My Kidneys My Health

Living with early stage chronic kidney disease

Kidney® Health Australia

Prevent, Detect, Support.

Contents

Acknowledgements:
Kidney Health Australia acknowledge with thanks the following people who contributed their professional and personal expertise to the development of this resource; Debbie Fortnum, Kirren Grennan, Joy Harrington, Dr Marie Ludlow, Fabian Marsden, Prof Kirsten McCaffery, Dr Angus Ritchie, Wendy Shepherdley, Dr Tim Usherwood, Dr Sheena Wilmot and Dr Tim Mathew. We also appreciate the patients who contributed their personal stories.

Kidney Health Australia would like to thank the funders of this project; The John and Thirza Daley Charitable Trust who provided a Perpetual Grant and Joe White Bequest.

Citation:
My Kidneys My Health
Living with early stage chronic kidney disease
Kidney Health Australia, Melbourne 2015

JOY'S STORY

My name is Joy. I am now a kidney transplant recipient. My story started many years ago when I was 40 and had high blood pressure. I routinely saw my General Practitioner (GP) every six months. Although at times my blood pressure was much higher than it should have been, I had no worrying symptoms. Even though my GP talked to me about the possible risk to my kidney health I didn't have regular kidney health checks.

Several years later I was feeling very unwell. After a kidney health check my GP referred me to a kidney specialist. I was told that I had lost over

90% of kidney function. The kidney specialist explained, that like me, most people with serious kidney disease have no warning signs or symptoms and feel quite well until their kidneys have almost stopped working.

I still wonder whether my long term outcome may not have been so serious if I had asked more questions of my GP, and been more involved in the monitoring and management of my blood pressure. I realise now that I didn't have a good understanding of the importance of taking medicines as prescribed.

The diagnosis of end-stage kidney failure was an unexpected shock for my family and me. However, I was very fortunate to have a kidney transplant last year, when my partner Phil generously donated his kidney.

I hope that this booklet can help you, and your family, through the initial diagnosis stages of chronic kidney disease (CKD). Kidney disease can be slowed down. You are not alone, and there is a community available to you for help and information.

Joy

About this handbook

Welcome to the *My Kidneys, My Health* handbook. This handbook has been created to answer some questions and provide guidance for people newly diagnosed with early stage chronic kidney disease. You may be the person who has just received this diagnosis of kidney disease, or you may be a loved one.

Detect
Understand kidney disease and how it is diagnosed

Prevent
Ways to slow down or stop kidney damage

Support
How to help yourself and how others can help you

Introduction

1 in every 10 adult Australians has some sign of kidney disease, so you are not alone and you can still lead a full and positive life.

- You can slow the damage by following simple treatments
- It is easy to continue to get your kidneys checked
- Blood pressure tablets actually protect the kidneys
- Your health care team are there to support you

My Kidneys, My Health aims to answer questions that you may have about kidney disease, and help to support you through your journey.

It can connect you to resources, networks, and organisations that provide you with guidance, peer support, and a sense of community. It provides basic information about:

- The kidneys
- What happens when kidneys are damaged
- Kidney diseases
- Tips for healthy living and lifestyle changes that reduce the kidney damage
- Treatments that slow the damage to your kidneys

This book does not replace advice from your health care team. It may be your doctor, a practice nurse or an Aboriginal health worker who helps you to monitor and manage your kidney disease. They are all part of a health care team.

Detect

Understand kidney disease
and how it is diagnosed

How to use this handbook

REMEMBER

Highlights important and encouraging information to keep in mind as you begin your kidney journey.

CALL TO ACTION

Contains simple actions you can do now to begin taking control of your health.

RESOURCES

Highlights available resources to learn more and help you manage your health.

- Written material including Kidney Health Australia fact sheets, books and handbooks which can be freely downloaded from **www.kidney.org.au**
- Videos
- Health or government websites
- Phone apps, to help manage your health
- Social and support groups
- Freecall national phone services including the Kidney Health Information Service (KHIS) **1800 454 363***

This handbook is meant as an introduction only and does not replace advice from your healthcare team. Always consult your healthcare team for more advice.

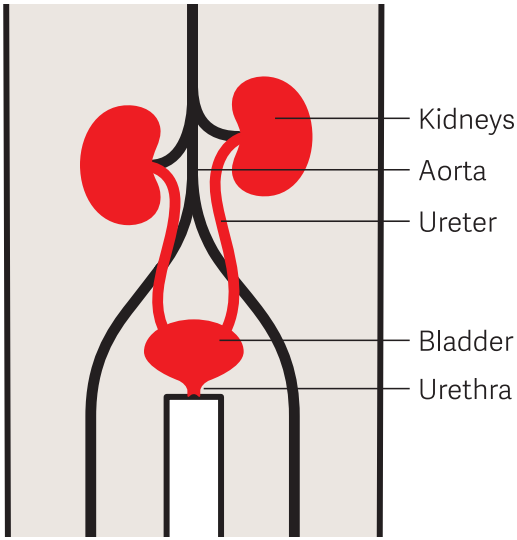
*KHIS is a free service that offers information, support, referral and advice to both those affected by kidney disease and health professionals. The KHIS service also offers TelEConnect which is a national service that connects anyone affected by kidney disease with others who have a similar experience. Call our Kidney Health Information Service to connect today!

Healthy kidneys

What are kidneys?

Most people are born with **two kidneys**, each growing to the size of your fist. Your kidneys are bean shaped and are positioned near the middle of your back, on either side of your backbone (spine).

Your kidneys are part of the body's urine system.



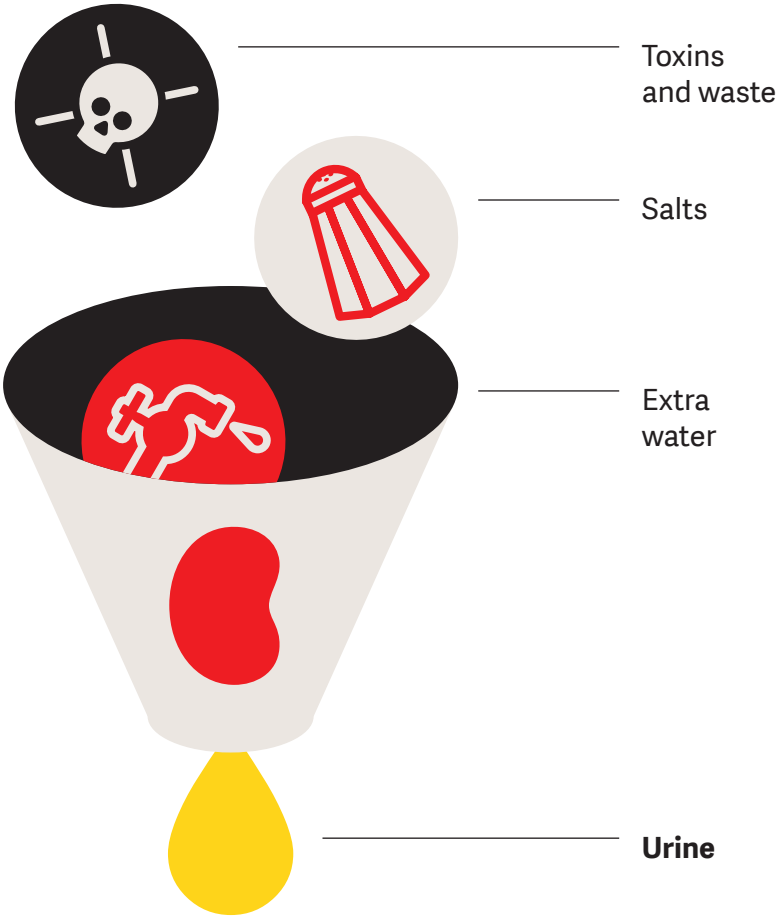
What do healthy kidneys do?

Kidneys are the unsung heroes of the body! Your kidneys have many important roles to play in keeping your body healthy and getting rid of body wastes.

Making urine

Every day you drink and eat food that is absorbed from your stomach (*tummy or belly*) into your blood. This becomes energy for your body to use.

