



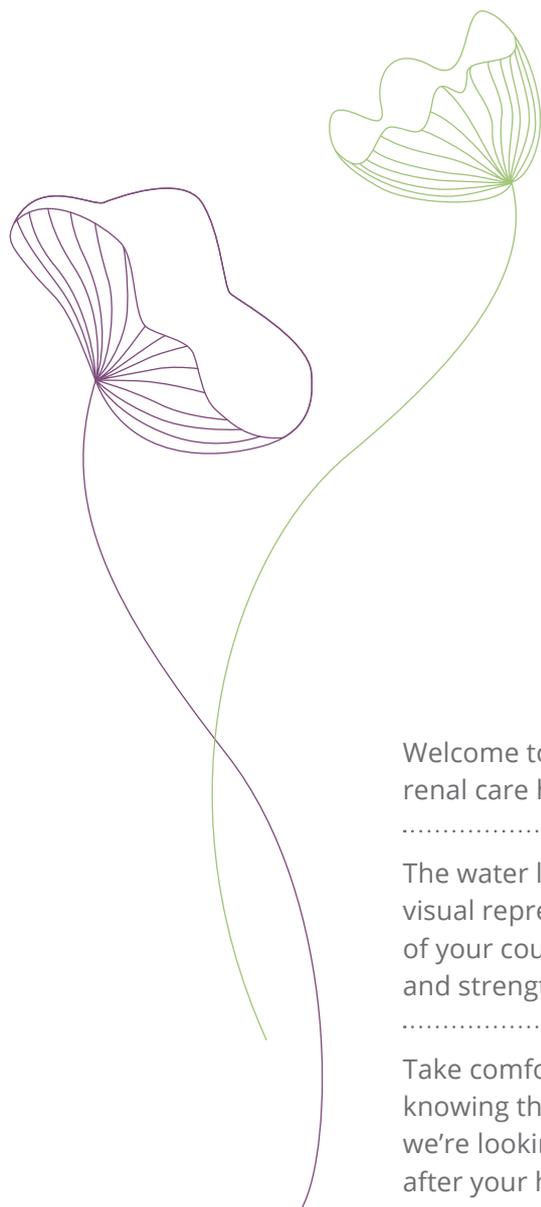
Kidney Care Programme

Write it on your heart
that every day is the
best day in the year.

~ Ralph Waldo Emerson



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Welcome to your renal care handbook



As a dialysis patient, it's important that you are actively involved in your treatment and that you closely watch your fluid intake and eating habits.

Your health matters to us. At Discovery Health we know that people living with chronic conditions need extra care. This book is one way in which we want to help you cope better with your condition.

We recognise that it's sometimes difficult to have a totally positive outlook on the future when you live with kidney disease and face the many unique situations the condition presents. You have to cope with these demands as well as the challenges and opportunities that life presents, all while trying to balance the limitations that your condition creates.

Helping you to take charge of your life

We've also included a section that we hope will be helpful in empowering you, or your child, to cope with kidney failure. It's important to understand how a positive outlook can help keep you healthy.

We hope you find this information valuable in reaching overall wellness.

We want to help you to face and embrace these challenges

As a dialysis patient, it's important that you are actively involved in your treatment and that you closely watch your fluid intake and eating habits. Therefore you need a clear mind to make the best decisions for your care. How you deal with these challenges is important to your overall health. We hope this information gives you what you need to help you face and embrace these challenges in a way that has a positive impact on both your physical and mental health.

The water lily is the visual representation of your courage and strength

This brightly coloured flower has a prominent place in many religions and cultures and has been held sacred across many religious beliefs from Egyptian mythology to the Greek and Roman Christian churches as well as Hindu and Buddhist beliefs. To the native Americans, the flower symbolises the sun's power to transform energy into food.

We recognise the unique challenges your condition presents and have therefore used the water lily (or lotus flower) as the visual representation of your courage and strength.

From the muddy bottom of a pond, the water lily rises through the murky water to reveal its perfectly formed petals that make up the water lily flower. As the lotus flower grows up from out of the mud into an object of great beauty, so people also grow and change into something more beautiful. The symbol represents the struggle of life in its most basic form and each petal represents the different stages of one's journey, with the flower's centre being the destination.

The water lily, or lotus flower, is a symbolic representation of re-birth but, in addition to its religious meaning, the lotus is also a symbol of all that is true, good and beautiful, representing good fortune, peace and enlightenment.

The water lily appears in literature too: the stalk of the lotus flower is often referred to in Chinese poetry. The stalk's ability to bend acutely without breaking easily is thanks to its strong fibres. Chinese poets liken this quality to the bonds in special relationships, as between lovers or family members.

Take comfort in knowing that we're looking after your health

Your medical scheme, along with Discovery Health, recognises that, as a member on chronic dialysis, you deserve special attention. I'm a paediatrician who manages children in chronic renal failure who, like you, need chronic dialysis and transplantation. I fully appreciate the demands that dialysis places on you and the health challenges involved.

This book is one of the exciting initiatives that we're bringing to you and is aimed at giving you the extra support and care that you need, together with your treating doctor and renal team. It's a team effort.

Your educational book gives you information to help you understand your condition. By keeping your health information together in one place you can track your health and your response to the treatment with your doctor. I hope this information helps you to make educated and informed choices about your treatment, in consultation with your doctor.

I look forward to partnering with you on this programme.

Prof Errol Gottlich
Clinical specialist



Working with your doctor

Together with a dedicated team at Discovery Health, I manage the Kidney Care programme that monitors members on dialysis. This programme, in partnership with your doctor and dialysis service provider, aims to:

- Ensure joint participation by patients, doctors and dialysis care providers to improve quality of care.
- Measure and report on the comprehensive management of the patient to institute improvement of care programmes.
- To provide educational material to patients via a booklet and a daily SMS health message.
- Improve the quality of life for patients on chronic dialysis and reduce additional costs incurred caused by repeat hospital admissions and avoidable complications in care.



POSITIVE

Keep your face always toward the sunshine
– and shadows will fall behind you.

~ *Walt Whitman*



Courage is resistance
to fear, mastery of fear
- not absence of fear.

~ Mark Twain





My condition
and treatment



My condition

Healthy kidneys
remove waste
products from
the blood



Kidney disease and the implications it has for me

Being aware of your condition and other factors that affect your health is an important step for you to take control of your health.

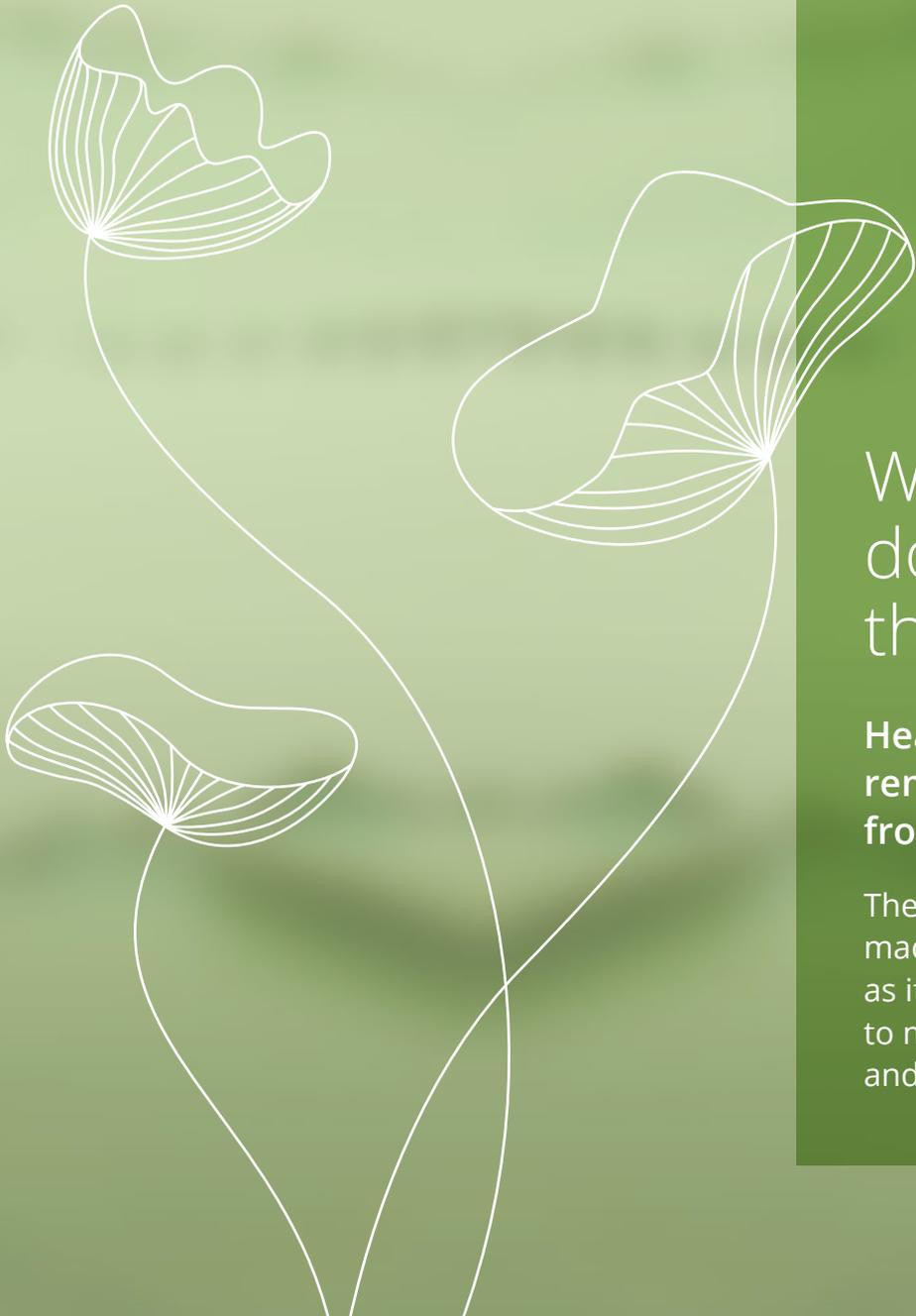
This section explains what the kidneys do and gives details about kidney disease, the treatments for it, and why it's necessary to have the treatment.



How healthy kidneys work

Where in my body are my kidneys and what do they look like?

The kidneys are a pair of bean-shaped organs that are found at the back of the body about the level of the waist. Each kidney measures 10 to 15cm in length and weighs about 160 grams. Each kidney holds thousands of small filtering units called nephrons and each nephron holds a sieve-like structure called a glomerulus.



What they do and how they do it

**Healthy kidneys
remove waste products
from the blood**

These waste products are made normally by the body as it uses nutrients from food to make energy, repair damage and maintain healthy tissues.



01

As blood moves through the glomerulus, it is filtered

so that waste products and extra water are removed, but normal cells and proteins are left behind. Once it has filtered through the glomerulus, the waste water passes through a series of tubes where further waste is added to it; however salts and water that the body needs to keep, are taken up again.

02

After passing through the tubes the waste water drains

into the bladder from where it is passed out as urine. Your kidneys do not only get rid of waste, they also make hormones that are necessary for a healthy body. These include:



Erythropoietin, which stimulates the making of red blood cells that carry oxygen around the body.



Calcitriol, changed from vitamin D, keeps calcium levels normal for healthy bones.



Renin, which helps to control blood pressure.

Why my kidneys stop working

Common reasons for kidney failure

Kidney (renal) failure happens when the kidneys stop working or the level of efficiency is less than 10%.

When the small filtering units, or nephrons, are damaged the kidneys can't filter waste from the blood. This is when waste products and extra fluid start to build up and cause damage to the body. These waste products and fluids are poisonous in large quantities.

When the body can't get rid of these poisons you start to feel nauseous and have headaches and dizziness. You might not want to eat or will not eat properly. Other symptoms include loss of concentration and difficulty to focus, fatigue (extreme tiredness), itchy skin and yellowing of the skin. You will retain fluid, which results in oedema (large build up of fluid in the body's tissues)

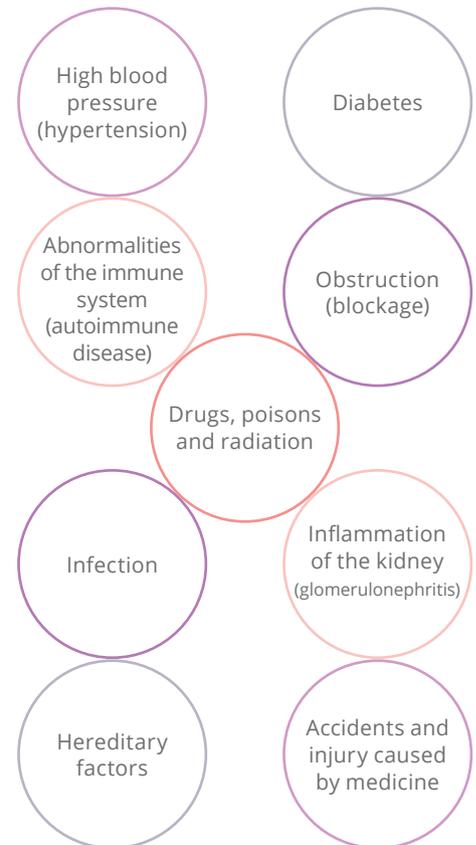
leading to a higher body weight. You will also develop high blood pressure and find it difficult to breathe.

Kidney failure leads to weak bones and you become anaemic (when you have too few red blood cells) with low iron levels.

Because there are so many nephrons in each kidney, you do not see kidney damage until a large portion of them (more than half) is damaged. This may make mild kidney failure difficult to see without specific diagnostic tests.

As kidney damage gets worse, the kidneys may stop filtering the blood altogether, resulting in a condition called uraemia. They also stop making erythropoietin, calcitriol and renin. This stage of kidney failure is called stage 5 or end-stage kidney disease.

Some of the factors leading to kidney failure:



Testing my kidney functions

Blood tests are regularly done. These tests check your levels of electrolytes and other elements in your blood to see how effective your dialysis treatment is. Here are some of the kinds of tests you will have done:

Kinds of tests I will have done

- **Albumin:** to see if your body is absorbing (taking in) protein well
 - **Calcium:** to see if your calcium levels are as good as possible for healthy bone development
 - **Chloride:** affects the sodium level in your body and should be kept at a steady level
 - **Creatinine:** to see how much creatinine, a waste product, is in your body
 - **Ferritin:** to see how much iron is present in your body
 - **Haemoglobin:** to assess the red blood cell content in the blood
 - **Magnesium:** there is a high level of magnesium in patients with kidney disease
 - **Phosphorus:** to ensure your treatment is removing phosphorus from your body well
 - **Potassium:** to ensure your treatment is removing potassium from your body well
 - **Serum CO₂ /Bicarb:** the kidneys control the levels of bicarbonate in your body
 - **Sodium:** too much sodium in the body can lead to excessive thirst and therefore drinking more, which leads to fluid retention and higher blood pressure
 - **Urea:** to see how much ammonia, a waste product, is left in the body
 - **Parathyroid hormone:** to assess the effect of chronic kidney disease on the bones.
-

Normal ranges

Albumin	35 – 60g/L
Calcium	2.2 – 2.7mmol/L
Chloride	98 – 107 mmol/L
Creatinine	44 – 88mmol/L
Ferritin	15 / 160ng/mL
Haemoglobin	10 – 12g/dL
Magnesium	0.66 – 1.07 mmol/L
Phosphorus	1.45 – 1.78mmol/L
Potassium	4.1 – 5.3mmol/L
Serum CO ₂ / Bicarb	21 – 29mmol/L
Sodium	136 – 145mmol/L
Urea	2.1 – 7.1mmol/L
Parathyroid Hormone	130 – 585pml/L

The kidney is a very important organ and adds to a healthy body in a number of different ways. Kidney failure is therefore linked to many health worries that need to be treated.

Treatments that may be necessary

- Healthy lifestyle changes, including a healthy diet and regular exercise and managing fluid intake
- Medicine to control blood pressure and improve anaemia and bone health
- Dialysis
- Kidney transplant

Some of the effects of kidney failure

- Build up of waste products in the blood (uraemia)
- Lower production of red blood cells (anaemia)
- High blood pressure (hypertension)
- High cholesterol (hyperlipidaemia)
- Insufficient making and keeping of bone mass
- Itching (due to uraemia)
- Difficulty in sleeping.

Treatments

Diet, fluid intake and lifestyle changes I must make

Why it is important to follow a Renal Way of Life

Good nutrition principles, limiting of fluid, regular physical activity and taking your medicine as prescribed are the base for greater wellbeing in patients with kidney conditions.

Which foods should I avoid?

When you are in kidney failure, you have to make changes to your diet to prevent health problems. Foods that have high levels of certain nutrients like protein, phosphorus and potassium must be limited or taken out of your diet. A dietitian can help you determine what foods are best to eat.

Regular physical activity and taking your medicine as prescribed are the base for greater wellbeing in patients with kidney conditions.



High protein foods: The kidney clears the waste products from protein out of your body. Foods that have high levels of protein can make more waste than your kidneys can clear and can lead to faster kidney deterioration.



High potassium foods: High potassium levels in the blood can cause heart and muscle problems. If you have kidney failure you have to be careful of eating large amounts of foods with high potassium levels. Many foods like oranges and potatoes have high amounts of potassium.



High phosphorus foods: High phosphorus levels in your blood lower the amount of calcium in your bones. Since the kidney manages the levels of phosphorus in the blood, people in kidney failure often have high levels of the mineral.



High sodium foods: Sodium can cause your body to hold on to extra fluid which can lead to high blood pressure and can put more strain on your heart and kidneys.

Unhealthy fats: It is important that you eat less saturated and trans fats (bad fats) to avoid high cholesterol levels. You need fat in your diet because it can be used for energy and to create very important hormones in the body. Including healthy fats can make sure that you get the necessary fats and extra calories you need. Examples of healthy fats are olive oil, corn oil and peanut oil.

Why I have to limit my fluid intake

When you are experiencing kidney failure, you are unable to pass adequate volumes of urine and when you drink fluids, these fluids store in your body. The extra fluid in your body puts pressure especially on your lungs and your heart.



Medicine I might have to take

Because the kidneys have a number of functions that contribute to a healthy body, dialysis is only one of a number of treatments that help to replace kidney function. Your doctor may put you on dialysis as well as prescribe medicine to keep you in the best possible health. Here are some of these medicines:

Medicine to treat anaemia

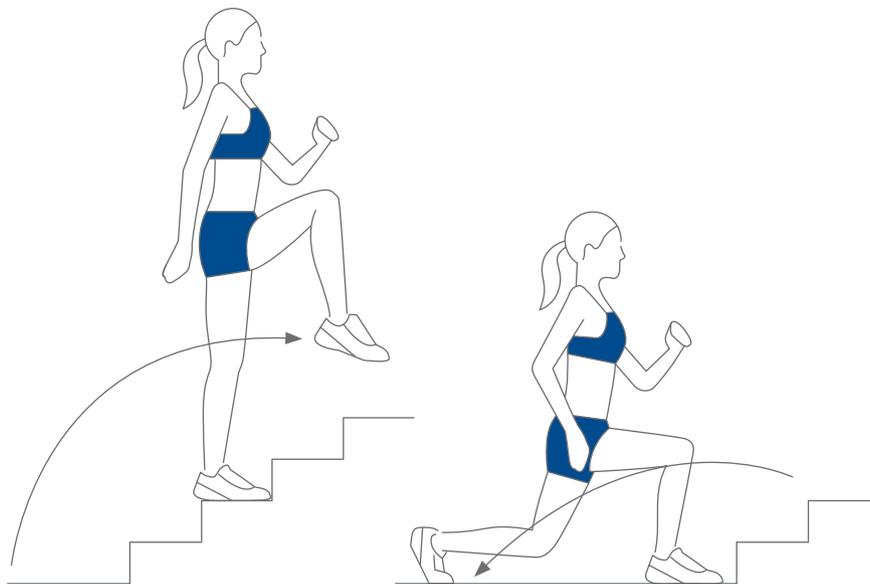
In kidney failure, the kidneys no longer make erythropoietin, a hormone that stimulates red blood cell formation. When the body doesn't make enough red blood cells, it results in a condition called anaemia. Anaemia causes a lack of energy and tiredness and may damage your heart.

