Live Kidney Donation

Information for donors about the tests, the operation and what life will be like after donation

December 2017

About this booklet

Talk to your doctor or transplant co-ordinator after you have read this booklet.
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What is this booklet about?

This booklet has been written for people like you who have decided to become live kidney donors and want more information.

This booklet includes information about the tests you need to do, the operation and how you will feel after the operation.

Please bring this booklet to all meetings you have with people about live kidney transplants, such as meetings with transplant co-ordinators and kidney doctors.

At the back of this booklet there are some pages where you can write down the results of each test and see how many tests you have got left to do. Keep this booklet with you so you can write down these results.

You can also call 0800 LIVE DONOR – 0800 5483 3666 for more information on being a donor.

There is another booklet written for people who have kidney disease and are thinking of having a live kidney transplant to treat their kidney disease. This booklet is called Being a recipient– Information about live kidney donation for people with kidney disease and is available though the recipient’s kidney doctor, their transplant co-ordinator or 0800 LIVE DONOR – 0800 5483 3666.

www.kidneydonor.org.nz
You will need to have tests to find out if you can become a donor.

The kidney doctors and nurses (the kidney transplant team) call these tests your **workup**.

These tests are done for two reasons:

1. To make sure you are healthy enough to donate a kidney.

2. To make sure your kidney is suitable for your recipient.

Some tests will happen quite quickly, while others might take longer.

This is because some tests are simple, while others are more complicated and it takes longer to get the results.

There are a lot of tests you will need to do as part of your workup.

These tests are done over a period of 4–12 months.
Can anyone donate a kidney?

Not everyone can become a kidney donor.

People with certain medical problems will not be able to become donors. These medical problems are sometimes called exclusion criteria.

- If you have diabetes, blood clots (thrombosis), serious heart disease or serious long-term lung disease or have recently had some types of cancer, you will not be able to donate a kidney.

- If you have poorly-controlled blood pressure, an active infection or kidney disease or have previously had kidney surgery, you also might not be able to become a kidney donor.

This is because it might not be safe for you to donate a kidney or for the recipient to receive your kidney. You will need to be carefully assessed by the kidney transplant team who will make a decision about whether you can go ahead with donating your kidney.

You might also need to be assessed by other specialists, for example:

- a urologist (a specialist in urinary tract disorders),
- a gynaecologist (a specialist in the female reproductive system) or,
- a cardiologist (a heart specialist),

to see if it is safe for you to donate your kidney.
Your BMI is based on your weight and height. So, if you are 180cm tall and you weigh 117kg your BMI is 36. This means you will need to lose some weight to get your BMI down.
If you are very overweight, you will need to lose weight before you can donate a kidney.

You will be weighed and your height will be measured at the hospital to get your body mass index (BMI). Your BMI is a measure of how much fat you have and is worked out based on your height and weight.

If you want to donate your kidney, your BMI must be less than 35. Sometimes your BMI might need to be lower depending on other factors such as the amount of fat around your tummy. The renal transplant team will assess your risks and your transplant co-ordinator will talk to you about what you need to do. If your BMI is too high, you will need to bring your BMI down.

Talk to your transplant co-ordinator about this if you are not sure.

You will have to arrange to lose weight yourself. For example, you can join a gym or exercise with a friend or family member. Ask your transplant co-ordinator if they can refer to to Green Prescription or phone 0800 ACTIVATE (22 84 83) yourself.

The kidney transplant team cannot pay for this. However, some transplant teams do have a dietitian (a person who gives advice about healthy eating) you can talk to.

Ask your transplant co-ordinator if a dietitian is available for you to talk to.
There are lots of tests that you will need to do. This is all part of being a live kidney donor.
What tests will I need to do?

If you want to become a kidney donor, you need to have:

- blood and urine tests,
- an ECG (electrocardiogram),
- X-rays and,
- a CT (computed tomography) angiogram scan.

The ECG is to check your heart health, and the X-rays are to check your lung and heart health.

The CT angiogram scan is to make sure that the blood vessels to your kidneys are in good condition for the transplant. This scan helps the transplant doctor decide which kidney should be transplanted. (You keep your best kidney.)

