



# **Pre-dialysis** kidney care



# Contents



# Welcome to your renal care handbook



It's often only when our kidneys begin to fail that we realise the extent of their work.

The kidneys and how they work are a mystery to many of us. Their work is not as obvious as organs such as the heart or lungs, but the kidney's functions are no less important to sustaining life.

The major job of these powerful chemical factories is to remove waste products and excess fluid from our bodies through urine. The kidneys also produce hormones that affect how other organs work. Other hormones produced by the kidneys help control blood pressure and how the body uses calcium.

## THE KIDNEY'S FUNCTIONS INCLUDE:



controlling the production of red blood cells



removing waste products from the body



releasing hormones that control blood pressure



removing drugs from the body



producing a form of vitamin D that promotes strong, healthy bones



balancing the body's fluids

In this book you will find plenty of information about caring for your health as a chronic kidney disease patient – take out the messages that apply to you and your stage.

There are different degrees of renal disease, from mild to moderate to severe. Some people stay in the mild/moderate category for life, while some others progress to severe disease. Whichever situation applies to you, a healthy lifestyle and regular monitoring is important.

There are usually no symptoms to indicate the kidneys are damaged in early stage kidney disease. Because your kidneys work hard even when they're not functioning at 100%, most people will not know they have stage 1 or 2 kidney disease.

The first signs of trouble usually show up during tests for other conditions, such as diabetes or high blood pressure (the two leading causes of kidney disease).

Depending on your stage of kidney disease, it may feel like you're walking through a door into an unfamiliar world of new routines, new rules, new people, and possibly strange machines and tests. You probably have a lot of questions.

The purpose of this book is to provide information and inspiration to help you understand and adjust to this new phase of life; to try to answer some of your questions; and to remind you that you are not alone.

10% of all people in the world have some form of kidney disease. And in South Africa, an estimated 7.5 million people are affected by some sort of kidney disease.

There's a lot that you can do to live a good life with kidney disease.

Whatever your health status, being equipped with knowledge about your condition and treatment options helps you feel in control of your situation.

**Your health – and your outlook – are in your hands.  
Take charge today.**

A handwritten signature in black ink that reads "Errol Gottlich". The signature is written in a cursive, slightly slanted style.

Prof Errol Gottlich  
Clinical specialist



# Understanding your condition

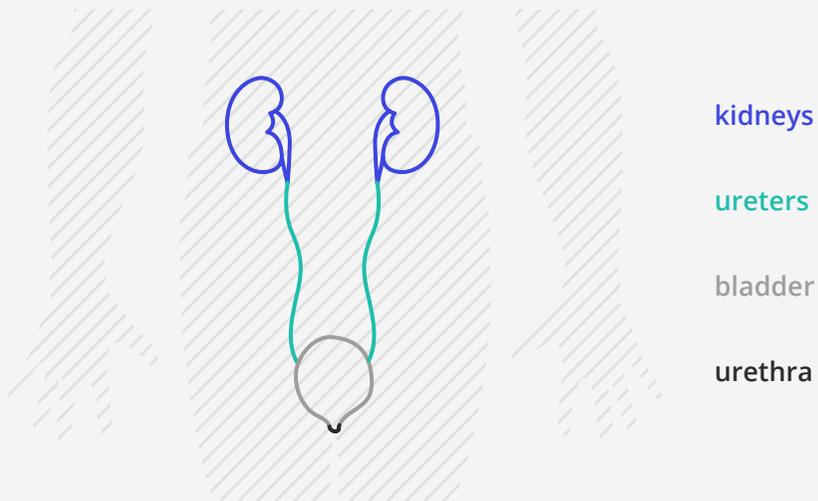
# All about kidney disease

In this section we explain how the kidneys function, what can go wrong, how kidney disease is treated and why it's important to have this treatment.

The more you know and understand about kidney disease the better equipped you'll be to take control of and improve your health.

## HOW DO HEALTHY KIDNEYS WORK?

Your kidneys are a pair of bean-shaped organs that are found at the back of your body, at about waist-level. Each one measures 10 to 15cm in length and weighs about 160 grams. Each kidney is about the size of a computer mouse.



Now that you've got the picture, let's talk about what your kidneys do. Think of them as the filters of your body. When your body is working to look after you it uses nutrients from your food to make energy, repair damaged cells and maintain healthy tissues.

Waste products from these processes go into your blood to be transported out of your body. When your blood travels through your kidneys these organs get to work, sieving out the harmful waste products for excretion in your urine.

Healthy kidneys  
remove waste products  
from the blood

## HOW DO KIDNEYS FILTER BLOOD?

Each kidney has thousands of small filtering units: these are called nephrons and each nephron has a sieve-like structure called a glomerulus.

When blood enters the glomerulus it is filtered so that waste and extra water are removed; this leaves behind normal cells and proteins that your body needs.

The water-waste travels down tubes called the ureters into your bladder where it leaves your body via the urethra as urine. The water and salts that are needed by your body are reabsorbed.

### But that's not all your kidneys do!

Removing waste from your blood is the most important job your kidneys do but they also produce hormones that help your body to function.

## IMPORTANT HORMONES

The kidneys produce three important hormones that are responsible for regulating red blood cells, ensuring healthy bones and controlling blood pressure:



### Red Blood Cell Regulator: Erythropoietin (Epo)

This tells your body to make red blood cells that carry oxygen around your body.



### Calcium Controller: Calcitriol

Calcitriol is a hormone that is converted from Vitamin D and it keeps calcium levels normal so that you have healthy bones.



### Blood Pressure Regulator: Renin

Renin helps to control your blood pressure. This is important in the prevention of heart disease and stroke.

# Kidney disease in South Africa

**10%**

of all people in the world have some form of kidney disease.



It's estimated that

**15%**

of South Africans are affected.



The kidneys filter around

**200 litres**

of fluid a day



(about 2 and a half bathtubs full), and excrete 1 – 2 litres of waste.

Kidney failure in South African adults is often due to inherited



hypertension/  
high blood  
pressure

**60 – 65%**



or type-2  
diabetes

**20 – 25%**

Around



**20 000**

new patients are diagnosed every year in South Africa.

Kidney failure in the black population is

**4 times higher**



than other ethnic groups due to the high incidence of hypertension.

Unlike the developing world, where chronic kidney disease affects mostly older patients, it affects many

**young adults**  
**20 – 25 years**



in Sub-Saharan Africa, primarily due to hypertension and glomerular diseases.

# Why kidneys stop working



*Kidney failure occurs when those filtering units, the nephrons, are damaged, preventing the kidneys from filtering waste from your blood.*

The waste products start to build up, causing damage to the body. These waste products become poisonous when they aren't removed and the build-up of excess fluid in the body is also harmful.

Nephron damage occurs very slowly and because each kidney contains a lot of nephrons, the damage may not become obvious for a long time. Many people suffer from kidney damage for years without even realising it.

Renal disease will only become obvious when more than half the organ is damaged.

Because the kidneys have so many functions, you, with your doctor's help, may need to manage some of the effects of kidney failure.

### COMMON CAUSES OF KIDNEY FAILURE

- High blood pressure (hypertension)
- Diabetes
- Infection
- Abnormal immune system (autoimmune disease)
- Drugs, poisons or radiation
- Blockage or obstruction
- Hereditary factors (genetics)
- Accidents and injury

### EFFECTS OF MODERATE TO SEVERE KIDNEY FAILURE

- Build up of wastes in the blood (uraemia)
- Lower production of red blood cells (anaemia)
- High blood pressure (hypertension)
- High cholesterol (hyperlipidaemia)
- Decrease in bone mass
- Itching (due to uraemia)
- Difficulty sleeping

### COMMON SYMPTOMS OF MODERATE TO SEVERE KIDNEY FAILURE

- Nausea, headaches and dizziness
- Loss of appetite
- Loss of concentration and difficulty focusing
- Extreme tiredness
- Itchy and yellowing skin
- Fluid retention and oedema (swelling from a build up of fluid in the body's tissues)
- High blood pressure
- Difficulty breathing



### REGISTER FOR DISCOVERY'S CHRONIC ILLNESS BENEFIT

When you are first diagnosed with kidney disease, you should apply for Discovery's Chronic Illness Benefit. Find the form on [www.discovery.co.za](http://www.discovery.co.za); your doctor will fill it in and send it off for you to ensure your approved treatments are covered. Alternatively your doctor can apply electronically through HealthID.

For any questions about your cover, call: 0860 998877 and choose the chronic illness option.

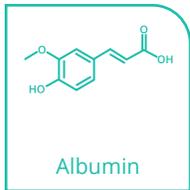


# Testing kidney function

# Decoding the numbers

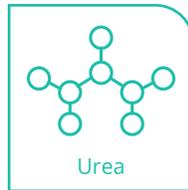
Kidney function is tested through blood tests that look at numerous factors and levels. It's a good idea to get to grips with your kidney 'numbers' to understand blood and urine test results and what they mean.

Your doctor may need to analyse your blood tests, focusing specifically on albumin, creatinine, sodium, calcium, phosphorus and potassium. Below are the normal ranges for the key renal function indicators.



This test shows how well your body is absorbing protein. Too much albumin in the urine is an early sign of kidney damage.

**Normal range:** 35 – 50g/L (grams per litre)



This shows how much of the potentially harmful waste product, ammonia, is in the body.

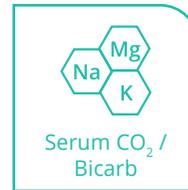
**Normal range:** 1.8 – 6.4mmol/l (millimole/ litre)



This indicates the percentage of red blood cells in the total blood count.

Red blood cells are needed to transport oxygen.

**Normal range:**  
% Male: 41 – 50,  
% Female: 36 – 44



This test shows your electrolyte balance (and is usually done together with sodium, potassium, and chloride as part of the electrolyte panel). When you lose or retain fluid, the acid-base balance can be upset.

**Normal range:** 21 – 29mmol/l (millimole/ litre)



This shows how much iron is in your body.

Low iron levels show anaemia. Nearly everyone with end stage renal disease has anaemia.

**Normal range:** 15 – 120ng/ml (nanograms per milliliter)



Kidney disease patients may have high levels of magnesium. Too much magnesium can become toxic.

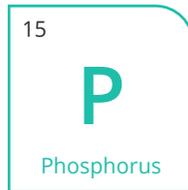
**Normal range:** 0.7 – 0.87mmol/L (millimole /litre)



Potassium needs to be removed from the body.

Too much potassium in the blood can cause heart and muscle problems.

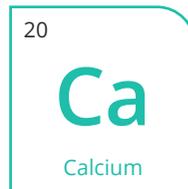
**Normal range:** 3.4 – 4.7mmol/L (millimole / litre)



This shows whether treatment is removing phosphorus from the body.

Too much phosphorus in the blood lowers the amount of calcium in your bones.

**Normal range:** 1.45 – 1.78mmol/l (millimole/ litre)



To check whether there is enough calcium for healthy bone development.

**Normal range:** 2.2 – 2.7mmol/L (millimole per litre)



This affects the sodium level in your body and should be kept steady.

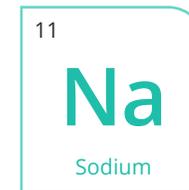
**Normal range:** 98 – 107mmol/L (millimole per litre)



To check whether waste products are being removed efficiently.

Waste build up can become toxic.

**Normal range:** 80 – 115umol/L (micromoles per litre)



When sodium levels are too high they can lead to excessive thirst that leads to drinking more, and that leads to fluid retention and high blood pressure, putting more strain on heart and kidneys.

**Normal range:** 136 – 145mEq/L

## THE IMPORTANCE OF EFGR

One of the medical terms you'll be hearing a lot is eGFR.

eGFR stands for estimated glomerular filtration rate and it is an indicator of kidney function done through a blood test.

eGFR is the number that tells your doctor how much kidney function you have. As chronic kidney disease progresses, your eGFR number decreases.

To calculate your eGFR your doctor takes your creatinine levels, your age, body size and gender and uses the eGFR formula to assess your stage of kidney disease and help plan your treatment.

## 5 STAGES OF KIDNEY DISEASE

Kidney disease is divided up into five stages with Stage 1 being the least severe and stage 5 the final or end stage. By stage 5, there is no function in the kidneys, and the ultimate aim is dialysis or, if possible, a transplant.

Stage	Kidney status	EFGR
1	Kidney damage (e.g., protein the urine) with normal GFR	90 or above (mild)
2	Kidney damage with mild decrease in GFR	60 to 89 (mild)
3	Moderate decrease in GFR	30 to 59 (moderate)
4	Severe reduction in GFR	15 to 29 (severe)
5	Kidney failure	Less than 15 (severe)

It is important to note that as per legislation one can only register on CIB for benefits for chronic kidney disease once your eGFR is < 60

Source: National Kidney Foundation (US)

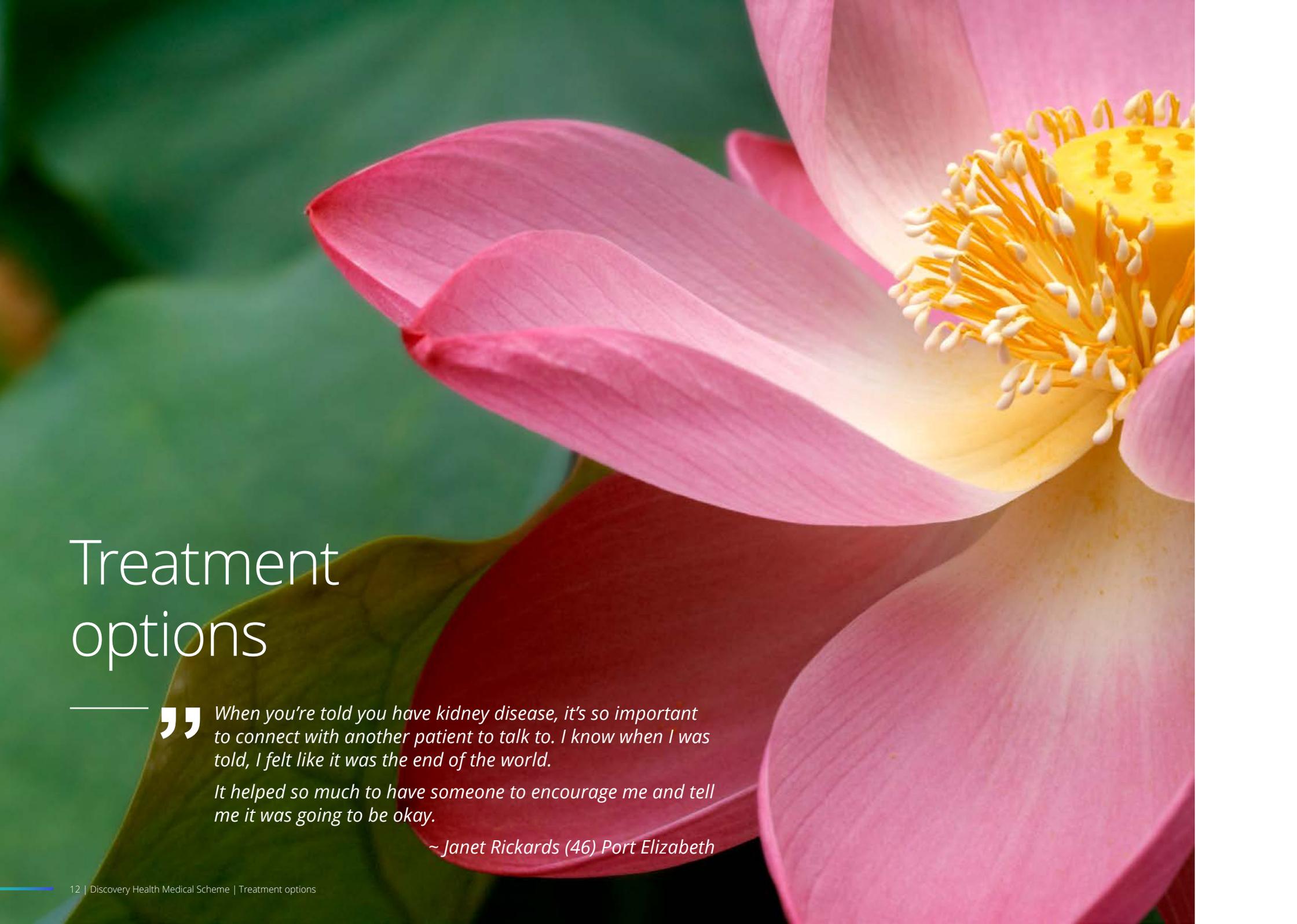
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My EGFR was 48 when I started to read my lab results. I'm learning everything I can. I feel more in control when I am involved.