However there are lots of leftover waste that your body does not need and has to get rid of. This is where the kidneys come in.

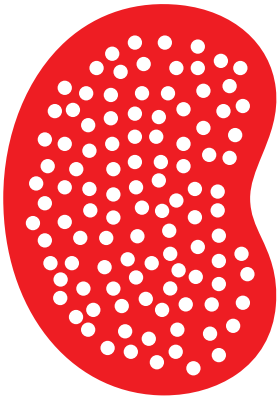


The kidneys have over a million tiny filters (*nephrons**) that clean the blood removing the extra water, salts and waste products. This becomes your urine (*wee*).

Urine leaves the kidneys and flows down through narrow tubes called ureters to the bladder where it is stored.

When your bladder is full you feel the need to pass urine.

When you go to the toilet urine passes out of your body through a tube from the bladder called the urethra.



**Most kidney diseases attack the nephrons, and stop them working properly.*

What else do kidneys do?

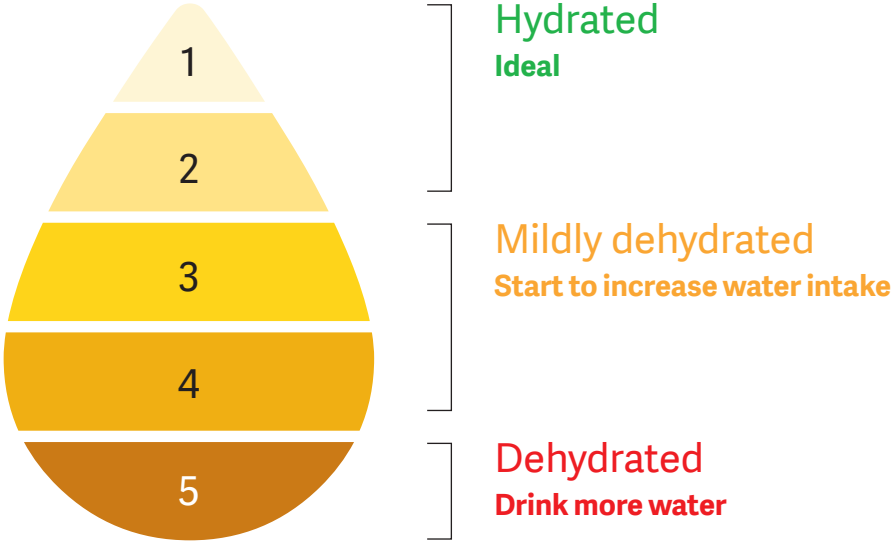
Improve health of bones and blood
Kidneys activate vitamin D which is needed to keep your bones strong. They also make a hormone, erythropoietin (*EPO*) that tells your bone marrow to make more red blood cells.

Controlling blood pressure
Kidneys make hormones that control how well your blood vessels expand and contract. This controls your blood pressure.

What can the colour of my urine tell me?

Urine colour can tell us a lot. The colour of urine can range from a dark brown to strawberry yellow to pale yellow.
Healthy urine should be pale yellow and clear.

What colour is your urine?



The amount of water in your body is called hydration.

Hydration is related to the amount of water you are drinking each day. Heat and exercise affect your body's hydration levels. It is important to drink water when exercising or in hot weather.

A sign of your body having enough water (being hydrated) is that your urine will look a pale yellow colour. If your body does not have enough water your urine will be dark yellow/brown.

What else should I look for in my urine?

Speak to your doctor if you notice:

- Frothy urine – a sign of protein in the urine
- Unexplained changes to how often you pass urine
- Urgency or pain
- Blood in your urine that is not due to a menstrual period
- Changed urine colour – it is important to note this can be due to foods or medicines

CALL TO ACTION

Check the colour of your urine regularly and if the colour is too dark drink some water. If the colour is unusual, red or the urine is frothy speak to your doctor or health care team.

RESOURCES

www.kidney.org.au

Kidney Health Australia fact sheets:
Albuminuria (protein in the urine), Urinary incontinence, Urinary tract infections, Blood in the urine, Kidney stones, Drink water instead

Kidneys that are not working properly

What is the difference between healthy kidneys and kidneys that are not working properly?

Kidneys usually start healthy. They can then stay healthy, be damaged slowly (*chronic damage*) or be damaged quickly (*acute damage*). Your kidneys age as you age so they do slow down.

You cannot see the difference between healthy kidneys and kidneys that are not working properly. Changes happen inside your body. If you know your kidneys are not working perfectly it is probably because your doctor did a blood test or a urine test.

A healthy kidney does not let albumin pass into the urine. A damaged kidney lets some albumin pass into the urine. The more albumin that is in your urine, the greater the damage to your kidneys.

	Healthy Kidney	**Kidneys that are not working properly**
Blood pressure	Should be 120/80 mmHg or below	140/90 mmHg and above
Urine	– Clear – No protein (*albumin*) – No blood	– Protein (*albumin*) or – Blood or – Cloudy or – Normal
Blood test for: urea, creatinine or estimated glomerular filtration rate (*see page 19*)	– Normal level of urea – Normal levels of creatinine – Normal level of eGFR	– Above normal levels of urea and creatinine – Low level of eGFR

Is kidney damage permanent?
Acute damage happens quickly. For example, your kidneys may stop working properly because of a sudden loss of large amounts of blood (*e.g. during surgery*) or as a result of an accident. A sudden change in kidney function is called **acute kidney injury**. Most kidneys will get better after acute kidney injury but it does increase your risk of chronic kidney disease.

Chronic damage happens over a long period of time this is known as **chronic kidney disease (*CKD*)**. It is an ongoing condition. It is permanent, but for some types of kidney disease the damage can be slowed down. Your doctor can advise if there are treatments to slow down the damage to your kidneys.

Chronic kidney disease is called a *silent disease* as there are often no warning signs. It is not uncommon for people to lose up to 90 per cent of their kidney function before getting any symptoms.

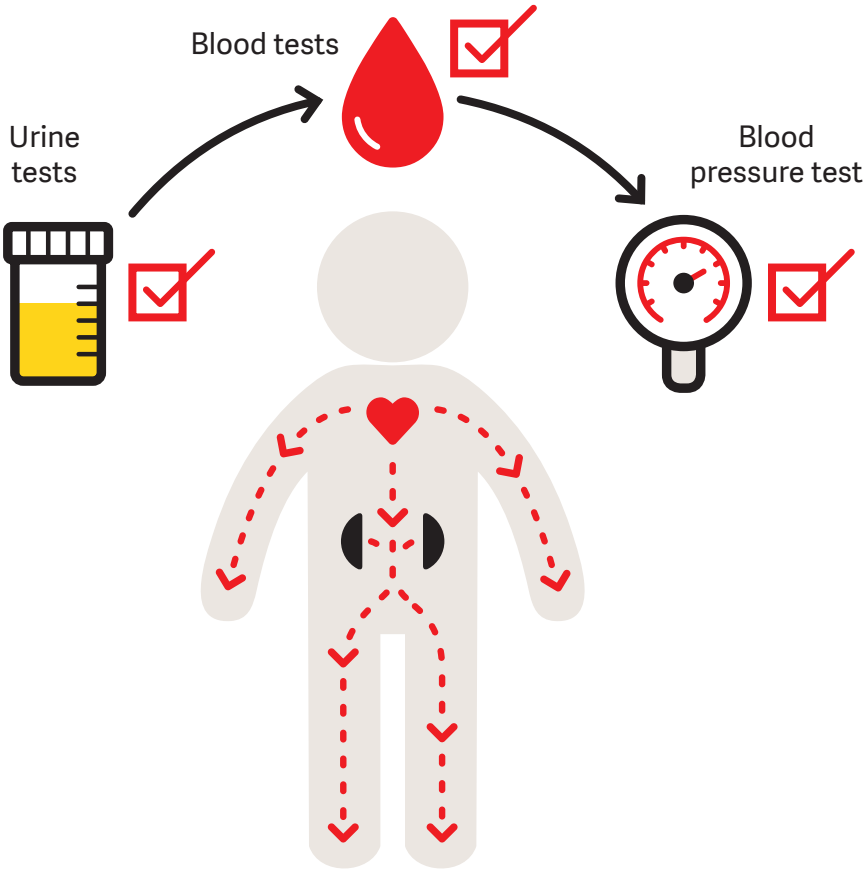
RESOURCES

- **www.kidney.org.au** > Acute Kidney Injury
- **Kidney Health Australia fact sheets:**
  All about chronic kidney disease, Acute kidney injury

What are the tests that measure kidney health?

