Being A Recipient

Information about kidney transplants for people with kidney disease

December 2017

About this booklet

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

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The purpose of this booklet is to give people with kidney disease information about receiving a kidney transplant from a live or deceased donor.

This booklet has general information about kidney transplants. This booklet has been written to support the information you get from your health professional.

It’s important that you talk to your health professionals and family and friends before you decide to go ahead with a kidney transplant.

Please bring this booklet to all meetings you have with health professionals (including kidney doctors, transplant co-ordinators and others) about kidney transplants.
There are also two booklets available for people who are thinking of becoming live kidney donors. The first donor booklet is called *Becoming a live kidney donor – General information to help you decide*. This first booklet gives information to help people decide if they want to become a live kidney donor.

The second donor booklet is called *Live kidney donation – Information for donors about the tests, the operation and what life will be like after donation*. This booklet has been written for people who have already decided they want to go ahead and become a live kidney donor.

People who want information about becoming a live kidney donor can get these booklets from transplant co-ordinators or by calling 0800 LIVE DONOR – 0800 5483 3666.

www.kidneydonor.org.nz
What is end-stage kidney disease?

Many diseases can damage the kidneys so that waste isn’t properly removed from your body.

When this happens, the waste builds up in your body. Over time, your health will seriously deteriorate (get worse).

If the damage becomes very bad, your kidneys don’t recover.

Without treatment, you will live as long as your kidneys can support you. The length of time that your kidneys continue to support you can depend on other medical conditions.

This is called end-stage kidney disease.

One option that is appropriate for some people with end-stage kidney disease is a kidney transplant from either a live or deceased donor.
Blood enters the kidneys through an artery from the heart.

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

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

Newly cleaned blood returns to the blood stream through the veins.

How kidneys work
What are my treatment options if I have end-stage kidney disease?

End-stage kidney disease is treated in a number of ways.

Not all options are suitable for all people with end-stage kidney disease.

You should discuss which options are suitable for you with your kidney team.

Your kidney team includes all the health professionals who are involved with your kidney treatment.

Option 1: Transplant

There are 2 types of kidney transplant.

1. Live donor kidney transplant

You can get a new kidney from a healthy relative or friend. This is called a live kidney donation. It is sometimes also called directed donation because the donor (your family member or friend) ‘directs’ that their kidney goes to a particular person – you.

A live donor kidney transplant is often the best treatment option for end-stage kidney disease because it gives you the best possible quality and length of life. After a successful live donor kidney transplant, you won’t need dialysis and you will be able to live a more independent life.

If you have a live kidney donor this means you do not have to wait for a kidney from a deceased donor.
2. Deceased donor kidney transplant
You can go on the waiting list for a kidney transplant from a deceased donor.

A deceased donor is a person who has died and their family has agreed to donate the deceased person’s kidneys.

Most people will need to be on dialysis while they wait for a kidney to become available from a deceased donor.

It is difficult to say how long you will have to wait, but most New Zealanders who eventually receive a kidney from a deceased donor have been waiting about 3 years from the time they started dialysis.

You need to know that more than 80–90% of people with end-stage kidney disease in New Zealand are not able to get a deceased donor kidney transplant because they are either too sick to have a kidney transplant or they die while they are waiting.

This is one of the reasons a live donor kidney transplant is better if you have someone who wants to donate one of their kidneys to you.

Option 2: Dialysis
There are two types of dialysis – haemodialysis and peritoneal dialysis.

The average time a person lives on dialysis is 4–5 years, although some people live much longer than that.
Option 3: Medical care without dialysis or transplantation

This is also called conservative management or supportive care.

If you choose this option, you are choosing not to have dialysis or a kidney transplant.

If you chose this option you will only live as long as your kidneys can support you, which is different for different patients.

However, for some patients, this option allows them to have a better quality of life or even a longer life, compared to what they would have had on dialysis or with a kidney transplant. For example they can avoid operations and medical procedures, and spend more time with their family and friends.
Receiving a live donor kidney

How safe is live kidney donation for the donor?

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

This means it is safe for a healthy person to donate one of their kidneys.

Donors will only be accepted after they have had thorough medical tests including:

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

These tests are to make sure that a donor is healthy enough to safely donate one of their kidneys.

About 3 in 1000 live kidney donors go on to develop end-stage kidney disease.

This is similar to the risk of developing end-stage kidney disease in the general population who have not donated a kidney.
About 3 in 1000 donors go on to develop end-stage kidney disease.
Finding a live kidney donor

Some of your family members or friends may offer to donate to you.

Think carefully about all offers you receive.

All donors must be over 18 years old and be in good health with two healthy kidneys.

In New Zealand, it is illegal to pay people for donating a kidney.

Some people who have end-stage kidney disease will receive offers of a kidney from family and friends. It is OK to take your time to think about these offers.

“Thank you so much for your offer. It really means a lot. I need to talk to my kidney doctor and the transplant co-ordinator to make sure it’s OK for me and you. Can we talk about it again after that?”
Remember, generally:

- it is safe for a healthy person to donate a kidney
- a healthy person can live for the rest of their life with only one kidney
- your live kidney donor will have a lot of medical checks to make sure it is safe for them to donate a kidney to you.

