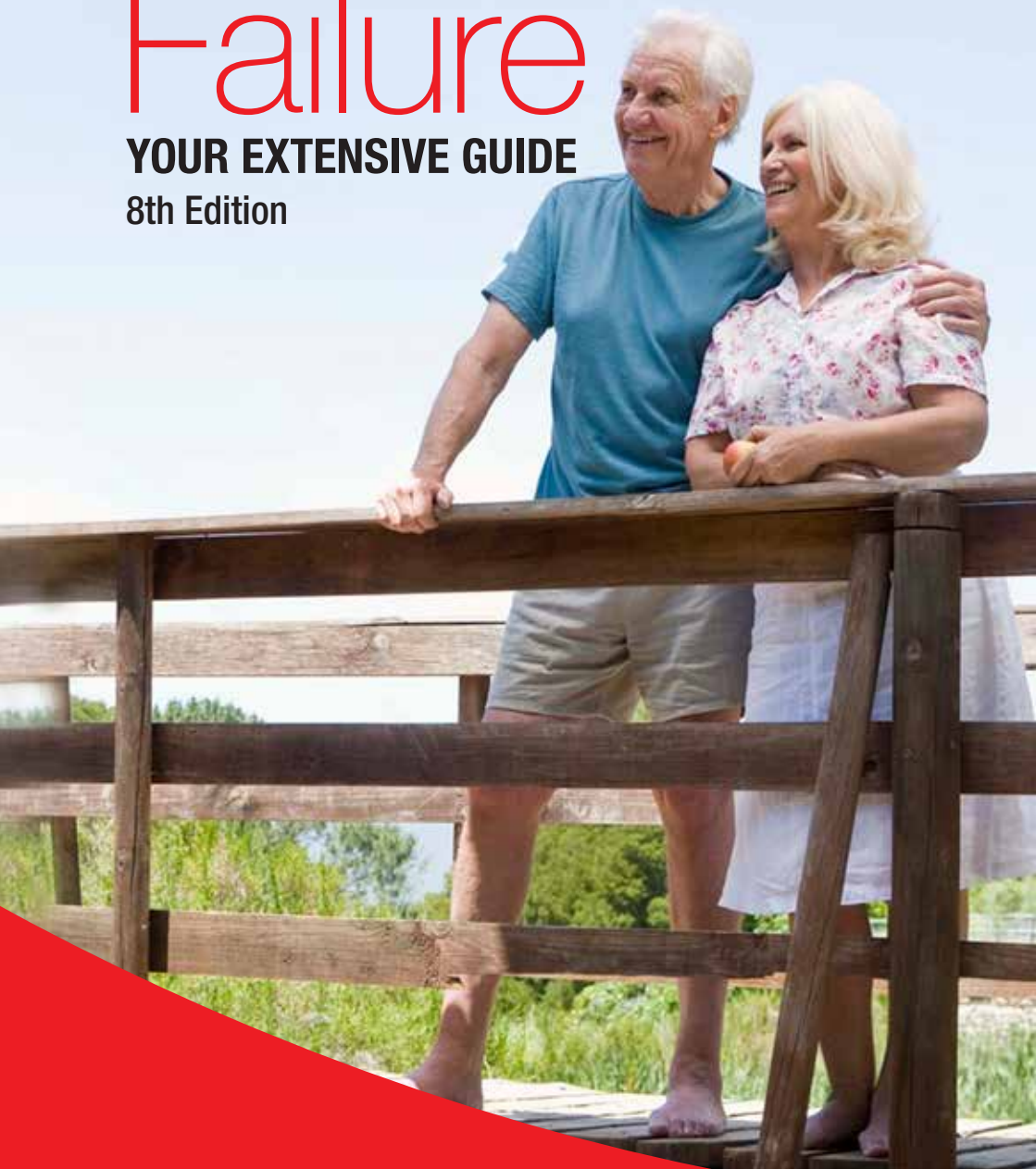


Living with Kidney Failure

YOUR EXTENSIVE GUIDE

8th Edition



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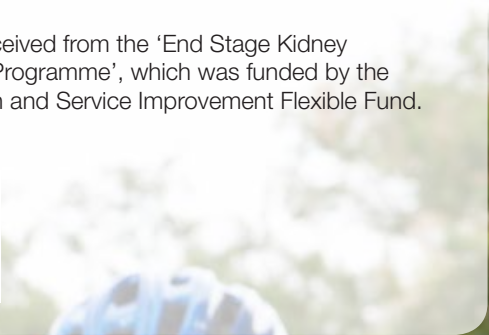


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At first glance, as a kidney patient, the Guide to Living with Kidney Failure may seem a little daunting if only because of its size. It is actually very easy to read because it is written in plain easy-to-understand English. The way to get the most benefit out of the book is to firstly read the sections that have the most relevance to you as a patient as shown in the Index, then you move to other sections once you understand the original chapters.

I strongly support the Guide's recommendation to make full use of your renal team at the hospital. The renal team can cover such people as your nephrologist, renal dietician, dialysis nurses, transplant nurses, social workers, psychologist plus many others. You are ultimately responsible for your own well being; however, please use the resources provided by this team to achieve the best health outcome for yourself. Always ask questions of your team until YOU understand the answer and its implications to your treatment.

The Guide takes you through the whole kidney journey covering the treatment options for kidney disease, all types of dialysis, supportive care, how transplants work, and the transplant waiting list. It also has many real life examples of patient's stories where you may find an example very close to your own circumstances. This helps you even more to understand the real world of your possible treatment(s).

The Guide also has a chapter listing many other sources of information from websites and organisations like Kidney Health Australia. Importantly it has sections on how to look after yourself, from many points of view like exercise, diet, family, friends, work and psychological well being.

As a fellow kidney patient, I commend this Guide to you, as the information it contains will help you better understand your condition and treatment options, as well as help improve your well-being and health outcomes.

Evan Eggins

Chair, National Consumer Council, Kidney Health Australia
(CAPD, 31 yr transplant, haemodialysis)



Introduction

If you are reading this book, then it is likely that you have been told that you have kidney disease. Kidney disease touches the lives of many Australians. Most people think of kidney disease as something confusing, complex, and hard to understand. It can be a life-changing experience to be told by your doctor that your kidneys are not working properly, and in the future you may need dialysis or a kidney transplant to stay alive. It takes time for the news to sink in, and it can take a long time to come to terms with. There is no standard response – some people are angry, some are upset, some people want to find out as much information as possible, some people don't want to talk about it. Some people move through all of these reactions.

It is important to remember that you are not alone on this journey. As well as your family and friends, you will also develop a network of health professionals who will work with you to support you in maintaining your health and lifestyle.

It may be helpful to think of living with kidney disease as a journey. Sometimes the road is straight and is easy to move along. Sometimes it gets very steep and tiring. The journey can also be full of turns and detours, which you are not expecting. It is important to remember that you are not alone on this journey. As well as your family and friends, you will also develop a network of health professionals who will work with you to support you in maintaining your health and lifestyle.

Who is my health care team?

Living with kidney disease means you will have contact with a great many health professionals. It is important to be an active part of your health care team. They can answer your questions and assist you with the health challenges that arise. The members of your health care team will change depending on your needs and circumstances. Health professionals who may be a part of your health team are depicted in the diagram below. See the Glossary for more information about the specific roles of these health professionals.



Getting the most out of your health care team

When you visit a member of your health care team, remember that they are there to help, advise and inform you of your condition and the treatment options available. However you are ultimately responsible for your well-being.

To make the most of your visit, try the following suggestions.

Before the visit

Make a list of two or three questions you need answered. Add to your list any symptoms, concerns or changes in your life that may have occurred since your last visit.

Be familiar with the name and dosage of medications you are taking (take your Medication List if you have prepared one – See Chapter 10). If you need repeat prescriptions, make a note to ask for them.

During the visit

Ask your questions and write down the answers as most people remember only about half of the information given to them.

Before leaving, make sure you have a clear idea of your treatment plan. If you don't understand something or if think you can't follow any instructions, tell the doctor so that you avoid problems later on.

If there are several medications to take or other complicated treatments to follow, ask the doctor to write them down for you.

After the visit

Make a list of recommendations given to you and keep this visible, e.g. on the fridge. Follow the advice you receive to the best of your ability. Don't be afraid to contact your doctor or health care team between visits with any concerns.

Trust and respect is important in any relationship. If you don't feel comfortable with your doctor, it may be worthwhile seeking a second opinion. Different people are suited to different styles so find a doctor you can relate to.

Paul's Story




I never used to pay much attention to my health. But I have found since I was diagnosed with Stage 3 kidney disease that it is important to take an interest in your medical problem. That way you know what the situation is when it arises and your doctor and nursing staff will be more open to you when you ask questions. I used to feel embarrassed about asking questions or getting them to write things down, but I found that it was pretty hard to remember everything they told me. I think I have a pretty good relationship with my health team - we all try to work together so I can feel my best.

Helpful HINTS

These are sample questions you may wish to ask your doctor:

- Can you describe my condition in simple language?
- How will this condition affect me in the future?
- How serious is this condition?
- Will I need regular check-ups?
- What sort of tests will be needed?
- What sort of treatment will be needed?
- Why do I need this test, treatment, surgery or procedure?
- When will I need to start treatment?
- What are the benefits of this type of treatment?
- Are there any risks to this treatment?
- What is success or failure rate of this treatment?
- Are there any immediate side effects to this treatment?
- Does this treatment cause any other long-term changes either physical, social, emotional, mental or sexual?

- 
- Are there any other treatment choices?
 - What might happen if I don't have this treatment?
 - What happens if I choose to have no treatment?
 - How long will I have to undergo treatment?
 - What should I expect after treatment?
 - When do I need to decide about my treatment?
 - How much is this treatment going to cost?
 - Do you have any information about this condition or treatment that I can take with me?
 - Is there someone I can talk to about this?
 - Is there somewhere I can get more information?
 - Are there any good websites I can look at?

Where to go for more information?

Usually the most common place where people get information about their health is from their health care team. This can either be written information (like brochures or fact sheets), or verbal information (someone explaining something to you). It helps to have a good relationship with your health care team so that you feel comfortable getting information, asking questions and being involved in making decisions about your health.

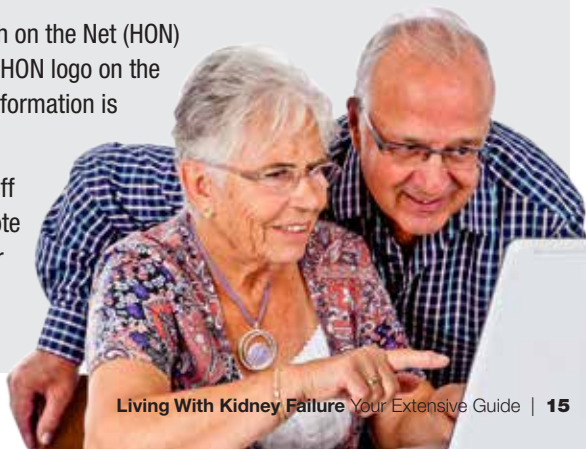
Apart from your health care team there are also many other places to get health information:

- Renal unit education days: Most renal units have 'open days' where you can come along and see the renal unit, meet the staff, and participate in an interactive education session. A lot of people say that this is a really good way of learning about dialysis.
- Talk to other people with kidney disease: Sometimes the best way to learn about kidney disease is to talk to other people who have the same condition. Remember though that everyone is different, and information from other people may reflect their experience and may not be accurate or appropriate for you.
- Find out about organisations that can support you: Kidney Health Australia is a non-profit organisation whose mission is to promote good kidney health through education, advocacy, research, and support. There is a free number to call (1800 454 363), where you can ask questions, order fact sheets or booklets, and find out about the programs run by Kidney Health Australia to support people with kidney disease. The information on Kidney Health Australia's website (www.kidney.org.au) has been prepared by a team of trained health education experts.
- Library: Most community libraries have books on health, and if there is a particular book about kidney disease they should be able to order it for you.
- Internet: The Internet is a popular place to obtain information, but you need to be careful that the information you receive is accurate and applies to the Australian health system.

Tips for accessing reliable and accurate information on the Internet

When you are looking at health information on the Internet ask yourself these questions:

- Who is responsible for the website? Web addresses that end in '.gov' are hosted by federal or state governments; '.org' is often used by non-commercial organisations and '.com' usually means a commercial business.
- Is the information evidence-based? Websites should state the source of their claims and information provided. Avoid sites that cannot prove their claims with more than personal experiences or unclear sources.
- Is the content balanced? Some sites only provide information that focuses on one point of view and provides a lot of unusual or unrelated information. These sites should be viewed with caution and further research into supposed 'facts' should be made to confirm their claims.
- Is there any conflict of interest? Why was the website created? Was it to provide health information or promote a product? If one brand stands out in the website content, then it may not be from a balanced source.
- How current is the information? Does the website say when the information was last updated?
- Is there a privacy policy? Websites asking for your personal details need to explain what they will use them for. Read the website's Privacy Statement to make sure that any information you supply will be kept confidential, will not be sold to a third party, and that ongoing communications from the site will only be sent at your request.
- Does the website have Health on the Net (HON) accreditation? If you see the HON logo on the website you know that the information is evidence-based and reliable.
- Don't be shy about printing off the information or making note of it to take to your doctor for him/her to view at your next appointment.



Frequently Asked Questions

I have been referred to see a nephrologist on a regular basis. Do I need to keep seeing my general practitioner?

Yes, it is important you keep seeing your general practitioner for regular follow-ups. Your general practitioner can work with you to coordinate referrals to other members of your health team and oversee your general health. They can also assist you with medications. In some cases your general practitioner can set up a care plan for you which can allow you to access extra health services.

I have been diagnosed with kidney disease and I do not have private health insurance, is this going to be a problem?

No. The health care system in Australia means that treatment for kidney disease in a public hospital is covered by Medicare. If you have private health insurance you may have shorter times to wait for elective surgery (such as for vascular access), and you may have more choices regarding where you can dialyse. However, having health insurance will not influence the type of dialysis you may have. It also will not change whether you are suitable to go on the transplant waiting list, and it does not mean you will receive a transplant any sooner.

How can I keep working and doing things I enjoy like travelling now that I have kidney disease?

This book is designed to provide you with information and advice about how to maintain your lifestyle after you have been diagnosed with kidney disease. In particular, Chapter 13 covers issues such as employment, holidays and travel while Chapter 11 looks at nutrition and exercise. If after reading this book you would like further information, don't hesitate to contact the Kidney Health Australia Information Service on 1800 454 363 or www.kidney.org.au.



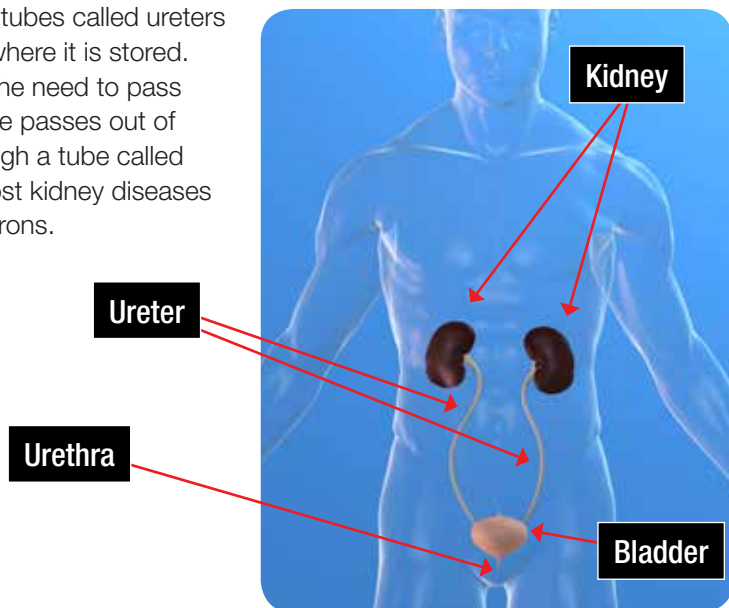
About your kidneys

Your kidney and urinary system is made up of the organs that produce, collect and remove urine from the body. It includes the kidneys, ureters, bladder and urethra.

Most people have two kidneys, each about the size of an adult fist and weighing 150 grams. The kidneys are bean shaped and reddish brown in colour. A large padding of fat, several muscles and lower ribs protect your kidneys. They are located in the middle of your back on either side of the backbone, just under the ribcage.

Inside each kidney there are about one million tiny units called nephrons. The nephrons are the part of the kidney that filter the blood. Each nephron is made up of a very small filter called a glomerulus. As blood passes through the nephron, water and waste products are removed.

The kidneys make urine from excess fluid and unwanted chemicals or waste in your blood. Urine flows down through narrow tubes called ureters to the bladder where it is stored. When you feel the need to pass urine (wee), urine passes out of your body through a tube called the urethra. Most kidney diseases attack the nephrons.



Jobs of the kidney

The kidneys play a number of important roles in the body such as:

- filtering waste products from the blood
- controlling body fluids
- stimulating the production of red blood cells
- regulating blood pressure
- controlling potassium, calcium and phosphorus levels
- regulating vitamin D

What happens when the kidneys don't work properly?

Sometimes kidney function can decline 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 drop in kidney function is called acute kidney injury. This is often short lived but can occasionally lead to lasting kidney damage.

More often kidney function worsens over a number of years – it is a chronic, or persistent, condition. 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% of their kidney function before getting any symptoms.

Fast FACTS

- About one-quarter of all blood pumped by your heart goes directly to your kidneys.
- An adult has about five litres of blood.
- Your body's total blood supply circulates through the kidneys about 12 times each hour.
- In each kidney, the blood is filtered through 225 kilometres of tubes and millions of mini-filters called 'nephrons'.
- About one to two litres of waste and extra fluid then leaves your body as urine each day.

Symptoms of kidney disease can include:

- Increased blood pressure
- Changes in the amount/frequency of urine
- Blood in the urine
- Discomfort or burning when passing urine
- Frothy or foaming urine
- Puffiness, e.g. around the eyes and ankles
- Pain in the kidney area
- Tiredness
- Loss of appetite
- Difficulty sleeping
- Headaches
- Trouble thinking clearly
- Itching
- Shortness of breath
- Nausea and vomiting
- Bad breath and a metallic taste in the mouth
- Muscle cramps
- Pins and needles, e.g. in the fingers and toes



How is kidney disease diagnosed?

If kidney disease is suspected, you will have 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’

- Urine tests: To assess for albuminuria and/or blood in the urine (haematuria)
- Blood tests: To assess your glomerular filtration rate (GFR)
- A blood pressure test

Urine tests

Urine tests are used to investigate if you have albuminuria or haematuria. You will need to collect a sample of your urine (wee) for these tests. The urine may be sent to the laboratory for investigation, or the doctor may use a dipstick to test the urine immediately.

Albuminuria occurs when your kidneys are damaged, so that albumin, a kind of protein, leaks into the urine. A small or ‘micro’ amount of albumin in the urine is called microalbuminuria, and a larger ‘macro’ amount is called macroalbuminuria. Albuminuria is often an early warning of kidney disease but can also be present for

other reasons. Albuminuria can be detected by a special urine test called an albumin:creatinine ratio (ACR). An ACR is performed on a single sample of urine.

Haematuria (blood in the urine) occurs when red blood cells leak into the urine. It can turn urine a red or dark cola colour. Sometimes you cannot see the blood in the urine, but it is picked up by a urine test where the urine is studied under a microscope. This is called microscopic haematuria. Blood in the urine is a common sign of urinary tract infections but can also be the first sign of a problem with the kidneys or the bladder.

Blood tests

A sample of blood is taken from your arm or other part of your body for these tests.

A blood test is used to find out the level of waste products in the blood and calculate your glomerular filtration rate (GFR). GFR is the best measure of your kidney function. It shows how well your kidneys are cleaning the blood. It is difficult to measure GFR, so it is usually estimated (eGFR) using the results of a creatinine blood test, your age, and your gender. eGFR is reported in millilitres per minute per 1.73m^2 (e.g., 67 mL/min/ 1.73m^2).

Your eGFR can also be used by your doctor to work out your percent of kidney function. This is an estimate of the level that each kidney is working. A GFR of 100 mL/min/1.73m² is in the normal range so it is useful to say that 100 mL/min/1.73m² is about equal to '100% kidney function'. A GFR of 50 mL/min/1.73m² could be called '50% kidney function' and a GFR of 30 mL/min/1.73m² could be called '30% kidney function'.

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

Blood pressure

A blood pressure test is also typically performed. Kidney disease causes high blood pressure, which can damage the small blood vessels in the kidneys. High blood pressure can also cause kidney disease.

Other tests

You may also require an ultrasound or Computed Tomography scan (CT scan) to take a picture of your kidneys and urinary tract. These tests show the size of your kidneys, locate kidney stones or tumours and find any problems in the structure of your kidneys and urinary tract.

A kidney biopsy, where a small piece of kidney tissue is removed and

looked at under a microscope to investigate the kidneys in greater detail may also be necessary.

At any stage in this process your general practitioner may refer to a kidney specialist called a nephrologist for further management and care. See Chapter 4 for more information about common tests and procedures that are used for people with kidney disease.

Christopher's Story



I went to see my doctor about some constant headaches that I had. He took my blood for testing as well as urine. That night I was admitted into Royal Adelaide and started dialysis two days later. It was a complete shock and it took me quite a while to adjust. Looking back, the signs that something was wrong had been there for awhile, but I was too busy to notice. I've got a young family so I needed to find a way of fitting dialysis into my work and family commitments. I've been on peritoneal dialysis for two years, and my brother is getting worked-up to see if he can donate a kidney to me. My kids were pretty scared to see me so sick, but now they're happy that I can still take them to sport and do the things we enjoy like fishing and hiking. I try to live each day to the fullest.

Stages of kidney disease

Stage of CKD	eGFR (mL/min/1.73m ²)	Description
1	≥90	If your kidney function is at Stage 1 or 2, you are only regarded as having chronic kidney disease if you have albuminuria, haematuria, a pathological abnormality or a structural abnormality*.
2	60-89	
3a	45-59	Mild-moderate decrease in eGFR
3b	30-44	Moderate-severe decrease in eGFR
4	15-29	Severe decrease in eGFR
5	<15	End stage kidney disease

* A pathological abnormality is when there is disease of the kidneys present at the level of the kidney cells. This is usually diagnosed through a kidney biopsy. A structural abnormality is when the structure of the kidneys is not normal and is usually diagnosed through imaging (e.g., ultrasound) of the kidneys.

Description of kidney disease stages

Please note that the following descriptions are a general guide only, and may not apply to everyone. Some people reach end stage kidney disease (Stage 5) without experiencing any symptoms, while some people may start to feel unwell in the early stages of kidney disease. Many factors affect the progress of kidney disease and these are not completely understood.

Early stages (Stages 1-2)

Some people have no symptoms of chronic kidney disease; however there is more risk of dehydration and a higher sensitivity to medications. It is very important to talk to your doctor before starting any new medications including over the counter and 'natural' or herbal medications. The risk of heart (cardiovascular) disease also starts to increase. Management includes maintaining a healthy blood pressure and making healthy lifestyle choices to delay or prevent progress to the next stage.

Middle stages (Stages 3-4)

Discovering kidney disease during this stage is more common as the level of waste (urea and creatinine) in the blood rises. You may begin to feel unwell and notice changes in the number of times you pass urine. As kidney function slows down, blood pressure rises. Early signs of bone disease and anaemia may appear. Management can slow the progress of kidney disease and reduce the likelihood of further complications.

Later stages / end stage kidney disease (Stage 5)

Changes may occur in the amount of urine passed. High blood pressure is almost always present. The amount of protein in the urine increases, as do the levels of creatinine and potassium in the blood. You are more likely to feel unwell, and you may also experience other complications of kidney disease, such as low haemoglobin (anaemia).

Even with the best management, kidney disease sometimes leads to Stage 5 (or end-stage kidney disease), which requires dialysis or a kidney transplant to maintain life.

Fast FACTS

- Approximately 1 in 10 Australian adults has some clinical sign of kidney disease, but the vast majority are unaware of their reduced kidney function.
- Over 2,000 people start renal replacement therapy (dialysis or transplant) every year
- There are currently 11,000 people receiving dialysis in Australia
- Over 800 kidney transplants are performed every year
- Diabetes is the most common cause of kidney failure

Frequently Asked Questions

My eGFR is over 60 mL/min/1.73m², but is less than 100 mL/min/1.73m² – what does this mean?

If your result is over 60 mL/min/1.73m², your kidney function is normal or close to normal. However, you may be diagnosed with chronic kidney disease if you have abnormal results on your urine tests, ultrasound or biopsy.

If your eGFR is above 60 mL/min/1.73m² and there are no signs of kidney damage, your doctor may still decide to monitor your kidney function and/or discuss healthy lifestyle choices.

