

# **Living with Kidney Disease**

**A comprehensive guide  
for coping with  
chronic kidney disease**

Second edition

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MANATŪ HAUORA

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Some of the material in this publication is also available on the Kidney Health New Zealand website: [www.kidneys.co.nz](http://www.kidneys.co.nz)

## A note on kidney words

Confusingly, three different English words are often used to refer to the kidneys, kidney diseases and the study of the kidneys.

- ‘Kidney’ comes from the medieval English word ‘kidenei’. It is the everyday word that most people use when they talk about kidneys.
- ‘Renal’ comes from the Latin word ‘ren’, meaning kidney, and is an adjective meaning ‘to do with the kidneys’. Doctors and nurses often refer to kidney failure as renal failure, and to the kidney clinic as the renal clinic.
- ‘Nephrology’ comes from the Greek word ‘nephros’, which also means kidney. The science of kidney medicine is referred to as nephrology. Inflammation of the kidneys (a cause of kidney failure) is usually called nephritis.

Doctors who specialise in kidney disease can be referred to as kidney specialists, renal physicians or nephrologists. It’s not the most sensible system of names, but it’s the one we have, and the one we have to put up with!

# Introduction

Kidney disease is a serious, long-term medical condition that touches the lives of many New Zealanders, but to the average person it is a confusing and complex subject. It can be seriously frightening for a person to learn from their doctor that their kidneys have stopped working properly, and that they may soon need dialysis treatment and perhaps a kidney transplant. It takes time for the news to sink in – and once it has, the first request a patient makes is usually for more information. There is such a lot to learn. It takes months – and sometimes years – to come to terms with kidney disease and its effects on individuals and families.

These days there are many sources of health information. The internet provides a lot of advice, some of which is useful and some of which is not. Other information may come from magazines, newspaper articles or conversations with friends. It can be hard to sort out the facts from the folklore.

*Living with Kidney Disease* provides a source of authoritative, accurate information for New Zealand kidney disease patients and their families.

This edition of the handbook takes into account recent advances in the diagnosis and management of chronic kidney disease.

If you or a member of your family are coming to terms with chronic kidney disease, then this handbook is for you. We hope that it will answer many of your questions, and will help you to continue to enjoy a full and happy life.

One of the most important members of your health care team is you. The other members of the team rely on you to raise the questions and explore the health issues that are particularly important to you. As you read this handbook, it might be a good idea to make a note of any questions you would like to ask your team.

# Chapter 1: Chronic kidney disease in New Zealand

Here are some facts and figures on chronic kidney disease (CKD) in New Zealand.

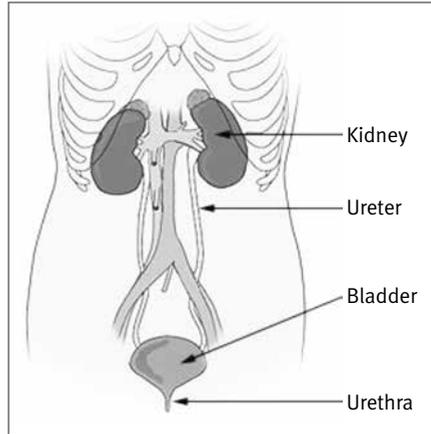
- ‘Chronic kidney disease’ means long-term, permanent reduction in kidney function.
- In a small minority of patients, CKD gets worse to the point that the kidneys are no longer able to keep the person alive. This is called end-stage kidney disease (ESKD).
- About one in ten adult New Zealanders have a sign of CKD.
- About 400,000 New Zealanders have CKD.
- Each year, about 1000 New Zealand adults are diagnosed with ESKD, and about half of those will start dialysis treatment.
- Chronic kidney disease can affect any member of our community, regardless of age or wealth.
- Chronic kidney disease is more common in Māori, Pacific and Asian people.
- Over half of ESKD cases are caused by two common, treatable diseases – diabetes (46%) and high blood pressure (10%).
- Chronic kidney disease is silent. Eighty to ninety percent of people with CKD are unaware they have it.
- Chronic kidney disease can be detected with simple urine and blood tests.
- Dialysis will prolong the life of a person with ESKD, but they will not have a normal quality of life.
- The life expectancy of someone on dialysis is lower than that of the general population.
- Transplant patients live much longer and have a better quality of life than those on dialysis.
- The best treatment for ESKD is a living donor transplant before dialysis is needed.
- People on home dialysis live longer and have a better quality of life than those who have dialysis at hospital or in a satellite unit.

# Chapter 2: Your kidneys

## What your kidneys do and how do they work

Your kidneys clean your blood. Most people have two kidneys. The kidneys are found on either side of the spine, just below the ribs. They work as a filter to remove water and wastes from the body.

Urine is water that contains wastes: what is left over in the blood from food used by the body and the body's many functions. Some of the body's wastes are passed out in urine, which flows down drainage tubes (ureters) into the bladder.



The kidneys in the body

## When your kidneys don't work properly

If the kidneys stop working properly, damage to other parts of the body can result. Kidney disease can happen very slowly without anyone noticing.

Kidney disease damages the kidney filters so that they can't remove wastes and water. When this happens, the body fills up with excess fluid and wastes.

Over time, this makes a person feel very unwell. If the damage becomes really bad and the kidneys can't get better, doctors call it 'kidney failure' or end-stage kidney disease (ESKD).

It is possible that a person with kidney disease is still passing a lot of urine, but that the urine is not getting rid of enough wastes to keep the person healthy, so that they are building up in the body.

People cannot live if their blood is not cleaned properly within their body. If the kidneys fail completely, a person would normally die. However, a treatment called dialysis can do the job of filtering and cleaning the blood. People who have ongoing regular dialysis treatment can live for many years even if their kidneys don't work.

Unfortunately, dialysis cannot make diseased kidneys work again.

## **How do I know if I have kidney disease?**

Most kidney diseases do not cause any symptoms until the late stages. Your doctor can do some simple tests to see if you have kidney disease.

The main tests are:

- a blood pressure check – high blood pressure can be caused by kidney disease, or can cause kidney disease
- a urine test for protein – leaking of protein from the kidneys is an early sign of kidney damage in people with diabetes. The more damage to the kidneys, the more protein they leak
- blood kidney function tests – these test for creatinine and the estimated glomerular filtration rate (see pp 10 and below).

## **Measuring how your kidneys work – the eGFR**

The glomerular filtration rate (GFR), which measures filtration in millilitres per minute, is the best test to measure levels of kidney function and determine the stage of a patient's kidney disease. Your GFR can be estimated from the results of a blood creatinine test, along with your age, your race, your gender and other factors. This figure is then referred to as the estimated GFR (eGFR). Most laboratories in New Zealand will automatically report an eGFR when a doctor orders a blood creatinine test. Your eGFR tells your doctor how bad your kidney disease is. Your doctor can use it to track changes in your kidney function over time: it helps your doctor plan your treatment.

| <b>Stages and signs of chronic kidney disease</b> |                      |                                                         |                                                                         |
|---------------------------------------------------|----------------------|---------------------------------------------------------|-------------------------------------------------------------------------|
| <b>Stage</b>                                      | <b>eGFR (ml/min)</b> | <b>Signs</b>                                            | <b>Actions</b>                                                          |
| <b>Stage 1</b>                                    | greater than 90      | Kidney damage but kidneys still removing waste normally | Treat blood pressure if necessary                                       |
| <b>Stage 2</b>                                    | 60–90                | Kidney damage with mildly impaired kidney function      | Extra tests and medications may be needed                               |
| <b>Stage 3A</b>                                   | 45–59                | Moderate reduction in kidney function                   |                                                                         |
| <b>Stage 3B</b>                                   | 30–44                |                                                         | Usually time for referral to a kidney specialist                        |
| <b>Stage 4</b>                                    | 15–29                | Severe reduction in kidney function                     | Time for education about treatment choices and preparation for dialysis |
| <b>Stage 5</b>                                    | less than 15         | End-stage kidney disease                                | Time for starting dialysis or having a kidney transplant                |

## Chronic kidney disease doesn't always lead to end-stage kidney disease

Most people with kidney disease do not develop end-stage kidney disease (ESKD). Only a few people with kidney or urinary tract problems develop chronic kidney disease (CKD), and an even smaller number progress to ESKD. Urinary tract infections do not usually cause CKD unless there is some other abnormality involved, such as a blockage to the urinary tract. Enlargement of the prostate gland is another disease process affecting the urinary tract that rarely causes kidney damage, unless it is left untreated.

End-stage kidney disease only ever develops if a disease affects both of your kidneys. The kidneys have a large reserve capacity. If only one kidney is affected by some problem, or even if it is removed completely, the other kidney can perform all of the necessary functions, and CKD does not develop.

## **Types of kidney disease**

### **Acute kidney injury**

Acute kidney injury was previously called ‘acute kidney failure’, and is the sudden loss of kidney function over a few hours or days. It can be due to one of the various types of kidney disease, or it may be the result of a drug reaction, infection or shock after an accident. Loss of kidney function in acute kidney injury is usually temporary, but can be life-threatening. In most cases, this type of kidney failure is reversible, but if it does not respond to treatment it may progress to CKD or ESKD. Acute kidney injury is more common in men than in women.

When a patient presents with acute kidney injury, doctors investigate to find the cause. Their investigations may include a kidney biopsy (see p 10). Sometimes a specific cause means that doctors can specifically treat acute kidney injury, but often it is simply a case of watching the patient’s blood pressure and blood chemistry, controlling their fluid intake and diet and waiting for kidney function to return. In some cases, dialysis is needed while the kidneys recover.

### **Chronic kidney disease**

When loss of kidney function occurs slowly and is permanent, doctors refer to it as chronic kidney disease, or CKD. Chronic kidney disease has no symptoms until it has progressed a long way. A blood test (eGFR: see p 10) can show the stage of CKD (how far the disease has progressed) in a particular patient. Knowing the stage helps doctors to plan treatment and refer a patient to a kidney specialist if necessary.

As CKD gets worse, symptoms may develop due to the kidneys not removing fluid and wastes properly.

People at increased risk of CKD include:

- people with diabetes or high blood pressure
- people with a family history of kidney disease
- Māori, Pacific and Asian people
- people aged over 50 years
- people with cardiovascular disease
- obese people
- smokers.

## End-stage kidney disease

End-stage kidney disease (ESKD) means that the kidneys no longer work well enough to support life. Some people with ESKD stop passing urine completely; others will still pass some weak, watery urine but their bodies are unable to use it to remove toxic wastes. End-stage kidney disease can be treated by dialysis or by kidney transplantation. Without treatment, a person with ESKD will die. Dialysis is usually highly effective in removing a build-up of fluid and waste products.

It is very uncommon for kidney function to return in a patient with ESKD.

## Prevention of kidney disease

Many of the causes of CKD are random and cannot be predicted or prevented. Others, such as diabetes and high blood pressure, may be present for many years before they cause CKD. In this case, there is an opportunity for early diagnosis and prevention of the progression of CKD to ESKD. Recent advances in our understanding of the nature of kidney disease have identified some types of drugs that protect the kidneys and slow, or in some cases prevent, the gradual deterioration of the kidneys.

Early detection and prevention programmes are particularly targeted at high-risk groups, such as people who have diabetes, high blood pressure or a family history of kidney disease, or are Māori or Pacific peoples.

If you or a member of your family fall into these groups, talk to your doctor about being tested for CKD. High blood pressure and/or protein in the urine, simply diagnosed with a dipstick test, can often be a marker for silent kidney disease.

### **Key facts**

- Your kidneys work as a filter to remove water and wastes from your body.
- Chronic kidney disease usually progresses slowly and silently.
- Doctors can detect CKD with simple blood and urine tests.
- The estimated GFR test measures how well your kidney is working and guides your treatment if there is a problem.
- Over half of kidney disease cases leading to ESKD result from diabetes and high blood pressure.
- Chronic kidney disease is more common in Māori, Pacific and Asian people.
- Early diagnosis and management of CKD can slow or stop the progress of kidney deterioration.

# Chapter 3: Chronic kidney disease

## Signs and symptoms

Most people with chronic kidney disease (CKD) are unaware they have the condition. Symptoms often only develop when CKD is advanced. Many of the signs and symptoms of CKD are common in other conditions, and so may be attributed to other causes. They include:

- discomfort or burning when passing urine
- passing blood in the urine
- a change in the frequency and quantity of urine
- needing to pass urine frequently at night
- frothing (or foaming) urine
- pain in the loin area
- ankle swelling
- persistent puffiness around the eyes, especially in the morning
- headaches
- tiredness
- lack of concentration
- shortness of breath
- high blood pressure
- loss of appetite
- itching
- nausea and vomiting
- pins and needles in the fingers and toes
- restless legs.

A person with CKD may experience all or only some of these symptoms, and sometimes advanced CKD can be present without any warning signs or symptoms at all. If you or a member of your family has experienced any of these problems, consult your doctor about their meaning.

## Diagnosis

Once CKD is confirmed (see p 5), the following tests will determine the type of kidney disease, the extent to which the kidneys are damaged and the treatments that may be effective.

- **Blood tests:** these look for the amounts of a range of waste products, salts, minerals and glucose in the blood. Some of the common blood tests are described in detail in the next section.
- **Urine tests:** these look for certain substances in the urine, such as blood, protein, glucose and red and white blood cells.
- **Imaging:** doctors use ultrasound, CT scans, X-rays and other imaging techniques to take pictures of the kidneys and find out more about the disease process.
- **Kidney biopsy:** this involves using a needle to remove a small portion of kidney tissue for examination under a microscope. The test usually requires a day in hospital, and is done under a local anaesthetic with the use of an ultrasound machine to localise the kidney.

## Blood tests

People with CKD have regular blood tests to check the progress of their condition. Several tests can be performed on the one blood sample, including tests involving the following.

### Urea and creatinine

Urea is the main waste product from the body's intake of protein. Creatinine is a waste product from muscle. Creatinine and urea are carried in the bloodstream to the kidneys to be removed. High concentrations of creatinine or urea in the blood usually mean a reduced rate of filtration of urea or creatinine from the blood into the urine. A blood creatinine test is the most commonly used test to measure kidney function. The eGFR (see p 4) is calculated from the creatinine result. It is important to note that urea and creatinine are not 'poisons' – they are simply convenient markers of the degree of abnormality of kidney function.

## **Phosphate**

Phosphate is common in food, especially dairy products, and the amount in a normal diet is more than the body needs. Healthy kidneys remove the extra phosphate. Chronic kidney disease causes phosphate concentrations to increase. A high phosphate concentration can make the skin itchy. It is also a partial cause of bone and blood vessel disease.

## **Calcium**

Calcium is important for healthy bones. Blood calcium concentrations can be altered by CKD or its treatment with calcium or vitamin D tablets. A raised calcium concentration may cause headaches, nausea, sore eyes, aching teeth, itchy skin, mood changes and confusion.