**How can I ask someone to be a donor?**

If you don’t receive an offer, you could talk about donation with your family or friends.

If you find it hard to talk to your family and friends, there are a number of things you can do:

- Some transplant co-ordinators might be able to come and talk to your family at home. Not all transplant co-ordinators do this so ask your co-ordinator if they are able to do this. These family meetings can be a really good way to introduce your family and friends to live kidney donation. It’s often easier to hear general information about live kidney donation from someone outside the family, and it often means that your family and friends are more comfortable to ask questions.
• Take family members to your next appointment with your kidney doctor and ask your doctor to explain why you need a new kidney and how live kidney donation works.

You could say something like this:

“I’ve been looking into live kidney donation as a treatment for my kidney disease. Have you heard about this? What it means is that a healthy person donates one of their kidneys to someone like me. My doctor says it’s really safe and people only need one kidney to live a perfectly healthy life. Apparently, it’s the best treatment for someone like me. What do you think? Would it be OK to come to my next appointment and talk to my doctor about this?”

• Talk to your local Kidney Society or Kidney Health New Zealand about different ways you can ask people to become your donor.
Receiving a deceased donor kidney

Information about the deceased donor list

Even though it is called a waiting list a kidney is not always given to the person who has been waiting the longest. This list is like a pool of people who might be offered a kidney from a deceased donor.

Kidneys from non-directed donors are also allocated through the deceased donor list. Non-directed donors are people who are alive and decide to donate one of their kidneys to someone they don’t know.

How do I get onto the list?

Once you get to the stage when your kidneys are only just working (called end stage kidney failure) the team looking after you will talk to you about dialysis and transplant. Many people who have end stage kidney failure can go on the list for a kidney transplant from a deceased donor.

However, not everyone is suitable for a kidney transplant from a deceased donor. Some people may be told that they can have a kidney transplant from a live donor but not from a deceased donor because of:

- previous transplants
- other health conditions
- the person’s overall health
- how their kidney disease has affected the rest of their body
- other surgery the person may need at the time of transplant
- lower than 80% chance of living more than 5 years after a deceased donor transplant.
How do they work out my chance of living more than 5 years?

Usually there are more than 400 people on the active waiting list. In New Zealand about 100 kidneys are donated each year from deceased donors. This means only people with a good chance of doing well after a transplant are able to go on the list.

Your kidney doctor and the team at your transplant centre will discuss:

- your health
- your test results
- how your kidney disease has affected your heart and the rest of your body.

This discussion is to check if you are fit enough to have a transplant at any time. This is called your Comorbidity Score.

Looking at all these things helps doctors to make the same decisions across New Zealand. This means deciding who gets a kidney from a deceased donor is as fair as possible. If you are assessed as having a lower than 80% chance and your doctor doesn’t think that is correct, your doctor can ask for the decision to be reviewed.

Everyone on the waiting list is reviewed every one to two years to make sure they are still well enough to stay on the list.

So what are my chances of getting a kidney?

You may be lucky and get a kidney quickly. However most people will wait for several years. Sometimes this is because of your blood group or antibodies. Some people on the waiting list may never be offered a kidney from a deceased donor.
Deciding who gets a kidney

When a family offers a kidney for transplant the New Zealand Blood Service uses the information from your monthly blood tests as well as how long people have been waiting to decide who gets offered the kidney.

Kidneys are offered to people based on two things. First who has been waiting the longest time on the list and secondly the best match. There is no way of guessing the blood group of the next donor and what antibodies a person needing a transplant might have against the kidney.

**Deciding who gets a kidney is based on two things:**

1. Waiting time on the list.
2. Most compatible recipient.

*Example where the deceased donor has Blood Group A*

- **400** people are on the active waiting list
- **- 350** people cannot receive this kidney
- **= 50** people could receive this kidney

<table>
<thead>
<tr>
<th>200</th>
<th>people are Blood Group O – cannot receive this kidney</th>
</tr>
</thead>
<tbody>
<tr>
<td>90</td>
<td>people are Blood Group B – cannot receive this kidney</td>
</tr>
<tr>
<td>60</td>
<td>people have antibodies that react to this kidney. This is called a positive cross match. So these people cannot receive this kidney</td>
</tr>
</tbody>
</table>

The computer system checks how long these 50 people have been waiting and how compatible they are to the kidney.

These people are ranked from 1 to 50 and the top two people will be offered a kidney from this donor.
What other transplant options do I have?

If your health is not good enough to be on the deceased donor list you could still be well enough for a transplant from a live donor. These sorts of transplants are more likely to happen, happen more quickly and you do not always need to have the same blood group. Talk to your family and friends about them donating a kidney to you.

You can find out more information about live kidney donations at http://kidneydonor.org.nz/ or by calling your local transplant coordinator.

More information

How successful are kidney transplants?

Live donor kidney transplants are the best treatment for many people with end-stage kidney disease.

Live donor kidney transplants have high success rates.