My eGFR is less than 60 mL/min/1.73m² – what does this mean?

An eGFR value below 60 mL/min/1.73m² suggests some loss of kidney function. To confirm this, your doctor will most likely repeat the blood test. Monitoring changes to your eGFR also tells your doctor how fast or slowly your condition is progressing.

To be diagnosed with chronic kidney disease you must have a GFR less than 60 mL/min/1.73m² for more than three months, or some other signs of kidney damage (such as albuminuria, haematuria, or abnormal kidney ultrasound or kidney biopsy results).

How can I stop my kidney function from deteriorating?

Once you have been diagnosed with kidney disease there are many actions you can take to slow down the damage to your kidneys and keep you away from treatment such as dialysis and transplantation for as long as possible:

- Quit smoking - even if you have tried before it is worth trying again
- Control your blood pressure by getting it checked regularly and taking your medication exactly as prescribed
- If you have diabetes, have your blood sugar levels regularly monitored and controlled
- Control your cholesterol levels
- Maintain your weight within the healthy range
- Adopt a healthy diet, and follow any special diet and fluid instructions
- Exercise regularly
- Limit stress in your life
- Take an active role in your health care and follow the advice of your health team



Kidney diseases

There are many different types of kidney disease which can lead to kidney failure. The most common causes of kidney disease are described here. However, there are many other causes of kidney disease, and sometimes the cause is not known. Regardless of the cause of kidney disease, some parts of the treatment are common to all. However, your doctor will always attempt to find the cause of your kidney disease as it may have important implications. If the cause of your kidney disease is genetic or unknown, your doctor may recommend your relatives also be checked.

Diabetic kidney disease (diabetic nephropathy)

Diabetes is a common cause of chronic kidney disease. Diabetes is caused by problems with the production and/or action of insulin. Insulin is a hormone that controls the amount of sugar in your blood. The pancreas does not make enough insulin (Type 1 diabetes) or the body cannot use the insulin effectively (Type 2 diabetes).

Diabetes can damage blood vessels in your kidney filters. Over 30% of people with diabetes will end up with some kidney damage. This is called diabetic kidney disease, or diabetic nephropathy. If severe, this can lead to end-stage kidney disease. Diabetic kidney disease can also worsen diabetes complications such as nerve and eye damage.

Diabetes also affects your kidneys in other ways. It changes the level of sugar in the blood or urine and can lead to bacterial growth in the bladder, which increases the risk of kidney infections.



If you have diabetes, your chance of progressive kidney damage greatly increases if you smoke and/or have high blood pressure, high cholesterol or protein in your urine. It is also affected by:

- The length of time you have had diabetes: Although kidney damage may be present when diabetes is first diagnosed, this may remain undetected for years. The longer diabetes is present, the greater the chance of developing kidney damage.
- Your family history and genetic factors: If there is a family history of high blood pressure or cardiovascular disease, your risk of diabetic kidney disease increases. If your parent(s) have this condition then you are more likely to have it.
- High blood sugar (hyperglycaemia): Poorly controlled sugar levels are a strong risk factor for developing diabetic kidney disease. It damages the small blood vessels in the kidneys, particularly to the capillaries in the kidney filters. Monitoring and controlling your blood sugar levels may slow down the development of diabetic kidney disease.

If you have diabetic kidney disease, regular monitoring of your blood sugar levels is very important. You may need adjustments to your diabetes medication as insulin is excreted via

the kidneys. Good control of blood sugar levels and blood pressure can reduce or in some cases prevent further kidney damage.

Nephritis (glomerulonephritis or GN)

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

Nephritis can vary from a mild, non-damaging condition to a serious problem which causes end-stage kidney disease. As each form of nephritis acts differently, the best course of treatment can only be determined after the type of nephritis is identified. Proper identification often requires a kidney biopsy and also considers factors including your age and the characteristics of the urine. Some types of nephritis need observation and no treatment as they rarely lead to long-term kidney damage. Some people will need blood pressure treatment. Severe

forms may need rapid treatment and if treated early enough, may respond well to medication.

Types of nephritis include:

1. Nephritic syndrome

The main features of nephritic syndrome are blood in the urine (haematuria) and high blood pressure (hypertension) caused by damage and inflammation of the glomeruli. Some protein and increased levels of waste in the urine is also common. If untreated, nephritic syndrome can cause end-stage kidney disease. Compare this to nephrotic syndrome.

2. Nephrotic syndrome

Damage to the glomeruli causes them to leak large amounts of protein into the urine (proteinuria). Swelling due to fluid retention and high cholesterol can also be signs of nephrotic syndrome. Nephrotic syndrome can make the blood sticky, which can lead to blood clots. Blood clots can go into the lungs causing chest pain, breathlessness or coughing up blood.

3. IgA (Immunoglobulin A) nephropathy

IgA nephropathy is the most common, serious form of nephritis. IgA refers to the IgA antibody molecule. This is a normal substance present in all of us which helps us to fight infection in the throat, airways, and intestine. In IgA nephropathy, the IgA antibody

gets deposited abnormally in the filter units of the kidneys. The build up of this material triggers inflammation and damages the filter units, allowing protein and blood to leak into the urine. Both kidneys are equally affected in this condition.

IgA nephropathy is found more often in males than females and is usually diagnosed before the age of thirty. In most cases the disease is not thought to be hereditary, however in some families there may be a genetic link. A less common form of IgA called Henoch-Schönlein purpura also affects other parts of the body as well as the kidneys, such as skin, joints and bowel.



Margaret's Story

After I left the specialist with my head reeling, no idea what kidney disease meant, I felt like my world had fallen in. I went home, cried bucket loads and felt like crawling into a shell for a while. Then I picked myself up and got on with things. My treatment hasn't always gone smoothly, and I've had my ups and downs, but I try not to let it get me down. I've had to make some changes to my life, and have learnt to accept help when it is offered. My family have been great, and they help to keep me positive.

Hypertension (high blood pressure)

High blood pressure damages the small vessels that take blood to the kidney filters and can also damage the filters themselves. If left unchecked, it thickens the blood vessel walls causing blood vessels to narrow. High blood pressure can also lead to kidney disease, heart attack, strokes and loss of vision.

It is possible to get into a 'vicious cycle' where high blood pressure causes kidney damage which leads to higher blood pressure and more kidney damage.

Usually high blood pressure does not give any warning signs and is often detected accidentally. Some people with high blood pressure experience:

- Headaches
- Dizziness
- Nosebleeds
- Vision changes

Polycystic kidney disease (PKD)

PKD is the most common, inherited cystic kidney disease. It is caused by genetic defects, which lead to the growth of thousands of cysts in the kidneys.

Both kidneys are affected but one kidney may develop the cysts earlier than the other. The cysts gradually grow, making the kidneys larger and reducing healthy kidney tissue. Some people develop high blood pressure and end-stage kidney disease as a result of PKD.

PKD affects males and females in equal numbers, but men usually progress faster to end-stage kidney disease. The cysts may appear at any age.

There are two types of inherited PKD:

1. Autosomal dominant PKD

This is the most common inherited form of PKD. A parent with autosomal dominant PKD has a 50% chance in each pregnancy of passing the faulty gene and associated disease to each of their children. If a person doesn't inherit the gene, there is no chance of their children developing the disease because it never 'skips' a generation. Occasionally, a person develops the disease when there is no family history and it is thought that a different

inheritance or a genetic mutation may be responsible. Special blood tests can help to find the abnormal chromosomes linked to PKD and genetic counselling is available for affected couples.

2. Autosomal recessive PKD

This is a less common form of inherited PKD. Both parents have to carry this gene defect for a child to inherit this disease. If both parents are affected, they have a 25% chance of passing it on to their child.

Medullary cystic kidney disease (MCKD)

Medullary cystic kidney disease (MCKD) is an inherited kidney disease. The kidneys gradually lose their ability to work properly because of cysts in the medulla (centre of the kidneys). It often causes kidney failure between 20 and 50 years of age. In a few cases there is no family history, which may indicate a new genetic mutation.

The childhood disease juvenile nephronophthisis is very similar but usually occurs in young children. It can also be linked to non-kidney related complications often affecting the eyes, whereas MCKD is limited to the kidneys.

In both diseases, cysts develop in the inner part of the kidney (medulla), the kidneys shrink as the cortex (outer section) thins and kidney failure begins to develop. The kidneys can't concentrate urine properly, leading to an over production of urine, loss of sodium and dehydration. Other health problems usually follow, including anaemia, kidney bone disease, gout and high blood pressure.

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.

Causes of reflux nephropathy can include:

- Problems with the ureters' location when entering the bladder.
- Repeated urine infections.
- Blockage in the bladder outlet causing backpressure to build up in the kidneys.
- Problems with the ureter valves. When the bladder is being emptied these valves stop the urine moving from the ureters into the kidney. One or both of these valves may not work properly.

Reflux nephropathy is often found in young children with frequent urine infections. Reflux usually fixes itself, although sometimes an operation is needed. Some doctors give long term daily antibiotics to try to prevent infections and scarring. Usually the damage is only minor, however long-term problems like high blood pressure can occur much later in life. The damage caused by infection can sometimes be permanent.

Frequently Asked Questions

If I have one of these diseases will I progress to needing dialysis?

The rate of disease progression can vary enormously from person to person. For this reason it is important to discuss your own situation with your specialist. Your specialist will guide you regarding the urgency with which you may need to start preparing yourself for dialysis and/or transplantation.

Will the disease that initially caused my kidneys to fail come back in my transplanted kidney?

This is known as recurrent disease, and the risks of this happening are different for each disease. Diabetes and high blood pressure can affect a kidney transplant just as they affect your original kidneys. It is therefore important to have good control of these conditions after your transplant. Some of the medications used to prevent transplant rejection can raise the blood pressure and blood sugar levels, so control may be more difficult after the transplant.

Diseases that affect the filtering unit of the kidney are called glomerular diseases. If you have a glomerular disease, you should discuss the risks of recurrence with the transplant team prior to your surgery.

Cystic kidney diseases and reflux nephropathy do not recur in transplanted kidneys.



Kidney disease test and procedures

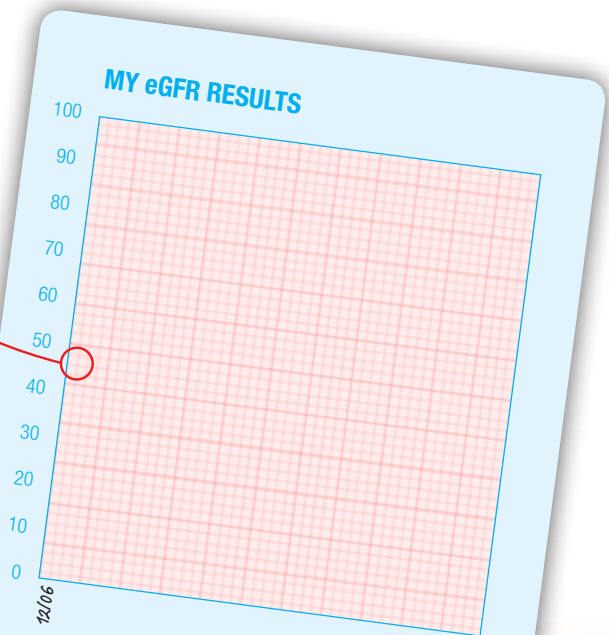
People with kidney disease undergo a large range of medical tests and procedures. They are needed to confirm a diagnosis, plan treatment or check progress.

You may find it useful to buy a folder, or set up a file on your computer, to keep records of your health appointments, test results, and procedure details. This way you can follow the developments of your tests yourself. You may also like to use some graph paper to plot your test results (see example).

Some tests have names that may be difficult to pronounce. Don't hesitate to ask your doctor to write things down for you.

Some of the most commonly used tests for people with kidney disease are outlined in this chapter.

*Example of
eGFR 45*



Tests for kidney function and damage

Blood tests

- **Estimated Glomerular Filtration Rate (eGFR)** –The best measure of your kidney function. It shows how well your kidneys are cleaning the blood. Your GFR is usually estimated (eGFR) from the results of the creatinine blood test. eGFR is reported in millilitres per minute per 1.73m^2 (mL/min/ 1.73m^2). An eGFR of $100\text{ mL/min}/1.73\text{m}^2$ is in the normal range so it is useful to say that $100\text{ mL/min}/1.73\text{m}^2$ is about equal to ‘100% kidney function’. An eGFR of $50\text{ mL/min}/1.73\text{m}^2$ could be called ‘50% kidney function’.
- **Creatinine** – A waste product made by the muscles. It is usually removed from the blood by the kidneys and passes out in the urine. When the kidneys aren’t working well, creatinine stays in the blood. Creatinine varies with age, gender and body weight so is not an accurate way of measuring overall kidney function.
- **Urea** - A waste product, which is made as the body breaks down protein. High urea levels suggest decreased kidney function.

Urine tests

- **Albumin:Creatinine Ratio (ACR)** – Used to measure the amount of albumin (a kind of protein) that leaks into your urine when your kidneys are damaged. A small or ‘micro’ amount of albumin in the urine is called microalbuminuria, and a larger ‘macro’ amount is called macroalbuminuria.
- **Urinalysis** - An examination of a urine sample to detect medical conditions like kidney and liver disease, diabetes and urinary tract infections. This can be a visual examination for colour and clearness. For example, blood in the urine (haematuria) may make urine red or an infection can make it cloudy. A chemically treated strip or dipstick is used to test for pH, sugar (glucose), blood, protein (or albumin), bacteria or waste products. A dipstick test can be performed at the doctor’s clinic, or a urine sample can be sent to a laboratory for further examination.

Blood tests for diabetes

- **Glucose** - Blood glucose monitoring is a measurement of glucose (sugar) in the blood. Values can vary depending on physical activity, meals and insulin administration. Your glucose level is raised in diabetes.
- **Glycosylated haemoglobin (HbA1c)** - A test that measures the amount of glycosylated haemoglobin in the blood. Glycosylated haemoglobin is a molecule in red blood cells that attaches to glucose (blood sugar). There are higher levels of glycosylated haemoglobin if you have more glucose in your blood. This test is used to assess the average glucose content over the past three months.

Tests for heart health

- **Blood pressure** - The pressure of the blood against the walls of the arteries as the heart pumps the blood around your body. Blood pressure is recorded as two numbers, for example 140/90 mmHg. The larger number indicates the pressure in the arteries as the heart squeezes out blood during each beat. This is called the systolic blood pressure. The lower number indicates the pressure as the heart relaxes before the next beat. This is called the diastolic blood pressure.

Blood tests

- **Cholesterol** – A naturally-occurring, waxy substance made by the body. It is an essential building block of cell membranes, hormones and vitamin D. Too much cholesterol in the blood can cause clogging of the arteries and lead to heart disease.
- **Low-density lipoprotein (LDL) cholesterol** – Known as the “bad” cholesterol. The higher the amount of LDL cholesterol, the higher the risk of heart disease.
- **High-density lipoprotein (HDL) cholesterol** – Known as the “good” cholesterol. The lower the amount of HDL cholesterol, the higher the risk of heart disease.
- **Triglycerides** - the most common type of fat stored in your body. A high level of triglycerides in your blood can increase your risk of heart disease.

Blood tests for vitamin and mineral levels

- **Potassium (K⁺)** - A mineral found in many foods. If your kidneys are healthy, they remove extra potassium from the blood. If your kidneys are damaged, the potassium level can rise and affect your heart. A low or high potassium level can cause an irregular heartbeat.
- **Sodium (salt, Na⁺)** - A substance which together with chloride makes up common salt. High levels of sodium in the blood may indicate dehydration.
- **Calcium (Ca)** - Needed for healthy bones and teeth. Most of the cells in the body need calcium to work properly. Raised calcium levels may cause headaches, nausea, sore eyes, aching teeth, itchy skin, mood changes and confusion.
- **Phosphate (PO₄)** - A mineral, which together with calcium keeps your bones strong and healthy. Too much phosphate causes itching and pain in the joints, such as the knees, elbows and ankles. When the kidneys are not functioning properly, high levels of phosphate accumulate in the blood.
- **Vitamin D** - A vitamin that is made in your skin after you have been in the sun. The kidneys change Vitamin D so that your body can use it.

Blood tests for anaemia

- **Haemoglobin (Hb)** - The oxygen-carrying part of red blood cells that gives them their red colour and transports oxygen around the body.
- **Haematocrit (Hct)** - A measure of the percentage of blood made up of red blood cells.
- **Transferrin saturation (TSAT)** - measured as a percentage, it is the ratio of serum iron and total iron-binding capacity, multiplied by 100. A value of 15% means that 15% of iron-binding sites of transferrin is being occupied by iron.
- **Ferritin** - A protein that stores iron in your body.

Blood tests for hormones

- **Parathyroid hormone (PTH)** - Helps control calcium, phosphate, and vitamin D levels within the blood and bone. Kidney disease can cause the parathyroid glands to produce too much PTH.

Imaging and other tests

- **X-rays** - Uses very short energy beams to produce an image of body parts such as bones and organs.
- **Ultrasound** - Examination of the kidneys, prostate or bladder using sound waves to outline the structure of organs.
- **Computed Tomography (CT) Scan or Magnetic Resonance Imaging (MRI)** – These tests use multiple small X-ray beams, or radio-frequency wavelengths and a strong magnetic field to provide clear and detailed pictures of internal organs and tissues. Sometimes you may be asked to swallow a liquid containing a positive contrast material or ‘dye’, or the contrast may be injected into your bloodstream. This allows the radiologist to see your organs more clearly.
- **Kidney biopsy** - A procedure where a needle is passed through your skin into the kidney and a small piece of kidney tissue is removed for examination under a microscope. Local anaesthetic is used and it is a relatively painless procedure.
- **Fistulogram** - Used to check fistula function. Dye is injected into your fistula to allow its structure to show up on an x-ray.
- **Cystoscopy** - This test uses a thin, flexible, tube-like telescope called a cystoscope to view the inside of the bladder and some parts of the kidney.
- **Radionuclide scan** - A small amount of radionuclide (a chemical which emits a type of radioactivity called gamma rays) is put into your body, usually by an injection. After a few hours a special camera views the gamma rays and turns it into a picture. The pictures can show if your kidneys are damaged or scarred.

Other common tests

Testing for blood borne virus infections

Blood tests for blood borne viruses such as Hepatitis B, Hepatitis C and Human Immunodeficiency Virus (HIV) are typically performed before starting dialysis and regularly while on dialysis. This is done to reduce the risk of spreading any infections.

Testing for multi-resistant organisms

Multi-resistant organisms are bacteria that are resistant to a number of different antibiotics. Some are better known than others, and are often called by their initials. Examples are MRSA (Methicillin-Resistant Staphylococcus Aureus), VRE (Vancomycin-Resistant Enterococci) and ESBL (Extended Spectrum Beta Lactamase producing organisms).

You may undergo tests for multi-resistant organisms before you start dialysis and regularly while on dialysis. This is done to reduce the risk of spreading any infections. Tests for multi-resistant organisms are usually performed by using swab stick which is an absorbent pad or piece of material to collect samples such as tissue, fluid and skin cells from the nose, rectum and groin area.

What do my test results look like?

Your laboratory test results form will look different depending on what tests you have, and what laboratory performs the tests. However, there are a number of things that are common to most test results forms.

Sample test result form:

	Your test result	The reference range for each test. Results within this range are considered 'normal'
GENERAL CHEMISTRY		
Sodium	144mmol/L	(136-146)
Pot.	4.3 mmol/L	(3.5 - 5.2)
Chlor.	106 mmol/L	(98 - 109)
Bicarb.	26 mmol/L	(20 - 32)
Urea	6.5 mmol)	(3.0 - 9.0)
Creat.	55 µmol/L	(40 - 85)
eGFR	84 mL/min/1.73 ²	
Urate	0.35 mmol/L	(0.15 - 0.45)
*Gluc	9.5 mmol/L	(Random: 30 - 6.9; Fasting: 3.0 - 5.4)
Albumin	40 g/L	(35 - 50)
*Random glucose at this level may indicate increased risk for diabetes. A fasting glucose is suggested.		

What is being tested. The names are often abbreviated (e.g., creat = creatinine), so ask if you are not sure.

Any results that are outside of the reference range will be marked with an*, and a note below regarding what action is recommended.

You may find it worthwhile to keep copies of your test results forms, and even to plot the values on graph paper.

Consent for medical tests

You need to give consent for a medical test. However, consent for a test can mean just cooperating, such as holding out your arm for your blood pressure to be taken. This is called informal, inferred or implied consent.

If a test is invasive, carries a particular risk, or may have implications for therapy and management then you may be asked to provide written informed consent before the test is performed. You will be provided with an information sheet outlining the details of the procedure and the risks involved. You will be asked to sign a form confirming that you agree to the procedure being performed.

It is important that you take your time when reading the consent form. Make sure you understand all the words and descriptions, and don't hesitate to ask for more information if you need it.

If English is not your first language and you are unsure about what you have been told, ask for an interpreter to be with you or discuss the tests with a doctor who speaks your first language.

Frequently Asked Questions

How often will I have blood tests if I have kidney disease?

This will depend on how severe your kidney disease is. In later stages of kidney disease, as the need for dialysis is approaching, blood tests every 1-2 months will probably be necessary. Additionally, if there are specific concerns (e.g., potassium levels), then more frequent blood tests may be needed. People with stable kidney disease may only require blood tests once or twice per year.

Is it safe to have an imaging test using contrast dye if I have kidney disease?

Some imaging tests, like CT scans and MRIs, use contrast dyes to get clearer pictures. These contrast dyes can cause more damage to your kidneys when you already have kidney disease. If your doctor orders an imaging test make sure they are aware you have kidney disease.

There are various options to lessen the risk of kidney damage during contrast dye procedures, including instructing you to drink lots of fluids before the procedure or giving fluids through an intravenous line, using a type of dye that is less damaging to the kidneys, limiting the volume of dye and giving medications that may protect the kidneys. As with many medical decisions, it comes down to the balance between the risks and benefits.





Treatment options for stage 5 kidney disease

If your kidney function declines to the point where you have Stage 5 kidney disease you will need to make a decision about your choice of treatment.

This choice is not set in stone and often patients will move through several of the different treatments throughout their kidney disease. Decisions take time, and important decisions should not be rushed.

This is why you may be provided with information about the different treatments and encouraged to consider your options before you reach Stage 5 kidney disease.



The treatment choices for someone with Stage 5 kidney disease are:

1. Dialysis
2. Kidney transplantation
3. Non dialysis supportive care

Each treatment offers a very different lifestyle and daily routine. It is important that you make the best choice to suit your lifestyle priorities at this point in time.

Dialysis

Dialysis replaces some but not all of the work of your kidneys and is not a cure but a treatment choice. Dialysis is the process of cleansing or filtering the blood and removing excess fluids.

There are two forms of dialysis treatment – peritoneal dialysis and haemodialysis. Peritoneal dialysis occurs inside your body using the peritoneal membrane as a filter. Peritoneal dialysis is performed as a home dialysis treatment. Haemodialysis is where your blood is cleaned using an artificial kidney (dialyser). Haemodialysis may be performed at home, at a non hospital based satellite unit, or at a hospital renal unit.

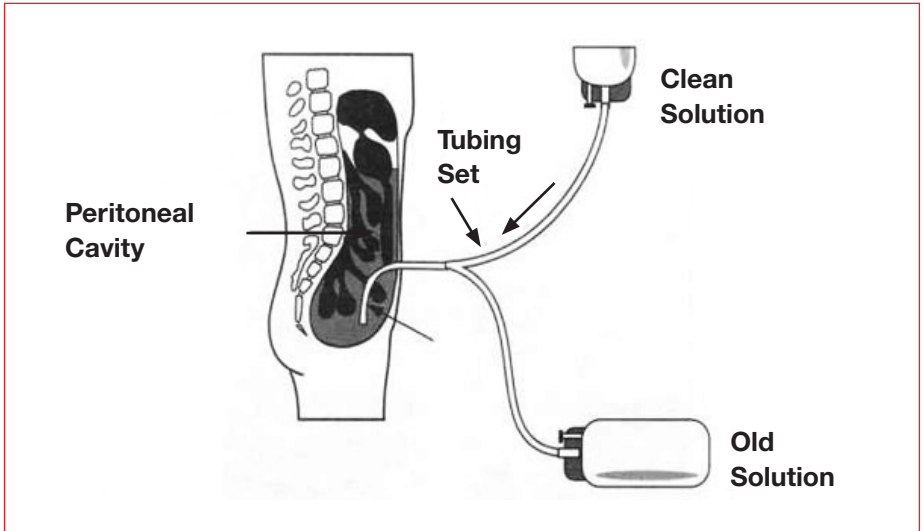
Research has shown that home dialysis treatment has the best outcomes. However, for a variety of reasons not everyone can undertake dialysis at home. This is all taken into consideration when your treatment options are being discussed. Provided there is no medical reason why one form of dialysis is more suitable than another for you then, your choice of dialysis will be influenced by your own personal circumstances and lifestyle.