## **Potassium**

Potassium is found in many foods – particularly fruit and chocolate. Most excess potassium is normally removed from the body by the kidneys. Potassium is important for your general health and for the proper function of muscles and nerves, but too much potassium can upset the electrical impulses that control the beating of the heart and sometimes even cause the heart to stop. Blood tests are the only way to check potassium levels. Potassium problems are best avoided by attention to diet.

## **Haemoglobin**

People with CKD often have low haemoglobin levels: they have low red cell counts in their blood. This means they are anaemic. The anaemia is usually caused by a lack of erythropoietin (EPO), a hormone made by the kidneys. In other cases it may be caused by low iron stores, which may be caused by blood loss (for example because of a bleeding stomach ulcer) or due to CKD effects on the body's iron handling. Many people with advanced CKD are treated with synthetic EPO to improve their red cell count.

## Diseases that cause the kidneys to fail

Many different diseases can lead to end-stage kidney disease (ESKD). Here are some brief descriptions of the more common of these.

### Diabetes

Diabetes and high blood pressure are the most common causes of kidney disease, and people often have both. Māori and Pacific people with diabetes have an increased risk of CKD. Diabetes not only causes damage directly to the filtering membranes in the kidney; it also damages blood vessels throughout the body, increasing the risk of high blood pressure, which in itself can cause kidney damage. The presence of protein in the urine in patients with diabetes is an indicator of the extent of damage to the filters of the kidneys. End-stage kidney disease in people with diabetes is becoming more common, especially in those with type II diabetes (adult onset diabetes), but there is convincing evidence that good control of blood sugar levels and of blood pressure can reduce or, in some cases, prevent progressive kidney damage.

### High blood pressure

High blood pressure can result from CKD and is also a cause of CKD in its own right. It damages the small vessels that deliver blood to the kidneys filters, and can also damage the filters themselves. This means that if high blood pressure is not identified and treated it is possible for the body to enter a 'vicious cycle' in which high blood pressure leads to kidney damage, which leads to even higher blood pressure, which leads to even more kidney damage.

High blood pressure has almost disappeared as a cause of ESKD in young people, but is still a common cause in middle-aged and older people. Blood pressure is measured as two numbers – the higher number (systolic) measures the pressure as the heart pumps, and the lower number (diastolic) measures the pressure as the heart refills with blood for its next beat. For adults, blood pressure is considered to be high if it is greater than 140 systolic or greater than 90 diastolic. Effective treatment for high blood pressure can reduce the risk of kidney damage by half.

## **Glomerulonephritis or nephritis**

Nephritis is inflammation of the filtering units of the kidney – the nephrons. It is the second most common cause of ESKD in New Zealand, and is more common in males. In people with nephritis, the body's own immune system attacks the nephron (the kidney filter) and causes inflammation, damage and scarring, for reasons that are poorly understood. Some forms are treatable, but most are not. Very little is known about what causes nephritis – this is a very active area of medical research around the world. Some forms of nephritis can be hereditary, but most cases occur at random. Nephritis affects both kidneys and can occur very rapidly, causing acute kidney injury, or very slowly, causing the silent onset of CKD. Some people with nephritis recover without treatment; a few respond to immunosuppressive medication; and others develop CKD.

## **Polycystic kidney disease**

Polycystic kidney disease (PCKD) is an inherited disorder in which healthy kidney tissue is gradually replaced by many cysts (fluid-filled sacs). As these cysts grow in size they cause the kidneys to enlarge and eventually fail. Polycystic kidney disease is the most common genetic cause of ESKD, and accounts for about 10 percent of all dialysis patients. There are two types of PCKD: dominant and recessive. Dominant PCKD accounts for 90 percent of cases, and usually affects adults. Recessive PCKD accounts for the remaining 10 percent, and usually affects children.

Kidney disease in people with dominant PCKD usually develops very gradually – only around 50 percent of people with the condition will have developed ESKD by the age of 60. People who are born with the gene for PCKD have a 50 percent chance of passing it on to their children. If you have PCKD and you are worried that other members of your family might be affected, you should speak to a kidney specialist about family genetic studies.

## Reflux nephropathy

Primary vesicoureteric reflux (VUR) is a common congenital abnormality of the urinary tract that may be inherited. Some patients with VUR have frequent urinary tract infections, even as children. The condition is most commonly picked up on an antenatal scan or during tests to explain a urinary tract infection in early childhood. Vesicoureteric reflux may progress to cause kidney scarring and CKD, in which case it is known as reflux nephropathy. Reflux nephropathy is an important cause of high blood pressure in children, which can further damage the kidneys. Reflux nephropathy is responsible for approximately 10 percent of all cases of treated ESKD, and is the commonest cause of ESKD in children. Vesicoureteric reflux often resolves spontaneously, although sometimes operations are performed to correct it. Some doctors give children with VUR daily antibiotics to reduce the chance of further infections and further scarring.

It is rare for children to develop reflux nephropathy if their kidneys are normal when they have their first urine infection. In most cases of reflux nephropathy kidney damage is already quite extensive when the problem first comes to medical attention.

## Vascular conditions

Smoking, too many fatty foods, high cholesterol, lack of exercise and obesity all place a strain on the body's vascular system (the system of blood vessels). Many older people have atherosclerotic vascular disease, where fatty plaques completely or partially block small vessels. This problem commonly causes heart attacks and strokes, but can also cause kidney disease. In fact, any condition which blocks blood flow to the kidneys, in either large blood vessels leading to the kidney or smaller blood vessels within the kidney, can cause CKD.

# Chapter 4: Treatment options

Chronic kidney disease (CKD) is incurable, and usually gradually worsens. If you find out about your CKD at an early stage, it is more likely that doctors can slow down the speed of its progression, so that your kidneys can last a long time.

## What can I do to help myself?

In the case of almost all kidney diseases, certain things help to slow down kidney damage. Here are some actions you can take to help yourself.

- Make sure you attend your kidney specialist appointments. People who attend clinics regularly before starting end-stage kidney disease (ESKD) treatment live 20 percent longer than those who do not.
- Have regular blood tests to monitor your kidney function. Your doctors will advise you how often these should be.
- If you have high blood pressure, maintain good control of it, usually with medication. This is very important in protecting your kidneys.
- If you have diabetes, maintain control of your blood sugar and blood pressure.
- Reduce your salt intake.
- If you are a smoker, quit. (Ask a health professional for help if you feel you need it.)
- Exercise and try to maintain a healthy weight.
- Get a diet plan from a dietitian.
- Avoid getting dehydrated: drink lots of fluids.
- Avoid medications that could damage your kidneys, such as Brufen, Nurofen and Voltaren.
- Have an influenza vaccine each year.

Some kidney diseases require special action on your part in addition to these steps – your kidney specialist will advise you if this is the case.

## Treatment choices

Despite your own and health professionals' best efforts, in a very few cases CKD may progress to the point that the kidneys fail completely. This leads to symptoms and eventually death, and is known as end-stage kidney disease (ESKD). If kidneys reach this point they very seldom recover.

Usually, ESKD comes on slowly, and you and your health care team will have time to make a plan for you to manage your health at the point your kidneys fail. Making a plan ahead of time is important, to make sure you get the best personalised care.

There are three treatment options for ESKD:

- dialysis (haemodialysis or peritoneal dialysis)
- kidney transplantation
- conservative treatment.

Decisions about your treatment are ultimately your responsibility, but your kidney team is there to help you make all the decisions you need to. An important first step is to understand what you might expect from each treatment option and how effective each is likely to be for your condition.

It is important to realise that this handbook focuses on the average experience for an average patient. The likely outcome for any treatment will vary. For example, a person with few other health problems might expect to deal with their kidney disease and carry on with little disruption to their life, whereas a person with significant other health problems might find even relatively straightforward treatment very difficult to deal with. You should always listen to your team's advice about your particular prospects.

Additionally, some of the reported success rates of different treatments may be due not to the treatment itself but to the general health of the types of participants who tend to undergo that treatment. For example, patients with very poor health (such as patients with cancer and ESKD) cannot receive a kidney transplant, but may receive dialysis. This means that the average success rate for dialysis patients is less than

it is for transplant patients. Talk to your kidney team about how this information applies in your own situation.

### **Key facts about the effectiveness of various treatment options**

- The average life expectancy for people being treated for ESKD is less than for the normal population.
- Patients with CKD are at a much higher risk than the general population of developing strokes and heart attacks.
- In general, among people receiving treatments for ESKD, younger people and those without diabetes or heart disease live longer.
- The best treatment for many people with kidney failure is a living donor transplant before dialysis is needed.
- People who receive a kidney transplant have an overall five-year survival rate of around 90–95 percent. In other words, about 18 or 19 people out of 20 who receive a transplant now will be alive in five years.
- On average, only one in three people are alive five years after starting dialysis. (See Appendix 1 for more detailed information.)
- There is no difference between peritoneal dialysis and haemodialysis in terms of average survival rates.
- People on home dialysis live longer than those on hospital or satellite unit dialysis (See Appendix 2 for more information.)
- People on home dialysis report a better quality of life than people on hospital or satellite unit dialysis.

## **Delaying progression through diet**

(See Chapter 5 and Kidney Health New Zealand’s website [www.kidneys.co.nz](http://www.kidneys.co.nz) for further information on this topic.)

If you have CKD, what you eat is very important for your health. Helping the kidneys to control body chemistry by eating a sensible diet is important therapy for kidney disease, and may delay the need for dialysis. Your diet plan will be based on the nature and stage of your

CKD and your blood test results. There is no standard ‘kidney diet’. For example, many patients are advised to limit the salt, phosphate, potassium and fluid content of their diet. However, some patients lose phosphate and potassium in their urine, and have to take supplements to replace it. Phosphate and potassium pass large volumes of urine and have to drink a lot of water to keep up with the flow. Your diet has to be designed with your particular situation in mind.

Severe kidney disease depresses the appetite. Many patients have difficulty eating the right amount of healthy food, and become malnourished. It is very important to maintain a healthy diet, even if you don’t feel much like eating. If you are losing weight inappropriately your dietitian may recommend special diet supplements.

Limiting the amount of protein in your diet may slow the progression of CKD. Most Western diets include 3–5 times the minimum daily amount of protein recommended by the World Health Organization to stay healthy. One common approach to kidney disease is to limit a patient’s daily protein intake to the recommended daily intake for people with normal kidneys. Note that eating little or no protein at all would cause malnutrition, so it’s important to get the balance right.

Your kidney doctor or dietitian will advise you on what dietary changes are important for you, and how to achieve and manage changes to your diet. A successful kidney transplant restores kidney function, so that the dietary restrictions may no longer apply. However, it is still very important for transplant recipients to eat a healthy diet and to keep their bodies in good shape.

## Medications

### General

Among medications in general, some drugs are removed from the body by the kidneys, and so they tend to build up in anyone with poor kidney function. Often it will be necessary to reduce the dose of these sorts of drugs in patients with reduced kidney function. Some drugs (especially some pain medication) are harmful to people with CKD, and should be avoided.

If you have CKD, you should mention that to any doctor or other health professional whom you see away from your regular team, or about an unrelated condition. Your kidney problem may influence their choice of medications and other treatments. Virtually all medications have side effects. Some people experience them; others don't. It is important to know the possible side effects of the medicines you are taking, and to report back to your doctor if you think you are experiencing them. Your doctor can alter the type of medication or strength if necessary.

There are a variety of medications your doctor may prescribe to treat CKD. Most of these are designed to control blood pressure and help regulate the body's chemistry. Each medication is given for a particular reason and should be taken as directed.

### **Blood pressure drugs or anti-hypertensives**

Blood pressure drugs or anti-hypertensives are medications designed to lower your blood pressure. Untreated high blood pressure can cause permanent damage to the small arteries of the kidneys, as well as to the heart and the brain. Different types of blood pressure tablets work in different ways, and often more than one type of tablet needs to be prescribed. Your doctor may alter the dose of a blood pressure tablet from time to time, according to individual requirements. The blood pressure tablets known as angiotensin converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARBs) are believed to have specific kidney protective effects, and are often the preferred choice for patients with high blood pressure and CKD.

### **Erythropoietin**

Erythropoietin (EPO) medication is used to treat anaemia. Anaemia is common with CKD and ESKD and causes many symptoms, including tiredness and lethargy, loss of appetite, reduced exercise ability and sometimes breathlessness. Although there are many causes of anaemia, the main one in patients with kidney disease is reduced production of EPO, which a healthy kidney normally produces. Synthetic EPO acts just like natural EPO to stimulate the production of

new red blood cells in the bone marrow. Your doctor will monitor your haemoglobin levels to determine the EPO dose required to treat your anaemia. EPO treatment has to be administered by injection (using a prefilled syringe), which you can do yourself.

## **Iron replacement therapy**

To make red blood cells your body also needs iron. People with both kidney disease and anaemia also need extra iron to make healthy red blood cells. EPO therapy may not work if you are short of iron. Blood tests can show whether you have enough iron. If your iron levels and blood count are low, you have iron deficient anaemia. Iron supplements are required to correct this. There are two forms of supplement – oral or intravenous (IV). Oral iron comes in a tablet form. Although it can be effective in restoring iron levels, it is often not very well tolerated, and may not provide enough replacement iron. Intravenous iron is very effective at correcting iron deficient anaemia. Treatment can be given as a once-only total dose or as a number of smaller doses. IV iron is given by a drip and usually requires a visit to the hospital.

## **Phosphate binders**

Phosphate binders are medications to help control the amount of phosphate in the body. Blood phosphate concentrations usually increase as your kidneys fail, because the kidneys cannot remove phosphate efficiently. When blood phosphate increases, the parathyroid glands become overactive and make more parathyroid hormone (PTH). This can lead to thinning of the bones and abnormal bone formation, which may weaken the skeleton and increase the risk of fractures, and may contribute to blood vessel disease. Phosphate binders reduce the amount of phosphate absorbed into the blood stream by binding to phosphate in food. To be effective phosphate binders should be taken with meals.

## **Vitamins and minerals**

Water-soluble vitamins are removed during dialysis, and need to be replaced. This is particularly important for older people and people with a small appetite. The active form of vitamin D is produced by

normal kidneys, and so extra vitamin D is commonly prescribed for people with CKD. Some patients may need extra calcium. Calcium-containing medications are often used as phosphate binders (see above).

## **Cholesterol-lowering drugs**

High blood cholesterol is common, and is associated with an increased risk of a heart attack. Kidney disease patients are more at risk than most people of developing vascular diseases (heart attack, stroke and peripheral vascular disease). It is unclear if the usual cholesterol-lowering agents are effective in people on dialysis, but they appear to be beneficial at earlier stages of kidney disease.

## **Diuretics**

Diuretics help you pass more urine. They are often used together with other drugs, to treat high blood pressure. They are sometimes used in severe CKD to help the kidneys remove excess water from the body.