If you are reading this handbook, then it is likely you have already had some tests to measure how well your kidneys are working and to help plan your treatment.

The following three tests are often called the *Kidney Health Check* and you may already be familiar with these:



Urine tests
Urine tests are used to check if your kidneys are leaking things into your urine that are not supposed to be there. Sometimes when your kidneys are damaged they can leak a substance called albumin into your urine. Albumin is the same as protein. This is called albuminuria. Albuminuria is best detected by a special urine test called albumin:creatinine ratio (*ACR*).

You will need to collect a sample of your urine (*wee*) for this test.

Blood tests
A blood test is used to work out how well your kidneys are cleaning your blood and removing wastes. This is called your estimated glomerular filtration rate (eGFR).

eGFR means:
- estimated (*worked out by sums*)
- Glomerular (*kidney filters – glomeruli*)
- Filtration (*filter*)
- Rate (*how well they filter*)

Your eGFR result is written in millilitres per minute per 1.73m^2. It may look something like this: 67 mL/min/1.73m^2.

Your eGFR tells how much of your kidneys are working (*percent*).

100 mL/min/1.73m^2	**=**	**working well**
50 mL/min/1.73m^2	**=**	**working at 50% percent**
30 mL/min/1.73m^2	**=**	**working at 30 percent**

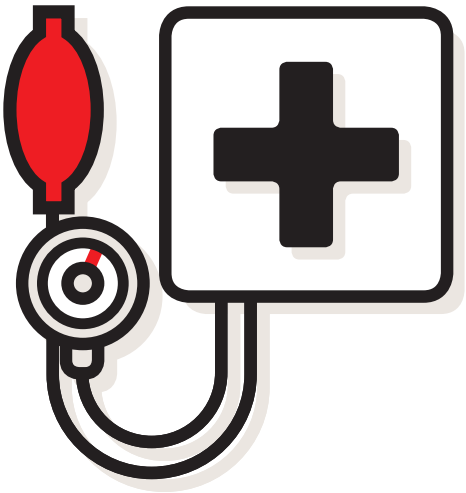
Blood pressure
A blood pressure test is also usually performed as part of a Kidney Health Check. Blood pressure is usually measured by wrapping an inflatable cuff around your upper arm.

Blood pressure is recorded as two numbers, for example *140 on 90*.

It is recommended that you talk to your health professional to work out your ideal blood pressure result.

To be diagnosed with chronic kidney disease, your Kidney Health Check blood tests or urine tests must be abnormal for at least three months.

Other tests
You may also require other tests or scans to better understand what is happening to your kidneys.



Confirming the diagnosis
At any stage in this process your doctor may refer you to a kidney specialist called a nephrologist for further care. This is not always necessary, as most cases of early chronic kidney disease can be successfully managed by your doctor.

CALL TO ACTION

If you have early chronic kidney disease, it is recommended that your doctor or health care team do a Kidney Health Check every year.

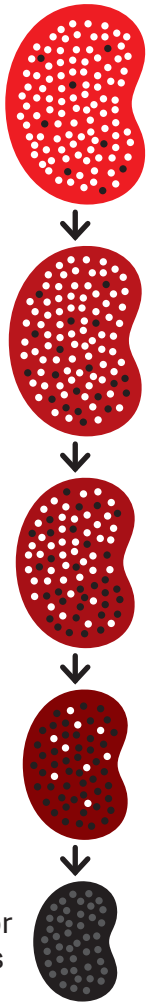
RESOURCES

- **www.healthtalk.org** > Categories > Long term conditions > Kidney Health > How and why kidney function is monitored
- **Kidney Health Australia fact sheets:** Kidney disease tests and procedures, eGFR, Blood pressure and chronic kidney disease

Stages of chronic kidney disease

Kidney Disease is classified into stages depending on your eGFR. At every stage the albumin level can vary. Albumin indicates more damage happening to your kidneys.

Stage	eGFR	Amount of albuminuria		
		Normal	Small albumin level	Large albumin level
1	More than 90			
2	60–89			
3	30–59			
4	15–29			
5	under 15 or on dialysis			



The following descriptions are a general guide only, and may not apply to everyone. When you feel unwell may be different to other people. Many factors affect the progress of kidney disease and these are not completely understood.

Early stages (*Stages 1–2*)
Most people with early chronic kidney disease feel normal. If your chronic kidney disease is in the early stages it is important to talk to your doctor before starting any new medicines. This includes any medicines that you can buy from the chemist or supermarket, and also includes vitamins, and *natural* or herbal medicines. Management includes keeping your blood pressure in the normal range and making healthy lifestyle choices.

Middle stages (*Stages 3–4*)
Discovering kidney disease during this stage is more common as the level of wastes (urea and creatinine) in your blood rises. You may begin to feel unwell and notice changes in the number of times you pass urine. As kidney function slows down, your blood pressure may rise. Management can slow the progress of kidney disease and reduce the chance of other complications.

Later stages / end stage kidney disease (*Stage 5*)
Even with the best management, chronic kidney disease sometimes leads to Stage 5 (*or end-stage kidney disease*), which requires dialysis or a kidney transplant to stay alive.

If you need to know more chat to your doctor or practice nurse.
Your health care team are there to support you.

RESOURCES

Kidney Health Australia fact sheets:
eGFR, Chronic kidney disease, Albuminuria

Why do I have chronic kidney disease?

First it is important to know that you are not alone
1 in every 10 adults in Australia will have signs of chronic kidney disease.

1 in 100 people know they have it

9 in 100 people have it but don't know

There are many reasons that you are more at risk of having kidneys that are not working properly.

Do any of these risk factors apply to you?

Diabetes

Smoke cigarettes

High blood pressure

Over 60 years old

Established heart problems (heart failure or heart attack) and/or have had a stroke

Of Aboriginal or Torres Strait Islander origin

Family members with kidney failure

Acute kidney injury earlier in your life

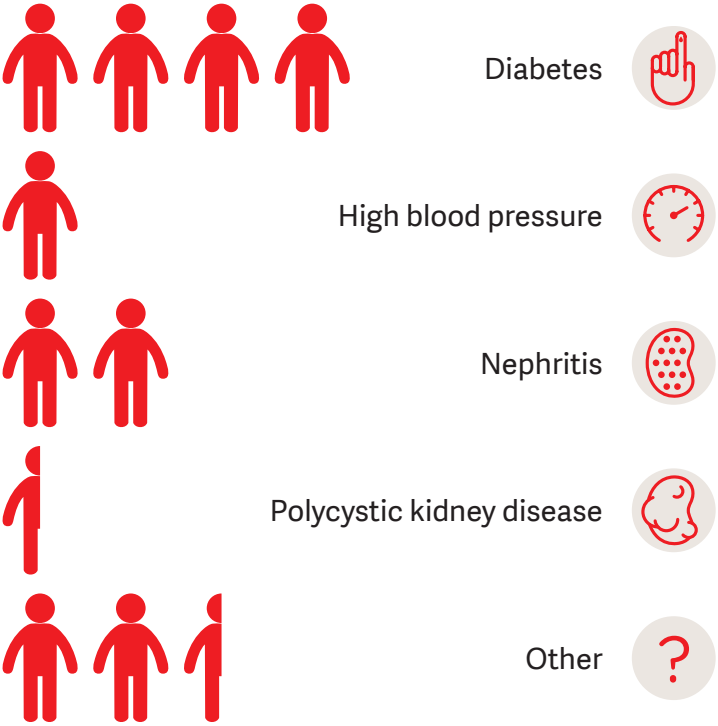
Very overweight or obese (Body Mass Index BMI – over 30 kg/m^2)

If you find that one or more of these apply to you and it is something you can change then it is important to take action. Sometimes there is no obvious cause for chronic kidney disease.