~ *Alastair Chetty (43) Durban*

### Top tip:

Learning to read your blood results means you can see at a glance what's happening in your body, and how to make necessary adjustments to manage your health effectively.



# Treatment options

” *When you're told you have kidney disease, it's so important to connect with another patient to talk to. I know when I was told, I felt like it was the end of the world.*

*It helped so much to have someone to encourage me and tell me it was going to be okay.*

*~ Janet Rickards (46) Port Elizabeth*

# Mild kidney disease

When your kidneys start to falter in performing their jobs, their ability to filter wastes from your blood and produce hormones is compromised.

Regular testing for protein in the urine and serum creatinine can show whether kidney damage is progressing. Living a healthy lifestyle can help slow the progression of kidney disease. For people with mild kidney disease (stages 1 or 2), treatment usually involves:

- 01** | Eating a healthy diet: Including a variety of wholegrains, fresh fruit and vegetables; foods low in saturated fat and cholesterol and moderate in total fats. It's important to limit refined and processed foods that are high in sugar and salt. Aim for a healthy weight and strive to get active physically every day. Keep protein within a healthy level, and seek the help of a renal dietitian to create tasty and nutritious menus. Potassium and phosphorous are not usually restricted at these stages, unless blood levels are above normal.
- 02** | Working towards keeping blood pressure at healthy levels: Levels recommended by the National Kidney Foundation for diabetes and CKD stages 1-4 are: Not more than 130/80; and some experts favour a lower target of 125/75 for those with diabetes with proteinuria (abnormally high quantities of protein in the urine).
- 03** | Keeping blood sugar or diabetes under control.
- 04** | Having regular check-ups with your doctor and doing serum creatinines test to measure GFR.
- 05** | Always taking medicines as prescribed by your doctor.
- 06** | Exercising regularly.
- 07** | Stopping smoking.

In early kidney disease, you aim to maintain function as much as possible, based on exercise, diet, and compliance to treatment.

# Moderate kidney disease

As kidney function declines waste products can build up in the blood causing a condition known as uraemia (high levels of urea in the blood). In stage-3 kidney disease, you're more likely to develop high blood pressure and anaemia (a shortage of red blood cells) and you may be prone to early bone disease.

You might experience symptoms such as: Fatigue, fluid retention, swelling (oedema) of extremities and shortness of breath. Also, changes in the colour of urine and urinating more or less than normal. You could also experience difficulty sleeping and muscle cramps.

You may see a nephrologist at this stage to help you manage your condition.

## YOUR TREATMENT PLAN WILL MOST LIKELY INCLUDE SOME OF THESE ELEMENTS:

**01 | Diet:** For stage 3 kidney disease, a healthy diet could consist of: Eating high-quality protein and potassium and some grains, fruits and vegetables (depending on potassium and phosphorus levels). Limiting phosphorus to help PTH levels (parathyroid hormone, which controls calcium, phosphorus, and vitamin D levels in the blood) to remain normal, prevent bone disease and possibly preserve existing kidney function.

You may need to reduce calcium, and if you have diabetes – carbohydrates. Cutting down on saturated fats will help lower cholesterol. Lower sodium also helps. Consulting a dietitian early on can help you work within healthy guidelines, make adaptations, and find recipe ideas that suit your tastes and preferences.

**02 | Medication** at this stage might include those for diabetes or high blood pressure. By keeping glucose levels under control and maintaining a healthy blood pressure, you can preserve kidney function. Studies have shown that ACE (angiotensin converting enzyme) inhibitors and ARBs (angiotensin receptor blockers) help slow the progression of kidney disease, even in people with diabetes who do not have high blood pressure.

Talk to your doctor about all your concerns, discuss your medicines and remember to take them exactly as prescribed.

Note and discuss any symptoms or reactions you experience. Some people experience side effects of ACE inhibitors such as: dizziness, headache, drowsiness, diarrhoea, weakness, cough and low blood pressure. Common side effects of ARBs include: dizziness, headache, drowsiness, nausea, vomiting and sometimes cough.

In addition to eating right and taking prescribed medicines, exercising regularly and not smoking are helpful to prolonging kidney health.

Make sure to ask your doctor about any potential side effects of your medicine or treatment.

# Severe kidney disease

In stage 4, you are likely to develop complications of kidney disease such as hypertension, anaemia, bone disease and heart and other cardiovascular diseases.

In stage 4, you might have symptoms such as: Fatigue, fluid retention, oedema and shortness of breath; as well a urination changes, sleep disturbances, nausea, vomiting, a metallic taste in the mouth, loss of appetite, difficulty concentrating, and numbness or tingling in the toes or fingers.

In severe kidney disease, when there is very little kidney function remaining, you may need dialysis treatment to carry out the blood cleaning work normally done by your kidneys.

You will meet with a kidney disease specialist, your nephrologist, who will discuss your treatment needs and options with you.

In addition to dialysis to cope with waste products and excess liquid you may need medicine to control your blood pressure, improve anaemia and ensure good bone health.

You doctor may also ask you to control your intake of fluids and make some healthy lifestyle changes including a healthy diet and regular exercise (see the section from page 84 for advice on taking charge of your life through diet and exercise). This will ensure optimum health when you have kidney disease.

This is where the help and involvement of a renal specialist dietitian really makes sense. Having someone in your corner monitoring your nutritional intake and helping you make the right choices for your body can make an enormous difference to how you feel and function.

There are two main types of dialysis: haemodialysis, peritoneal dialysis.

## A DIETITIAN CAN:

- Help you balance nutrients like protein, carbs, fat, sodium, phosphorous, potassium, and vitamins and minerals in the correct amounts for your needs
- Develop a personalized eating plan
- Create shopping lists, recipes and meal plans
- Advise on eating tips and strategies
- Determine your kilojoule intake
- Make adjustments based on your health, weight, or changes to test results
- Help you enjoy nutritious eating within healthy guidelines
- Answer your nutrition questions and encourage and support you

Also, keep in regular contact with your doctor. Letting him/her know how you are feeling and responding to treatment at every stage can assist him or her in keeping you as healthy, comfortable and functional as possible.



# Linked conditions

## DIABETES

Diabetes and poor blood sugar control is one of the major contributors to renal failure. The two conditions often co-exist.

With diabetes, the small blood vessels in the body are injured, and your kidneys cannot clean your blood properly. Your body will retain more water and salt than it should and you may have protein in your urine. Waste materials build up in your blood.

Diabetes also may cause damage to nerves in your body. This can cause difficulty in emptying your bladder. The pressure resulting from your full bladder can back up and injure the kidneys.

About 30% of patients with type-1 diabetes and 10 - 40% of those with type-2 diabetes may eventually suffer from kidney failure, according to the US National Kidney Foundation.

Your body produces a hormone called insulin that controls how your body uses blood sugar for energy.

Diabetes prevents the pancreas from producing enough insulin, or the body does not respond to insulin properly.

The result is that the body has abnormal blood sugar levels – too high after eating and too low in between meals.

### Why you need to control blood sugar levels

Abnormal blood sugar levels cause kidney damage over time. It's important to maintain good glucose control because you can slow down the damage to your kidneys.

It can be particularly challenging to manage diabetes as well as kidney disease because of the dietary restrictions of both conditions. Speak to your dietitian for a healthy eating plan that works for you.

### Other conditions linked to diabetes

- Eye disease and blindness
- Heart attacks and strokes
- Damage to nerves
- Skin damage, sores and ulcers
- Infections

### Top tips for people with diabetes

- Follow your treatment plan: Take all your medications when prescribed.
- Follow your diet plan: monitor your blood sugar levels (record them in your health diary).
- Learn as much as possible about diabetes and how to keep it under control.
- Have regular eye tests.
- Look after your skin and feet.
- Floss and brush your teeth daily.
- Follow an exercise plan that is right for you.
- Achieve and maintain a healthy weight.
- Dietitian involvement
- Regular follow up appointments are vitally important

Whether you have high blood pressure, diabetes, heart disease, anaemia, or bone disease, staying healthy and strong will help you cope. Following a healthy diet, getting some regular physical activity and checking your blood pressure, lab and test results is a great place to start!

## **BLOOD PRESSURE**

Blood pressure is the force of blood against the walls of the arteries as it circulates in the body. High blood pressure occurs when blood vessels become narrow or stiff, forcing the heart to pump harder to push blood through the body. High blood pressure is both a cause and complication of chronic kidney disease.

In South Africa, where we have an extraordinarily high rate of hypertension, high blood pressure is one of the leading causes of kidney failure.

Blood pressure control is important to prevent heart disease in patients with any stage of chronic kidney disease.

## **BONE DISEASE**

Bones contain cells, fibers, blood vessels, nerves and lots of minerals: mostly calcium and phosphorus. For bones to stay strong and healthy, calcium and phosphorus must stay in balance. In kidney disease, these two minerals become unbalanced. Regular testing will monitor your bone health.

## **CARDIOVASCULAR DISEASE**

Over time, the blood vessels that bring blood to the heart and brain can become blocked from a buildup of cells, fat and cholesterol. This lowers blood flow to the heart and brain, and can cause heart attacks and strokes. Because people with kidney disease are more likely than others to have cardiovascular disease (CVD), it's very important to take action to prevent heart and vascular problems, to prevent heart attacks and strokes.

Discuss with your doctor any potential risk factors for and the signs of CVD and take action to lower risk: such as stopping smoking, reducing fat in your diet, starting an exercise programme, lowering high cholesterol and high blood pressure as well considering your family history of CVD.



# Managing the emotional aspects of kidney disease

“ I keep my friends and family informed about my health, even when the news isn't good. This keeps communication open, and they know when I need a bit more support. During bad times is when they've really showed they care.

~ Duduzile Cele, 60, Pretoria

Having a chronic illness adds significantly to your stress levels. You may be worried about your illness and treatments and concerned about what the future holds and how you are going to cope.

You have probably been absorbing a lot of medical information about kidney disease and this may feel like 'information overload' at times.

Some of the restrictions that may be placed on you in the severe stage of kidney disease may be particularly frustrating to cope with. When you need to have regular lab tests, or you can't

eat your favourite food or drink liquids without measuring how much you've had, life can feel pretty unfair.

We know it's not easy; we encourage you to look after your mind as well as your body. Do what you need to do to get the help and support you need to be strong and carry on.

There are many professional counsellors who can help you through this journey; and there are also support groups (some of these are listed on page 117) where you can meet other people going through the same things as you.

Don't forget – you do not have to live with fatigue 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.

Share your feelings. Friends and family will want to help, if you can tell them what you need, whether a healthy meal, a walk by the sea, to go with you to treatment, or just to listen.

Your medical team will focus on your physical wellbeing and treatment but your emotional and psychological state are equally important.

## COMMUNICATION IS THE START FOR EMOTIONAL HEALTH

It's important to find someone you trust to be able to talk about what you're going through. Talking will lower your feelings of loneliness because you will be connecting with other people and this, in turn, creates a sense of support and care.

A big plus about talking about your feelings is that when you do this it helps you to understand why you feel the way you do. It also gives you insight into why you respond in a certain way.

A trained and qualified counsellor can help you develop strategies to get back a sense of control.

## HANDLING STRESS

Develop ways to deal with stress: you may find relaxation and stress management exercises useful. Sitting quietly, listening to music and reading can all help you to relax. You may want to try some specific stress management techniques, such as deep breathing, meditation, visualisation, self-hypnosis and muscle relaxation.

Their faith also helps many people to find hope and serenity each day amid the challenges of living with a chronic illness. Prayer can bring peace and meaning to your challenges.

## YOUR SUPPORT SYSTEM

Make the most of your support system and try to avoid carrying the load all on your own. When you need help remember your support system is there:

### Your healthcare providers

You have a network of healthcare professionals looking after you and they are there to explain your condition and treatments. Ask for help when you need it. If you're feeling depressed or worried they will also be able to refer you to counsellors who can help you through difficult times and show you how to develop effective coping skills.

### Your friends and family

Tell your family how you're feeling: they're probably also experiencing some of the emotions that you are feeling. Clear up any misconceptions about your condition and encourage them to ask questions. When they offer to help let them do so: be specific about what you need help with.

If they know about your condition and treatment it will help them understand how your life has changed, and why you need to be serious about your renal eating plan, why you need more rest, and why you need to make time for appointments or treatment.

### Support groups

Getting together with people who are going through the same experience as you are and understanding how you feel can be a great support and source of advice and inspiration. Ask your doctor to refer you to a support group. Or perhaps you can form your own group with some like-minded people from your clinic?

## THE ROLE OF PROFESSIONAL COUNSELLORS

Having a long-term or chronic illness can disrupt your life in many ways. You will experience physical challenges which will affect your daily functioning, as well as emotional symptoms which would affect your coping mechanisms. There will also be additional 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 regain 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).



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

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.

~ Leonie

## CALL FOR HELP

SADAG offers telephone counselling every day of the year, and can also refer 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.