## **Antibiotics**

Antibiotics are used to treat infections caused by bacteria. Sometimes antibiotics are harmful to people with kidney disease, and so they should not be taken without medical advice.

## **Treatments for itching**

People with kidney disease frequently experience the discomfort of itchy skin. The causes of this itchiness are not fully known, but include dry skin, abnormal blood calcium or phosphate concentrations, uraemic toxins (waste products) and vitamin imbalances. This itching can be alleviated with moisturisers (such as glycerine, sorbolene or Alpha Keri lotion). Your doctor may prescribe antihistamines. If these don't work, consider consulting a dermatologist, who might suggest PUVA (psoralens and ultraviolet A) therapy.

To combat itchiness, it is also important to have adequate dialysis and try to keep your calcium and phosphate concentrations within the normal range. Sometimes an unexpected bonus of treating anaemia

with EPO (see p 19) is a reduction in itching. Alternatively, surgical removal of the parathyroid gland can help. A specialist can assist in determining which option will be best for you.

## **Alternative therapies**

Alternative medical therapies include chiropractic, acupuncture, homeopathy and herbal remedies. The safety and effectiveness of these practices remain largely unknown. It makes sense to discuss any alternative therapies you are using, or thinking of using, with your kidney doctor. Some may be harmful for your kidneys or interfere with treatments provided by your kidney team.

## **Dialysis**

When the kidneys have failed completely – that is, when a person has end-stage kidney disease (ESKD) – dialysis can take over the kidneys’ job of filtering and cleaning the blood. While dialysis is more hassle than having healthy kidneys – it takes time and effort – it gives people with ESKD a chance to lead a reasonable life.

There are two types of dialysis: haemodialysis and peritoneal dialysis. Most people can choose the type of dialysis that best suits them, but in other cases doctors may recommend a particular type of dialysis because of a patient’s other medical problems. The choice of haemodialysis or peritoneal dialysis depends on many factors, including the availability of resources, your age, your overall health and your lifestyle. You, your clinical team and your family will need to weigh up the advantages and disadvantages of each type of dialysis. You may change if you find that the first treatment you undertook no longer suits you or your lifestyle. You should discuss a potential change with your doctor, and be prepared to undertake the necessary training for the alternate dialysis treatment.

## Haemodialysis

The ‘haemo’ in haemodialysis means blood. With this treatment, the filtering happens outside the body using a dialysis machine (also called a kidney machine).

When you ‘go on the machine’, needles connected to tubes are put into a special vein in your arm called a fistula (which is made by a small surgical operation: see ‘Access for dialysis’ on p 27). The

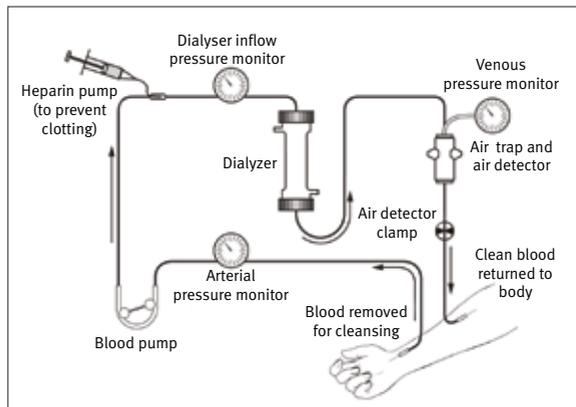
blood flows through these tubes out of your body into a filter (called a dialyser) attached to the dialysis machine and then back into your body. Your blood goes round and round through the filter, just as it does with a normal kidney.



Haemodialysis

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The dialyser (see right) consists of a plastic cylinder that contains thousands of very fine tubes. Each of these has tiny pores in its walls that are only small enough for waste and extra fluid to pass through. Blood cells and protein cannot fit through them. Blood is pumped to the dialyser and flows through the



The haemodialysis system

fibres. A specially formulated fluid called ‘dialysate’ washes around the fibres. Dialysate has a similar chemical composition to healthy blood, and so the various salts and other chemicals in the blood of the patient that are at abnormal levels can equilibrate (balance) against it and be returned to the normal range. The dialysate also helps to draw waste and excess fluid out across the pores of the fibres, leaving clean blood to flow out of the dialyser and be transported back to the body. The

impurities and fluid removed into the dialysate during dialysis go down a drain into the ordinary sewage waste. Germs (bacteria or viruses) cannot cross the walls of the fine tubes in the dialyser, so there is no risk of introducing infection to a patient.

Over the course of one dialysis session (usually 4–8 hours) the whole five litres of blood in the average person's body will flow through the machine, or artificial kidney, approximately 6–10 times.

Haemodialysis is usually performed three or more times a week at regularly spaced intervals, either during the day or at night. Your doctor may advise a different frequency or length of treatment session, depending on your needs. You do not feel the blood being removed from your body or cleaned. You won't feel weakened by lack of blood, as only about 300 ml of blood (approximately two cups) are out of the body at any one time. A local anaesthetic is often used before the insertion of the needles. People on haemodialysis can read, talk, play board or card games, watch television, use the telephone, write, use a computer or sleep. However, they cannot get up and move around.

Haemodialysis treatment usually takes place at home, in a self-care 'satellite' dialysis centre close to your home, or in a hospital kidney unit. Home dialysis is the preferred option for many patients. If this is your choice, special plumbing will be installed in your home and your water supply tested for suitability. Most people need some help to get themselves set up on a haemodialysis machine, but in some cases patients are able to dialyse alone. If you choose home haemodialysis, you will be fully trained to manage your own dialysis with the assistance of a partner or spouse, parent or friend. Some patients may choose to dialyse in the evening after work, or overnight while asleep.

If you need some help with dialysis and there is no one to help at home, you may be able to go to a community dialysis house or a self-care centre, or receive help from a paid helper at home. Dialysis in a hospital kidney unit is reserved for those with other serious medical problems who need immediate access to medical care during dialysis.

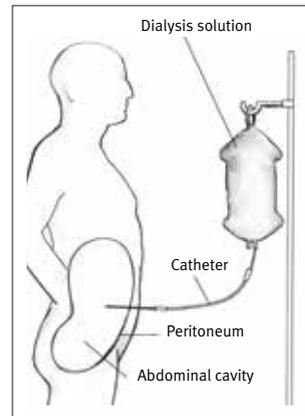
## Peritoneal dialysis

With peritoneal dialysis (PD) the cleaning of the blood is done inside the body instead of in an artificial filter. The peritoneal membrane lines the peritoneal or abdominal cavity and covers the abdominal organs (stomach, liver, spleen and intestines). It has a lot of blood vessels, and is an ideal dialysis membrane. Special dialysis fluid is put into your peritoneal cavity from a plastic bag through a soft tube called a catheter (put in place by a small surgical operation). Part of the catheter is in your body and the rest remains outside your body. The skin heals around the catheter, which causes no discomfort apart from the time immediately after the initial operation to insert it. You will be taught to care for your catheter exit site.



Peritoneal dialysis

During PD the peritoneal cavity is filled with dialysis fluid through the catheter. Waste and extra fluid are drawn out of the blood vessels and transferred to the dialysis solution. After a set period, the fluid is drained out of the body and replaced with fresh fluid. Each time this cycle is repeated is called an 'exchange'. The number of exchanges performed each day varies for each person. The amount or volume of the PD fluid used for each exchange also varies, depending upon body size and individual need. Adults can usually hold a volume of 2–3 litres per exchange comfortably. Children require smaller volumes.



The peritoneal dialysis system

There are two types of PD: continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD).

With CAPD, you connect a bag of sterile peritoneal dialysis fluid to a short plastic tube attached to your peritoneal catheter. When the fluid bag is raised to shoulder level or higher, the fluid flows into the peritoneal cavity under the influence of gravity. When the bag is empty you simply disconnect it, place a protective cap on your catheter set and discard the tubing and bag. Complete dialysis begins straight away, and you are free to continue your normal daily activities. After a few hours (usually 4–6) you remove the protective cap from the catheter set and attach it to a new sterile exchange set, which has tubing, a drain bag and a peritoneal dialysis solution bag. Simply lower the drain bag to drain the waste-filled fluid from your peritoneal cavity, and then run the new peritoneal dialysis fluid into your peritoneal cavity. CAPD is usually performed four times each day. Each exchange takes about 45 minutes to perform, and can be done almost anywhere, provided the area is clean. In between each exchange you are free to undertake the regular activities of daily living.

Automated Peritoneal Dialysis requires a machine to control the movement of fluid into and out of the peritoneal cavity. You attach yourself to the machine at night before you go to sleep, and while you sleep the machine performs 6–8 exchanges for you. During the day solution is left in the peritoneal cavity so that dialysis can still occur slowly.

Peritoneal dialysis is a home-based treatment. If you choose PD you are required to undertake a comprehensive training programme to ensure that you can perform your treatment properly. Meticulous attention to hand washing and cleanliness is required, to prevent germs from entering the body through the tube.

## **Access for dialysis**

Both haemodialysis and peritoneal dialysis require means by which to access the waste products in the blood, in order to filter them. This access requires an operation.

Haemodialysis requires access to the body's blood circulation, so that the blood can flow to the artificial kidney to be cleansed. A 'vascular access' is created surgically for this purpose, either through a fistula or

a graft. A fistula uses the body's own blood vessels, while a graft makes use of a synthetic tubing material.

A fistula is created surgically by joining a vein and an artery, usually near the wrist. Arteries carry blood at high pressure, and have strong walls to handle the blood flows. Veins have low blood flow and weak walls that tend to collapse and squeeze shut if they are used for dialysis. By joining an artery to a vein, the strong blood flow from the artery enters the vein and, over time, in response to the increased pressure, the vein begins to enlarge and strengthen its walls. Once it has become stronger it can be used for dialysis.

The operation to create a fistula is done under a local or general anaesthetic by a surgeon who specialises in blood vessel surgery. You should have this operation at least several weeks and preferably a few months before dialysis, in order to give the blood vessels time to heal and strengthen. The size of the incision (skin cut) to make a fistula is about 4–8 cm: it will leave a small, fine scar. The arm and hand can and should be used normally after the operation. The forearm veins enlarge and become quite prominent; needles can then be placed into them to allow dialysis. A working fistula has a distinctive feel: as the blood surges from the artery into the vein it creates a 'buzzing' or 'purring' sensation. This buzzing is an indication that the fistula or graft is working. If the buzz stops, or is quieter than usual, contact the kidney unit immediately, because this suggests that the fistula might be blocked.

A graft, the second type of access for haemodialysis, is used if a person's veins are too small or diseased to be used to create a fistula. In this case the artery and vein are joined together by a loop of soft synthetic tubing. Sometimes, instead of tubing, a piece of vein taken from the leg might be used. The graft is usually placed in the forearm, but it may also be placed elsewhere; for example at the front of the thigh. Grafts require more complex surgery, but they are a good solution for people with small veins and they function just like a natural fistula, although they are more likely to block or become infected.

Sometimes people need dialysis immediately, and so a temporary way to access blood is needed. A special tube can be placed in a large vein, either near the collar bone or at the top of the leg, if a patient does not have a functioning fistula. Two such temporary access devices are the Vas Cath and the Permcath. Caps are taken off the ends of the tube to connect them for haemodialysis treatment. After treatment, the caps are closed and kept clean. These tubes can only be used temporarily until a fistula or graft is ready, because of the risk of infection and clotting.

The risks of infection and clotting are lower with a fistula than with a graft or venous catheter. A fistula usually lasts much longer than these other types of vascular access, and is safer in the long run.

For peritoneal dialysis, the standard access device is a peritoneal catheter. This is a soft silicone tube inserted into the abdomen in an operation that requires a general anaesthetic and a few days in hospital. The catheter is about 0.5 cm in diameter, and remains in the body permanently. Several centimetres of one end stick out from the abdomen from under the skin to be connected to a bag containing the dialysing fluid. Most of the catheter is inside the body. The dialysis fluid can be run in and out of the peritoneal cavity through this catheter. The catheter leaves the body in the lower part of the abdomen, below and to the side of the navel. This area is called the 'exit site'. The exact placement is planned by you, your doctor and a PD nurse so that the tubing can be worn comfortably and can be easily hidden under clothing. Bandages are not required to cover the catheter. Once the catheter area heals, it must be kept clean. The exit site can be cleansed in the shower. Once the area is dry, the catheter is secured to the abdomen with a piece of adhesive tape. Patients receive specific instructions for long-term care of the catheter as part of dialysis training.

Peritoneal dialysis catheters and fistulas often seem strange at first. However, they are a necessary part of the treatment process, because they provide the means by which dialysis treatment is delivered. In a very short time, people tend to become accustomed to their presence.

## Choosing a type of dialysis

Peritoneal dialysis and haemodialysis each have their advantages and disadvantages. Some patients find they prefer one form of dialysis, some the other. The choice can be influenced by the availability of different forms of dialysis in your local area. Many ESKD patients end up experiencing both forms of dialysis over time. Peritoneal dialysis and haemodialysis produce the same rates of patient survival in the first one to two years of treatment.

Here are some of the differences between the two forms of dialysis, to help you choose.

### Difference between the two forms of dialysis

#### Peritoneal dialysis

- Peritoneal dialysis is performed every day of the week, for continuous control of blood chemistry.
- Continuous ambulatory peritoneal dialysis is relatively portable – it's easy to take with you for holidays or travel for work. Automated peritoneal dialysis is also reasonably portable: machines will fit in the boot of a car. Your supplies can be sent to most places in the world if you are going overseas.
- Peritoneal dialysis is usually done by patients themselves, and is usually easy for one person to manage. If required, a family member can be trained to assist or perform the treatment.
- Peritoneal dialysis is done at home, and can usually fit around your normal activities.
- The main complication of peritoneal dialysis is the risk of infection – peritonitis (on average these occur every 2–4 years, but the risk can be reduced with good hygiene). Other risks include blocking or leakage of the peritoneal catheter.
- Peritoneal dialysis doesn't last forever – on average about 20 percent of people are still on PD after five years (less so for people with diabetes).

## Haemodialysis

- Haemodialysis is performed at least three times a week, usually for 4–6 hours each time, but can be as frequent as every day – blood chemistries vary from day to day. Accordingly, a patient can have as many as four days ‘off’ per week.
- Haemodialysis has to be done where there is a machine and proper plumbing. If you want to travel you will need to plan well ahead: for example, by booking in to a haemodialysis unit close to where you will be, or renting a mobile dialysis unit.
- Some people need some help to get themselves set up on a haemodialysis machine, but in some instances patients are able to dialyse alone. Most home haemodialysis patients need the assistance of a partner or spouse, parent or friend. In some cases a family member or nurse may be trained to do the dialysis at home for the patient.
- Haemodialysis can be done at home, in a community dialysis home or self-care ‘satellite’ centre (if there is one near your home), or at a hospital kidney unit.
- A significant complication of haemodialysis is partial or complete blockage of the fistula or graft providing vascular access.