Why I should exercise

There are many benefits of physical exercise. In short it makes you healthier, as it:

- Improves fitness
- Lowers blood pressure
- Helps to prevent diabetes and cardiovascular disease (problems with your heart and blood vessels)
- Improves muscle strength
- Helps to strengthen bones and lessen joint stiffness
- Helps you to lose weight (only if you stick to your diet as well)!
- Helps to improve your mood and makes you feel better.

You must try to exercise 30 to 60 minutes on most days of the week. It is very important to talk to your doctor before you start an exercise programme.



**Please see
pages 79 to 111**

for detailed information on food, fluid limitations, recipes, exercise tips, travelling tips and tips on looking after your bones.

To replace (put back) your natural erythropoietin, your doctor may prescribe erythropoietin injections. Depending on the type of medicine, these may be given a few times a week, once a week, every two weeks or even only once a month. Because you need iron to make red blood cells, you may also have to take extra iron which is usually given intravenously (through the vein).

There are a variety of medicines with different active ingredients that can be used to treat the same condition. Ask your doctor or clinic sister to explain to you what each of your medicines is for, how they work and most importantly, how you should take them.

Medicine for bone disease

Calcium and phosphorus are necessary for healthy bones. Your parathyroid gland together with a healthy kidney is important to control the amount of calcium and phosphorus in your body and to control their activity. In kidney disease, this controlling activity is lost:

- The kidney normally turns vitamin D into a hormone called calcitriol. In kidney disease, not enough calcitriol is made. This makes the actions of calcium, phosphorus and the parathyroid gland to become abnormal.
- Calcium is lost from bone, causing weakening of the bones, which gives you a higher risk of breaking a bone.
- Because the kidneys cannot take out phosphorus, phosphorus starts to build up in the body.
- Calcium and phosphorus join to make deposits that collect in blood vessels and damage the blood supply to organs like the heart and intestines. Medicine that can help to avoid these effects include:
 - Phosphate binders – these tablets are taken with meals to stop the body from taking up phosphorus so that it does not build up in the body.
 - Calcitriol – to give you higher levels of calcitriol as it is not being made by the kidneys.
 - Cinacalcet – helps control the working of the parathyroid gland.

Other medicines that may be required

- Medicine to help reduce itching, for example antihistamines
 - Medicine to control cholesterol levels, for example statins
 - Medicine to reduce blood pressure, for example calcium channel blockers and ACE inhibitors
 - Anti-diabetic medicines to control blood sugar, for example oral tablets or insulin injections.
-

What dialysis is and how it works

What dialysis is

Your condition is treated by a kidney specialist called a nephrologist or a doctor with a special interest in kidney disease. Your doctor will suggest treatment options to you, which will most likely include dialysis.

Dialysis is a medical treatment to filter waste and water from the blood when the kidneys are no longer working.

There are two different methods of dialysis, haemodialysis and peritoneal dialysis.

- Haemodialysis uses an external filter to clean the blood. Blood is removed from the body, passed through the filter and then returned to the body.
- Peritoneal dialysis uses the body's own abdominal cavity (open space in the belly) to clean the blood.

Haemodialysis

Before starting haemodialysis, a tube will be inserted into a specially created blood vessel in your forearm known as an AV fistula (or arterio-venous fistula). The tube is then linked to a haemodialysis machine (also known as an artificial kidney), which pumps blood out of your body, cleans it and returns it, usually through a second tube.

How the haemodialysis machine works

Connected to the haemodialysis machine is a filter called a dialyser. The dialyser is divided into two sections, separated by a membrane. The membrane is a film covered with many microscopic holes.

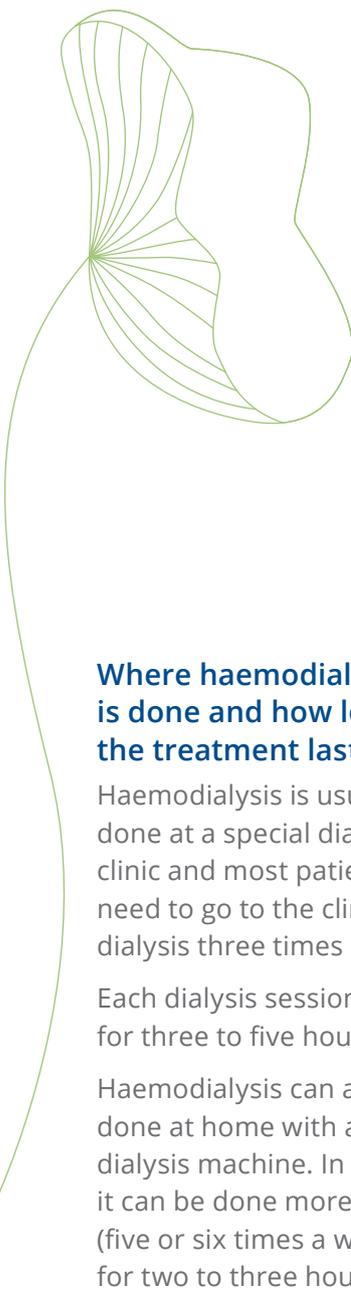
Blood is pumped through one section of the dialyser and the other section is filled with a special dialysis fluid,

which draws waste products out of the blood through the membrane. This membrane is semi permeable (some things can move through it) and in this way the dialysis fluid cleans the blood, but the fluid and blood cannot mix.

The time it takes for your dialysis treatment is the best possible time it takes to clear all the waste products, poisons and extra fluid from your body.



The haemodialysis machine also has different monitors, so that it makes sure that blood is pumped out and back into your body at the correct speed and that your blood pressure stays at a healthy level.



Why does haemodialysis happen so often and take so long?

Healthy kidneys work 24 hours a day, 7 days a week to remove the waste products from the body. Remember that dialysis replaces only a small amount of your kidney function and if you're not getting enough dialysis, you will start to have symptoms of kidney failure, such as a metallic taste in your mouth, itching, loss of appetite and fatigue.

If dialysis were to take the place of healthy kidneys completely, you'd need to be linked up to a dialysis machine all the time.

The time it takes for your dialysis treatment is the best possible time it takes to clear all the waste products, poisons and extra fluid from your body. It can be longer or shorter, depending on your urea and creatinine blood test results. The amount of time on dialysis is worked out on an individual basis by your

attending doctor but should usually not be less than three sessions of four hours a week.

Peritoneal dialysis

Peritoneal dialysis uses the body's own abdominal cavity (open space in your belly) to clean the blood. Dialysis solution (a mixture of sugar, salt, and other minerals dissolved in water) is introduced into the peritoneal (abdominal) cavity through a catheter (tube). A peritoneal dialysis procedure is called an exchange because the used solution is removed and replaced with fresh solution. This can be done at home four times a day or continuously at night.

There are significant benefits to having peritoneal dialysis

Because it can be done at home, peritoneal dialysis may offer more freedom than haemodialysis. For some people, performing dialysis at night is sufficient, leaving the day free for other activities.

Where haemodialysis is done and how long the treatment lasts

Haemodialysis is usually done at a special dialysis clinic and most patients will need to go to the clinic for dialysis three times a week.

Each dialysis session lasts for three to five hours.

Haemodialysis can also be done at home with a home dialysis machine. In this case it can be done more often (five or six times a week) for two to three hours each session, or at night.

Today I choose life. Every morning when I wake up I can choose joy, happiness, negativity, pain... To feel the freedom that comes from being able to continue to make mistakes and choices - today I choose to feel life, not to deny my humanity but embrace it.

~ Kevyn Aucoin



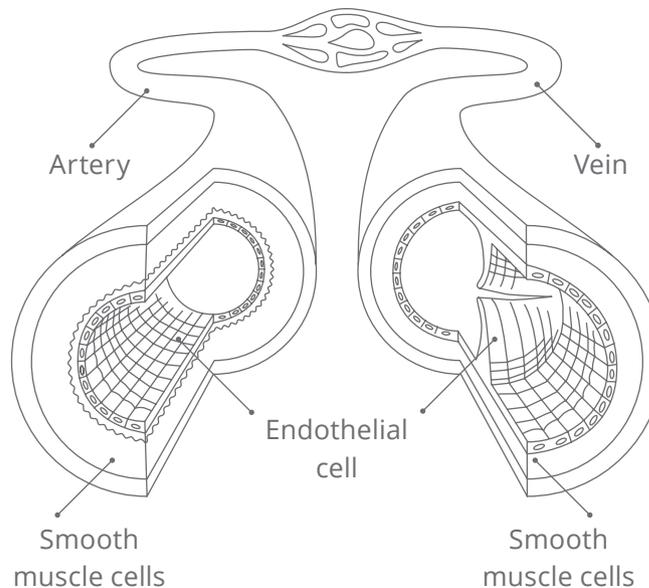
When I am on haemodialysis, how will they get access to my blood vessels every time?

When you need dialysis urgently, they will create temporary access, but for continuous dialysis the doctor will create an arterio-venous fistula.

What temporary access is and how it is created

Temporary access can be created in cases where urgent dialysis is needed and one cannot wait two to three months for the fistula to mature.

Temporary access is established using a subclavian catheter or internal jugular catheter. The subclavian catheter is a set of tubing put into the subclavian vein near the neck. The internal jugular catheter is placed into the veins on the side of the neck. Although temporary catheters can be used for a period of time they are more likely to get an infection and blockage and are more uncomfortable than a fistula.



What permanent catheter access is and how it is created

A permanent catheter is often resorted to once a patient has had a fistula or a graft fistula, but due to complications (mostly clotting or infection) a fistula is no longer possible to establish.

These permanent catheters (usually called a Permcath) are inserted under general anaesthesia into a neck vein and positioned on the upper chest. Dialysis is performed by opening each port of the catheter and connecting the catheter to the dialysis machine. In some instances, Permcaths are complicated by infection and clotting and may need to be replaced. They also need to be protected when showering. Bathing and swimming are generally not recommended. Unfortunately, dialysis is usually less efficient via a Permcath than a fistula and for that reason fistulas are always the preferred access route for haemodialysis.

What an arterio-venous (or AV) fistula is

An AV fistula is the access point for haemodialysis. The AV fistula is created internally and used for a long time. To create it, the surgeon joins the artery and vein under the skin. The ideal site is the forearm (radiocephalic fistula) but it can also be done on your wrist or elbow.

During your treatment, two needles are placed in your arm to allow the blood that has built up with toxins to flow through a tube to the dialyser. The dialyser cleans the blood and it is returned to your body through the other needle. A fistula takes about six to eight weeks to mature.

What an arterio-venous graft is

This is similar to an AV fistula except that an artificial (man-made) blood vessel is used to join an artery (a blood vessel that delivers blood from the heart to the tissues and organs of the body) and a vein (a blood vessel which carries blood back to the heart). This is done when your own blood vessels are too small for fistula construction.

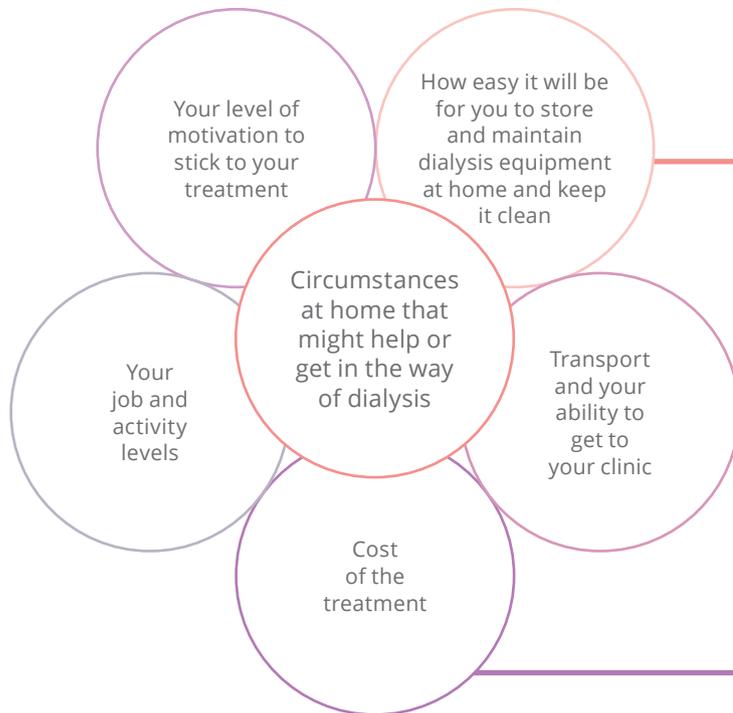
The graft may be straight or looped and is close to the surface of the skin. The graft is made of artificial material, or the doctor can take it from your own body tissues, for example a vein in your thigh.

How do I take care of the fistula or graft?

It is important to always keep the area clean and dry.

To make sure that the fistula is working, you can feel if blood is flowing through it (called a feeling for a thrill) by putting your finger on the area.

Avoid constriction of the area by not wearing tight clothing and jewellery and not having your blood pressure taken or intravenous administration (fluids or medicine given directly into the vein) done on the fistula arm. Avoid too much pressure on puncture sites (where the needles went through the skin) and make sure the clinic nurses rotate needling to prevent aneurysm (a localised, blood-filled balloon-like bulge in the wall of a blood vessel).



Things I need to think about when deciding on the type of dialysis that is appropriate for me

Your doctor will discuss dialysis options with you and together you will decide what type of dialysis is right for you at this time.

In time, many patients may need both types of dialysis. When deciding what type of dialysis is right for you, various factors need to be considered.

Think about these things

Advantages and disadvantages of haemodialysis



Advantages

- No equipment needed at home
- Treatment is done three times a week
- Less chance of infection at external access points
- Regular contact with staff and other dialysis patients
- Only connected to a machine during dialysis (free of machine for four days a week)
- Lower risk of infection
- Treatment is given by a healthcare professional



Disadvantages

- Travel to dialysis centre
- Takes up a lot of time
- Very specific times
- Cannot move around during treatment
- Two needles inserted at each treatment
- Waste builds up between treatments
- Diet and fluid limits

Advantages and disadvantages of peritoneal dialysis



Advantages

- Greater independence and flexibility because the treatment is self-managed at home
- No needles are needed
- Less limits on diet and fluid intake
- Greater blood pressure control
- Freedom of movement during treatment.



Disadvantages

- Treatment consists of daily exchanges therefore no 'off days'
- You have a permanent catheter in place
- Risk of infection is greater
- Possibility of picking up weight and upsetting your glucose control
- Needs training and storage of supplies at home

When I need to consider a kidney transplant and how it works

A kidney transplant is the best treatment for end-stage kidney failure. However, kidney transplantation is not suitable for everybody. Some people have conditions like cardiovascular disease or cancer that make them unsuitable for surgery, or that gives them a bigger chance to reject the new kidney.

What a kidney transplant is

A kidney transplant is when a kidney is received from a donor. A donor may be someone who has died with healthy kidneys, or a living person with two healthy kidneys.

Kidney transplantation lets a person with kidney failure get back their previous quality of life and reach a level of health that lets them be productive in school, work, and other activities.

Actively supporting local organ donation programmes makes this a reality for more people with kidney failure.

World Kidney Day, which is usually held in March of each year, focuses on spreading this message to governments, health authorities and communities.

Where I will find the right kidney for my body

Before getting a transplant you will need to have some medical tests done, including blood tests, to help identify a kidney that most closely matches your own.

Because a kidney from a family member is more likely to match your tissue, that type of donor is preferable. However, kidneys from donors that are not family, also can result in successful transplantation with a good long-term outcome.

Deceased donors

Transplant patients, who do not have a living donor who can give them a kidney, will get their kidney from a deceased donor. The success rate of transplants from deceased donors, although slightly lower than those from living donors, is still very high. Patients waiting for a suitable kidney from a deceased donor are placed on a waiting list. Allocation of donor kidneys is based on a system that makes sure that each organ goes to the best possible recipient.

Factors in choosing a recipient include:



The patient's medical condition



Tissue matching – blood type, tissue type, antibodies



How long the patient has been waiting.



Kidney donation is a gift of life
from one person to another.

Living donors

Most people are born with two kidneys, but some are born with only one, and they live healthy, normal lives. That is why it is possible for living donors to donate one kidney. There are two types of living donors:

Related donors – family members are more likely to have a good tissue match to you, with a smaller chance of rejection. The donor can be anyone older than 18 years and who is part of your family, like a parent, sister or brother (sibling), child, aunt or uncle, nephew or cousin.

Non-related donors – if you cannot find a family member who is able to donate, it is possible to get a kidney from someone who is not directly related, such as a husband or wife or a close friend.

Unfortunately, the number of deceased donors remains low so over the last few years it has been noted that worldwide, living donation has been increasing as a percentage of all kidney donations.

Why I need to take medicine for the rest of my life after the transplantation

Because your immune system (white blood cells) sees that the new kidney is foreign and does not belong in your body, it will attack the kidney after it has been transplanted, causing it to fail. This is called organ rejection and is your body's natural reaction.



The earlier your name is put on the waiting list, the more likely you are to get a kidney transplant.



You'll need to take medicine before and after the transplant operation to suppress the immune response and reduce the chance of organ rejection. These medicines are called immunosuppressants.

Immunosuppressants, like any medicine, do have side effects

- Depending on the type of medicine, some of these side effects include:
- A higher risk of getting an infection
- A change in appearance – fullness around the face, acne and weight gain
- Diabetes
- Osteoporosis (thinning of the bones)
- Hirsutism (abnormal growth of hair)

Why I might wait a long time to get a kidney

Because the number of people who need a kidney transplant is far more than the available donors, the waiting list for a kidney transplant is long. Some people may have to wait for many years before a kidney is available for them. According to the National Kidney Foundation of South Africa, the average waiting time for a kidney transplant in South Africa is four years.

Discuss the possibility of a kidney transplant with your doctor. Unless you have a family member who is willing and able to donate a kidney, the earlier your name is put on the waiting list, the more likely you are to get a kidney transplant.

All about the time leading up to my kidney transplantation

Medical tests I will have before my transplantation

Before you can get your transplant you will have a lot of different medical tests. These tests identify health problems that could put you at risk during or after your transplant. Whenever possible, these problems are treated before your operation. Tests include:

- Blood tests
- Tests to establish the condition of your heart and lungs
- Dental check-up and x-ray of your teeth

- Gynaecological evaluation, including a Pap smear test, pelvic (lower belly) examination and a mammogram (x-ray of the breast) (for patients older than 40 years)
- A session with a psychologist or social worker

Setting up my transplantation

If you have a living donor and your full evaluation is complete, your surgery will be set up for a time that suits you, your donor and the transplant team.

If you are waiting for a kidney from a deceased donor, you will be placed on the waiting list.

Let us know where you are and how we can reach you!

A donor can be found at any time – day or night, weekdays, weekends, holidays. This means we will need to contact you quickly when a donor is found. We must always know how to reach you and you must give an up-to-date cellphone number to your doctor and to the transplant unit. If you are leaving your town or city for any length of time, tell the transplant office when you are leaving, when you will get back home and how you can be reached. Please keep your cellphone on and with you in case that special call comes through that you have been called up for a possible transplant.

I must stay healthy

- Follow your dialysis routine correctly
- Take your medicines as prescribed
- Watch your weight and if you are overweight, try to lose weight
- If you smoke – stop now
- Exercise is a very important part of the programme to get ready for the transplant, if your health allows it. You must please consult your doctor, a physiotherapist or a biokineticist who is experienced in exercise training to help you and make sure you are exercising correctly.

I must tell the transplant team about any change in my health, no matter how small

Report any of these changes to your doctor immediately. Any illness or infection or any other medical condition could put you at risk of complications and your doctors may decide not to do your transplant surgery at that time. Your doctor will tell the transplant unit if you have any of the following issues if they have an impact on your transplantation:

- Any illness
- Any changes in medicine or any new medicine
- Any hospitalisation
- Any changes in the days you have dialysis
- Any changes in doctors
- Any blood transfusions you get.

I will have regular blood tests done

While you are waiting for a kidney, your transplant team will need regular new blood samples from you, to allow them to look for new antibodies and match you with possible donors. Make sure you have these tests done whenever asked to do so. If you don't have these done when asked to do so and you are waiting for a donor organ transplant, your name may be taken off the waiting list.