The CT scan is usually done at the end of the workup process.

You might have to do other tests as well.

If you are a woman, you will need to have a cervical smear test. This is a test for cancer of the cervix (or the lower part of the uterus).

If you are a woman over 45 years, you will need to have a mammogram. This is a test for breast cancer. You will probably need to arrange this test yourself though your family doctor.
You will probably also need to have your blood pressure taken over a 24-hour period.

To do this, you will need to wear a blood pressure cuff on your arm that measures your blood pressure throughout the day and while you are sleeping. During sleep, your blood pressure will not be measured as often as during the day.
Blood tests are a big part of the workup. Initial blood tests are done to check that your blood is compatible with your recipient’s blood.

The good news is that, these days, even if your blood group is not compatible with your recipient’s blood group, you may still be able to donate to the recipient. The recipient has to have a treatment called desensitisation just before the transplant at Auckland City Hospital or Christchurch Hospital.

If your recipient can have this treatment and if this treatment is successful, you will be able to donate your kidney to your recipient.

If this treatment doesn’t work or the doctors don’t think your recipient should have this treatment, you might still be able to donate by joining a programme called the **Kidney Exchange**. You and your recipient will both need to join this programme. There is more information about the Kidney Exchange programme on page 12.
Your blood will also be tested against the recipient’s blood. This is to look for the presence of recipient antibodies against your kidney.

Antibodies are proteins that help the immune system reject anything that it does not recognise, such as bacteria and viruses.

This test for these antibodies (called a crossmatch) is usually done halfway through your workup.

However, sometimes this test can be done at the beginning of the workup in situations where it is more likely there could be a positive cross-match. Situations could include donating

- to your mother
- to someone who has had a previous transplant
- if a male partner is donating to his female partner, such as a husband donating to his wife or a boyfriend donating to his girlfriend.

In these situations it is more likely that the recipient will have antibodies against your kidney resulting in a **positive cross-match**. This means you will not be able to donate to your recipient.
If you and your recipient have a positive cross-match, you may still be able to donate through the Kidney Exchange programme.

Your transplant co-ordinator can talk to you about the Kidney Exchange programme. See “Kidney Exchange programme” on page 12.

Some of the workup tests will be carried out at a hospital while other tests will be done at a laboratory.

Some of these tests might show you have medical problems you didn’t know about. If this happens, you will be told about any problems.

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.

If this happens it will be very upsetting for you and your proposed recipient.
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
You should be able to get results for each of your tests within 7–14 days.

If you don't hear from your transplant co-ordinator, you will have to follow up on your tests by calling, texting or emailing the co-ordinator and asking for the results.

This will help make sure there aren’t any delays in your workup process.

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.

Remember there are some pages at the back of this booklet where you can write down the results of your tests.
Talking to a psychologist

The kidney transplant team needs to be sure that it is your own decision to donate your kidney and that you will be able to cope well with life after the transplant operation.

The transplant team also wants to make sure that you understand:

- what happens when you donate your kidney
- that you have thought carefully about how you would feel if the transplant fails.

Psychologists or psychiatrists are health professionals who are trained in how the human mind works. You may be asked to meet with a psychologist or psychiatrist to talk about donating your kidney.

This meeting will take around 1 hour.

You may have part of this meeting on your own and part of it with your recipient.

The psychologist or psychiatrist will talk to you about the risks of the operation.

They might ask you what you know about the operation and why you have decided to donate your kidney. They might also ask you if you think your relationship with your recipient will be different after the donation and, if so, how your relationship will change.
You might find some of the questions very personal and surprising.

However, the purpose of these questions is just to make sure you are well informed and have thought carefully about donating your kidney.
Once most of the tests and assessments are completed, you will see a kidney doctor who will look over all your results.

You will also see a transplant doctor from the hospital where you are having your operation.

If you live in Auckland or somewhere else in the northern part of the North Island, you will see a transplant doctor from Auckland City Hospital.