About 19 out of 20 kidneys transplanted from a live or deceased donor will be working well after 1 year. More than 10 out of 20 of all kidneys transplanted from a live or deceased donor will still be working well after 20 years.

About 19 out of 20 kidneys transplanted from a living donor will be working well after 1 year.

Most people have a longer, better life with a kidney transplant than with dialysis.
What are the benefits of a kidney transplant?

With a successful live or deceased donor kidney transplant, you will:

- no longer need dialysis
- have much greater freedom about what you eat and drink
- have a more normal lifestyle, for example, you will be able to travel.

If you are a woman, you might be able to get pregnant. Many women have successful pregnancies and healthy children after a transplant.

There are a number of reasons that it is better to get a kidney from a live donor than a deceased donor.

The main advantage of live donor kidney transplants is that a kidney from a live donor usually works for longer than a kidney from a deceased donor.

Another advantage of live kidney donation is that the kidney is usually transplanted into the recipient as soon as it is taken out of the donor. The transplant operation can be booked in advance and proceed more smoothly.
There will never be enough deceased donor kidneys in New Zealand.

More New Zealanders are getting end-stage kidney disease and needing a kidney transplant, and the number of deceased donors is not increasing.

Getting a kidney from a live donor is quicker, and the shorter the time you have on dialysis, the healthier your body will be.
What are the drawbacks of a kidney transplant?

A live or deceased donor kidney transplant involves having an operation.

All operations have some risks.

If you have a live or deceased donor kidney transplant, you will need to take anti-rejection medicine every day for the rest of your life, or while your transplanted kidney is still working.

You will also need blood tests to check your transplanted kidney in case the medicine needs changing.

Anti-rejection medicine has side effects.

The most serious of these side effects is the increased risk of infection. This means that you might get infections more easily after your transplant. There are other side effects that you need to think about including an increased risk of diabetes, bone disease (osteoporosis) and some cancers.

Live donor kidney transplants

You need somebody to offer to donate you their kidney.

If you don’t get any offers straight away, you might need to think about how you can talk to someone about donating their kidney. There is more information about how to ask someone to donate a kidney on page 13 of this book.

Most transplants from live kidney donors are successful, but approximately 1 in 20 fail in the first year.
Deceased donor kidney transplants

There are a number of drawbacks if you wait for a deceased donor kidney transplant:

- you could wait for a long time (in 2017 it was 2–4 years depending on blood type)
- you don’t know when you are likely to be offered a kidney
- your health could change while you are waiting for a deceased donor kidney transplant and you would have to come off the waiting list
- there is a higher risk that you could have to have dialysis after your transplant
- your long term outcomes are slightly worse than someone who has a live donor kidney transplant.
**When is the best time to have a kidney transplant?**

**Live donor kidney transplant**

If a live donor kidney transplant is a suitable option for you, it is best to have the transplant as soon as possible, even before you start dialysis.

This is called a **pre-emptive transplant**.

However, even if you have been on dialysis for a long time, you can still have a live donor kidney transplant.

For most people, a live donor kidney transplant is a better option than staying on dialysis.

**Deceased donor kidney transplant**

Remember you can't choose the time when you will have a deceased donor transplant.

**How safe is a transplant operation?**

Kidney transplants are generally safe operations.

The risk of death for both live donors and recipients from a kidney operation is 1 out of 3500 operations. This is very low.

Although kidney transplants are safe operations, there is still some risk involved.

General risks include problems with anaesthesia and infections. These risks are the same for all operations.
The risk of death for both live donors and recipients from a kidney transplant operation is 1 out of 3500 operations.
What are the main stages of a kidney transplant?

Live donor kidney transplant

1. Talk to your kidney doctor (specialist) about live donor kidney transplantation. If this is an option for you, decide if this is something you would like to do.

2. Talk to your family and friends about the fact that you need a new kidney and see if any of them offer to donate a kidney to you.

3. Think about any offers you get and then decide whether you want to go ahead.

   Remember, a live donor kidney transplant is often the best treatment option for someone with end-stage kidney disease.

4. You and your potential donor(s) will need to have lots of tests to see if you are a suitable match. If you have more than one potential donor, the transplant team will advise you on the best match. If you have no matching donor, there are options to help your donor to still donate and you to still receive a kidney. One of these options is to join the Kidney Exchange programme.

   There is more information about the Kidney Exchange programme on page 42.

5. Have the transplant operation. You and the donor will usually have your operations in the same hospital and at the same time.
Deceased and live kidney transplant

Your transplant co-ordinator will talk to you about:

- how you get evaluated for a transplant
- how you get selected for a transplant (remember there is information earlier in the book)
- the advantages and disadvantages of live and deceased donor transplants
- the need for you to have monthly blood tests
- your operation
- what will happen in hospital after your operation
- the medicines you will need to take after the operation and the side effects of those medicines
- follow up in the transplant clinic.
Who will I be dealing with if I have a kidney transplant?

You will have to see different health professionals at different times before and after your transplant.

Kidney doctor (specialist) – This is your main health professional and the member of the team that you will probably see most often throughout your life. They have overall responsibility for your treatment.