Getting ready for my transplant

Your transplant could happen at any time, so it is best for you to be ready. There are a lot of practical things you can plan to make you ready and for things to run as smoothly as possible when the time comes for your operation:

- Read everything your transplant team gives you and ask questions when you're not sure of something

- Have a plan for how you will get to the hospital (it is best not to drive yourself, if nobody can take you, plan to take a taxi).
- Make plans for how you will get home from the hospital.
- Make plans for someone to take care of your children or others in your care for the time you will be in hospital.
- If you live far from the transplant hospital, you will need to arrange a place to stay during the first few weeks after your operation so that you can make the frequent check-up visits to the hospital necessary after the transplant.
- Arrange for someone to drive you to the hospital for clinic visits once or twice a week during the first month before you are allowed to drive yourself.
- You may need laboratory tests once or twice a week for the first few weeks.
- If you have problems organising your medicines by yourself, have someone

who can come to the hospital to be shown what to do.

Before I go to the hospital

- If your kidney is going to be from a living donor, your operation will be planned for a specific date.
- As the date gets closer, you must tell your doctor and the transplant team immediately if:
 - You have any illness, including a cold, a problem with a tooth, or an infection
 - You are taking any new medicines, including over-the-counter or herbal medicines, or food supplements
 - You are planning any trips away from home
 - There are any changes in your contact information.

What I must take to the hospital

- If you know a friend or family member is going to visit you in hospital after the surgery, bring as little

as possible, otherwise bring the basics you will need, such as toiletries, pyjamas and slippers, books or magazines and clothes to travel home in. Do not bring jewellery or expensive electronic devices.

- Make sure you bring all your current medicines.

Getting to the hospital

Unless you have no other choice, don't drive by yourself to the hospital – get a family member or friend to take you, or go by taxi. The transplant nurse or doctor will tell you if you must go to the admitting office or directly to the transplant unit of the hospital.

If you are waiting for a deceased donor, you may get the call telling you to come to the hospital for a transplant at any time during the day or night. Tell the transplant unit more or less how long it will take you to get to the hospital (keep in mind the time of day, the distance and the amount of traffic).

Don't waste time; go directly to the hospital.



When I get to the hospital

Don't be surprised if other patients have also been called to come in at the same time as you. This is done in case the first patient is not right for the kidney or for the operation.

When you arrive at the hospital, there will be a lot of things going on. A number of routine tests and investigations will be done, including blood tests, an ECG (a test to measure the electrical activity of your heart) and chest x-ray.

A final very important blood test, called a final or repeat crossmatch, may be done. During this test your blood cells are mixed with those of the donor. If your blood cells do not react to those of the donor, the crossmatch is negative and the transplant can go on. If your cells react to the donor cells, the crossmatch is positive, showing that the donor kidney is definitely going to be rejected quickly. If the laboratory already has a recent blood sample from you and if you have not received a blood

transfusion since your last blood sample was taken, it may not be necessary to do the repeat crossmatch.

Nurses and doctors will give you a complete physical examination, and if you have any infections or other medical conditions that could put you or your transplanted kidney at risk, your doctors may decide not to do your transplant operation at that time.

As soon as the tests are completed and your new kidney is ready, the transplant can begin.

You will be told when to come to the hospital – it could be one day before or even on the day of the operation.

If you are waiting for a deceased donor and you get a call from your transplant team, you must not eat or drink, except for taking heart or blood pressure medicines with a sip of water. Ask the transplant nurse or doctor who calls you which medicines you should take.

What happens while I am in theatre having my surgery

Whether you receive a kidney from a living donor or a deceased donor, the operation is the same.

Transplantation is performed under general anaesthetic. This is a combination of medicines that will put you in a deep sleep so that you will feel no pain, given by a specially trained doctor called an anaesthesiologist or anaesthetist. When the hospital staff bring you to the operating room area, the anaesthetist will put a drip up by putting a needle into a vein in your arm to get you ready for anaesthetic.

A nurse or doctor will insert a catheter into your bladder when you are under the anaesthetic, and it will stay in place for several days after the surgery. This is necessary to check your urine output after the transplantation.

The nursing staff will watch how much liquid you take in against how much liquid leaves your body.

A cut of about 20 centimetres long is made in your lower abdomen. The donor kidney, which has been removed with its artery, vein and ureter still attached to it, is placed in your lower abdomen, in a little hollow space just outside the abdominal cavity, called the iliac fossa, and its artery and vein are attached to the nearby blood vessels. Finally, the ureter is linked to the bladder.

The cut is then closed, first on the inside, using stitches, and then on the outside with stitches or staples, which are removed about 10 days after the operation.

The operation usually takes about three to four hours.

About the donor's operation

Transplantation operations are now highly successful procedures and it is seen as routine surgical practice for treating kidney failure.

Traditionally, the donor operation has been through a single cut of about 10 – 18cm, but live donation is more and more done by laparoscopic surgery (a modern method in which operations in the belly are performed through small cuts (usually 0.5 – 1.5cm long).

This new method gives less pain and scarring, and speeds up the donor's healing process. As more donor operations are done by laparoscopy, making the operation far less large-scale than before, more people have become live donors.

The donor stays in hospital for about as long as the recipient does. However, with laparoscopic surgery or other new methods that use smaller cuts, it may be possible for the donor to leave the hospital in two to three days.

01 | After my operation

Immediately after

When you awake after your surgery, you may feel groggy or dazed from the anaesthetic and you may be tender and sore around the cut. You may even feel surprisingly well.

The nurses will ask you to breathe deeply and to cough. This is important to clear your lungs.

From the recovery area in theatre you will probably be moved to the transplant unit.

The nurses will ask for another chest x-ray and ECG and will also do blood tests. They will also measure your urine and check your blood pressure, pulse, oxygen saturation levels (check the levels of oxygen in your blood) and temperature regularly.

02 | My visitors

Once you are settled in your room, the nurses will allow you to get visitors when you are fully awake and your condition is stable.

Some patients may need to stay in the intensive care unit (ICU) for a time so that the medical team can monitor their heart and lung functions more closely. Visiting hours in the ICU are limited.

For many patients and their family members, the filling of the urine bag is a welcome sign.



03 | Controlling my pain

You will be able to give yourself pain medicine directly into your drip (IV) through a device called a patient-controlled analgesia (PCA) pump. If you feel pain, simply push the button. Do not worry about taking too much pain medicine; it is important that you are not in pain so that you can begin to move comfortably as soon as possible.

As soon as you can eat food, you will be given pain-relieving medicine by mouth.

04 | Getting up and about after your operation

It is important for your health and recovery to get up and move around as soon as you can.

Exercise will help prevent pneumonia (lung infection) and blood clots and will help your bowel work. A physiotherapist will visit you after your operation to start a programme that is focused on preventing:

- Lung collapse
- Muscle atrophy (wasting away of your muscles), joint stiffness and lower blood circulation that could form clots in the blood vessels
- Swelling, slow wound healing and other major complications.

What I can expect to happen the days after my operation

Other medicines I will need after surgery

Immediately after your surgery, you will begin to take anti-rejection and other medicines like antibiotics. Some of these will be given through your drip and others will be given by mouth.

By the first evening, the nurses may begin to teach you about your medicines, especially those you will take when you go home. It is important to start taking note and learning early on what medicines you are taking and why you are taking them.

Measuring and monitoring

The nurses will continue to measure your blood pressure and other vital signs (pulse, temperature and oxygen saturation levels) frequently as well as measure your urine output every hour.

Getting moving

You must do the deep-breathing exercises your physiotherapist has shown you. Don't forget to cough. When in bed, turn every one to two hours. You may be given an oxygen mask for the first day. With each day you will become more active, and you should walk the halls of the transplant unit at least three times a day once you are allowed to get out of bed.

My drip may be left in place for a few days

Your drip may be left in place for quite a few days to give fluids, take blood samples and give you medicines. You will continue to learn about your medicines and how to care for yourself when you go home.

Looking after my incision (operation site/cut)

The incision will most likely be covered with a plaster right after surgery, and you may have a drainage tube in place. The incision itself will be sore and the area around it will be numb for several months until the nerves heal. The nurses will show you how to care for your incision.

Doctors will take out any stitches or staples when your incision has healed. Follow your doctor's orders about caring for the healed wound and don't try to take off any plasters unless your doctor has told you to do so.

Getting food in

You will begin eating on the second or third day after your transplant, depending on your recovery. This will mostly be in a semi-liquid form and then they will bring in more solid food as your bowels begin to function normally. Your nurses will ask you about your stomach and whether you have had a bowel movement. If you don't have a bowel movement by the second or third day, the nurses may give you medicine to help you have a bowel movement (laxative).

My catheter will be removed

The nurses will take out the catheter from two to seven days after the transplant. Once it is taken out, you must empty your bladder regularly, whether you feel like going or not. This is very important to help the bladder heal properly.

I may need to stay in hospital longer

Some patients may have to stay in hospital longer if complications come up after the transplant.

These may include:

- The new kidney has acute tubular necrosis (ATN) (where the tubule cells of the kidney are damaged) or there is delayed graft function (DGF) where the transplanted kidney doesn't function immediately after being transplanted

- They require added anti-rejection medicines
- They have a fever
- They are having trouble emptying their bladder completely
- They have complications or other medical problems that may or may not be related to the transplant.

It is very important to stick to all treatment as not taking your medicines properly may cause chronic kidney rejection (when your body's immune system rejects your new kidney, which destroys the transplanted tissue) and failure and result in your transplant being unsuccessful.

Going home

If there are no complications, most patients go home about eight to ten days after their operation. You are ready to go home if:

- You have no fever
- You have had a bowel movement
- You are able to eat, drink and take your medicines
- Your creatinine is dropping, which means your transplanted kidney is working well
- Your incision looks good or is getting better on antibiotics.

By the time you are ready to go home, you should be able to set up your own medicines and know why, how and when to take them.

If my transplanted kidney does not work

The most common cause of delayed graft function (where the transplanted kidney doesn't work immediately after being transplanted) is acute tubular necrosis or ATN – where the tubule cells of the kidney are damaged.

There is no specific treatment for ATN other than avoiding fluid overload and controlling potassium, calcium and phosphate levels. Some immunosuppressant medicines are harmful to the kidney and may be replaced by other, less damaging medicines during this period. It may also be necessary in severe cases where the transplanted kidney does not work, to put you on dialysis for a time until the transplanted kidney starts functioning well enough.

Delayed graft function can, in most cases, be healed.

Other reasons why your transplanted kidney will not work properly soon after your transplant include:

- Low blood pressure
- A blood clot in the kidney's artery, vein or ureter
- Certain anti-rejection medicines
- Rejection.

Each of these problems can, in most cases, be treated.

Care after my transplantation

Taking care to reduce my risk of rejection

Once you have had a transplant, the goal of your treatment is to prevent your body rejecting your new kidney. Rejection is the body's natural process to protect itself from anything foreign.

When rejection is picked up and treated early, it can be controlled. However, all anti-rejection treatments available today work by suppressing (holding back) the body's immune system, making your body less able to fight off diseases caused by intruders such as bacteria, viruses and fungi. The immune system can no longer effectively see and destroy abnormal cells that can lead to tumours or cancer.

Self-monitoring is very important to be aware of warning signs of rejection. Keep a personal health diary, perform self-tests to monitor whether any of the signs (listed on page 44) are present and write down the results.

Also make sure you never miss a set up blood test or clinic visit, where a range of tests may be done to monitor the working of your new kidney.

In some cases, even with the most aggressive treatment, it is not possible to turn around the rejection process, and the patient goes back on dialysis treatment. Another transplant is usually possible. Unless the transplanted kidney is causing health problems, it will not be removed.

You can lower your risk of rejection

It is important to find the right balance between protecting the transplanted organ and protecting the health of the rest of the body. To lower your risk, you can:

- Take your anti-rejection medicines as prescribed
- Learn what the early warning signs of rejection are
- Attend all clinic and doctor visits that are set up for you.

Keeping infections at bay

Transplant patients are at greater risk of infections caused by viruses, bacteria and fungi. You can take steps to lessen your risk of getting infections, but if necessary, the right medicines will be prescribed to fight any infections you do get.

Because of your high risk of infections, you should try to avoid fast foods after your transplant because they are full of bacteria, which can cause serious food poisoning.



After you go home, YOU become the most important member of the transplant team.

Warning signs of rejection

If you get any of these symptoms, call your doctor or the transplant team immediately:

- Flu-like symptoms
- Drop in the amount of urine output
- Fever of over 37.8 °C
- Pain or burning during urination
- Fluid retention, seen in fast weight gain
- Dark, bloody or bad-smelling urine or swelling of your ankles
- Dark or bloody stools
- Higher blood pressure
- Pain or redness in the area of your surgery

I may get diabetes after my transplant

New onset diabetes mellitus (NODAT) can happen as a side effect of some of the immunosuppressive medicines given to transplant patients. Your doctor may change your medicines and doses to lower your risk while on immunosuppressants.

You may get counselling about the importance of lifestyle changes including weight control, the right diet and following a sensible exercise programme.

Your glucose levels will be monitored on an ongoing basis after transplantation. If you do develop new onset diabetes mellitus (NODAT), your condition will be managed with oral anti-diabetic medicines. But about 40% of patients may in the end need to change to insulin therapy.

My life after transplantation

After you go home, YOU become the most important member of the transplant team.

It's important for you to know the name of each medicine you take, the dose, its side effects, when to take it, as well as how to prepare it.

You must be able to list the signs and symptoms of rejection and infection and describe the ways of preventing them.

Some of the things you should know when you go home after transplantation

- Things you need to have at home
- How to care for your incision

- How to care for your hair and skin – remember the importance of sunscreen lotions and hats when outdoors
- How to care for your eyes and teeth
- Good nutrition and weight management
- Getting active and staying healthy
- Driving and work
- How the operation may affect your sexuality
- Dealing with your emotions
- Travel and holidays
- Staying away from smoking, alcohol and non-prescribed medicine
- Clinic visits.

The role of my family members or friends

Family members or friends can first choose to be a donor if you need a transplant operation.

They can also help you in different ways before and after the operation. When you get the call to come to the hospital for the transplantation, you can make sure you have one or a few family members or friends on standby to drive you or go with you to the hospital. After you have been admitted, they can bring you any items you may need during your stay in hospital and visit you once it is allowed after your operation, to give very necessary emotional support.

Once you can go home from hospital, they can drive you home again because you will not be allowed to drive until the doctor says it is okay to do so.

In the early stages after surgery, they can possibly help you at home in any way necessary, like helping you get used to your medicine and exercise schedule and take you for follow-up tests and clinic visits.

Family members and friends can continue to give emotional support and to get you help if necessary for depression if you have complications after the transplant, or if your body rejects your new kidney and you have to go back to dialysis.

How I can promote organ donation

To become an organ donor, a person has to register as a donor. Registering is free and there will be no cost to their family after their death. Visit the Organ Donor Foundation's website at www.odf.org.za to register.

Becoming a living donor means you have to be committed and willing to donate, well-matched with the patient and in good health.

Sources:

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Organ Transplant
Information System
(OTIS) (Roche)

www.odf.org.za

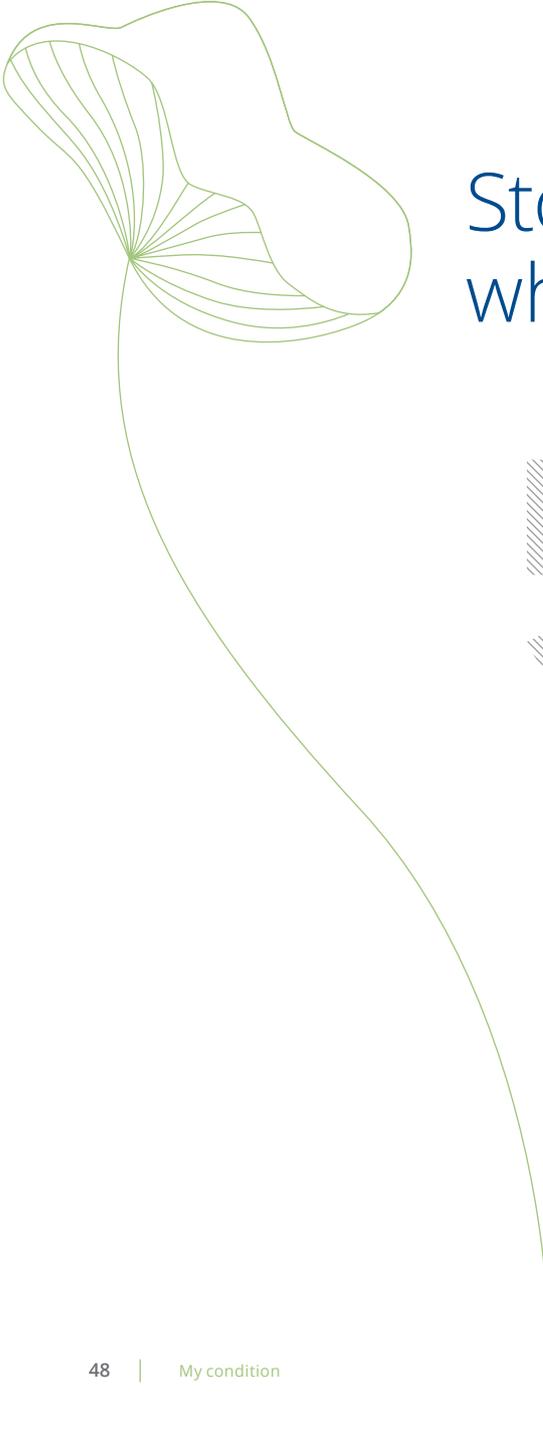


PERSEVERANCE

I will always find a way and a way will always find me.

~ Charles F. Glassman





Stories from other people who have had transplants



Facing the possibility of a kidney transplant can be scary. It can help to calm your fears by knowing that many people and their families are enjoying happier, fuller lives after a successful transplant.

Here are a few of their stories...

Transplant is the best thing that's ever happened to me – Tevin (13)

When Tevin was nine years old he started complaining of joint pain. "We ignored it," says his mom Tess. "We didn't take it seriously, thinking he was just trying to get out of school. But when the pain didn't go away we took him to the doctor."

The doctor found a high level of inflammation after blood tests, and prescribed some medicine. But after two rounds of medicine, hospitalisation and many tests, Tevin still wasn't better. Eventually a urine test showed that Tevin had kidney failure.

"We had to be so careful with his diet," says Tess. "He could only have one litre of water a day, including the fluid in his food. At one time he stopped urinating altogether." This restriction (limitation) was especially difficult for an active young boy. And, at his age, he didn't fully understand the strain his body was under. Sometimes he was so thirsty he would secretly drink water.

When Tevin's kidneys failed he began dialysis. "I can honestly say dialysis was the worst time of his life," says Tess. "It was a total change for Tevin. He went from being a normal, active child who could eat almost anything and swim whenever he wanted, to suddenly not being able to have any foods containing potassium, like bananas or chocolates. He couldn't swim any longer because we feared infection of the catheter in his tummy. He couldn't even bath, and this was very difficult for a child to bear."

Tevin's sudden decline and peritoneal dialysis were very difficult for the whole family. Eventually an infection in his belly meant he had to change to haemodialysis. "This was even more difficult, as we had to go to the hospital three times a week. I had no control over the treatment, and even more discipline was necessary at home," remembers Tess.

Then in 2006, doctors confirmed Tevin's glomerulonephritis (inflammation of the membrane tissue in the kidney that serves as a filter) was not active, and the risk wasn't as high as it was before. Tevin went onto a donor list. "Eight months later, at 4 am, we got a call to say there was a kidney for Tevin. At first I was highly irritated to be woken up in the middle of the night, then I realised what the caller was saying and I just screamed with joy – we were all in tears! We woke Tevin up at 5 am and told him there was going to be no school that day. Instead we were going to the hospital to get a new kidney. We had no doubt that the transplant was going to be a success, we were very sure. My child just cried: thank you, thank you!" says Tess.

Since his surgery five years ago, Tevin has been a different child. He can eat, swim and play just like all his friends. "Swimming is the love of his life; and this transplant is the best thing that's ever happened to him and to us," says Tess. "When people meet him they can't believe he's had a transplant, he's so 'normal'."

A new kidney saved my life – Kutlwano (4)

“He was ill from birth, but we didn’t realise immediately that it was kidney disease,” says his mom Lorraine. Kutlwano was at first misdiagnosed and treated for bronchial pneumonia (infection of the lungs). “His urine wasn’t coming out normally, and there was water on his lungs,” she remembers. It was only when Kutlwano was one year and two months old that doctors realised he had kidney failure.