If you live in the southern part of the North Island, you might see a transplant doctor from Wellington Hospital, and if you live in the South Island, you might see a transplant doctor from Christchurch Hospital.

Your results will be discussed at a meeting at the transplant hospital.
You will then see the surgeon from the transplant hospital who will decide if you are suitable for surgery.

The final test is the CT angiogram test. This is usually done at this stage.

Once everyone from the hospital transplant team is satisfied with your test results, you will be given a date for your operation.

These tests do not always take place in this order.

Some donors have all their tests done before they see their surgeon, while other donors have to wait till the very end to have their CT angiogram or cross-match test done.

One of the reasons is that these tests are expensive so it makes financial sense to leave them until last. If you pass all your other tests, these expensive tests can be ordered.

Remember, if the possibility of a positive cross-match is higher (such as a person donating to their mother, a male donating to his female partner or a person donating to someone who has already had a kidney transplant), the cross-match test is often done at an earlier stage.
Time off work

Going to appointments and doing the tests can take up a lot of time.

You will probably have to do these tests during work hours. If you are going to miss work because of an appointment, you should talk to your employer. Explain why you are doing these tests and talk about how you can organise the time off.

Your employer might want to know how much time you are going to have off for your operation. Some businesses are really good and let you have time off because they know you are doing a good thing. Other businesses ask you to take sick leave. You may be able to apply for financial assistance if you are taking unpaid time off work for your tests.

Talk to your transplant co-ordinator about the extra help and if you are finding it really hard to take time off work. They might be able to organise some appointments on the same day.
Travel and other costs

You need to think about the costs of travelling to appointments and any childcare costs if you need to arrange for someone to look after your children while you are going to appointments, in hospital for your operation and recovering after your operation.

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

Some of your travel costs will be paid up front, for example, if you have to fly within New Zealand. Other travel costs like petrol or taxis might not be paid up front. You should keep all your travel receipts in case you need to claim for these costs.

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

Your transplant co-ordinator can give you current information about the National Travel Assistance Scheme and help you fill out any forms.
I will need to take time off work for the operation and recovery and I will not be earning any money. Can I get any help with this?

Yes, if you qualify, you could get compensation for the income you lose by not being at work.

The Compensation for Live Organ Donors Act 2016 (the Act) was passed in December 2016. The Act came into effect on 5 December 2017.

To qualify for compensation:

- you must have been accepted as a suitable donor by the New Zealand health system, and
- the donor surgery (operation) must take place in New Zealand and
- the person receiving your kidney must be eligible for publicly funded health services in New Zealand.

You need to lose income to be eligible for the compensation (so if you take sick leave/annual leave you are NOT eligible even though you might spend that leave).

The Act says that live organ donors (including live kidney donors) will be compensated for loss of earnings from the date of your operation to the date you go back to work. Loss of earnings will be paid for up to 12 weeks. Many donors will be signed off by the hospital to go back to work earlier than 12 weeks – usually within 6 weeks after their operation.

The Ministry of Health manages these compensation payments.

Talk to your co-ordinator about how you apply for compensation under the Act. Your co-ordinator will be able to help you to apply or refer you to someone.
who can help you with your application. You need to start your application as soon as possible once you are assessed as being able to donate as the Ministry of Health has to approve your application for compensation before your operation.

For more information about the Act please see the Ministry’s website: www.health.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.
Having a plan

It’s really important that you think about who will look after your family, home and pets while you are in hospital. You also need to think about who is going to look after you while you recover. You need to plan for this before you have your operation. Remember there are some pages at the back of this booklet where you can write down your plan.
You are doing a great thing

The workup can be difficult and stressful.

Remember that there are always people you can talk to about this. Your transplant co-ordinator or your family doctor can both offer you some help.

You can also talk to your local kidney societies. They can listen and give you advice and put you in touch with other people who have donated their kidneys.

Contact details for Kidney Health New Zealand and local kidney societies are on page 40.

Don’t forget your family and friends. It’s important to talk to them early on so they can understand your reasons for wanting to be a donor and support you from the beginning.