Peritoneal dialysis

Peritoneal dialysis has been used as a home dialysis therapy since the late 1970's. Currently in Australia nearly 20% of the people on dialysis are using peritoneal dialysis at home. About 4 out of 10 new patients choose peritoneal dialysis as their first treatment. Peritoneal dialysis is a gentle dialysis treatment and works 24 hours a day. Peritoneal dialysis has been shown to be good at preserving any kidney function you still have.

Peritoneal dialysis is performed daily. There are two types of peritoneal dialysis. Depending on your lifestyle this will influence your preferred choice of peritoneal dialysis.

Peritoneal dialysis occurs inside your body using the peritoneal membrane as a filter to help clean the blood. The peritoneal membrane is a fine layer of tissue with a rich blood supply. The peritoneal membrane lines the peritoneal (abdominal or belly) cavity and covers your organs such as your intestines. A catheter is placed into this peritoneal cavity.



Continuous Ambulatory Peritoneal Dialysis (CAPD)

Continuous Ambulatory Peritoneal Dialysis, known as CAPD, is the most portable type of dialysis. It is simple and is usually learnt in about one week. It does not require needles. You are taught to connect and disconnect sterile bags of dialysis fluid to the catheter (called an exchange) approximately four times a day. Each exchange takes approximately 40 minutes. In between exchanges you go about your day as normal.

CAPD works by gravity. When the drain bag is placed at floor level the peritoneal dialysis fluid drains out of the abdomen. By raising the new dialysate bag above shoulder level, the new dialysate flows by gravity into your peritoneal cavity.



Automated Peritoneal Dialysis (APD)

Automated Peritoneal Dialysis, known as APD, uses a machine (cycler) overnight to control the dialysis fluid going in and out of your abdomen. During the day some fluid may be left inside your abdomen to continue the dialysis. Each night your catheter is attached to the tubing of the cycler. It does several automated exchanges, moving the dialysate fluid in and out of your abdomen whilst you are asleep. APD is done every night and usually takes between 8–10 hours. In the morning you disconnect yourself from the cycler, put a cap on the catheter in your abdomen, and go about your day.

Getting started on peritoneal dialysis

Before starting peritoneal dialysis a small operation is required for the peritoneal dialysis catheter to be placed into a special cavity in your abdomen known as the peritoneal cavity. A peritoneal dialysis catheter is a soft, flexible plastic tube about 0.5 cm in diameter. The catheter stays in your body for as long as dialysis is needed. Part of the catheter is on the outside of your abdomen. This catheter is used to move dialysis fluid (dialysate), a special fluid that helps to clean your blood, in and out of your abdominal cavity painlessly.

The catheter is usually below and to one side of your navel (belly button). The place where the tube comes out of your abdomen is called the 'exit site'. You and your health care team will decide on the best location for the catheter. The catheter is taped down comfortably and is easily hidden under clothing. You are taught to look after the exit site as part of your daily routine, as care must be taken to avoid infection. The catheter may seem strange at first but most people become used to them quickly.

You will be referred to a surgeon for the catheter operation. The operation requires one to two days in hospital but the actual procedure only takes a short time. The catheter is then usually rested for two weeks before peritoneal dialysis training can begin.



How do I learn to do peritoneal dialysis?

Most people can learn how to do peritoneal dialysis in about one week. Special nursing staff will help you to learn. The nurses will help to set up your home (you may need a suitable table that can be wiped down, a blood pressure monitor, and accurate scales) and will continue to support you for the time that you are on dialysis. Any waste can be placed in your general rubbish bin.

During training you will learn to:

- Perform the exchanges
- Care for your exit site
- Manage your general health
- Manage any problems with dialysis
- Order and look after your supplies

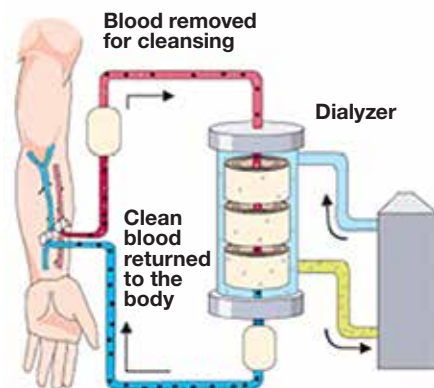
Haemodialysis

During haemodialysis, two needles are inserted into your fistula. These are connected to tubing which takes your blood to the dialysis machine, where it passes through a special filter called a dialyser before being returned to your body. The dialyser removes waste products by diffusion, and helps to balance fluid, minerals and chemicals in your blood.

The dialyser is a plastic cylinder containing thousands of very fine tubes. Blood is pumped into the dialyser and flows through the fibres. Each tube has tiny pores in its walls big enough for waste and extra fluid to pass through, but too small for blood cells and proteins.

A special fluid called dialysate washes around the fibres. The dialysate does not come into direct contact with your blood; however, it interacts with your blood to balance the various salts and other chemicals, to return them to normal range. The dialysate also helps to draw waste and excess fluid out of your blood across the pores of the fibres, leaving clean blood to flow back to your body.

Haemodialysis process



Where do I go for haemodialysis?

There are several location options for haemodialysis:

- **Your own home:** You are trained by nurses to manage your own dialysis at home.
- **Self-care unit:** You are trained to manage your own dialysis in a community setting.
- **A satellite dialysis unit:** These units are often located in the community. A team of nursing staff support your dialysis.
- **Hospital or in-centre dialysis:** This is usually for those who require extra medical support.

Home haemodialysis

In Australia approximately 1 in 10 of people on dialysis use home haemodialysis. Your lifestyle on home haemodialysis is flexible and allows you to control your dialysis schedule. Current research suggests that home haemodialysis is the best treatment for many on haemodialysis as it offers a good quality of life, improved life expectancy and less time spent in hospital. When you dialyse at home you can dialyse for longer periods, and you have more control over your treatment. These factors often lead to better outcomes.



Dialysis treatments occupy at least 15 hours per week, but can be done at any time of the day including overnight (called nocturnal haemodialysis). Sessions can last between two and eight hours, and you can have between three and seven dialysis sessions each week. Many people using home haemodialysis choose to dialyse for longer periods of time as this makes them feel healthier and means less diet and fluid restrictions are required. You can work with your health care team to plan a dialysis schedule that allows maximum flexibility for work, lifestyle activities and time to be spent with your family.

To dialyse at home you must learn to use a home haemodialysis machine, and to insert and remove your dialysis needles. This haemodialysis machine will be installed free of charge in your home. Full training is given to you and your support person (if you choose to have one). Training can take between six and twelve weeks. All dialysis supplies you need are delivered free of charge to your home. Additional things you may need include a suitable reclining chair and a blood pressure monitor. Rebates are available to assist with electricity and water costs.

Many people worry about how they will cope with any problems that occur when dialysing at home. The training will teach you how to manage these problems and when to call your specialist nurses or doctor for further assistance.

Self-care unit

Depending on where you live in Australia you may have access to a haemodialysis self-care unit. These are units set up in the community where you can go to perform your own haemodialysis. They are a good option if you would like to take control of your haemodialysis schedule, but for some reason your home is not suitable for haemodialysis. You will need to organise your own transport to and from the self-care unit.

Satellite centre or hospital renal unit

If you dialyse at a satellite centre or renal unit you will have permanent regular dialysis session appointments, typically at least three times a week, e.g. Monday, Wednesday and Friday or Tuesday, Thursday and Saturday. Appointment times vary depending on the unit, but you typically have either a morning or afternoon time slot. Each unit dialysis session is for 4-5 hours. Some satellite units are relatively self-care, where you can do a lot of the dialysis yourself. In other satellite units, and in hospital renal units, the dialysis is usually done for you by dialysis nurses. You will need to organise your transport to and from the satellite centre or renal unit at the specified days and times.

Getting started on haemodialysis

For haemodialysis to be performed, access to the blood stream is needed. This is known as 'vascular access'. The vascular access surgery is usually done as a day surgery procedure. It can take up to two months for the access to 'mature' ready for dialysis.

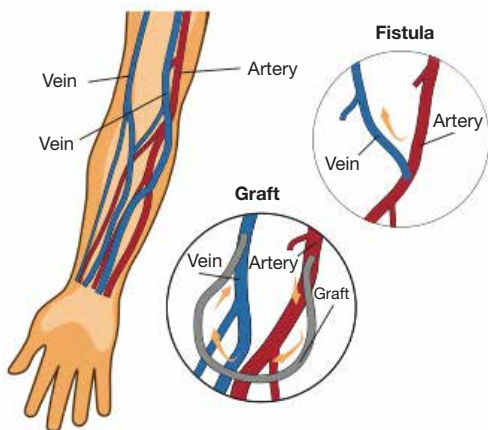
There are three types of vascular access.

1. Fistula: A fistula is made by surgically joining one of your arteries to a vein. Arteries carry blood at high speed and have strong walls. Veins have lower blood flow and weak walls that may collapse if used repeatedly for dialysis. After a fistula is made, the blood from your artery flows into your vein. Over time this makes your vein larger and stronger so it can be used for dialysis. A fistula is usually in your lower or upper arm.

A fistula is created a number of weeks or months before dialysis is needed. This gives the blood vessel time to grow and strengthen. The cut to make a fistula is about 4 - 8cm. Your arm can be used normally after the operation; although a few general rules need to be followed. Your health care team will discuss these rules with you, along with how to regularly check your fistula. A fistula should last for many years if it is well cared for.

There is a 'buzzing' feel as the blood moves from the artery into the vein. This feels like a cat purring and is called a 'thrill'. The buzzing means the fistula is working well. If the buzzing stops or changes in any way, contact your renal unit or doctor immediately as the fistula may be blocked.

Fistula and graft vascular access



Central venous catheter

2. **Graft:** Uses a piece of tubing to attach one of your arteries to a vein. It is used if your own blood vessels cannot be used to make a fistula. During surgery your artery and vein are joined together by soft tubing, which can be punctured repeatedly. The graft is usually put in your arm but can also be in your thigh. Grafts are more difficult to make, but are a good solution if you have small, weak or damaged veins. Recovery time after a graft procedure is longer than after a fistula as it is more invasive surgery.
3. **Central venous catheter:** A central venous catheter (also called a vascular access catheter) is usually a tube put in temporarily until a fistula or graft is ready to use. Catheters can be used immediately. A catheter is usually placed in a large vein in your neck near your collarbone. It is also occasionally located in a large vein in the groin (top of your leg). A catheter has two separate channels. One channel takes blood to the dialysis machine and the other returns cleaned blood. A small operation is required to insert the special tube and then remove it when it is no longer needed. You will learn about your catheter from the dialysis nurses, who will clean and dress it after dialysis. It is important to remember that catheters are usually a temporary access until a fistula or graft is ready to be used, and should be kept clean and dry.

How will you feel after haemodialysis?

Sometimes during or after dialysis you can feel sick, dizzy, tired, washed out, or have muscle cramps. This is usually caused by quick removal of a large amount of fluid which results in a drop in your blood pressure. These symptoms are usually reduced if using home haemodialysis, where you can dialyse for longer hours and more frequently.



Danielle's Story

I have been extremely lucky with my lifestyle changes. My family have been very supportive. They changed the laundry into my own personal retreat to do dialysis. My grandpa also made a few changes in his house to accommodate my needs and so did my boyfriend and his parents. Everyone helped me get better and for that, I am forever grateful!



Differences between peritoneal dialysis and haemodialysis

Both peritoneal dialysis and haemodialysis are useful and important treatments and the choice of treatment is influenced by many factors. Some of these are presented in the table below:

	Peritoneal dialysis	Satellite or centre haemodialysis	Home haemodialysis
Frequency	Daily routine, treatment must be done every day or every night.	Three times per week, 4-5 hours. No dialysis in between.	Flexible. At least 15 hours per week. Any time, any day.
How long to train	1-2 weeks.	None.	6-8 weeks.
Independence	Treatment can be done at any suitable place, or at night while sleeping	Limited. Treatment done at specified place and time.	Treatment done at home, at any time on any day.
Equipment	Very little equipment needed. Storage space for supplies	None.	Need machine at home with small changes to plumbing. Storage space for supplies.
Food and fluids	Changes may be needed in amounts and types of food eaten. There may be a limit on fluid intake. Restrictions will be less than that for haemodialysis.	Changes will be needed in amounts and types of food eaten. There will be a limit on fluid intake.	Changes will be needed in amounts and types of food eaten. There will be a limit on fluid intake. If dialysing for longer sessions restrictions may be reduced.
Body image	Permanent catheter in abdomen. Some abdomen fullness. May also have a fistula.	Fistula looks like a swollen vein (usually on arm) and can go lumpy.	Fistula looks like a swollen vein (usually on arm) and can go lumpy.

	Peritoneal dialysis	Satellite or centre haemodialysis	Home haemodialysis
Infection	Catheter increases the risk of infection.	Care needed when inserting needles due to risk of infection. Not frequent.	Care needed when inserting needles due to risk of infection. Not frequent.
Needling	No needles required for treatment.	Need to insert two needles each treatment.	Need to insert two needles each treatment.
Activities	Some restrictions on swimming/bathing because of risk of infection	No restriction on swimming/bathing. Wear protective cover on access limb if playing contact sport.	No restriction on swimming/bathing. Wear protective cover on access limb if playing contact sport.
Work and hobbies	Can choose daytime or overnight peritoneal dialysis to suit your priorities. Can do CAPD away from home.	Routine is set. Need to check when your local unit is open.	Flexible dialysis schedule allows you to dialyse when it suits you.
Travel	Can travel freely with minimal planning, though transport of dialysis bags overseas can be expensive. There is provision for some supplies to be delivered per year to most holiday destinations.	Must be pre-planned, and can be expensive. Need to book into other dialysis units, and must do this early.	Requires planning, but you may be able to take your home haemodialysis machine with you, or go to a fixed dialysis house which has a machine installed. You can also book into other dialysis units, but must do this early.
Duration of treatment	Works very well for most people for several years.	Can usually be maintained long term.	Can usually be maintained long term.

Kidney transplant

Kidney transplantation is the most effective treatment for kidney disease for those people who are suitable. Compared with dialysis, transplantation is associated with improved life expectancy and quality of life. The best outcomes are usually seen in people who have a pre-emptive transplantation (this is when a kidney is transplanted from a living donor before dialysis is started).

A transplant offers a more active life, free from dialysis as well as food and fluid restrictions. However, the new kidney requires management and care. Anti-rejection medications are necessary for as long as the transplanted kidney functions. How long a transplanted kidney functions can vary depending on many factors. In Australia our data shows that half of transplanted kidneys last at least 14 years. Some individuals have had kidney transplants that have lasted more than 30 years.

A kidney transplant is not a cure for kidney disease. If a transplanted kidney stops working, dialysis treatment will be necessary again. Another transplant may also be possible.

You can go on the waiting list for a transplant if you are considered to be medically suitable. Unfortunately a transplant is not suitable for all patients, as the risks are sometimes too great. However, it is every person's right to be considered for a transplant. You will need to speak with your nephrologist for further information about your individual circumstances.

Factors affecting your suitability include:

- Agreement with the idea of transplantation and acceptance of risks involved
- General good health, apart from kidney failure
- Willingness to go through with the tests and operation
- Willingness to undertake the lifelong anti-rejection medications

Most metropolitan cities have a hospital that performs kidney transplants. If you live in a regional or rural area of Australia or in a city that does not have a transplant hospital you will be required to travel to the closest transplant hospital for your kidney recipient evaluation, and for the transplant procedure itself. Your health care team will be able to discuss these travel arrangements with you.

Kidney donors

Kidneys for transplantation come from living or deceased donors. Live donors are usually relatives such as parents, brothers, sisters, or adult children. If blood group and tissue typing results are suitable, people unrelated to you such as your partner or friend may also donate a kidney.

The tests to determine whether someone is a compatible donor for you are very complex. It is best that you discuss your situation with your nephrologist and the transplant team, to better understand your options. Transplants can often now be done that were previously hard or impossible to perform because of new techniques that are available (e.g., a blood group incompatible donor).

The ability to overcome compatibility difficulties is easier with live donors. Sometimes with pre-treatment of the recipient to remove antibodies it is possible to perform what otherwise would be an incompatible transplant.

There are two possible issues to overcome:

- 1) Blood group incompatibility – due to incompatible blood groups and antibodies in the recipient against the A and/ or B blood groups
- 2) Immunological incompatibility - due to tissue typing or HLA antibodies in the recipient.

There are new techniques, which may be able to adequately overcome these problems. If not, then it may be possible to participate in the Australian Paired Kidney Exchange Program. See Chapter 6 for more information about live kidney donation.

The main benefit of having a live donor is in the timing. It can sometimes take years before a transplant becomes available from a deceased donor. Live donation may mean you can have a transplant before you even need to start dialysis, or shortly after you start dialysis. It also means that the time between a kidney's removal and its transplantation (called the 'cold ischaemia time') is less so the success rate improves. An additional advantage is that the quality of the kidney usually tends to be slightly better from living donors. Hospital admission and surgery can also be planned ahead of time, allowing the donor and recipient plenty of time to prepare for the surgery and recovery. The surgery and pre-surgical care for recipients is the same whether the kidney is from a deceased or live donor.

Deceased donors are people who die, with relatively healthy organs that are considered suitable for transplantation. Deceased donors may have indicated they would like to be an organ donor, or their family makes this decision after their death. Organ donation requires special conditions and is only possible in less than 1% of all hospital deaths. People are around 10 times more likely to need an organ transplant than to become a deceased organ donor.

Allocation of kidneys from deceased donors

When you have been evaluated as being suitable for a kidney transplant your name will go on the transplant waiting list. The kidney transplant waiting list is more complex than a simple queue where you slowly work your way to the front. The amount of time you have been waiting is an important factor in determining the allocation, but there are other factors that are also considered.

Each time a deceased donor kidney becomes available a recipient is chosen taking into account the blood group, the tissue typing and match, the HLA antibodies, and the waiting time on dialysis, of all the possible recipients in Australia. A computer generates a score for these and other factors, and the recipients with the highest score will be offered the kidney. Although some people get an excellent "match", in most cases people receive a very compatible kidney that may not be greatly matched and is still expected to do very well.

Young children get priority in most states, particularly if dialysis is interfering with their growth and schooling. There are so few children waiting that this policy has little influence on the average waiting time. Overseas visitors are ineligible for an Australian transplant; people on the transplant waiting list must be permanent Australian residents.

It can sometimes take months or even years before a person on the kidney transplant waiting list receives a kidney from a deceased donor. If your health worsens while waiting for a kidney, you may be taken off the waiting list for a while until it improves. The transplant would have less chance of success and could even be life threatening if you are not well. This can be frustrating and often depressing. It may seem unfair that one person will wait for many years while someone else will get a lucky break within months of starting dialysis. You can only congratulate them and hope that you will be next.

Are kidney transplants successful?

Kidney transplants are very successful. On average, 95% of transplants are working one year later, and 80% are working five years later. About 40% of transplanted kidneys are still functioning 15 years after transplant.

To give your transplant the best chance of success, it is important that you look after yourself beforehand by doing the following:

- Maintain your dialysis schedule
- Follow your recommended diet and fluid restrictions
- Maintain good blood pressure control

- Stay fit by exercising regularly (see Chapter 11 for tips)
- Look after your teeth and gums: Visit your dentist regularly as the risk of a mouth infection increases after transplant surgery if teeth and gums are in poor condition.
- Protect your skin which will help to prevent skin cancer after transplantation.
- Maintain a healthy weight (see Chapter 11 for tips)
- Be a non-smoker
- Provide your tissue typing and antibody blood tests each month to make sure that the information used for matching a kidney is current
- Have regular reviews with your health care team and discuss any concerns about your transplant preparation.

More information on the kidney transplantation process is provided in Chapter 6.

Non dialysis supportive care

Non dialysis supportive care means you choose not to receive dialysis (or transplant) treatment for your Stage 5 kidney disease. Non dialysis supportive care is usually chosen when the burden of dialysis would outweigh the benefits. The decision not to have dialysis treatment and to choose the supportive care pathway should be made in consultation with your health care team. Some people choose the non dialysis supportive care option after other treatments for kidney disease have been exhausted. Others choose non dialysis supportive care as their primary treatment pathway as the burden of dialysis would outweigh the benefits and given them a worse quality of life.

Non dialysis supportive care is an appropriate choice for some people when dialysis is unlikely to improve their quality or length of life. Choosing not to have dialysis or a kidney transplant will eventually lead to death. However, studies have shown that if you are frail and elderly and have a complicated medical history, you may live just as long being treated with non dialysis supportive care as you would with dialysis treatment. This may also apply to people of any age who have other complex illnesses in addition to their underlying kidney disease. If a

kidney transplant fails, some people may choose non dialysis supportive care rather than return to dialysis, particularly if they have experienced complications with dialysis in the past.

What is non dialysis supportive care?

The only treatment difference between dialysis and non dialysis supportive care is whether you have dialysis treatments or not. With non dialysis supportive care your treatment is still overseen by your nephrologist. Diet and medications are used to preserve kidney function for as long as possible and to manage symptoms of kidney disease. Without dialysis or transplantation, you become increasingly tired as wastes and fluid build up in your body. This build up can make it more difficult to breathe so oxygen and diuretic medication can be provided. Pain medication can be prescribed for any discomfort. As your kidney function deteriorates you may be referred to a palliative care team for specialised management of symptoms, for support, and for end of life planning.

Conflict over decisions to have non dialysis supportive care

Sometimes family members have unrealistic expectations of what dialysis can achieve and it may be difficult for them to come to terms with your decision or your doctor's recommendation that you be treated with non dialysis supportive care. At other times, medical staff may recommend dialysis when you are committed to a non dialysis supportive care pathway. Sometimes, reaching agreement can be difficult.

What happens if I change my mind?

Treatment decisions can always be reviewed. If you choose non dialysis supportive care and change your mind, a decision to start dialysis may be discussed with your doctor. Likewise, if you start dialysis but decide that it is not what you expected, you can stop dialysis treatment.

Stopping dialysis treatment

Stopping or withdrawing from dialysis treatment is not an uncommon decision for people who have been on dialysis for a long time, particularly those who are elderly and in poor health. If you decide dialysis treatment is no longer the treatment choice for you, your health care team will talk to you about non dialysis supportive care.



Nora's Story

I chose not to have dialysis. I wasn't frightened of it or anything, I just didn't want to have it. I thought that it takes your quality of life away - to be there for three days and so many hours each time. I wanted to be doing other things because I do different things each day of the week - visiting my friends, going shopping, seeing my great-grandkids. It's a long stretch of time and takes a good hole in your week. I'm 83 now. I thought that I'll enjoy life while I can and I've got a lot of living to do yet. The doctors and nurses have been very supportive of my decision.

Frequently Asked Questions

When will I need to start dialysis?

In the early stages of kidney disease you do not need dialysis. Some people do not ever progress past the early stages of kidney disease, and do not ever need dialysis. However, if you reach Stage 5 kidney disease, dialysis or a kidney transplant will be needed to keep you healthy and ultimately alive. Your health care team will help you decide when it is necessary to choose a treatment for Stage 5 kidney disease (See Chapters 6 and 7 for more information about treatment choices).

If I decide to do in-centre or satellite haemodialysis, is transport available to bring me to and from dialysis?

In most cases transport is not provided by the renal unit to transport patients to and from dialysis and it is the organisational and financial responsibility of the patient or their family to arrange this. If you have to travel a very long way to get to your dialysis centre you may be eligible for assistance from a patient travel assistance scheme. Dialysis transport information booklets are also available to download from www.kidney.org.au or ask your renal unit for more information.

If I live alone, is it possible for me to dialyse at home?

While most patients who dialyse at home have got a support person living with them, it is certainly possible to do dialysis independently if living alone at home. About 10% of patients on home haemodialysis live alone. Many renal units will offer a telephone service staffed by nurses who are experts in home dialysis and who can offer advice and support over the phone.

If I live in an isolated rural area, what is the best form of dialysis for me?

For many people who live a significant distance from a dialysis unit, home dialysis may be the only viable option for them. Depending on your preference either peritoneal dialysis or home haemodialysis will usually be possible. In some cases, water quality or supply may be an issue but there are usually ways of overcoming these problems.



Frequently Asked Questions

If I am on home haemodialysis and my support person or I need a temporary break, are there options to temporarily dialyse at an in centre dialysis site?

Most dialysis units will certainly provide respite in-centre dialysis. This option is an important part of supporting you in being successful with dialysing at home. There may be periods in your life where due to illness or emotional stress you need a break from being responsible for your own dialysis and it is important to seek help in these situations.