Congenital nephrotic syndrome is linked with severe loss of protein and is quite rare. The symptoms include generalised swelling, anaemia, failure to grow,

In many cases this condition can be deadly, as transplants can only be done when babies weigh more than 10kg.

Kutlwano was very small and needed long-lasting dialysis, which was very difficult. Unfortunately Lorraine was not able to donate her kidney to her son as she has high blood pressure.

He was on a transplant list for over a year before a kidney donor was found.

But in December 2009, the family was overjoyed to hear that he could have a transplant. “After the surgery Kutlwano was so much better. He was so much happier and



After the surgery Kutlwano was so much better. He was so much happier and was really well for the first time in his life

bone disease – which is complicated by low calcium, poor appetite, and delayed developmental milestones.

was really well for the first time in his life,” Lorraine says. Kutlwano is looking forward to starting at crèche soon.

My mom gave me the gift of life, again – Albe (9)

Albe was diagnosed with polycystic kidneys (when cystic growths appear in the kidneys) and other complications at birth. “We kept track of his kidney function and in those first few years there were no problems,” says his mother Natasha. But his kidney function deteriorated, and by the age of seven, Albe showed signs of being very tired. “He had some blood tests, and we were notified that he needed a transplant immediately,” says Natasha. In two weeks, Albe’s kidney function had halved. “We thought we still had six months to a year before we had to think about a transplant; it was a big shock emotionally,” she says.

Right away Natasha and her husband, Albert, were tested to measure if their tissue matched as donors. “Testing



An hour after the operation the change was remarkable. He was flushed pink with the healthy new blood. That's something I will never forget – he was literally a new child.

was the worst day of my life," says Natasha. "The decision about whether our child lived or died was out of our hands, and we were just waiting to hear a yes or no that would decide our futures." In addition to the blood tests and scans that are used to check whether someone can be a donor, the test includes how the donor would cope physically with only one kidney. Luckily Natasha was a match and Albe got one of his mother's kidneys.

"People think being a donor is very painful and very dramatic," says Natasha, "But it's not at all. The worst part was the needle – and the waiting."

"We were very blessed," she says. She describes how yellow and pale Albe's skin was before the operation. "An hour after the operation the change was remarkable. He was flushed pink with the healthy new blood. That's something I will never forget – he was literally a new child."

Albe has now lived one year with his new kidney and he's a happy and active boy. "He'd always been a lot smaller than friends of the same age, but now he's growing about a centimetre a month, it's incredible!" she laughs. "I think our biggest accomplishment was handling Albe as normally as possible, we never treated him as ill," she says.

The first thing Albe wanted after his operation was a peanut butter sandwich, which he'd longed for, but had never been able to have. "Everything was new and bright and exciting. His sense of taste was better than before, he didn't feel sick and he had a new energy and excitement for life," says Natasha.

Natasha welcomes communication from other mothers in similar situations. If you would like to contact her, please email her at: Natashag@autotec.co.za

The gift of life: My organ transplant story – Andre Murphy (53)

“I was 21 when cystic growths appeared in the kidneys, which meant that I had to inject myself with insulin twice a day and watch my diet. But I did not control my diet well for the first five years,” admits Andre.

By the time Andre reached his 40s, he had 50 percent kidney function. “Three years ago my wife, Marcelle, and I were on holiday when I started getting more intense daily headaches. I had dark circles around my eyes and was constantly tired,” says Andre. Back in Johannesburg Andre had some blood tests: “My specialist called to say that my kidneys were drastically compromised and that I needed to meet him in ICU immediately.”

Andre’s kidneys were no longer functioning and he had to begin dialysis. “The two weeks I spent in ICU made me evaluate what’s really important in life,” he says.

“Four-hour dialysis sessions three times a week were very tiring, but the support I received from family, friends and colleagues kept me going,” says Andre. “When I was 49 my doctor suggested a simultaneous kidney and pancreas transplant, but the cut-off age for this operation is 45. He was persistent and I made a strong case as I was very fit, my heart was in good shape and my health was well-controlled.”

Andre was approved for transplant and then began the anxious wait for a donor. “I was at the office when I got a call to say it was time, there was a match for me. My wife and I met at the Donald Gordon Transplant Centre with a mix of emotions: fear, excitement and gratitude. I thanked God for this miracle which was about to take place in my life.”

“I had only been on dialysis for six months, which is very short compared to the many friends I made at the dialysis centre, who have waited many years. The feelings were so mixed as we knew that someone had died and in turn, was giving me a new life. We continue to pray for my donor’s family and are forever grateful,” says Andre.

Although there were times when Andre felt low, he has an incredibly positive attitude, and he feels this made all the difference through the difficult times. “I just wanted to get up and start living a fuller life again,” he says. It has been three years since the transplant, and the Murphys’s lives are forever changed. “I live a healthy lifestyle and see my specialist once a month to ensure that we keep my very precious organs healthy. No more dialysis, toxicity, diabetes, or insulin – what a blessing.”

I am grateful every day for this miracle – Manfred Becker (60)

“I had a routine medical check-up when I took out an insurance policy some years ago,” says Mannie. The tests showed some blood in his urine, but it didn’t seem anything to worry about, although Mannie started taking medicine for high blood pressure.



Four-hour dialysis sessions three times a week were very tiring, but the support I received from family, friends and colleagues kept me going.

After eight years of living and feeling well, Mannie wanted a second opinion about what he’d been told might be some scarring on his kidneys. This time he was told his blood pressure and cholesterol were too high and needed further treatment. He continued having regular check-ups two or three times a year.

But a few months after one of these check-ups, all was not well: “I broke out in a skin rash and blisters all over my body, and I was extremely tired all the time,” remembers Mannie. “But I went to see a dermatologist – I didn’t associate these symptoms with my kidneys.”

“Six months later I was at work when I started to feel very bad, so I went to my house doctor with what I thought was flu. My blood pressure was 240/220 so my doctor called for my latest blood test results. When my specialist saw them he told me to come to the hospital immediately. He and his team were waiting at the doors to rush me to ICU. In minutes I was semi-conscious and connected to a dialysis machine,” says Mannie. Mannie was told both kidneys had collapsed and he would have to be on dialysis for the rest of his life, or until he could have a transplant.

During dialysis, which Mannie had three times a week for three hours, he says he just worked, ate, and mainly slept. Although Mannie has a wife and three grown-up sons who all offered their kidneys, he decided he did not want them to take any chances with their own health, so he applied for a donor organ. "I was told it could take anywhere from two months to the more likely two to three years," he says.

"One night six years ago, my specialist called me at home at 11:30 pm to say there was a kidney available for me. I got such a shock, I dropped the phone and cried for at least an hour!" says Mannie.

"Early the next morning I was admitted to a private, isolated ward in ICU. I couldn't believe what was about to happen. I felt nervous thinking about whether I would survive the ordeal, and also happy that I had been given this wonderful gift of life.

A few hours later I was wheeled into theatre and saw two nurses rushing by with a container on a trolley – my kidney had arrived."

When he got home, Mannie says his wife had disinfected the whole house. "She looked after me like a newborn baby!" Mannie could not go out to public places

It is really wonderful being part of the world today.

for at least two months, and his visitors had to wear masks. But he believes this and the support of his loving family was a big part of his successful recovery.

Although Mannie has had a few complications, including drug-induced diabetes, he lives every day with an appreciation of the second chance he's been given. "It is really wonderful being part of the world today," he says.

All the patients whose stories are featured here wish to express their sincere gratitude and appreciation to their doctors, Dr Errol Gottlich and Dr Roger Phillips.

Andre and Murphy's offer their support and personal experiences if you are awaiting a transplant or have had one already. Email: marcelle.murphy@telkomsa.net





LOVE

Write it on your heart that every
day is the best day in the year.

~ Ralph Waldo Emerson



Linked conditions

Diabetes, how I must manage it and what the effects of diabetes are

What diabetes is

In people with diabetes, the pancreas does not produce enough insulin, or the body does not respond to insulin in the way that it should. Because insulin is the hormone that controls how the body uses blood sugar (glucose) for energy, the body no longer responds correctly to glucose that is absorbed from food, it does not make glucose correctly for itself, and it does not use the glucose that is available in the bloodstream correctly.

This results in abnormal blood sugar levels – too high after eating and too low in between meals. Both high and low blood sugar levels cause illness.

Some conditions that are caused by diabetes include:

- Kidney disease and in the end, kidney failure
- Eye disease and blindness
- Heart attacks and strokes, and blockage of arteries in the legs and other parts of the body
- Damage to nerves, causing loss of sensation, pain and abnormal function of the blood vessels, bladder and digestive tract
- Skin damage, sores and ulcers (especially of the legs and feet)
- More likely to get infection.

Why it's important to keep my blood glucose levels under control

Good glucose control can slow down the damage linked to diabetes. Using diet and medicine to control glucose, and keeping blood glucose levels as close to normal as possible, is necessary to slow down the development of these linked conditions listed on the previous page. Even if you have some of these conditions already, it is necessary to control your blood glucose as best you can to prevent them from getting worse and to help prevent other problems.

Diabetes can cause damage all over the body.

Controlling my blood glucose levels

Controlling blood glucose levels in end-stage renal disease and dialysis is challenging. Some of the reasons why it may be more difficult to control your blood glucose levels during dialysis are:

- Lower or no kidney function means that medicine usage may need to be more closely monitored and controlled
- Insulin may be the only medicine that can work, but because the kidneys do not excrete it properly, dosing may be complicated
- Because there are limits on the things you may eat and drink, it is difficult to control your blood glucose levels by eating right.
- Sugar concentrations in dialysis fluid may affect glucose control.

Tips to keep me healthy

You've most likely had diabetes for a while and therefore you are at greater risk for other conditions like eye problems, sores and ulcers. That is why it is important that you do everything you can to help control your diabetes and keep yourself healthy.

Know as much as you can about diabetes and how to control it

- You must be able to know low blood sugar (hypoglycaemia) and know what to do when it happens
- Your doctor can send you to a diabetes educator if you have not seen one already.

Follow your treatment plan

- Take all your medicine as prescribed – the correct dose at the correct time
- Follow your dialysis plan – don't miss sessions.

Follow your diet plan

- Monitor your blood sugar as prescribed
- Keep track of your sugar levels with a diary – it will help your doctor.

Have your eyes checked regularly by an ophthalmologist

- Ask your doctor how often this must be.

Look after your skin and feet

- Keep your feet clean and toe nails short
- Check your feet and toe nails every day for redness, cuts and scratches
- Wear properly-fitting shoes
- Don't walk barefoot.

Floss and brush your teeth every day

Follow a physical activity plan that is right for you

Don't neglect cuts, sores or ulcers on your skin

- Get advice if you damage yourself
- Keep any sores or ulcers that you may have clean and correctly dressed
- If necessary, seek advice from your healthcare professional or podiatrist (foot doctor).

Tell your doctor if you feel unwell

- If you have a fever
- If you experience anything new that worries you, for example dizziness, diarrhoea or trouble passing urine.

People with kidney disease are more likely to have other conditions linked to diabetes.



When you are
diagnosed with kidney
disease you still stay
who you are.





Me and
my thoughts

My emotional and mental needs

Starting dialysis can be a huge shock and a major upset in your life, whether you manage your dialysis at home, or have sessions at a hospital.

Some new limitations and having to fit the rest of your life around your dialysis can feel restrictive and depressing. You need to feel strong physically and mentally to tackle this phase of your treatment. That's why it's so important to care for your mind as well as your body.

And you don't have to do this alone. These days there is a lot of professional support available for people on dialysis – and talking to other people who are in a similar situation to you can help you feel supported and relieved that there are others who share your feelings and worries. Don't forget, you do not have to live with tiredness

and pain. If these are causing you to feel upset, angry or depressed, talk to your doctor.

It's important to reach out before you start to feel overwhelmed.

Why is communication important?

It is important to talk about your feelings and experiences with someone you trust. It lowers your feelings of loneliness as you connect with other people, which creates a sense of support and care. Through talking about your feelings you are better able to understand why you feel like you do and it gives you insight into why you respond like you do. Talking to other people on dialysis will also help you understand that your fears and worries are shared by many others.



You don't have to do this alone.

Why I must get counselling

“Having a long-term or chronic condition can upset your life in many ways. You will have physical challenges that will change your daily functioning, as well as emotional symptoms that would affect your coping mechanisms. There will also be extra changes and challenges affecting relationships, family, work, finances and friendships. These changes can cause stress, anxiety and anger. If they do, it is important to seek help. A trained and qualified counsellor can help you develop strategies to get back a sense of control. You will find that you are not alone, and you may learn some new tips on how to cope,” says Cassey Chambers of the South African Depression and Anxiety Group (SADAG).

Handling the stress

We all have stress in our lives – at work, in the traffic and at home. Having a chronic condition adds a lot to that stress. You may be worried about your condition and treatments, and worried about what the future holds and how you are going to cope. It is not unusual or abnormal to feel worried, anxious or depressed. The important thing is that you do not ignore those feelings or live with them without seeking help.

Get enough sleep

Experts recommend you get seven to eight hours worth of quality sleep every night.

Practise and use relaxation and stress management exercises

Sitting quietly, listening to music and reading can all help you to relax. There are other specific stress management techniques, including deep breathing, meditation, visualisation, self hypnosis and muscle relaxation. If you are interested in learning more about these techniques, there are various books available at the library or in the book shop and information on the internet. Alternatively, ask your healthcare provider or social worker to send you to someone who can explain more to you.

My support system

Share the load. Connect with others by talking openly to family, friends, support group members or professional counsellors.

Your healthcare providers

You have a network of healthcare providers who can explain your condition and treatments to you. If you are feeling very depressed or worried they can also refer you to other professionals and counsellors who can help you through the difficult times and help you to develop skills to cope better.

Your friends and family

Don't keep your feelings to yourself. Tell your family how you're feeling. They're probably also sharing some of the emotions that you are feeling. By talking about how you feel and what is worrying you can help to get things into the open. It helps to show everyone where they can help each other. This helps to avoid any conflict or misunderstandings and to find solutions to challenges.





Support groups

Getting together with people who are going through the same experiences as you are, and understanding how you feel, can be a great support and source of advice and inspiration. Ask your healthcare provider to send you to a support group, or talk to some of the other patients at the clinic. Perhaps you can form your own group of friends who meet regularly.

“Support groups are a crucial foundation for patients and their loved ones coping with a life changing condition like chronic kidney disease,” says Leonie Ackerman of the National Renal Care (NRC).

“Support groups allow those who share a common diagnosis to come together and share ideas, coping tips, and experiences, and most importantly, to exchange emotional support. Most support groups are facilitated by leaders who have personal experience with the disease and who have become advocates for others. The primary goal of most groups is to ensure that no one living with the disease or condition that the group serves ever has to feel alone again,” says Leonie.

In addition to providing important emotional support, support groups also serve as educators, disseminators of news about important advancements or therapies, and advocates on your behalf.

Calling for help

The South African Depression and Anxiety Group (SADAG) offers telephone counselling every day of the year, and can also send you to a professional therapist in your area, or give you the details of organisations that offer help and support groups, counselling centres and information. We hope you find this information valuable in reaching overall wellness.

SMS | 31393

Call | 0800 70 80 90/

0800 20 50 26

(toll-free, 8:00 to 20:00,
seven days a week)

www.sadag.co.za

Keeping busy

There are times when you will not feel up to doing things. However, doing a work activity, sport or hobby, especially if it involves interaction with other people, can help you to stay positive and motivated.

Fill up your diary. Keeping busy will help you feel focused, purposeful and motivated. But plan carefully. Only choose activities that you feel able to manage comfortably.

Prioritise by doing the most important tasks first, so you can fit in your treatments and necessary everyday tasks.

Learning more about my condition

The more you understand about your condition, the better able you will be to look after yourself, feel the best that you can, and avoid unexpected surprises. You need to understand your treatments, what you can and cannot eat and drink, and what support structures are available to you.

Use trusted and honest sources of information to find out more about kidney failure, dialysis, transplant and answer any questions you have.

Knowledge can be very empowering, and help you take control of your treatment.

Eating healthily

Follow your diet plan. Eating the wrong foods can make you feel unwell and may be dangerous to your health. Avoid alcohol.

Children living with chronic kidney disease

Children are in their formative years and are therefore quite vulnerable to how they will see, think and react to the typical loss and limitations kidney failure brings. This makes the role of parents and caregivers important in giving guidance and helping to protect the child from stress.

Children with kidney failure will experience more frequent doctor and hospital visits. Some of their treatments may be scary or painful and hospital stays can be frightening and lonely. They may feel “different” because their activities may be limited and their families often have to change how they live to accommodate the child. This in itself creates stress for the parents, family and caregivers.

The way children react to the diagnosis of kidney failure depends on several factors, including the child’s personality, the extent of the kidney failure, and their family. One big factor is the child’s developmental stage. Children’s understanding of illness and their coping strategies change as they grow older. That is why it is important that parents know and understand these developmental stages (stages a child goes through as they grow up) to be able to deal with their child’s mental reactions to their condition.

Dialysis isn’t easy for anyone, but children particularly find it difficult to cope with the trouble of constant treatments, differences in how they look, as well as limits in the things they can eat, how much outdoor activity they can do, and having to be more careful in every aspect of their lives. It’s really hard to be different to other kids.

“It’s important to teach our children to have confidence in themselves as well as give them crucial coping mechanisms to deal with adversity, whatever the situation,” says Cassey Chambers from the South African Depression and Anxiety Group (SADAG).

“Always encourage your child to speak about his or her feelings,” she advises.

Mothers of children on dialysis suggest trying to keep as normal a routine as possible, and create a happy, healthy environment for your child. It helps too if the rest of the family is supportive in their dietary choices, this can help reduce feelings of being deprived or excluded.



It's important to teach our children to have confidence in themselves as well as give them crucial coping mechanisms to deal with adversity, whatever the situation.

Toddlers and chronic kidney disease

Toddlers (children between the ages of one and three) are beginning to develop trust and an overall sense of security. Illness can interrupt this and may leave them feeling anxious and angry because their parents do not make the illness disappear. This may show itself in aggressive behaviour.

Toddlers generally have very little understanding of their condition. They experience pain, limitation of motion, and separation from parents as challenges to developing trust and security.

Parents can help by being there for painful procedures, staying with their children (when possible) during hospitalisations, holding, soothing and interacting with their toddler as much as possible.

Pre-school children and chronic kidney disease

Pre-school children are beginning to develop a sense of independence. They may understand what it means to get sick, but they may not understand the cause and nature of the condition. For example, they may believe that throwing up causes them to get sick, rather than the other way around.

Being in the hospital or getting used to medicine schedules can challenge the child's developing independence. The child may try to stop losing control over their life by testing boundaries set by their parents.

Setting well-defined boundaries is important to help the child. Being firm with things the child does not have a choice over. Never ask: "Do you want to take your medicine now?", because almost all children will say: "NO!" Rather offer choices, for example: "Which do you want to take first, the pink medicine or the purple?" or "Do you want to sit on my lap while you have your blood drawn or in the chair with me holding your hand?"



COURAGE

is knowing what not to fear.

~ Plato



Six and seven year-old children and chronic kidney disease

Children in this age group are developing a sense of mastery over their environment. They can describe reasons for illness, but these reasons may not be totally logical. Six and seven year-olds often have magical thinking and they bring this in to their reality. They may believe they caused their condition by thinking bad thoughts, hitting their brother, or by not eating their vegetables.

Parents can help by allowing their children to help in the management of their condition (with close adult control). They should also reassure their children that the condition is not their fault. Support and reassurance are very important.

Eight to twelve year-old children and chronic kidney disease

This age group is quite mixed in terms of development but generally they are more capable of understanding their condition and its treatment. However, it is important that they must not be expected to react as adults do.

They may feel left out when they miss school or activities with their peers. Giving more detailed explanations that the child can take in and understand would be advisable.

Parents may feel the need to protect their children by limiting them from activities with other children. This is a natural reaction, but it can get in the way of the child's independence and sense of mastery. Get information from your child's doctor about what your child can and can't do and use that

as guidance by supporting the child to take part in school and other activities.