What are the types of kidney disease?

There are many different types of actual kidney disease. The most common types of kidney disease are listed here and described in more detail over the following pages. There are many other types of kidney disease, and sometimes the type is unknown.

Out of every 10 people needing treatment for kidney disease, the causes are:



More detail about kidney diseases

Your doctor will always attempt to find the cause of your kidney disease. If the cause of your kidney disease is genetic (*passed on through family members*) or unknown, your doctor may recommend your relatives also be checked for signs of kidney disease. Regardless of the cause of kidney disease, some parts of the treatment are common to all.

Diabetic kidney disease (*diabetic nephropathy*)
Diabetes is a common cause of chronic kidney disease. Diabetes can damage blood vessels in your kidney filters. 1 in 3 people with diabetes will end up with some kidney damage.

Nephritis (*glomerulonephritis or GN*)
Nephritis is a general term used to describe a group of diseases that cause swelling or inflammation of the kidney filters (known as *glomeruli*). It is a common cause of kidney disease. For reasons that are not always understood, the body's immune system attacks the kidney filters causing swelling and scarring. This reduces the kidney's ability to filter waste from the blood.

High blood pressure (*hypertension*)
High blood pressure damages the small vessels that take blood to the kidney filters and can also damage the filters themselves.

Polycystic kidney disease (*PKD*)
Polycystic kidney disease is the most common, inherited cystic kidney disease. Inherited means it is passed down from the parents. It leads to the growth of many cysts in the kidneys.

Medullary cystic kidney disease (*MCKD*)
Medullary cystic kidney disease is an inherited kidney disease. The kidneys gradually lose their ability to work properly because of cysts in the medulla (*centre of the kidneys*).

Reflux nephropathy
Nephropathy describes any type of non-inflammatory kidney condition. Reflux nephropathy is a form of kidney disease, linked to problems in the kidneys and urinary tract that block the flow of urine, and is often present at birth.

RESOURCES

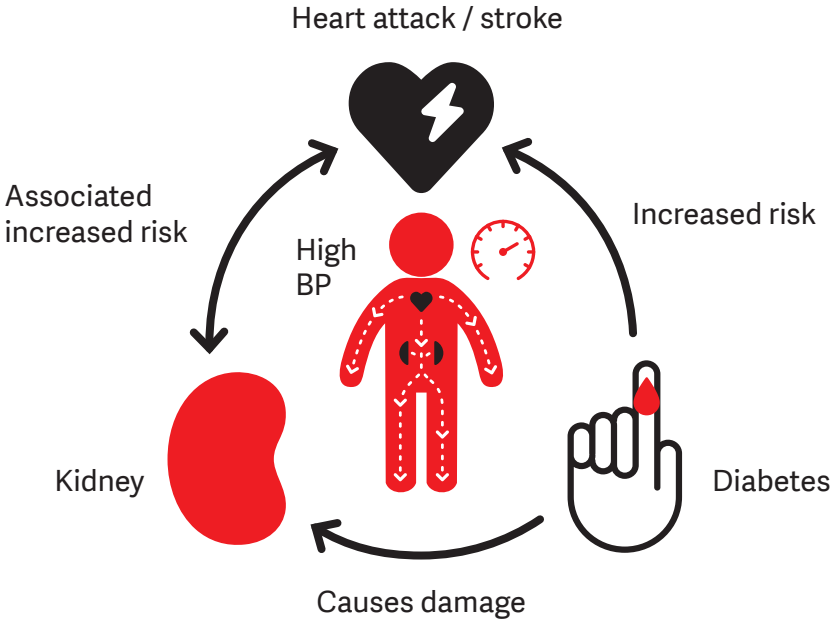
- **Kidney Health Australia fact sheets:**
  IgA nephritis, Diabetic kidney disease, Kidney cysts, Lupus nephritis, Polycystic kidney disease, Alport syndrome, Membranous nephropathy
- **www.kidney.org.au** >
  Kidney stones and urine infections
- Kidney Health Information Service (KHIS) **1800 454 363**

Prevent

Ways to slow down
or stop kidney damage

Simple steps that may slow the kidney damage

It is important to prevent your kidneys becoming damaged further. Having protein in your urine also increases your chance of having a heart attack, stroke and / or high blood pressure.



Keeping your kidneys as healthy as possible in the early stages of chronic kidney disease can slow down any damage and help your heart. There are simple ways to keep your kidneys as healthy as possible:

- No smoking
- Eat healthy
- Take blood pressure medicines
- Exercise
- Manage diabetes

What difference will looking after my kidneys make?

Kidney disease can progress quickly but for most people it happens slowly over many years. Looking after your kidneys can slow the damage considerably. This means you will feel better and live longer. Some people can double the time it takes for early stage kidney disease (*stage 2–3*) to progress to the late stages of kidney disease (*stage 4–5*).

RESOURCES

Kidney Health Australia fact sheets:
Linking kidney disease and cardiovascular disease,
Looking after yourself with chronic kidney disease,
Diabetes and kidney disease

YVONNE'S TIPS

Educate yourself about your kidney disease, ask for your test results and keep a chart with your blood results, especially your eGFR.

You can also change your lifestyle, de-stress, be motivated into action to *take care of yourself* – diet, exercise and healthy positive living.

Then watch your results improve and smile because you have slowed the progression of your kidney disease.

Yvonne

Simple actions you can take

Medicines

The doctor may prescribe some medicines for your kidney disease or a related condition, such as diabetes or high blood pressure. Taking these medicines regularly is the best way to slow down the damage to your kidneys.

How can I find out more about medicines?
Your GP or local pharmacist (*chemist*) are both excellent sources of information if you have any questions about any medicines.

Your local pharmacist can tell you all about your particular tablets and how they work. Pharmacists can also do a review of your medicines at home. Or call MedicineWise, a free telephone service providing consumers with information on prescription, over-the-counter and complementary medicines.

RESOURCES

NPS MedicineWise **1300 633 424**

www.nps.org.au – NPS MedicineWise

Why do I need to take blood pressure tablets?

Blood pressure tablets actually protect your kidneys.

Blood pressure has two numbers which are:

- Your heart when it beats (*the higher number*)
- Your heart at rest (*the lower number*)

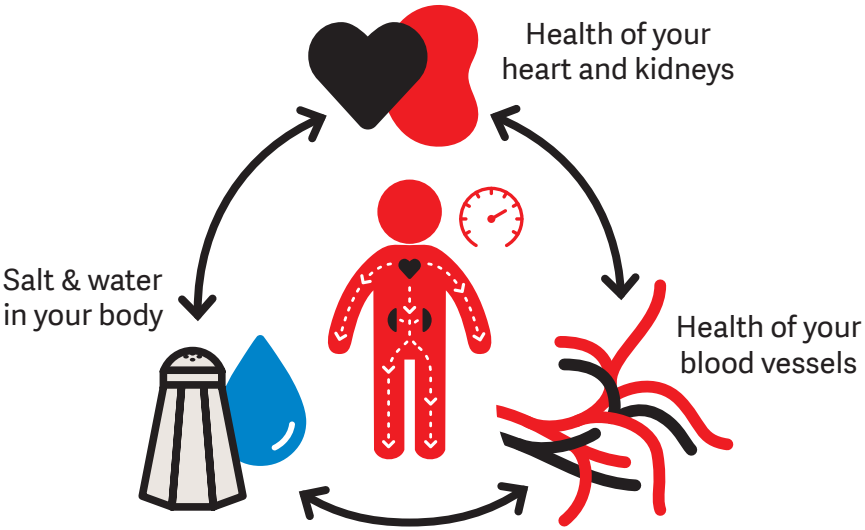
CALL TO ACTION

Ask your doctor what your blood pressure is and what it should be. The table below gives some idea of recommended blood pressures for the average person.