Will I be out of pocket financially if I dialyse at home?

Patients on peritoneal dialysis have all the consumables provided and should therefore not be at any financial disadvantage. Doing haemodialysis at home does involve increased water and electricity bills. Some States provide funding to patients to help cover these costs but you should enquire from your own Nephrology unit to get an accurate figure on how much you may be out of pocket. Visit www.homedialysis.org for information on financial support if you are undertaking home dialysis.

If I choose to have non dialysis supportive care, what will my quality of life be like?

Research has shown that for people who choose non dialysis supportive care this treatment option can provide quality of life which is better than going on dialysis. Every person is different, and your health care team will be able to provide more information which is relevant to you.

If I stop dialysis how long will I live?

This varies from person to person, and may range from one week to several weeks. How long you live depends on how much kidney function you still have (which may maintain your blood chemistry levels longer) and whether you have other health problems.

How long is the waiting list for transplant?

There are approximately 1,000 people waiting for a kidney transplant in Australia. The average waiting time is around 4 years, but waits of up to 7 years are not uncommon.

Where to go for more information

Choosing treatment for Stage 5 kidney disease can be a very confusing and overwhelming process. Many renal units now have a dedicated pre dialysis educator who will support you through this process. Chapter 7 contains more detail about issues to consider when choosing your treatment. Chapter 15 also has information regarding relevant resources, contacts and supports to help with this process.



The kidney transplant process

Kidney recipient evaluation

Before you can be placed on the kidney transplant waiting list you will need to undergo a series of tests to ensure that you are considered medically, surgically and psychologically suitable for a transplant. Transplant surgery and medications used to prevent rejection can place a strain on your body and cause problems if you are not well. Medical tests that are used to assess your health before a transplant include:

- Physical examination
- Blood tests
- Dental check
- Pap smear and mammogram (females) or prostate tests (males)
- X-rays of the heart and lungs
- In some circumstances, extensive checks of heart health may be required
- Surgical review of your arteries, veins and bladder

Transplant waiting list

When you have been evaluated as being suitable for a kidney transplant your name will go on the transplant waiting list. Your waiting time is based on the day you started dialysis, regardless of when you were officially placed on the waiting list. If you come off the list temporarily for some reason, the same 'dialysis start' date is used again when you go back on the list.

When a suitable kidney from a deceased donor becomes available for transplantation the Organ Donor Coordinator consults the national allocation list to determine which potential recipient will be offered the organ. They then contact the transplant unit responsible for that patient to discuss the potential for transplantation.

If you are chosen to receive a transplant, the hospital will contact you. Make sure the hospital has your current fixed and mobile telephone numbers, as well as the numbers of people you may be contacted through. Sometimes people on the waiting list are issued with a pager to ensure the hospital can reach them easily. If you cannot be found and do not contact the hospital within a certain time, the kidney may need to be given to the next person on the allocation list.

The identity of the deceased donor is not revealed to the recipient but you are able to write anonymously to the family via the Organ Donor Coordinators and DonateLife (see contact details in Chapter 15).

How are kidneys matched?

Each time a deceased donor kidney becomes available a recipient is chosen, taking into account blood group, tissue typing, HLA antibodies in the recipients, and waiting time on dialysis. The allocation takes into account all these factors to try and determine the best way to use each kidney that is made available. Transplant units being offered the kidneys for their listed patients need to take into consideration many factors in the donor including the age, potential organ function, anatomical issues, and possible risks involved in using a specific kidney.

Recipient blood group	Can receive a kidney from someone with blood group
O	O
A	A, O
B	B, O
AB	O, A, B, AB

Blood group

Kidney donation blood group compatibility is similar to blood donation blood group compatibility. The following table shows blood groups that are compatible with each other for the purposes of kidney donation:

Even if your blood group is suitable, the cross match test with your serum must also be 'negative'. This indicates that you don't have a high level of HLA antibodies against the donor and that you are less likely to immediately reject the donor kidney. A positive cross match with a potential donor means you have a very high risk of quickly rejecting the kidney from that donor. For this reason you will not be offered a kidney from a donor that results in a positive cross match with your serum.

Tissue typing and HLA antibodies

We all have special proteins on our cells (HLA proteins), which are unique to us and are recognized by our immune system. These proteins are assessed when we have our tissue typing done. They are also assessed in deceased

and living donors. Our immune system recognizes foreign proteins not belonging to us, and this is the basis of our immune system's ability to defend us against infections. This is also the underlying cause of transplant rejection.

How similar our typing is with someone else's refers to our 'match'. It is important to point out that with new anti-rejection treatments, matching is less important than it was a few decades ago. Most transplants performed do not have a high level of matching and still have excellent results. Many people would wait a long time or never get transplanted if they waited for a very good match.

Of greater importance is the possible presence and level of 'cytotoxic antibodies' against these foreign HLA proteins, already in the recipient's blood before they receive a transplant. If these antibodies are not present then the situation is much easier. However, some people have already been exposed to foreign HLA proteins prior to a transplant through previous blood transfusions, pregnancy, or a previous transplant. This means that they may have already made antibodies against other people's tissue types, which in some cases makes it difficult to find a suitable donor.

This previous exposure is similar to how a vaccination works, in that it primes or prepares the immune system to attack a foreign protein that it has previously been exposed to before. The testing for these antibodies has advanced a lot in the last few years and it may be necessary for you to discuss these issues in detail with your transplant team depending on your individual situation.

What happens during a kidney transplant?

Before surgery

After admission to hospital, you will have a physical examination and details of your medical history will be recorded. A dialysis session may be required. Any active infections or other significant medical problems can cause cancellation of the operation. Anti-rejection medications are given before and after surgery to suppress the immune system and stop your body from rejecting the new kidney.

During surgery

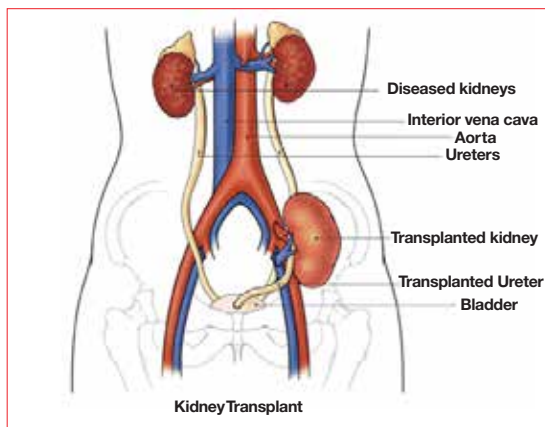
Surgery for a kidney transplant takes about two to three hours. A cut is made in the lower part of your body, on the right or left side. The new kidney is placed in the pelvis. The renal artery and vein of the kidney are connected to an artery and vein in your pelvis (usually the iliac vessels that lead down towards the leg).

The ureter of the kidney is connected to your bladder so urine can flow. Your kidneys are not usually removed. Sometimes if you have large polycystic kidneys, one may be removed to make space for a transplant. This procedure would be done as part of the transplant workup.

A temporary tube or catheter is placed in your bladder for up to five days to drain urine into a bag. This tube comes from your urethra, the exit point for urine. It helps the medical team to check that your kidney is working well. Often there are tubes from your wound draining away fluid. These are usually removed after a few days.

After surgery

Many people begin to produce urine immediately after the new kidney has been transplanted. A catheter will be inserted into your bladder during the operation so any urine that is produced will pass through this into a collection bag. Others may need dialysis for a while until the transplanted kidney begins to work. This does not mean that it will not work, just that it needs time to start. There may be temporary injury to the kidney, which can take several days or even weeks to recover. Daily blood tests are taken to check the



function of your transplanted kidney, measure medication levels and detect early problems so they can be treated quickly.

It is important to do coughing, breathing and leg exercises while you are restricted to bed rest in order to:

- Minimise the risk of a chest infection.
- Reduce the chance of clots in the legs after surgery.
- Maintain clear air passages.
- Promote blood flow.

A physiotherapist may assist you with your exercise plan. Most people sit out of bed after the first day and are able to walk within a couple of days.

Your length of time in hospital depends on how fit you are, how well the body responds to the new kidney and whether there are complications. Most people are in hospital between six and ten days. Some people feel

better immediately after their surgery while others take longer to adjust. You may need to return to hospital for a brief time if you have problems. It is not advisable to do any heavy lifting for six weeks, or to drive until two to four weeks after a transplant. This will allow you to heal and your abdomen to regain strength after the operation.

Post transplant care

Caring for yourself after the transplant is very important. The first few months following the transplant are often when things are the most unstable and you are at risk of developing problems. You will have regular medical check-ups to monitor the function of your new kidney. These will be daily at first, then weekly, then monthly. It is important that you report any changes in your health to your health care team as soon as possible.

As the transplanted kidney is foreign to your body you must take anti-rejection medications for as long as the transplanted kidney functions. These medications partially block the activity of your body's immune system, preventing it from attacking the transplanted kidney.

In the early period of your transplant, you may be diagnosed with rejection episodes. These can usually be managed with adjustments to your current medications or added

medications. Some rejection episodes require additional treatments such as plasma exchange (to remove antibodies in your blood) or special infusions. The great majority of rejection episodes can be managed successfully. However, rejection can take place at any time after your transplant so it is very important that you follow any medical instructions and receive regular monitoring.

Acute rejection

Acute rejection appears as an active inflammation in the kidney and usually needs relatively prompt diagnosis and action. Mild rejection is very common in the first year after a transplant. Acute rejection sometimes causes pain and fever but usually has no symptoms. A biopsy of the kidney transplant is needed to diagnosis rejection and to determine the best course of action in treating the episode, as there are several options for treatment depending on the type of rejection and its severity.

Chronic rejection

Chronic rejection refers to a gradual process, which leads to scarring and irreversible damage in the transplant. This usually occurs over several years and can be very difficult to treat. During this time the kidney is gradually losing its function and may eventually fail, leading to the need for dialysis and repeat transplantation.

Anti-rejection medication

There are many different medications which are used to prevent rejection. It is important to talk to your health care team about your transplant medications to get advice about:

- When and how to take them
- Missed doses
- Possible dietary restrictions
- Interactions with other medications
- Side effects
- Storage and care of medications

Medication side effects

Anti-rejection medications have a number of possible side effects, including an increased risk of infections, because the body's immune defences are suppressed. Fortunately, these side effects usually are manageable and related to dosage. If side effects do occur, changing the dose or type of the medications often improves things.

Some of the most common side effects include:

- Puffiness of the face and abdomen
- Unwanted hair growth, or in other cases hair loss
- Increased appetite and weight gain
- Mood swings
- High blood pressure
- Diabetes
- Greater risk of infections
- Greater risk of tumours (particularly skin cancer)
- Acne
- Muscle weakness
- Hand tremors
- Indigestion
- Diarrhoea

You may also require additional medications to maintain blood pressure and prevent stomach ulcerations and infections. If you become concerned about any possible side effects, you should discuss them with your health care team. Do not stop taking your medication unless told to do so by your health care team.

If you need treatment from other health professionals such as dentists, advise them that you have had a kidney transplant. Consult your kidney specialist before taking any prescription or over-the-counter medication prescribed by another health professional as it may affect your anti-rejection medications.

Looking after yourself following transplantation

It is important to take good care of yourself following a transplant. As the anti-rejection medications are suppressing your immune system you may be unusually susceptible to certain infectious illnesses.

Always report any illnesses to your health care team. Contact them immediately if you experience any of these symptoms or other symptoms your doctor tells you to watch for:

- Discharge of fluid, redness or warmth at the site of the operation
- Abdominal pain or diarrhoea
- Feeling unwell, e.g. vomiting, persistent coughing or a sore throat fever or chill
- Reduced urine output or trouble urinating
- Blood in the urine
- Sudden weight gain
- Pain in the area of the transplanted kidney

Reduce your risk of infection

See 'Looking After Your Health' in Chapter 13 for tips on how to reduce your risk of infection.

Manage your cancer risk

The anti-rejection drugs suppress the immune system's normal monitoring of cancer cells so there is an increased risk of cancer following transplantation. To reduce your risk of skin cancer, remember to 'slip, slop and slap' when you are in the sun. Women should be aware of the increased risk of breast cancer and cancers of the reproductive tract.

It is important to be a non-smoker. Health problems caused by smoking increase after a transplant, particularly the risk of lung cancer, strokes and heart attacks. The function of the transplanted kidney and the chances of a long-term, successful transplant can also be reduced if you smoke.

Healthy diet and exercise

See Chapter 11 for tips on how to adopt a healthy lifestyle that includes a nutritious diet and regular exercise.

Sexual activity

See Chapter 12 for more information on sexuality and fertility following a transplant.

Emotional well-being

Having a transplant has a positive effect on most people's lives. However it is still a major, life-changing event causing a range of emotions before or after the operation. You may have mood swings and feel stressed or depressed as you adjust to the return to better health, and as your body responds to the anti-rejection medication.

You may also:

- Have to come to terms with having another person's organ inside you. Some people worry that they may develop the donor's personality but this is not possible.
- Have conflicting feelings about a deceased donor transplant. Relief and happiness at having a new kidney but upset because the donor's family and friends are experiencing loss.
- Be overwhelmed by feelings of being 'normal' again.
- Find that your relationships change as your family and friends adjust to you becoming more active.
- Experience a 'roller-coaster' of emotions about the possibility of rejection. You may feel anxious about attending medical appointments and then relief after being told that the kidney is doing fine.

- Be overwhelmed at the thought of taking so many medications with their possible side effects.
- Feel guilty about your transplant because there are other people still on dialysis.

People deal with a transplant in different ways. Your emotions affect your health so it is important to talk about your thoughts and feelings with your family, friends and health care team. Try not to think or worry about things that may never happen.

The live kidney donation process

Live kidney donation is when a living person donates one of their kidneys for transplantation to another person. Live donors are often relatives such as parents, brothers, sisters or adult children. Living donation can also come from someone who is emotionally related to the recipient, such as a husband or wife, an in-law, or a good friend. Recently there has been a new type of live donation called 'non-directed kidney donation' or 'altruistic donation'. This is where someone anonymously donates a kidney to a recipient on the transplant waiting list. In this situation the donor has no say in who receives their kidney.

Live donor evaluations

To be a live donor, a potential donor must have normal kidney function, overall good health, and be emotionally suitable for live donation. The evaluation process includes blood tests and other investigations, as well as a medical, surgical and psychological assessment. Blood group, tissue typing and HLA antibodies are all considered to determine if the kidney from the potential live donor is a suitable match.

If bloods groups are not compatible, it may still be possible to proceed with the transplant depending on the level of anti-blood group antibodies in your blood (antibodies against the A or B blood group). These will need to be overcome with additional treatment to remove the antibodies around the time of the transplant. These special types of transplant are known as 'ABO incompatible transplants' and these are now being performed in many Australian transplant units with excellent results.

If you have a high level of HLA antibodies against your potential living donor, then it may be difficult to proceed with a direct donation and other options may need to be considered including the Australian Paired Kidney Exchange Program.

The Australian Paired Kidney Exchange (AKX) Program

The AKX Program helps patients seeking a kidney transplant, whose potential living kidney donor is unsuitable for them due to often severe blood group and/or tissue incompatibility. The AKX Program uses a computer program to search the entire available database of registered recipient/donor pairs to look for combinations where the donor in an incompatible pair can be matched to a recipient in another pair. If the computer finds a compatible match, two or more simultaneous transplants can occur by exchanging living donors. By early 2013, more than 50 transplants had already been successfully performed in the AKX program.



Myra's Story

My sister was diagnosed with kidney disease about ten years ago. Eventually it got to the point where dialysis or a transplant was needed. I wanted to help, and at 53 years of age I was so fortunate to be in good health to be a suitable donor. Everything went well with the surgeries, and my sister is now travelling around Australia with her husband. Six years down the track, I am feeling great and still walking five kilometres each day.

Medical testing

Live kidney donors need a thorough health check by a doctor, who is in many cases not necessarily part of the transplant team. Medical tests assess whether donating a kidney will be safe in both the short and long term for the donor. The transplantation team also has to decide whether the donor is fit for surgery and has a suitable kidney to donate.

Conditions that may prevent someone from being a live kidney donor include:

- Previous or current cancer
- Diabetes, or an increased risk of developing diabetes in the future
- AIDS
- Hepatitis
- Major heart or breathing problems
- Weight problems
- High blood pressure
- Smoking
- Psychological or Psychological concerns

Other tests to make sure that the live donor kidney is suitable may include:

- Tissue typing
- Serum cross-matching: mixing donor cells with recipient serum and observing the reaction (a test for HLA antibodies in the recipient's serum)
- Radiology tests
- Kidney function tests
- Viral screens
- Cardiovascular tests

During these medical investigations, donors may find out that they have a health problem. If this happens they will receive support and referral to a specialist.

Psychological assessment

A psychological assessment is part of the testing to make sure the live kidney donor is certain about donating and making a voluntary and informed choice. This may be done informally as part of the medical assessment or as a formal interview with a social worker, psychologist or psychiatrist.

Live kidney donors must be fully aware of the risks to their own health. The transplant team helps the donor to weigh up the risks and/or benefits and understand the medical procedures. This is called informed consent. It also helps to make sure that the donor is:

- Comfortable with the idea of donation
- Is not being forced or paid for the donation
- Has a good understanding of the physical and emotional outcomes of kidney donation.

The donor can change their decision to donate at ANY time; right up to the time that the surgery takes place.

Live donor transplant surgery

During the week before surgery, the donor and recipient are re-tested to make sure they are healthy and emotionally ready. Another serum cross match test is done to confirm that nothing has significantly changed. The day before surgery, the donor and recipient go to hospital. The recipient may have a dialysis session or other special treatments.

There are two types of surgery for the donor, keyhole (laparoscopic) or open nephrectomy. Your transplant team will discuss these procedures in detail with you.

- *Laparoscopic nephrectomy or keyhole surgery*

The surgeon inserts special instruments into your abdomen through three small cuts. One is a thin tube with a video camera on the tip called a laparoscope, which allows the surgeon to see inside your body to operate.

The kidney is collected in one of two ways:

1. Endo catch - a drawstring bag is used to catch the kidney and draw it out of the body through a small cut about 10-12cms long.
 2. Handport - the surgeon's hand is used to remove the kidney.
- *Open nephrectomy*

The surgeon makes a cut on the side or front of the abdomen. The cut is along the bottom of the lower rib to a point just above the umbilicus (belly button). It will be on the left or right side depending on which kidney is being donated. The vessels connecting the kidney to its blood supply are clamped and cut, and the ureter (which is connected to the bladder) is disconnected.

The first few days after surgery can be painful so medication is provided. A live donor's hospital stay varies from four to ten days followed by up to six weeks recovery at home and up to two months with no heavy lifting. Keyhole surgery reduces the recovery time. Everyone's experience is different so it is important to talk about recovery with the health care team, family and friends.

What are the risks to live donors?

The risk of serious complications and death following a transplant surgery is the same as with any other type of major elective surgery such as a gallbladder operation, hysterectomy, or joint replacement. The risk of death is approximately 1 in 3,000-4,000 and is generally related to a risk of severe bleeding, pulmonary embolus (clot to the lung) or a heart attack.

Complications during surgery include:

- Punctured lung (pneumothorax)
- Lung infection (pneumonia)
- Nerve damage
- Blood clots (thromboembolism)
- Bowel perforation
- Bleeding

Donating a kidney does not reduce your life expectancy or make you more likely to have kidney failure or another medical condition. Live donors are unlikely to develop kidney problems in the future. Removal of one kidney triggers the other to increase in size and function. The remaining kidney can provide up to 75% of normal kidney function rather than the expected 50%. Any decrease in overall kidney function is usually mild and life span is normal.



However you may be at increased risk of kidney disease if the remaining kidney is injured or disease unexpectedly develops (unrelated to donating). There is also a small risk of increased blood pressure and protein in your urine, as you get older. You should be able to live a normal life and not have increased life insurance premiums.

An annual check-up including a general health review, blood pressure measurement, a urine test for protein and a blood test for kidney function are recommended for all kidney donors every year after donation, in order to monitor and preserve the remaining kidney's function as much as possible.

Emotional recovery

Most living donors say they feel great satisfaction with the donation experience because they have helped to improve another person's quality of life. Even if the transplant is not successful, many donors say they feel positive about their decision because they did their very best to help another person. However, there is a small chance for donors to experience some negative or mixed feelings after the donation. These feelings have been more likely to occur in cases where the outcome of the surgery did not meet the expectations of the donor and/or recipient, or in cases where the donor was unsure of his or her decision.

It is also common for people donating a kidney to experience depression and anxiety after surgery. This is normal, and happens after many different types of surgery. Your health care team can suggest ways of helping you manage this.

Frequently Asked Questions

What are the costs involved with live kidney donation?

Public hospital costs, including medical tests, are covered by the usual hospital payment arrangements. There is generally a six- week recovery period before you can return to work. You will also need to have medical tests before the operation and check ups afterwards. As of 1 July 2013 the Australian Government is funding a two year pilot of a Live Donor Leave Scheme. The scheme will provide up to six weeks paid leave at minimum wage to employers, who will pass it on to those eligible employees who become live organ donors.

People who want to be private patients need to check with their health insurance company to find out to what extent their expenses are covered. Approaches should be made to the hospital if donation involves overseas donors.

If you have to travel a long way from home for the medical tests or donor operation, ask the transplant team if there is any financial assistance for transport and accommodation costs.

Donating a kidney should not affect any current health insurance arrangements. However it may affect new health insurance arrangements as some companies could consider the loss of an organ through donation a 'pre-existing condition'. Check your health and life insurance for any impact on future claims or charges.

What if the donated kidney does not work?

Even if the donor and recipient are both very healthy, and are highly compatible with each other there is no guarantee that the transplant will work. While the success of kidney donation is very high, there may be technical or medical reasons that prevent the transplanted kidney from working properly. If the transplanted kidney fails your health care team will discuss your treatment options with you.

Will the disease that initially caused my kidneys to fail come back in my transplanted kidney?

See Frequently Asked Questions in Chapter 3 for more information.

If my transplant fails can I go on the waiting list again?

Yes. You will need to be reassessed for your overall suitability again.

Frequently Asked Questions

Does a live kidney donor receive continuing follow up from a renal team in the weeks and years after their kidney donation?

Yes. There is a Living Donor Registry, which collects outcome data on all Australia live donors. Kidney donors are encouraged to have a follow up at least every year.

Do I have to be on dialysis before I receive a transplant?

No, not if you receive a transplant from a living donor. This can be performed before dialysis is required (called a pre-emptive transplant). In order to be on the waiting list for a deceased donor, you do need to have started dialysis.

Who is eligible to go on the transplant waiting list?

Anyone on dialysis and considered suitable based on a variety of criteria and tests can be placed on the transplant waiting list. There is no specific age cut-off. In general, the risk of having a transplant has to be low enough to make it worthwhile. If the risk seems too high, then it may be recommended that you remain on dialysis and not try to receive a transplant.

In some cases there may be factors that can be addressed to improve your eligibility, such as losing weight, stopping smoking, successful treatment of other conditions (e.g., if you have a heart problem).



Your treatment choice

There are several factors to consider when making your treatment choice for kidney disease and some of these are summarised in the table below. Your health care team are there to support you in making the best decision for you.

	Dialysis	Kidney transplantation	Non dialysis supportive care
Summary	Your kidney failure is treated using special equipment to remove waste products from your blood.	You receive a kidney from another person. They may be a living or deceased donor.	Your kidney failure is managed through diet and medication. You will get specialised support for symptom management and end of life care.
How the treatment is done	Treatment can be done either at home or in a dialysis centre using a machine or special dialysis fluid.	You will have an operation where you receive a kidney.	You will continue seeing your kidney specialist, who will help manage your symptoms, diet and medication.
My suitability for this treatment	Most people with kidney failure are suitable, unless you have serious illness affecting other body systems.	A transplant is usually suited to younger patients without serious health issues besides kidney disease.	This is generally an option if you have a number of serious health problems in addition to kidney disease where it is thought dialysis may not offer you a significant survival advantage with an acceptable quality of life.
My life and work	There are different types of dialysis. Home dialysis provides more flexibility and control over management than others	Most people are able to resume normal activities and work within 3–6 months after transplant.	In general this choice is made if you have a greater burden of illness. Your health is likely to progressively decline but your choice not to have dialysis may mean you spend less time in a hospital environment.