## Kidney transplantation

### Types of transplant and donors

A kidney transplant is an operation to transfer a healthy kidney from a person with healthy kidneys to a person with end-stage kidney disease (ESKD).

A kidney transplant is the best treatment for most people with ESKD – but like dialysis it does not provide a complete cure.

There are two types of kidney donors: living and deceased.

- Among living donors, donation may be directed or non-directed.
  - ‘Directed donation’ is when someone you know offers a kidney to you for transplant. These donors may be a blood relative (such as a brother, sister or cousin) or unrelated (such as a husband, wife, partner or friend). This is usually the best option for a kidney transplant, as the transplant can be arranged at a time to suit your (and your donor’s) needs, and you do not need to wait on the waiting list for a kidney (see below).
  - ‘Non-directed’ (or altruistic) donation is a term used for donation by someone who intends to give a kidney to someone they don’t know. In these cases the kidney is allocated to the best matched person on the waiting list.
- When a transplant comes from a person who has died, the family of the donor will have agreed for the organ to be donated. In this case kidneys are allocated to patients on the national waiting list based on waiting time and tissue matching.

Anybody thinking of being a kidney donor should contact the transplant coordinator at the renal unit closest to them. More information is also available at [www.kidneys.co.nz](http://www.kidneys.co.nz) or 0800 543 639 (KIDNEY).

When a patient has a successful kidney transplant, they no longer need dialysis. A year after a transplant operation, about 9 out of 10 kidneys transplanted from a living donor will be working well. About half of these kidneys will still be working well 15 years later. Three-quarters of kidneys from deceased donors are working five years after the operation.

## Who can have a kidney transplant?

Most people with severe CKD can be considered for a transplant. If you have CKD, it is important that you talk to your kidney doctor about whether or not you are able to have a kidney transplant. If your health is not good, having a kidney transplant may not be the best option for you.

A kidney transplant is not recommended for people who have a high risk of complications due to surgery; for example, people at high risk of heart attack or stroke. People who have an active cancer or infection cannot have a transplant.

Anyone having a kidney transplant needs to be in good general health. You will have a general medical check-up first, and some people will then require some additional tests, which may include checks of your heart function, a cervical smear and a prostate cancer check. In some cases, where the urine drainage system has been damaged, a review by a urology surgeon will be required.

Also, if you are overweight you will need to lose weight before you can receive a kidney transplant, as extra weight can increase the risk of slow wound healing and blood clots or chest infections after the operation.

A kidney transplant surgeon will review all patients before they are accepted for a kidney transplant. The surgeon will explain the operation, and will examine you for any problems that might make surgery difficult. Other specialists may be consulted, depending on your medical history.

## Live donor transplants

Anybody in good health with two normal kidneys may be able to give one of their own kidneys to another person (that is, become a kidney donor). A potential donor should have a genuine interest in donating to the person needing the transplant (the potential recipient). The potential donor does not have to be a relative.

The main difference between the surgery for living and deceased kidney transplants is the timing. The surgery and presurgical care are the same, but the difference is that a living donation can be planned.

Hospital admission and surgery can be scheduled ahead of time, allowing the donor and recipient plenty of time to prepare for both the surgery and recovery. The donor is left with one healthy functioning kidney, which is more than enough to work effectively for the rest of the donor's life. The donor will be able to live a normal life, and should not have to pay increased life insurance premiums (if in doubt, speak to your health insurance company). Kidney donors have no increased risk of ESKD compared to the general population. However, the risk of high blood pressure over their lifetime may be slightly higher than if they did not donate.

All people have one of four major blood groups: O, A, B or AB.

A potential donor and recipient are said to have compatible blood groups when the recipient does not have antibodies against the potential donor's blood group. This varies depending on the two particular blood groups involved. For example, a person with an O blood group would have antibodies against donors with blood groups A, B and AB, but is compatible with another person of blood group O.

The following matches are possible.

- O recipients can only receive an O kidney.
- B recipients can receive a B or O kidney.
- A recipients can receive an A or O kidney.
- AB recipients can receive an A, B, O or AB kidney.

In some cases it is possible for a live donor transplant to take place when the donor and potential recipient do not have a compatible blood group. Your local transplant coordinator or kidney doctor can tell you more about the kidney exchange programme and ABO incompatible transplants.

## **Advantages and disadvantages**

Advantages of a kidney transplant are as follows.

- A successful transplant means no more dialysis.
- Most transplant recipients experience an improved duration and quality of life (compared to dialysis).

- Transplant allows a greater choice of food and fluids in a patient's diet.
- Transplant enables a more normal lifestyle; for example, travel is easier.
- Fertility can improve after a transplant. Many people have successful pregnancies and healthy children after a transplant.

Disadvantages of a kidney transplant are as follows.

- Transplant involves an operation which always involves a certain amount of risk.
- Transplant recipients need to take medications daily for the rest of their life, or until the kidney fails.
- Kidney transplant failure involves some uncertainty. Most transplants are successful, but approximately 1 in 20 will fail in the first year: many of those soon after transplant.
- The anti-rejection medicines have side effects. The most serious of these is an increased risk of infection. Transplant patients also have an increased risk of certain cancers, especially skin cancer.

## The transplant waiting list

The three New Zealand kidney transplant teams meet regularly to discuss and review all patients who want to go on the transplant waiting list. These teams use a new nationally agreed method or tool for assessing the health and suitability of people who want to go on to the deceased donor kidney waiting list – the 'transplant list'. Once all the required tests have been completed, your kidney doctor will discuss your suitability for a transplant at these meetings. Only patients with good enough health can be accepted on the waiting list, because of the shortage of kidneys for transplantation. If you are accepted, you will go on the waiting list. If not, you can talk to your kidney doctor about the decision. People on the waiting list are reviewed every year to make sure they are still well enough to receive a transplant. If your health deteriorates, you may come off the waiting list – there is no guarantee if you go on the waiting list that you will receive a kidney. Further information on how people are assessed for the transplant list can be found at [www.kidneys.co.nz/resources/file/new\\_scheme\\_for\\_assessing\\_patients\\_v2-1.pdf](http://www.kidneys.co.nz/resources/file/new_scheme_for_assessing_patients_v2-1.pdf)

## How does the transplant waiting list work?

New Zealand has one national waiting list for kidneys called the National Kidney Allocation Scheme which is held centrally and kidneys are allocated nationally. Once you are accepted onto the waiting list, you will undergo simple blood tests to determine your blood group, tissue type and tissue antibody status. This information is stored on a computer, along with the date you went on the waiting list. Once you are on the waiting list you'll need to supply a fresh blood sample each month. If you do not have your monthly test you will not have a chance of being offered a kidney that month.

A deceased donor kidney transplant can occur when the family of a recently deceased medically suitable person has consented to the donation. The identity of the donor is never revealed to the recipient, but you are able to write anonymously to the family via the donor coordinator to communicate your thanks.

Transplant coordinators allocate kidneys to people on the waiting list according to a number of rules. Patients who have a close match to the donor are given first priority, no matter how long they have been on the waiting list. If two people are both closely matched to the donor, then the person who has been waiting longer will get the kidney. About half of all kidneys are allocated to patients this way. The other half will not be such a close match to anyone waiting on the list. In these cases the allocation is done in a different way, and time spent on the waiting list plays a bigger role. If a closely matched donor does not become available, you will be offered a kidney when you have reached the top of the list in terms of the time you have been waiting.

How long people wait for a kidney depends on a number of things, such as their blood group, tissue antibody status and tissue type. While some people will get a transplant very quickly, most people will have been waiting for years by the time they get a kidney transplant through the deceased donor waiting list. It is possible to go on the waiting list before you start dialysis, but waiting time will not be counted until you have started dialysis. A closely matched kidney could become available for you before you start dialysis, but almost all people start dialysis before they receive a kidney transplant through the deceased donor waiting

list. It is almost impossible to predict how long a person will wait for a kidney transplant.

While you are on the waiting list, make sure to maintain your health, including through attending appointments, doing dialysis and managing your diet and medication.

In addition, make sure the hospital has your current landline and mobile telephone numbers, as well as the numbers of people you may be contacted through. If you cannot be found, and do not contact the hospital within a certain timeframe, a donated kidney may be given to the next most compatible person, and you will go back on the waiting list.

## **The transplant operation**

When you are admitted to hospital for your kidney transplant, you will undergo a thorough physical examination, and details of your early and recent medical history will be recorded. A dialysis session may be required. Any active infections or other significant new medical problems may cause the operation to be cancelled.

Immunosuppressive (anti-rejection) medications will be given to you before and after the surgery. These will suppress your immune system to prevent your body from actively rejecting the new kidney. Surgery for a kidney transplant takes about 2–4 hours. During the operation, the surgeon will make a cut about 20 cm long in your lower abdomen, near the groin, either on the right or left side of the body. The surgeon will connect the renal artery and vein of the new kidney to a main artery and vein in your pelvis, and connect the ureter of the new kidney to your bladder to allow urine to flow into it. Then they will place a catheter in your bladder for a few days to drain the urine made by the transplanted kidney. When you wake up after the operation you will notice this tube coming out of your urethra (the normal exit point for urine from the body). Many patients begin to produce urine immediately after the new kidney has been transplanted. Sometimes dialysis is needed for a short period of time until the new kidney begins to function. After surgery, fluids and medications are given through intravenous lines (also called ‘a drip’), which may be inserted in the

arm or neck. Pain relief is provided after the operation, but severe pain is not usually a problem.

The length of your stay in hospital for the surgery will depend on you as an individual – how fit you are, how well your body responds to the new kidney and whether any complications arise. Most people are in hospital for 4–7 days. Some patients feel better immediately after their surgery, while others take longer to adjust. You may need to return to hospital for a brief period of time if complications arise.

## **After the transplant**

Everybody responds differently to a transplant. Don't expect that everything will return to normal within a particular period of time. Allow your body time to recover at its own rate. You can assist your recovery by following your doctor's advice. Caring for yourself after the transplant is vitally important. The first three months following the transplant are the most vulnerable and unstable. You will need to go to hospital regularly to monitor the functioning of your new kidney – daily at first, then weekly, then monthly. You should report any changes in your health to your health team as soon as possible to avoid harming your transplant.

Because the transplanted kidney is foreign to your body, you must take immunosuppressive drugs (anti-rejection drugs) for as long as the transplanted kidney functions. These drugs partially block the activity of your body's immune system, preventing it from attacking the transplanted kidney. In the early months of your transplant you may experience a number of rejection episodes. These can usually be controlled by higher doses of medication or extra medication. Sometimes a biopsy of the transplanted kidney will be necessary to aid diagnosis and treatment. The great majority of rejection episodes can be reversed. However, rejection can take place at any time after your transplant. It is very important that you follow the instructions you are given regarding taking your anti-rejection medication. If the transplant fails because your body rejects the new kidney, or for any other reason, you will have to go back on dialysis.

## Anti-rejection medications

The drugs used to prevent rejection are many and varied. Confusingly, most drugs have two names – the proper generic or chemical name, and the trade name given to them by the drug company. The generic names of drugs used in transplantation include:

- prednisone
- azathioprine
- cyclosporine
- mycophenolate
- tacrolimus
- sirolimus.

Drugs given by injection to prevent or treat rejection include:

- methylprednisolone
- ATG (antithymocyte globulin)
- dacluzimab.

New drugs to prevent rejection are regularly tested in transplant clinics. You may be asked to participate in a clinical trial of a new drug, or you may be given other new drugs which are not in this list. All immunosuppressive drugs have side effects. You may experience some or all of them for a period of time. Many of the side effects do not last, and are related to dosage. Some of the most common side effects include:

- puffiness of the face and abdomen
- unwanted hair growth
- increased appetite and weight gain
- mood swings
- high blood pressure
- acne
- muscle weakness
- hand tremors
- upset stomach
- indigestion

- diarrhoea
- swelling of the gums, and gum infections
- increased risk of infection
- increased risk of cancer
- diabetes
- altered blood count (low white cells, low red cells, low platelets)
- thinning of the bones (osteoporosis).

### **Caring for yourself after the transplant**

It is very important to take good care of yourself following the transplant. Because the anti-rejection drugs are suppressing your immune system, you may be unusually susceptible to infectious illnesses. Always report any illnesses to your health care team. Call them immediately if you experience any of these symptoms, or other symptoms your doctor has told you to watch for:

- discharge of fluid, redness or warmth at the site of the operation wound
- abdominal pain or diarrhoea
- vomiting
- fever
- reduced urine output or trouble passing urine
- blood in the urine
- sudden weight gain
- pain over the transplanted kidney.

In order to stay as healthy as possible you should take precautions to prevent illness. Avoid getting sick by using common sense. Keep away from people who have highly contagious diseases such as chicken pox or measles, and remember to follow basic hygiene precautions such as washing your hands, particularly when you have been working in the garden or have been using the bathroom. A yearly flu shot to help ward off common strains of influenza is a good idea.

Because some of the drugs make your skin more sensitive to sunlight, skin cancers are common in transplant recipients. To reduce your risk

of skin cancer, make sure you avoid prolonged exposure to the sun, and remember to wear a hat, long sleeves and a high-protection sunscreen when you are outdoors.

Women should be aware of the increased risk of breast cancer and cancers of the reproductive tract after transplant surgery, and have regular mammograms and cervical smears. Men also have a higher likelihood of developing cancers.

Weight gain following a transplant is not uncommon – if this is the case for you, try to return to a normal healthy weight when your body has stabilised by eating a healthy diet and participating in light regular exercise. Do not smoke. The dangers of smoking, particularly the risk of lung cancer, are increased after a transplant by the anti-rejection drugs. Smoking may damage the transplanted kidney and reduce its chances of long-term success.

As for any major surgery, normal sexual activity can be resumed 4–6 weeks after the transplant. Reliable contraception is recommended. Dialysis patients often notice that sexual function improves after a transplant. Pregnancy is not advised for 18–24 months after a woman receives a transplant, until the body is stable and good kidney function is assured. Careful medical supervision is necessary for pregnant women who have had a transplant; in particular, health professionals will monitor blood pressure and be aware of the possibility of premature labour. Seek medical advice if you are considering pregnancy following a transplant.

If you need treatment from other health professionals, such as dentists, advise them that you have had a kidney transplant. Speak to your transplant physician before taking any prescription or over-the-counter medication prescribed by another health professional, to ensure it does not conflict with your anti-rejection medications.

Your goal following a transplant is to lead a normal life. By simply following your doctor's advice and leading a healthy lifestyle you will give your transplant the best possible chance of long-term success.

## Choosing not to start dialysis (conservative treatment)

You have the right to make your own choices about how you are treated for ESKD. That means you can choose not to start dialysis or have a transplant. Some people decide to have 'conservative' treatment (also called palliative or supportive care) instead. Perhaps as many as half of all patients with ESKD never start dialysis.