SMS: 31393 and someone will call you back.

Call: 0800 70 80 90 / 0800 20 50 26  
(toll-free, 8am to 8pm, seven days a week)

Visit: [www.sadag.co.za](http://www.sadag.co.za)

## TIPS FOR TAKING CARE OF MIND AS WELL AS BODY

Use these strategies to care for your emotional and mental wellbeing:



### Share the load:

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



### Learn about your illness:

Use trusted and reputable sources of information to find out more about kidney failure, dialysis and transplant, if that's relevant to you, and answer any questions you have. Knowledge can be extremely empowering, and help you take control of your treatment.



### 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.



### Sleep well:

Make sure you get enough good quality sleep, at least eight hours a night.



### Reduce stress:

Learn relaxation and stress management techniques, like deep breathing, meditation, and visualisation.

It's not always possible to avoid stressful situations, but we can control our responses to and management of stress.

## TAKING CARE OF BUSINESS

Fortunately there are several innovative products available to cover a variety of needs. You may want to consider an income protector, such as the Discovery Life Income Continuation plan, which is designed to protect you against a shortfall in cash flow when you become ill. It provides you with a monthly income to cover your expenses.

Speak to your financial adviser or visit:

**[www.discovery.co.za/portal/individual/life-protect-your-income](http://www.discovery.co.za/portal/individual/life-protect-your-income)**

The Severe Illness Benefit looks after both you and your loved ones too, paying out a lump sum in the case of severe illness. Discovery's unique multiple claims facility allows you to claim more than once.

Visit: **[www.discovery.co.za/portal/individual/life-cover-for-you-your-family](http://www.discovery.co.za/portal/individual/life-cover-for-you-your-family)**

When your ability to earn an income and plan for the future is affected by chronic kidney disease it's important to take steps to protect yourself financially, and put your mind at ease.

## FAMILY MATTERS: FOR THOSE CARING FOR A LOVED WITH RENAL DISEASE

It can be stressful when a loved one is suffering with chronic kidney disease. When family members become caregivers, they may feel overwhelmed or worried about how they'll cope.

Anxiety can manifest in a number of ways, including: changes to sleeping and eating patterns, fatigue, anger, tearfulness, feeling moody or sad, using alcohol or drugs to feel better. If you notice any of these signs, it's important to put some strategies in place to help you care for yourself and your loved one:

- Exercise is a great stress-buster.
- Make time for relaxation and fun.
- Make sure you get enough sleep and good quality nutrition: if you have no energy it's even more difficult to cope.
- Build a support structure for yourself: Who can you lean on? Have you someone you can talk to? You don't have to carry responsibility, stress and worry all by yourself.

Don't hesitate to seek the help of a professional counsellor if you start to feel you're not coping.



# Caring for kids living with chronic kidney disease

# How you can help your child cope with kidney disease

An important factor in the child's reaction is their developmental stage.

*The way children react to the diagnosis of chronic kidney disease depends on their personality, the extent of the kidney failure and their family.*

A preschooler will have only limited understanding of his/her illness but an older child will be able to understand more complex ideas and their understanding will increase as they get older.

## IS THERE A DIFFERENCE BETWEEN KIDNEY DISEASE IN ADULTS AND CHILDREN?

Children with kidney failure will have more medical appointments than an adult and they may find some of the treatments scary or painful. Children find it particularly difficult to understand and cope with dialysis, dietary restrictions and limits on exercise. 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.

~ SADAG's Cassey Chambers.

## COMMON CHILDHOOD KIDNEY DISEASES

The most common childhood kidney problems are ones kids are born with. These include:

- **Foetal hydronephrosis:** The enlargement of one or both of the kidneys caused by an obstruction in the developing urinary tract or a condition called vesicoureteral reflux (VUR) where urine flows backward from the bladder into the ureters.
- **Polycystic kidney disease (PKD):** Many cysts develop in both kidneys. The cysts can multiply so much and grow so large that they lead to kidney failure.
- **Multicystic kidney disease (MKD):** Large cysts develop in one kidney that hasn't developed properly, eventually causing it to stop working.
- **Renal tubular acidosis:** The kidneys don't control the amount of acid in the body.
- **Wilms tumor:** A type of childhood cancer in the kidney.
- **Glomerulonephritis:** When the glomeruli in the nephrons become inflammation or infected it can affect the kidney's ability to filter waste.
- **Nephrotic syndrome:** The body loses a lot of protein through the urine, usually due to a change in the nephrons.
- Congenital problems with the urinary tract

Severe kidney disease isn't easy for anyone, but children particularly find it difficult to cope with the disruption of constant treatments, differences in their appearance, as well as restrictions 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.

Generally children worry less if they are prepared and they know what's going on. Take time to plan what you'll say to your child, and make sure you are calm and confident when you talk about their health. They will respond to the way you feel and behave, so make sure you're in control. They will feel secure too, when they see you managing the situation in an organised and calm way.

Talk to your child in an honest and age-appropriate way that they understand. And remember, they still need to be kids.

Be careful not to overload them with too much complex information, or things to worry about. They need time for school and play – the main jobs of childhood.

Most of all, let children know they are loved and will continue to be loved and cared for.

## HOW DO OTHER PARENTS COPE?

Mothers of children with kidney disease suggest trying to keep as normal routine as possible and create a happy, healthy environment for your child. It's also helpful if the rest of the family supports a kidney-friendly diet, to reduce feelings of being deprived or excluded.

## AGES AND STAGES

Your child's age and developmental stage will determine how much they are able to understand about their condition. Here are some pointers to guide you:

### Toddlers

Toddlers (1-3 years) are beginning to develop trust and an overall sense of security. Being chronically ill can disrupt this stage and may leave them feeling anxious and angry because their parents were not able to 'make them better'. This may show itself in aggressive behaviour. Bear this in mind if your child starts behaving aggressively and seek professional advice if you feel it would help.

#### Top tip:

It will help if you can be there for painful procedures, stay with your child during hospitalisations, hold, soothe and interact with your toddler as much as possible. EMLA patches applied to the skin an hour before injections or the insertion of a drip will provide topical anaesthesia and avoid painful injection experiences.

### Preschoolers: 4-6 years

Preschoolers are beginning to develop a sense of independence and they may understand what it means to get sick. However, they may not understand why and how they get sick. If your child is hospitalised or on long-term medication they may feel that their new sense of independence is under threat and test boundaries set by authority figures.

#### Top tip:

Set clear boundaries and make it clear to your child that he does not have a choice about certain things. So whether or not they take the medicine is non-negotiable; which colour medicine to take first is something that your child may choose. Or whether they would like to walk or be carried into the dialysis centre.

### 6 to 7 years

At this age children are developing a sense of mastery over their environment. They often indulge in 'magical thinking' and use it to explain their reality. They may believe they caused their condition by thinking bad thoughts, hitting a sibling or by not eating their vegetables.

#### Top tip:

Allow your child to help in the management of their condition (under close supervision), and make some safe choices to exercise their will.

### 8 to 12 years

At this age children are generally more able to understand their condition and its treatment: but remember – they are not adults and should not be expected to react like adults.

They may feel left out when they miss school or activities with their peers due to their kidney condition. It's important to be honest when speaking to your child about their illness and it will help them to adjust to the limitations and restrictions associated with their condition. Reassure your child that although he or she is sick they will be getting

lots of care and although the treatments may feel frightening they're part of helping them to feel better.

When you are explaining the illness and its treatment try to give clear and honest answers to questions in a way that your child can understand.

It's also important to accurately explain and prepare your child for any treatments – and possible discomfort that might go with along with those treatments.

#### Top tip:

Try to avoid saying 'this won't hurt' if a procedure is likely to be painful: rather be honest if it is likely to cause some discomfort, pain, pressure, or stinging. Give your child plenty of reassurance that the discomfort will be temporary and that you'll be there to offer support while or after it's done.

## CAN MY CHILD GET INVOLVED IN SCHOOL ACTIVITIES?

You may feel very overprotective towards your child and this is, of course, natural. But try to remember that children want to feel a part of things so try not to be over-cautious when it comes to your child's life. Find out from your child's doctor about what activities at school your child can and can't do and encourage your child to take part in school and other activities.

## HOW DO I HELP MY CHILD EMOTIONALLY?

Encourage your child to talk about what he or she feels and thinks. This will teach them how to start to control their emotions.

For many questions, there won't be easy answers. And you can't always promise that everything is going to be fine. But you can help your child feel better by listening, saying it's okay and completely understandable to have those feelings, and explaining that you and your family will make him or her as comfortable as possible.

If a child asks 'why me?' it's okay to offer an honest 'I don't know'. Explain that even though no one knows why the illness occurred, the doctors do have treatments for it (if that's the case). If your child says 'it's not fair that I'm sick', acknowledge that your child is right. It's important for kids to know it's okay to feel angry about the illness.

Remember that children often show unhappiness and anxiety by acting out: changes in behaviour can help you to identify when your child is struggling with something.

Encourage your child to write down their feelings, what's bothering them and how they'd like to take charge of their life.

Just like any adult, a child will need time to adjust to the diagnosis and the physical changes and is likely to feel sad, depressed, angry, afraid, or even to deny that they are sick. Think about getting professional counselling if you see signs that these feelings are interfering with daily function, or your child seems withdrawn, depressed, and shows radical changes in eating and sleeping habits unrelated to the physical illness.

## TOP TIP:

Perhaps you could buy them a journal and encourage them to draw or write about what's happening to them, how it makes them feel, what they'd like to do.

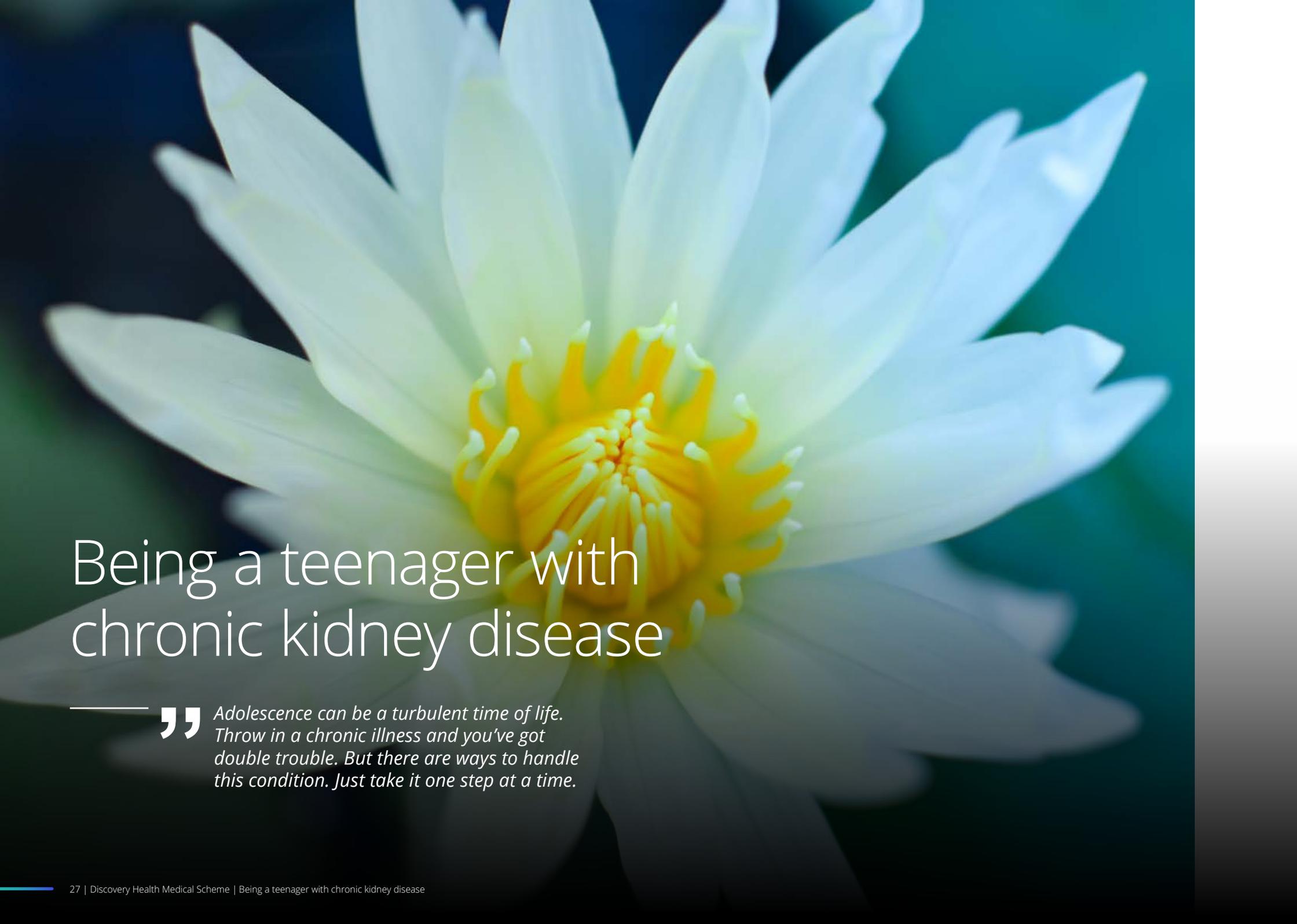
### **KidneyBeanz Trust**

Supporting children with life threatening kidney disease

[www.kidneybeanz.co.za](http://www.kidneybeanz.co.za)

For great educational material on childhood kidney diseases, visit the website:

[www.infokids.org.uk](http://www.infokids.org.uk)



# Being a teenager with chronic kidney disease

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*Adolescence can be a turbulent time of life. Throw in a chronic illness and you've got double trouble. But there are ways to handle this condition. Just take it one step at a time.*

# 01

## YOU'RE AWESOME!

You might find that a chronic illness like kidney disease affects how they feel about yourself. You might feel different, or feel separated from your friends by the illness and the demands of treatment. Remind yourself that you are not your disease – you are so much more! You are still you: it may mean that you need to do some things differently but it doesn't define who you are.

Think of ways that you can still keep in touch with your friends even if you can't go to school or socialise every day. You still have lots to offer, and there are lots of ways to contribute.

” I am still the same likeable person.

### Top tip:

Do something that you enjoy with your friends: join a regular art workshop, music sessions or community project. Stay in touch with WhatsApp, Facebook, or start a blog.

# 02

## LOOK AFTER YOURSELF

Your parents may be tempted to be overprotective of you when you're diagnosed with chronic kidney disease, but you need to show them that you are the same strong person you were before, that you can do a lot for yourself, and you still need the same rules and boundaries.

You'll need some extra physical care; this means sticking with the treatment programme, getting enough rest, following a kidney-friendly diet, doing regular exercise and behaving in a responsible way. Be kind to yourself and give yourself time to adjust.