And don’t ever forget that you are doing a very kind and generous thing. Donating your kidney will make a very big difference to your recipient’s life.
The operation

Donating a kidney involves having an operation.

The operation lasts about 3 hours.

You will be under general anaesthetic (asleep) for the entire operation.

Your operation is called a donor nephrectomy.

How safe is the operation?
Kidney operations are generally very safe.

The risk of death from a kidney operation is very low. The number of donor deaths is 1 in every 3500 operations.

There can still be a small risk that the donor could have problems after they donate their kidney.

What are the risks?
Although kidney operations are safe, they do have some risks.

These risks include problems with:

- the anaesthetic,
- bleeding,
- blood clots and,
- infections after your operation.

These risks are the same for all operations.
What kind of surgery will I have?

The most common type of surgery used in kidney transplant operations for donors is laparoscopic (keyhole) surgery.

Keyhole surgery usually results in fewer problems after surgery.

Generally donors who have keyhole surgery also have less pain.

The other type of surgery is called open surgery. Open surgery is only done when keyhole surgery is not possible.

Open surgery is not common and might be performed when the donor has more than one artery connecting to their kidney.

All donors need to give their consent (permission) before surgery can be performed. This includes agreeing to open surgery in the rare situation that the surgeon is unable to do laparoscopic (keyhole) surgery.
Will I have any scars?

You will have some scars after your operation.

The exact position of your scars will depend on your surgeon and what they think is the safest way to remove your kidney.

Talk to your surgeon about where your scars will probably be.

This is what a donor surgery scar could look like five months after your operation.
When do I go to hospital?

You will go into hospital the day before your surgery or on the morning of your surgery.

The time from when you arrive at the hospital to when you have your surgery will be about getting you prepared for your surgery.

You may be seen by the transplant team as well as by the anaesthetist to make sure you are still fit and well enough to have the surgery.

Some blood tests, an electrocardiogram to check your heart and a chest X-ray may also be done at the same time. You may also have some other tests.

Sometimes your operation might be cancelled at the last minute because of unexpected problems. This will be very upsetting for you, your family, your recipient and your recipient’s family. There is nothing hospital staff can do when these problems happen. Later you will be given another date for your operation.
How will I feel after the operation?

When you wake up from your operation, you will feel weak and unwell. This is common. You will feel like this because you were perfectly well before the operation and you have just had major surgery.

You will also have pain when you wake up.

The pain can sometimes be quite severe. You will be offered medicine after the operation to manage your pain. Talk to your anaesthetist about pain relief before the operation.

Sometimes the pain may last for a week or two after the operation. Some donors have pain for a longer period of time. Make sure you talk to staff about medicine for your pain.

It is important that you tell the team caring for you how much pain you are in so they can control this for you.

You may have some constipation (trouble going to the toilet) after your operation. You might also experience some nausea (feel sick).

Both of these side effects are common and can be treated with medication.

Make sure you tell the doctors and nurses if you are having these problems.

You won't be discharged from the hospital until your pain is under control and you are going to the toilet regularly.

Most donors stay in hospital for 2–5 days after their operation.
How long will it take me to recover?

Recovery time is different for different people.

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.

It usually takes most donors 6–12 weeks before they can get back to their normal activities.

A letter can be sent from the hospital to your employer explaining why you need to take this time off work.

If you are the person who usually does the cooking, cleaning and shopping, you will need to get some help with these jobs while you recover. You might even need help with getting dressed and washing yourself when you first come home.

If you and your recipient live in the same house, you will probably need extra help, as you will both be recovering after your operations.

This period of time might be frustrating for you, especially if you are the person who usually looks after everyone else in your household.

It is important that you take the time to rest and heal. You’ve just had a big operation, and you need to give your body time to recover.
A few weeks after your operation, you will have an appointment with a transplant doctor from the hospital transplant team.

This appointment is to check that you are making good progress and recovering well after your operation.

This doctor will ask you some questions about how you are feeling and if you have any pain. They will also check your wound to make sure it is healing well.

Some donors may see the doctor from the hospital transplant team around 6–12 weeks after their operation.