You have the right to decide not to start dialysis if you feel that the burden would outweigh the benefits and reduce your quality of life. You also have the right to stop dialysis at any time after starting dialysis. Only you know what it is like for you to live with ESKD. It is very important that you have plenty of time to discuss the issue thoroughly with those close to you and with members of the kidney team looking after you. The team will ensure that you receive the necessary information to make a good decision, and will support you.

Here are some facts to consider.

- People with ESKD will eventually die of the condition if they don't have treatment with dialysis or a kidney transplant.
- Dialysis treatment can greatly improve the quality of life of many people with ESKD.
- However, dialysis treatment is demanding and time-consuming, and requires lasting changes to lifestyle.
- Many people on dialysis are able to make these adjustments and still lead a fulfilling life, but dialysis is not a cure-all.
- In some cases, dialysis may not improve quality of life, particularly if a person has other serious health problems, such as heart disease or cancer.

### What is conservative treatment?

The aim of conservative treatment is to manage the symptoms of kidney failure without using dialysis or transplantation. Conservative treatment includes medical, emotional, social, spiritual and practical care for both the person with ESKD and their family/whānau. Although many people who choose conservative treatment are older, old age is not the only reason to choose this option.

If you choose to have conservative treatment, your kidney unit will continue to look after you. On the other hand, you may wish to be cared for by another service, such as a hospice or palliative care service, or by your general practitioner.

### **Why might I decide not to have dialysis treatment?**

There are a number of reasons why somebody might decide to have conservative treatment for their kidney disease, either upon first being diagnosed with ESKD or after a period of time receiving dialysis treatment.

A person may have been advised that they have other serious illnesses (such as severe or worsening heart failure) that will shorten their life, and that the burden of dialysis treatment would be greater than any likely benefits.

Alternatively, they may consider the dialysis treatment so demanding and time-consuming that it will change their lifestyle so that they will have a very poor quality of life.

### **What does conservative treatment involve?**

Conservative treatment involves a team of people from the hospital, the community and your home. Your medical care will normally be managed by your kidney doctors together with your family doctor.

Doctors, nurses and other people in the kidney care team will make sure that you have:

- medicines to protect your remaining kidney function for as long as possible
- advice on the right diet for you
- advice on preventing further kidney damage from some drugs (for example, advice not to use painkillers such as Brufen or Nurofen)
- advice on how to avoid dehydration, especially during illnesses causing diarrhoea and/or vomiting
- an annual flu jab if you want one
- medicines to treat other symptoms of ESKD, such as feeling short of breath, anaemia (low blood count), a poor appetite or itchy skin

- adequate community support, such as home help or a district nursing service
- referral to a local palliative care service (if you agree). The aim of palliative care is to keep you active and independent for as long as possible. Palliative care focuses on support and comfort, and works alongside your family doctor
- adequate information on financial support, making a will and making an advance care plan or advanced directive, if you have particular wishes about end-of-life care that you want to be respected
- family and bereavement support. Family members sometimes need counselling to cope with the prospect of losing a loved one. Ultimately, once you have died your family may wish to receive bereavement support. Your family doctor or palliative care services can coordinate this if need be.

### **What if I can't decide?**

Sometimes it is difficult to decide whether dialysis will be worthwhile. In this case, your kidney doctor may suggest you have a trial period of dialysis: usually a few weeks. During this time you, your family and the kidney team will see how dialysis is affecting you, medically and psychologically. The doctor and other members of the team will then be able to talk with you and decide together whether it is in your best interests to continue dialysis. Talking to a trusted family doctor might help you come to the right decision for you.

### **How long will I live if I don't have dialysis?**

How long you will live without dialysis varies from person to person, and depends on many factors. An accurate prognosis is very difficult to make without knowledge of the individual situation.

Important factors are:

- how much kidney function remains
- how sick you are from other serious illnesses
- how determined you are to live.

Chronic ill health affects both your physical and emotional strength – sometimes it is just too hard to fight any more. If this is the case for you

then it may mean that you deteriorate more quickly than anticipated. This is a sensitive and emotional issue. If you are worried about how you will cope, you can talk it through with a member of the kidney team that you trust.

### **Will I have a choice of where I die?**

Many people would prefer to die at home, where they feel more comfortable. This is especially so when there is help at home from family, friends or carers. Alternatively, you may wish to go into a hospice, if hospice care is available and well developed in your area. A hospital admission may be another option.

You should discuss this issue with the kidney team. Their priority is to support you and your family as much as they can. You may like to consider making an advanced care plan: this allows you to write down your wishes about your end-of-life care, in case you are unable to tell your family or medical team later on.

### **Is deciding not to have dialysis suicide?**

Deciding not to have dialysis is not suicide. No one should feel obliged to receive treatments that are not right for them, and you do not have to have life-prolonging treatments if that is not your wish. Each person should be encouraged to make their own decisions regarding their health, and everybody should respect this. Most religions believe that people have the right to decline medical treatment, including dialysis, if they feel it will not help them. You may wish to speak with a religious advisor if you have concerns about this.

If you have other questions or concerns, feel free to ask your kidney team or your family doctor.

# Chapter 5: Nutrition and kidney failure

## Why is what I eat so important?

Eating well when you have kidney disease is very important, to help you stay as healthy and strong as possible. Eating the right kinds and amounts of foods each day can help your kidneys to work more easily and keep you well for longer.

Sometimes having kidney disease can make you feel unwell. Your appetite may not be so good, and food may taste different. This is because waste products produced from the foods you eat build up in the blood instead of being removed by the kidneys. The need to make changes to your diet depends on how well your kidneys are working. What is right for others may not be right for you. Your doctor can refer you to a dietitian for advice on your diet.

## Protein

Protein foods are essential to help keep your body healthy, repair body muscle and tissues and heal wounds. Beef, lamb, chicken, fish, eggs, milk and dairy foods are all examples of protein foods. When you have kidney disease, eating too much or too little protein can make you feel unwell. Eating moderate portions of protein can help to reduce the work load of the kidneys and reduce high levels of waste products in your blood. Choose palm-sized portions of meats at meals.



Palm-sized portions

## Sodium (salt)

Too much salt affects the amount of fluid the body holds on to, and this can cause problems like high blood pressure or puffy or swollen feet and ankles. A health professional may tell you to use less salt in cooking and cut down on salty foods.

To help keep your salt intake down:

- use no more than a pinch of salt (iodised) in cooking
- avoid adding salt to food at the table
- avoid foods high in salt, such as:
  - ham, bacon, sausages, corned beef and smoked fish
  - salted chips, crisps and salted nuts
  - instant noodles and soups, stock cubes and salty crackers
  - salty sauces and pickles
  - most takeaway foods.



Salty foods

Buy fresh foods and make meals at home. Use fresh herbs, spices, flavoured vinegars and lemon juice for extra flavour. Don't use salt substitutes like 'Losalt', as these have potassium in them and are not suitable for people with kidney disease.

## How much should I drink?

Examples of fluids include water, tea, coffee, soft drinks and cordials. Many solid foods have a lot of fluid. You should continue to drink the usual recommended amount of fluids – at least 6–8 cups/glasses per day – but this will change if you start dialysis. Soon after starting dialysis most people start to pass much less urine, and most will

eventually stop passing urine altogether. One of the hardest things to adjust to after starting dialysis is the need to restrict your fluid intake. This is not easy: on dialysis, your feeling of thirst is not a reliable sign that you need to drink. If you drink too much between each dialysis treatment fluid builds up in your body – particularly in your lungs. It makes you feel short of breath, raises your blood pressure and puts a strain on your heart. The only way to remove extra fluid is during the next dialysis.

## Potassium

Fruits and vegetables are important in your daily meals. They contain a mineral called potassium. As kidney disease progresses, potassium in the blood may start to rise, because the kidneys are not able to remove extra potassium. This can be dangerous. You may be advised to limit or avoid certain types of fruits and vegetables that are high in potassium.

These include:

- bananas
- pure fruit juices
- dried fruit
- potatoes
- silver beet
- tomatoes.



High-potassium foods

Your doctor will regularly check your blood potassium levels, and will tell you if you need to cut down on high-potassium fruits and vegetables.

Your doctor can refer you to a dietitian for help to choose suitable fruits and vegetables.

# Phosphate

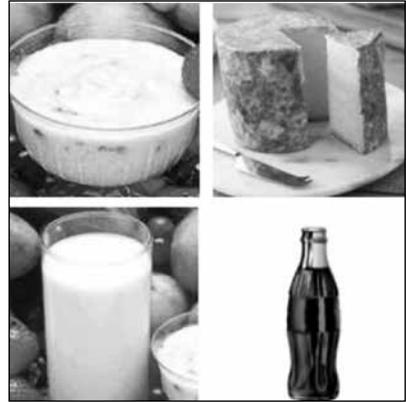
Phosphate is a mineral that, together with a mineral called calcium, helps to keep your bones strong. When your kidneys are not working properly phosphate builds up in the blood instead of being removed by the kidneys.

High phosphate levels can cause problems such as:

- itchy and dry skin
- hardening of your blood vessels
- painful joints
- weak bones.

Phosphate is found in many foods, for example:

- milk, cheese, yoghurt and ice cream
- calcium-enriched milk
- peanut butter
- sardines
- Coca-Cola and Pepsi.



High-phosphate foods

Your doctor may give you tablets to help keep phosphate levels in your blood normal.

# Carbohydrates and fats

Maintaining a healthy weight is important for everyone. You may need to meet your energy requirements by increasing the amount of carbohydrates (starchy foods) and healthy fats (oils and margarines) you eat. Starchy foods include breakfast cereals, breads, crackers and biscuits, rice and pasta.



Carbohydrates and fats

Healthy oils and margarines include those made from sunflower, canola, rice bran and olives.

Eating well can help you feel your best and to stay at your well weight when you have chronic kidney disease. If your appetite is not so good and you are not eating as much as you normally would, try eating smaller meals and snacks more often over the day. You can ask your doctor to refer you to a dietitian if you need further help.

## **What if I have diabetes?**

If you're a diabetic, in some cases you may be asked to make a few changes to your diabetic diet to fit around managing your reduced kidney function. If you are advised to have smaller portions of protein, you must be sure to get enough calories from other foods. You can ask your doctor to refer you to a dietitian if you need further help with changing your diabetic diet.

## **What if I am a vegetarian?**

If you are vegetarian you may need good advice from a dietitian. Vegetarian diets can be high in potassium and phosphate because of all the vegetables, fruits and whole grains they contain. The goal is to eat the right combinations of plant proteins while keeping potassium and phosphate under control.

## **Will I have to take vitamins and minerals?**

Vitamins and minerals come from a variety of foods in your diet. If your diet is limited it may be difficult to meet your vitamin requirements through food, so you may need to take certain vitamins and minerals. You must only take the vitamins and minerals your doctor prescribes for you. Others may be harmful for people with kidney disease.

## Other points to remember

In general, you should also keep to the following guidelines.

- At first you may need to measure the food and fluids you eat and drink, to make sure you're getting what you need. Measure with a cup or scales and don't guess.
- Take your medication as prescribed.
- Request regular reviews and follow-up with your dietitian.
- Keep an eye on the changes in your body weight, blood pressure and blood results.
- Let your doctor or dietitian know if you are losing weight when you didn't mean to, or if have any concerns about your diet.
- Remember that following a suggested nutrition plan may not treat or cure your kidney problem, but it could help reduce some of the symptoms, and improve your general feeling of wellbeing.

## Smoking and alcohol

Smoking can have serious long-term effects on your kidney function. It contributes to blood vessel damage, which in turn contributes to further damage to the kidneys and the heart. If you also have high cholesterol and are overweight or unfit, the damage is likely to be much worse. People with kidney disease are already more prone to heart disease, stroke and general blood vessel disease than the general population. Smoking and high blood pressure will accelerate these processes. If you have kidney disease you should stop smoking altogether.

Contrary to popular belief, the most harmful effects of alcohol occur in the liver rather than in the kidneys. People with kidney disease can enjoy alcohol in moderation. However, if you're a dialysis patient, you must include the alcoholic beverages in your daily fluid allowance. Talk to your physician and dietitian if you have questions about this.

## Nutrition after a kidney transplant

Your diet will change after a kidney transplant. It will not be as strict as the dialysis diet, but you will need to look after your new kidney by eating and drinking in moderation and staying in shape. Prednisone, one of the commonest drugs used to prevent rejection of a transplant, increases your appetite, and there is a risk of putting on weight. Some of the other medications that you take to prevent your body from rejecting the transplanted organ may increase your risk of developing diabetes. Your body is likely to respond differently to the foods you eat, which may lead to post-transplant diabetes mellitus (PTDM). Although most anti-rejection medications may increase the risk of diabetes, some are positively linked with a higher risk.

After you have a transplant you should eat a sensible balanced diet and take regular exercise. You should be aware of your changing appetite and the risk of putting on weight. The kidney unit dietitian will help, but there are no magic diets or simple solutions for an overweight transplant patient. If you have diabetes or high blood pressure you will need to maintain any previous dietary restrictions concerning sugar, salt and energy intake. Potassium, however, is generally not a problem for transplant patients.

In the longer term one serious problem that will threaten you and your new kidney is atherosclerosis, or hardening of the arteries. This affects most adults in Western societies, but is more common and more severe in kidney failure patients. Looking after your arteries requires that you maintain a sensible weight, stop smoking and watch your blood pressure, blood sugar, blood cholesterol and salt intake. Many transplant patients find that their cholesterol levels rise after the transplant. You may need cholesterol-lowering medication to help protect your arteries. It is important for your health to maintain a balance between adequate nutrition and ideal weight. Weight loss is often important in keeping people with kidney disease healthy.

Your dietitian will be able to give you specific advice. A balanced diet containing plenty of fresh fruit and vegetables and limited amounts of salt, sugar and fat, together with regular exercise, will be a great start to a long life. Get your family and friends involved in your new lifestyle too!

# **Chapter 6: Living with kidney failure – information and tips for patients, family members, friends and carers**

## **Living with change**

### **Adjusting to kidney failure**

Finding out you have end-stage kidney disease (ESKD) and living with it from then on can be overwhelming. Your energy will be directed to your treatment and physical wellbeing. But looking after your emotional wellbeing is just as important as looking after your health. The information in this chapter is to help you do that.

End-stage kidney disease does not just affect you: it affects your entire family, your friends and those who care for you. Many of the changes and emotions affecting patients also apply to these people, and much of the following information applies to them as well.

You may feel that your life has been turned upside down. Having ESKD means that you will probably experience important life changes: in your working life, in your personal and family life, in your finances and in other activities. These changes can cause a great deal of stress and a range of emotional reactions.

### **Who can I talk to?**

Recognising and understanding feelings experienced by others living with ESKD can help you feel less isolated and get you the support you need. Meeting and talking to other people with ESKD can be helpful. Check out [www.kidneys.co.nz/Patient-Support-Centres-Map](http://www.kidneys.co.nz/Patient-Support-Centres-Map) to find a kidney patient support group near to you, or ask your kidney team to help you find one.