” I am able to cope.

### Top tip:

Do something kind for yourself every day. Write a journal or blog about your experience.

# 03

## BE STRONG

Try to avoid negative thinking and thought patterns about yourself – they are not helpful and you may fall into a habit called 'learned helplessness'. This is a state of mind where you think that you are unable to influence your behaviour, thinking and feelings. This is not true, you have the power, you are in control. Try to think positively.

” I am stronger than this challenge.

### Top tip:

Give yourself a daily mantra, such as: I can find solutions; I am able to cope; I am still the same likeable person. I am strong, I can do this!

## 04

### KEEP THE DOOR OPEN

You might have a lot of strong feelings and emotions that are new – it's okay to feel all these things, it's totally natural. It might help to share your thoughts and feelings with those close to you, this way the burden is shared. Some people also like to paint or draw or express their feelings and experiences creatively through art, poems or music.

#### Top tip:

If you feel you need privacy, or more time with your parents, say it. Your family wants to help you feel better and be well, so rather than shutting them out, keep communication channels open and let them know what you need.

## 05

### BECOME YOUR OWN HEALTH ADVOCATE

You are your doctor's best partner in this journey. Take control and find out as much as you can about your condition. Ask as many questions as you want. When you see your doctor take a list of questions with you so that you don't forget what to ask. Write down the answers. Soon you'll be an expert!

The more you know, the more you can own it.

#### Top tip:

Learn as much as you can about chronic kidney disease. Knowledge is power! Get informed, participate in decisions about your care.

### NOTE TO PARENTS

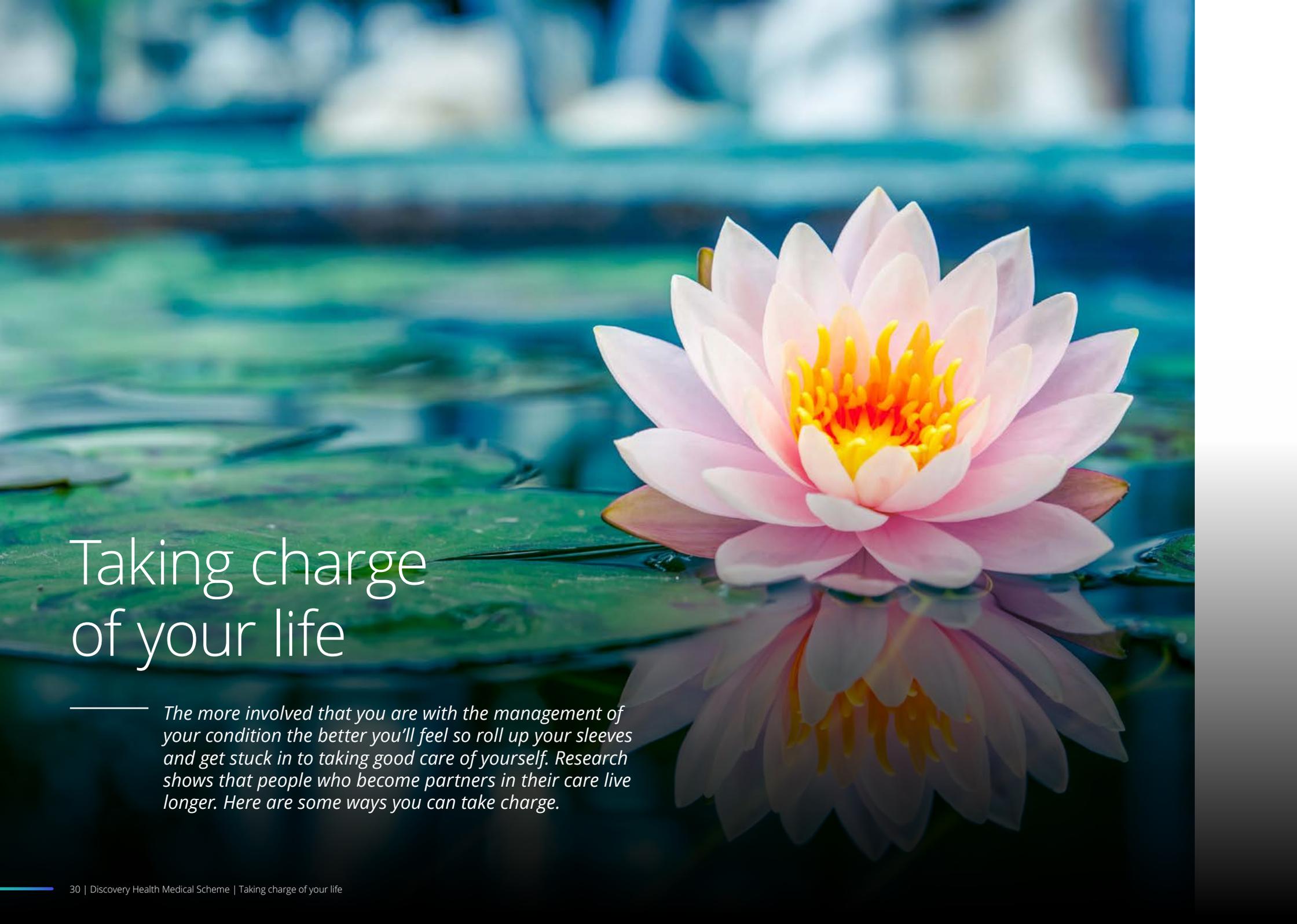
Your role as a parent is to raise a young adult who is able to care for themselves and this still applies when your child has a chronic illness such as chronic kidney disease.

Encourage independence and respect your child's wishes if they ask for privacy in some areas.

Perhaps they've asked to see their doctor on their own: if your child's previous behaviour has shown that they are ready for this it is an important step in the development of self-reliance.

They will take their cue from you. If your attitude is positive and empowering, children and young adults are likely to follow suit.

Straight-talking help for young people:  
[kidshealth.org](https://www.kidshealth.org)



# Taking charge of your life

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*The more involved that you are with the management of your condition the better you'll feel so roll up your sleeves and get stuck in to taking good care of yourself. Research shows that people who become partners in their care live longer. Here are some ways you can take charge.*

## GET ORGANISED:

Planning is very important – you may need to schedule doctor’s and dietitian’s appointments, or clinic visits, treatment sessions, taking medicine at certain times, changes to your weekly menus, as well as shopping and food preparation, and exercise and social activity. Planning ahead can help you feel more in control of all you need to do.

Get a calendar or diary to help you keep track of all your commitments. Don’t forget to schedule some downtime. Record your appointments, lab results, and any questions you want to ask at the back of this book.

## LOOK AFTER YOUR BONES:

You will also need to take special care of your bones. Your kidneys play an important role in maintaining healthy bones but if your kidneys aren’t working well your bones may suffer and you may be at risk of bone disease or renal osteodystrophy (also known as brittle bone disease).

## CONTROL YOUR DAILY DIET:

What you eat and drink on a daily basis is very important: your kidneys need extra care and support at this time.

With some planning and consultation with a dietitian you can cook up some delicious kidney-friendly recipe ideas, appropriate for your stage of kidney disease.

## MAINTAIN A HEALTHY WEIGHT:

Being overweight makes your kidneys work harder: It increases your risk of developing other medical problems, in addition to your kidney disease. Some of these include cardiovascular disease (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 kidney disease are already at a higher risk of developing some of these conditions. Being overweight may also make other treatments for renal disease, such as dialysis or surgery, more difficult. Losing weight may help your kidneys maintain function for longer.

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**TOP TIP:** Keep an eye on your waist circumference.

As a simple rule of thumb, measuring your waist circumference can tell you if you are at increased risk of weight-related problems:

**MEN:** waist should be less than 102cm

**WOMEN:** waist should be less than 88cm.

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## EXERCISE REGULARLY:

Physical exercise is very important to help you keep as healthy as you can be. See page 84 for more.

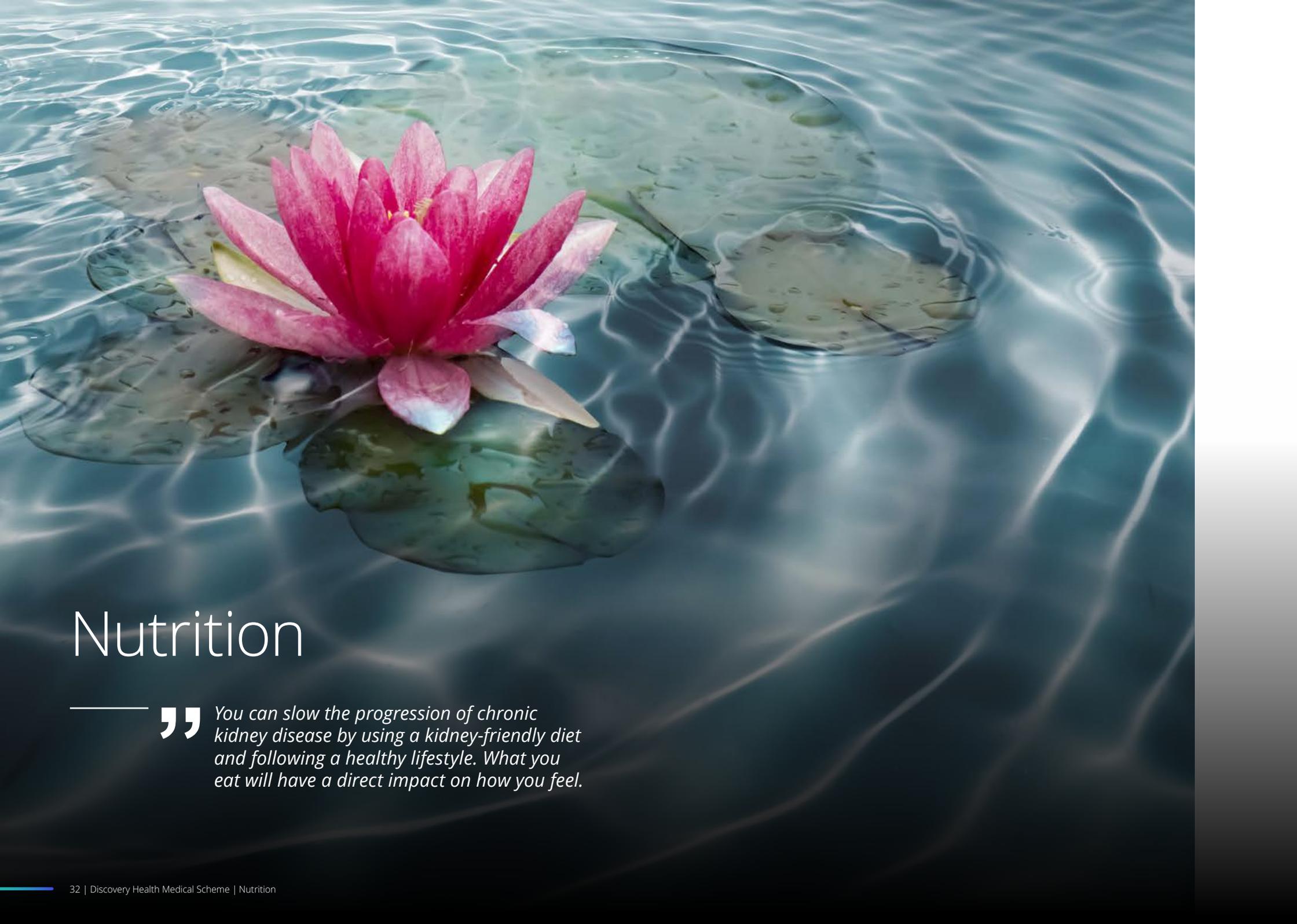
## STUB IT OUT:

Smoking can harm kidneys. It slows the blood flow to vital organs like the kidneys and can worsen already existing kidney disease. Now is the time to get really serious about stopping. Do whatever it takes to quit.

## GET ENOUGH SLEEP:

Try to make sure that you get enough sleep and speak to your doctor if you’re not sleeping soundly. It may also help to do some relaxation exercises before sleep to calm and relax your mind. When you follow the same routine at the same time each night, it can help to set you up for a restful night. Create a haven in your bedroom, without TV, electronic devices or pets. If you don’t sleep well at night, try and find an hour in the day to take a nap, this can keep you falling into a sleep deficit.

Taking charge of your life is as much mental and emotional as it is practical. Decide today that you are going to be in charge, you are going to be involved in making informed decisions about your care, and that you are the boss of your body and your illness. Kidney disease is a challenge to be met head-on.



# Nutrition

”

*You can slow the progression of chronic kidney disease by using a kidney-friendly diet and following a healthy lifestyle. What you eat will have a direct impact on how you feel.*

# Create a kidney-friendly kitchen

*A renal dietitian will help you work through your prescribed kidney diet and suggest ways to makeover your grocery list and recipe book. You'll be eating foods that are both delicious and kidney-friendly in no time.*

For meal ideas, check out the nutrition section at the back of the book. There are also more than 800 recipes on **DaVita.com**. It's helpful to work with a registered renal dietitian because as the stages of kidney disease change, so will the diet.

Blood pressure was my biggest problem. A different way of eating and exercising helped me get it under much greater control.

*~ Jim Marshall (65) Johannesburg*

## FOR MILD KIDNEY DISEASE

In stages 1 and 2 of kidney disease it's recommended to:

- Include a variety of grains (especially whole grains), fresh fruit and vegetables.
- Choose a diet that is low in saturated fat and cholesterol and moderate in total fats.
- Limit intake of refined and processed foods high in sugar and sodium.
- Choose and prepare foods with less salt or high-sodium ingredients.
- Aim for a healthy weight and include physical activity each day.
- Keep protein within a healthy level, as recommended by a renal dietitian.
- Make sure you get adequate calories.
- Consume vitamins and minerals as recommended by a doctor.
- Potassium and phosphorous are usually not restricted at this stage unless blood levels are above normal.

## FOR MODERATE KIDNEY DISEASE

Some guidelines for eating in stage 3 kidney disease:

- Eat high-quality protein and potassium (if blood levels are above normal)
- Get some grains, fruits and vegetables (potassium and phosphorus are at normal levels)
- Limit phosphorous to help PTH levels remain normal, prevent bone disease and even preserve existing kidney function
- Lower calcium consumption
- Cut back on carbs if you have diabetes
- Decrease saturated fats to help lower cholesterol
- Low sodium especially if you have high blood pressure
- Limit calcium if blood levels are too high
- Ask your doctor about supplements such as: water soluble vitamins such as vitamin C and vitamin B complex.