The exact date will depend on the transplant team whose care you have been under.
**What will I feel like after the operation?**

Even though you’ve just done a really amazing thing, you might feel a bit down after the operation.

Some donors feel like this once they’ve donated their kidney.

There are many reasons why donors can feel down after their operation. Sometimes it’s because the build-up to donating a kidney is suddenly over or because donors feel an unexpected sense of loss.

These feelings can be quite strong and can last a while, so it’s important that you have someone to talk to and share your feelings with.

Your transplant co-ordinator should call you a few weeks after your operation to have a chat with you and check how you are feeling.

Your transplant co-ordinator or family doctor can refer you to someone to talk to. You can also contact your local Kidney Society. Contact details of Kidney Health New Zealand and local kidney societies are on page 40. Kidney Health New Zealand has other important information on kidney transplantation that people find helpful.
How will my life be different after the operation?

You should be feeling normal and getting back to your normal activities about 6–12 weeks after your operation.

You may experience some pain or odd sensations from time to time over the first few months after the operation. This is normal and is just your body adjusting and healing properly.

After you have made a full recovery, your life will probably be very similar to how it was before your operation.

You should have a medical checkup every year for the rest of your life.

These medical checkups will focus on how your kidney is working and your blood pressure.

Your urine will also be checked because this gives the doctor information about how well your remaining kidney is working.

These checkups may be done in a hospital clinic by kidney doctors or by family doctors or other specialists who send your information to the hospital.
You need to think carefully about playing high-impact sports like boxing, rugby, rugby league and martial arts after kidney donation. This is because there is a small chance you could damage or injure your remaining kidney.

It's important to talk to a kidney specialist if you were playing these sports before your operation and you really want to continue.

Doctors strongly recommend you lead a healthy lifestyle after your operation. This includes eating healthy food and maintaining a healthy weight.

You need to make sure that you exercise regularly.

Walking, swimming, running, playing touch, cycling or going to the gym are good ways to exercise.

If you smoke, it's a good time to give up.

If you didn't have a very healthy lifestyle before your operation, you'll probably have become much healthier during your workup.

It is really important you keep up this good level of health after your operation.
What are the long-term risks to my health?

Almost all donors manage with one kidney without any problems for the rest of their lives.

The risk of donors developing end-stage kidney disease (kidney disease where you need treatment such as dialysis) is small.

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

For comparison, about 1 in 20 New Zealanders will develop bowel cancer at some point in their lives, and about 1 in 10 New Zealand women will develop breast cancer. These are considered to be high risks.

If you are a healthy person who has not donated a kidney, your risk of developing end-stage kidney disease is about 2 in 1000.

There are some long-term risks that relate to donating your kidney. As a potential donor, it’s important that you know about these.

For example, you could get more protein in your urine (proteinuria) as a result of donating your kidney.

This happens to about 1 in 10 donors.

If you have increased levels of protein in your urine, it is a sign that your kidney might need some help to get rid of waste from your body. Your doctor might prescribe some medicine to help with this.
About 3 in 1000 donors will go on to develop end-stage kidney disease.
Another possible long-term risk for donors is having poorly-controlled blood pressure where the donor needs to take blood pressure medicine.

However, for most donors, their blood pressure will not become poorly-controlled, and they won’t need to take blood pressure medicine.

After kidney donation, most female donors will have normal pregnancies. However, if you do get pregnant you need to tell your midwife and doctor that you have donated a kidney. There is a risk that you could get high blood pressure when you are pregnant and your midwife and doctor will need to monitor you more closely.

Some kidney doctors recommend that women have all the children they want to have before they donate a kidney.
What donors say about live kidney donation

Most donors lead full, active lives after donating their kidney.