## How do people react when they learn they have end-stage kidney disease?

People diagnosed with ESKD experience a range of emotions. Different people react in different ways. These are some of the emotions you may experience.

- **Stress:** One of the main causes of stress is change. All human beings find change stressful. Even change we are looking forward to, like moving house, can raise our stress levels. As a person with kidney failure, you will have to deal with more change than most people do: not just the initial change of lifestyle that comes with the diagnosis, but ongoing changes as you deal with alterations in your diet, medication and forms of treatment. These changes will mean you have to take in a great deal of new information, make decisions and learn new practical skills. You also have to adjust to new ways of doing things, to doing less than you would like to, and to asking for help. This can be extremely stressful, and it comes in addition to coping with the physical effects of ESKD.
- **Shock:** Being told you have kidney failure can come as quite a shock. Suddenly, and for reasons you may not understand, you have a life-threatening disease. You may feel numb and not believe what is happening. It may be hard to talk about how you feel, or you may find you can only take in small amounts of information, or may have to be told the same thing over and over again. Some people may find their feelings make talking about their illness with family and friends difficult. Others may feel the urge to talk about it as a way of helping to accept the news themselves.
- **Grief:** You may feel sad or overwhelmed with grief over the loss of function, the changes it brings to your life and your loss of normality; a bit like the death of someone close to you. You may have a feeling of helplessness and have trouble dealing with everyday life.
- **Fear:** You may have a specific worry related to something in particular, or a more general sense of 'being on edge' or 'not feeling safe'. You may feel scared. Fear and anxiety are common emotions when you have been diagnosed with a chronic disease. You will wonder how this disease will affect you and your life, your family

and your future. Treatment for kidney disease can sometimes add to the anxiety. You'll need to make some choices: for example, about whether you'll go to a clinic for dialysis or treat yourself at home. You may worry about the disruption to your family life, especially if you opt for treatment at home. Will your loved ones adjust to seeing you attached to a machine? Will they dislike the constant reminder that you are not as healthy as you once were?

- **Loss of control:** When you are first diagnosed with ESKD, you may fear that you'll lose your independence, or become a burden to those you love. Such feelings can be frightening, and may lead to some of the other emotions discussed here. You may feel you could once predict your day, and now you are feeling uncertain about what each day will be like.
- **Anger:** Feelings of anger are common among patients with ESKD. You may be angry that this has happened to you. You may be mad at yourself for getting sick. Some people are mad at the medical people for not taking better care of them or diagnosing the disease earlier. Many patients direct their anger at their family members or spouse. Anger and resentment can build to the point where it strains the relationship between you, your health care team and your family.
- **Feeling down:** Feeling down is a normal part of kidney disease. You may feel sad and 'need a good cry' sometimes. Even if you don't feel depressed, sometimes you may have some typical symptoms of depression, like irritability, loss of appetite, decreased interest in sex and difficulty sleeping. If the sadness turns into a real sense of despair or hopelessness and lasts for more than two weeks, you should tell your doctor. This may be a sign of depression, and you need to seek further help.
- **Depression:** People who are depressed often have trouble getting motivated to do things that bring enjoyment. Sometimes feeling depressed causes sleeping problems, or affects a person's ability to think clearly. It is normal for a person to be upset and cry about the diagnosis of ESKD. Expressing feelings, good and bad, is a healthy way to cope. If the feelings of unhappiness are intense and persistent and they don't go away even when things improve, you might have depression. You should seek help from a doctor or social worker. Those professionals are there to help with these kinds of problems.

- **Tiredness or fatigue:** Both physical and emotional fatigue can play a major role in reducing your quality of life; for example, by giving you a decreased ability to exercise and participate in social activities. Sometimes the many changes and stresses of your disease, especially if they go on for a long time, can lead to emotional exhaustion. Just as you become physically exhausted after spending six hours climbing a steep mountain, you can become emotionally exhausted when you are constantly facing stressful situations. When you're physically exhausted you cannot move. When you're emotionally exhausted, you are not able to 'move' in the direction you need to go because your ability to provide and receive emotional support decreases. Emotions such as worry and frustration and continuous mental strain all contribute to emotional exhaustion.

Fatigue can come on slowly, and you might not feel it is a symptom worth telling your doctor about. Many patients are reluctant to tell their health professionals about their fatigue – even if it is severe – for fear of being considered unmotivated or weak. Don't be afraid to talk about it – your health professionals are there to help you.

## Lifestyle changes

### Work

Many people with kidney disease successfully return to work. The treatments available for kidney disease make your return to work a real and worthwhile possibility, whatever the stage of your kidney failure. A great deal will depend on your physical and emotional health. As a first step you should discuss your return to work with your treating doctor. He or she will want to know what your job involves: for example, the hours you work, the equipment you work with and any special factors, such as whether you work with chemicals or in dangerous conditions.

An occupational therapist will be able to give you specific information about the implications of your kidney disease for your employment. An occupational therapist's assessment of your skills and abilities, your work and your workplace will provide you with information about whether you need to change things to make work more suitable for you.

It's important to maintain your contacts at work – both formal and informal – when you are off sick. Don't let your employer forget your unique and valuable contribution, and keep yourself up to date with changes at work.

Whether or not you can still do the same job will depend on the work itself and the state of your health. Time-consuming dialysis and low energy levels can be obstacles to work that require some thought and careful planning to get around. You might want to work out a haemodialysis schedule that does not cut into work time, or you may be able to go onto home haemodialysis. If you are on peritoneal dialysis, bag changes can often be done in a suitable location at work. As far as physical impairments (especially loss of stamina) are concerned, a change in working hours to take advantage of those times you perform at your best, or a reduction in hours, or a change to less demanding work may provide the answer. People with ESKD are affected by the disease in different ways. Some people are able to return to full-time or physically demanding jobs, while others have to modify their working lives considerably to cope. Whatever you do it's important not to exceed your limitations, especially following a transplant. Sometimes, in the first flush of recovered energy after a transplant, people forget that it takes time to recover from a major operation, as well as adjust to the anti-rejection drug regimen.

## **Leisure time**

Leisure time and interests that make you happy are important components of wellness. It is important to keep up with your hobbies and leisure activities. Involvement in interesting activities can shift your focus away from medical treatment and health concerns. Sharing leisure time with others can do the same. By maintaining the interests you had before you developed kidney failure, you'll also be able to stay in contact with people who might be able to support you when times get tough. Some people on haemodialysis find they need activity to fill in the time while dialysing, while other people prefer to use the time to rest. Both approaches are fine; use the one that suits you best.

## Food

Your appetite and diet may change as a result of your ESKD, but remember that eating is a human social activity, and meals are an important part of life with family and friends. Even if you don't enjoy your food as much as you used to, or if there are some things you can't eat any more, try to enjoy the ritual of eating with friends and family as often as possible, and the informal social support that eating in or out can offer. If you are going to a restaurant, you may be able to telephone them in advance to let them know of your requirements.

## Fitness and exercise

Gentle regular exercise, like walking or swimming, is as important for people with ESKD as for anyone else. As well as the physical benefits of developing or maintaining muscle tone and flexibility and strengthening your heart and lungs, exercise will add to your overall sense of wellbeing. In other words, it will make you feel good. The body's natural painkillers, called endorphins, are released into the bloodstream during exercise, and can continue to exert their pleasant effects for several hours after you have stopped exercising. Exercise can be short and simple, yet its effects will last throughout the day. Deep breathing and relaxation exercises help to relax the mind and body and reduce stress. Gentle exercise such as yoga and t'ai chi may also be useful. Some people with ESKD find strenuous sport or vigorous activities too tiring. Others throw themselves enthusiastically into fitness programs, and some transplant patients compete nationally and internationally, in the transplant games. Some doctors recommend that certain contact sports such as rugby should be avoided, especially after a transplant. For people choosing peritoneal dialysis as their treatment option careful consideration should be given to catheter care on the sports field. Talk to your nurse or physician about this.

## Holidays

Holidays are important: they can provide an excellent 'pick-me-up' for you and your family or friends after the stress of coping with kidney failure. New Zealand and overseas travel is still possible with

kidney disease, but will require some extra planning. Here are some possibilities.

- If you are on haemodialysis, consider using a holiday facility equipped for dialysis treatment. The patient association in your area may offer a holiday house where self-care dialysis is possible.
- Kidney Kids hosts a national camp for kids with kidney disease each year. Check your kidney unit for details.
- Arrange to have dialysis in another kidney unit. Global Dialysis ([www.globaldialysis.com](http://www.globaldialysis.com)) maintains a listing of dialysis units around the world that you may be able access. Your kidney unit can assist you, or do some research online. Remember, you will have to pay for your dialysis treatment when you're overseas – it is often quite expensive.
- Although New Zealand has reciprocal health care agreements with Australia and the United Kingdom, these do not provide for you to have your regular haemodialysis free of charge: rather, they entitle you to free emergency treatment for new or existing health conditions. Further information can be found at [www.health.govt.nz/new-zealand-health-system/eligibility-publicly-funded-health-services/reciprocal-health-agreements](http://www.health.govt.nz/new-zealand-health-system/eligibility-publicly-funded-health-services/reciprocal-health-agreements)
- If you're on peritoneal dialysis, it will be relatively easy to travel. In most instances fluid supplies can be delivered to your holiday destination.

If you have had a transplant you will need to make sure that you have good supplies of your medications to cover your time away and a letter describing your condition in case you need to see a doctor. There are costs involved with these options, and it pays to find out what they are in advance so you don't receive any nasty surprises. Check with your kidney unit. If a big trip seems daunting, or out of your reach, consider even a couple of days away between dialysis sessions. A change of scenery and a break from normal routines and chores can work wonders.

## Sexual function

‘Sexuality’ refers to the way we feel about ourselves as men or women. It is not just about sexual activity. Humans are sexual beings, whether or not they choose or wish to engage in sexual activities. It’s common for people with kidney disease to notice changes in their level of interest in sexual activity. For men, impotence can be a particular problem, even in young men. A decline in sexual activity or in the desire for sex can be disturbing and difficult to understand. It can also be hard to talk about, and so it can have a damaging effect on self-esteem and on relationships.

End-stage kidney disease often decreases sexual libido (desire), but this does not mean that people with ESKD cannot be happy with their sexuality, or that they can’t enjoy sex. End-stage kidney disease can make a person feel tired and low in energy, and can make you look pale. It can also cause an unpleasant breath and taste in the mouth, and anaemia. All these things can make it difficult to feel good about yourself as a person: especially a sexual person. There are specific treatments that can help improve sexual performance for dialysis patients who are concerned about the effect of kidney failure on this aspect of their lives. If this issue is worrying you, discuss your concerns frankly with your health care team, and if you feel that you are not making progress ask for a referral to a specialist in sexual therapy for people with chronic illnesses.

## Menstruation

ESKD can affect menstruation in a variety of ways. Most women find that their periods become less frequent, or even stop altogether. However, some women are troubled with heavy periods, particularly after starting dialysis. In some instances, dialysis actually returns periods to normal. A functioning transplant usually removes any effects that kidney failure has had on menstruation.

## Fertility

ESKD decreases fertility for both men and women, but pregnancy can still occur, so if you don't want to get pregnant you'll still need to use contraceptive precautions. It is not advisable for women on dialysis treatment to become pregnant, as it is extremely rare for a pregnancy in this situation to be completed successfully to full term. Normal pregnancy can be achieved readily after transplantation, and many healthy babies have been born to women with kidney transplants. If you are thinking about having children, you should discuss the decision with your doctor.

### Key facts

- Kidney failure affects women's periods.
- Pregnancy is less likely, but contraception is still needed.
- You may find doctors and nurses are reluctant to ask about sexual problems – you may have to raise the subject yourself.
- Sex and relationship counselling can be helpful.
- Talk to your doctor about a referral if you think that you and your partner could benefit.

## Getting support

Although you can't change a diagnosis, you can change the way you deal with it.

### Some suggestions to help you manage

Here are some ideas to help you manage the changes and feelings that come with a diagnosis of kidney disease.

- Pay attention to how you're feeling and don't ignore it. Even if you think it could be nothing, report your symptoms. You need to be involved in your care, and learn as much as you can about your disease and its treatment. As you learn more and talk to others with ESKD, it won't seem so scary.

- You may want to talk about how you're feeling, or you may find it hard to talk. Generally, it helps to talk about changes and feelings, and what they mean to you and your family. Keeping your concerns to yourself could increase your stress levels. As well as your friends and family, you may want to talk to your GP, someone from your kidney care team, others with ESKD, or someone else you trust. Remember that family and friends are not mind-readers. It is hard for them to know how to help you if you don't tell them.
- Your cultural and spiritual beliefs are very important, and can affect the way you feel about your kidney failure. Most kidney services have people you can talk to regarding cultural or spiritual matters, or they can refer you to the appropriate service.
- Find out about your condition: knowledge is power. Learn as much as you can about your illness and the treatment you are having. Don't be afraid to ask questions. Staff like being asked and are happy to help.
- Seek out professional support. Talk to a social worker about your fears and concerns: they may be able to find different ways to help you with some of the issues you are having. Find out if there are support groups in your area.
- If you don't feel comfortable talking to people, keep a diary of your thoughts and feelings. Sometimes writing things down can help you cope with feelings, and eventually it makes talking about feelings easier.
- Take good care of yourself. Talk to your dietitian about what you need nutritionally. Talk to your doctor about beginning an exercise program. Indulge yourself in things that bring you pleasure (healthy things). Listen to relaxing music, read your favourite magazines or go to the movies. It's OK to tell people you can't do something because you just don't feel up to it.
- Accept help when you need it. People offer because they want to help. It makes them feel they are needed. It is really important to maintain your independence as much as you can.

## Your kidney team

Your kidney team includes the following people.

- **Nephrologist** (kidney doctor): A nephrologist is a doctor who specialises in kidney diseases and treatment and, together with you and the other team members, plans the best treatment for you.
- **Nephrology registrar**: A nephrology registrar is a senior trainee kidney doctor, who will become a nephrologist, and often works beside the nephrologist.
- **Renal social worker**: Often described as the ‘glue’ for the family, the social worker’s role can vary, but they are there to help you to understand the information and processes involved in managing your disease, including applying for financial support, and assisting you with housing and travel. Renal social workers will work together with you and other team members to assess your needs and your social/family situation to find a way for you to best manage your disease. Each DHB has clear guidelines as to what support their renal social workers provide. It is important when you start attending clinic appointments for your kidney problem that you ask the nurse or receptionist for the contact details of a social worker.
- **Pre-dialysis nurse**: Each renal unit has at least one pre-dialysis nurse, who is a valuable resource and can assist with your concerns. They will also be able to refer you to the appropriate people as necessary.
- **Renal technician**: Technicians provide technical support for the machinery involved in haemodialysis, help people to set up machines at home and are responsible for maintaining quality control. Many are also qualified in dialysis treatment.
- **Occupational therapist**: These health professionals will help you find solutions to problems you may encounter in carrying out your daily activities because of kidney disease. These might include physical or emotional difficulties with work, daily tasks, leisure activities, relationships and changes in your life.
- **Renal nurse**: A renal nurse works closely with you during your treatment; they also work with the rest of the kidney care team to ensure you are getting the best treatment. They provide education and support for you and your family.