Transplant co-ordinator – The co-ordinator organises tests and appointments, and will tell you what you need to do next. This is the first person you should call if you have any questions about what is happening.

Transplant surgeon – This is the person who will be doing your operation. They are specialists in performing kidney transplant surgery. You will see them after the transplant operation while you are still recovering in hospital.

Transplant doctor (specialist) – This doctor could be the same person as your kidney doctor or a different doctor. Your transplant doctor is a specialist who will look after you in the first few days or weeks after the transplant operation. When the transplant doctor is satisfied, you will be handed back to your own kidney doctor (if this is a different person).

Dietitian – This person will give you advice about healthy eating.

Hospital psychologist or psychiatrist – This person is specially trained in how the human mind works. They may talk to you about how you are feeling about the transplant. They will help you deal with any concerns you might have.

Social worker – This person can help you with personal and financial problems, transport problems or problems with your benefits.
The tests I need to have

What is the ‘workup’?

You need to do a number of tests to find out if you are healthy enough to have a kidney transplant.

These tests are often called your workup.

These tests will make sure:

- you are healthy enough to have a kidney transplant operation
- you are compatible with your live kidney donor if you are having a live donor kidney transplant.
How long does the workup take?
Some tests will happen quite quickly because they are easy to arrange while others will take longer.

Sometimes test results lead to other tests or appointments, which may take more time.

The tests that you have to do will depend on how old you are, your health and how healthy you have been in the past.

It should take you about 4 months to get all your tests done, although it can take longer if you need to have more tests.

Some of these tests will be done at hospital, while others will be done at a laboratory.
Do I need to lose weight?

If you are very overweight, you will need to lose some weight before you can have a kidney transplant.

You will be weighed and your height will be measured 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.

Some transplant teams have different requirements around BMI. Talk to your transplant co-ordinator about what your BMI needs to be.
Talking to a psychologist

You may also have an interview with a hospital psychologist or psychiatrist (health professionals who are specially trained in how the human mind works).

During this interview, you might discuss what happens when you have a kidney transplant, what your life will be like after the transplant and how you will cope if your kidney transplant fails.

Live donor kidney transplants

Your donor will also probably be in this interview with you.

Your donor will probably also have their own interview with the psychologist or psychiatrist.

In their own interview, your donor will be asked to talk about why they are donating a kidney. This is done to make sure that the donor has given informed consent. Informed consent means the donor knows exactly what is involved in donating their kidney and that it is their decision to be a live kidney donor.
Can I get support while I am going through my workup?

The workup can be a difficult and stressful time for you, your family and your donor if you are having a live donor kidney transplant.

There are always people you can talk to about this.

Apart from your friends and family, your transplant co-ordinator, hospital psychologist, your local Kidney Society and Kidney Health New Zealand can all help you as well.
What tests will I need to do and why?

You will need to do a number of tests including:

- blood tests
- urine tests
- a chest X-ray to check how well your lungs are working, that there is no fluid on your lungs and the size of your heart
- an electrocardiogram (ECG).

The ECG is like an electrical photograph of your heart that records the rhythm of your heart and gives important information about how well your heart is working.

Other heart tests

If you are over 40 years of age and have a history of heart disease or diabetes, you will have more heart tests.

These extra tests might include tests to check how well your heart works under stress. You will have to go to a hospital or a clinic to have these ‘stress tests’, which are done in monitored and safe environments. You will be put on a treadmill to exercise or be given some medicine to increase your heart rate while the technicians scan your heart to ensure that it can cope with the stress.

If any of these tests show you have a problem, you will need to see a heart specialist to see whether it is safe enough for you to have a transplant operation.
Blood tests

Blood tests are a big part of your workup.

Your blood tests will check your blood clotting times, liver function and protein levels.

Your blood will also be tested for HIV, hepatitis B, hepatitis C and other viruses you might have.

Blood tests are also done to check what your blood group is and that your blood is compatible with any possible donor's blood.

Your blood will also be tested to see if you have antibodies against the kidney of any possible donor.

Antibodies are proteins that help the immune system fight anything that it does not recognise as its own, like bacteria and viruses.

Your blood test may show that you have antibodies against your donor. This is called a positive cross-match.

Other tests

Some transplant teams may ask you to have a dental check as well. The dental check will make sure you don’t have any infections in your gums and teeth.
If you are a man over 50 years, you will need to have a blood test to check for prostate cancer.

If you have a family history of prostate cancer and are over 40 years, you will also need to do this test.

If you are a woman, you will need to have a cervical smear test to check for cancer of the cervix.

If you are a woman over 45 years, you will also need to have a mammogram test to check for breast cancer.

These tests need to be arranged through your family doctor.
Can anyone have a kidney transplant?

Not everyone who goes through the workup will be able to have a kidney transplant.

For example, if you have a serious heart problem, cancer or an active infection, you will not be able to have a kidney transplant.

The tests you do as part of your workup will show if you are well enough to have a kidney transplant.

Remember there is information earlier about how recipients get on the kidney transplant waiting list.
**Getting my test results**

You should be able to get results for each of your tests within 14 days.