Group	Blood pressure should be:
Healthy person (*no diabetes or kidney disease*)	**120/80 or below**
Diabetes or protein in your urine	**130/80 or below**
Diagnosed chronic kidney disease	**140/80 or below**

What is the link between blood pressure tablets and kidney damage?
If you have high blood pressure it may be causing kidney damage. This is because high blood pressure damages the many small blood vessels of the kidneys.

Kidney disease also causes high blood pressure. **Blood pressure tablets lower blood pressure and protect the kidneys.**



The amount of salt and water in your body and the health of your blood vessels will also affect your blood pressure.

Are there different types of blood pressure tablets?
Yes. Different types of blood pressure tablets work in different ways so it is not unusual for more than one type to be prescribed. The dose may be changed according to your blood pressure. Below is some information about the most common types of blood pressure tablets that protect your kidneys.

Tablet type	Common tablet names *	Important information
Angiotensin converting enzyme Inhibitors (*ACE Inhibitor*)	Renitec Tritace Coversyl Zestril	– Can cause a cough. Speak to your doctor if this is a problem. – Swelling of the tongue or throat is rare but serious. Stop taking the tablet and see your doctor.
Angiotensin receptor blockers (*ARB*)	Karvea Avapro Micardis Atacand	– Can cause cough, dizziness and headaches. ARBs are usually prescribed if you experience side effects from ACE Inhibitors.

When you are very unwell, or having vomiting or diarrhoea, you may need to stop taking your blood pressure tablet until you recover. Check with your doctor.

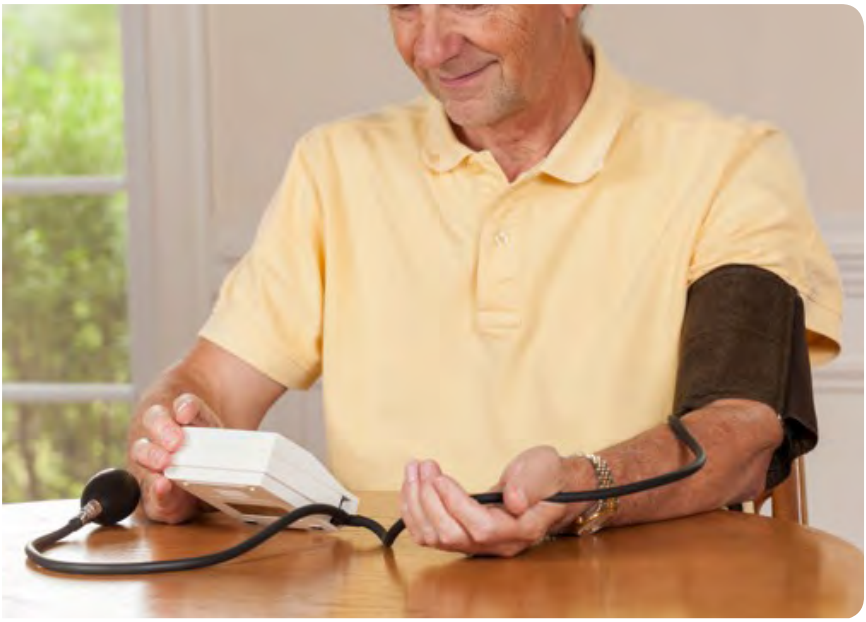
You are usually prescribed either an ACE Inhibitor or an ARB, but should not take both. Your pharmacist can provide more information about the possible side effects of your blood pressure tablets.

**You may be prescribed another similar tablet*

Do I need to measure my blood pressure at home?
It is possible to buy a blood pressure monitor so you can measure your blood pressure at home. This can allow you to keep records of your blood pressure and you can see if your blood pressure changes over time.

It is important to remember that your blood pressure will change:

- At different times of the day
- If you are active rather than resting
- If you are stressed or tired
- If your blood pressure cuff is not fitted properly



If you choose to measure your blood pressure at home ask your doctor or pharmacist for tips on how to measure it correctly, and do it the same way every time.

Do not change your medicines based on your home blood pressure readings.

RESOURCES

- **www.nps.org.au** – NPS MedicineWise

  www.heartfoundation.org.au – Heart Foundation

- My heart, my life – **www.myheartmylife.org.au**
  Track your blood pressure

  MedicineList – NPS Medicine Wise
  Manage your medicines, and record important health information

- Kidney Health Information Service (KHIS) **1800 454 363**

- **Kidney Health Australia fact sheet:**
  Blood pressure and chronic kidney disease

Why do I need to take my diabetes medicines or insulin?

Keeping your blood sugar as healthy as possible will reduce the damage to your kidneys. It will also protect the blood vessels to all different parts of your body.

Managing diabetes includes:

- A healthy diet with *good carbohydrates**
- Keeping a healthy body weight
- Exercise
- Taking tablets or insulin if prescribed
- Monitoring your blood sugar at home (*regularly if you are taking insulin*)
- Having your blood sugar checked at the doctors regularly

**Good carbohydrates are those that release energy slowly. Talk to your dietitian or diabetes specialist.*

RESOURCES

- Diabetes Australia – **www.diabetesaustralia.com.au**
- **Kidney Health Australia fact sheet:** Diabetes and chronic kidney disease

CLARE'S STORY

I was diagnosed with diabetes when I was just six-years old. For a number of years, I rebelled against my diabetes diagnosis and my mother used to warn me that I would end up on dialysis, but I always thought that kind of stuff only happened to other people.

At the age of 27, my diabetes eventually led to being diagnosed with severe kidney failure. I am now on dialysis every night for nine hours and am on the waiting list for a triple transplant – two kidneys and a pancreas – all of which has to be from one donor to reduce the risk of organ rejection.

Now at age 30, I hope my experience can help other young people reduce risky behaviours, especially young diabetics. My mother's warnings used to wash over me, but may have made a difference if there had been more public discussion and awareness about kidney health.

I encourage everyone with diabetes, and those who might have an increased risk of kidney disease, to get their kidneys checked.

What about other medicines?

Some common medicines that you can buy from a supermarket or chemist **need to be avoided** or taken in smaller doses if you have chronic kidney disease.

These include:

- Alka Seltzer, baking powder or bubbling remedies, as they are high in sodium
- Milk of Magnesia or antacids containing magnesium
- Aspirin as it can affect blood clotting and can cause bleeding
- Nonsteroidal anti-inflammatory medicines (*NSAIDS*), which are anti-inflammatory medicines, such as ibuprofen (*such as Nurofen*), naproxen (*such as Naprosyn*), diclofenac (*such as Voltaren*) and celecoxib (*such as Celebrex*)
- Enemas and laxatives unless suggested by your doctor
- Vitamins or food supplements as they may contain potassium and magnesium

RESOURCES

National Medicines Line **1300 633 424**

www.nps.org.au – NPS MedicineWise

Herbal or complementary medicines may also have side effects, they can interact with other medicines, or they may be unsuitable if you have kidney disease.

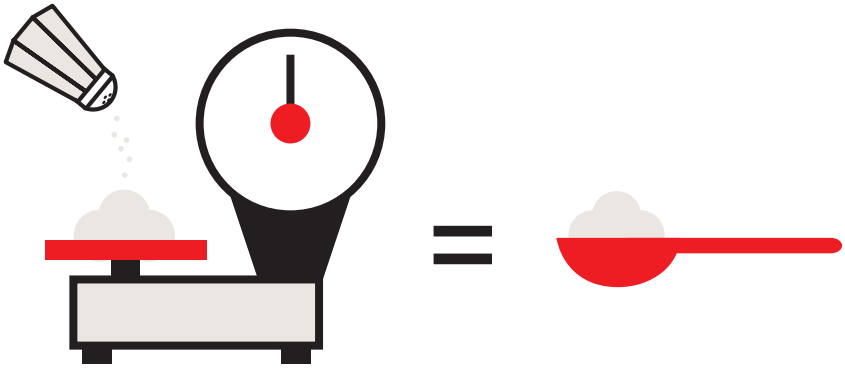
If you are seeing a health professional tell them about your kidney condition as this may influence their choice of medicines and other treatments.