	Dialysis	Kidney transplantation	Non dialysis supportive care
My diet and fluids	You will need to maintain a healthy eating pattern. There are some things you may need to limit and avoid, but it depends on the type of dialysis. Home dialysis has less restriction.	You will need to maintain a healthy eating pattern. Medications to look after your new kidney may increase your appetite.	You will need to maintain a healthy eating pattern. There are some things you may need to limit or avoid.
My travel and holidays	You can travel more easily with some types of dialysis. Others need planning, and travel may not always be possible.	You can travel, but discuss safety and provision of ongoing treatment with your doctor.	You can travel, but discuss safety and provision of ongoing treatment with your doctor.
My treatment costs	There are standardised costs for medication and follow-up appointments. The majority of treatment costs are covered by the health system. You may have travel costs, depending on whether you have dialysis at home or at a centre. There may also be extra costs for water and electricity for those doing home haemodialysis.	There are standardised costs for medication and follow-up appointments. The majority of treatment costs are covered by the health system.	There are standardised costs for medication and follow-up appointments. The majority of treatment costs are covered by the health system
My health	Your health and wellbeing is less than that of people with normal kidney function or a transplant, but better than before you started dialysis.	You will need to take medications for the rest of the transplanted kidney's life, to help your body accept the new kidney. Transplant operations can have complications.	You will manage symptoms from kidney failure through diet and medication. In most people, life expectancy will be decreased compared to other treatment options, but there is less need for hospital procedures and admissions.

	Dialysis	Kidney transplantation	Non dialysis supportive care
My body	You have an operation on your arm or abdomen, depending on the type of dialysis	You have a 2–4 hour operation, and will stay in hospital for 1–2 weeks.	You have no operations or changes to your body.
My home	You will have to store equipment and supplies at home or attend a centre-based dialysis centre.	No major changes/impact at home.	No changes/impact at home.

What is important to YOU?

When making a decision it may be helpful to think about the specific areas of your life and how the different treatment options may change them. Some examples are provided in the table below, but you may think of others.

Your life now	How you feel about yourself	Your life in the future
<ul style="list-style-type: none"> • Work or study • Relationships with family at home • Relationships with other family and friends • Leisure activities and hobbies • Sporting activities and exercise • Travel or holidays away from home 	<ul style="list-style-type: none"> • Being in charge of your own life • Being able to do things for yourself • Needing others to look after you 	<ul style="list-style-type: none"> • Having flexibility in your treatment • Travelling to a centre for treatment • Being in your own home for treatment • Storing treatment equipment in your house • Not having treatment • Explaining your choice to your family

Your choice

When people are told they need to have treatment for their kidney disease (dialysis or transplantation) it is not uncommon for people to postpone or refuse treatment. They often feel shock and become depressed and anxious and not ready to face the future. This is a normal reaction but a more positive approach usually follows once you have learnt about the different treatments available to you.

It is important to allow enough time to make a decision so that preparations can be made (for example access for haemodialysis or peritoneal dialysis and screening for potential kidney donors) without being rushed.

Are you ready to make a choice?

- Do you understand all the treatment options available to you?
- Have you spoken to your health care team for their advice?
- Have you spoken to your family for their advice?
- Do you still have questions?

More information

The information in this chapter is adapted from the 'My Kidneys, My Choice' Decision Aid. Visit www.homedialysis.org.au or call 1800 454 363 to download or order a free copy.



Common kidney disease symptoms and management options

Kidney disease can affect many aspects of your health. These complications may be caused either by kidney disease itself, or by its treatment (e.g., side-effects of medications). Issues such as cardiovascular disease (Chapter 9) and sexuality and fertility (Chapter 12) are covered in separate chapters. This chapter looks at common symptoms of reduced kidney function (presented in alphabetical order), outlines some possible causes, and discusses commonly used treatments.



Increasing your awareness about these possible symptoms/complications of kidney disease can help, as some of these complications can be prevented or reduced by acting early. Treatments are available for most of these symptoms, so don't hesitate to talk to your health care team if you notice any changes in your body.

Anaemia

Anaemia means that there are not enough red blood cells in the blood. Red blood cells are the most common cells in blood. Their main function is to carry oxygen from the lungs to all parts of the body so it can be used as energy. As kidney function decreases the likelihood of having anaemia increases.

Anaemia can lead to feelings of tiredness, shortness of breath, dizziness, depression, confusion, feeling cold, trouble sleeping, and lack of appetite. If you experience any of these symptoms it is important to tell your health care team so they can check for signs of anaemia.

Possible causes

Anaemia can have many causes, including:

- Hormone disorders – low levels of hormones that stimulate red blood cell production, such as erythropoietin, thyroid hormone (e.g., hypothyroidism), and androgens (e.g., hypogonadism)
- Dietary deficiency – lack of iron, vitamin B12 or folic acid in the diet
- Bone marrow disorders
- Inherited disorders – such as sickle cell disease or thalassaemia

- Autoimmune disorders – such as autoimmune haemolytic anaemia, where the immune system attacks the red blood cells and decreases their life span
- Chronic disease – such as rheumatoid arthritis or lupus or cancers
- Infection – both chronic long standing infections and acute illnesses such as septicaemia which reduce the life span of red blood cells

Anaemia may also be due to blood loss (e.g., surgery or trauma) or certain medications (including alcohol, antibiotics, anti-inflammatory medications or anti-coagulant medications).

Possible treatments:

The good news is that anaemia can be treated. The treatment varies greatly depending on the type of anaemia.

For people with kidney disease, the most common cause of anaemia is a deficiency of a hormone called erythropoietin. Erythropoiesis stimulating agents (ESA's) are used to treat this, and can be given intravenously (directly into the blood) or into the fat tissue, under the skin. Many people are taught to give themselves this injection and find it easy and convenient.

Anaemia caused by dietary deficiency can be managed by having a balanced diet containing dairy foods, lean meats, fresh fruits and vegetables, nuts and legumes. Sometimes a nutritional supplement of iron, B12 or folate is needed. Extra iron can be given in the form of tablets, injections or as an IV infusion (drip). If the anaemia is caused by dietary or vitamin deficiencies, the use of appropriate supplements for some weeks or months may resolve the condition. In other cases, the anaemia may be permanent, and lifelong treatment will be needed.

Bone disease

Kidney disease can contribute to a number of bone problems including bone and joint pain, muscle weakness and increased risk of bone fracture.

Possible causes

Kidney disease causes a change in the phosphate, calcium and active vitamin D balance in the blood, which can lead to an increase in parathyroid hormone (PTH) levels. This leads to thinning of the bones and weakened bone formation.

The kidneys change vitamin D into its active form (calcitriol). Calcitriol stimulates calcium absorption from food, which increases your blood calcium levels. People with kidney disease produce less calcitriol, so have lower calcium levels.

The kidneys are also responsible for maintaining the acid/base balance in the blood. Decreased kidney function can lead to a high level of acid in the blood (acidosis). This causes your bones to soften, as they absorb acid that is usually removed by the kidneys.

Suggested treatments:

- Depending on the cause of bone disease and your level of kidney function your doctor may prescribe medication such as phosphate binders, calcitriol, and cinacalcet.
- Your renal dietitian may recommend changes to your diet, including phosphate restrictions.
- Some people may need surgery to remove their parathyroid glands to help control high phosphate levels and high parathyroid hormone levels.
- If you are on dialysis, the length of time on dialysis as well as the dialysate can be adjusted to help bring your calcium and phosphate levels into balance.



Depression, anxiety and stress

Disorders in mood are commonly experienced by people at all stages of kidney disease.

Possible causes

Depression, anxiety and stress can be a reaction to your diagnosis. Some depression, anxiety and stress symptoms may also be the result of physical changes caused by kidney disease. For instance, the build up of waste products in your blood can cause changes in:

- Behaviour- including irritability, edginess, moodiness, memory loss and confusion.
- Problems with sleep resulting in fatigue, low energy levels, depression and anger.

Depression, anxiety or stress may also be a side-effect of your medications.

Possible treatments:

Depression, anxiety and stress are treatable. It is important to talk to your health care team if you are feeling depressed, anxious or stressed as there are therapies and medications that can help. Your health care team can also investigate physical causes of depression, anxiety or stress, or possible medication side-effects.

Well-being and kidney disease

General well-being is linked strongly with your state of mind. Many people with kidney disease experience different emotions at different stages of their journey with kidney disease. Feelings of disbelief, mourning, frustration, despair, fear, lack of control and even depression are commonly experienced. It is normal to experience these emotions but they should not be long-term.

To help yourself you may need to talk to a friend, relative or health professional. Social workers and psychologists are specially trained to help you find solutions to problems that are worrying you.

If you are concerned that you have depression ask yourself:

- Do I struggle to get out of bed and do daily activities regularly?
- Do I feel as if I am surrounded by a black cloud?
- Do I cry regularly?
- Do I get angry easily for no reason?
- Have I stopped paying attention to how I look?
- Am I eating for comfort or refusing to eat at all?
- Do I consider harming myself?

If you answered yes to one or more of these questions talk to your health care team who can refer you to a counsellor to help you and determine if medications may help you.

For immediate help, contact Beyond Blue Infoline - 1300 224 636.



Insomnia

Insomnia is when you have trouble falling asleep, staying asleep or you don't feel refreshed after sleeping. There are many possible causes and suggested treatments for insomnia (summarised below).

Possible causes	Suggested treatments
1. Many people with kidney disease have interrupted sleep for some weeks before they are put on dialysis and it is usually due to waste build up.	<ul style="list-style-type: none">• Should improve when dialysis starts
2. Itchiness, restless leg syndrome, and muscle cramps	<ul style="list-style-type: none">• See treatment suggestions for these conditions
3. Feelings of anxiety, depression or stress	<ul style="list-style-type: none">• Talk to your health care team about strategies for managing these conditions
4. Inadequate dialysis	<ul style="list-style-type: none">• Ask your health team to check that you are receiving adequate dialysis



Muscle cramps

Many people with kidney failure find they get muscle cramps, particularly leg cramps. At times, for some people these can be severe.

Possible causes

Imbalances in fluid and electrolytes, nerve damage or blood flow problems are thought to be some of the causes. Sometimes people experience cramps during or after haemodialysis. This may be due to a drop in blood pressure or a rapid loss of fluid or sodium in which case you may be given saline.

Suggested treatments:

Some suggestions to relieve cramping include:

- Doing stretching exercises
- Massaging the cramp area
- Using a heat pad
- Having a hot shower or bath
- Drinking fluids
- Wearing comfortable shoes
- Making sure you keep to your fluid and diet restrictions

Cramp relieving products available at pharmacies may also be effective. Some doctors prescribe Quinine for frequent cramps. This medication does have some risks so check with your health care team before taking it for lengthy periods.



Restless leg syndrome

Restless leg syndrome (RLS) is a common movement problem of the nervous system. Your legs feel as if they want to exercise or move when you are trying to rest. It can make it hard to sleep and relax. Some people have described RLS as a crawling, creeping, prickly, tingling, itching, burning, pulling or shock like sensation. The problem can vary from a minor irritation to a severe condition. You may find that your arms are also affected.

Possible causes

The cause of RLS is not clear but there appears to be a problem with the function of a chemical in the central nervous system.



Steve's Story

For me, the jumpy legs has been the worst. They make it hard to sleep and the next day my calf muscles ache. I've tried lots of things, and everything works a bit. My wife also used to get them when she was pregnant with our daughter, so it helps that she knows what I'm going through. My doc has been good too. He keeps offering different suggestions and I give them a go. Every month or so I book myself in for a proper massage and that stops it for awhile.

Suggested treatments:

All people with RLS should be treated with iron replacement therapy. Other approaches which may be helpful include:

- Avoidance of aggravating factors such as caffeine, alcohol and nicotine
- Massage
- Warm baths
- Warm/cool compresses
- Relaxation techniques
- Exercise
- If on haemodialysis, short daily sessions seems to help in some people

If RLS is occurring only occasionally and is not too troublesome then you can be reassured that the symptoms will get better in time. If RLS is occurring frequently and is severe, then medications can be considered and generally are helpful.

Skin and hair health

Skin and hair problems are common with kidney disease. The good news is that most of these problems can be managed.

Bruising

Possible causes

It is not uncommon for people on dialysis to bruise easily as waste products that are not removed from the body by the kidneys can affect the functioning of the clotting cells (called platelets). Medication used to thin the blood, or low platelet levels can also cause bruising.

Suggested treatments:

- Check with your doctor to see if your medication may be causing the problem (e.g. heparin).
- Talk to your health care team about your blood platelet levels

Hair loss

Possible causes

Malnutrition (particularly low protein levels) can cause hair to break more easily and fall out. Hair loss can also be linked to other causes, e.g., thyroid problems, zinc deficiency, medication side-effects and changes in dialysers.

Suggested treatments:

- Talk to your health care team about possible causes
- Talk to a dietitian experienced in kidney disease about your protein levels
- Treat your hair gently e.g. don't use perms, hair dyes, or tight rubber bands
- Get some tips from your hairdresser for managing thinning hair



Alice's Story

I thought I was dealing with my kidney disease okay until my hair started falling out. First it was just coming out when I brushed my hair and it was brittle and hard to manage. Then whenever I ran my fingers through my hair a handful would come out. I've always had really long hair, so for me this was the last straw. I mentioned it to my nephrologist, and she said it was quite common. I had an appointment with my dietitian and we looked at increasing my protein levels. I also got my thyroid function checked, and it turns out I needed treatment for that. In the last six months the hair loss has slowed down and I'm starting to feel better about it. I took the opportunity to get a new shorter hair style, and people have commented on how it makes me look younger.

Itchiness

Itchy skin or ‘pruritis’ is a commonly reported side-effect of kidney disease. There are a number of possible causes and suggested treatments for this (summarised below), so tell your health care team if itchiness is becoming a problem.

Possible causes	Suggested treatments
1. As your kidneys fail, the levels of calcium and phosphate become unbalanced. When phosphate combines with calcium, crystals form and these are deposited all over the body. The crystals deposited in your skin irritate the nerve endings and cause itching.	<ul style="list-style-type: none"> You may need to take medication such as a phosphate binder Get advice from a dietitian experienced in kidney disease about limiting the amount of high phosphorus foods you eat
2. When kidney function is reduced, waste products build up in the blood. These act on nerve endings in the skin and cause itching.	<ul style="list-style-type: none"> Make sure that you are receiving adequate dialysis
3. If the parathyroid gland becomes overactive, it causes some cells to multiply rapidly in the skin. These cells release a substance called histamine, which causes itching.	<ul style="list-style-type: none"> You may need to take a phosphate binder, anti-histamines, change your diet or take vitamin D or calcitriol In some cases surgical removal of part of the parathyroid gland is needed
4. Itchiness can also be caused by a reaction between your blood and the tubing or dialyser used during haemodialysis. Histamine may be released as a response to heparin or certain medications.	<ul style="list-style-type: none"> Treatment depends on the cause of the allergy Talk to your doctor about side effects of your medications You may need to use a different type of lines or dialyser
5. High levels of magnesium, vitamin A and nerve changes in the skin sometimes cause itching.	<ul style="list-style-type: none"> Some people find that getting out in the sun for a while helps with itching; the reasons for this are unclear
6. Scabies is another possible cause of itchiness and is linked with a rash.	<ul style="list-style-type: none"> Be aware of ingredients that may cause itching and read the label before using
7. Itching can also be caused by allergies. They can happen at any time, even from products you have used before such as soaps, perfumes and detergents.	

If these suggestions don't work, consider speaking to a dermatologist (a doctor who specialises in skin). They can supervise treatments such as ultraviolet light (phototherapy). This is a form of treatment for skin conditions using artificial light wavelengths from the ultraviolet (blue light) part of the sun's spectrum. There is some evidence that ultraviolet light B (UVB) treatments can relieve itching for up to six months.

Skin dryness

Possible causes

If you have reduced kidney function, skin glands produce less oil and perspiration. This makes your skin drier and can increase itchiness.

Suggested treatments:

- Talk to your pharmacist about lotions to improve dry skin e.g. sorbolene, glycerine and emollient moisturising lotions
- Use a non-perfumed, moisturising soap when you wash
- Avoid skin contact with alcohol-based products
- Don't use very hot water when washing
- Avoid long hot baths



Tiredness

Possible causes

Tiredness may be a direct result of your decreasing kidney function. It may also be due to medication side-effects, or other physical conditions such as anaemia, depression, insomnia or sleep apnoea.

Possible treatments:

Some people find that their energy levels improve once they start treatment for kidney disease. Talk to your health care team to rule out physical causes of tiredness, or possible medication side-effects.

Dealing with tiredness may require a change in attitude or behaviour:

Explore other options:	Brainstorm ways to continue involvement in the activities you enjoy. For example, if you are actively involved in sport you can take on a more supportive role in the club.
Break activities down:	It is important to decide which activities will give you the most satisfaction. Break the activity down into small steps and think about spreading the steps over a period of time.
Be realistic:	Don't take on too much and be realistic about your energy levels. Tune into your body's early warning signs so that you don't push yourself too hard when you are becoming tired.
Be flexible:	Tiredness can be unpredictable so be prepared to change your plans for the day if you don't have the energy to do what you hoped.
Do things you enjoy:	Divide your tasks into those that have to be done, those that can wait and those you would like to do. Make sure that you save some energy for things that you enjoy doing during the day.



Heart, kidney and blood vessel health

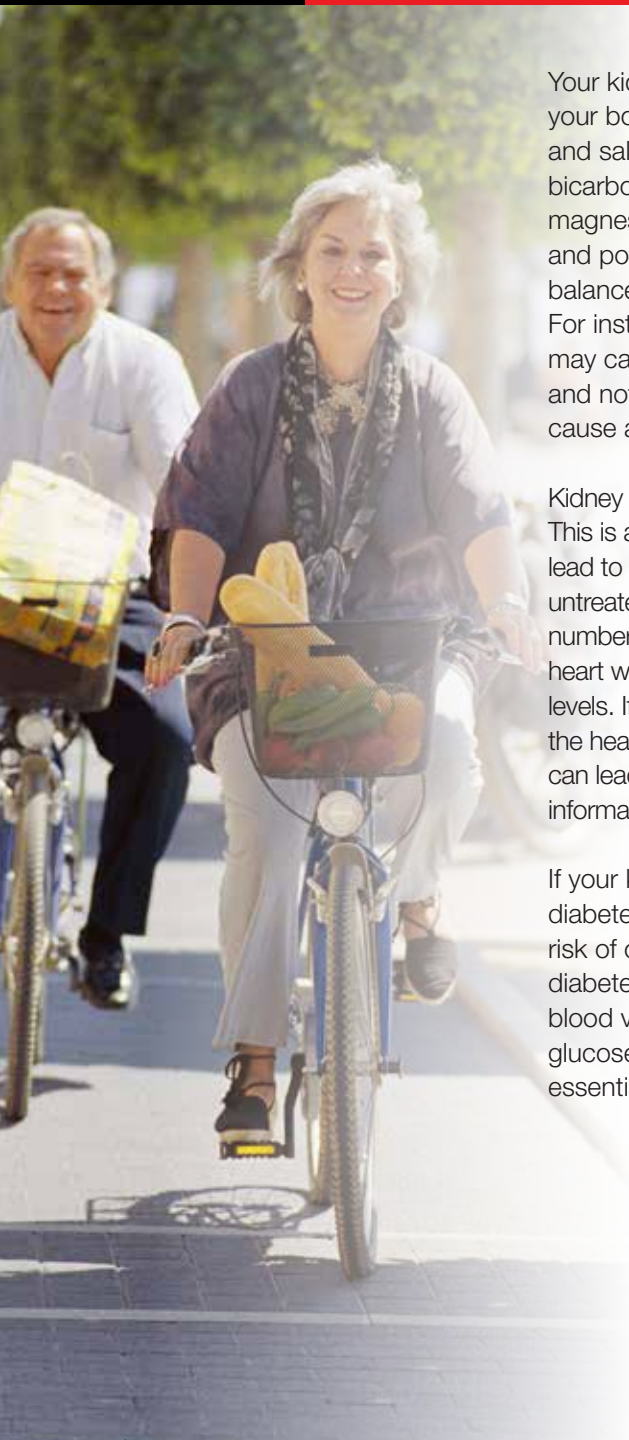
People with kidney disease often also have high blood pressure and/or cardiovascular disease. Cardiovascular disease includes all diseases and conditions of the heart and blood vessels, such as arteries and veins. The most common diseases and conditions include heart attack, heart failure, stroke, blockages in the blood vessels and vascular kidney disease.

People at every stage of kidney disease are at more risk of cardiovascular disease, although those in the later stages have the highest risk. People with kidney failure are 10-20 times more likely to have a heart attack than people without kidney disease.

Why does kidney disease increase your risk of cardiovascular disease?

The kidneys help to control and maintain your body's chemical balance. For example, the kidneys make hormones that regulate the electrolytes and fluid balance. Hormones such as renin and angiotensin control how well the blood vessels expand and contract, so the kidneys play an important role in maintaining healthy blood pressure.

If your kidneys aren't working properly your blood pressure can rise. Blood pressure is the pressure of the blood in the arteries as it is pumped around the body by the heart. If high blood pressure is left unchecked it tends to thicken the blood vessel walls which can cause the blood vessels to narrow. High blood pressure can also damage the small blood vessels taking blood to the kidney filters. It can also damage the kidney filters themselves. Severe, uncontrolled blood pressure weakens the heart muscle, enlarges the heart and can cause kidney failure. If you have kidney disease, uncontrolled high blood pressure can cause your kidney function to decline.



Your kidneys control the acid level in your body plus the levels of minerals and salts such as potassium, chloride, bicarbonate, phosphate, sulphates, magnesium, sodium (salt), calcium and potassium. If these are out of balance, it can impact on your heart. For instance, too much potassium may cause an abnormal heart rhythm, and not enough magnesium can cause an irregular heartbeat.

Kidney disease often causes anaemia. This is a serious condition which can lead to other health problems if left untreated. For example when the numbers of red blood cells drop, your heart works harder to maintain oxygen levels. If the heart works too hard, the heart muscle becomes larger and can lead to heart failure. For more information on anaemia see Chapter 8.

If your kidney damage is caused by diabetes, you are at a much higher risk of cardiovascular disease because diabetes also affects the heart and blood vessels. Good control of blood glucose and blood pressure levels is essential.

What are the risk factors for cardiovascular disease?

Risk factors for cardiovascular disease include:

- **Age:** Your risk increases with age. Women are more at risk after menopause as their cholesterol levels increase.
- **Gender:** Males are more at risk than females. In females the hormone oestrogen provides some protection from cardiovascular disease, until after menopause.
- **Family history of cardiovascular disease:** Having a close relative with cardiovascular disease puts you at increased risk.
- **Racial background:** Some groups of people are at higher risk, e.g., those of Aboriginal and Torres Strait Islander origin.
- **Other health conditions:** Conditions such as chronic kidney disease, high blood pressure, high cholesterol, obesity and diabetes increases your risk.
- **Mental health:** Depression may increase your risk of cardiovascular disease.
- **Lifestyle choices:** Healthy lifestyle choices can help to improve your overall health and lower your risk of cardiovascular disease.

Eating a balanced and nutritious diet, exercising moderately on most days of the week, quitting smoking, and reducing alcohol intake can all help to improve your health.

How can you reduce your risk of cardiovascular disease?

Some of these risk factors for cardiovascular disease are things that you can't change. The best way to reduce the risk of cardiovascular disease is to make healthy lifestyle choices. It is also important to control and maintain a healthy blood pressure, cholesterol level, and blood glucose level if you have diabetes. If you have kidney disease, this usually means using medication as well as having a healthy lifestyle. Identifying kidney disease early and slowing the progression to kidney failure is important in reducing your risk of cardiovascular disease.

Healthy lifestyle choices can help to improve your overall health and lower your risk of cardiovascular disease. They can also reduce the amount of medication you need or make your medication work better.

Some things you can do to improve your heart health include:

- Being a non-smoker
- Eating a healthy diet with plenty of fruit and vegetables plus foods low in salt and saturated fat (unless otherwise directed by your doctor)
- Staying fit by doing at least 30 minutes of physical activity on most days of the week
- Maintaining a healthy weight
- Doing things that help you to relax and reduce stress
- Drinking alcohol only in moderation

Talk to your health care team to get practical advice about the best way to reduce your risk of cardiovascular disease. See Chapter 11 for more detail on healthy eating plans, and Chapter 13 for information on how to live well with kidney disease.

Why is exercise important?

Regular physical activity or exercise can help lower your risk of cardiovascular disease by:

- Improving your cholesterol levels
- Improving fitness of heart and lungs
- Helping to maintain a healthy weight
- Helping to control blood pressure and blood sugar

See Chapter 11 for more detail on the importance of exercise, and tips on how to start an exercise program.





Stan's Story

I'm 53 years old and went to the Emergency Department with heart failure and was found to have kidney disease. I had gout, hypertension and have been overweight for many years but never really took it seriously. I did see my GP for short periods but often stopped following up with her as I thought I was young and would be okay! However, after the experience of my legs swelling and being short of breath I came to the realisation that I was deteriorating. I was still young with young children and I decided that I could take control of my own future. I decided to start taking my tablets regularly and now also attend my specialist visits regularly.