## FOR PATIENTS WITH SEVERE KIDNEY DISEASE

In stages 4 and 5 kidney disease, dietary guidelines may include:

- Reducing protein consumption to help decrease the buildup of protein waste. If you start dialysis, you may need to replace protein lost in dialysis. Your dietitian will assess and guide you here.
- Consuming some grains, fruits and vegetables (if potassium and phosphorus are at normal levels). You might need to limit or avoiding wholegrains and certain fruits and vegetables that are high in phosphorous and potassium.
- Limiting phosphorus to help PTH levels remain normal, prevent bone disease and even preserve existing kidney function
- Restricting potassium if blood levels are above normal
- Lowering calcium consumption
- Cutting back on carbs if you have diabetes
- Decreasing saturated fats to help lower cholesterol, especially if cholesterol is high or if you have diabetes or heart disease
- Lowering sodium. Limit your intake of refined and processed foods (often high in salt), and avoid adding salt in cooking or at the table
- Limiting calcium if necessary
- Limiting fluids
- Ask your doctor about supplements such as: water soluble vitamins such as vitamin C and vitamin B complex; Vitamin D and iron tailored to your individual requirements



Once you begin dialysis, you will need to make changes in what you eat and drink. Your diet is a big part of your treatment, so you will most likely be working with a dietitian who will help you make the best choices for your body.

Depending on the dialysis treatment you choose and your lab test results, your dietitian will help create a meal plan based on your individual requirements to keep you feeling your best. Your dietitian will explain what foods are restricted and which ones are recommended.

Aim for a healthy weight by consuming adequate calories and including physical activity each day within your ability.

## 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.

## WHAT I CAN EXPECT TO HAPPEN THE DAYS AFTER MY OPERATION

### 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.

# Tips for all stages of kidney disease:

## MAKE FOOD WITH LESS SALT

- This helps keep your blood pressure at a healthy level. Aim for less than 2 300 milligrams of sodium each day.
- Buy more fresh food: Sodium is added to many pre-prepared and packaged foods.
- Use spices, herbs, and sodium-free seasonings in place of salt.
- Read food labels: A daily value of 20% or more means the food is high in sodium.
- Rinse tinned vegetables, beans, meats, and fish before eating.
- Avoid salt substitutes.

### Look for foods labeled:

Sodium free

Salt free

Very low sodium

Low sodium

Reduced or less sodium

Light in sodium

No salt added

Unsalted

## CHOOSE HEART-HEALTHY

- To protect your blood vessels, heart, and kidneys, bake, roast, stew, grill, broil, or stir-fry foods instead of frying.
- Cook with nonstick cooking spray or a small amount of olive oil instead of butter.
- Trim visible fat from meat and remove skin from poultry before eating.

As your kidneys become more damaged, you may need to eat foods that are lower in phosphorus and potassium. Tests will help you keep an eye on your levels

## TIPS FOR SEVERE STAGE KIDNEY DISEASE:

### Opt for less phosphorus

- Help protect your bones and blood vessels by looking out for phosphorus (or PHOS) on ingredient lists. Many packaged foods have added phosphorus.

### Get potassium right

- For your nerves and muscles work optimally, potassium levels need to be just right.
- Salt substitutes can be very high in potassium. Read the ingredient label for potassium chloride, and avoid if you need to limit potassium.

## WHY IS WHITE BREAD SUGGESTED FOR THE RENAL DIET?

White bread is lower in potassium and phosphorus than whole grain bread. As kidney function declines, so does the kidney's ability to filter potassium and phosphorus. Excess potassium and phosphorus in the blood can cause problems for your heart and bones. To limit potassium and phosphorus, choose lower potassium and phosphorus grains products like white bread, sourdough bread, 60% whole wheat bread or light rye bread.

## SALTY FACT

Our body only needs about 1 500mg (less than one teaspoon or 3.7g) of sodium daily to function but many people get much more than this in their diet. Aim to eat no more than 1500mg-2000mg (less than one teaspoon) of sodium per day. Keep in mind that most of the sodium in our diet comes from processed foods and not the salt we add to food.

## EAT THE RIGHT PROTEIN

- The right type and amount of proteins helps to protect your kidneys.
- Eat small portions of protein foods.
- Talk to your dietitian about how to choose the right combination sources (plant/animal) for you.

What you eat and drink may help slow down kidney disease. Some foods may be better for your kidneys than others. Cooking your food from scratch gives you control over what you eat.

## 5 WAYS TO CREATE A KIDNEY-FRIENDLY KITCHEN

A well-stocked kitchen can help ensure you have everything you need to cook kidney-friendly meals. Here's how to get started.

01 

### COMPARE BRANDS AND READ LABELS.

Sodium and potassium levels can vary significantly from one brand to another.

02 

### LOOK FOR LOW-SODIUM LABELS ON PACKAGING.

Stock up on the lowest sodium broths, stocks and condiments.

03 

### CHOOSE FRESH VEGETABLES

Or frozen or canned veggies with no added salt or sodium. If they're not available or unaffordable, drain canned vegetables and rinse to remove some of the sodium.

04 

### USING TOMATOES

Use only 1/4 as much of the tomato sauce and canned tomatoes that a recipe calls for to limit potassium and sodium.

05 

### BAKE FROM FRESH

Avoid baking and pancake mixes that have salt and baking powder added. Instead, make a kidney-friendly recipe from scratch.

All recipes are suitable for those with mild, moderate and severe kidney disease, those not on dialysis and on dialysis

~ Source: *Recipes for kidney diet from DaVita.com*

# Recipes – Let's get cooking!



## ROTISSERIE CHICKEN NOODLE SOUP

**Portions:** 10

Suitable for: Chronic kidney disease non-dialysis, dialysis, diabetes

### Ingredients

- 1 prepared rotisserie chicken
- 8 cups low-sodium chicken broth
- 1/2 cup onion
- 1 cup celery
- 1 cup carrots
- 170 grams wide noodles, uncooked
- 3 tablespoons fresh parsley

### Preparation

- 01** | Remove chicken from bones and chop into bite-sized pieces. Measure 4 cups for the soup. Store remaining chicken in refrigerator for a later meal.
- 02** | Pour chicken broth in a large stock pot; bring to a boil. (Low-sodium broth contains 140 mg sodium or less per cup. Avoid low-sodium broth with potassium chloride – it's high in potassium.)
- 03** | Chop onion; slice celery and carrots.
- 04** | Add chicken, vegetables and noodles to stock pot.
- 05** | Bring to a boil and cook approximately 15 minutes until noodles are done.
- 06** | Garnish with chopped parsley.

### 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



## TUNA VEGGIE SALAD

**Portions:** 4

Suitable for: Chronic kidney disease non-dialysis, dialysis, diabetes

### Ingredients

- 1/2 cup red pepper
- 1/2 cup green pepper
- 1 cup courgette
- 1/4 cup green onions
- 1/4 cup fresh basil
- 1 garlic clove
- 140 grams canned tuna packed in water
- 2-1/2 tablespoons red wine vinegar
- 1 tablespoon olive oil
- 1/8 teaspoon black pepper

### Preparation

- 01** | Dice peppers and thinly slice courgettes. Chop green onions and basil. Mince garlic.
- 02** | Pour ¾ cup of water into a medium saucepan.
- 03** | Place peppers and courgette into a steamer basket and place over the saucepan. Heat water to a boil and steam vegetables for 10 minutes.
- 04** | Remove vegetables from heat, drain off any excess water and transfer to a serving bowl.
- 05** | Add tuna, green onions and basil. Toss to combine ingredients.
- 06** | To make dressing, combine vinegar, oil, garlic and black pepper in a jar with a tight-fitting lid and shake well.
- 07** | Pour dressing over tuna and vegetable mixture, and mix well.

### NUTRITIONAL VALUES FOR EACH SERVING:

Energy Kilojoules (kJ):	548
Protein (g):	5.2
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– of which is sugars (g):	0
Fibre (g):	4.1
Sodium (mg):	201
Phosphorus (mg):	105
Potassium (mg):	233

## HAWAIIAN CHICKEN SALAD SANDWICH

### Portions: 4

Suitable for: Chronic kidney disease non-dialysis, dialysis, diabetes

### Ingredients

- 2 cups chicken, cooked
- 1 cup pineapple pieces
- 1/2 cup low-fat mayonnaise
- 1/2 cup green pepper
- 1/3 cup carrots
- 1/2 teaspoon black pepper
- 4 pieces flatbread or tortillas

### Preparation

- 01** | Dice cooked chicken.
- 02** | Drain pineapple; chop pepper and shred carrots.
- 03** | Combine all ingredients in a bowl.
- 04** | Refrigerate until chilled.
- 05** | Serve chicken salad open-face on flatbread or wrapped in a 6-inch flour tortilla.

### 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



## SPICY BASIL BEEF STIR-FRY

### Portions: 6

Suitable for: Chronic kidney disease non-dialysis, dialysis, diabetes

### Ingredients

- 250 – 500 grams beef, flank or sirloin steak
- 1/2 cup basil leaves, fresh
- 1-1/2 tablespoon peanut oil
- 1-1/2 tablespoon garlic, minced
- 1/2 cup onion, sliced
- 1/4 teaspoon red pepper flakes
- 1 tablespoon reduced-sodium soy sauce
- 1-1/2 cup low-sodium beef broth
- 1/4 cup lime juice, fresh
- 1/2 cup red pepper, sliced
- 1 tablespoon cornstarch
- 3 cups cooked rice

### Preparation

- 01** | Slice beef into bite-size pieces.
- 02** | Wash and dry the basil leaves, and chop coarsely.
- 03** | Mix the beef, basil and 1/2 tablespoon peanut oil in a bowl.

- 04** | Preheat a wok or large skillet over medium heat for 3 minutes. Add the remaining peanut oil and swirl it around the pan.
- 05** | Add the garlic and onion, stirring a few times. Cook until the onion is soft, about 5 minutes.
- 06** | Turn the heat up to high and add the beef-basil mixture. Stir quickly and add the red pepper flakes. Cook just until meat loses its redness, about 3 to 5 minutes depending on the size of the beef pieces.
- 07** | Stir soy sauce into cornstarch, beef broth and lime juice. Add to beef and cook until bubbling. Turn off heat, stir in raw red pepper and serve over rice.





## EASY CHICKEN AND PASTA DINNER

### Portions: 2

Suitable for: Chronic kidney disease non-dialysis, dialysis, diabetes

### Ingredients

- 1/2 cup red pepper
- 1 cup courgette
- 1 tablespoon olive oil
- 2 cups cooked pasta, any shape
- 140 grams cooked chicken breast
- 3 tablespoons low-sodium Italian dressing

### Preparation

- 01** | Slice pepper and zucchini.
- 02** | In a nonstick skillet, heat olive oil and sauté zucchini and peppers until tender-crisp. Remove to a plate.
- 03** | Cut chicken into strips.
- 04** | Heat cooked pasta and chicken strips in microwave in separate dishes.
- 05** | Toss pasta with Italian dressing. Top with chicken strips and sautéed vegetables. If you require a higher or lower protein diet adjust the portion of chicken in this dish.

### 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

## HIGH-PROTEIN APPLE OATMEAL IN A MUG

### Portions: 1 Serving size: 1 mug

Suitable for: Chronic kidney disease non-dialysis, dialysis, diabetes

### Ingredients

- 1/3 cup quick-cooking oatmeal\*
- 1 large egg
- 1/2 cup almond milk
- 1/4 teaspoon cinnamon
- 1/2 medium apple

### Preparation

- 01** | Core and chop apple half.
- 02** | Combine oatmeal, egg and almond milk in a large mug. Stir well with a fork. Add cinnamon and apple. Stir again until fully mixed.
- 03** | Cook in microwave on high for 2 to 3 minutes. Fluff with a fork. Stir in a little more milk or water if thinner cereal is desired. Drizzle oatmeal with 2 teaspoons of honey if desired.

### 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

\* Oatmeal is higher in potassium and phosphorus compared to refined grains, but can be included in most kidney diets. Discuss with your dietitian if you are unsure.

## MICROWAVE MUG EGG SCRAMBLE

Portions: 1 Serving size: 1 cup

Suitable for: Chronic kidney disease non-dialysis, dialysis, diabetes

### Ingredients

- 1 large egg
- 2 large egg whites
- 2 tablespoons 1% low fat milk
- 1/8 teaspoon black pepper

### Preparation

- 01** | Spray a 12-ounce mug with cooking spray. Combine the milk, egg and egg whites in the mug and beat until blended.
- 02** | Place coffee cup in microwave and cook for 45 seconds; remove and stir. Microwave an additional 30 to 45 seconds, until eggs are almost set. (Microwaves vary in cooking time. Adjust as needed to avoid overcooked eggs.)
- 03** | Sprinkle with pepper and enjoy. Add a dash of hot sauce if desired.

### 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



## SNACKS FOR A KIDNEY DIET

*Some people eat three meals a day. Some eat six small meals. Whether you're a regimented eater or a constant 'grazer', at some point, you're likely to eat a snack.*

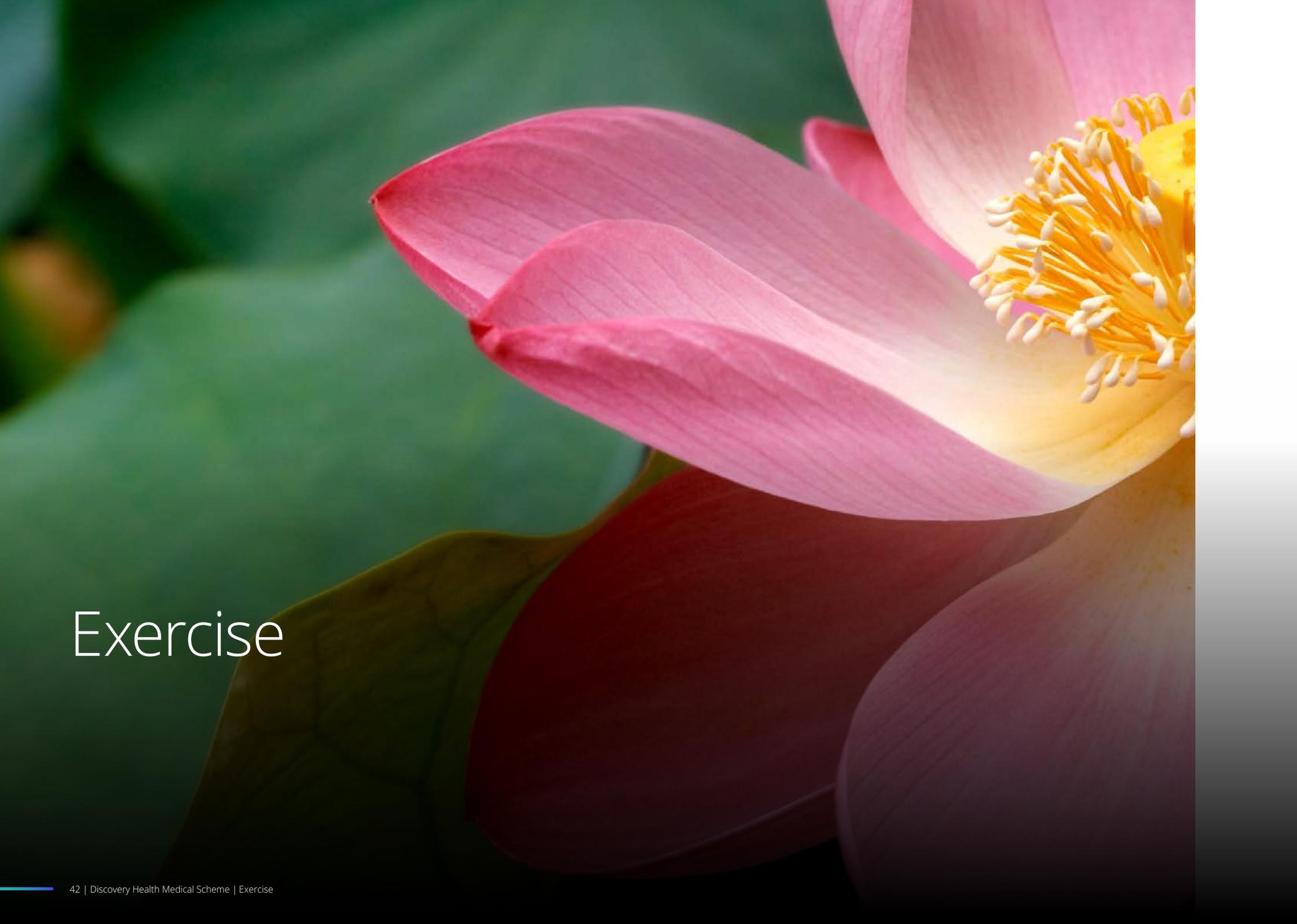
If your kidney disease is severe, your doctor or dietitian may recommend that you limit your intake of phosphorus, potassium, sodium and calcium if your kidneys are no longer able to keep these minerals in balance.