Salt – the other cause of high blood pressure

Why should I reduce my salt intake?
Salt is also known as *sodium*. Salt and water go hand in hand. Salt causes the body to hold on to water. Excess water in your body causes your blood pressure to go up. This damages all your blood vessels and increases the risk of heart attack and stroke.

Salt is hidden in many processed food items, such as takeaway foods and ready made meals. Your goal should be to **eat less than six grams of salt per day**. Look for the salt content on food packaging.

6 grams = just over one teaspoon.



You can choose to reduce your salt intake by making healthy food choices.

- Swap processed foods for fresh foods
- Prepare more meals at home and rely less on takeaway foods
- Use herbs and spices instead of salt to flavour your food
- If you currently have a high salt diet, take small steps to reduce your salt intake slowly over time to reach the recommended daily amount. Salt is an acquired taste – your tastebuds will grow to like less salty foods

RESOURCES

Food Switch BUPA – this app suggests simple, healthier food switches

General healthy lifestyle

Do my kidneys benefit if I quit smoking?

Yes. Smoking damages the tiny blood vessels found inside your kidneys. You will feel the benefits of quitting straight away as your body repairs itself. Quitting smoking can be one of the most difficult, yet rewarding things a person can do.

Most smokers say they would like to quit, and may have tried at least once. Some are successful the first time, but many other people try a number of times before they finally give up for good.

CALL TO ACTION

Quitline doubles your chance of quitting smoking for good. Call 13 78 48.

RESOURCES

www.icanquit.com.au
Learn about the benefits of quitting smoking, and to keep you motivated during your quit smoking journey.

www.quitbecauseyoucan.org.au

National Quitline **13 78 48**

Is healthy eating important?

Yes. Eating a varied, well-balanced diet means eating a variety of foods from each food group daily, in the recommended amounts.

Choosing a variety of foods will help to make your meals tasty and interesting. You should eat healthy foods and make sure the energy (calories) of the food will help you to keep or get to a healthy body weight. If you wish to lose weight talk to your GP or an accredited dietitian.

Food restriction of phosphate, potassium or protein are not necessary in early stage kidney disease. They become important in later stage kidney disease.

CALL TO ACTION

You can choose to swap a processed food like biscuits for a piece of fruit or a handful of nuts.

RESOURCES

www.eatforhealth.gov.au/guidelines
Up-to-date advice about the foods we need to eat for health and wellbeing.

www.csiro.au > Our research > Health > CSIRO diets > CSIRO Healthy Diet Score

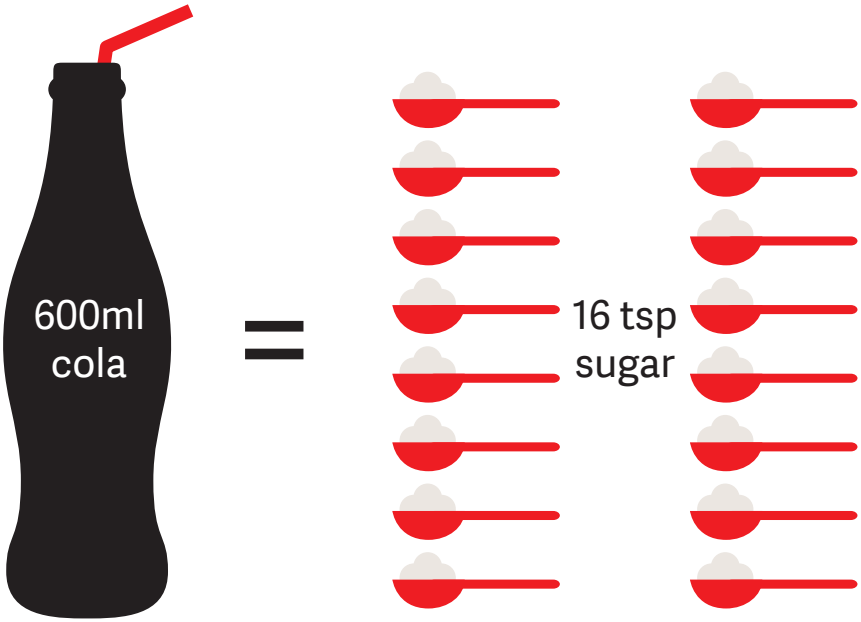
Diabetes Australia – meal planning
www.diabetesaustralia.com.au/diabetes-australia-app

What is the advantage to drinking water?

The human body contains lots of water. Our body can last weeks without food but only days without water.

Plain water (*tap or filtered*) is the recommended fluid to satisfy thirst – and it is the natural choice. Choosing water as your preferred drink will have a positive impact on your health because:

- Water contains no kilojoules (*soft drinks can have up to 16 spoons of sugar*)
- It is inexpensive and readily available
- It can help keep your kidneys healthy



If you are drinking enough water, you will pass urine a few times a day and your urine will be pale in colour.

CALL TO ACTION

Check your urine to see if you're drinking enough water. It should be pale in colour.

Choose to swap a soft drink or fizzy drink for water. As a simple rule of thumb, for every cup of tea or coffee you drink, follow it up with a glass of water.

RESOURCES

www.kidney.org.au – Drink water instead

How is exercise linked to keeping my kidneys healthy?

Regular physical activity or *exercise* is important for everyone. There are so many benefits to being active. Some of the benefits include:

- A healthier state of mind (*stress reduction, better concentration, self-confidence*)
- Feeling better (*more energy, better sleep*)
- Better health
- Reducing weight, blood pressure and cholesterol which lowers the risk of stroke, heart disease osteoporosis

Experts suggest that we should be doing at least **30 minutes** of moderate physical exercise on most days of the week. **Are you getting enough?**

There are plenty of ways to include exercise in your day, even if you're busy. Could you find time to:

- Go for a 15 minute jog around the block
- Join a local sporting team such as soccer or netball
- Include exercise into daily living, such as riding a bike to work
- Take a brisk 30 minute walk
- Take the stairs

In the beginning, a chat with your GP is a good idea to make sure there is nothing to stop you exercising safely.

CALL TO ACTION

Remember to drink water before and after exercise to stay hydrated.

RESOURCES

- **www.healthyactive.gov.au** – Information on a *healthy weight*, tips on how to incorporate exercise into your day.

Managing your own health – take control

Remember: It is easy to get your kidneys checked

How do I get my kidneys checked?
If you have early chronic kidney disease it is recommended that your doctor conducts regular checks of your kidneys. This may involve blood and urine tests at least once every year.

Some pharmacies also offer a KidneyCheck program, which includes tests of your urine that you can do at home. Even if you use the KidneyCheck program it is still important to have your kidneys checked by your doctor at least once every year.

CALL TO ACTION

Ask your GP / Health Clinic for a Kidney Health Check (urine, blood pressure, blood test) with your annual health check.

Remember: You can slow the damage by following simple steps

How does slowing the kidney damage improve my general health?

- Kidney disease increases your risk of heart disease
- Diabetes, high blood pressure, and obesity can lead to kidney disease
- All of these conditions are prevented or helped by living a healthy life

What can you do to manage your kidney health?

If you have diabetes, keep your blood sugar at the recommended level

try to do at least 30 minutes of exercise every day

Keep your blood pressure at the level recommended by your doctor

Eat healthy food

Take your medicine exactly as prescribed

Learn about your kidneys

REMEMBER

You can play an important role in improving your health and the health of your kidneys. If you have any questions, don't hesitate to ask your health care team – they are there to help you.

How do I become actively involved in improving my kidney health?

Taking care of yourself is also known as self-management. Self-management is what a person does to manage their own health, which is different to what the heath professional does.

This is as simple as:

- Asking questions when you visit your doctor
- Making health decisions with your doctor
- Swapping a poor lifestyle habit for a good one
- Managing your medicines
- Monitoring your blood pressure and / or blood sugar

My Health Record
When you are co-ordinating your own care between different health professionals it can be hard to keep track of all your health information. Having an online health record will help you take control of your health and your healthcare information.

Visit **www.myhealthrecord.gov.au** to develop your own personally controlled health record.

Managing your health may also be a partnership with someone else close in your family. Talk to your health care team to see what you can do to manage your own health.