If you don't hear back from your transplant co-ordinator, follow up by calling, texting or emailing the co-ordinator and asking for your results. You might need to leave a message for the co-ordinator to call you back.

You might be near the end of your tests only to find out you are not well enough to get a transplant.

This will be very upsetting for you and your family.

However, the kidney transplant team can only go ahead with your transplant operation if it is safe for you.
What tests will my live donor do?

If you are having a live donor kidney transplant, your donor will be doing their own tests during this time to check that they are healthy enough to donate one of their kidneys to you.

Remember, donors will only be accepted after they have passed all of their medical tests.

The donor’s tests will be done independently from your tests. To protect their privacy, the donor’s test results will not be shared with you, and to protect your privacy, your test results will not be shared with the donor.

Occasionally, your live donor might have a health issue that needs to be discussed with you before the transplant can proceed.

Sometimes you might have a health issue that needs to be discussed with the donor.

In both cases, the transplant team will explain why this is and get the other person’s permission to share the health information between your donor and you.
What happens if my blood is not compatible with my live donor?

These days, even if your blood group does not match (is not compatible with) your live donor’s blood group, you might still be able to receive your donor’s kidney.

You will need to have special treatment called desensitisation which is available at Auckland and Christchurch Hospitals.

If you are able to have this treatment and it is successful, you might be able to go ahead with the transplant. If the treatment is not successful, you and your donor can go into the Kidney Exchange programme.

There is more information on the Kidney Exchange programme on page 42.

What happens if my live donor and I have a positive cross match?

You will not be able to receive a kidney from your donor if the result is a positive cross-match.

In this case, you and your donor can go into the Kidney Exchange programme. Go to page 42 for more information.
Kidney Exchange programme

Your live donor might not be able to donate to you for a number of reasons.

This could be because their blood group is not compatible with yours or because of a positive cross-match.

If your donor is not able to donate to you, you might still be able to get a live donor kidney transplant if you and your donor join a programme called the Kidney Exchange.

The aim of the Kidney Exchange programme is to find pairs of donors and recipients that can donate to each other.

If you are matched up with another pair in the Kidney Exchange programme, your donor will give their kidney to another recipient and you will get a kidney from another donor.

Your kidney doctor or transplant co-ordinator can give you more 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
Who makes the final decision about whether I have my transplant?

Once all the tests are completed, a final decision will be made about whether your transplant operation can go ahead. This is done at a monthly meeting at the transplant hospital.

Even though you might have most of your workup done at another hospital (for example, Middlemore Hospital if you live in South Auckland), the final decision to go ahead with your operation is made by the transplant team in the hospital doing the kidney transplant.

Transplant hospitals in New Zealand are Auckland City Hospital, Wellington Hospital and Christchurch Hospital.
Money

Time and financial costs
Doing tests and going to appointments can take up a lot of time.

You might also have transport costs and childcare costs, and if you are working, you may need time off work.

Talk to your transplant co-ordinator or social worker. They can give you advice or refer you to other people for help.

What can I do if I have financial problems?
There is help available from Work and Income if you are having financial problems.

If you can't work because of your kidney disease, you might already be on the Supported Living Payment.

If you are working part-time or are trying to work full-time, you might be able to get financial assistance through Jobseeker Support. Many kidney recipients go on this benefit while they are trying to get back into work after their transplant.
You might be able to get additional help through the Disability Allowance.

This is a weekly payment for people who have regular, ongoing costs because of a disability or illness. These costs include doctors’ visits, medicines, clothing and travel to and from medical appointments. If you have ongoing, regular costs because of your kidney disease, you might be able to get this allowance.

You may also be able to get the Temporary Additional Support payment.

This is a weekly payment for people who haven’t got enough money for their basic living costs (such as, mortgage or rent payments, hire-purchase payments for essential items at home and so on).

You need to be over 16 and be a New Zealand citizen or permanent resident to get this payment.
The assistance you get from Work and Income is all income and asset tested.

This means that the amount you get for any of these benefits or payments will depend on your own personal circumstances. This means your benefit will be reduced if you are already working part-time, getting another benefit or have a partner who is working.

To find out what you are entitled to get, you will need to ring Work and Income on 0800 559 009 or visit the Work and Income website at www.workandincome.govt.nz and make an appointment to see a case manager at your local service centre.

You will need to fill out application forms for the benefits you are applying for.

These can be sent out to you in the post, or you can download them at www.workandincome.govt.nz/individuals/forms.html.

You should try and complete these forms before your appointment, but if you can't, the case manager you see at Work and Income will be able to help you.
Everything you need to take with you to your appointment will be written on these forms.

Usually you will need to take:

- your passport or other photo identification
- a copy of a bill that has your home address written on it
- copies of your last few bank statements
- a letter from your kidney specialist if you can’t work or you need to work fewer hours
- your IRD number
- your tenancy agreement (a contract between you and your landlord) if you rent your house
- proof of your income, like pay slips or a letter from your employer (your case manager will talk to you about how Work and Income will check this).