These children do relate to others and reading what other children have to say about their experiences of kidney failure can make them feel less alone. Encourage your child to talk about what he or she feels and thinks. This will teach them how to start to control their emotions and take control of their lives.

Remember that children often show their unhappiness and anxiety by acting out – this is especially true for boys. Changes in behaviour can help to identify a child's emotional turmoil.

If you as a parent or caregiver feel unable to cope with, or you are unsure as how to deal with your child, it may help to talk to a clinical psychologist, to give further assistance.

My plan to take charge of my life

Today's date

What's bothering me?

What I need to do to help me take charge...

How does this make me feel?

Talk to:

To feel better, I want to be able to...

Find out this information:

I want to do this by...

I will ask these people for help...

My plan to take charge of my life

Adolescents living with chronic kidney disease

As an adolescent there are specific aspects of dealing with the problems of living with chronic kidney disease. We've included these in the following information. However, most of what has been talked about in the section for adults would apply to your age group, and should be thought about.



When you are diagnosed with kidney disease you still stay who you are.

Chronic kidney disease, identity and self-esteem

Your identity and the establishment of self-esteem

Simply put, identity and self-esteem is a sense of self – who am I". The development of identity and self-esteem is a major, if not the most important, developmental task of adolescence.

The self-concept is a combination of an individual's physical, emotional, social, intellectual and educational traits. The self-concept is also about who you are as a person. Self-esteem is the value you apply to yourself, such as asking questions like: "Am I special?", "Am I important?", "Am I a failure?" As an adolescent you will choose some personal traits that you value and use them to develop self-esteem.

Young people need to pass through psychosocial development during adolescence to have a realistic view of themselves. A task of this developmental process is to achieve a realistic and positive self-esteem.

Chronic conditions may have an effect on your self-esteem

Being chronically ill may make you more likely to be socially isolated and less involved in peer groups. As a result, you may spend more time alone or with your family. It is therefore important to continue with your relationships with your peers because this will help you to develop a positive self-esteem and also allow your peers to learn to accept you.

Parents have a big effect on an adolescent's self-esteem. Research has shown that there are three factors linked with good self-esteem in adolescents:

- 01 | Acceptance by parents
- 02 | Clearly defined boundary setting
- 03 | Parental respect for the adolescent and realistic allowance for freedom within the limits of the boundaries.

Show your motivation and determination

Parents and caregivers should be careful not to start to overprotect the adolescent due to the diagnosis of kidney failure, because this will indirectly create a message of "I am unable to look after myself". This in turn will affect the adolescent's self-esteem and independence.

It's important to understand that if you are diagnosed with kidney disease, you still stay who you are, although it may mean that you need to change and do things differently. Your motivation and willpower in showing your friends and family that you can go through hard times in a positive way will make them respect you more.

Your motivation and willpower will make your friends and family respect you more.

Be careful of allowing negative thinking about yourself to become a habit as this can lead to what is called learned helplessness. Learned helplessness is a condition where you believe that you are unable to influence your behaviour, thinking and feelings. Instead rather think: I can find solutions, I am able to cope, I am still the same likeable person.

Your motivation and willpower will make your friends and family respect you more.



Chronic kidney disease and your body image

Body image is the changing awareness of one's body – how it looks, feels, and moves.

It is formed by awareness, emotions and physical sensations. It is not static, but can change with your mood, physical experience and environment. As adolescents go through puberty, they experience important physical changes in their bodies. This means they are likely to experience big changes in body image. Body image is influenced strongly by self-esteem and self-evaluation.

An illness can influence the way you view your body

Losing weight or looking ill may create the idea that you are not attractive anymore or that friends do not want to be associated with you. This may become worse when people make negative comments about your body state. Remember that more people will be helpful towards you than the minority of peers that may make nasty comments. The reality however is that when you become ill, changes do happen. You can help work against the negativity by focusing on all your other positive traits.

Speak to your doctor about what to expect and how long body changes may last

If you need a transplant it is okay to ask questions about scarring and how to deal with it. A small scar that will fade is a small price to pay for one's health! A future boyfriend or girlfriend is not going to fall in love with a scar but with you. Young people are naturally more sensitive about their body image, but as you mature you will become more comfortable with your body. Accept that your physical traits are a given and that you cannot change certain things about your body.

As an adolescent, you still need to work towards building a positive body image for yourself. Body image is how you see your body in your own mind – your own internal view of how you look rather than your actual appearance. Therefore although your condition may affect your body, you still control what you think!

Chronic kidney disease and self-reliance

When you become an adolescent, you need to become more independent. We may call this being self-reliant, acting responsibly, as well as self-management of the disease where possible. Parents need to understand this process.

This could mean that as an older adolescent you may want to have some privacy when consulting with your doctor. It might also include looking at and talking about how your privacy at home will be respected. For parents of young people with a chronic condition, the difficulty lies in how to keep a management role while helping young people to independently manage their health. Parents may feel blamed for being overprotective when, from their view, they are simply doing their parental duties.

The development of self-management methods for adolescents with a chronic condition needs active involvement of both young people and their parents, with attention to the psychosocial world (mental and social world) of the young person. It would be good to begin with self-management because this will help you to stick to your treatment.

Self-management will also help you to get to self-reliance as an adolescent with kidney failure.

Chronic kidney disease, peer group and intimate relationships

As an adolescent you begin to develop peer relationships more independently. From this peer group of young people the adolescent has to identify and choose someone who will become a significant other. This relationship may develop into an intimate relationship. This is necessary because it allows someone to explore relationships and know who they are attracted to.

Your condition may affect the way you view your body. Help yourself by focusing on all your other positive traits.



Having a chronic condition like kidney failure may influence the adolescent's focus to develop these special relationships. It is however important to encourage these relationships because relationships are important for support and integration into society. It will therefore help with future developments such as work, becoming independent, developing loyalty in relationships and to set structure to one's life.

Relationships with your peer group give you the chance to talk about your emotions and to learn to become aware of your emotions and how to control them.

My plan to take charge of my life

Today's date

What's bothering me?

What I need to do to help me take charge...

How does this make me feel?

Talk to:

To feel better, I want to be able to...

Find out this information:

I want to do this by...

I will ask these people for help...

My plan to take charge of my life

Notes

A series of horizontal dotted lines for writing notes.

Taking charge
of your life.





Me and
my lifestyle

Taking charge of my life

How long you can live with your kidney condition depends on your age, other health problems, and how involved you become in your care. Most people with early chronic kidney disease will never have kidney failure. Others will reach kidney failure and may live for decades with dialysis or kidney transplants.

There are major advances in today's healthcare. We have better medicines, know more about how to slow down kidney failure, and have updated dialysis machines. But the most important factor is still the person who has the condition. Research shows that people who become partners in their care live longer. So, ask questions, and with your doctor and care team look at the best way for you to help manage your disease.

Planning ahead

You may be spending a lot of time on dialysis and at the clinic. This will mean that you need to make sacrifices and perhaps have less time to do some of the things that you used to do. By planning ahead, you can make sure that you are ready for activities that you have to do and make time for the things that you want to do.

Planning meals ahead of time can make sure you have food available at home, so that you eat the right foods and don't skip meals. Some things to think about when planning ahead:

- When are you going to the clinic?
- How are you going to get there and get home?
- How long will you spend there?
- When are you going to work?
- Are there deadlines for specific projects?
- When can you fit that work in?
- When will you go shopping?
- When are you going to eat?
- What are you going to eat?
- What are some of the things that you really enjoy doing?
- When will you fit those in?
- When are you going to spend time with friends and family?
- When are you going to plan some physical activity and time for hobbies?

Looking after my bones

I need to take special care of my bones

Our kidneys play an important role in maintaining healthy bones. As a patient with chronic kidney disease, you may be at risk of bone disease or 'renal osteodystrophy'.

When the kidneys fail, they can't maintain the proper levels of calcium and phosphorus in the blood, leading to abnormal bone hormone levels. The result is that your body cannot take up calcium from food, so it "borrows" the calcium it needs from the body's biggest calcium storage depot: your bones, making them brittle (weak) and likely to break.

Preventing injury – safety around the house

Having brittle bones makes you prone to fractures (when the bone breaks).

Prevent injury with these guidelines:

- Remove loose rugs around the house
- Cover slippery floors – especially in the bathroom
- Get rid of any low furniture
- Use anti-slip devices where possible
- Wear good quality, stable, non-slip shoes
- Ask your doctor about hip pads if you have osteoporosis as these can help prevent hip fractures if you have a fall
- **Eat well:** Eat a healthy and balanced diet right for renal failure (turn to pages 82 to 90 for nutritional advice and get some tasty recipes on pages 91 to 100)
- Prevent osteoporosis by regularly monitoring your blood calcium and phosphate levels, and taking steps to correct bone disease due to your chronic kidney failure (secondary hyperparathyroidism)
- Take special care after haemodialysis, especially if you feel faint for a while. Ask a family member or friend to collect you and rest until you feel better.

What to do when injury happens

No matter how hard you try, you may at some point injure yourself. Here's what to do if this happens:

- If you are mobile get medical care at your GP or casualty unit
- If you are not mobile call an ambulance for help. Make sure you keep all important emergency telephone numbers on hand at all times.

It is important to have a MedicAlert bracelet so that medical staff can immediately get all your medical information, especially if you are unconscious after a fall. For application details, turn to the "Making sure everyone knows about my condition if an emergency arises" section of this book on page 114.

If you have fallen, make the necessary changes to prevent it happening again.

My daily eating and drinking

Good nutrition principles, limitation of fluid, regular physical activity and taking your medicine as prescribed are the foundation for greater wellbeing in patients with kidney conditions.

Because your kidneys are not working, your body is not getting rid of extra water and waste as it normally would do. So, in between dialysis sessions you need to be careful of how much fluid you take in and what type of foods you eat.

It is necessary that you meet with a dietitian, who will guide you on the dietary changes that you need to make and give you a detailed eating plan with a focus on the foods you need to cut down or stay away from.

The type of dialysis you are getting will affect which foods you can eat and which ones you should stay away from.

Limiting my fluid intake

When you have kidney failure, you are not able to pass urine and when you drink fluids, these fluids store in the body. The extra fluid in the body puts strain on especially your lungs and your heart.

Remember all foods that are fluids at room temperature hold water, for example drinks, soup, ice cream and jelly.

Many fruit and vegetables have a lot of water in them, for example pawpaw, peaches, oranges, nectarines, tomatoes, celery and grapes.

Stay away from salty foods that are likely to make you thirsty.

Dealing with thirst

Try sucking on an ice cube or ice chips (1 ice cube = 25 ml water), cold sliced fruit or sour sweets; or chew sports gum with citric acid, which may ease a dry mouth.

What I can and what I can't eat

Limiting my protein

Protein is necessary to maintain a healthy body and to prevent infection. However, breakdown products from proteins in the diet put an extra strain on the kidneys. In people with kidney disease, this may speed up the worsening of your kidney function.

Therefore, people with chronic kidney disease who are not on dialysis need to lower their protein intake. Dialysis will help to take out breakdown products of proteins and so, if you are getting dialysis regularly, you may have more protein in your diet again.

Sources of good quality protein include beef, pork, chicken and turkey, fish, and eggs.

Including healthy fats in my diet

Fats are necessary for health. They give energy and form building blocks of cells and hormones that control body function. However, there are different types of fat in foods and some are healthier than others. A healthy diet must have 'healthy' fats, but stay away from 'unhealthy' fats.

Healthy fats (polyunsaturated and monounsaturated fats) include omega-3 and omega-6 fats and are found in oily fish like salmon and sardines. Vegetable oils like sunflower oil and olive oil also contain healthy fats. Patients with chronic renal failure may eat more total fat than the general population (up to 35% of the total energy), but it must be healthy fats.

Less healthy fats (saturated fats) are found in red meat, poultry and dairy products. When including these in your diet, look for trimmed meat and 'low fat' or 'fat-free' options.

Fats that are very unhealthy (trans fatty acids) and that should be avoided are found in baked, fried and processed foods like chips, pies, confectionery (cakes and puddings) and fast foods.

Staying away from sodium

Sodium is found in salt and seasonings. Processed foods (for example canned and frozen foods, fast foods and snacks) often have lots of salt in them. Sodium causes your body to store water and makes your blood pressure higher, and you must stay away from it.

Look for 'low salt' or 'salt-free' options when choosing food or ingredients for making a meal. However, be careful of salt substitutes (replacements), because they may have potassium, which you must also stay away from.

Lowering my potassium intake

High potassium levels may have a bad effect on your heart. Because potassium levels may get higher in between dialysis sessions, it is important to lower the amount of potassium That you eat.

Potassium is a mineral found in fruit, vegetables and dairy products such as milk and yoghurt.

It is therefore important that potassium levels are watched closely. Generally people on dialysis can have one serving from the high-potassium group of foods, two servings from the medium-potassium group and two to three servings a day from the low-potassium group. Use the handy table on page 85 to guide you when choosing foods that have potassium.

Instead of salt and traditional seasonings, try these options to pack food full of flavour:

- Any fresh and dried herbs
- Spices: cinnamon, ginger, coriander, garlic, cayenne pepper, any pepper, curry powder, chillies, Tabasco, paprika
- Vinegar.

Potassium-containing foods

High potassium-containing fruits

Oranges, orange juice, kiwi fruits, watermelon, grapes, mango, melons, nectarines, prunes, prune juice, raisins, dried fruits, bananas, fresh peaches

NOTE: Stay away from star fruit altogether.

High potassium-containing vegetables

Unleached potatoes, including french fries, chips, sweet potatoes, parsnips.

Unleached carrots and beetroot tomatoes, tomato sauce, gem squash, butternut, avocado, cooked small leaf/ baby spinach and rhubarb.

Medium potassium-containing fruits

Apple, canned fruit cocktail, plums, canned pineapple/ apple/pear, grapefruit juice, pineapple juice.

Medium potassium-containing vegetables

Broccoli, carrots, celery, eggplant, mushrooms, mixed vegetables, hubbard pumpkin, leached potatoes, sweet potatoes, parsnips, carrots, beetroot, swiss chard spinach, boer pampoen / flat white pumpkin, asparagus, cauliflower, green beans and peas.

Low potassium-containing fruits:

Berries, cherries, (drained), pineapple, plums (canned), pears (fresh or canned), tangerine/ naartjie and cranberry juice, grape juice.

Low potassium-containing vegetables

Cabbage, cucumber, garlic, lettuce (all types), onions, corn, peppers (all types), radishes, watercress, frozen zucchini and yellow squash.

How to leach or lower the potassium in foods

Soaking high-potassium vegetables (especially potatoes, sweet potatoes, parsnips, and dried beans) in water may lower the potassium content. The procedure for soaking includes:

01 | Peel vegetables and slice thinly. Rinse well. Place in a bowl of warm water, using four times more water than vegetables: For one cup of vegetables use four cups of water. Soak for at least one hour. Drain and rinse again.

02 | The soaked vegetables can be cooked, mashed, scalloped, added to soup or stews or served fresh. If you are boiling the soaked vegetables, use four times more water and cook as usual.

03 | Dried beans should be cooked, chopped, and soaked, using the instructions above. Canned beans can be rinsed, chopped, rinsed again and then soaked.

Most fruit juices have a mixture of different juices – and some of these may be high in potassium. This is why fresh fruit is recommended instead of fruit juices. Plus fruit has fibre, and this can help to prevent constipation.

Talk to a dietitian
to help you choose
the best foods for
your condition.



Limiting foods that are high in phosphorus

High levels of phosphorus weaken your bones and you will more likely get bone disease and fractures. Foods that are high in phosphorus include dairy products (milk, cheese and yoghurt), beans, nuts and peanut butter, processed meats, soft drinks and eggs.

Phosphate is the most difficult molecule to take out when dialysing. It also gives the most problems when there is too much in your body, both short and long term. This is why it is important for you to stick to your prescription when on dialysis.

Phosphorus is a mineral that is in all foods but found in large amounts in milk (whole, low-fat or skim), cheese, nuts, dried beans and peas, meats, and soft drinks. Eating foods high in phosphorus will make

the blood phosphorus level higher. If your phosphorus levels stay high for long periods of time, calcium is taken from your bones as your body tries to balance the calcium/phosphate levels. This leads to weak and brittle bones. Other consequences of high phosphorous levels include joint or bone pain, red eyes and severe itching. Phosphorus may also enter soft tissue leading to the formation of hard or soft lumps (vascular calcification).

Keeping your phosphorus at a safe level will keep your bones healthy. To do this it's necessary to keep phosphorous intakes low and calcium high. However this is difficult because foods that have high levels of calcium such as milk and dairy products are also high in phosphorus. Also the high-protein recommendation may

also lead to high phosphorus intakes. To help control the high levels of phosphorus in your blood, you may need to chew phosphate binders with your meals and snacks as prescribed by your doctor. Taking extra calcium and active vitamin D are commonly prescribed to prevent complications such as metabolic bone disease.

Limit high-phosphorus foods to one portion a day, which is equivalent to:

- ½ cup of low-fat or fat-free milk or yoghurt
- 2 scoops of tub ice cream (not soft serve)
- 60g ricotta or cottage cheese.

Include food products low in phosphorus:

- Soft-tub margarine
- Rice or soya milk.

High phosphorous foods and drinks to avoid:

- Coffee creamer
- Cola-type drinks
- Beer
- Maas
- Soya products
- All nuts
- Organ meats
- Cakes and puddings
- Chocolate

Learning to read and understand food labels

Read labels carefully, and don't forget that what you eat can have a major impact on your condition.

Most foods that come in tins or packets have a label that tells you what the nutritional content of the food is. By understanding these labels you can make informed decisions about which foods you buy. Ask your dietitian to show you how to read and understand a food label.

Stop constipation

Due to fluid limitations, low fibre intake, and maybe the use of phosphate binders, you may battle with constipation. Eating a mixture of fruits and vegetables (in line with the dietary guidelines for dialysis), oats porridge, brown rice and brown bread could help. Including oil in your diet is also important.



Maintaining a healthy weight



Being overweight puts you at a higher risk of getting other medical problems, in addition to your kidney disease. Some of these include cardiovascular diseases (like high blood pressure, heart attack or stroke), diabetes, sleep disorders and painful joints and arthritis.

Maintaining a healthy weight is important, because people with chronic kidney disease are already at a higher risk of getting some of these conditions. Being overweight may also make other treatments for kidney disease, such as dialysis or transplant surgery more difficult.

Keeping an eye on the size of my waist

Your healthcare provider or dietitian can tell you what a healthy weight is for you. As a simple rule of thumb, measuring your waist circumference (all the way

around your waist) can tell you if you are at a high risk of weight-related problems.

- In men, waist circumference should be less than 102cm
- In women, waist circumference should be less than 88cm.

However, remember that if you are on peritoneal dialysis, the fluid in your abdomen will make your waist circumference bigger.

Losing weight if I am overweight

If you are overweight, you can help to improve and care for your health by losing weight. The general principles of losing weight are simple – you need to use up more energy than what you take in when you eat and drink. That means eating fewer calories and doing more exercise.

Eating less food and making healthy food choices.

Your dietitian will advise you on healthy food choices that are right for you.

The following tips may help you to cut down the amount of food that you eat during the day:

- Eat a good breakfast every day
- Drink a glass of water before your meal
- Eat slowly and chew each mouthful
- Use smaller plates, serve smaller portions and take smaller mouthfuls
- Eat at the table and not in front of the television
- Don't shop when you are hungry
- Try not to snack in between meals
- Eat smaller meals more frequently (for example five small meals during the day, instead of three large ones).

Short-term changes in my weight may be due to fluid retention

Because your kidneys are not working properly, your body will store water in between dialysis sessions, causing you to weigh more. Your weight after completing a dialysis session is called your dry weight.

Your dietitian will tell you how to control your fluid intake so that you maintain the best possible dry weight.

What you eat has an important impact on the management of your disease

Eating well is the key to giving your body the right kind of fuel – while not damaging necessary organs and functions. You need to keep your energy levels up, and feed your body and mind with the right kinds of foods while you are dealing with kidney failure and getting treatment. Eating badly and making unwise food choices gets in the way of your body's functioning and your response to treatment.

In the next section, we'll show you how you can eat well within the guidelines for people on dialysis

And you'll be pleased to know you don't need to feel deprived, we've included some healthy treats too. Enjoy!