- **Renal dietitian:** A dietitian works with doctors and other members of the kidney team to establish a diet plan that suits you and your lifestyle as part of your treatment.
- **Clinical psychologist:** A clinical psychologist works with you and your family using a wide range of assessment and treatment methods to promote mental health and to alleviate discomfort and help you cope with kidney failure.
- **Clinical pharmacist:** A pharmacist provides advice on the safe, effective use of your medications.
- **Surgeon:** A surgeon is a doctor who is specially trained in surgical techniques. Surgeons create vascular access for haemodialysis, put in and remove peritoneal dialysis catheters and perform kidney transplants.
- **Transplant coordinator:** A transplant coordinator assists in coordinating necessary tests, studies and other activities to determine your suitability for transplantation.
- **Urologist:** A urologist is a surgeon who specialises in treating diseases of the urinary system.

## Where else can I find support?

Your family, or close friends, may be your main source of support. If you live alone it might be community groups and other organisations. Your kidney care team can recommend specialised help such as psychiatrists, psychologists or hospital chaplains.

Local kidney patient support groups can be very helpful, especially if you want to talk to someone who is unrelated or not connected to your health care team about your concerns. Often these groups are run by people who have been on dialysis or had a transplant, or supported someone who has. To find out more about these groups and to contact them go to [www.kidneys.co.nz/Patient-Support-Centres-Map](http://www.kidneys.co.nz/Patient-Support-Centres-Map) or talk to your kidney team.

Message boards on the internet are another way of getting in touch with people in a similar situation at any time of the day or night. You can read about other people's experiences and share your own if you

want to. Some sites to look at include <http://bigdandme.wordpress.com> and [www.globaldialysis.com/forum.html?lang=en](http://www.globaldialysis.com/forum.html?lang=en)

### **For family members, friends and carers**

Caring for or living with someone with ESKD can turn your life upside down. Sometimes, it gets steadily worse without you noticing how it's taking over your life. Helping someone you care about to manage ESKD can be overwhelming for anyone. Your life will have changed in ways you had never planned, and it is easy to become totally absorbed in the new demands placed on you, or to become depressed yourself about how the change has affected your life. You may feel it's up to you to fix things when the person you are supporting is unhappy, angry or upset about their illness or its treatment. In fact, they usually prefer it if you don't try to provide answers, but just listen and understand so they don't feel so alone.

You can get help from your local patient support group. Please ring 0800KIDNEY or go to [www.kidneys.co.nz](http://www.kidneys.co.nz)

# Chapter 7: Dealing with your kidney care team

It is important to remember to fit your treatment (for a kidney patient that usually means dialysis) around your life, rather than your life around your treatment. Although treatment may be necessary, it is important not to let it control your life.

If English is your second language, it is also important to ask for help when you don't understand what your health care team is saying. There are translation services available. Ask your social worker about this service.

## Making the most of your visits

When you visit any medical or health care professional, remember that they are there to help, advise and inform you of your condition and the treatment options available to assist you. To make the visit more productive, try these tips.

Before the visit:

- Make a list of questions you need answered so that you don't forget anything: most people remember only about half of the information given to them. Add to the list any symptoms, concerns or changes in your life that may have occurred recently or since your last visit.
- Know the name and dosage of any medications you are taking regularly or occasionally.
- If you need repeat prescriptions, make a note to ask for them.
- If you don't know much about your conditions, read up or try to obtain more information, so that you're familiar with vocabulary or terms that might be used.
- If you feel anxious, it may be worth considering taking a family member or close friend with you.
- Be aware of your own and your family's medical history.

During the visit:

- Tell the person if you have some questions.
- Write down their answers – don't trust your memory.
- Tell your doctor if you are currently in consultation with or receiving treatment from another doctor.
- Your doctor should provide a clear explanation of your condition, planned treatment, alternative procedures available and possible side effects. If they don't, or if it's not clear, ask them for further information.
- If you think you may not be able to follow any particular instructions the doctor gives, tell them immediately, to avoid problems later.
- Before leaving, make sure you have a clear idea of your treatment plan and also any recommended reading materials that may assist you in understanding or coping with your condition.
- If there are several drugs you must take, or other complicated treatments you must follow, ask the doctor to write them down for you.

After the visit:

- Don't be afraid to phone between visits with any concerns.
- Make a list of recommendations given to you, and keep it visible (eg, on your fridge).
- Trust and respect is important in any relationship. If you don't feel comfortable it may be worth seeking a second opinion. Different people are suited to different styles; find someone you can relate to.
- Follow the advice you receive to the best of your ability.
- Remember that you are ultimately responsible for your own wellbeing.

Consider keeping a record of your contacts with health professionals in an exercise book.

# Chapter 8: Financial assistance

Help with living expenses may be available from Work and Income (WINZ), depending on your circumstances. Your renal social worker is the first person you should talk to about your situation. If you don't know who this is, ask your kidney nurse or doctor how to contact them.

For information you can also:

- phone WINZ on 0800 559 009 (for people under 65) or 0800 552 002 (for people 65 and over), Monday to Friday: 7am–6pm, Saturday: 8am–1pm
- visit the WINZ website: [www.workandincome.govt.nz/individuals](http://www.workandincome.govt.nz/individuals)

## Applying for a benefit

Anyone who has financial problems can apply for a benefit through WINZ, but not everyone is entitled to one. Kidney failure alone does not automatically mean you need to be on a benefit.

Whether you qualify for a benefit and how much you can get depends on your circumstances.

Apply for assistance as soon as possible. Work and Income may be able to grant you assistance backdated to the date that you first contacted them (so long as you complete your form within 20 working days of that date) or to the date that you submitted your application: whichever comes first.

Before you spend your holiday pay, redundancy pay or other income, it is important that you find out from WINZ how this might affect your benefit.

To qualify for any WINZ benefit you need to:

- be a New Zealand citizen or permanent resident who normally lives here
- have been here for at least two years at any one time since becoming a New Zealand citizen or permanent resident
- meet income and sometimes other criteria.

## Income and asset tests

Most benefits are income tested: that is, they are determined according to the amount of your income. 'Income' includes your partner's incomes, income from rental properties, interest on money in the bank and income from insurance payments. Depending on your income, you may be eligible for a full benefit, a part benefit or no benefit at all. Some benefits are also asset tested. Assets are cash or savings, investments or shares, loans made to other people (including family trusts), boats, caravans and campervans, investment properties and (under certain circumstances) your house and car.

## What benefits are available?

Benefits most commonly used by kidney patients are as follows.

### Health and disability job support

This benefit helps people with general living costs when they have financial difficulties because of limited or no employment due to sickness.

It is income tested.

It is important that you are aware of any extra entitlements you may be eligible for.

You may get support if, because you are sick, you:

- have had to reduce your hours
- have had to stop working
- are not working, or are working part-time and find it hard to look for and do full time work.

You will need a medical certificate from your doctor, or you may be able to provide existing reports or assessments or a report from your specialist.

## **Supported living payment**

See [www.workandincome.govt.nz](http://www.workandincome.govt.nz) – search for supported living payment.

This benefit helps people with a permanent sickness, injury or disability that stops them working.

It is income tested.

It is slightly more than the jobseeker support.

You may get the invalid's benefit if:

- you are unable to work regularly, 15 hours or more a week, because of a sickness, injury or disability that is expected to last at least two years
- your life expectancy is expected to be less than two years and you are unable to regularly work 15 hours or more a week
- you are blind with a specified level of restriction in your visual field or in the sharpness of your vision.

You will need a medical certificate from your doctor, or you may be able to provide existing reports or assessments or a report from your specialist.

## **Disability allowance**

See [www.workandincome.govt.nz](http://www.workandincome.govt.nz) – search for disability allowance.

This benefit is a weekly payment for people who have regular ongoing costs because of a disability, such as visits to the doctor or hospital, medicines, extra clothing or travel. It is available to people who qualify for a Community Services Card, including those on a benefit and people who are working.

It is income and asset tested.

You may get a disability allowance if you:

- have an ongoing disability, which is likely to continue for a minimum of six months
- have regular, ongoing costs because of your disability that are not fully covered by another agency, for example, ACC.

## Extra assistance

You may qualify for extra assistance, depending on your circumstances.

For a full list of extra assistance see the WINZ website:

[www.workandincome.govt.nz/individuals/a-z-benefits/disability-allowance.html](http://www.workandincome.govt.nz/individuals/a-z-benefits/disability-allowance.html)

Here are some examples.

- Working for Families is a package designed to make it easier to work and raise a family: see [www.workandincome.govt.nz](http://www.workandincome.govt.nz) – search for working for families.
- You may be eligible for an accommodation supplement: see [www.workandincome.govt.nz](http://www.workandincome.govt.nz) – search for accommodation supplement
- Anyone on a benefit can be assessed for entitlement to assistance for such things as dental work, glasses, car repairs and so on. Check with your social worker or WINZ case manager about this.
- Temporary additional support is a weekly payment that helps someone who can't meet their essential living costs from what they earn or from other sources: see [www.workandincome.govt.nz](http://www.workandincome.govt.nz) – search for temporary additional support.
- Recoverable Assistance Payment Grant is a one-off payment for people who are struggling to pay for essential things such as food, power, clothing or furniture: see [www.workandincome.govt.nz](http://www.workandincome.govt.nz) – search for recoverable assistance payment grant
- Live organ donor assistance is a payment that helps people who are donating a kidney or liver tissue for transplant within New Zealand and experience loss of income and/or childcare costs: see [www.workandincome.govt.nz](http://www.workandincome.govt.nz) – search for live organ donor assistance

- Civilian amputee assistance is help for amputees, or those born without a limb(s), with travel and/or accommodation costs if they need to go to an artificial limb centre: see [www.workandincome.govt.nz](http://www.workandincome.govt.nz) search for civilian amputee assistance

## Where do I start?

The easiest way to start applying for a benefit is to:

- phone WINZ on 0800 559 009 (for people under 65) or 0800 552 002 (for people 65 and over), Monday to Friday: 7am–6pm, Saturday: 8am–1pm
- explain your circumstances
- make an appointment
- ask what you need to bring with you.

Some phrases that might be helpful as a guide when talking to WINZ are:

- ‘Hello my name is ... I want to apply for a sickness benefit, can you send me out a form and can I make an appointment for one week’s time?’
- ‘Hello, my name is ... I am on the DPB and I would like to change this to an invalid’s benefit.’

Make sure the appointment is for half an hour, instead of the usual 10 minutes, as you will need a little longer for your first visit.

Allow yourself a week before the appointment to give you time to gather the information you will need to take with you (eg, for your GP to sign the forms WINZ will send you).

## Getting the information you need

It is important that before you have your first meeting with WINZ, you have everything you need. To ensure you have all the information you need before your visit, you can call the 0800 information number. They can also answer questions to help you to determine which entitlement might apply to you.

You might want to ask questions such as:

- ‘How many hours can I work before I do not qualify for a benefit?’
- ‘How much does my partner need to earn before I don’t qualify for a benefit?’

You will need to bring proof of:

- your identity and lawful residence in New Zealand
- your (and your partner’s) IRD number (contact Inland Revenue if you don’t have it)
- bank account numbers
- your and your partner’s last pay slip (this will show your holiday pay)
- income details for the last 52 weeks
- details of your housing costs
- details of any assets you own that could earn income
- a medical certificate from your doctor about your condition
- details of visits to the doctor and medications over the last 12 months.

‘Income’ means any income you (and your partner) get from any source, such as work, regular insurance payments like ACC, investments, business, private pensions, rent or boarders.

‘Assets’ means anything you or your partner own that you can earn income from, such as savings, shares, stocks, loans to others, or property you don’t live in.

Ask the practice nurse at your family doctor to give you a copy of a record of all the times you have been to see your GP in the past 12 months, and ask your pharmacy for a list of the medication you have had over the 12 months.

If you have a partner, they'll also need to answer some questions and have the relevant information ready.

WINZ may ask you to see a budget advisor or fill out a budgeting plan before they give you assistance. To do this you will need to provide a breakdown of all you spend over a year: for example on car registration, warrants of fitness, clothing, groceries, entertainment, sport, car payments and mortgage/rent.

For further information about what to bring, see [www.workandincome.govt.nz/what-to-bring-to-your-first-meeting.html](http://www.workandincome.govt.nz/what-to-bring-to-your-first-meeting.html)

## Visiting WINZ

When you first go to visit WINZ you will be seen by a case manager, who will work out what benefit you are entitled to. You may not see the same person every time, but all WINZ workers have access to your file on computer.

You are able to take somebody with you as a support person if you want. A number of people find this helpful.

How much money you can get depends on your personal situation.

Write down any questions you may have and take these with you when you visit WINZ. The staff must answer any questions you have, but may not offer the information unless asked.

For information on current benefit rates, see [www.workandincome.govt.nz](http://www.workandincome.govt.nz)

## Filling out the forms

You will need to fill out a number of forms to apply for a benefit. When you phone WINZ to make an appointment, ask them to send you out the forms they need you to fill in, or you can download them from the WINZ website: see [www.workandincome.govt.nz](http://www.workandincome.govt.nz)

It is a good idea to fill the forms out as much as you can before your first visit to WINZ, and ensure any medical certificates have been signed by a doctor.

Make copies of all the forms you have filled out, so that you have a record. You may see a different case manager every time you visit, so it is important you know what you have filled out.

Ask a case manager for a copy of everything you receive from WINZ so that your social worker can help you if you need further assistance.

You may need to meet with a case manager at WINZ more than once; usually if your circumstances change and you need to apply for another benefit.

## **Subsidy cards and other assistance for health care**

Various cards and other assistance are available for those with health problems, as follows.

### **Community Services Card**

The Community Services Card can help you and your family with the costs of health care. With this card, you'll pay less for some health services and prescriptions: see [www.workandincome.govt.nz](http://www.workandincome.govt.nz)

If you get a main type of income support, you and your partner will automatically get the Community Services Card. This means you don't have to separately apply for the Community Services card if you get the sickness benefit, invalid's benefit or emergency benefit. Note, however, that if you get the sickness benefit you should call WINZ free on 0800 999 999 as soon as you are approved, so they can send you a card straight away.

## High Use Health Card

If you don't qualify for the Community Services Card, you may be able to get the High Use Health Card. This can help if you visit the doctor often for an ongoing medical condition (12 times or more in the last 12 months). It gives you the same subsidies on doctors' visits and prescriptions as the Community Services Card, but it is not a family card. Talk to your GP if you think you might qualify.