If you are having trouble making an appointment or filling in the application forms, your local Kidney Society might be able to help you with your Work and Income application. See the list of national contacts at the back of this book.
Help with travel and accommodation costs

You might also be eligible for National Travel Assistance (NTA).

This is a special allowance to help people who need to travel long distances to get specialist medical treatment.

Talk to your transplant co-ordinator or social worker about the National Travel Assistance scheme. They can tell you how to apply for this.

Most hospitals have a travel co-ordinator who can help you.
My live kidney donor will need to take time off work for the operation and recovery and will not be earning any money. Can my donor get any help with this?

You may be worried about asking someone to donate a kidney to you because they will have to take time off work for the operation and to recover. The good news is that your donor may now qualify to get compensation for loss of earnings from the date of your donor’s operation until a doctor says they are recovered and can go back to 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

• your live kidney donor must have been accepted as a suitable donor by the New Zealand health system

• your donor’s surgery (operation) must take place in New Zealand

• the recipient of the kidney (you) must be eligible for publicly funded health services in New Zealand.

Your donor needs to lose income to be eligible for the compensation (so if they take sick leave/annual leave they are NOT eligible even though they might spend that leave).

This Act says that live organ donors (including live kidney donors) will be compensated for loss of earnings from the date of the donor’s operation to the date the donor goes back to work. Compensation for 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.
This means you do not have to worry that your donor will not be earning any income when your donor has their operation and while they recover.

There is more information about the Act on the Ministry’s website: www.health.govt.nz

**What if my donor is on a benefit?**

Your donor is not entitled to any compensation. However depending on what sort of benefit your donor is on, your donor may be exempt from work test obligations from the time of their operation until they have recovered. This means your donor may not have to apply for jobs until a doctor has said your donor is well enough. This will be for a maximum of 12 weeks from their operation date. Remember most donors usually recover within 6 weeks of the operation.

If your donor earns income on top of their benefit, they may be eligible for compensation to cover this while they are recovering. Your donor needs to talk to their case manager about their situation in case they need to change to a different benefit while they are recovering.

Talk to your transplant co-ordinator if you are not sure about anything.
The transplant operation

**Your transplant operation**

**Live kidney donor transplant**
Live kidney donation means that both you and your donor will have an operation.

The operation lasts about 3 hours.

In this operation, a kidney is taken out of your donor and then placed (transplanted) into your body.

You and your donor will be operated on the same day and usually in the same hospital. Usually you will be in the Intensive Care Unit after your operation and your donor will be in a ward.

Both you and your donor will have a general anaesthetic for your operation.

**Deceased kidney donor transplant**
You will be called into hospital when a compatible kidney is available. This could be any time, day or night. That means you

- always need to be able to be contacted by phone
- you need a plan about how you will get to the hospital (e.g. family or friends). Talk to your co-ordinator or social worker about transport.
How safe is the operation?
Kidney transplant operations are generally very safe.

The chance of either a live donor or the recipient dying during a kidney operation is very low.

What are the risks of the operation?
Kidney transplant operations 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 new medicines will I need to take?
You will be given a special medicine called immunosuppressive or anti-rejection medicine.

This medicine helps your body to accept your new kidney. The medicine works by suppressing or weakening your immune system so that it doesn't attack and reject your new kidney.

You will need to keep taking this medicine every day for as long as your transplanted kidney is working.
When do I go to hospital?

Live kidney transplant

You will be admitted to hospital the day before your operation.

You will need to have a final medical examination at this time to make sure you are still healthy enough to have surgery.

You will need to have more blood tests, an ECG, a chest X-ray and a physical examination by one of the transplant doctors.

You will have already done these tests as part of your workup, but they need to be repeated just before your operation as well.

Occasionally, these tests show up a problem that wasn’t picked up during the workup.

This might mean that the kidney transplant can’t go ahead.

If this happens, it will be very upsetting for you, your family and your donor.

Deceased kidney transplant

Remember you may be called into hospital at any time day or night. Make sure you can always be contacted by phone. Sometimes your transplant may not go ahead because the kidney was unsuitable for transplanting. If this happens, it will be very upsetting for you and your family.
What happens during the operation?

When the kidney is removed, the surgeon also takes the artery, vein and ureter (urine tube) of this kidney.

During your operation, the surgeon will make a 15–20 cm long cut in your lower abdomen, near your groin. This can either be on the left or right side of your body.

Your surgeon will place the new kidney inside your body and join the artery and vein of the transplanted kidney to the main artery and vein in your pelvis. The ureter from the transplanted kidney is then joined to your bladder.

The surgeon will also place a urinary catheter in your bladder to help drain the urine made by your transplanted kidney.

A catheter is a hollow plastic tube that looks like a straw. The urine will go into a drain bag.

Your diseased kidneys are not removed during the transplant operation and will stay inside your body.
What will it be like when I wake up?

When you wake up after your operation, you will be closely monitored, either in the Intensive Care Unit or by a nurse who is looking after you only. This is so the transplant team can make sure your new kidney is working and you are not having any problems.

You will have some pain around the operation wound. This is normal, and you will be given pain relief to manage this.

As the blood begins to flow through your new kidney, it should start to make urine. For some people, this happens straight away.