There are many kidney-friendly, healthy and tasty options available.

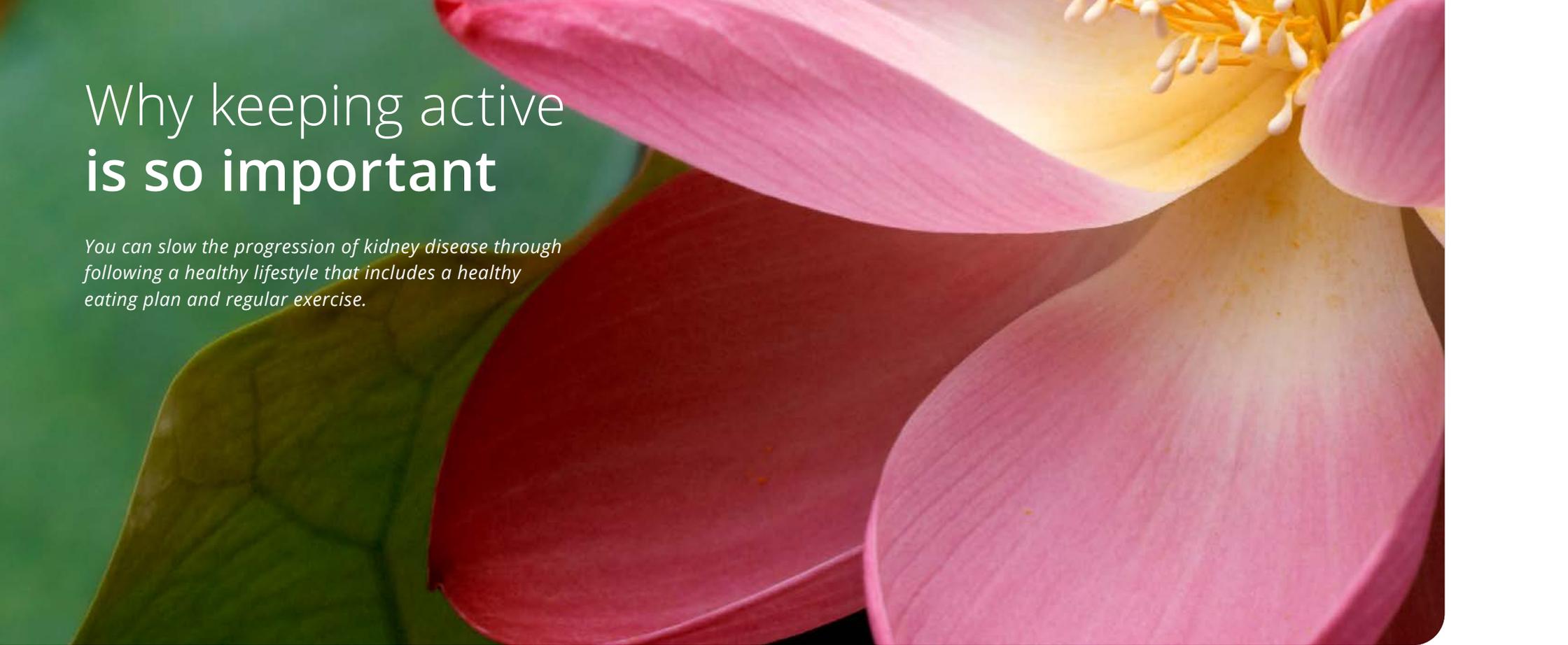
Such as:

- Apples
- Blueberries
- Carrot sticks
- Cherries
- Dried, sweetened cranberries
- Grapes
- Raspberries
- Red bell peppers
- Red leaf lettuce
- Strawberries
- Unsalted popcorn

Snacking can help you increase your kilojoule count when your overall intake and your appetite is low; if you see a renal dietitian, he/she will discuss the best snack choices for you.



# Exercise



# Why keeping active is so important

*You can slow the progression of kidney disease through following a healthy lifestyle that includes a healthy eating plan and regular exercise.*

If you haven't been all that keen on exercise until now it can be difficult to motivate yourself to get up on that couch! But remember: it's not so much what type of exercise you do that counts but the fact that you get some form of exercise on a regular basis.

So if you walk three to four times a week for 45 minutes that's a good start. Try to vary your speed to get your heart rate up, include some stretching at the beginning and end of your walk and see whether you can do some simple strength exercises as well.

Discuss starting any new exercise plan, or continuing a program you're already on when you find out you have early stage kidney disease, with your doctor.

The type of exercise you choose depends on your current physical condition and past exercise. If you have not exercised in a while, it's best to start slowly. Regular training will build strength and fitness.

Kidney disease can make you feel tired, and you should aim to get plenty of rest. But exercise is just as important and activity may help your kidney condition, particularly if you are in the early stages. Exercise can generate energy too! Once you become fitter, you'll probably find your exercise routine less tiring.

In addition to gaining strength, flexibility and endurance, exercise boosts your health by helping you maintain a healthy weight. It can also reduce depression and anxiety and improve your psychological well-being.

No matter what stage of kidney disease you're in, exercise is important for your overall health. Be sure to consult your doctor before you start any exercise routine and work with your dietitian so you are eating a health diet. Working out and eating right go hand-in-hand.

## THE BENEFITS OF EXERCISE



**Weight loss:**  
Exercise burns kilojoules, increases your metabolic rate and delivers a firmer body.



**A stronger heart and healthier lungs:** They adapt and tasks become easier



**Increased energy and better sleep at night.**



**Improved ability to fend off infections.**



**Increased fitness:**  
You'll be able to exercise harder and do more without getting out of breath as easily as before.



**Weight-bearing exercise builds strong bones,** which will stand you in good stead as you get older.



**Protects joints by easing swelling, pain and fatigue and by keeping cartilage healthy.**



**Improved self esteem:**  
Keeping in shape will have you looking good and feeling great.



**Decreased levels of depression, anxiety and stress:** Any form of exercise lowers stress hormones in your blood and increases your body's feel-good hormones, which gives your mood a natural boost and helps you relax.



**Decreased risk of cancer and chronic lifestyle diseases:** Exercise improves your overall health and vitality and lowers blood pressure. The more exercise you do, the lower your risk of developing chronic lifestyle diseases like high blood pressure, diabetes and heart disease.



**Live long – live better:**  
Exercise not only extends your lifespan, it also ensures a better quality of life.

## HOW MUCH EXERCISE SHOULD I DO?

Aim for 30-60 minutes of exercise most days of the week. Choose a cardiovascular activity that you enjoy – for example, walking, running, swimming or cycling. Start slowly and aim to gradually 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.

### Top tip:

Exercise has been scientifically proven to boost mood. It's a great lift-me-up! The best exercise is the one that you enjoy doing the most! As long as its regular, gets your heart rate up and produces a sweat.

## DO YOU HAVE 10 MINUTES? IT ALL ADDS UP!

Many people battle to find time for a half-hour's exercises session every weekday, instead you can build up your daily quota with 10-minute bursts of activity throughout the day – it all adds up!



In 10 minutes you can: Dance to three of your favourite songs, walk around the block or take a quick bike ride.

## GO FOR IT!

Try to do exercise that boosts your heart rate, builds your strength and improves your flexibility.

There are other ways in which you can be more active:

- Gardening and mowing the lawn
- Taking the stairs, not the lift
- Parking the car further from the door at the shops or clinic
- Taking up a sport, such as tennis or bowls
- Taking the dog for a walk
- Dancing

## WILL I LOSE WEIGHT IF I EXERCISE?

Research shows that exercise combined with healthy eating is the best way to lose weight – and keep it off.

### Top tip:

Speak to a personal trainer about a manageable exercise programme. Figure out your exercise preferences: are you a gym bunny or a mountain goat? Choose the exercise that feels right for you.

## DEAR DIARY

Buy yourself a diary dedicated to your health, specifically your kidney disease.

Use your health diary to keep track of important medical information, such as blood and urine test results.

Your health diary is an important tool for you to organise your appointments and treatments.

Use your health diary to make a note of any questions and concerns that you may have for your doctor between visits.

Why not use your health diary to make notes about your activity levels and new forms of exercise that you'd like to try?

## HOW TO SET SMART GOALS

Setting targets is an essential part of getting and staying fit. Ensure success with these smart strategies:

**Specific:** Make goals clear and unambiguous.

**Think:** What do I want to achieve, why (what are the benefits), who, where and with which requirements?

**Measurable:** If a goal can't be measured, how do you know you have made progress or achieved it?

**Think:** How many/ how much do I need to do?

**Achievable:** Make goals realistic and achievable.

**Think:** How can I make it happen?

**Relevant:** Choose goals that matter and you will get support.

**Think:** Is it worthwhile?

**Time bound:** Give goals a target date. A commitment gives focus, motivation and a sense of urgency.

**Think:** What can I do in six months/ six weeks, what can I do today?



# Sticking to your treatment plan

” *Because kidney disease is a condition that sometimes deteriorates over time it is important for you to support your kidney function as much as possible. Through controlling your diet and living a healthy lifestyle you will be able to slow down the loss of kidney function.*

# Medicine 101

*If your doctor prescribes medication for your condition it is very important that you take it as prescribed. Sometimes patients say that they decided to stop taking a certain medication because 'they were taking too many pills' or 'I don't like the side effects of those pills'.*

**Some other reasons for non-compliance, and their solutions, include:**

## 'I ONLY TAKE THE IMPORTANT ONES'

Think about it: would your doctor prescribe 'unimportant' pills? When it comes to the treatment of kidney disease all pills are important and in many cases the dosage is carefully calculated in conjunction with other medication that you are on.

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### Top tip:

Take your pills in order of size or sort into colours and take all the white ones first, or the biggest pills first.

## 'I CAN'T REMEMBER WHEN AND HOW TO TAKE THEM'

Ask your healthcare provider or pharmacist to help you to draw up a daily, weekly or monthly schedule to remind you when to take your pills

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### Top tip:

Buy a pill box that shows the day and time and organise your pills each week.

## 'I GET HORRIBLE SIDE-EFFECTS'

All medicines can have side effects so first check that you are taking the medication properly, for example: the right dose, at the right time, should they be taken with or without food? And speak to your doctor – perhaps there is an alternative medication.

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### Top tip:

Never break tablets, chew them or open capsules to sprinkle powder on your food.

## 'I DON'T LIKE INJECTING MYSELF'

This is understandable – injections can be unpleasant. Speak to your clinic sister to make sure that you are doing it properly.

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### Top tip:

Ask about ways to make the injections less uncomfortable eg. Applying an EMLA anaesthetic cream or patch to numb the area or using ice or massaging the skin.

## 'I FORGET TO TAKE MY MEDICINE'

Put your medicine somewhere that you will see it. eg. next to the kettle. Try to get into a routine when it comes to taking your meds.

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### Top tip:

Set reminders for yourself on your cellphone or ask a friend to help you to remember.

## 'I CAN'T AFFORD THEM'

Depending on your Discovery plan and the cost of your medicines you may find that you need to pay towards your medicine. If this is difficult for you please speak to your doctor or social worker.

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### Top tip:

There are often less expensive choices, discuss these options with your doctor.

## OTHER MEDICINES:

When you are living with chronic kidney disease there are several over-the-counter medicines that you may need to avoid or take in moderation.