I'm now enjoying much better quality of life, and no longer have leg swelling or shortness of breath. I'm now walking every day with my neighbour. He knows my situation and gives me a 'push' when I'm getting lazy again! I'm still overweight but now 'fit and overweight'. My blood pressure is better controlled, and although my renal function has only improved a bit, it is no longer on the decline. My eGFR is now stable at 33mL/min. This is positive and I now feel like I'm in control of my health again. Apparently even if my kidney function does decline and I need dialysis, the fact that my risk factors are better controlled and I'm exercising means my overall risk for strokes and further heart failure has reduced and I should have a better future. I still plan to lose more weight. I'll keep on trying!

The link between cholesterol and cardiovascular disease

Cholesterol is a white and waxy substance. It is a type of fat or lipid, which the body needs to stay healthy, although too much of it can cause problems. It is not necessary to eat foods that are high in cholesterol as your body is very good at producing its own.

There are two types of cholesterol:

- Low-density lipoprotein (LDL) cholesterol – you need a small amount of LDL but sometimes it is called the 'bad' cholesterol because the excess goes into your bloodstream and clogs up your arteries.
- High-density lipoprotein (HDL) cholesterol - called the 'good' cholesterol because it helps to take the LDL cholesterol out of the bloodstream.

When there is too much cholesterol circulating in our bloodstream, it can build up into fatty deposits. These deposits cause the arteries to narrow and can eventually block the arteries completely. This leads to heart disease and stroke.

Triglycerides are the most common form of stored fat in your body. Usually only a small amount is found in your bloodstream. Triglycerides may not cause fatty deposits in your arteries but are often linked to low HDL or a tendency towards diabetes. Both increase your risk of cardiovascular disease.

If you have diabetes your LDL particles are unusually small and dense, which can be more harmful to blood vessels. Your triglycerides and HDL levels are often also too low, so people with diabetes are at higher risk of cardiovascular disease.

Can diet help to reduce cholesterol? You can reduce your cholesterol level by making some changes to your eating habits.

Here are some suggestions:

- Limit the amount of cholesterol-rich foods you eat.
- Eat plenty of fresh fruit, vegetables and wholegrain foods. These are high in fibre and may improve your blood lipid levels.
- Choose low or reduced fat milk, yoghurt and other dairy products or have 'added calcium' soy drinks.
- Choose lean meat (meat trimmed of fat or labelled as 'heart smart').
- Limit fatty meats, including sausages and salami, and choose leaner sandwich meats like turkey breast or cooked lean chicken.
- Have fish (fresh or canned) at least twice a week.
- Replace butter and dairy blends with polyunsaturated margarines.
- Use unsaturated cooking oils labelled as 'polyunsaturated' or consisting of canola or olive oils.
- Include foods in your diet that are rich in soluble fibre and healthy fats, such as nuts, legumes and seeds. Be aware that some nuts such as brazil and macadamia are high in saturated fats.
- Limit your dairy foods such as cream, whole milk and cheese.

If you have kidney disease it is important to talk to your doctor or a dietitian experienced in kidney disease before making any major changes to your diet. Your eating plan has to be designed with your special needs in mind.

How do medications help to improve your heart health?

Managing your medication is an important part of treating your kidney disease and reducing the risk of cardiovascular disease. Your doctor may prescribe a variety of medications. Most of these medications are designed to control blood pressure and help regulate the body's chemistry.

These medications can include:

- Cholesterol or lipid (fat) lowering medications (e.g., statins)
- Blood pressure medications (e.g., angiotensin-converting enzyme (ACE) inhibitors, angiotensin receptor blockers (ARB), calcium channel blockers, beta blockers, diuretics)
- Phosphate binders
- Bicarbonate supplements
- Aspirin
- Erythropoiesis-stimulating agents

Medication should only be taken as advised by your health care team. Each medication is given for a particular reason and should be taken as directed. See Chapter 10 for more information on medications typically prescribed to people with kidney disease.

Frequently Asked Questions

Do all people with kidney disease get heart disease?

No, not everyone with kidney disease has heart disease. However, if you have kidney disease the risk of having heart disease is greatly increased, and this is true for all stages of kidney diseases.

How can I combine a healthy heart diet with (high fibre, plenty of fresh fruits and vegetables) with low potassium /low phosphate foods needed for my dialysis diet?

Many healthy foods like fruits, vegetables and dairy are high in potassium and phosphate. If you have kidney disease your intake of these foods often needs to be controlled. This may mean avoiding some fruits and vegetables altogether, while for others a small serve and eating them less often may be enough. It is important to get advice from a dietitian on how best to include foods from all food groups to maintain an overall healthy low potassium meal plan. Chapter 11 has more information on how to eat healthily when you have kidney disease.

Does having a kidney transplant reduce my risk of heart disease compared to being on dialysis?

Yes. In general, the heart suffers much more while on dialysis. The risks are related to blood pressure, volume changes, calcification of arteries and lipid abnormalities (cholesterol and triglycerides). People who have received a kidney transplant patients are at a higher risk of heart problems than the general population, but a transplant is usually associated with less risk than being on dialysis.



Medications

Managing your medication is an important part of treatment for kidney disease. Each medication is given for a particular reason and should be taken as directed. It is important that you do not stop taking any medications without checking first with your health care team.

Understand your medications and how to take them

When you get your medication it is wise to check that it is the same as your doctor ordered. It may have a different brand name so ask your pharmacist if in doubt. Ask for an information leaflet called 'Consumer Medicine Information' (CMI) for each of your medications (these are usually also available on the Internet). This leaflet includes detailed information on a medicine in plain English, including the usage, side effects and precautions. A CMI is available at your pharmacist or from the pharmaceutical company and may be provided by your doctor. In some cases it is tucked inside the medicine packaging.



Taking medications safely

- Check your medications immediately in the pharmacy to ensure the dosage is correct and that the medications are as you expected – don't be afraid to ask the pharmacist any questions.
 - Make sure you check for warnings, e.g. 'don't use with alcohol' or 'don't use if driving or operating machinery'.
 - Ask your doctor, pharmacist or health professional for directions, e.g. does it need to be taken with food?
 - Nearly all medications can have side effects. If you get a reaction, make a note of your symptoms and talk to your doctor, pharmacist or someone else in your health care team. Your doctor can change the tablet or its dosage if needed.
 - Tell your doctor about any medications or supplements you buy from the supermarket or pharmacy (called over-the-counter medications). Also tell your doctor if you are taking any vitamins, minerals or herbs (called complementary medications).
 - Don't use out of date medications as they are less effective and may even be harmful. You can take these medicines to a pharmacist for safe disposal. Never throw them in the rubbish.
- Ask your general practitioner for a 'home medicine review'. This is where a pharmacist comes to your home to provide one-on-one advice regarding your medications. Depending on your circumstances, a home medicine review may be free, or there may be a small fee.

Reducing medication costs

- Beware of buying prescription medicines over the Internet as you may run the risk of buying dummy, out-of-date, inappropriate or unapproved medication.
- To avoid paying extra for your medication, ask your doctor to prescribe the cheapest brand or ask your pharmacist if there is a less expensive brand.
- Ask your pharmacist about the 'safety net'. Once you have reached a threshold level medications get charged at a lower rate, depending on your circumstances. Your pharmacist will help you set up a 'safety net' record and help you maintain it.

Medication memory aids

Tips for remembering when and how to take medications:

- Use a dosette box. These have separate sections to place your tablets for each day. They can hold a week's or month's worth of medication. At a glance you can see if a dose has been missed. The boxes are available through most pharmacies and some discount shops.
- Ask your pharmacist for a 'Webster Pack'. If you find dispensing your medication difficult or confusing, your pharmacist can make up weekly dosette packs for you (called a Webster Pack) and hold all your prescriptions and medications for you. Depending on your circumstances this may be free or there may be a small fee.
- Put a reminder somewhere you will see it such as next to your toothbrush or on the fridge door.
- If you need to get a repeat prescription, mark it on your calendar a week before it is due.

Make a medication list

- Note any medication allergies you have at the top of the list, ideally in Red and/or capitals.
- Write down the medicine's name, when to take it and the dose. This list can help you manage your

medication. Remember to update this record if your medication changes. It is also important to record your medication allergies.

- Make sure that you include prescription, over-the-counter and complementary medicines, e.g. vitamins, minerals and herbs.
- Take your medication list with you when you visit any member of your health team – it is advisable you always carry it in your wallet or handbag.
- Some dosette boxes contain a medication chart that you or your health care team can complete.

NPS Medicine Wise have a medicines list that you can download from their website at www.nps.org.au.

A sample is provided at the end of this chapter. Versions in languages other than English are also available, and there is also an app for your iPhone available as a free purchase from the AppStore.



Tell health professionals if you have kidney disease

If you are seeing a new health professional tell them about your kidney condition as this may influence their choice of medications and other treatments. For an example some medications are filtered through the kidneys and will build up if you have kidney failure. Some medications need to be avoided, whilst others need to be at a much lower or safer dosage.

Some common medications that you can buy from a supermarket or pharmacy need to be avoided or taken in smaller doses, including:

- 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 medications (NSAIDS), which are anti-inflammatory medications, 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.
- Herbal or complementary medicines may also have side effects, can interact with other medications or may be unsuitable if you have kidney disease.

Types of Medications

Medication plays a vital role in helping your body stay in balance when your kidneys stop working. Your blood test results are often used as a guide for prescribing medication.

It is usual for most medications to have two names; one name is the approved pharmaceutical name that can sometimes be difficult to say and spell. The other is the brand name, which is the name that the pharmaceutical company uses to promote its brand.

Common medications that are prescribed to people with kidney disease are listed here in alphabetical order.

Aspirin

Low doses of aspirin may be given to improve blood circulation. Caution should be taken if you are on dialysis or have received a transplant.

Bicarbonate

Bicarbonate capsules may be prescribed to manage the acid levels of your blood. Your doctor may also add bicarbonate (haemodialysis) or lactate (peritoneal dialysis) to your dialysis fluid.

Blood pressure or anti-hypertensive medications

Angiotensin-converting enzyme (ACE) inhibitors and angiotensin receptor blockers (ARB) are commonly used to keep blood vessels open and relaxed. Both these medications also help protect your kidney function. Beta-blockers help to lower blood pressure by allowing it to beat slower and less forcefully. Calcium-channel blockers help the blood vessels to relax by keeping calcium out of your blood vessels and heart.

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 also alter from time to time according to your blood pressure.

Diuretics

Diuretics increase the flow of urine. They are sometimes used in the advanced stages of kidney disease to help the kidneys remove excess water from the body. Sometimes blood pressure medication has a diuretic built in.

Erythropoiesis Stimulating Agents (ESAs)

ESAs are prescribed by Nephrologists to correct anaemia in people with kidney disease. ESAs are expensive and approved for subsidised use only when the haemoglobin level has fallen to a particular level.

There are several ESAs currently available in Australia. All are available as pre-filled syringes and are usually administered by injection under the skin (or intravenously directly into the blood if you are on haemodialysis). The pre-filled syringes have been designed so that they are easy to use. They look like large pens and are similar to devices that people with diabetes use to give themselves insulin. You may learn how to give yourself this injection and find it easy and convenient.

Iron therapy

It is common for people with kidney problems to have low iron stores. If you have anaemia, you may be given iron to help you rebuild red cell numbers. Iron is particularly necessary if you are being treated with injections of EPO. Extra iron can be given in the form of tablets, injections or as an IV infusion (drip).

Lipid lowering medications

Various medications can lower lipid or cholesterol levels. Not everyone takes the same type of medication and often a combination of medications is used. One common medication is called a statin. Statins lower LDL (“bad”) cholesterol and triglyceride levels and boost the HDL (“good”) cholesterol levels.

Phosphate binders

Your doctor may prescribe medication called a phosphate binder to take with your meals and snacks. These medications help control the levels of phosphate and calcium in the body. Phosphate binders come as tablets and reduce the amount of phosphate absorbed into the blood. It is important to take these with the first mouthful of food otherwise their action is ineffective. They act like a sponge soaking up phosphate that is released from your food and trapping it the gut. Phosphate then leaves the body with your solid waste.

Vitamins

Reduced kidney function, poor appetite, or dietary restrictions can result in inadequate levels of specific vitamins.

Low levels of thiamine (B1), riboflavin (B2) and pyridoxine (B6) are common in people with kidney disease, and usually require supplementation. Folic acid is a water-soluble B vitamin. It may be prescribed to help lower amino acid levels. Folic acid is often used in combination with other B vitamins. Vitamin D is normally activated by the kidneys so extra vitamin D is commonly prescribed for people with kidney disease. Active Vitamin D is usually prescribed as calcitriol. It is taken either as a tablet or an injection.

Your doctor will advise you if vitamin supplementation is required and will prescribe specific products for you. If you are on dialysis the vitamins should be taken after your dialysis session as they are water soluble and can be dialysed out.

When your kidney function is reduced it can be dangerous to take too much of certain vitamins. It is recommended that you do not take any over-the-counter vitamins without checking with your doctor or pharmacist first.

Frequently Asked Questions

Do I need to take my medication with me if I am admitted to hospital?

It is very useful for you to bring your own medications from home so that medical and nursing staff can see exactly what medications you are taking.

Can I take medications on board a domestic flight?

Yes. You can take prescription medicine, non-prescription medicine and prescribed medical devices on board domestic flights. It is a good idea to carry at least a few days worth of medication in your carry-on luggage in case your checked-in luggage is misplaced by the airline. Pack your repeat prescriptions too, in case you need to buy more medication while you are away.

Can I take medications on board an international flight?

Prescription medicine and prescribed medical devices are exempt from liquids, aerosols and gels restrictions for international flights. This includes storage containers required to control the temperature of medicines on board. Medications in solid form (e.g. tablets) are not affected by these restrictions as they are not liquids, aerosols or gels. You are free to carry these in your carry-on baggage as normal. It is a good idea to carry at least two weeks worth of medication in your carry-on luggage in case your checked-in luggage is misplaced by the airline, or you experience flight delays.

Security screening officers may request supporting documentation (ID cards, letters from doctors, etc.) to determine if the medications you are carrying are exempt. Make sure the name on the label of the prescription medication matches the name on your boarding pass. It may also be in your best interests to have a letter from your doctor explaining what the medicine is, how much you are carrying and that it is for your personal use. Pack your repeat prescriptions too, in case you need to buy more medication while you are away.



Diet and exercise

Managing your diet

Managing what you eat when you have kidney disease can be a challenge but can have a positive influence on how you feel and the other treatments you might need. It is important to recognise that as kidney disease progresses your dietary needs will more than likely change. It is also important to recognise that every person with kidney disease is different and has different food preferences and individual dietary needs.

What you eat can affect how well the kidneys function, but kidney function can also affect what you feel like eating. There is no standard 'kidney disease' diet, but there are some common issues that arise as kidney function deteriorates. Some people have high levels of potassium, phosphate and urea in their blood; others lose protein, phosphate and potassium in their urine. Some people retain too much fluid so have to cut back their salt and fluid intake; others pass large amounts of urine and have to drink a lot of water to keep up with the flow to prevent dehydration.

It is common for appetite to drop as kidney disease progresses and there are many reasons for this, including anaemia, high blood urea levels, or medication side-effects.

A dietitian experienced in kidney disease is the best person to speak to about what you can eat and drink. The dietitian will assess what you are currently eating and advise if changes are needed.

Dietary assessment includes review of your intake of energy and important nutrients such as:

- Protein
- Sodium/salt
- Potassium
- Phosphate
- Fluid
- Fat
- Carbohydrate

Advice is given on a personal basis, taking into account what you like to eat, how you are feeling, your age, lifestyle, weight, muscle size, health status and blood test results. You may find that initially the suggested changes might be small, but as kidney disease progresses more significant changes may be required.

Things you can do to get the most out of your dietitian appointment:

- Write down what you eat for a few days and bring it with you to your appointment
- Bring your medication list with you
- If someone else normally cooks for you – bring them with you to the appointment
- Ask questions so that you know what you need to do and why
- Organise regular follow up appointments to monitor your own progress



Eating well with kidney disease

Just like servicing your car, your diet also needs regular review. If kidney function changes, the amount of energy, protein and other nutrients you need changes. There are also different requirements if you start dialysis or receive a transplant. If you start dialysis, you may need to change your salt, protein, phosphate, potassium and fluid intakes over time. People with kidney transplants have different dietary requirements. The focus is more likely to be on healthy eating rather than a restricted diet.

Dietary supplements are sometimes required if your nutritional intake is inadequate. A dietitian will assess the most appropriate option for you. Some vitamin supplements (e.g., vitamin A supplementation can be harmful for people with kidney disease) are not recommended for people with kidney disease, so only take supplements or medications that are recommended by your dietitian.

Staying at a healthy weight

Maintaining a healthy weight can make it easier to manage your health.

Unplanned weight loss

Some people with kidney disease do not feel like eating or have difficulty eating enough food to stay healthy. Malnutrition can develop when food intake is inadequate and the body does not get the right amount of the vitamins, minerals and other nutrients it needs. This is more common for people who are getting close to needing dialysis, but it can also persist when dialysis starts.

Risk factors for malnutrition include:

- Build up of waste products causing nausea, taste changes and poor appetite
- Infections and other illnesses
- Not eating enough due to other dietary restrictions

It is very important to try to stick to the eating plan your dietitian suggests even if you do not feel like eating. Tell your doctor or dietitian if you are losing weight that is not planned, or have any concerns about your diet.

Gaining weight

Weight gain can also be a serious problem. It can be harder to gain access for dialysis if you are overweight. Fatter arms can make it more difficult to reach the veins and harder to make a fistula. Peritoneal dialysis is less likely to work for someone who has a lot of fat around the stomach. Being overweight may also mean you are not suitable for a transplant operation. If weight gain is a problem your dietitian can assist you with a kidney-appropriate weight loss eating plan.

Important nutrients

Energy

Just like your car needs petrol, your body needs fuel. Getting the right amount of energy (kilojoules or calories) is important to your overall health and well-being as well as body weight.

Carbohydrate and fat are the body's main energy sources:

- If protein has been restricted in your diet, your energy needs may be met by increasing your intake of fats and carbohydrates.
- Carbohydrates come from foods such as breads, cereals, rice, pasta, noodles and grains
- Choose 'good fats' such as polyunsaturated and/or monounsaturated found in olive, canola and sunflower oil.

Protein

Getting the right amount of protein is important to your overall health.

Your body needs the protein for:

- Building muscles
- Repairing tissue
- Fighting infections

However, if you have kidney disease it is often important to control the amount of protein-rich foods you eat to minimise waste build up. Protein requirements also change when you are on dialysis, and should be discussed with your dietitian.



Phil's Story

When I was told I had kidney failure I thought 'oh no'. I am a diabetic so am on a restricted diet already. My specialist gave me a referral to a dietitian. My wife does most of the cooking in our house, so she came to the appointment too. We spent a lot of time working out what my wife and I like to eat, and how to make things that are okay for my kidneys and my sugar levels. I have a real sweet tooth, so the dietitian gave me a list of treats that are okay for me to have.... in moderation! We have bought a few recipe books for people with kidney disease, and my wife is enjoying making new things.

Protein comes from:

- Animal foods including eggs, fish, meat, chicken
- Dairy foods such as cheese, milk and yoghurt
- Plant foods like nuts, peanut butter, lentils, baked beans, bean soup mix, beans salad mix and chickpeas also contain protein, but are sometimes less suitable because of potassium and phosphorus content

Phosphate

Controlling dietary phosphorus is important at all stages of kidney disease. In many cases reducing protein intake (as above) will also reduce phosphorus intake. Sometimes phosphate binder medications are also needed to reduce the amount of phosphate that reaches the bloodstream.

Phosphate binders work in your gut by binding to the phosphorus in the food and the end result is some of the phosphate is removed through your bowel movements. For this reason it is very important to take phosphate binders when eating. A dietitian can help to guide you how best to take phosphate binders with your meal plan.

Sodium (salt)

Sodium is a mineral found naturally in foods. It is also commonly added to packaged and processed foods. It affects the amount of fluid that your body retains.

Too much sodium and fluid may cause:

- High blood pressure
- Swelling of ankles, feet, hands and puffiness under the eyes
- Shortness of breath
- Increased protein in urine

Eating a lot of sodium also makes you thirsty, which becomes even more important when urine output slows down (usually after starting dialysis).

Typically foods that have a lot of sodium include:

- Seasonings including season-all, lemon pepper, garlic salt
- Sauces like soy, fish, black bean and teriyaki sauce
- Canned foods and some frozen foods
- Processed meats like ham, bacon, sausage, smallgoods and cold cuts
- Snack foods like chips and crackers
- Stock mixes and packaged soups
- Take-away foods

Beware of salt substitutes as some contain potassium instead of sodium.

Potassium

Nearly all foods contain some potassium. Many healthy foods like fruits, vegetables and dairy are high in potassium. If you have kidney disease your intake of these foods often needs to be controlled. This may mean avoiding some fruits and vegetables altogether, while for others a small serve and eating them less often may be enough. It is important to get advice from a dietitian on how best to include foods from all food groups to maintain an overall healthy low potassium meal plan.

The amount of potassium you should eat when you are on dialysis will depend on which type of dialysis you choose. It is more common to need to restrict your potassium intake if you are having haemodialysis. In fact, if you are having peritoneal dialysis, you may have to increase your potassium intake. Some people also need to take medications to control the amount of potassium in their blood.

Fluid

The amount of fluid intake varies for different stages of kidney disease. Some people need to drink large amounts of fluids but others may need to limit their fluid intake. Your suggested fluid intake will depend on your urine output, fluid build-up and blood pressure. Urine output usually drops off the longer you are having dialysis. As this happens fluid intake should be adjusted. Remember that fluid-type foods need to be included in your fluid allowance.

Fluids include:

- Water and ice cubes
- Tea, coffee, juices, soft drinks, milk and milk products
- Gravy, sauces and soups
- Ice cream, jelly, custard and yoghurt

After a kidney transplant

After receiving a kidney transplant your dietary needs change towards a focus on healthier eating rather than dietary restrictions. Anti-rejection medications used after a transplant increase the risk of weight gain, diabetes and high cholesterol. High blood pressure can be a problem if your weight increases too much. After receiving a transplant you should speak with a dietitian to plan a balanced diet to support your new kidney function.

The importance of physical activity and exercise

Whatever your stage of kidney disease there are lots of reasons to stay fit, including:

- Increasing your energy levels
- Keeping your muscles strong
- Helping to maintain body weight
- Helping to control blood pressure and blood sugar
- Lifting your mood and helping to fight depression through the release of endorphins
- Reducing stress
- Reducing your risk of heart problems by lowering your 'bad' cholesterol, increasing 'good' cholesterol and reducing triglyceride level
- Improving your sleep
- Can help with restless legs and muscle cramps

As kidney disease progresses maintaining or improving your fitness may be difficult but it is still very important. Do as much as is comfortable and think of it as part of your treatment.

Some contact sports may need to be avoided, particularly after a transplant. If you have a catheter, you need to protect your catheter while exercising, and special care is needed when swimming. Talk to your health care team about what exercises are suitable for you.

Getting started

The key to improving or maintaining your fitness is to start slowly and gradually increase the time and intensity of your activities. If you are only starting out, aim to do some physical activity for at least 30 minutes three to four times each week. The 30 mins can be broken down into smaller blocks, e.g. 3 x 10 mins, which can be increased as you become stronger.

Stretching to improve or maintain flexibility is also an important part of getting fit. Stretching reduces cramping and helps you to move more comfortably. It also helps you to unwind when you are finished.

Signs to stop exercising

It is important to exercise safely and to know when to stop. Don't exercise if you are feeling unwell and avoid the very hot or cold times of the day if you are exercising outside.

If you experience any of the following while exercising then you should stop exercising, cool down and tell your health care team:

- Chest pain or pressure
- Dizziness or light-headedness
- Irregular or very fast heart rate
- Excessive shortness of breath
- Nausea
- Severe leg cramps
- Pain or pressure in neck or jaw
- Excessive tiredness
- Blurred vision



Jenny's Story

I'm 61 years old. Now that I'm on the transplant waiting list and feeling well on dialysis, I decided I should focus on my health, in particular my fitness. I had been told that better fitness would help me recover more quickly from surgery. I wrote out what I wanted to achieve and how I would measure it. I decided I would go swimming three times a week in the morning before dialysis as there is a pool in the same complex as the dialysis unit where I go. Because this is convenient and easy I felt I might have more chance to keep committed to my plan.

When I looked into the pool setup, I noted there were showers there and if I bought multiple passes it would be cheaper. I hoped that it would make me more relaxed during dialysis, and swimming was something I have always enjoyed. As I had not swum for a long time I was unsure of how much I would be able to achieve and what my starting level would be. I decided that for the first week I would see how many laps I could do comfortably in 10 minutes, and from there, increase the time I swam as I felt able. When I commenced this routine, I discovered that it did relax me during dialysis and that I enjoyed it.