Sometimes, though, it can be a while before your new kidney starts to work. In this case, you might need to go on dialysis until your new kidney starts to work properly.

When the doctors are sure that everything is stable and your new kidney is working properly, you will be transferred out of the Intensive Care Unit to a general ward.
**How long will I be in hospital?**

Most people are in hospital for 5–7 days after their operation.

How long you stay in hospital depends on how fit and healthy you are, how your body responds to your new kidney and if there are any problems after your operation.

Many recipients feel better soon after the operation. This is often because they were very unwell before the operation and feel much better as soon as they get a new kidney.

Before you are discharged from hospital, you will need to know the names of your medicines and how to take them every day.

The hospital pharmacist or your transplant co-ordinator will talk to you about these medicines so you know when to take them and how to take them.
**Will I have any scars?**

You will have some scars after your operation.

The largest will be about 15–20 cm long and will usually run across the right side of your lower abdomen.

This is where the surgeon transplants and attaches your new kidney to your veins and arteries. Sometimes this scar will run along the left side of your lower abdomen.
How will I feel after my transplant?

You will probably feel much better after your operation. However, it’s important to give your body plenty of time to recover.

Most recipients need at least 4–6 weeks to recover after a kidney transplant.

If there are problems after the surgery, the recovery time will be longer.

The first 3 months after your transplant are very important because this is when your body is most likely to reject your new kidney.

Always do what your kidney specialist tells you. Make sure you go to all your appointments and take your medicine as you are meant to.

Taking good care of yourself after your transplant is really important to keep your new kidney healthy and working well.
**What follow-up will I have after my transplant?**

You will need to have blood tests done every day for at least 4 weeks after your transplant.

This also includes the first week when you are still in hospital.

When you are discharged from hospital, you have to come back to the hospital where you had your transplant every day for these tests for at least the first month. You will then be transferred to your local hospital.

If your new kidney is working well, these blood tests will then be reduced to three times a week, then twice a week, then weekly, then monthly.

Generally, once you don’t need to have blood tests every week, you can have your tests done at your local hospital or clinic.

These blood tests are very important because they show if your new kidney is working properly.

If there are problems with your new kidney, the kidney specialists need to know immediately so they can adjust your medicine or order more tests.

You will need to have a plan in place for how you are going to get to and from the hospital for these tests.

One year after the transplant, most recipients will be having a check up every 3–6 months.
What challenges will I face?

Taking medicine every day at the right time and in the right way is really important to keep your new kidney healthy.

The medicine works by weakening your immune system so that your immune system does not reject your new kidney.

This medicine does have some side effects. Many of these side effects will go away after a period of time.

The most common side effects are:

- infections
- puffiness around the face and abdomen
- unwanted hair growth or hair loss
- weight gain
- mood swings
- high blood pressure
- acne and pimples
- muscle weakness.
Because the medicine will make your skin more sensitive, you will have a higher risk of getting skin cancer.

You will need to take special care when you are out in the sun.

This includes wearing sunblock and covering up when you are outdoors.

You should also get your moles and freckles checked every 6–12 months after your transplant.

Occasionally, some recipients develop diabetes as a result of their medicine.

However, it is really important that you do not stop taking your medicine, even if you are having these side effects.

There is also a risk of some other types of cancer after a kidney transplant.

For most recipients, cancer is not a problem after their transplant.

Women need to have a cervical smear test every year and well as regular mammograms.

Men should have regular prostate checks done.

It is also really important to go to all your appointments with your kidney doctor and family doctor.
How long will my new kidney last?

No one knows how long your new kidney will last.

Current statistics show that 19 out of 20 kidneys donated from a living or deceased donor are still working well 1 year after transplantation.

About 10 out of 20 kidneys from live donors will still be working well 15 years after the transplant operation. This is similar for deceased donor kidneys.
How will my life be better?

For most recipients, their lives are completely different after a kidney transplant.

If you have been on dialysis, you will not need dialysis any more.

If you have a pre-emptive kidney transplant, you won’t need to go on dialysis.

You will have more energy and greater freedom to do what you want.

You will be able to take part in activities you weren’t able to before. These could include working, travelling or playing sports.

You will be able to eat and drink a greater range of food and drink.

For most people, sexual function improves after a kidney transplant and many women have successful pregnancies.

However, if you are thinking of having a baby, you will need to first talk to your kidney specialist.

Many health professionals recommend that you wait for a year after your transplant before getting pregnant.

If you get pregnant, you will need to see a doctor who specialises in high-risk pregnancies as well as a midwife.

For many recipients, the best thing about having a new kidney is that they are able to spend better quality time with their family and friends and can look forward to a longer life.
Who can I talk to about kidney transplants?

There are a number of different people you can talk to about live kidney donation.