REMEMBER

It is easy to get your kidneys checked.
You can slow the damage by following simple treatments.
Your health care team are there to support you.

CALL TO ACTION

Choose at least one positive action in this book and improve your health.

RESOURCES

www.gethealthynsw.com.au – State Government websites including *Get Healthy NSW* – Health coaching provides expertise advice on how to reach your health goals

www.myhealthrecord.gov.au – To keep your personally controlled health record online

www.smilingmind.com.au – Mindfulness

Kidney Health Australia fact sheet:
Making the most of your visit to the doctor

How do I get more involved in making health decisions?

Shared decision making

Shared decision making is as simple as talking with your health care team about your choices and making a decision together.

Your health care team understands about diseases and their treatments. However, you are the expert on your own body and knowing how your body feels and what it can do.

You can talk to your health care team to choose which tests, treatments, or life changes are best for you. It involves sharing information about options, lifestyle and outcomes, and using this together to make decisions. If you feel like the conversation with your health team is rushed, you may like to ask them to slow down or recap on some of the information.

If you make decisions with your doctor you are more likely to:

- Follow that treatment
- Work out the best options for you so you can get on with your daily life
- Understand your choices and feel that the decision is right

RESOURCES

www.healthtalks.org.au > Categories > Improving health care > Shared Decision Making

Kidney Health Australia fact sheet:
Make the most of your visit to your doctor

There are three key questions to ask before you make any decisions:

1. What are my options?
2. What are the benefits or disadvantages to each option?
3. How would each treatment affect me?

This website contains more information about the three questions to ask: **www.askshareknow.com.au**

There is also written information about most diseases so ask your GP, nurses or Health Clinic for some written information to take home.

Support

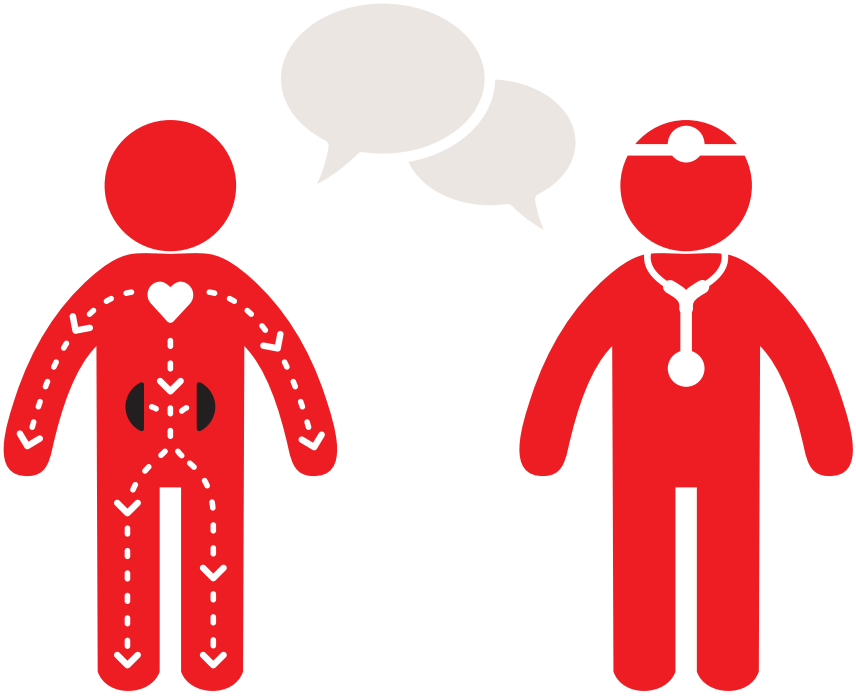
How to help yourself and
how others can help you

You are not alone – your health care team is there to support you

Who is my health care team?

The most important and powerful person in your health team is actually **you**! There are many steps that you can take to become a valuable advocate in your own health care and disease management. Learning about your kidney disease and understanding ways that you can prevent further kidney damage are incredibly valuable.

There is also a range of health professionals that become part of your chronic kidney disease team. The health professionals that are involved in your care will depend on your personal circumstances such as other health conditions (*ie. if you have diabetes or heart problems*).



Here is a list of health professionals and the role they will take to help you to keep your kidneys healthy:

Doctor / General Practitioner (*GP*)	– Education about your kidney disease – Manage your blood pressure medicines – Monitor the health of your kidneys
Nephrologist / Kidney Specialist	– You will be referred to a kidney specialist when your kidneys need specialised help
Practice Nurse	– Education about your disease and healthy living – Monitor the health of your kidneys
Pharmacist	– Education about medicines – Home medicine review
Dietitian	– Advise you about a healthy diet
Aboriginal health worker	– Education about your kidney disease – Monitor the health of your kidneys

RESOURCES

Kidney Health Information Service (KHIS) **1800 454 363**
We're also here to help. You can call us for support.

Coping emotionally

What is the usual reaction to learning you have kidney disease?

Many people experience different emotions at different stages of their journey with kidney disease. Initially there may be disbelief that this is happening to you. Some people may feel angry, sad or fearful when learning of their diagnosis.

What can I do to help myself?

Chatting with a loved one, friend or even your GP can be helpful. You are not alone. Contact Kidney Health Australia to be connected with a network of people who have also received a diagnosed of chronic kidney disease through our TelEConnect service **1800 454 363**.

Connect with us

Facebook
Kidney Health Australia

Twitter
@KidneyHealth

Instagram
@KidneyHealth

YouTube
Kidney Health Australia

Could I be depressed?

Depression is more than a passing phase of being unhappy or sad.

Do you often feel like:

- You cannot get out of bed
- You have a black cloud hanging over you
- Unreasonably moody or angry or anti-social
- Not interested in how you look
- Ending your life
- Eating excessive amounts of food or drinking excessive amounts of alcohol

If you answered yes to any of these, you may be depressed. There is treatment for depression. First you need to talk to someone you trust who can assess you properly. Your doctor is one good option.

Where can I get support?

RESOURCES

Beyond Blue **1300 224 636**

Lifeline **13 11 14**

www.beyondblue.org.au

Kidney Health Australia fact sheet:
Depression and kidney disease

Remember you are not alone, your health care team is there to support you.

Sexuality and fertility?

Dealing with the health problems caused by chronic kidney disease can be difficult. It is easy to get caught up in the medical side and overlook the impact on your personal life and relationships. Sexuality is more than just sex. It is an important part of who you are, how you see yourself, how you express yourself, your sense of self-worth, and your sexual feelings for others. It can be affected when you have a chronic illness, although with kidney disease the effects are more pronounced in later stages of the disease.

What is important to know is that fertility, your ability to father a child or become pregnant, decreases as your kidney function declines. This doesn't mean that women can't conceive or men are unable to father children but it may be more difficult. This means if you are considering having a family sooner may be better than later. Talk to your GP if this is you.

As with all medical problems, the best treatment depends on the cause of the problem and personal preferences. It is important that you talk to someone who knows your health history and understands the medications that you are taking. If you are experiencing issues or are concerned about other aspects of your sexuality please speak with your own GP or Health Clinic.

RESOURCES

www.kidney.org.au

Kidney Health Australia fact sheet:
Sexuality, fertility and kidney disease

Family and Carers

Should I share information about my kidneys with my family?

Yes. They may be at risk too!

Many people find that communicating with their partner and family becomes an important part of the diagnosis process and ongoing journey. Family can offer support and can enable a team approach in the management of the disease. Your family and friends may also be worried about you and it is good to have an open conversation.

CALL TO ACTION

You might like to invite a loved one or friend along to your next health appointment.

RESOURCES

www.kidney.org.au

RICHARD'S STORY

I was diagnosed with kidney disease at the age of 17, and I knew I was going to have difficult stages in my future life. Everybody has a different story to tell. My kidney disease was caused by reflux from birth. Reflux is not passed down, which is very different to polycystic kidneys. This also means that my sisters are fully healthy.

The hard part about kidney disease is that you can't tell its happening. I find it hard to describe the feeling when I am having a bad day. It's like an overall feeling of *yuk*.

