will be reviewed by the transplant team to decide if you can donate your kidney.
Even if the tests show that you are healthy enough for surgery but you can’t donate to your recipient because you aren’t compatible, you can still help by joining a programme called the Kidney Exchange.

Both you and your recipient will need to join this programme.

The Kidney Exchange programme works by finding compatible donors and recipients.

Your transplant co-ordinator can give you information about the Kidney Exchange programme.
The Kidney Exchange programme works by finding compatible donors and recipients. Donor 1 cannot donate to Recipient 1. Nor can Donor 2 donate to Recipient 2. But Donor 1 is compatible with and can donate to Recipient 2. And Donor 2 is compatible with and can donate to Recipient 1. By taking part in the Kidney Exchange programme both recipients can have a live donor kidney transplant. Sometimes the Kidney Exchange could be more involved and might involve more than two pairs and possibly a non-directed donor.

Kidney Exchange programme – 0800 717 777
What else do I need to think about?

As well as finding out if you are a suitable donor, you need to think about practical things.

Donating a kidney involves an operation.

You will be in hospital for 3–5 days after your operation.

You will need time off work to recover from the operation. Depending on how you recover, you can expect to get back to your normal activities within 6–12 weeks.

You will need to organise things at home such as someone to look after your children or pets.
You may be able to get some assistance for loss of income while you are recovering from your donation surgery.

As of 5 December 2017 live organ donors can be compensated for loss of earnings and for up to 12 weeks to recover from donation surgery. Organ donors may also be reimbursed for travel and accommodation costs linked with the organ donor tests and surgery.

You won’t need to use your annual or sick leave unless you need to be off work over than the maximum 12-week period the Ministry of Health covers under the Compensation for Live Organ Donors Act.

If you are already getting a main Work and Income benefit, this will change over to the Emergency Benefit for a few weeks while you recover. If you are earning money on top of the benefit, the Ministry can cover that under the Act.

Talk to your donor or transplant co-ordinator for more information or have a look at: www.health.govt.nz/liverorgandonation or email: liveorgandonation@moh.govt.nz.
What if I am on a benefit?

You are not entitled to any compensation. However you will be exempt from work test obligations from the time of your operation until you have recovered and a doctor says you are ready to apply for work again. This will be for a maximum of 12 weeks from your operation date. Remember most donors usually recover within 6 weeks of the operation. Talk to your case manager about your situation. You may need to go on a different sort of benefit while you are recovering from your operation.

If you earn income on top of your benefit, you may be eligible for compensation to cover this while you are recovering. Talk to your case manager about this and look at the information on the Ministry of Health’s website.

As a donor, you will be able to get most of your travel costs covered by the National Travel Assistance Scheme.

You should keep all your travel receipts in case you are able to claim for these costs.

You may also be able to get some help with accommodation costs if you have to travel away from your home.

Your transplant co-ordinator can give you information about the National Travel Assistance Scheme and help you fill out any forms.
The time from making first contact with the transplant team to the transplant operation can take between 4 and 12 months.

Your transplant co-ordinator is there to

- help you know what tests you have to do
- let you know about your results, and
- what you need to do next.

Talk to your transplant co-ordinator about the best way for them to contact you (mobile, text, email, phone). Also make sure you know the best way to contact your transplant co-ordinator. If you want to do your tests as quickly as possible then talk to your co-ordinator about how this can happen.

And if something happens in your life and you want to delay your tests for a while then talk to your co-ordinator about how that could work. The renal team don’t want to put pressure on you to donate your kidney so the team might not contact you about your tests.

But the role of your transplant co-ordinator is to stay in contact with you so you know what is happening.
Kidney transplants are generally safe operations.

The risk of death from a kidney operation is 1 out of 3500, which is very low.

The transplant operation usually involves laparoscopic (keyhole) surgery. This means that you will have several smaller scars and an 8 centimetre scar instead of one very big scar.

The operation lasts about 3 hours.

You will probably be sent home from hospital 3–5 days after the operation.

You may feel weak and unwell for some time after the operation. This is normal. After all, you were well before the operation.

You will also have some pain after the operation, but you will be given medicine for the pain.
How long will it take me to recover?

You can expect to be able to go back to work 6–12 weeks after your operation.

The amount of time you will need to take off work will depend on the type of work you do and how quickly you get better after your operation.

Driving is not recommended for 1–2 weeks after your operation or while you have pain.

You shouldn't do things like heavy lifting, digging or playing sport for at least 6 weeks after your operation.

Donating a kidney is a wonderful thing, but it can sometimes be more difficult than expected.

For someone who is usually healthy, it can be difficult to suddenly become a patient, especially if you are usually the person who looks after the recipient.

It is a big operation, and sometimes donors can feel tired for a few weeks after the operation before you get your energy back.

It is very important that you and the recipient both take time to recover properly and don't try and do too much too early.

It is also important that both you and your recipient have people who can look after you.
Your surgeon will see you within a few weeks after your operation to make sure you are healing well.

You may also see your kidney doctor 6–12 weeks after your operation.

After that, you should get a check-up at the hospital or with your GP once every year.
For the first few weeks afterwards I was in pain and then I felt a bit depressed. I had really good family support, but it took me a while to get back to feeling as good as I did before the surgery.
Once your kidney has been removed, you cannot get it back.

You can change your mind at any time about being a live kidney donor until the moment you go into surgery.

If you change your mind about being a live kidney donor, the recipient will not be told that you have changed your mind. The recipient will just be told that you are not a suitable donor.
What happens to my information?