Even though it is not an easy thing to do, most donors are very pleased they donated their kidney. Many donors have said that it’s the best thing they’ve ever done.
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
Email: kidneysociety@adks.co.nz

Auckland/Waikato
ADKS Centre
5 Swaffield Rd
Papatoetoe
Manukau 2025
www.kidneysociety.co.nz
Ph: (09) 278 1321
Freephone: 0800 235 711
Email: kidneysociety@adks.co.nz

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
Linda Richards
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
Charles Hill
(President)
Email: tincow@xtra.co.nz

Timaru
South Canterbury Kidney Support
Kim Hewson
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

Dunedin
Otago Kidney Society
Anita Lloyd
(Secretary)
Ph: (03) 486 2268
Email: mosb@xtra.co.nz

Gore
Gore Kidney Support Group
Email: rocketralph@hotmail.co.nz
active infection – A current infection which could involve any part of your body. An active infection at the time of your operation could stop your transplant operation from going ahead.

anaesthetist – The doctor that gives you your anaesthetic (medicines for the operation) and makes sure you remain safe during your operation.

antibodies – Proteins that help the immune system reject anything that it does not recognise as its own, such as bacteria and viruses. Antibodies are a common cause of kidney rejection.

artery – One of the tubes you have inside you that carries blood away from your heart to the cells and organs around your body.

body mass index (BMI) – The calculation of how much fat you have. Your BMI is worked out by a formula using your height and weight.

bowel – Your large intestine. This is the long tube under your stomach that helps you digest food and carry solid waste out of your body. You empty your bowel when you go to the toilet.

blood clots – Clumps or lumps of blood that can block the flow of blood in your body.

cardiologist – A doctor who specialises in the heart and how it works.

cervical smear test – A screening test for cervical cancer. Only women have this test.

compatible – When two things are compatible, they work well together.
**computed tomography angiogram scan (CT scan)** – A scan that shows the condition of the blood vessels to your kidneys. This scan helps the transplant doctor decide which kidney should be transplanted. (You keep your best kidney.) This scan is often done towards the end of the donor workup.

**constipation** – When you have trouble going to the toilet (emptying your bowel). Constipation is a common problem after surgery, including kidney operations.

**cuff** – A type of band that you wear at the top of your arm to measure your blood pressure.

**desensitisation** – A blood treatment that your recipient can have if tests show that your blood groups are not compatible.

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

**dietitian** – A person who specialises in healthy eating and nutrition.

**electrocardiogram (ECG)** – A test that looks at how healthy your heart is.

**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.

**exclusion criteria** – Things that stop you from doing something. In live kidney donation, some medical problems like diabetes or cancer can stop you from donating. These medical problems are called exclusion criteria.

**general anaesthetic** – Anaesthetic (medications for operations) that allow you to sleep through your surgery. When you wake up, surgery is finished and you will be in the recovery room.

**gynaecologist** – A doctor who specialises in women's health and reproduction.

**high-impact sports** – Sports that have a lot of physical contact. These include boxing, rugby, rugby league and martial arts.
laparoscopic surgery – Keyhole surgery. In this type of surgery, several smaller incisions (cuts) are made instead of a single larger incision. Laparoscopic surgery is less painful and results in faster recovery times and less scarring than open surgery.

mammogram – A screening test for breast cancer. Only women have this test.

midwife – A person who is specially trained to help women during pregnancy, childbirth and for the first few weeks after childbirth.

nausea – Feeling sick or wanting to vomit. Nausea is common after surgery.

nephrectomy – The medical word for the kidney operation you will have.

open surgery – Surgery that is not laparoscopic (keyhole) surgery. Open surgery is traditional surgery where a larger incision (cut) is made on the body of the patient.

positive cross-match – When the recipient has antibodies against the donor. The transplant cannot go ahead if tests show a positive cross-match because the recipient will most probably reject their new 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.

proteins – Natural substances that are found in living things including the human body.

psychologist and psychiatrist – Health professionals who are trained how the human mind works. Donors and recipients will see either a psychologist or psychiatrist as part of their workup assessment.

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.

transplant co-ordinator – The person who organises the tests and assessments you do as part of your workup. The
co-ordinator is also there to answer any questions you have about being a donor and to put you in touch with the right people at the right time, such as social workers and travel co-ordinators. The transplant co-ordinator is usually a nurse.