## Pharmaceutical Subsidy Card

The Pharmaceutical Subsidy Card is also known as a Safety Net Card, Prescription Subsidy Card, Exemption Card or Discount Card. It allows the cardholder and named family members to pay a lower amount on government prescription charges. There is no income testing. The purpose of the card is to help people who face high prescription costs but who do not have a Community Services Card or High Use Health Card.

## Additional help for kidney patients

Additional help for renal patients includes the following.

- MedicAlert bracelets, able to be ordered through your GP at a cost: see [www.medicalert.co.nz](http://www.medicalert.co.nz)
- St John's – join up as a supporter for \$80 per year per household and \$50 per year for an individual (including GST: as at June 2018). This means you won't have to pay for an ambulance should you need one in an emergency: see [www.stjohn.org.nz/donate/supporters.aspx](http://www.stjohn.org.nz/donate/supporters.aspx)
- Home help/personal care – this can be applied for through your GP or hospital social worker, who can refer you for an assessment to identify the areas in which you need help. They will fill out the form with you, identifying the areas where they think you need help. You need a Community Services Card to qualify for home help. There are no income criteria for personal care assistance.
- Disabled parking – applications for this have to be certified by a doctor. Your doctor or the local CCS Disability Action office will have application forms for you to fill in: see [ccsdisabilityaction.org.nz/mobility-parking](http://ccsdisabilityaction.org.nz/mobility-parking)

With all of the changes and challenges that kidney failure brings, it is easy to feel overwhelmed. However, thousands of people have already met the challenge of kidney failure and its treatment and returned to a normal lifestyle, even if that life is different to what it was before. The important thing is to learn to face the challenges one by one. If you deal with each situation as your strength and motivation allow, your victories will accumulate. Don't try to accept and adjust to everything at once.

Most importantly, you need to remember that you aren't alone. Help and support are available to you – you just have to ask for it.

# Chapter 9: Resources, contacts and support

## Kidney Health New Zealand

Kidney Health New Zealand may be contacted at:

PO Box 20072

Bishopdale

Christchurch 8543

Phone: 0800 KIDNEY (543 639)

Website: [www.kidneys.co.nz](http://www.kidneys.co.nz)

Email: [info@kidneys.co.nz](mailto:info@kidneys.co.nz)

Charities Commission number: CC 11348

## Useful websites

Here are some useful websites:

[www.kidney.org.au](http://www.kidney.org.au) (Kidney Health Australia)

[www.transweb.org](http://www.transweb.org) (an excellent site for living donor info)

[www.kidney.ca](http://www.kidney.ca) (Kidney Foundation of Canada)

[www.anzdata.org.au](http://www.anzdata.org.au) (Australian and New Zealand Dialysis and Transplantation Registry)

[www.tsanz.com.au](http://www.tsanz.com.au) (Transplant Society of Australia and New Zealand)

[www.kidneykids.org.nz](http://www.kidneykids.org.nz) (supporting children with kidney diseases)

[www.dialysisescapeline.com.au](http://www.dialysisescapeline.com.au)

[www.dialysisabroad.com.au](http://www.dialysisabroad.com.au) (Australian provider of escorted dialysis tours)

[www.carers.net.nz](http://www.carers.net.nz) (a charity that provides information and support for families with health and disability needs)

[www.wellingtonkidneysociety.org.nz](http://www.wellingtonkidneysociety.org.nz) (Wellington Region Kidney Society)

[www.kidneysociety.co.nz](http://www.kidneysociety.co.nz) (Kidney Society Auckland)

[www.cari.org.au](http://www.cari.org.au)

# Appendix 1:

## Survival of people on dialysis

Percentage survival for people on dialysis, according to age at the start of dialysis

| Age (years) | After one year | After two years | After five years |
|-------------|----------------|-----------------|------------------|
| 0–24        | 95             | 93              | 75               |
| 25–44       | 99             | 94              | 74               |
| 45–64       | 90             | 80              | 52               |
| 65–74       | 84             | 71              | 34               |
| 75–84       | 76             | 54              | 20               |
| Over 85     | 61             | 42              | 19               |

Source: Australia and New Zealand Dialysis and Transplant Register: [www.anzdata.org.au](http://www.anzdata.org.au)

## **Appendix 2:**

# **Facts and figures about dialysis**

- People who are able to get a kidney transplant live much longer than those who stay on dialysis.
- People able to start and stay on home haemodialysis live about twice as long as those who stay on hospital or satellite haemodialysis.
- People who start and stay on peritoneal dialysis for the first 3–4 years of their dialysis treatment live about 20–30 percent longer than those who stay on hospital or satellite haemodialysis.
- A fistula has fewer complications (such as clotting and infection) than an arteriovenous graft or a central venous dialysis catheter.

# Glossary

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|                                                      |                                                                                                                                                                                                                                  |
|------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Acute kidney injury</b>                           | Rapid loss of kidney function                                                                                                                                                                                                    |
| <b>Advanced directive</b>                            | A written or oral directive by which a consumer makes a choice about a possible future health care procedure, which is intended to be effective only when he or she is not competent                                             |
| <b>Anaemia</b>                                       | A medical condition in which the percentage of red blood cells circulating in the blood is reduced                                                                                                                               |
| <b>Angiotensin converting enzyme (ACE) inhibitor</b> | A type of blood pressure-lowering drug                                                                                                                                                                                           |
| <b>Angiotensin receptor blocker (ARB)</b>            | A type of blood pressure-lowering drug                                                                                                                                                                                           |
| <b>Artery</b>                                        | A blood vessel taking blood from the heart to other parts of the body                                                                                                                                                            |
| <b>Atherosclerosis</b>                               | The build-up of a waxy plaque on the inside of blood vessels                                                                                                                                                                     |
| <b>Automated peritoneal dialysis (APD)</b>           | A form of dialysis in which dialysis fluid is exchanged by a machine at night while you sleep; during the day dialysis still occurs slowly as dialysis solution is left in the peritoneal cavity                                 |
| <b>Blood group</b>                                   | People have one of four major blood groups: O, A, B or AB. A potential kidney donor and recipient are said to have compatible blood groups when the recipient does not have antibodies against the potential donor's blood group |

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|                                                                           |                                                                                                                                                                                                                   |
|---------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Blood typing</b>                                                       | A procedure to determine the compatibility between donor and recipient red blood cells                                                                                                                            |
| <b>Calcium</b>                                                            | A mineral found mainly in the hard part of bones, where it is stored                                                                                                                                              |
| <b>Catheter</b>                                                           | A hollow tube used to transport fluids to or from the body                                                                                                                                                        |
| <b>Centre (or hospital) dialysis</b>                                      | Dialysis provided in a hospital-based unit                                                                                                                                                                        |
| <b>Cholesterol</b>                                                        | A substance important and necessary for human health; however, high levels of cholesterol in the blood have been linked to damage to arteries and cardiovascular disease                                          |
| <b>Chronic kidney disease (CKD), also known as chronic renal disease</b>  | Kidney damage or reduced kidney function (irrespective of the cause) that persists for more than three months                                                                                                     |
| <b>Conservative treatment (also called palliative or supportive care)</b> | An alternative to dialysis or transplant that aims merely to manage the symptoms of kidney failure, and includes medical, emotional, social, spiritual and practical care for the patient and their family/whānau |
| <b>Continuous ambulatory peritoneal dialysis (CAPD)</b>                   | A form of continuous peritoneal dialysis in which dialysis fluid is exchanged at regular intervals throughout the day                                                                                             |
| <b>Creatinine</b>                                                         | A waste product of muscle activity that is removed from the body by the kidneys and excreted in the urine; high levels of creatinine represent reduced kidney function                                            |

|                                                     |                                                                                                                                                                                                                                                          |
|-----------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Deceased donor</b>                               | A donor whose kidney is removed after death                                                                                                                                                                                                              |
| <b>Diabetes mellitus (commonly called diabetes)</b> | A disease of the pancreas in which production of insulin (a hormone produced by the pancreas that regulates the level of glucose in the blood) is decreased or insufficient for the body's needs, resulting in disturbed levels of glucose in the blood  |
| <b>Diagnosis</b>                                    | Identification of a problem from a patient's symptoms, examination and tests                                                                                                                                                                             |
| <b>Dialyser</b>                                     | The part of a kidney machine that acts like a filter to remove wastes from the body                                                                                                                                                                      |
| <b>Dialysis</b>                                     | A treatment for kidney failure that removes wastes and water from the blood, in a process by which small molecules pass from one fluid where they are in high concentration to another fluid where the concentration is lower, through a porous membrane |
| <b>Dialysis fluid or dialysate</b>                  | A special fluid used in dialysis, into which wastes are passed                                                                                                                                                                                           |
| <b>Donor</b>                                        | A person who donates (for example, a new organ)                                                                                                                                                                                                          |
| <b>End-stage kidney disease (ESKD)</b>              | The stage in kidney disease when treatment, such as dialysis or a kidney transplant, becomes necessary. 'End-stage' refers to the end of kidney function                                                                                                 |
| <b>Erythropoietin (EPO)</b>                         | A hormone made by the kidneys that stimulates the bone marrow to produce red blood cells                                                                                                                                                                 |

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|-----------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Exchange</b>                                           | One complete cycle of peritoneal dialysis; consisting of inflow, equilibration and outflow of dialysis fluid                                                |
| <b>Fistula</b>                                            | A commonly used method of providing access to the bloodstream in which a vein and an artery are joined together                                             |
| <b>Glomerular filtration rate (GFR)</b>                   | The flow rate of filtered fluid through the kidney. The eGFR is an estimate of this flow rate obtained from a blood creatinine test                         |
| <b>Glomerulonephritis, often referred to as nephritis</b> | A condition in which the glomeruli, the tiny filters in the kidneys, are damaged                                                                            |
| <b>Glucose</b>                                            | Sugar in the blood                                                                                                                                          |
| <b>Graft</b>                                              | A commonly used method of providing access to the bloodstream in which a vein and an artery are joined together with a piece of special plastic-like tubing |
| <b>Haemodialysis</b>                                      | A treatment for kidney failure in which the blood passes through an artificial dialyser to remove wastes and water                                          |
| <b>Haemoglobin</b>                                        | An oxygen-carrying pigment in the red blood cells                                                                                                           |
| <b>Health</b>                                             | Complete physical, mental, emotional and spiritual wellbeing. Not merely an absence of disease. A resource for life                                         |
| <b>Heart attack</b>                                       | Heart damage from a blockage of a heart artery (also called a myocardial infarction)                                                                        |

|                                |                                                                                                                                                                                                         |
|--------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Hypertension</b>            | High blood pressure, which may be either the cause of, or the result of, kidney disease                                                                                                                 |
| <b>Immunosuppressive drugs</b> | Drugs that prevent or treat the rejection of a transplant (also called anti-rejection drugs)                                                                                                            |
| <b>Kidney biopsy</b>           | Extraction, using a needle, of a small piece of kidney tissue, which can then be examined under a microscope                                                                                            |
| <b>Membrane</b>                | In the artificial kidney, a porous material used to filter waste from the blood                                                                                                                         |
| <b>Nephritis</b>               | See Glomerulonephritis                                                                                                                                                                                  |
| <b>Nephrology</b>              | The branch of medical science that deals with the kidneys                                                                                                                                               |
| <b>Nephron</b>                 | The structural and functional unit of the kidney, numbering over a million in each kidney. The nephron filters the blood to form urine.                                                                 |
| <b>Organ</b>                   | A structurally distinct part of the body that usually performs a particular function (for example kidney, heart, lung or liver) and is made up of several types of tissue in a very organised structure |
| <b>Palliative care</b>         | See Conservative treatment                                                                                                                                                                              |
| <b>Peritoneal cavity</b>       | An abdominal cavity that contains the intestines and other internal organs and is lined by the peritoneum or peritoneal membrane                                                                        |

|                                  |                                                                                                                                                                                                     |
|----------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Peritoneal dialysis (PD)</b>  | A treatment for kidney failure in which dialysis fluid is introduced into the peritoneal cavity to remove wastes and water from the blood                                                           |
| <b>Peritoneum</b>                | A thin membrane that encloses the peritoneal cavity and surrounds the abdominal organs                                                                                                              |
| <b>Phosphate</b>                 | A mineral in the body fluids that is regulated by the kidneys and, at normal levels, keeps bones and other parts strong and healthy. At high levels it causes itching and painful joints            |
| <b>Phosphate binder</b>          | A medication that binds with phosphate in the intestine, causing more phosphate to be passed in the faeces                                                                                          |
| <b>Polycystic kidney disease</b> | An inherited kidney disease that produces fluid-filled cysts in the kidneys that produce chronic kidney failure over many years                                                                     |
| <b>Potassium</b>                 | A mineral in the body fluids that is regulated by the kidneys and, at normal levels, helps nerves, muscles and other cells work well. At high levels it may result in cardiac arrest or arrhythmias |
| <b>Prednisone</b>                | An immunosuppressive drug used to treat some forms of kidney disease and to prevent and treat transplant rejection                                                                                  |
| <b>Protein</b>                   | A substance obtained from food that builds, repairs and maintains body tissues                                                                                                                      |
| <b>Recipient</b>                 | A person who receives (for example, a new organ)                                                                                                                                                    |

|                                      |                                                                                                                           |
|--------------------------------------|---------------------------------------------------------------------------------------------------------------------------|
| <b>Reflux nephropathy</b>            | Kidney scarring associated with vesicoureteric reflux                                                                     |
| <b>Satellite dialysis</b>            | Dialysis that takes place in a unit separate from the hospital                                                            |
| <b>Sodium</b>                        | A mineral in the body fluids that is regulated by the kidneys and affects the level of water retained in the body tissues |
| <b>Stroke</b>                        | Damage to the brain caused by a blockage of, or a haemorrhage from, an artery                                             |
| <b>Tissue</b>                        | Cells of a particular type massed together; for example, blood or nerves                                                  |
| <b>Transplant</b>                    | The act of transferring an organ or a portion of tissue from one person to another                                        |
| <b>Ultrasound scan</b>               | A painless test that uses sound waves to create images of organs and structures inside the body                           |
| <b>Urea</b>                          | A waste product from the breakdown of protein                                                                             |
| <b>Ureter</b>                        | A muscular tube that propels urine from the kidneys to the urinary bladder                                                |
| <b>Urinary tract infection (UTI)</b> | A bacterial infection that affects a part of the urinary tract                                                            |
| <b>Urology</b>                       | The branch of medicine dealing with the urinary system in females and the genito-urinary system in males                  |
| <b>Vein</b>                          | A blood vessel returning blood to the heart                                                                               |

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**Vesicoureteric  
(or vesicoureteral) reflux  
(VUR)**

A condition in which urine flows from the bladder back up the ureter and back into the kidneys

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**Vitamin D**

A fat-soluble chemical that is activated naturally in the body on exposure to sunlight

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