## THE MEDICINES TO AVOID/USE WITH CAUTION ARE:

- **Painkillers:** some analgesics, including Aspirin and non-steroidal anti-inflammatories such as Ibuprofen.
- **Laxatives and antacids:** those that contain magnesium and aluminium, such as Milk of Magnesia.
- **Ulcer medicine:** that contains H2-receptor antagonists.
- **Decongestants:** those that contain pseudoephedrine (Sudafed)
- **Indigestion:** some remedies have large amounts of salt.
- **Herbal medicines.**

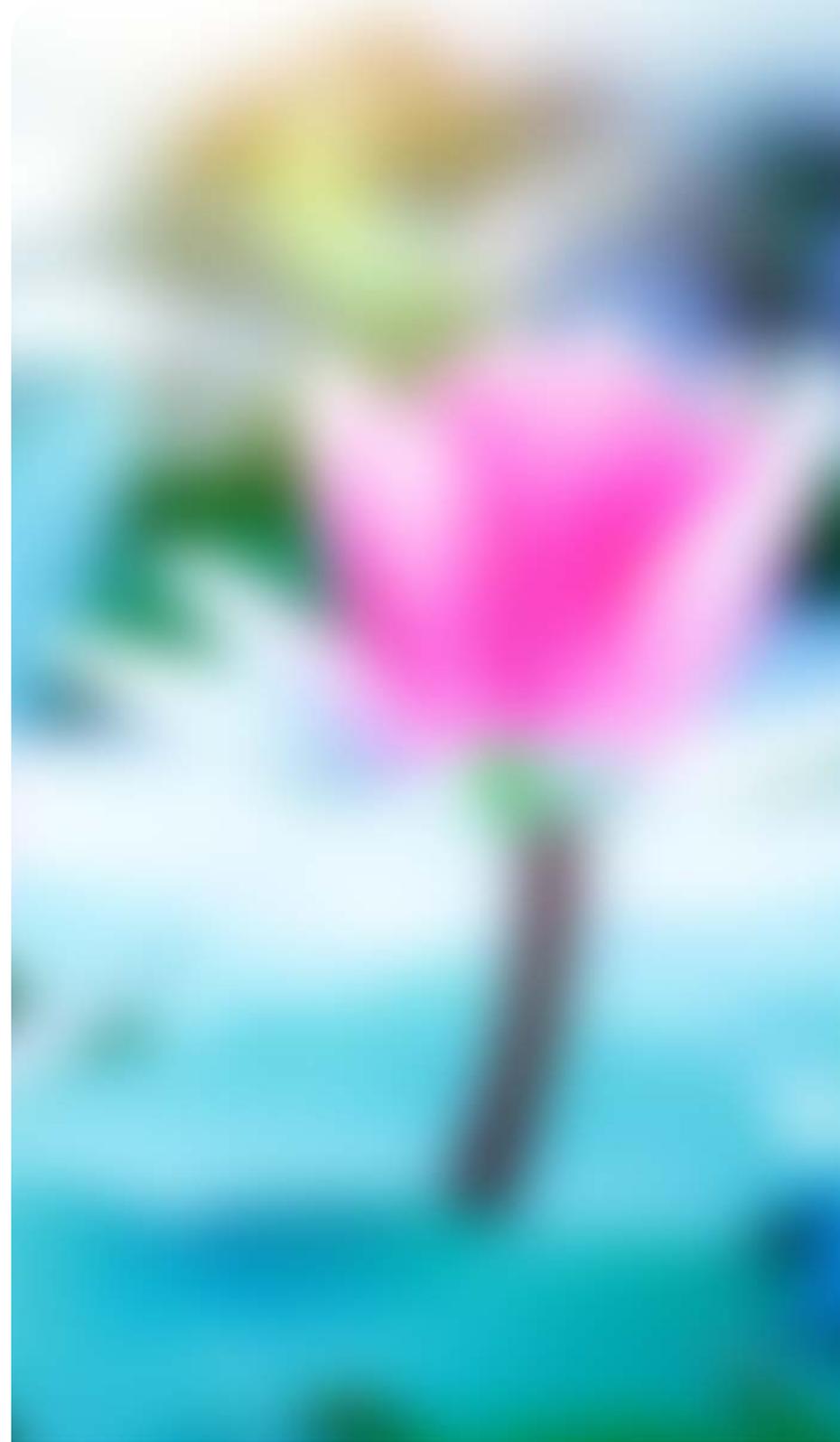
## LET'S RECAP

Your doctor is the only person who can decide whether or not you can stop taking a certain medicine so it's important that you discuss your concerns with him/her before changing your medication. If you have unpleasant side-effects or struggle to take the number of prescribed medicine, talk to your doctor at your next appointment.

**And remember:** your treatment is daily and ongoing so try to work around this. If you are travelling be sure to pack all the medications that you will require during the time you are away. Consistency is the key to success!

Be sure to chat to your doctor about any over-the-counter medicines you are thinking of using and talk to your pharmacist: ensure that she is aware of your kidney condition.

If you have diabetes, high blood pressure or high cholesterol you must take all prescribed medicines and see your doctor for regular check-ups.





# Considering dialysis and transplant

# 5 Ways to Prepare for Dialysis

*It's good to go in with a game plan when it's time for dialysis, whether it's your first session or your 50th. Here are 5 ways to help you prepare and maintain your quality of life on dialysis.*

01 

## GET CLUED UP

Stay in the know about your condition. Read articles from reliable sources and ask questions and learn from your kidney care team. There are some great resources at the end of this book. Other dialysis patients can also share their experiences with you so you get an idea of what to expect; but do bear in mind, it's different for everyone.

02 

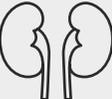
## CALL A MEETING

Talk to loved ones and friends about your need for dialysis and how you're feeling. Preparing them with information can help you feel more prepared too. Getting support early on and often can help you feel prepared for dialysis.

03 

## DECISIONS, DECISIONS

Choosing which type of dialysis is right for you is a big deal. Discuss your options with your nephrologist so you can work together to find what's right for your life stage. You may need to think carefully about your priorities.

04 

## GET ORGANISED

When you are first diagnosed with kidney disease, you should apply for Discovery's Chronic Illness Benefit. Find the form on [www.discovery.co.za](http://www.discovery.co.za); your doctor will fill it in and send it off for you to ensure your approved treatments are covered. For any questions about your cover, call: 0860 998877 and choose the chronic illness option.

You will be given advice on finding an approved dialysis centre close to you.

05 

## BUSINESS AS USUAL

Experts recommend keeping life as normal as possible as you set off on your dialysis journey. Maintaining important relationships and getting to work are key to well-being, both mentally and financially. Talk to your employer about how your job can be tailored to your needs, to allow time for dialysis and so on, once you begin treatment. Find ways to keep up as many normal activities as possible.

Some kidney disease patients never require dialysis, and maintain kidney function at mild or moderate stages, but if your kidney disease is more severe, it may be necessary to start talking about dialysis treatment.

For many people with kidney failure, dialysis greatly improves their quality of life. With some adjustments to diet, lifestyle and sticking with a renal programme, you and your healthcare team will be able to ensure your quality of life is maintained at a high a level as possible.

## PREPARING FOR YOUR FIRST DIALYSIS TREATMENT

Here are some tricks to help you on your way:

- Do 5 minutes of deep breathing to relax: breathe in to the count of 10, hold for 10, breathe out for 10, hold for 10, repeat. Works like magic!
- Speak to a counsellor or therapist if you feel that you're overly nervous and not coping.
- Plan what you're going to do during your dialysis downtime: Take a book, write a journal, pen some old-fashioned letters, plan the week's healthy meals, play games, do an online course, watch a movie on your laptop.
- It can be chilly in the dialysis centre so some home comforts like a small soft blanket or pillow, gloves and a scarf will keep you warm and cozy.

It's completely natural to feel anxious before your first dialysis treatment. Soon it will be routine, and you'll be an old pro.

## ANSWERS TO YOUR QUESTIONS

### At what point is dialysis necessary?

You need dialysis if your kidneys no longer remove enough wastes and fluid from your blood to keep you healthy. This usually happens when you have 10 to 15% of your kidney function left. Some people have symptoms such as nausea, vomiting, swelling and fatigue. But, even if you don't have symptoms yet, you can still have toxic levels of waste in your blood. Your doctor will most likely do some tests that will help him/her work out when it's time for you to start dialysis treatment.

### What does dialysis do?

Dialysis does the following:

- Removes waste, salt and extra water from your body to prevent them building up and making you sick
- Helps to maintain safe levels of potassium, sodium and bicarbonate in your blood
- Helps to control blood pressure

With failed kidneys and without dialysis you could eventually die, this is why it is important to make dialysis as comfortable as possible; it will become part of your life.

### How will I feel after the treatment?

Many people feel tired after dialysis. Try to keep your schedule free for a while after a session.

### Are there different types of dialysis?

Yes, there are two types, called:

- 01** | Haemodialysis and
- 02** | Peritoneal dialysis.

### What is haemodialysis?

In haemodialysis, an artificial kidney machine is used to remove waste and extra chemicals and fluid from your blood.

### How do I choose which dialysis treatment is right for me?

Your choice of either haemodialysis or peritoneal dialysis treatment will have a big impact on your day-to-day lifestyle, such as being able to keep a job if you are working. Consider factors like your situation at home, family support, whether you can travel to a clinic a few times a week, your work situation, and so on. Read up and learn about your options, and ask lots of questions, so you can make an informed choice. If you find that your first choice is not a good fit for your life, you can change treatments later on. Discuss your options with your health care team, family, and friends. It helps to have their support.

### I've chosen haemodialysis – now what?

Several months before your first haemodialysis treatment, an access point to your bloodstream will need to be created. This is done during a minor surgery. Some patients stay overnight in hospital, while others have their access created on an outpatient basis. This access provides an efficient way for blood to be carried from your body to the dialyser and back, frequently, without causing discomfort.

The two main types of access are a fistula and a graft.

Sometimes, an access is made by joining an artery to a vein under your skin to make a bigger blood vessel called a fistula.

If your blood vessels are not appropriate for a fistula, the doctor may use a soft plastic tube to join an artery and a vein under your skin. This is called a graft.

Occasionally, an access is made by means of a narrow plastic tube, called a catheter, which is inserted into a large vein in your neck. This type of access is often for temporary use, but is sometimes used for long-term treatment too.

### How do I care for my fistula/graft?

Always keep the area clean and dry.

Don't wear tight clothes or accessories on the area to avoid constriction.

Avoid having your blood pressure taken or any intravenous injections or drips on your fistula arm. Don't put pressure on the places where the needles went in, and remind your clinic nurse to rotate needling to prevent problems (like aneurysm – bulging) in the blood vessel wall.

### How long do haemodialysis treatments last?

The time needed for your dialysis depends on:

- how well your kidneys work
- how much fluid weight you gain between treatments
- how much waste you have in your body
- how much you weigh
- the type of dialysis machine you're going to use

Usually, each haemodialysis treatment lasts 3 – 5 hours and is done three times a week.

### I've chosen peritoneal dialysis – what happens next?

Before you have peritoneal dialysis a soft tube called a catheter will be inserted into your abdomen through a small cut, usually next to your belly button. Once your catheter has been inserted, it will remain in place.

### What can I expect at a peritoneal dialysis session?

During the treatment your abdominal area (called the peritoneal cavity) is slowly filled with dialysis solution through the catheter. The blood stays in the arteries and veins that line your peritoneal cavity; not mixing with the solution. Extra fluid and waste products are drawn out of your blood and into the solution. You are hooked up to a bag that looks like a drip, but you are free to move around, work, or do other activities at home.

### How long will I need dialysis treatment?

When kidney disease progresses to kidney failure over time, your kidneys can't recover and you will need dialysis for the rest of your life, or until you are able to receive a kidney transplant.

### Does dialysis hurt?

Treatment should not be painful. .

### What does it feel like to be a dialysis patient?

Many patients live normal lives except for the time they need to put aside for treatments. Dialysis usually makes you feel better because it helps many of the problems caused by failing kidneys. Give yourself and your family some time to get used to dialysis.

### Can I still travel?

Yes. There are dialysis centres all over South Africa and the world. You will need to research the centre in the location you want to go to first, then make an appointment before you go. Remember to take any information (like latest lab results) you might need. If you do peritoneal dialysis you would either take your equipment with you, or discuss with your doctor having in-clinic treatment while you're away.

### Can I still work?

Yes, most people go back to work once they have become used to dialysis treatment. Talk to your employer about the time you will need in order to attend clinic, and about the type of work that you can do. There are lots of reasons that keeping your job is a good idea, not least of all having a purpose, keeping you motivated and providing a sense of satisfaction.

Talk to your healthcare professional if you experience any discomfort during treatment

# Advantages and disadvantages of the two dialysis options

## ADVANTAGES AND DISADVANTAGES OF HAEMODIALYSIS



### ADVANTAGES

- No equipment needed at home
- Treatment is done three times a week
- You have regular contact with staff and other dialysis patients
- You're only connected to a machine during dialysis (leaving you free of the machine for four days a week)
- There is a lower risk of infection
- Treatment is administered by a healthcare professional



### DISADVANTAGES

- You need to travel to a dialysis centre
- It is time consuming (3-5 hours per session)
- The times may be inflexible
- You can't move around during treatment
- Two needles are inserted at each treatment
- Waste builds up between treatments
- You need to follow diet and fluid restrictions

## ADVANTAGES AND DISADVANTAGES OF PERITONEAL DIALYSIS



### ADVANTAGES

- You have greater independence and flexibility since treatment is self-managed at home
- No needles are required
- You have fewer restrictions on diet and fluid intake
- You have better blood pressure control
- You can enjoy freedom of movement during treatment



### DISADVANTAGES

- Treatment consists of daily exchanges so there are no 'off days'
- You have a permanent catheter in place
- The risk of infection is greater
- There is a possibility of weight gain and interference with glucose control
- It requires training and storage of supplies at home

# Kidney transplant

*Dialysis can help you live with and manage kidney disease for many years. However, not everyone is suitable for a kidney transplant. Some people have conditions, such as cardiovascular disease or cancer that make them unsuitable for surgery.*

## **WHERE DOES THE KIDNEY COME FROM?**

A kidney is received from a donor – either someone who has died with healthy kidneys or a living person with two healthy kidneys (we each only need one healthy kidney).

## **HOW DO I FIND THE RIGHT KIDNEY?**

Medical tests are done to establish that a kidney is found that most closely matches your own. Relatives are often able to donate a kidney because it is easier to find a good match with a blood relative than an unrelated donor. However, kidneys from unrelated donors can also result in successful transplant with a good long-term outcome.

## **HOW LONG DO I HAVE TO WAIT?**

The waiting list for donor kidneys in South Africa is a long one and the average waiting time in South Africa is more than four years, according to the National Kidney Foundation of South Africa. The number of people who need kidneys unfortunately far exceeds the number of donors. A kidney is an organ that can be donated by a living donor, as we each only need one kidney. The most suitable (most likely match) living donors are often family members over 18 years of age that meet stringent compatibility criteria.

Your place on the transplant list depends on a number of issues such as how long you have been waiting, and other health factors.

Donors can register with the Organ Donor Foundation: [www.odf.org.za](http://www.odf.org.za)

## **WHAT HAPPENS DURING A TRANSPLANT?**

The new kidney is implanted into your body while you are under general anaesthetic. A cut of about 20cm is made in your lower abdomen and the donor kidney is placed in a hollow space just outside the abdominal cavity, called the iliac fossa. The artery and vein are attached to nearby blood vessels and finally the ureter is linked to the bladder. The cut is closed inside and out. The operation usually takes three to four hours.

## **WHAT HAPPENS AFTER MY KIDNEY TRANSPLANT?**

You will need to take immunosuppressant medicine for the rest of your life to prevent your body from rejecting your new kidney. These medicines do have possible side effects, including increased risk of infection, change in appearance (fuller face, acne and weight gain), diabetes, osteoporosis (thinning of the bones), and hirsutism (abnormal growth of hair). Most of these side effects can be minimized or avoided completely by ensuring regular follow up and careful management of the drugs being used.

A kidney transplant, where a new kidney replaces the damaged ones in your body, is the best treatment for end-stage renal failure.



In case of  
emergency

# MedicAlert

## Make sure everyone knows about your condition in case of an emergency.

When you live with a chronic condition and get ongoing treatment, 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 do the right thing.