The recipes have been planned based on the dietary guidelines for people on dialysis due to kidney failure. It is necessary to talk to a registered dietitian so that an individualised meal plan can be worked out for you in line

with specific protein, phosphorous, potassium, calcium and sodium recommendations. We have also included some note pages where you can write down your own favourite recipes and make notes about the protein, phosphorous, potassium, calcium and sodium content of your favourite foods.

Recipes



Nutritional values for each serving:

Energy Kilojoules (kJ):	603
Protein (g):	11.1
Total fat (g):	9.4
Saturated fat (g):	2.1
Monounsaturated fat (g):	5.0
Polyunsaturated fat (g):	1.1
Cholesterol (mg):	210
Carbohydrates (g):	3.3
Of which is sugars (g):	0
Fibre (g):	0.7
Sodium (mg):	104
Phosphorus (mg):	166
Potassium (mg):	340

Breakfasts

Artichoke and mushroom omelette (Serves 4)

Ingredients

- 4 large eggs
- 4 egg whites
- 1 tablespoon olive oil
- 1 punnet mushrooms (220g), raw, thinly sliced
- 2 artichoke globes, sliced
- Black pepper, freshly ground

Method

- 01** | Heat the olive oil in a large non-stick pan
- 02** | Beat together the eggs and egg whites and pour the egg mixture into the pan once the olive oil is warm
- 03** | Allow the omelette to cook through until it is opaque in colour and has started to bubble, then add the sliced artichoke globes and mushrooms
- 04** | Fold the omelette over and slice into four portion sizes (or alternatively make four individual omelettes)
- 05** | Season with freshly ground black pepper, serve and enjoy.

French toast topped with mixed berries (Serves 4)

Ingredients

- 4 slices rye bread
- 1 egg, beaten
- ¼ cup fat-free milk
- 10 large strawberries (250g), washed and sliced
- ¾ cup blueberries (140g), washed
- ½ teaspoon cinnamon

Method

- 01** | Mix the egg and milk, and then dip the slices of bread into the egg mixture
- 02** | Spray a saucepan with a non-stick spray and heat the saucepan on the stove
- 03** | When hot add the egg-soaked bread to the saucepan, and cook the bread slice until golden brown on both sides and cooked through
- 04** | Remove from the heat, and top each slice of French toast with the strawberries and blueberries
- 05** | Sprinkle with cinnamon and serve.



Nutritional values for each serving:

Energy Kilojoules (kJ):	548
Protein (g):	5.2
Total fat (g):	2.2
Saturated fat (g):	0.5
Monounsaturated fat (g):	0.6
Polyunsaturated fat (g):	0.5
Cholesterol (mg):	54
Carbohydrates (g):	21.6
Of which is sugars (g):	0
Fibre (g):	4.1
Sodium (mg):	201
Phosphorus (mg):	105
Potassium (mg):	233

Main meals and accompaniments

Saucy chutney and coriander chicken breasts (Serves 4)

Ingredients

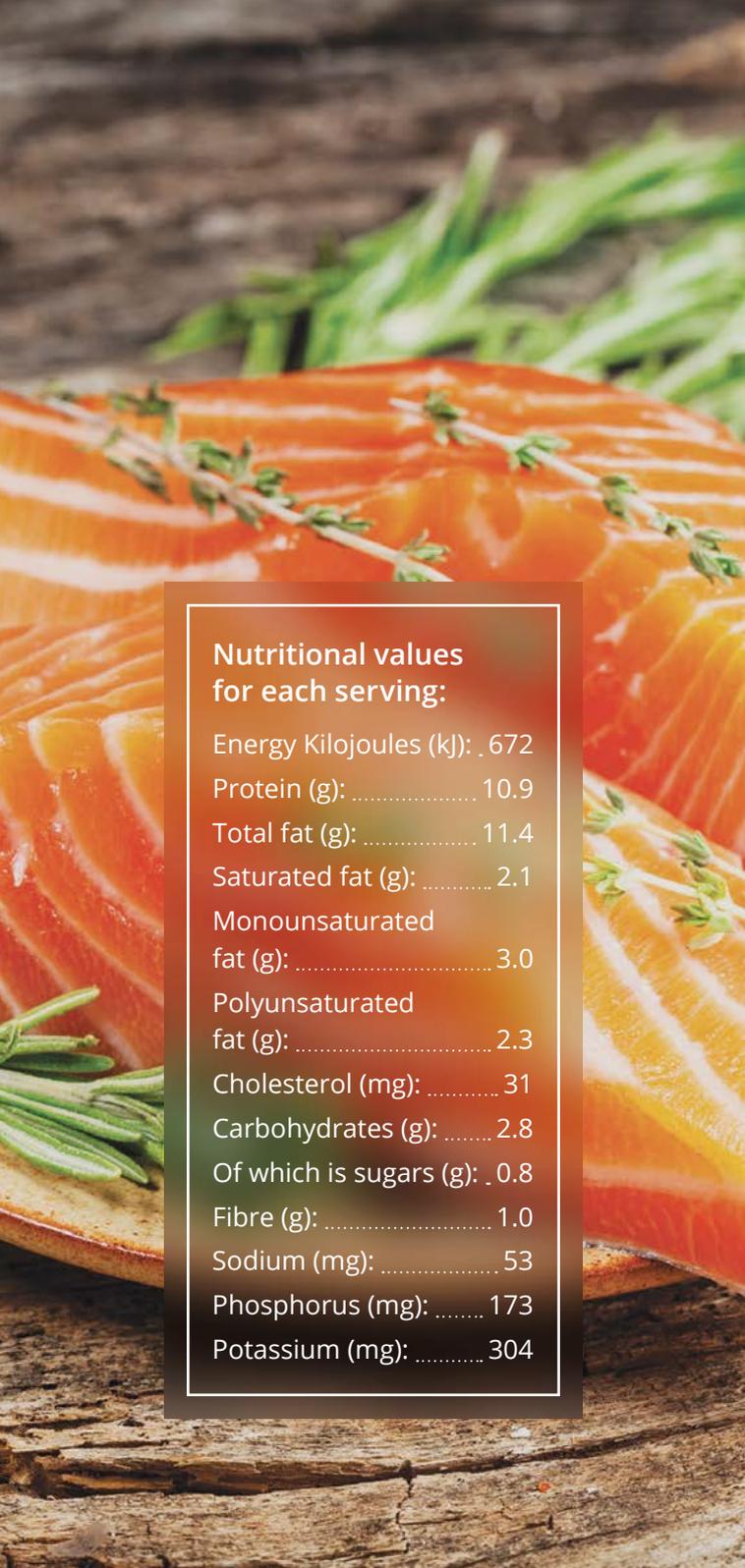
- 4 small chicken breasts, skinless (320g)
- 2 tablespoons fruit chutney
- 2 tablespoons low-fat mayonnaise
- 2 tablespoons lemon juice
- 2 garlic cloves, crushed
- 2 tablespoons balsamic vinegar
- 4 tablespoons coriander, finely chopped
- Black pepper, freshly ground

Method

- 01** | Preheat the oven to 180°C
- 02** | Place the chicken breasts into an oven dish
- 03** | Mix together the chutney, mayonnaise, lemon juice, garlic, and vinegar until well combined and then pour this mixture over the chicken breasts
- 04** | Bake the chicken breasts for 25 – 30 minutes, or until cooked through
- 05** | Remove the chicken from the oven, and serve garnished with chopped fresh coriander, and season with freshly ground black pepper.

Nutritional values for each serving:

Energy Kilojoules (kJ):	846
Protein (g):	23.4
Total fat (g):	8.6
Saturated fat (g):	2.1
Monounsaturated fat (g):	2.8
Polyunsaturated fat (g):	2.8
Cholesterol (mg):	74
Carbohydrates (g):	6.6
Of which is sugars (g):	3.9
Fibre (g):	0.1
Sodium (mg):	210
Phosphorus (mg):	160
Potassium (mg):	227



Nutritional values for each serving:

Energy Kilojoules (kJ):	672
Protein (g):	10.9
Total fat (g):	11.4
Saturated fat (g):	2.1
Monounsaturated fat (g):	3.0
Polyunsaturated fat (g):	2.3
Cholesterol (mg):	31
Carbohydrates (g):	2.8
Of which is sugars (g):	0.8
Fibre (g):	1.0
Sodium (mg):	53
Phosphorus (mg):	173
Potassium (mg):	304

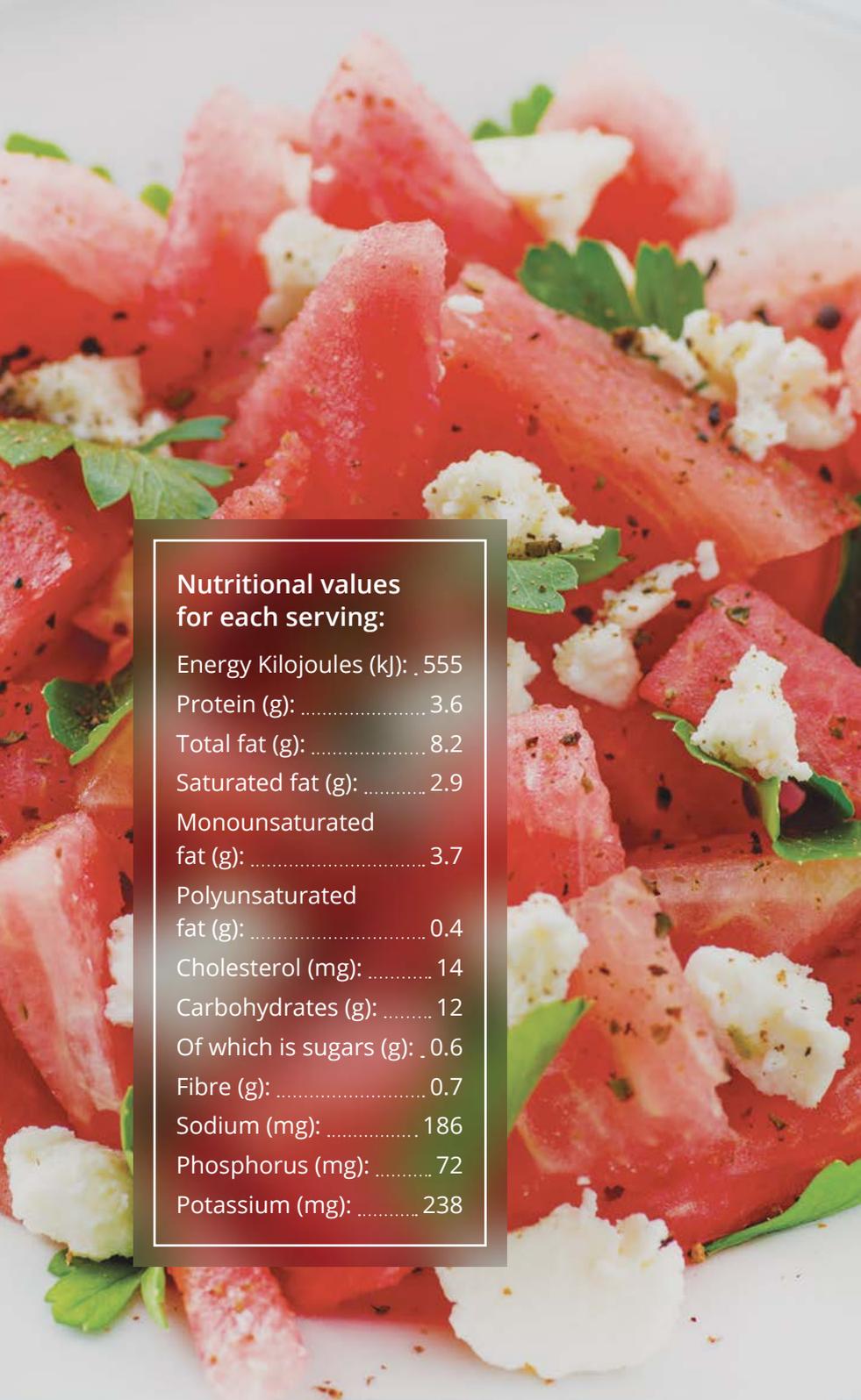
Cucumber-wrapped salmon bites (Serves 4)

Ingredients

- 1 medium cucumber (300g)
- 160g fresh salmon fillet, cut into bite-sized cubes
- 1 tablespoon sesame seed oil
- 2 tablespoons sesame seeds
- 2 teaspoons ginger, fresh, sliced
- 4 teaspoons balsamic vinegar
- Fresh coriander, to garnish

Method

- 01** | Rub the salmon with the sesame seed oil and then sprinkle over the sesame seeds
- 02** | Place them into a saucepan and sear on all sides, then remove from the heat and allow to cool
- 03** | Peel the cucumber and then use a vegetable peeler to shave long ribbons of cucumber
- 04** | Roll each cube of seared salmon in a cucumber ribbon and place onto an attractive serving plate
- 05** | Top each salmon bite with a slice of ginger, a drizzle with balsamic vinegar, then garnish with fresh coriander and serve.



Nutritional values for each serving:

Energy Kilojoules (kj):	555
Protein (g):	3.6
Total fat (g):	8.2
Saturated fat (g):	2.9
Monounsaturated fat (g):	3.7
Polyunsaturated fat (g):	0.4
Cholesterol (mg):	14
Carbohydrates (g):	12
Of which is sugars (g):	0.6
Fibre (g):	0.7
Sodium (mg):	186
Phosphorus (mg):	72
Potassium (mg):	238

Fresh watermelon and herb salad (Serves 4)

Ingredients

- 3 crowns watermelon (600g)
- 1 round feta cheese (60g)
- 1 bunch coriander, fresh
- 1 bunch basil, fresh
- 1 tablespoon olive oil
- 1 tablespoon balsamic vinegar

Method

- 01** | Cut the watermelon into bite-size cubes
- 02** | Finely chop all of the herbs, and mix them with the watermelon cubes
- 03** | Drizzle over the olive oil and balsamic vinegar, and crumble over the round of feta cheese
- 04** | Serve and enjoy!

Lemon foil-baked fennel fish (Serves 4)

Ingredients

- 4 small hake fillets (400g)
- 1 cup fennel, thinly sliced (87g)
- 4 sprigs fennel fronds
- 1 medium red onion (120g), finely sliced
- 4 teaspoons olive oil
- 1 lemon, juice and zest
- 2 tablespoons balsamic vinegar
- Black pepper, freshly ground
- 4 sheets of foil, doubled

Method

- 01** | Place each hake fillet into its own sheet of foil, and fold the side of the foil up into a boat shape
- 02** | Top it with the finely sliced fennel bulb and red onion and scatter over some fennel fronds
- 03** | Divide the lemon juice, lemon zest and balsamic vinegar between the fish parcels, season with freshly ground black pepper, and crush together the foil at the top so that it forms an enclosed parcel
- 04** | Place onto a braai or into the oven to grill for 15 – 20 minutes or until the fish flakes easily
- 05** | Serve with a fresh green salad.

Nutritional values for each serving:

Energy Kilojoules (kJ):	765
Protein (g):	23.8
Total fat (g):	6.3
Saturated fat (g):	1.0
Monounsaturated fat (g):	3.9
Polyunsaturated fat (g):	1.0
Cholesterol (mg):	70
Carbohydrates (g):	4.6
Of which is sugars (g):	1.2
Fibre (g):	1.1
Sodium (mg):	121
Phosphorus (mg):	222
Potassium (mg):	401

Desserts

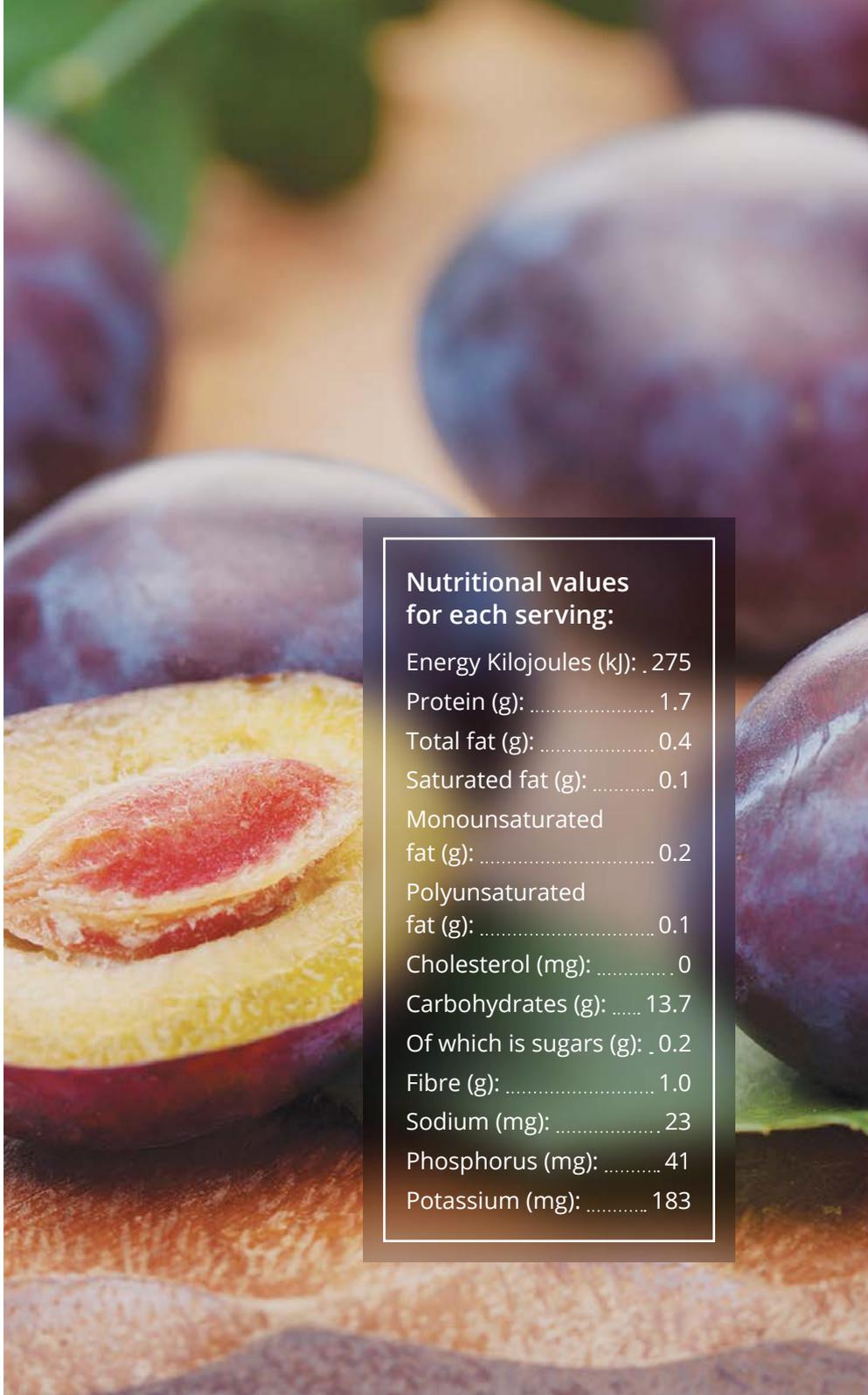
Cinnamon and spice plums (Serves 4)

Ingredients

- 4 plums (200g), halved and stoned
- 1 teaspoon cinnamon
- $\frac{3}{4}$ cup fresh apple juice
- 4 cloves
- 2 star anise
- 120 ml fat-free vanilla yoghurt

Method

- 01** | Preheat the oven to 180 °C
- 02** | Place the plums, facing down, in a baking dish, and pour over the apple juice, then add the cinnamon, cloves and star anise
- 03** | Place into the oven and bake until soft and fragrant, for about 30 – 35 minutes
- 04** | Remove from the oven and serve warm with a blob of fat-free vanilla yoghurt.