After three weeks I had increased the number of laps and the time I swam. I documented this in my planner and enjoyed the sense of achievement I felt doing something that made me feel better, that I enjoyed, and that was good for me. I decided that if I continued for two months, as a reward, I would buy a few sessions with a personal trainer for more motivation. I followed through with this plan exactly, except for one week when I was unwell. Whilst I was sorry about the interruption to my program, I was pleased at what I had achieved, and knew I would get back to my program even if I had to drop the length of time/ laps I swam. I've booked my personal trainer to start next week, and I've convinced my husband to join me!

Helpful HINTS

It is a good idea to talk to your general practitioner or a physiotherapist if you are new to exercise, or have not exercised in a long time. They can provide advice on suitable activities and teach you appropriate stretching techniques.

Here are some extra tips:

- Take every opportunity to be active.
- Try to incorporate physical activity into your daily life. Examples include walking the dog, taking the stairs, getting off the bus a stop earlier or mowing the lawns.
- Mild soreness or stiffness is common when doing new or more physical activity but you shouldn't feel pain. Next time you exercise you may need to modify what you do but don't stop your physical activity all together. If you are in pain seek medical advice.
- Ask family or friends to join you – having an exercise buddy is great motivation.
- Local community centres and gyms often offer low impact exercise and resistance/strength training classes. They can also provide personalised training programs.



Frequently Asked Questions

I am a vegetarian; now that I have been diagnosed with kidney disease can I still follow my vegetarian diet?

Yes, you can continue a vegetarian diet if you have kidney disease. It is particularly important that you work with a dietitian experienced with kidney disease to devise an eating plan to fit your nutritional needs.

I'm already tired from my kidney disease; shouldn't I be resting rather than exercising?

Adequate rest is important, but exercise is also beneficial. People often find they have more energy for their usual activities after they start an exercise program.

How do I get in contact with a dietitian specialised in renal problems?

Your nephrologist will be able to refer you to a dietitian who works specifically with people with kidney disease.

Are dietitian visits covered by Medicare or Private Health Insurance?

Most private health insurances will provide a rebate for dietitian services. The level of rebate will depend on your individual private health insurance plan. Medicare rebates for certain allied health services (including dietitians, psychologists, exercise physiologists) are available for people with chronic conditions as part of a 'chronic disease management plans' and 'team care arrangements'. These can be organised through your general practitioner.

If I exercise, can I eat restricted foods?

No. Exercise does not give you permission to go off your recommended eating plan. If you notice an increase in your appetite after you begin an exercise program, talk to your dietitian.

If I exercise, can I drink more fluids if I'm on dialysis?

If you are exercising and perspiring heavily, you may be allowed additional fluid. This will depend on many factors and should be discussed with your dietitian and Nephrologist.



Sexuality and fertility

Having kidney disease doesn't change the fact that you are a person, capable of giving great love to your partner, family and friends. Nor does it change your ability to be deeply loved by those close to you. Loving and being loved will continue to make you a valued person. The need to love, and to feel loved, desired and close to our partners, families and friends is an important part of what makes us men and women.

However, dealing with the health problems caused by kidney disease, and the treatments for it, can be difficult. It is easy to get caught up in the medical side and overlook the enormous impact being ill and being engaged with medication, doctors and hospitals and the like can have on your personal life and relationships.

This chapter looks at areas that are often overlooked – *sexuality* and also at the related issue of the impacts of your disease and its treatments on *fertility*. These are very personal topics and some people may not feel like talking about them, and many don't feel the need to seek further guidance. That's okay. However, many patients do seek advice from their doctors and other members of their health care team. The following information has been drawn from the experiences of fellow patients and their partners.

It is provided to help those who are aware of changes in their bodies and in their attitudes and feelings, and who are looking for some advice or answers.

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.

Self image and sexuality

Self-image is the mental picture that you have of yourself. It is affected by lots of things, including how you feel about your abilities, personality, interests, spirituality as well as physical appearance.

Self-image can also have an effect on your sexuality. 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. Sexuality starts in the mind. It is responsible for sexual arousal through fantasies, memories, imagination and feelings. These thoughts are created by what you see, smell, touch, taste and hear.

Sexuality includes feelings of desire, satisfaction, love, loss, hurt, intimacy, loneliness, caring, sharing, touching, jealousy, rejection, self-esteem, joy and many more. Sexuality is expressed in many ways - the clothes you wear, the way you move, the way you have sex and who you have sex with. We are all sexual beings and having kidney disease doesn't change that. However changes caused by kidney disease and the impacts of the treatments you may undertake may impact on your self-image and sexuality.

It is not unusual for people to experience self-image problems from time to time. However, having a chronic condition can have a direct impact on your self-image. Some people find it hard to maintain a positive self image as kidney disease makes them feel as though their body has let them down. Other people maintain a positive self-image by being mindful of what their body can do rather than focusing on the things they don't like about it.

The impact of kidney disease on the sexual development of young people

Our sexual identity and well-being develop throughout our life. Boys and girls learn to respond differently from an early age. The development of puberty confirms their differences. Puberty and the emergence of young adulthood can be a complex time for girls and boys as they come to understand their own sexuality, issues of fertility, and take an interest in the sexuality of others.

The effect of kidney disease on a child's sexual development depends on the age their disease occurs.

Young children with kidney disease are usually smaller than other children their age. The growth of children on dialysis is often more affected than those with kidney transplants.

Teenagers with kidney disease may find sexual development slows down or even stops. For example, teenage girls may not have periods. Teenage boys may notice that the growth of facial hair and pubic hair, and changes to their genitals may occur more slowly than for some of their peers. This causes some teenagers to feel different from their friends.

It is important for children and young adults to have someone to talk to openly about the physical, emotional and sexual changes. This could be a parent, another family member, a friend or a health professional, such as a social worker.



Physical changes that may affect your self-image and sexuality

Our sexuality and sexual well-being continue to develop throughout our life. Changes that occur may be linked to aging as well as to the impacts of illness and its treatments.

Kidney disease, and the treatments you undertake, may result in changes that can impact how you feel about your body and your sexuality. Some of the changes can be physical, such as weight changes, itchy skin, anaemia affecting your ability to maintain an erection or achieve orgasm, even the smell of your body can change because of the build up of urea. Other changes will be psychological, and affect your feelings and desires, as well as your body's ability to engage in sex. It is important that partners are aware of these side effects and understand they are not anyone's fault. It doesn't matter what the cause of these changes is, it is important that you seek help from your health care team if you feel concerned. As with all medical problems, the best treatment really 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.

Members of your health care team will understand, treat your conversations with respect and confidentiality and offer treatment or referral to other specialists. Talking with an understanding and helpful health professional can relieve a lot of fear and distress. There are many appropriate treatments that your doctor is used to recommending that may reduce or even fully resolve your particular problem. However difficult it may seem, try to communicate your concerns and your doctor's recommendations with your partner, so that you can start to resolve the sexual well-being issues that may potentially affect your relationship and life together.



Rose's story

I wasn't enjoying sex or getting an orgasm: my vagina was dry and I just didn't really feel like having sex. I went to a counsellor and got useful ideas for using water-based lubricant and having more foreplay. My partner came to the next visit – it was a bit embarrassing at first but we learned a lot and things are really good now, better than before I went on dialysis, we are both more relaxed about each other's bodies and needs.

Reduced sexual desire (also called libido) is one of the most common side effects of kidney disease. The kidneys are part of the system that produces hormones. Hormones are chemicals made by glands in your body and affect many feelings including sexual desire. Your doctor can tell from your blood tests if your hormones are changing. Medication can help to restore the balance. Sexual activity is safe after transplantation. The transplanted kidney cannot be damaged. However, if you or your partner are worried that having sex may be harmful in any way, speak with your doctor. As with any major surgery, it is wise to wait at least four weeks after your transplant before sexual intercourse. The good news is that with the right communication and advice, most couples can resume a satisfying sexual relationship.

After a transplant your sexual desire usually improves. However during periods of transplant rejection, increased medication can affect your sex life. Anxiety and depression is a common symptom of rejection and can reduce your sexual desire. Talk to someone you feel comfortable with on your medical team if this seems to be happening to you.

Doctor Statement



Some of my male patients ask for Viagra because they 'can't get it up', their penis will not go hard and they cannot maintain an erection: they fear they are impotent. I tell them that the causes might be psychological; they might feel stressed and anxious, or there may be physical causes. We know that dialysis and transplants can change hormone levels and there can be blood circulation problems or nerve damage. We talk it through and in most cases find a simple solution. Sometimes I refer them onto another specialist. It is better to talk about it, it's not that uncommon.

Renal dialysis nurse statement



I get lots of questions about whether having sex can damage your dialysis access point. Just take it easy I tell my patients; as long as you make sure that any sexual activity does not place too much pressure or tension on your dialysis site then the risk of damage is low. Some of my peritoneal dialysis patients worry that the tube is a 'turn off' for their partners and not very romantic. I suggest it is helpful to tape the catheter to your body. As long as proper hygiene is maintained, the risk of infection is low.



Fertility: pregnancy and contraception

Fertility can be affected by kidney disease, but this doesn't mean that women can't conceive or men are unable to father children.

For dialysis patients and their partners

Women undergoing dialysis may experience irregular periods or no periods at all. Some women have unusually heavy periods, particularly after starting dialysis. If this happens it is important to tell your doctor. Men on dialysis may have a lowered sperm count.

While some women on dialysis have been able to conceive, the chances of a pregnancy reaching full-term with a normal size baby are low. In addition, pregnancy may pose a risk to your own health. If you are considering becoming pregnant while on dialysis, it is essential that you and your partner discuss this with your doctor.

It is important to talk to your health care team about birth control options while undergoing dialysis. Some types of the contraceptive pill may raise blood pressure. It is also suggested that women using peritoneal dialysis do not use an intra-uterine device (IUD) as it can increase the risk of peritonitis.

For transplant recipients and their partners

Following transplantation, most people find that their fertility increases as their health improves. It is usually suggested that women wait at least twelve months to become stable on their anti-rejection medication before trying to conceive. In most cases, some of the medications will need to be changed to make pregnancy safer. Many transplant recipients throughout the world have given birth to healthy babies and both mother and child have remained well following the birth. Transplant recipients have an increased risk of premature delivery and small birth weight babies, so you will receive careful medical supervision during your pregnancy.

As a man's fertility and sexual functioning may improve after transplantation, his partner's chance of conception also increases. The use of contraceptives may be required if pregnancy is not desired.

For Polycystic Kidney Disease (PKD) patients & their partners

When you or your partner has polycystic kidney disease, each child has a 50% chance of inheriting the disease. A diagnosis of polycystic kidney disease does not mean that having children should be entirely avoided. Your doctor and social worker can provide advice about genetic counselling services and the possibility of genetic screening. It is important to talk with your partner and your health care team about the possibility of passing on the gene to your children and the consequences of this for them in later life.

Problems with conceiving

There is often an expectation in our society that people will have children. When this is not possible, it may cause some individuals to feel incomplete or unfulfilled. The inability to conceive a child may be a blow to your self-esteem, making you feel vulnerable and in need of love and support. It is important that you talk to your partner or someone you trust if you feel this way.

It is very easy to feel guilty about infertility. You may be worried that you have let your partner down and deprived them of the joys of parenthood. It is important for you and your partner to discuss your feelings about infertility and not to lay any blame. It may be useful to see a counsellor, or other member of your health care team.

For infertile couples wanting a child, it may be possible to look into alternative choices such as adoption, fostering a child, in-vitro fertilisation (IVF) or sperm injection. Ask your health care team about opportunities available to you.

One of the problems with infertility is the financial strain and the stress that treatment can put on a relationship. Treating infertility can be a lengthy process but don't be afraid to persist in finding the right people to talk to and seeking second opinions when necessary.



Megan's story

I was diagnosed with kidney disease when I was a teenager. My parents will say that it was a rollercoaster ride going through puberty and managing a chronic disease at the same time, but we got through. I'm now married, and my transplant has been functioning well for almost 18 months. I've talked to a lot of other patients and specialists about my chances of starting a family, and while everyone has different advice, the themes are the same: keep your body in peak condition, ask your doctor question after question, research, go to fertility specialists, IVF, have faith, adopt, foster, 'borrow' someone else's kids for a week, get a dog. But remember if it's not meant to happen, it's not meant to happen. I try to keep everything in perspective and be grateful for what I have. I still get sad from time to time, but that's okay.



Living well with kidney disease

Kidney disease brings with it many changes. Adjusting to kidney disease is more difficult for some people than others, even with time to prepare for it. When there is no time to prepare, the sudden impact makes dealing with kidney failure much harder. Having kidney disease means dealing with changes to your self-image (how you see yourself), your relationships, your emotions, and possibly your finances.

This chapter contains some tips on how to live well with kidney disease. You can live a normal life with kidney disease - you just need to work out what suits you.



Maria's Story

I was nine months old when I was diagnosed with the kidney disease haemolytic uraemic syndrome.

I was left with 25 percent of one kidney functioning and after the first five years of my life being in and out of hospital, I stabilised and was relatively well until that small bit of kidney function died at age 18. Six months after struggling through the last year of high school, I started haemodialysis. I think I cried every dialysis session for the first year as I couldn't accept what was happening to me. I contacted the Australian Kidney Foundation, now known as Kidney Health Australia, with a few questions and soon after I was recruited to do talks and tell my story of what life was like living with kidney failure. It wasn't until then that I felt I had a purpose and my purpose was to educate the community on organ donation and water awareness. I was able to pick myself up and started working in retail and enrolled into university.

I was on haemodialysis six years before I got my first transplant from my Mum. I will never forget waking up from the transplant surgery and everything seemed clearer. Colours, smells, my train of thought -- everything was just better. Having a transplant was the best thing that ever happened to me and when my kidney started showing signs of failing, I did everything to make it work. I exercised, ate well and listened to my specialist's advice -- I got married, travelled around Australia twice; we went to Lord Howe Island, Fiji, Hawaii and Europe. I made the most of my kidney that's for sure. But ultimately a severe stomach bug that wasn't diagnosed for two years killed my kidney six months ago. I hope that the next transplant isn't too far away as I am currently struggling with severe high blood pressure, one serious side effect to kidney failure.

I think having struggled my whole life with an illness, has made me accept my situation as I honestly know no different. I feel lucky that I have dialysis to keep me well enough in-between transplants. I remind myself how lucky I am that I can still work, see my friends and go on holidays, even if it means dragging my peritoneal dialysis bags everywhere I go. I once had a very sick friend tell me that a negative thought is a luxury. I totally agree. I have no time to be angry. Yes, I have some health issues, but I can still do what I want and I have such a good life. I know I have created this life and I just can't wait until what I will be able to achieve once I get my next kidney. For now, I will hold my head high and carry on. I know it's easy to give up but we have to encourage each other to keep going. We are in this together.

Maria keeps a blog and Facebook page where you can follow her journey. Like her page by searching for Maria 'Kidneyqueen' Wyer.



Photo courtesy of Becky Felstead from The Busselton Dunsborough Times

Maintain your relationships

Kidney disease can affect many parts of your life. If you are unwell, it can be harder to talk about your fears and worries or feel in control of your life. It is not surprising that many people with kidney disease find there are times when they feel isolated and think no one cares.

However, change also provides you with an opportunity to look at your lifestyle and relationships from a different perspective.

Family

Kidney disease can cause a great deal of stress for you as well as your family. Family rules may change, routines can become disrupted and family members may take on different roles. Understanding the stresses that kidney disease can put on relationships is part of adapting to change.

Maintaining your relationships with your family and friends is very important even if you don't feel your best. At first you may feel more detached from your family because you are focused on coming to terms with the changes kidney disease brings. Physical and emotional

tiredness may also mean you have less time and energy for your family. It may seem that family and friends continue with their own lives and don't understand the problems you are experiencing. This can cause resentment towards the people you most care about. One of the most helpful things you can do is talk to them about how you feel. Even the people closest to you can't read your mind.

Your Partner

Remember that your partner is part of your health care team. Your partner may also have concerns and questions so may want to attend some of your health care visits. You need to support each other, physically and emotionally. A partner's caring support can help you to stay positive and confident.

Children

Children sense when someone in the family has a problem. As a role model, they usually look to you to know how to react and deal with the problem. If your children ask questions about your health condition, you need to give them as much information as you think they can understand. Children may worry about you if they are 'left in the dark' so it is important to answer their questions honestly and simply.

Older children may already have some information and understanding of your condition so their reactions can be more emotional. They may become concerned if what they've heard about kidney disease has been negative. The more you know about your condition the easier it will be to respond to their questions and concerns. Maintaining a positive attitude can help you and your children deal with the changes that kidney failure may bring.

Friends

Some people don't feel comfortable talking to friends about their health in case they ask lots of questions or act differently. Others like to share their problems with friends for support and understanding. Some friends may find it difficult to know how to treat you when you have an illness. They may stop calling because they are worried about upsetting you by asking how things are going. Telling friends about your condition is a decision that only you can make but it may help them to understand the changes you are going through.

If there are activities you can no longer do with friends, you may want to let them know about your condition and explore other interests you can enjoy together. It may allow you to enjoy new and fun experiences together.

Work colleagues

As you have probably already found, most people know next to nothing about their kidneys. If you do choose to tell your work colleagues about your condition, you will hopefully find them understanding and supportive. Talking to them about kidney disease can help to reduce any misleading ideas they have. Your health care team can assist by giving you educational information for your workplace that will help to explain kidney disease and its treatment.

Benefits of staying employed

It is important to keep working if possible, as the benefits of contact with colleagues, contributing something valued, and utilising a skill you have, all are part of a full life. It may be necessary to modify your job in some way (e.g. working fewer hours to enable attendance for dialysis), but your doctor can help by writing letters to support any changes that may be needed. Whether or not you can still do the same job will depend on the work involved and the state of your health. Keep your employer fully informed as generally they will be willing to help.

As a first step you should discuss your work commitments with your health care team. An occupational therapist can help assess your needs and make recommendations to your workplace to help you get back to work. The social worker at your hospital is another helpful person to talk to.

Time-consuming dialysis and low energy levels can be obstacles to work that require some thought and careful planning to overcome. Some solutions can include:

- Doing home haemodialysis
- Changing your work hours or times to fit with your haemodialysis schedule
- Doing peritoneal dialysis bag changes in a suitable location at work or using a machine to do dialysis over night
- Easing slowly back into work after a transplant operation so that you have plenty of time to recover and adjust to the anti-rejection medications.

Liz's Story



Police officer for 34 years. Most recent kidney transplant = 22 years. Liz's story highlights the capacity for a full life after a successful kidney transplant. In 1989, she learned she had end-stage renal failure which came as a large shock with no family history of the condition and the fact that she was leading a fit and healthy lifestyle. Since then, she has had two transplants (the first failed shortly after surgery) and two rounds of dialysis. She points out that a supportive workplace and an emphasis on self-care dialysis liberated her and made her feel more in charge of her condition.

"I want people who aren't affected by kidney disease to know that it is possible to live a fulfilling life and earn money when you have kidney disease" says Liz. She adds "I believe that sensible eating and adhering to an exercise program has helped maintain the long life of my transplant". Liz was a member of Kidney Health Australia's South Australian Consumer Committee and has won three medals at the World Transplant Games.

Keep doing things that you enjoy

Living with kidney disease means more than just staying alive. The challenge is to live life to the fullest.

Leisure time

You may think that the effort you put into your treatment leaves little time and energy for other activities. Think again! Do not give up any leisure activity without trying it first. It may be harder than before but most activities are possible with the right support.

Doing things that you enjoy is important for your overall health. Keeping up with hobbies and leisure activities can shift the focus away from treatment and health concerns. Having fun and doing things with others can do the same. Maintaining the interests you had before you developed kidney failure can help you to stay in contact with your friends.



Dining

Your appetite and diet may change but remember that eating is a social activity and meals are an important part of life with family and friends.

You may not enjoy your food as much or eat all the things you used to but make sure you dine with friends and family as often as possible. In this way you can keep the informal social support which eating in or out can offer. If you are on dialysis, remember to monitor your fluid intake!

Holidays

Holidays are important and can provide an excellent 'pick-me-up' for you and your family. It is possible to still have a holiday, but it takes some planning. If a big trip seems out of your reach, even a couple of days away between dialysis sessions can allow a change of scenery and a break from normal routines.

You need to take charge of your holidays plans, but there is a dialysis community prepared to help.



Some suggestions include:

- If you are on haemodialysis, consider going to a holiday facility equipped for dialysis treatment. The patient association in your state may offer a holiday house for people who have experienced in home haemodialysis.
- Kidney Health Australia organises adult and children's camps and activities in some states.
- Arrange to have dialysis in another renal unit. Renal units do their best to accommodate short-term haemodialysis users but unfortunately the number of places is limited. Private dialysis centres often have more places available than public renal units, but if you don't have private health insurance you may be expected to pay up-front for any treatments. Kidney Health Australia has a list of available Australian dialysis units at www.kidney.org.au.
- Investigate haemodialysis units around the world on the Internet. Some overseas dialysis centres charge quite a lot of money, which may not be covered by health or travel insurance. Haemodialysis is possible in other countries, but the standard of care may not be the same in all countries. You can get travel insurance, although the conditions and terms vary. It is important to check what cover you are offered and shop around.
- People on peritoneal dialysis find it easier to travel. You may be able to make arrangements to do dialysis by taking your equipment with you. It is important to check all aspects of travel, health insurance and medical care carefully before you go. Your dialysis unit can assist with arrangement for overseas dialysis. In most instances, supplies can be delivered to your holiday destination. Remember that the electrical voltage is different in many parts of the world so your equipment may not work there.
- The Dialysis Escape Line (DELA) organises a sea cruise and a land-based holiday each year for people on haemodialysis. Call 0404 899 540 or email info@dialysisescapeline.com for more information

There are costs involved with each of these options and it pays to find out what they are in advance so you don't receive any nasty surprises that could ruin your holiday. Acceptance in many places can be conditional on negative swabs for multi-resistant organisms (such as VRE and MRSA), and negative blood tests for infectious diseases.



Richard's Story

In year 12, I was finally diagnosed with kidney disease, after suffering the symptoms my whole life. I was lucky to receive a kidney transplant from my mother in 2003. Life was easier with her gift of a kidney, but I sadly lost function in the donated kidney in January of 2012 after I developed pneumonia. Now I am on daily peritoneal dialysis treatment, which is usually performed overnight, so that I am able to keep regular hours as a sales agent.

My condition didn't diminish my big dreams of travelling Europe though. In September of 2012, I took off for the adventure of a lifetime with my longtime girlfriend, Lisa.

We saw some amazing sights in our 75 days of travel and I returned to Melbourne with millions of memories -- and a fiancée!

I maintain that having a serious medical condition should not deter anyone from getting out in the world and enjoying life. While I don't sweat the small stuff, it was actually the logistical aspects to my trip that were the most difficult. I didn't have a blueprint to follow - no one else has written about their experiences in coordinating such a long trip while on peritoneal dialysis, so I had to meticulously plan out my trip to ensure that I could get my PD bags dropped off at various points. I worked with a dialysis fluid provider to organise my drop offs and they ensured that I had an oversupply just to be sure that I didn't have any hiccups along the way. Everything ran so smoothly and I'm so glad that dialysis didn't get in the way of me living my dreams.

If you're considering travelling on dialysis, take a look at my blog for some practical tips: <http://travellingwithdialysis.wordpress.com/>.

Currently, I am on the transplant waiting list with no indication when I might receive 'the call'. Unfortunately neither my friends nor family are a match for me. So wait I must, but I will stay positive, because I think that can get you through anything.

Looking after your health

Your kidney disease may make you a little more prone to infections than usual. Your body does not react as it used to when you are exposed to infections. If you have diabetes your risk is even higher but early treatment can prevent serious disease. It is important to seek medical advice for any early signs of infection such as fever, pain, aches and feeling generally unwell.

An influenza (flu) vaccination is generally recommended for people with kidney disease. However, some dialysis and transplant medications interact with the 'fluvax' vaccination and may reduce its effectiveness. It is important to talk to your kidney specialist or doctor about getting your vaccine.

Learn about ways to reduce your exposure to infections, such as:

- Make hand hygiene a part of your daily routine, and use a hand sanitiser whenever there is a risk of touching contaminated items, such as after using the toilet, preparing food (use before as well), changing a nappy, touching an animal or animal toys, leashes or waste, blowing your nose, coughing or sneezing into your hands, treating wounds, touching a sick or injured person, handling garbage or something that could be contaminated, such as a cleaning cloths or soiled shoes.
- Remind your health care team to perform hand hygiene before touching your drips, drains, dressings if you think they have not done so.
- If you are waiting to visit your health care team and there are people visibly unwell in the waiting room, ask the practice manager or receptionist if you can wait in a secluded area, or wait outside and arrange for them to call you when your appointment is ready.