**transplant doctor** – A kidney doctor who has specialist knowledge of kidney transplants.

**sick leave** – Days off work that you take when you can’t work because you are sick. All employees get a certain amount of paid sick leave per year. Employees often take unpaid sick leave as well if they need more time off work because of their sickness or illness.

**urine** – The medical word for pee.

**urologist** – A doctor who specialises in (the plumbing of) the urinary tract, which includes the kidneys and bladder.

**workup** – All the tests and medical assessments you have before you can donate your kidney.
Workup template

This table shows the tests you need to do during your workup. You might not need to do all these tests. Likewise, you might need to do extra tests or do these tests more than once before you can donate your kidney. You might not do these tests in the order that you see them in the table.

Keep this table with you during your workup. Whenever you complete a test tick the ‘Date Completed’ box and write in the date. If you don’t pass a test make a note to yourself of what you need to do or what actions you need to take. This table should help you keep track of what tests you have done and what tests you still need to do.
<table>
<thead>
<tr>
<th>Test name</th>
<th>Why I have to do it?</th>
<th>Date completed</th>
<th>Result &amp; result date</th>
<th>What action do I take?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial blood tests</td>
<td>To check for any medical problems that might stop you donating your kidney.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urine tests</td>
<td>This gives the doctors an idea of how well your kidneys are working.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24 hour blood pressure test</td>
<td>To check how good your blood pressure is.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chest X-ray</td>
<td>To check how healthy your lungs are.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Test name</td>
<td>Why I have to do it?</td>
<td>Date completed</td>
<td>Result &amp; result date</td>
<td>What action do I take?</td>
</tr>
<tr>
<td>---------------------------------</td>
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<td>------------------------</td>
</tr>
<tr>
<td>Cervical smear test</td>
<td>To check for cancer in your cervix (the lower part of your uterus).</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Mammogram</td>
<td>To check for breast cancer. You will only usually have to do this test if you are a female over 45 years of age.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prostate screen</td>
<td>To check for cancer in your prostate (the area around your reproductive organs).</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>ECG (or Electrocardiogram)</td>
<td>To check how healthy your heart is.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Test name</td>
<td>Why I have to do it?</td>
<td>Date completed</td>
<td>Result &amp; result date</td>
<td>What action do I take?</td>
</tr>
<tr>
<td>---------------------------------</td>
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<td>------------------------</td>
</tr>
<tr>
<td>Cross-match blood test</td>
<td>To check that you don't have the same antibodies as your recipient. If the result is positive this means you can't donate to your recipient. You want your blood test result to be negative.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical assessment</td>
<td>To check you are medically suitable for the transplant operation and identify any potential long term risks.</td>
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</tr>
<tr>
<td>Surgical assessment</td>
<td>To check that you are suitable for the transplant operation. The transplant surgeon will examine you, and discuss the operation with you so that you have all the information you need.</td>
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</tr>
<tr>
<td>Psychological assessment</td>
<td>To check you fully understand what being a live kidney donor means, that the decision to become a live kidney donor was yours and that you are still happy with this decision.</td>
<td></td>
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</tr>
<tr>
<td>CT angiogram (or Computed Tomography angiogram)</td>
<td>To check that the blood vessels to your kidneys are in good condition.</td>
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<td></td>
</tr>
</tbody>
</table>
Your plan

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Actions</th>
<th>Date completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arrange childcare for hospital stay and while recovering at home.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arrange home-help for hospital stay and while recovering at home.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arrange gardening, etc help for hospital stay and while recovering at home.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arrange pet care for hospital stay and while recovering at home.</td>
<td></td>
<td></td>
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<tr>
<td>Arrange transport to and from hospital.</td>
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<td></td>
</tr>
</tbody>
</table>
## Your plan to apply for financial compensation

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Actions</th>
<th>Date completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collect information for application – information from employer, accoutant, other forms.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complete forms, including unpaid leave form with employer.</td>
<td></td>
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<tr>
<td>Send application to Ministry of Health.</td>
<td></td>
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</tr>
<tr>
<td>Received confirmation from Ministry of Health.</td>
<td></td>
<td></td>
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</tbody>
</table>