Nutritional values for each serving:

Energy Kilojoules (kJ):	. 275
Protein (g): 1.7
Total fat (g): 0.4
Saturated fat (g): 0.1
Monounsaturated fat (g): 0.2
Polyunsaturated fat (g): 0.1
Cholesterol (mg): 0
Carbohydrates (g): 13.7
Of which is sugars (g):	. 0.2
Fibre (g): 1.0
Sodium (mg): 23
Phosphorus (mg): 41
Potassium (mg): 183



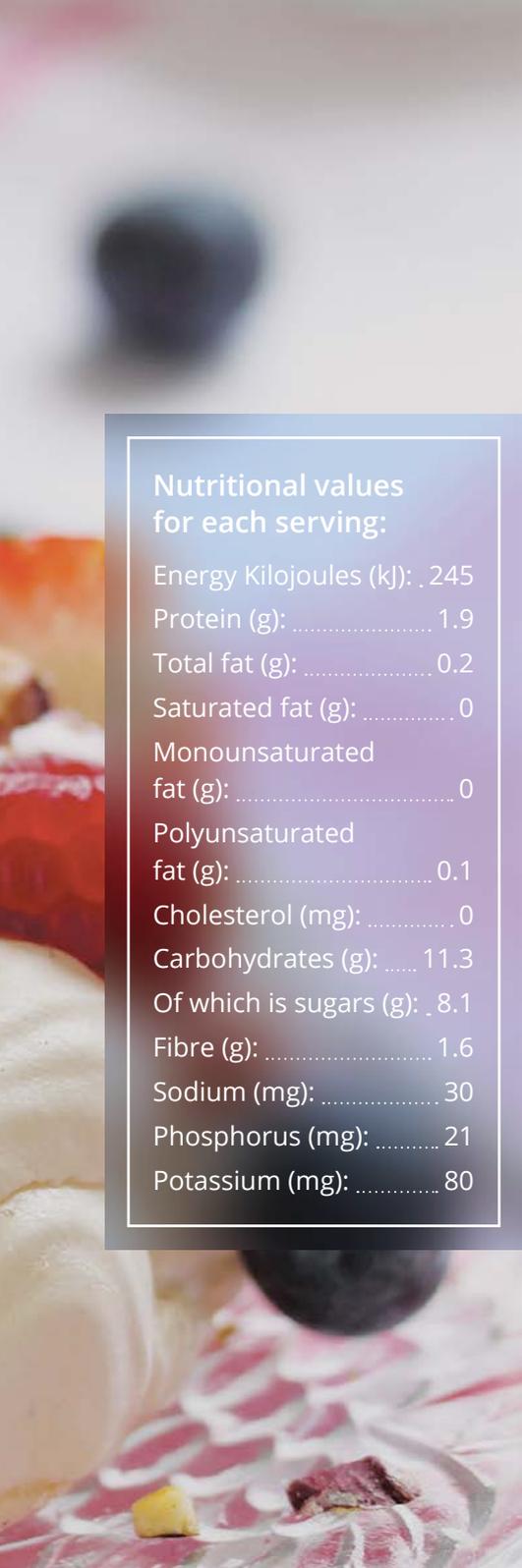
Raspberry and blackberry fruit pavlova (Serves 10 – 12)

Ingredients

- 2 egg whites
- ½ teaspoon vinegar
- 20ml cold water
- ½ teaspoon vanilla essence
- 1 ½ teaspoon corn flour
- 125ml castor sugar
- 25ml sucralose baking sweetener

Topping

- 4 tablespoons (50g) smooth, fat-free cottage cheese
- ½ cup fat-free vanilla yoghurt
- ½ vanilla pod
- 4 teaspoons sucralose baking sweetener
- 1 punnet fresh raspberries (220g)
- 1 punnet fresh blackberries (220g)
- 2 teaspoons lemon juice
- 2 tablespoons fresh mint, finely chopped



**Nutritional values
for each serving:**

Energy Kilojoules (kJ):	245
Protein (g):	1.9
Total fat (g):	0.2
Saturated fat (g):	0
Monounsaturated fat (g):	0
Polyunsaturated fat (g):	0.1
Cholesterol (mg):	0
Carbohydrates (g):	11.3
Of which is sugars (g):	8.1
Fibre (g):	1.6
Sodium (mg):	30
Phosphorus (mg):	21
Potassium (mg):	80

Method

- 01** | In a glass bowl beat the egg whites until stiff, then add the cold water and continue beating
- 02** | Gradually add the castor sugar to the egg whites
- 03** | Once all of the sugar has been added to the egg whites, add the sweetener
- 04** | Once the sweetener has been mixed in add the vinegar, corn flour and vanilla essence, and beat to combine all of the ingredients
- 05** | Spoon the mixture into a greased oven proof dish and bake for 25 – 30 minutes or until the Pavlova is cooked through and crispy
- 06** | Once the Pavlova has cooked, remove it from the oven and allow it to cool
- 07** | For the topping mix together the yoghurt, cottage cheese, and the remaining sweetener. Remove the seeds from the vanilla pod and add the pod to the yoghurt mixture
- 08** | Spread the yoghurt mixture so that it covers the entire rectangular section of the Pavlova
- 09** | Place the raspberries and blackberries on top of the yoghurt mixture and then sprinkle over the freshly chopped mint
- 10** | Roll the Pavlova lengthways, then place it onto an attractive serving dish, and slice just before serving.

Frozen apple and blueberry ice lollies (Serves 4)

Ingredients

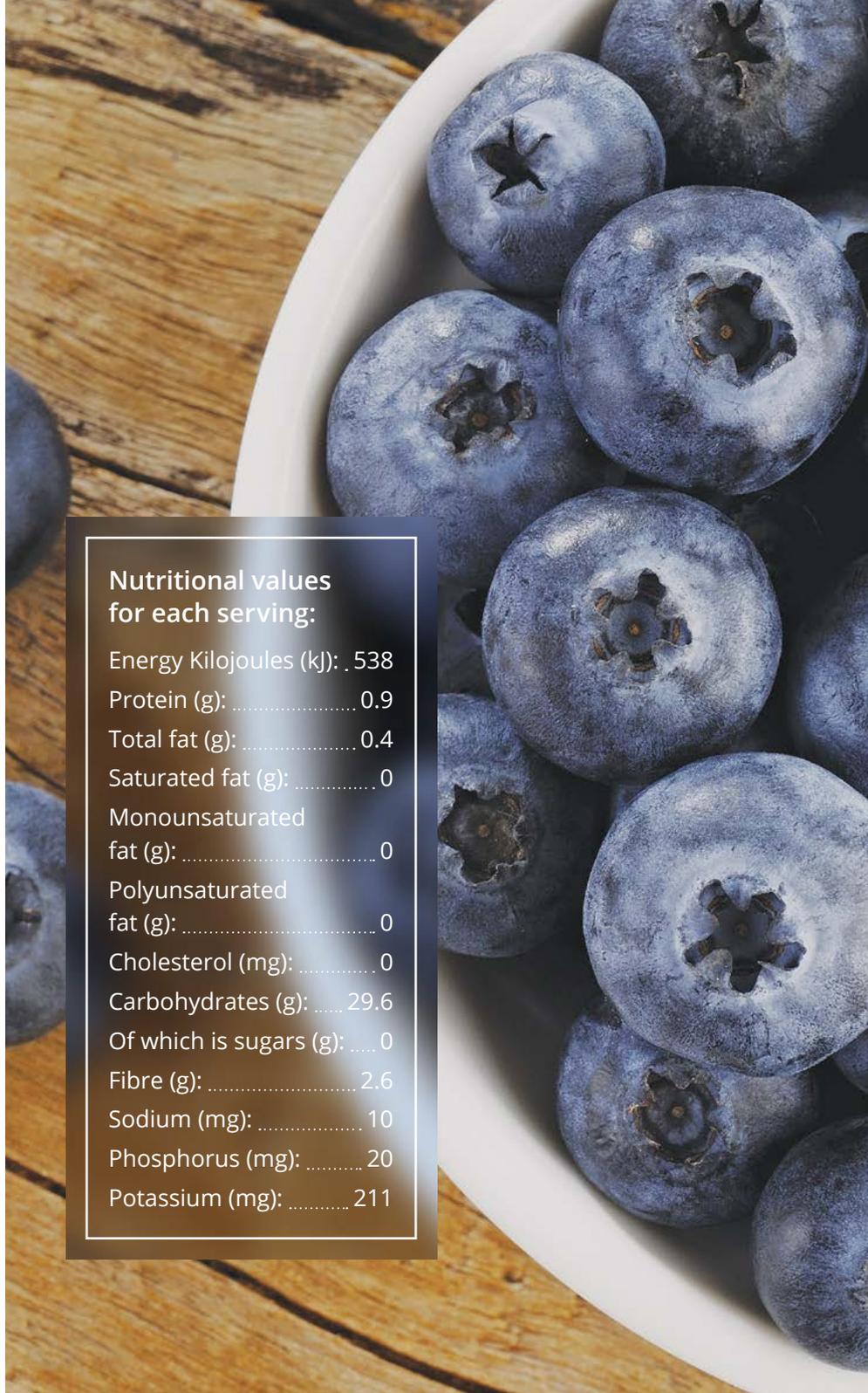
- 500ml apple juice
- 2 punnets frozen or fresh blueberries (440g)
- 4 ice lolly moulds

Method

- 01** | Place the apple juice and blueberries into the ice lolly moulds, put them into the freezer until frozen
- 02** | Serve and enjoy as a light and summery fruity treat.

Nutritional values for each serving:

Energy Kilojoules (kJ):	. 538
Protein (g): 0.9
Total fat (g): 0.4
Saturated fat (g): 0
Monounsaturated fat (g): 0
Polyunsaturated fat (g): 0
Cholesterol (mg): 0
Carbohydrates (g): 29.6
Of which is sugars (g): 0
Fibre (g): 2.6
Sodium (mg): 10
Phosphorus (mg): 20
Potassium (mg): 211



Notes

Pages to write down your own recipes and to make notes of the nutritional values of each serving

A series of horizontal dotted lines for writing notes.

Get some physical exercise

Benefits of physical exercise

- Improves physical fitness
- Lowers blood pressure
- Helps to prevent diabetes and cardiovascular disease
- Improves muscle strength
- Helps to strengthen bones and ease joint stiffness
- Helps you to lose weight (only if you stick to your diet as well!)
- Helps to improve mood and creates an improved sense of wellbeing.



Physical exercise is very important to help you keep as healthy as you can be.

Talk to your doctor before you start an exercise programme

If you have not been active, there are risks linked to starting an exercise programme. You need to choose activities that are right for you and the current state of your health.

Get advice from your doctor before starting or changing your exercise programme, especially if you:

- have high blood pressure, diabetes or cardiovascular disease
- have bone or joint disease
- have started or are changing your dialysis programme
- are taking any medicine or if you start new medicine
- are older than 40 years and have not been active for a while.

Exercising with a friend or in a group makes the activity more fun and will help to keep you motivated

Aim for 30 to 60 minutes of exercise on most days of the week. Choose a cardiovascular activity that you enjoy, for example walking, running, swimming or cycling. Start slowly and aim to step by step build up to about an hour of moderate intensity exercise five to seven days a week.

Moderate intensity means that you should not be uncomfortably out of breath while you are exercising.

Physical activity will improve your health even if you are overweight

However, if you want to lose weight, you must stick to your diet. Physical activity alone (without dietary changes) will not help you to get the weight loss results that you are hoping for. Having said that, once you have lost weight, physical activity is crucial to maintaining a healthier weight and preventing you from putting the weight back on.

Include some resistance training

An ideal exercise routine involves both cardiovascular (any exercise that gets your heart pumping at a high speed) and resistance training, which adds to muscle strength by working muscles against a weight, such as a dumbbell, barbell or special machines. It is important to note however, that wrong use of resistance equipment and bad technique

causes injuries. You should also concentrate on lighter weights and stay away from heavy lifting. A resistance training programme needs to be tailored specifically for you and it is best to get some advice from a qualified fitness trainer or biokineticist who will help you to get started at home or in the gym and show you how to use the equipment and do the exercises safely.

Whatever you choose, the important thing is to stay active!

Other things you can do to be more active

- Gardening and mowing the lawn
- Taking the stairs, rather than the lift
- Parking the car further from the door at the shops or the clinic
- Taking up a sport, such as tennis or bowls
- Walking with the dog
- Dancing.

Do not exercise if:

- You've recently had a medical procedure, for example catheter insertion, or AV fistula
- You've just started dialysis
- You're not feeling well or have a fever (see your doctor!)
- You feel chest pain, or are very out of breath when doing physical activity (see your doctor!)

Sticking to my treatment plan



Sticking to your dialysis schedule, your eating and drinking recommendations and taking your medicine as prescribed will help you to feel as well as you can feel and help to prevent getting other medical conditions.

Why it's important to stick to my treatment plan

It's very important to know why you have to take your medicine and also understand why you need to take it like you've been told to.

Why I must stick to my dialysis schedule

Missing dialysis sessions will allow waste products to build up in your body and make you feel ill

- Frequent dialysis sessions may be shorter depending on your doctor's dialysis prescription
- Frequent dialysis sessions are less likely to result in 'ups and downs' in how you feel from day to day
- Remember that it is your dialysis sessions that are keeping you alive
- If there is something that is worrying you, talk to your doctor or clinic sister
- Find out what your dialysis options are, so you can choose one that is right for you.

Why I must take all my medicine as prescribed

There may be times when it's right for you to stop taking a certain medicine. But only your doctor can make this decision, so always talk about your treatment with your team.

Reasons why I may not take my medicine

- **There are way too many medicines** – I only take the important ones
- **Ask your doctor or clinic sister about your medicines.** Make sure you understand what they are for. Ask your healthcare provider if they are still all necessary – maybe your medical condition has changed and your treatments can be looked at.

- **It's too difficult to remember when and how to take them**

It can get confusing when you have to take different medicines at different times.

Ask your healthcare provider or pharmacist to help you draw up a daily, weekly or monthly plan to help remind you when to take each of your medicines. Keep your plan in a place where you can check it easily.

Ask your pharmacist for a pill box that shows the day and time. Spend some time each morning or each week (with your plan as a reference) dividing up your medicine into the correct compartments in your pill box.

Ask your clinic sister or pharmacist to show you how to do this. You can

also ask a family member or friend to help by reminding you when to take your medicines.

- **I get side effects – my medicine makes me feel unwell**

All medicines can have side effects. It is very important to make sure that you are taking the medicine correctly – in the correct dose, the correct number of times a day, and at the correct times during the day (not too frequently).

Unless your doctor tells you to, never break tablets in half, chew tablets or open capsules to sprinkle the powder on your food.

If you are getting side effects that worry you, speak to your doctor or pharmacist. Don't stop taking your medicine without speaking to your doctor first.

- **I don't like injecting myself**

Injections can be unpleasant. Check with your clinic sister – make sure you are doing it the right way! Ask for tips on how to make the injections less uncomfortable, for example putting on an anaesthetic cream that numbs the area or massaging the skin.

- **I forget to take my medicine**

Keep your medicine in a place where you will see it. This could be next to your toothbrush or next to the kettle, for example.

You can also set reminders for yourself by setting the reminder alarm on your watch or cellphone or ask | a friend or family member to help you remember. It also helps to start a routine so that taking your medicines becomes automatic, like taking them with your meals.

- **I can't afford them**

Depending on your plan type and the type of medicine you're on, you may have to pay towards your medicine. If this is difficult for you and stops you taking your medicine as prescribed, please speak to your doctor or social worker.

There are often less expensive choices, or sometimes there are ways to get medicines on compassionate grounds or as a member in a medical study.



RESOLUTE

To accomplish great things we must not only act,
but also dream; not only plan, but also believe.

~ *Anatole France*



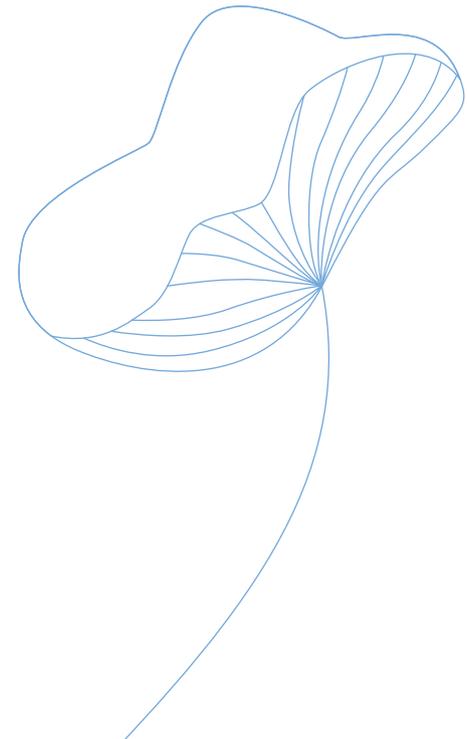
Taking medicine that is not prescribed for you

In chronic kidney disease, several medicines can be poisonous to the kidneys and you need to stay away from them or take them in lower doses. Among over-the-counter medicines, the following needs to be avoided or used with caution:

- Certain analgesics (painkillers): Aspirin; nonsteroidal anti-inflammatory medicines (NSAIDs, such as ibuprofen, [Motrin, for example])
- Fleets or phospho-soda enemas because of their high content of phosphorus content
- Laxatives and antacids containing magnesium and aluminum such as magnesium hydroxide (Milk of Magnesia) and famotidine (Mylanta)
- Ulcer medicine H2-receptor antagonists: cimetidine (Tagamet), ranitidine (Zantac), (decreased dosage with kidney disease)
- Decongestants such as pseudoephedrine (Sudafed) especially if you have high blood pressure
- Alka Seltzer, since this has large amounts of salt
- Herbal medicines

Always ask your doctor before you use over-the-counter medicine and tell the pharmacist about your kidney condition whenever you get medicine or advice.

If you have a condition such as diabetes, high blood pressure, or high cholesterol underlying your chronic kidney disease, take all medicines as prescribed and see your doctor as recommended for check-ups.



Tips for when I travel

The following information is to make life easier for you when you travel and tells you what to do and what to look out for when dialysing in renal units other than the one that you go to every week for dialysis.

Tips for haemodialysing locally

- Know your travel dates and where you are going to travel to.
 - Tell your kidney doctor and the manager of the renal unit of your travel plans.
 - The renal unit head (sister) will contact the relevant renal units in the area you are travelling to and book your dialysis for you.
 - **IMPORTANT:** Tell the sister when booking what time you would like to dialyse. Not all renal units operate at the same hours.
- The 'destination' renal unit will confirm the dates and times with you.
 - Make sure there is a specialist doctor on call at the 'destination unit' and what hospital services are available if you might need them.
 - Your regular renal unit sister will then communicate the following information to them:
 - Your medical history about your condition/disease
 - Your contact details
 - Your blood values
 - If you are on heparin or erythropoietin and what dosage
 - Your pump speed on the dialysis machine
 - Do you have a fistula, Perm-catheter or graft?
- Your dry weight – this is important to know, especially when they are taking fluid out of your body.
 - The size of your dialysis filter to prevent complications
 - Whether you have any complications or side effects during or after dialysis.
- Get a copy of the above details from your renal unit sister.

Make sure that you have the dialysis dates and times, contact details and directions to the units you will be visiting.
 - **IMPORTANT:** Erythropoietin must be stored in a cool place, if possible with an ice pack in a carrier bag.

Tips for haemodialysing when out of the country

- You must follow the same steps as above with the exception that you will need to have extra blood tests done at the 'destination' renal unit. They will do hepatitis A & B, HIV tests and take swabs off your body. Some 'destination' renal units will want these tests done before you get there.
 - Get as much information as you can on the renal unit and the way they do things.
 - Make sure there is a specialist doctor on call at the 'destination unit' and find out what hospital services are available if you might need them.
 - One of the important factors to keep in mind is costs; when abroad they charge per session and you must pay cash up front. You must then hand in these claims to your medical aid when you return home. Make sure that you keep all invoices and receipts and ask that these include as much information about your sessions as possible.
 - On your return you have 60 days in which to hand in your claims (or three months if you live outside the borders of South Africa.)
 - Discovery Health has an International Travel Benefit (ITB) form that you must complete and attach to your receipt. You must also include a copy of your air-ticket and of your passport with proof of entry and exit from the visited country. Fax these documents to Discovery Health on 0860 329 252.
- If you are on peritoneal dialysis make sure that there are support units at your destination in case you need any help.

You can plan your holiday according to your dialysis needs

Don't feel that you can't travel around South Africa because you need dialysis. There are professional organisations that can help make it possible for you and your family to travel without compromising on your health needs.



The more organised you are the easier it is to enjoy your holiday.

Speak to your dialysis sister who will advise you on how to organise dialysis in areas to which you would like to travel.