It is important to make sure your family and friends know what you are going through. I kept it quiet from my friends when I was in high school, but in retrospect I should have informed them as they would have been able to support me through the process. Family and friends are so important in our pursuit for happiness and communication is key in striving for this happiness.

Life is great and everyone should love life! Whilst being on dialysis, I've been overseas three times living a very active and fulfilled life. This was only possible by having my loving wife and gorgeous chocolate brown Labrador by my side. Now I do not hide from my kidney disease but openly promote that I have a chronic illness.

Richard

Where can I get more information about kidney disease?

This booklet contains information about *early stage* kidney disease. You may like to find more information about any stage of kidney disease. Here is a few suggestions on where to obtain information, support or to connect to a kidney community.

RESOURCES

- Living with Kidney Failure booklet 8th edition, Kidney Health Australia

  Community newsletter
- **www.kidney.org.au**
- Connect with us on Facebook, Instagram and Twitter
- Social groups – Kidney Club
- Kidney Health Information Service **1800 454 363**

  TelEConnect **1800 454 363**

My Kidneys My Health Phone App
The information from this book, as well as extra interactive features, are available in the phone app *My Kidneys My Health*. This is freely available from iTunes or Google Play.

Frequently asked questions

Answers to some of the most frequently asked questions

Frequently asked questions

How important it is to keep taking my blood pressure tablets?

Taking your blood pressure tablets is probably the most important thing you can do to protect your kidneys. Talk to your doctor if you have any concerns about your blood pressure tablets.

When do I need to see a kidney specialist (*also called a Nephrologist*) about my chronic kidney disease?

Your doctor should follow special guidelines. Usually you are referred to a kidney specialist when:

- Your eGFR drops below 30 (*see page 20 and 22*)
- Your kidneys get worse quickly
- You constantly have lots of protein in your urine
- Or you have a very high blood pressure that does not respond to treatment.

What should I do if I notice changes to my urine?

Urine can actually tell us an important story as to what's happening in the body. Here are some changes to look out for:

Frothy urine – this is a sign that there is protein in your urine. Protein in the urine may indicate damage to the kidneys. It is recommended that you let your GP know about frothy urine.

Changes to your urine colour – you might notice your urine is darker in colour. Read page 15 to understand more about drinking enough water and the kidneys.

Pain when passing urine – This is usually a sign of an infection. Speak with your GP to investigate what is causing the pain.

Frequency – Are you urinating more often than usual? If you are not drinking more fluids than usual and can't explain why, make an appointment to speak with your GP.

What does eGFR mean?

It is a blood test that can measure the health of your kidneys. Read pages 19–20 to learn more about measuring the health of your kidneys.

How long until I need dialysis?

Most people who are diagnosed with early stage chronic kidney disease will never start dialysis, but some will. The time from early kidney disease to dialysis can vary from a few months (rare) to over 20 years (more common).

Most people can delay the need for dialysis, but everyone is different and your doctor can advise about your type of kidney disease. The healthier your kidneys are the healthier your heart will be too.

Refer to page 33 to see how you can slow down the need for dialysis.

Refer to pages 35–42 to learn what you can do to assist in slowing or stopping the progression of chronic kidney disease.

Do I need to cut protein from my diet?

Most people diagnosed with early stage chronic kidney disease will not have to cut protein from their diet. One of the best ways to look after your kidneys at this early stage is to live healthily. This includes being a healthy body weight, doing regular exercise, eating healthy food, drinking plenty of water and living a smoke-free life.

For more information on eating healthily refer to page 48.

Will it help my kidneys if I reduce phosphate or potassium in my diet?

No, not when you have early stage kidney disease. One of the best ways to look after your kidneys at this early stage is to eat a balanced diet that is low in salt. If you have diabetes you should also follow the advice of your doctor about sugar and type of carbohydrates in your diet.

If you have late kidney disease your doctor will look at your blood results to let you know if you need to restrict phosphate, potassium or protein. Most people never have to restrict these dietary elements.

A dietitian who specialises in chronic kidney disease can provide you with individualised dietary advice. Visit the Dietitians Association of Australia (DAA) website for more information: **www.daa.asn.au** or call **1800 812 942**.

For more information on these topics and for links to other free healthy living resources refer to the *Prevent* section.

Kidney dictionary

Medical terms, acronyms and abbreviations

What does that word mean?

A

ACE – *Angiotensin-converting enzyme* inhibitors.
A medicine used for high blood pressure that can perform a dual function to protect the kidney by effecting protein leaks.
Albumin – A type of protein.
Anaemia – When there are only a small number of red blood cells in the blood or red blood cells are not working properly.
Aorta – A large blood vessel that takes blood from the heart to other parts of the body.
ARB – *Angiotensin receptor blockers*. A medicine used for high blood pressure that can perform a dual function to protect the kidney by effecting protein leaks.
Arteriosclerosis – Hardening of the arteries.
Artery – Blood vessel that carries blood from the heart to other organs.

B

Blood cells – Cells found in the blood.
Bone Marrow – Is found in some of the larger bones of the body. It produces blood cells such as red blood cells.

C

Calories / kilocalories / kcal – A unit of energy.
Capillary – Small blood vessels.
Cardiovascular disease – Includes all diseases and conditions of the heart and blood vessels, such as arteries and veins.
Cholesterol – One of the lipids (fats) found in blood.
CKD – *Chronic kidney disease* is the occurrence of kidney damage an/or reduced kidney function that lasts for 3 months or more.

Conservative treatment – Also known as *supportive care*. Uses diet and medicine to manage kidney failure.
Creatinine – A breakdown product of protein metabolism. The concentration of creatinine in the blood is used as a measure of kidney function.
Creatinine clearance – A test used to measure kidney function.

D

Diabetes – Is a chronic disease caused by problems with the production and/or action of insulin in the body.
Dialysis – A treatment for kidney failure, which removes wastes and extra fluid from the blood by filtering through a special membrane. There are two types of dialysis, haemodialysis and peritoneal dialysis.
Dietitian – An expert in food and nutrition.
Diuretic – Drug that increases the excretion of water from the body by increasing the production of urine. Diuretics are also known as *water tablets*.

E

eGFR – *Estimated glomerular filtration rate* measures how well the kidneys filter wastes from the blood.
Erythropoetin (*EPO*) – A hormone that is mainly made by the kidneys that causes the bone marrow to make red blood cells. A lack of this hormone can cause anaemia.

G

GP – *General Practitioner*.

H

Hormones – Substances that regulate various functions in the body.
Hyperparathyroidism – Excess production of parathyroid hormone.
Hypertension – High blood pressure.
Hypotension – Low blood pressure.

K

Kidney artery – Blood vessel that transports blood to the kidneys.
Kidney transplant – Placing another persons kidney (*donor*) into the person with kidney disease (*recipient*).
Kidney vein – Blood vessel that transports blood from the kidneys.
Kilojoules – A metric measure of the energy value of food.

N

Nephrons – Filtering units of the kidneys.

O

Oedema – Swelling caused by the accumulation of fluid in the tissue.
Osteoporosis – Reduction in bone mass and density, also known as brittle bones.

P

Polycystic kidney disease – A genetic kidney disorder characterised by multiple cysts in the kidneys.
Protein – Substance found in meat, fish and cheese etc. Necessary for building up muscles.
PTH – *Parathyroid hormone*.

R

Reflux nephropathy – A kidney condition caused by the backflow of urine from the bladder up the ureters into the kidney.

S

Serum – The liquid portion of the blood.
Serum creatinine – A measure of how much creatinine is in the blood.
Side effects – Unfavourable reactions to a medicine.
Symptom – Sign of a disease.

U

Uraemia – A build up of waste in the blood causing nausea, vomiting, tiredness and problems with concentration.
Urea – A waste product of the breakdown of protein (*protein metabolism*).

V

Vein – Blood vessel that carries blood back to the heart.
Virus – Small microorganism that causes certain infections.

W

White blood cells – Blood cells that form part of the immune system.

Connect with us
www.kidney.org.au
Freecall 1800 454 363