Frequently Asked Questions

Now that I am on dialysis can I claim disability benefits from my superannuation or insurance?

You may be able to claim disability benefits from your superannuation or Insurance, and you may be eligible for early access to preserved superannuation funds. As everyone's circumstances are different it is advised that you contact your superannuation or insurance provider for more information. If you are uncertain it is important to get advice from experts. Disability claims can be complicated and may take time, but it is important that you find out about your rights.

Will my kidney disease diagnosis affect my ability to get travel insurance?

Buying travel insurance when you have a pre-existing condition such as kidney disease may be a problem. If you had private health insurance cover before you were diagnosed with kidney disease you may be able to obtain travel cover from your health insurance company. If you do not have private health insurance, are experiencing dialysis issues, or multiple health conditions, you may not find a travel insurer. It is recommended to contact an insurance broker for assistance.

Can I carry my medications on board domestic and international flights?

See the Frequently Asked Questions at the end of Chapter 11 for information on travelling with medications.

I live in a small town and don't know anyone else with kidney disease. How can I stop feeling so isolated?

Kidney Health Australia runs Kidney Club events in most states and territories of Australia. These events offer a friendly environment where patients, carers and family members can talk openly about their personal experiences and ask questions from others. You may also like to connect with other people with kidney disease via social media such as Facebook (Kidney Health Australia has a dedicated page) or other online forums and support groups.



Caring for someone with kidney disease

“Receiving a chronic condition diagnosis such as kidney disease is like being on an emotional roller-coaster ride that never seems to stop.” “No-one told me it would be like this.” “Everyone seems to be worrying about my husband/wife/partner, but hey, what about me. I’m affected by this disease, too.”

These are just some comments from the carers of people who have been diagnosed with kidney disease. What they suggest is that the carers are also deeply affected by the problem. However, carers don’t have to go it alone. As well as friends and family, there are also many organisations that can help carers deal with the burden of caring for a loved one with kidney disease or any other chronic condition.

There are local council services such as Meals on Wheels, Home Help, in-home respite and personal care. The Carers Association in your State can help with respite (such as Personal Care Day Centre support), transport, case management, and overall care and liaison with different services that are available. The Aged Care Assessment Team (ACAT) offers community packages including individual assessments to meet your care needs. Community multicultural centres can provide support for patients and carers from culturally and linguistically diverse backgrounds.

Centrelink can provide financial assistance in regard to the carers’ payment (which replaces an existing Centrelink Benefit Assets test), carers’ allowance, concession cards, sickness benefits and disability payments. Further financial assistance can also be obtained through the Salvation Army and St Vincent De Paul. The Office of Public Advocate offers legal assistance with wills, power of attorney and guardianship.

The Carer's Bill of Rights

1. You have the right to express your feelings about the significant changes happening in your life.
2. You have the right to grieve for what you have lost.
3. You have the right to have a bad hair day and to eat what you want.
4. You have the right to say 'no' if you feel you can't meet the expectations everyone has of you.
5. You have the right to ask for help if and when you feel overwhelmed.
6. You have the right to expect to be included in any discussions and decision-making.
7. You have the right to be heard by your partner and health-care team.
8. You have the right to say, "I can't do that, I don't have the qualifications".
9. You have the right to expect intimacy in your relationship and to find new ways of achieving this.
10. You have the right to enjoy a good night's sleep.
11. You have the right to find balance
12. You have the right to refuse to take on responsibility for your partner's health problem without guilt – i.e., medications, lifestyle changes.
13. You have the right to feel tired, too. Being a carer requires energy.
14. You have the right to be acknowledged and thanked for what you do.

Between your life and your caring responsibilities take time for what you most enjoy.





Mary and Victor's Story

When Victor got sick he started dialysis at the local hospital. We live in the country so it meant a 30km trip each way, three times a week. I used to drive him there and back, and whilst he was on the dialysis I did a lot of waiting. Unfortunately the appointment times meant I had to take long term leave from my job which I found very difficult. I missed the company and the money.

One day I was chatting to Victor's nurse who suggested we consider home haemodialysis. Victor said no because he was worried about the needles but I figured it was something I could do to get some freedom back into our lives. We agreed to do it together. The training took us six weeks. When we first did the dialysis at home we were very nervous and often called the nurses for support.

Victor now dialyses four times a week in the evenings. I have been able to return to my part-time work and four times a week I help Victor with his dialysis. Victor sets up the machine and then I put in his needles and help him to connect up. Once Victor is on dialysis we have dinner and then we often sit and chat or watch TV.



Resources, Contacts and Support

Kidney Health Australia

Kidney Health Information Service 1800 454 363 (freecall)

www.kidney.org.au



Our Mission

To promote good kidney health through education, advocacy, research and support.

Our Vision

To save and improve the lives of Australians affected by kidney disease.

Our Work

Kidney Health Australia is a not for profit organization whose focus is to improve kidney health outcomes leading to substantial improvements to the quality of life for people with kidney and urinary tract diseases, their families and carers, as well as developing initiatives that reduce the incidence of kidney disease in the Australian community.

Our Services

Kidney Health Australia provides a range of services and programs for people with kidney disease and their family and friends, health professionals, and others with an interest in kidney disease. Our website offers a large range of fact sheets, brochures, and books on a wide range of kidney and urinary related conditions and treatments. Translated fact sheets are available for people from culturally and linguistically diverse backgrounds, and culturally-appropriate materials have been developed for people of Aboriginal and Torres Strait Islander origin. Opportunities to network and socially interact with other people with kidney disease are offered for all age ranges across the country. You can also sign up for the free monthly Kidney Community newsletter.

Other Useful Contacts

Adverse Medicines Event Line

To report a medicines problem call 1300 134 237 (Mon–Fri, 9am to 5pm AEST)

Alport Foundation of Australia

www.alport.org.au

Australian support group for patients and families affected by Alport Syndrome.

Australian and New Zealand Society of Nephrology

www.nephrology.edu.au

The aims of the Society are to promote and support the study of the kidney and urinary tract in health and disease, and to ensure the highest professional standards for the practice of nephrology in Australia and New Zealand.

Australian Indigenous HealthInfoNet

www.healthinonet.ecu.edu.au

Internet resource that aims to inform practice and policy in Indigenous health by making research and other knowledge readily accessible.

Australian Organ Donation Registry

To register your decision to be an organ donor:

- Visit www.donorregister.gov.au to register online
- Call 1800 777 203
- Visit a Medicare Service Centre

Better Health Channel

www.betterhealth.vic.gov.au

An initiative of the Victorian State Government, the Better Health Channel provides health and medical information that is reliable, easy to understand, and regularly updated.

BeyondBlue

www.beyondblue.org.au

An Australian, not-for-profit organisation that provides information about depression, anxiety and other related mood disorders to consumers, carers and health professionals. They also have a support line (1300 22 4636), you can chat online 7 days a week, or email your questions.

Cancer Council Australia

www.cancer.org.au

National peak body for cancer in Australia. The website contains evidence based cancer information on prevention, research, treatment and support. Call the Cancer Council Helpline 13 11 20 for free, confidential telephone information and support.

Carers Australia

www.carersaustralia.com.au
Australia's national peak body representing carers. The website contains downloadable information or call 1800 242 636 for more information.

Davita

www.davita.com
The website contains a wide range of information including articles, online learning modules, videos, and recipes. Please note that this is an American website, so not all the information will be relevant to Australia.

Diabetes Australia

www.diabetesaustralia.com.au
National peak body for diabetes in Australia. The website provides information and education relating to diabetes.

Dialysis Escape Line

Call 0404 899 540 or
email info@dialysisescapeline.com
for more information about how to organise a holiday on dialysis.

Dietitians Association of Australia

www.daa.asn.au
National peak body of dietetic and nutrition professionals in Australia. The website contains a searchable database of Accredited Practising Dietitians and up-to-date nutrition information via the Smart Eating for You program.

DonateLife

www.donatelife.gov.au
Website for the Australian Government's Organ and Tissue Authority which contains a wide range of fact sheets, statistics and myth busters about organ donation (from living and deceased donors) and transplantation in Australia.

Healthdirect

www.healthdirect.org.au
Healthdirect is a government funded organisation which manages Internet and telephone health services. Services include:

- *healthdirect Australia*: 24-hour telephone health advice line. If you have a health concern and you're not sure what to do, call 1800 022 222 and speak with a registered nurse. Available 24 hours a day, 7 days a week.
- *Healthinsite*: www.healthinsite.gov.au. Easy to access quality information and services about health.
- *Mindhealthconnect*: www.mindhealthconnect.org.au. Access a range of online programs, videos, fact sheets and online support groups for mental health issues.

- National Health Services Directory: www.nhsd.com.au. Comprehensive and up-to-date national directory of health services and provider information. It includes both public and private health service providers from all Australian states and territories. There is also an app to download for free for your smart phone.

Heart Foundation of Australia

www.heartfoundation.org.au
National peak body for heart disease in Australia. The website provides information and education relating to heart disease, and tips on how to be active every day.

Home Dialysis

www.homedialysis.org.au
Up-to-date information and education regarding all aspects of home dialysis.

Lab Tests Online Australasia

www.labtestsonline.org.au
Offers education and information on pathology tests to help patients better understand their health care.

Lifeline

For crisis support call 13 11 14, a confidential telephone crisis support service available 24 hours a day, 7 days a week.

National Kidney Foundation

www.kidney.org
Information brochures, fact sheets, and downloadable resources are available from their website. Please note that this is an American website, so not all the information will be relevant to Australia.

National Prescribing Service Medicines Wise

www.nps.org.au/medicines
Independent, evidence-based and not-for-profit organisation that provides reliable information on medicines available in Australia. The site also includes the consumer medicine information (CMI) for most prescription and some non-prescription medicines.

Palliative Care Australia

www.palliativecare.org.au
The peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life. The website provides information and education relating to palliative care in Australia.

Poisons Information Centre

For telephone advice in cases of acute and chronic poisonings call 131 126, 24 hours a day, 7 days a week

Quitline

www.quitnow.gov.au

13 7848 (8am to 8pm EST, Monday to Friday) Information, resources and tools, including a free Quit Pack, to assist you to quit smoking.

Renal Resource Centre

www.renalresource.com

Australian resource centre which provides information and education for people with kidney disease. The website contains a large range of brochures and pamphlets to download.

Renal Society of Australasia

www.renalsociety.org

Professional organisation with membership open to nurses, technicians, social workers, dietitian, unit managers, transplant coordinators, and other health care professionals working with patients with kidney disease.

Stroke Foundation

www.strokefoundation.com.au

Strokeline 1800 787 653

National peak body that works with stroke survivors, carers, health professionals, government and the public to reduce the impact of stroke on the Australian community. The website provides information and education relating to stroke.

Transplant Australia

www.transplant.org.au

An organisation representing transplant recipients, people currently undergoing dialysis treatment, those awaiting transplantation, and the health professionals working in the organ and tissue donation and transplantation sector. Transplant Australia works in the areas of advocacy, awareness and support.

For a more extensive list of recommended contacts and weblinks, visit www.kidney.org.au or call 1800 454 363.

A

Abdomen: the part of the body that contains the pancreas, stomach, intestines, liver, gallbladder and other organs.

Acute kidney injury: a loss of kidney function that happens quickly which may or may not be permanent.

Albumin: A protein in your blood plasma. In the blood, albumin acts as a carrier and helps to maintain blood volume and blood pressure.

Albuminuria: When albumin (a kind of protein) is present in the urine. There are filters in the kidneys that prevent large molecules, such as albumin, from passing through. If these filters are damaged, albumin passes from the blood in to the urine. See Microalbuminuria, Macroalbuminuria, Proteinuria.

Albumin:creatinine ratio (ACR): This test compares the amount of albumin in the urine with the amount of creatinine. It is used to detect whether albuminuria is present. See Albuminuria, Creatinine, Microalbuminuria, Macroalbuminuria.

Anaemia: when there are only a small number of red blood cells in the blood or the blood cells are not working properly. Red blood cells carry oxygen, so someone with anaemia can feel weak, tired and short of breath.

Angiotensin: a hormone produced by the kidneys which works to control blood pressure.

Antibodies: are made by the immune system, your body's protection mechanism, to attack tissue that is not normally part of the body, for example bacteria or toxins.

Automated Peritoneal Dialysis (APD): a type of dialysis where a special fluid is put into the peritoneal cavity (abdomen) through a soft, plastic tube (catheter) then drained out of the body continuously for a few hours by a machine called a cyclor, usually at night.

Artery: a blood vessel taking blood from the heart to other parts of the body.

B

Bicarbonate: a soluble mineral salt or mixture of salts that can neutralise acids.

Biopsy: a small piece of tissue is removed for testing and examination under a microscope.

Bladder: a muscular, elastic sac inside the body that stores the urine (wee).

Blood group: refers to the red blood cell groups (O, B, A or AB) that determine the compatibility for blood transfusion, and are part of the process for determining compatibility for kidney donation.

Blood pressure: the pressure of the blood in the arteries as it is pumped around the body by the heart.

C

Calcium: the most common mineral in the body and is essential for healthy bones and teeth.

Cardiovascular disease: Includes all diseases and conditions of the heart and blood vessels, such as arteries and veins. The most common diseases and conditions include heart attack, heart failure, stroke, blockages in the blood vessels and vascular kidney disease.

Catheter: a plastic tube used to transport fluids to or from the body.

Central venous catheter: a special tube which is surgically inserted into your neck, collarbone or top of your leg to allow temporary access for haemodialysis.

Cholesterol: A naturally-occurring, waxy substance made by the body. It is an essential building block of cell membranes, hormones and vitamin D. See HDL cholesterol, LDL cholesterol.

Chronic kidney disease: progressive reduction in kidney function or kidney damage which is present for at least three months.

Computed tomography: an imaging procedure that uses special x-ray equipment to create a series of detailed pictures, or scans, of areas inside the body.

Continuous Ambulatory Peritoneal Dialysis (CAPD): a type of dialysis where a special fluid is put into the peritoneal cavity (abdomen) through a soft, plastic tube (catheter) then drained out a few hours later. This is usually done 3 or 4 times during the day.

Creatinine: waste that is produced by the muscles. It is usually removed from the blood by the kidneys and passes out in the urine (wee). When the kidneys aren't working properly, creatinine stays in the blood.

Cystoscopy: an investigation where a special viewing camera is inserted via the urethra into the bladder.

D

Diabetic nephropathy: a serious outcome of diabetes, which affects the kidney filters and can lead to kidney failure. Also called diabetic kidney disease.

Dialyser: the part of a kidney machine which acts like a filter to remove waste from the body.

Dialysate: a special fluid used in dialysis to remove waste and extra fluid from the blood.

Dialysis: a treatment for kidney failure, which removes wastes and extra fluid from the blood by filtering it through a special membrane. There are two types of dialysis, haemodialysis and peritoneal dialysis.

Dialysis adequacy: refers to how well your dialysis is working. It measures the amount of waste removed from your blood and determines the amount of dialysis needed.

Diuretic: any substance that increases the production of urine.

E

eGFR: An estimation of glomerular filtration rate. See Glomerular filtration rate.

Electrolytes: elements or chemicals needed to enable the body and heart to work properly.

End stage kidney disease (ESKD): stage 5 kidney disease, when dialysis or transplantation is needed to maintain life. 'End stage' refers to the end of kidney function. Also called end stage renal failure.

Erythropoietin (EPO): a hormone made by the kidneys that causes the bone marrow to produce red blood cells.

Exchange: one treatment cycle of peritoneal dialysis.

F

Fistula: produced when a vein and an artery in the arm or leg are joined together to provide adequate access to blood for the haemodialysis process.

Fistulogram: examination of the blood vessels that make up your fistula. A small needle is placed in your fistula and dye is injected. This dye provides an image of the blood vessels that would otherwise be invisible on X-ray.

Fluid retention: when the body does not remove enough liquid (water). This can cause swollen or puffy ankles, face or hands.

G

General Practitioner: a doctor who treats acute and chronic illnesses and provides preventive care and health education to patients.

Glomerulonephritis: a type of kidney disease that damages the tiny filters in the kidneys. It is sometimes called nephritis.

Glomeruli: see nephron.

Glomerular filtration rate: the best measure of kidney function and helps to determine the stage of kidney disease. It shows how well the kidneys are cleaning the blood. GFR is reported in millilitres per minute. The GFR is usually worked out from the results of the creatinine blood test with age and gender. See eGFR.

Glucose: a type of sugar which is a major source of energy for most cells of the body.

Graft: commonly used method of providing access to the blood in which a vein and an artery in the arm are joined together with a piece of special plastic-like tubing.

H

Haematocrit: the percentage of blood cells as a proportion of the total blood volume.

Haematuria: Occurs when red blood cells leak into the urine. It can turn urine a red or dark cola colour, which is visible to the eye or may only be found by a urine test (microscopic haematuria). Blood in the urine is a common sign of urinary tract infections but can be the first sign of a problem with the kidneys or the bladder.

Haemodialysis: a treatment for kidney failure. The blood is pumped through special tubing to a haemodialysis machine. The machine acts like a kidney, filtering waste products from the blood before returning it to the body.

Haemoglobin: colouring matter of the red blood cells that transports oxygen in the blood.

HbA1c: Stands for glycosylated haemoglobin, which occurs when haemoglobin joins with glucose in the blood. The HbA1c test shows what a person's average blood glucose level was for the two to three months before the test. This can help determine how well a person's diabetes is being controlled over time.

HDL cholesterol: Known as the “good cholesterol”. The higher the amount of HDL cholesterol, the lower the risk of cardiovascular disease. See Cholesterol.

Health: physical, mental, emotional and spiritual wellbeing, not merely an absence of disease.

HLA (Human Leukocyte Antigen): proteins located on the surface of white blood cells and other tissues in the body and play an important role in the immune system. Each person has a unique set of HLA.

HLA antibodies: the body's immune system makes HLA antibodies against HLAs that are different from its own, most commonly following blood transfusion, transplant or pregnancy.

Heparin: substance added to blood during haemodialysis to prevent it from clotting in the dialyser.

Hormone: a chemical made by glands in the body. Hormones circulate in the bloodstream and control the actions of certain cells or organs.

Hypertension: another word for high blood pressure.

I

IgA nephropathy: a common type of glomerulonephritis where build up of the IgA antibody damages the kidney filters, allowing protein and blood to leak into the urine.

Insomnia: a sleep disorder in which there is an inability to fall asleep or to stay asleep as long as desired.

Insulin: a chemical or hormone made by the pancreas that controls the level of glucose (sugar) in the blood.

K

Kidney biopsy: a small piece of kidney tissue is removed for testing and examination under a microscope.

Kidney ultrasound scan: A probe is moved over the skin, sending and receiving ultrasound signals, which then make pictures of the kidneys and bladder. This is a diagnostic test, often used to measure the size of the kidneys.

Kilojoules: a metric measure of the energy value of food.

L

LDL cholesterol: Known as the ‘bad cholesterol’. The higher the amount of LDL cholesterol, the higher the risk of cardiovascular disease. See Cholesterol.

Libido: another word for sexual desire.

Lipid: another name for fats that cannot usually be dissolved in water.

M

Macroalbuminuria: when larger (‘macro’) amounts of a protein called albumin leak into the urine if the kidneys are damaged. Compare microalbuminuria.

Magnetic resonance imaging (MRI): a test that uses a magnetic field and pulses of radio wave energy to make pictures of organs and structures inside the body.

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

Membrane: a thin, elastic lining or sac connecting or covering parts of the body, which is used to filter wastes from the blood.

Microalbuminuria: when small (‘micro’) amounts of a protein called albumin leak into the urine if the kidneys are damaged. Compare macroalbuminuria.

N

Nephrectomy: surgical removal of one or both kidneys.

Nephritic syndrome: A type of glomerulonephritis characterised by blood in the urine and high blood pressure. See Nephrotic syndrome.

Nephritis: See Glomerulonephritis.

Nephrologist: a doctor who specialises in kidney function.

Nephrology: the area of medicine that deals with the kidneys.

Nephron: the tiny parts of the kidney that filter blood to make urine. There are over one million filters in each kidney.

Nephrotic syndrome: A type of glomerulonephritis characterised by large amounts of protein in the urine, swelling due to fluid retention, high cholesterol and blood clots. See Nephritic syndrome.

Nocturnal haemodialysis: where haemodialysis performed at night while the patient is asleep. This is usually performed at the patient’s home.

Nonsteroidal anti-inflammatory medications (NSAIDs): medications typically used to treat inflammation, mild to moderate pain, and fever (examples include aspirin, ibuprofen, and naproxen).

O

Occupational Therapist: health professionals who help you find solutions to problems you may meet when carrying out your daily activities including physical or emotional difficulties with work, daily tasks and leisure activities.

P

Parathyroid hormone: helps control calcium, phosphorus, and vitamin D levels within the blood and bone.

Peritoneal cavity: the space in the abdomen holding the intestines and other internal organs.

Peritoneal dialysis: treatment for kidney failure during which dialysis fluid is moved in and out of the peritoneal cavity to remove wastes and fluid from the blood.

Peritonitis: an inflammation of the membrane (called the peritoneum) which lines the inside of the abdomen and all of the internal organs.

Phosphate: a mineral, together with calcium, that helps to keep your bones strong and healthy.

Phosphate binder: medication that binds with the phosphate in the intestine causing some of the phosphate to be passed in the faeces (poo).

Pharmacist: a health professional who is qualified to prepare and dispense medications.

Physiotherapist: a health professional who aims to restore proper functioning to the body or, in the case of permanent disease or injury, to reduce the impact of any dysfunction.

Polycystic kidney disease: an inherited kidney disease that produces fluid-filled cysts in the kidneys.

Potassium: mineral in the body fluids regulated by the kidneys. It helps nerves, muscles and other cells to work well. At very high levels, may cause the heart to stop.

Pre-emptive transplantation: when someone receives a kidney transplant before beginning dialysis.

Protein: substance obtained from food, which builds, repairs and maintains body tissues. It also helps to fight infections and heal wounds.

Proteinuria: high levels of protein in the urine. It may be the first sign of an otherwise silent kidney condition.

R

Radionuclide scan: an imaging technique used to visualise parts of the body by injecting a small dose of a radioactive chemical into the body.

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

Renal: another word for kidney.

Renal Dietitian: a Dietitian experienced in kidney disease who can help you develop an eating plan needed as part of the management of kidney failure.

Renal Nurses and Nurse Practitioners: Nurses who work closely with you, your family and other team members so that you can learn about kidney disease and its treatment. They also help you develop the skills you need to manage your health.

Renal technician: technicians provide technical support for the machinery involved in haemodialysis, help people to set up machines at home and are responsible for maintaining quality control. They also support the nursing staff involved in your care.

Renin: an enzyme or chemical, which is made by the kidneys and helps to control blood pressure.

S

Satellite centre: A dialysis unit that provides haemodialysis away from the hospital. This is an option when home dialysis is not appropriate and hospital dialysis is not required.

Sleep apnoea: occurs when the walls of the throat come together or collapse during sleep, blocking off the upper part of the airway. A person with this disorder might have a sleep disturbance hundreds of times every night.

Social Worker: health professionals who are available to support and advise you and your family about daily stresses, lifestyle readjustments and practical issues associated with kidney disease.

Sodium: an essential nutrient that regulates blood volume, blood pressure and water in the body. Also called salt.

Surgeon: a doctor who is specially trained in surgical techniques. Surgeons create vascular access for haemodialysis, put in and remove peritoneal dialysis catheters and perform kidney transplants.

T

Tissue typing: a test to find out the level of compatibility or matching between the organs of a donor and a recipient.

Tissue: cells of the same type grouped together, e.g. muscles.

Transplant: to transfer an organ or portion of tissue from one person to another.

Transplant Coordinator: assists in organising the testing to determine your suitability for transplantation. They also provide support and information to the live kidney donors and transplant recipients.

Triglycerides: the most common form of stored fat in your body.

U

Ultrasound: an instrument is moved over the skin, sending and receiving signals to make pictures of the kidneys and bladder. This is test is often used to measure the size of the kidneys.

Urea: waste product from the breakdown of protein.

Ureter: the tube that connects the kidneys to the bladder.

Urethra: the tube that takes urine out of the body from the bladder.

Urine: another name for wee.

Urologist: a doctor who specialises in the urinary system.

V

Vascular access: access to the blood stream for haemodialysis.

Vein: a blood vessel returning blood to the heart.

Vitamins: a group of substances that are essential for normal cell function, growth, and development.

X

Xrays: an examination used to create images of your internal organs or bones to help diagnose conditions or diseases.

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