The recipient will not be given any medical or personal information about you unless you agree. You do not need to agree. In the same way, you will not be given any medical or personal information about the recipient.

However, if you want to, you can talk to your recipient about how your tests are going.
Who can I talk to about this?

You can contact the your local kidney society (contacts on page 33) or Kidney Health NZ 0800 543 639 and talk to someone. They will not discuss your information with anyone else.
Being a live kidney donor is a very generous thing to do.

It can make a big difference to how long and how well the recipient lives.

Thank you for thinking about becoming a live kidney donor.
Who can I contact?

Phone numbers for kidney transplant co-ordinators in New Zealand

North Island

Whangarei Renal Unit – 09 430 4101 ext 8508 or 8497
North Shore Hospital – 09 486 8920 ext 8930
Auckland City Hospital – 09 307 4949 ext 22881 or 22951
Middlemore Hospital – 09 276 0044 ext 9718 or 2890
Waikato Hospital – 07 839 8899 ext 23113
Hawke’s Bay Hospital – 06 878 8109 ext 2431 or 027 4494610
Taranaki Base Hospital – 06 753 8631
Palmerston North Hospital – 06 350 5088 ext 7131
Wellington Hospital – 04 806 0532

South Island

Christchurch Hospital – 03 364 1041 ext 81041 or 88654
Dunedin Hospital – 03 474 0999 ext 58884

Kidney Health New Zealand

Unit 7/337 Harewood Road
PO Box 20072
Bishopdale
Christchurch

Freephone: 0800 Kidney / 0800 543 639

E: info@kidneys.co.nz
Kidney Societies

North Island

Northland
C/- Renal Unit
Northland Kidney Support Group
Northland Base Hospital
Whangarei
www.kidneysociety.co.nz

Ph: (09) 278 1321
Freephone: 0800 235 711

Auckland/Waikato
ADKS Centre
5 Swaffield Rd
Papatoetoe
Manukau 2025
www.kidneysociety.co.nz

Ph: (09) 278 1321
Freephone: 0800 235 711

Whitianga
Mercury Bay Health Trust
PO Box 263
Whitianga 3542

Loretta Guthrie
Ph: 027 512 4419

Email: loretta.guthrie@rocketmail.com

Tauranga
Kidney Kin Tauranga
Regan Johnson
(Co-ordinator)

Email: kidneykin@gmail.com

Taranaki
Taranaki Renal Support Group
Erana Hoskin
(Secretary)
Ph: 06 755 4392

Hawkes Bay

Ph: (06) 855 4922

Email: vickyn@hotmail.co.nz

Wanganui
Wanganui Support Group
Lisa Bullock
Ph: (06) 345 3373

Email: gbullock@clear.net.nz

Palmerston North
Palmerston North Kidney Support Group
1C Hughes Avenue
Palmerston North 4410

Pat Burton
Ph: (06) 357 0594
Mob: 021 054 3803
Anita Milicich
Ph: (06) 353 2957
Mob: 027 440 4004

Email: pat.burton@vodafone.co.nz
## Wellington
Wellington Kidney Society  
102 Dymock Street  
Titahi Bay, Porirua 5022  
**Ph:** (04) 382 9693  
**Email:** info@wellingtonkidneysociety.org.nz

## South Island

### Nelson/Marlborough
Central NZ Kidney Group  
**Ph:** (03) 548 2748

### Christchurch
Christchurch Kidney Society  
230 Antigua Street  
Christchurch 8011  
**Ph:** (03) 379 5529  
**Email:** c.ks@xtra.co.nz

### Ashburton
Langs Road, R 5  
Ashburton  
**Email:** tincow@xtra.co.nz

### Timaru
South Canterbury Kidney Support  
**Email:** hewys@callplus.net.nz

### Queenstown
Paul Baker  
**Ph:** 021 0256 0694  
**Email:** kristanpaul@gmail.com

### Southland
Southland Kidney Society  
59 Helmsdale Street  
Rosedale  
Invercargill 9810  
**Ph:** (03) 217 2363  
**Email:** mosb@xtra.co.nz

### Dunedin
Otago Kidney Society  
**Ph:** (03) 486 2268  
**Email:** rocketralph@hotmail.co.nz

### Gore
Gore Kidney Support Group  
**Email:** rocketralph@hotmail.co.nz
compatible – When two things are compatible, they work well together.

dialysis – A treatment for kidney disease that cleans your blood. There are two types of dialysis: haemodialysis and peritoneal dialysis.

directed donation – When you donate your kidney to a particular person. Only that person can get your kidney.

end-stage kidney disease – The stage when the kidneys are so damaged they can’t recover. If you have end-stage kidney disease, you need dialysis or a kidney transplant to stay alive.

laparoscopic surgery – Keyhole surgery. In this type of surgery, several smaller incisions (cuts) are made instead of a single large incision. Laparoscopic surgery is less painful, and the patient has a faster recovery time and less scarring than if they had had one big incision.

non-directed donation – When you donate to someone you don’t know. If you are an non-directed kidney donor, your kidney will go to the most compatible person on the transplant waiting list. You won’t find out who gets your kidney.

pre-emptive transplant – A transplant that happens before starting dialysis. Pre-emptive transplants usually have better outcomes for the recipient than having a transplant after starting dialysis.

renal – The medical word meaning kidney.

renal failure – Kidney disease.

renal transplant team – The team that is involved in your kidney transplant. This team will include your kidney doctor and your transplant co-ordinator as well as other health professionals who work with kidneys.
Next steps