It is very important to make sure that all arrangements are made before you leave. These should include an up to date medical report, medical travel insurance, documentation required by airlines, arrangements to fund your required dialysis sessions and an adequate supply of medicine.

Making sure everyone
knows about my
condition in case of
an emergency.





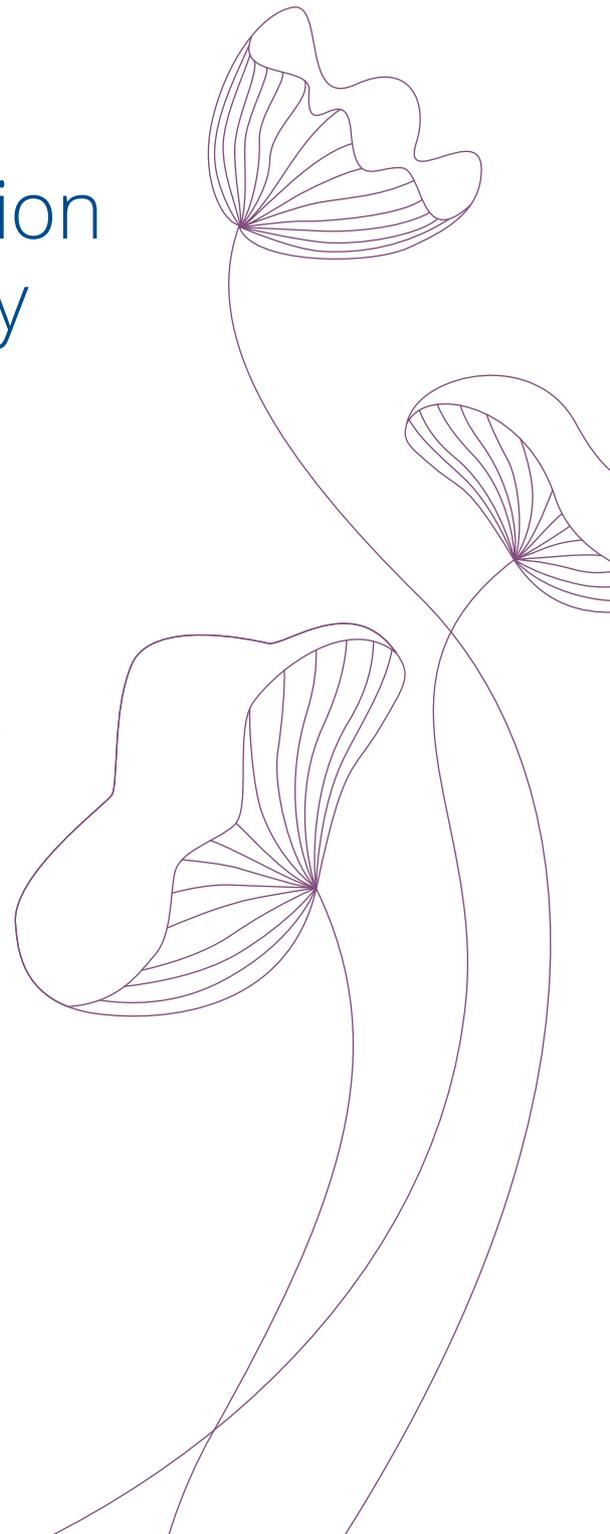
Me and my health
status and support

Making sure everyone knows about my condition in case of an emergency

When you live with a chronic condition and get ongoing treatment like dialysis, it's important to take steps to make sure you are properly taken care of in an emergency situation.

What you need is to be able to give a lot of very important medical information to the people first on the scene so they can act quickly, and act right.

MedicAlert is a non-profit organisation designed to give emergency medical staff immediate access to important medical information that could help them save your life.



How it works

When you become a member of MedicAlert all your medical information is recorded on a database. Your records will include your kidney disease, what kind of dialysis you are on, whether you had a kidney transplant, or are waiting for a donor organ, your blood type, any medicine you are on, allergies, any linked health issues or emergency needs, and the details of your close family members. You are given a unique membership number that a medical professional can use to get these records in an emergency situation.

Your membership number and very important information, like your chronic condition, are engraved on a bracelet or necklace that you should wear at all times.

Also engraved on your bracelet is the 24-hour phone number that paramedics or other emergency staff can call to get the detailed information on the database.

In an emergency

“A MedicAlert bracelet helps first responders to assess an emergency situation – it speaks for you when you cannot,” says Bruce Kimbrey, CEO of MedicAlert South Africa. “Everything a paramedic needs to know can be available with a phone call to our emergency room, which is staffed 24 hours a day by qualified personnel. All your medical details will be instantly on hand and can help first responders save your life.”

Bruce explains that medics are not allowed to look in your wallet or handbag for information about you, but with a unique membership number they can get everything they need to know to give you the best possible treatment, without wasting any valuable time.

MedicAlert is for you if...

MedicAlert is right for you as a dialysis patient, and if you:

- have any type of hidden medical condition, including co-morbidities like cardiovascular disease or diabetes
- have an allergy
- have had a kidney transplant, or any type of implant, pacemaker, heart valve or joint replacement
- take regular medicine
- would like your blood group to be recorded
- have a living will or wish to be an organ or body donor
- simply want someone else to know if you have been involved in an emergency.

The bracelet that speaks for you when you cannot

You may have seen the stainless steel MedicAlert bracelets engraved with the logo of the international MedicAlert Foundation and the rod of Asclepius emblem (a symbol of medicine and healing), this is the one most of us know. But there are a range of other options including necklaces, pendants and identity tags, in steel, sterling silver and gold, as well as Velcro wristbands to choose from. It's worth getting something you like, as it's very important that you wear your MedicAlert tag every day.

(See the options available on: <http://www.medicalert.co.za/under-products>.)



About joining MedicAlert:

Contact MedicAlert
Applications and
administration

Telephone
086 111 2979

Fax
021 425 6654

Postal Address
PO Box 4841,
Cape Town, 8000,
South Africa

Email
medicalert@
telkomsa.net

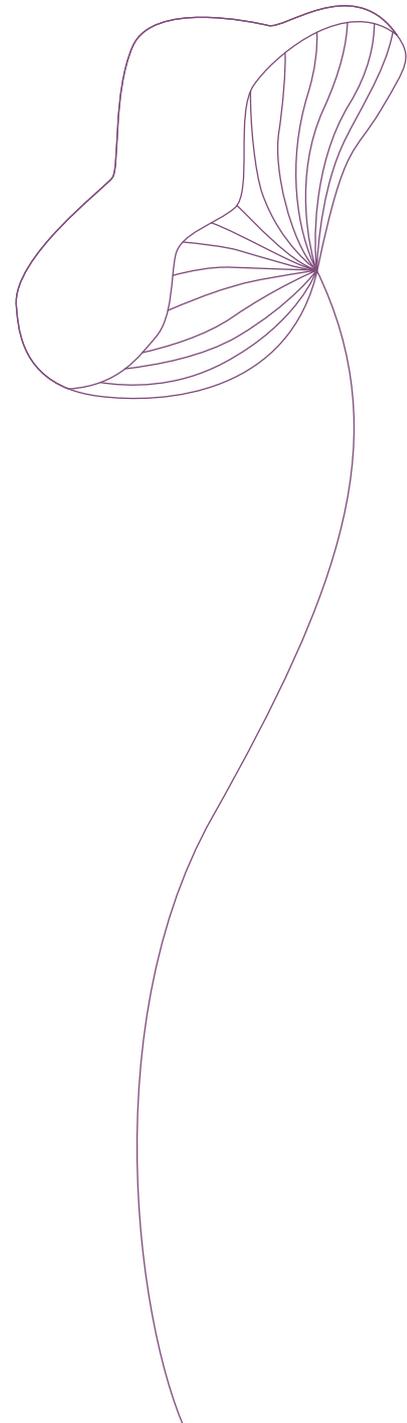
Emergency medical
information
084 194 4444
021 461 0000

Terms used by doctors and other medical staff

Understanding the meaning of these terms

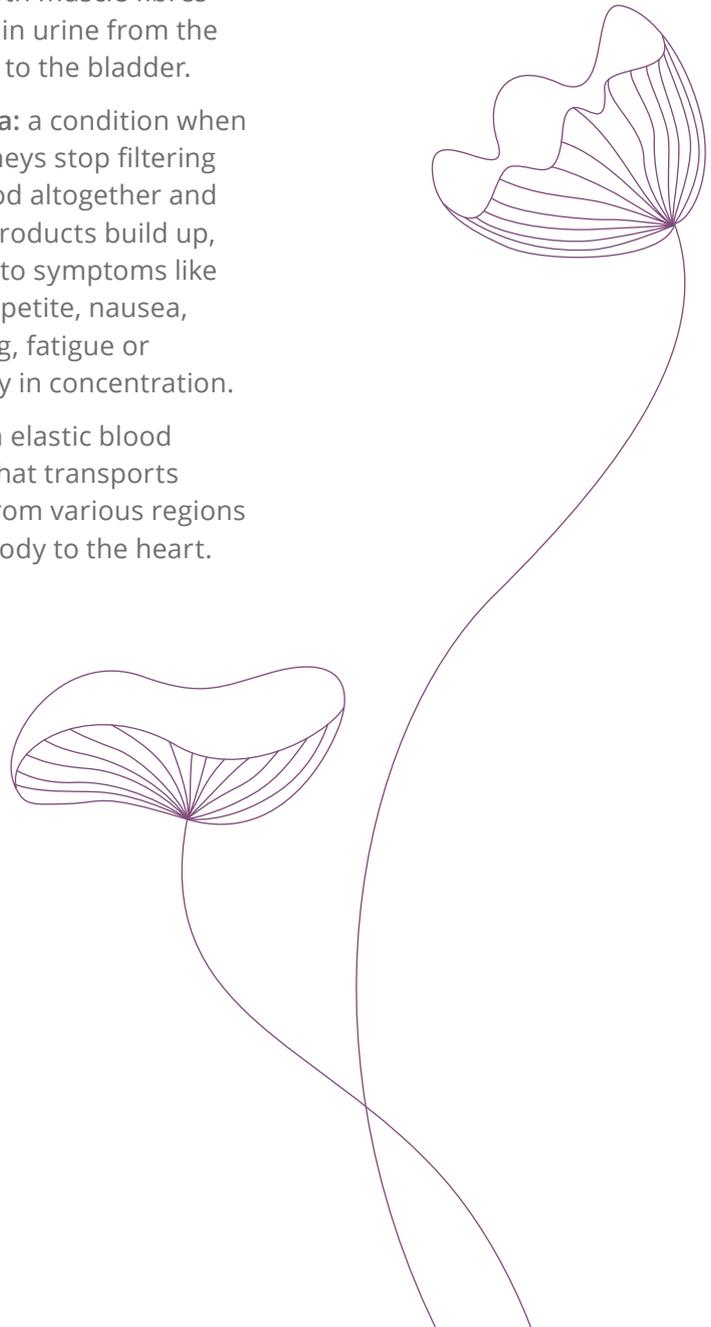
- **Abdominal cavity:** open space in your belly where they put a donor kidney during a transplant operation.
- **Anaemia:** the word means “lack of blood” and is a decrease in the normal number of red blood cells, or less than the normal quantity of haemoglobin in the blood.
- **Acute tubular necrosis (ATN):** When the internal structures of the kidney, mainly the tissues of the kidney tubule, become damaged or destroyed.
- **Antibodies:** Acting as the body’s army, antibodies are proteins generally found in the blood that pick up and destroy invaders, like bacteria and viruses.
- **Anaesthetic:** A specially trained doctor called an anaesthesiologist or anaesthetist will put you in a deep sleep so that you will feel no pain.
- **Artery:** is an elastic blood vessel that transports blood away from the heart.
- **AV fistula (or arterio-venous fistula):** is the access point for haemodialysis. The AV fistula is created internally and used for a long time. To create it, the surgeon joins the artery and vein under the skin, usually in your forearm.
- **Calcitriol:** a hormone that is converted from vitamin D by the kidneys, which maintains normal calcium levels for healthy bones.
- **Catheter:** A flexible tube inserted through a narrow opening into a body cavity.
- **Chest x-ray:** a test that shows the doctor what is going on inside your chest.

- **Chronic kidney rejection and failure:** Chronic rejection is a response of the patient's immune system and is usually not reversible. A patient's white blood cells make special proteins called antibodies that are made specifically to "latch onto" the transplanted organ. While attached to the organ, the antibodies alert the rest of the immune system to attack the organ slowly and continuously. Because chronic rejection is usually not reversible, the best defence is to prevent it from happening in the first place by taking the anti-rejection medicines exactly as prescribed.
- **Complications:** things that go wrong.
 - **Crossmatch:** During this test your blood cells are mixed with those of the donor. If your blood cells do not react to those of the donor, the crossmatch is negative and the transplant can go on. If your cells react to the donor cells, the crossmatch is positive, showing that the donor kidney is definitely going to be rejected.
 - **Cyst:** a closed sac-like structure – an abnormal pocket of fluid, like a blister – that contains liquid, gaseous, or semi-solid substances.
 - **Dialysis:** process of artificially removing waste products from the blood.
 - **Dialyser:** filter for haemodialysis machine.
 - **Donor:** a person who gives you a kidney.
 - **ECG:** is an electrocardiogram, which is a test that measures the electrical activity of the heart.



- **End-stage renal disease:** term for total chronic kidney failure.
- **Erythropoietin:** also called EPO. The kidneys normally produce this hormone that tells the body to produce red blood cells. If you do not have enough EPO, you get anaemia.
- **Feeling for thrill:** putting your finger on the AV fistula area to feel if blood is flowing through it.
- **Glomerulus:** A network of very small blood vessels (capillaries) that forms the basis of filtration of blood in the nephron.
- **Haemodialysis:** use of an external filter to clean the blood when the kidneys have failed. Blood is taken out of the body, passed through the filter and then put back into the body.
- **Hirsutism:** abnormal growth of hair.
- **Hypercholesterolaemia:** raised cholesterol levels.
- **Iliac fossa:** Small space in the abdomen where the donor kidney is placed.
- **Immunosuppressant:** medicines used to prevent activity of the immune system thereby preventing the rejection of a transplanted kidney.
- **Laparoscopic surgery:** a modern method in which operations in the belly are performed through small cuts (usually 0.5 – 1.5cm long).
- **Nephron:** The nephron is the functional unit of the kidney, responsible for the actual cleansing and filtration of the blood.
- **Nephrologist:** medical doctor who treats kidney problems.
- **Organ rejection:** when the body does not accept the transplanted kidney and the body's immune system attacks the organ.
- **Osteoporosis:** medical term for thinning of the bones where bone mineral density is lost, leading to a high risk for fractures (bone breaks).
- **Parathyroid gland:** four small glands in the neck that produce parathyroid hormone. The glands control the amount of calcium in the blood and within the bones.
- **Peritoneal cavity:** The peritoneal cavity is a fluid-filled gap between the walls of the abdomen (belly) and the organs in the abdomen.
- **Peritoneal dialysis:** uses the body's own abdominal cavity to clean the blood.
- **PCA pump:** patient-controlled analgesia pump which is connected to your drip (IV). If you feel pain, simply push the button and the pump releases pain medicine into your bloodstream which stops the pain very fast.

- **Peritoneum:** lining of the inside of the abdomen that is porous to waste products in the blood.
- **Peritonitis:** infection of the abdominal cavity.
- **Physiotherapist:** a healthcare professional who improves your physical condition by restoring normal body functions and prevents disability that may happen due to disease, trauma or injury.
- **Renal osteodystrophy:** bone disease.
- **Renin:** a hormone system that regulates blood pressure and water (fluid) balance.
- **Transplant:** Organ transplantation is the moving of an organ from one body to another or from a donor site on the patient's own body, for the purpose of replacing the recipient's damaged or absent organ.
- **Ureter:** a tube made of smooth muscle fibres that drain urine from the kidneys to the bladder.
- **Uraemia:** a condition when the kidneys stop filtering the blood altogether and waste products build up, leading to symptoms like poor appetite, nausea, vomiting, fatigue or difficulty in concentration.
- **Vein:** an elastic blood vessel that transports blood from various regions of the body to the heart.





ATTITUDE

is a little thing that makes a big difference.

~ *Winston S. Churchill*



Contact details and resources

Ask about specific support groups in your area at your hospital.
Or use this reference guide to services, help and information for kidney patients:

My healthcare providers

My GP

My kidney specialist

My dialysis clinic

My dialysis educator

My dietitian

Other

Local and international organisations

South Africa

- **National Kidney Foundation:**
www.nkf.co.za
- **SA Renal Society (for medical professionals):**
www.sa-renalociety.org
- **Renal Care Society of SA (A professional association for improving patient care):**
www.renalcaresoc.org
- **Cape Kidney Association:**
www.capekidney.org
- **KidneyBeanz (Supporting children with severe kidney disease):**
www.kidneybeanz.co.za

International

- **Renal Support Network:**
www.rsnhope.org
- **Beat Kidney Disease:**
Taking control of kidney disease the natural way:
www.beatkidneydisease.com
- **Davita: Health and medical information:**
www.davita.com
- **Renal Info Support and resources for people with kidney disease:**
www.renalinfo.com
- **Society for Kidney Support:**
www.societyforkidney support.org
- **Global Dialysis Empowerment for patients wanting to travel:**
www.globaldialysis.com
- **American Association of Kidney Patients:**
www.aakp.org
- **Nephkids Cyber support group:**
<http://cybernephrology.ualberta.ca/nephkids/>
- **Kidney Space Community of renal support network:**
www.kidneyspace.com
- **National Kidney Foundation (certain states, US):**
www.kidneyncf.org
- **Livestrong (The Lance Armstrong Foundation):**
www.livestrong.com/end-stage-kidney-disease
- **Facebook Support Group A kidney café & kidney disease awareness and discussion forum:**
www.facebook.com/group.php?gid=832518606657
- **Daily Strength Online support group:**
www.dailystrength.org/c/Dialysis/people

Support groups

Ask about specific support groups in your area at your hospital.

- Hospice Association
Telephone
021 531 2094 (Head office)
Website
www.hospicepalliativecaresa.co.za
For more information or the number of a Hospice in your area
- SA Depression and Anxiety Group (SADAG)
Website
www.sadag.co.za
To find a support group in your area call 011 262 6396
- Suicide crisis line
Telephone
0800 567 567
or sms to 31393

Linked organisations – for medical information

- National Kidney Foundation of South Africa
Telephone
011 447 2531
Website
www.nkf.co.za
- Diabetes SA
Telephone
086 111 3913
To get a number of a branch near you, visit the website
Website
www.diabetessa.co.za
- South African Heart Association
Telephone
021 931 8210
Website
www.saheart.org
- Organ Donor Foundation
Telephone
0800 22 66 11
Website
www.odf.org.za
- SAVES: Living Will Society
Telephone
031 266 8511
Website
www.livingwill.co.za

Medicine and poison information

- Medicine Information Centre (UCT)
Telephone
021 406 6829
Website
www.mic.uct.ac.za
- Poisons Information Centre (Red Cross Children's Hospital)
Telephone
021 689 5227
- Netcare Poison Centre
Telephone
0800 333 444
- Drug and Poison Information Centre (University of the Free State)
Telephone
082 491 0160

My appointments

Date

Time

Who the appointment is with

Address

What is the appointment about (check-up, dialysis, blood tests, etc)

What should I take with me (x-rays, blood results, etc.)

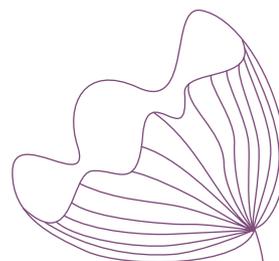
Note (do not eat before the appointment, someone must take and collect me, etc)

What questions should I ask my doctor?

No two people are alike. Asking questions is the best way to find out about your health. If you write down your questions and show the list to your doctor, you may be more likely to get them answered. Write down the answers, too – or have someone come along to help you remember the answers.

Sample questions

- What percent of kidney function do I have now?
- What is the cause of my kidney problem?
- What are my lab test results right now?
- What can I do to keep my kidneys working as long as possible?
- What treatment can I get for my symptoms? (List symptoms)
- What are the next steps for my treatment?
- Will I need dialysis or a transplant? If so, how long might it be until I get a donor kidney?



Choose to be
optimistic,
it feels better.

~ Dalai Lama XIV