MedicAlert is a non-profit organisation that ensures that in an emergency medical staff have immediate access to important medical information about you. This could help them to save your life.

### **HOW DOES MEDICALERT WORK?**

When you join MedicAlert your medical details are recorded on a database: this will include your kidney disease, what stage, and if you are on dialysis – what type of dialysis you are on. First responders to an emergency will be able to contact the MedicAlert hotline to access your files, ensuring that you receive appropriate treatment.

**A MedicAlert bracelet speaks for you when you cannot.**

**For more information:**

Call **086 111 2979**

Email **info@medicalert.co.za**

See **www.medicalert.co.za**

A close-up photograph of a pink lotus flower in full bloom, with numerous water droplets on its petals. The flower is reflected in a dark, still surface of water below it. The background is a soft, out-of-focus bokeh of pink and light brown tones, suggesting a pond or garden setting. The overall mood is serene and natural.

# Glossary of medical terms

## YOUR A TO Z OF KIDNEY HEALTH

### Acute Kidney Failure

Sometimes kidney failure occurs rapidly and this is called acute kidney failure. This may be a result of injury, infection, or other causes. For acute kidney failure, dialysis treatment may be urgently needed for a period of time, but kidney function often recovers.

### Anaemia

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.

### Calcitriol

A hormone that is converted from Vitamin D by the kidneys, which maintains normal calcium levels for healthy bones.

### Continuous ambulatory peritoneal dialysis (CAPD)

Form of peritoneal dialysis in which dialysis fluid is exchanged at regular intervals throughout the 24-hour day.

### Creatinine

Waste product of muscle activity.

### Cross match

Blood test to measure the compatibility of a blood transfusion, or of a transplant donor and recipient.

### Daily eating plan

Plan worked out by a dietitian and a kidney patient that determines the types and amounts of foods which should be eaten daily.

### Dialysis

From Greek, meaning 'to separate or dissolve'. A treatment for kidney failure that removes wastes and water from the blood.

### Dialysis fluid

Special fluid used in dialysis into which wastes are passed. Also called dialysate.

### Dialyser

The part of an artificial kidney machine that acts like a filter to remove wastes from the blood.

### End-stage renal disease (ESRD)

Stage 5 in chronic kidney disease when treatment, such as dialysis or transplant, becomes necessary. 'End-stage' refers to the end of kidney function. Also called end-stage renal failure or end-stage kidney failure.

### Erythropoietin (EPO)

Hormone that stimulates the bone marrow to produce red blood cells. The hormone is naturally produced by the kidneys, and is also available as a family of injectable medications.

### Fistula

Commonly used method of providing access to the bloodstream in which a vein and an artery in the arm are joined together.

### Graft

A vein and an artery in the arm are joined with a piece of special tubing. The graft provides access to the bloodstream for dialysis.

### Haemodialysis

Treatment for kidney failure in which the blood passes through a dialyser to remove wastes and water.

### Haemoglobin

The protein in red blood cells that carries oxygen.

### Heparin

Substance often added to blood during haemodialysis to prevent it from clotting in the dialyser.

### Home nocturnal haemodialysis

Method of carrying out haemodialysis at home while you sleep.

### Hormone

Chemical messenger that regulates bodily functions such as blood pressure and the making of red blood cells.

### Immune system

System that protects the body from foreign materials such as viruses and bacteria.

### Immunosuppressants

Medications that suppress (decrease) the body's immune system and help prevent rejection of a transplanted kidney.

### Insulin

Hormone produced by the pancreas that regulates the level of glucose (sugar) in the blood.

### Jugular vein

Blood vessel located in the side of the neck sometimes used to provide catheter access for haemodialysis.

### Kidney

One of two organs located at the back of the abdominal cavity on each side of the spinal column.

### Kidney failure

Progressive deterioration in kidney function. Also called chronic kidney disease (stages 1 to 5).

### Membrane

Porous material in the dialysis machine that is used to filter wastes from the blood.

### Nephron

The functional unit of the kidney that acts to maintain the body's chemical balance. Consists of a filter (glomerulus) attached to a tubule.

### Peritoneal cavity

Abdominal cavity (tummy) that contains the intestines and other internal organs.

### **Peritoneal dialysis**

Treatment for kidney failure in which dialysis fluid is introduced into the peritoneal cavity to remove wastes and water from the blood.

### **Peritoneum**

Thin membrane that encloses the peritoneal cavity and surrounds the abdominal organs.

### **Phosphate binder**

Medication that binds with some of the phosphate when the food is in the stomach and intestine causing the phosphate to be passed in the stool instead of letting it be absorbed into the blood.

### **Phosphorus (phosphate)**

Mineral in many nutritious foods. In the body fluids it is regulated by the kidneys. At normal levels, keeps bones strong and healthy. At high levels, causes itching, painful joints, and parathyroid and bone disease.

### **Platelets**

Cells in the blood that are involved in blood clotting.

### **Potassium**

Mineral in the body fluids regulated by the kidneys. At normal levels, helps nerves and muscles work well. At high levels, may affect the heart rhythm and function.

### **Protein**

Substance obtained from food that builds, repairs and maintains body tissues. High sources of protein are mainly from animal foods.

### **Red blood cells**

Cells in the blood that carry oxygen to the body tissues.

### **Renal artery**

Major vessel that delivers blood to the kidneys for cleaning.

### **Renal medulla**

The innermost part of the kidney, composed mostly of collecting tubules.

### **Renal pelvis**

Funnel-like structure that collects urine from the kidney and delivers it to the ureter.

### **Renal replacement therapy (RRT)**

A treatment, such as dialysis or transplantation, that attempts to replace the normal functioning of the kidneys.

### **Renal vein**

Major vessel that returns freshly cleaned blood from the kidneys to the circulatory system.

### **Renin**

Hormone produced by the kidneys that regulates blood pressure.

### **Serum creatinine level**

Blood test to measure the level of creatinine, that is a waste product of muscle activity. As kidney function decreases, the serum creatinine level increases.

### **Sodium**

Mineral in the body fluids that increases thirst and is regulated by the kidneys. Affects the level of water retained in the body tissues.

### **Subclavian vein**

Blood vessel located underneath the collarbone sometimes used to provide temporary access for haemodialysis.

### **Tubule**

Tube in the nephron that collects and processes urine from the glomerulus before the urine passes into the renal pelvis.

### **Ultrafiltration**

Process by which blood entering a dialyser is placed under pressure to remove excess water.

### **Urea**

Waste product from the breakdown of protein.

### **Uraemia**

From Greek, meaning 'urine in the blood'. Uraemia develops as the kidneys fail and are unable to remove wastes from the body. As the kidneys continue to fail, more waste products build up in the blood. Symptoms may become very severe, including shortness of breath, nausea and vomiting, itchy skin and headaches. Serious problems may occur because of high blood pressure, anaemia or the increase in acid and potassium levels in the blood. When severe uraemia develops, treatments such as dialysis and transplantation are usually needed.

### **Ureter**

Tube that takes urine from the renal pelvis and delivers it into the bladder.

### **Urethra**

Tube from the bladder that takes urine out of the body.

### **Urinalysis**

Test to measure the presence of infection, protein and other substances in the urine.

### **Urinary tract obstruction**

Kidneys may be damaged if there is an obstruction of the urinary outflow. Obstructions may occur in the ureters or at the outlet of the bladder. Birth defects can cause narrow ureters that could lead to kidney damage in children. In adults, an enlarged prostate gland, kidney stones and tumors can cause obstructions.

### **Vein**

Blood vessel returning blood to the heart.



# Contact details and resources

## IMPORTANT TELEPHONE NUMBERS

Name

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My GP

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My kidney specialist

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My clinic

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My dialysis unit

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My dialysis technologist/nursing sister

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Renal dietitian

---

Psychologist/social worker

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**Discovery Health: 0860 998877**

## CONTACT DETAILS FOR MEDICAL INFORMATION

### National Kidney Foundation of South Africa

Telephone: 011 447 2531

[www.nkf.org.za](http://www.nkf.org.za)

### Cape Kidney Association

[www.capekidney.org](http://www.capekidney.org)

### Renal Care Society of SA

A professional association for improving patient care

[www.renalcaresoc.org](http://www.renalcaresoc.org)

### Diabetes SA

Telephone: 086 111 3913

[www.diabetessa.co.za](http://www.diabetessa.co.za)

### South African Heart Association

Telephone: 021 931 8210

[www.saheart.org](http://www.saheart.org)

### Organ Donor Foundation

Telephone: 0800 22 66 11

[www.odf.org.za](http://www.odf.org.za)

### SAVES: Living Will Society

Telephone: 031 266 8511

[www.living.will.co.za](http://www.living.will.co.za)

## CONTACT DETAILS FOR SUPPORT GROUPS

### KidneyBeanz Trust

Supporting children with life-threatening kidney disease

[www.kidneybeanz.co.za](http://www.kidneybeanz.co.za)

### Hospice association

Telephone: 021 531 0277 (head office)

[www.hpca.co.za](http://www.hpca.co.za)

### SA Depression and Anxiety Group (SADAG)

[www.sadag.org](http://www.sadag.org)

Suicide crisis line: 0800 567 567 or SMS to 31393

### Facebook group: Let's Talk Dialysis

[www.facebook.com/pages/Lets-talk-Dialysis/346686432068446?fref=ts](https://www.facebook.com/pages/Lets-talk-Dialysis/346686432068446?fref=ts)

## CONTACT DETAILS FOR MEDICINE AND POISON INFORMATION

### Poisons Information Centre (Red Cross Children's Hospital)

Telephone: 021 689 5227

### Medicine Information Centre (UCT)

[www.mic.uct.ac.za](http://www.mic.uct.ac.za)

Telephone: 021 406 6829

## INTERNATIONAL INFORMATION AND SUPPORT

### Renal Support Network

[www.rsnhope.org](http://www.rsnhope.org)

### Beat Kidney Disease

Taking control of kidney disease the natural way

[www.beatkidneydisease.com](http://www.beatkidneydisease.com)

### Davita

Health and medical information

[www.davita.com](http://www.davita.com)

### Renal Info

Support and resources for people with kidney disease

[www.renalinfo.com](http://www.renalinfo.com)

### Society for Kidney Support

[www.societyforkidneysupport.org](http://www.societyforkidneysupport.org)

### Global Dialysis

Empowerment for patients wanting to travel

[www.globaldialysis.com](http://www.globaldialysis.com)

### American Association of Kidney Patients

[www.aakp.org](http://www.aakp.org)

### Nephkids

Cyber support group

[www.cybernephrology.ualberta.ca/nephkids](http://www.cybernephrology.ualberta.ca/nephkids)

### National Kidney Foundation (certain states, US)

[www.kidney.org](http://www.kidney.org)

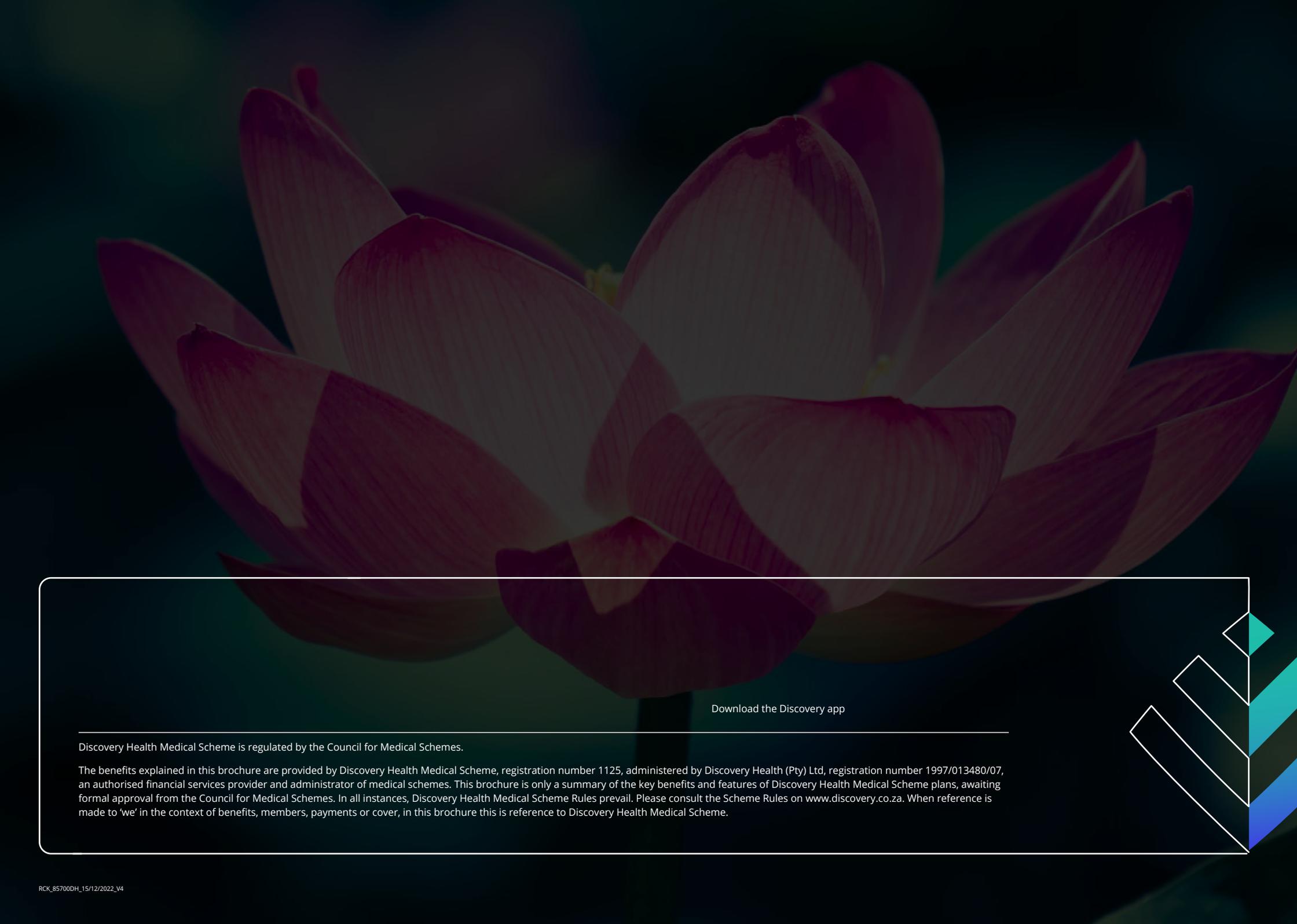
### Livestrong

[www.livestrong.com/sscat/kidney-disease](http://www.livestrong.com/sscat/kidney-disease)

### Daily Strength

Online support group

[www.dailystrength.org/c/Dialysis/people](http://www.dailystrength.org/c/Dialysis/people)



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