The community-based Kidney Societies details are on page 69. Kidney Health New Zealand is also able to give you advice and information on live kidney transplants. Contact them on 0800 543 639 or visit them at www.kidneys.co.nz.
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
Email: kidneysociety@adks.co.nz
Freephone: 0800 235 711

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

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

Gore
Gore Kidney Support Group
Email: rocketralph@hotmail.co.nz
abdomen – The medical word for your tummy.

active infection – A current infection that could involve any part of your body. An active infection at the time of your operation could stop your transplant operation from going ahead.

anaesthesia – Medicines used in operations that allow you to sleep through your operation. When you wake up, surgery is finished and you will be in the recovery room.

annual leave – The number of days you can take off work every year for a holiday or a break. All employees get a minimum amount of paid annual leave, but employees can sometimes take unpaid annual leave as well if they need or want more time off work.

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.

anti-rejection medicine – Medicine that you have to take to stop your body from rejecting your new kidney. This medicine is also known as immunosuppressive medicine.

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.

bladder – The place in your body where your urine is stored before you pee.

blood clots – Clumps or lumps of blood that can block the flow of blood in your body.
**blood clotting times** – How long it takes your blood to clot (form lumps and clumps). A blood test will show what your blood clotting time is. It is important that your blood clotting times are right for you to safely have your transplant operation.

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

**compatible** – Matching. When two things are compatible, they match each other or work well together.

**conservative management** – Also known as supportive care. This is when the patient chooses not to have either dialysis or a transplant. Patients who chose conservative management will only live as long as their kidneys can support them.

**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. (Your live kidney donor keeps their best kidney.) This scan is often done towards the end of the live kidney donor workup.

**desensitisation** – A blood treatment you can have if tests show that your blood group is not compatible with (does not match) the blood group of your live kidney donor.

**deceased donor** – A person who donates their organs when they die.

**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.

**directed donation** – When a live kidney donor donates their kidney to a particular person. Only that person can get their kidney.

**drawback** – The negative side of something. A drawback can cause some difficulty or a problem.

**electrocardiogram (ECG)** – A test that looks at how healthy your heart is.
eligible – Entitled to or able to. If you are eligible for National Travel Assistance, this means you are able or entitled to get this help.

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.

entitled to – This means you have a right to something. If you are entitled to some help through Work and Income, you are able to get this help.

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

groin – The area between your abdomen (tummy) and the top of your thighs.

hepatitis B – A virus that causes liver disease. You can get hepatitis B through contact with the blood or body fluids of an infected person.

hepatitis C – A virus that causes liver disease. You can get hepatitis C through contact with the blood of an infected person.

HIV – The human immunodeficiency virus. This is a virus that attacks the immune system.

immunosuppressive medicines – This is the same as anti-rejection medicines. This medicine works by weakening your immune system so you don't reject your new kidney.

independently – Separately. Your tests (workup) will be done independently from your live kidney donor’s workup, which means the tests will be done separately by different teams.

informed consent – Permission that a person gives once they fully understand all the information. Your live kidney donor needs to give informed consent to donate their kidney. This means that your live kidney donor has to sign a form that says “Yes, I fully understand kidney donation, and I give you permission to take one of my kidneys.”
kidney 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.

liver function – How well your liver is working. You need to do a blood test to find out what your liver function is.

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

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

pelvis – The part of your skeleton where your legs meet your hips.

personal circumstances – Your own personal situation. This could include how much money you make, if you are married or single and if you have children.

positive cross-match – When you have antibodies against a possible donor. The transplant cannot go ahead if tests show a positive cross-match because you will most probably reject your new kidney.

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

prostate cancer – Cancer of the prostate gland. Only men have this gland. The prostate is just below the bladder. The tube that carries urine runs through the middle of the prostate.

protein – A natural substance that is found in living things including the human body.

protein levels – How much protein you have in your body. You need to do a blood test to find out what your protein level is.

psychologist and psychiatrist – Health professionals who are trained how the human mind works. Live kidney donors and recipients will see either a psychologist or psychiatrist as part of their workup assessment.
sexual function – Being able to have sex with no difficulty.

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.

suppressing – Weakening. Anti-rejection medicine works by suppressing (or weakening) your immune system so that your body doesn't reject your new kidney.

thorough – Full or complete. Thorough medical tests are tests that check for many possible problems.

transplant co-ordinator – The person who organises the tests and assessments you do as part of your workup. They are also there to answer any questions you have about a kidney transplant 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.

transplant surgeon – The person who will be doing your operation. These surgeons have specialist training in kidney transplant surgery.
**travel co-ordinator** – The person who organises any travel you need to do as part of your workup or transplant operation. Larger hospitals will have a travel co-ordinator.

**treadmill** – An exercise machine where you walk or run while still staying in the same place. A lot of gyms have treadmills.

**ureter** – The tube that carries urine from your kidney to your bladder.

**urine** – The medical word for pee.

**urinary catheter** – A hollow plastic tube that looks like a straw and helps drain the urine made by your transplanted kidney. The surgeon will place a urinary catheter in your bladder during the transplant operation.

**vein** – One of the tubes you have inside you that carries blood from your cells and organs towards your heart.

**viruses** – Small infectious organisms that multiply inside your body. Viruses can make you very sick.

**workup** – All the tests and medical assessments you have before you can have your transplant operation.
The original text for this book was developed by Workbase® Education Trust with key input from:

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