

A decision-making
guide for the
treatment of
kidney failure

My Kidneys My Choice



The My Kidneys My Choice Decision-Making Guide

This decision-making guide is provided by Kidney Health Australia and has been developed in collaboration with expert healthcare professionals and consumer experts. We hope you find it useful.



For more information and support, scan the QR code, visit [kidney.org.au](https://www.kidney.org.au) or call our Free Helpline on **1800 454 363**



Healthcare professionals wanting information on how to use this guide, please scan the QR code or visit [kidney.org.au/hphub](https://www.kidney.org.au/hphub)

Front Cover Image: **Julie**

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Acknowledgements

Baxter

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Disclaimer

This decision-making guide aims to support discussion between individuals and their healthcare professional about the treatment options available for kidney failure. It may be used to learn about different kidney failure treatment options and which ones are best suited to achieve the desired outcomes. Use of this guide is voluntary, and the content provided is based upon the best information available at the time of publication. The guide is not intended to suggest a particular course of action. Healthcare professionals using this guide are responsible for evaluating the appropriateness of applying it in the setting of any particular clinical situation. Taking individual circumstances into account is recommended.

Why am I here?

Your doctor has found that your kidneys are not working as well as they should. This decision-making guide aims to provide you with helpful information about different treatment options for when your kidneys stop working.

While you may feel relatively healthy now, once your kidneys stop working (this is called kidney failure), you are likely to start noticing changes to your health and wellbeing. The impacts on your health will increase with reducing kidney function.

Kidney Failure affects many Australians and their families.

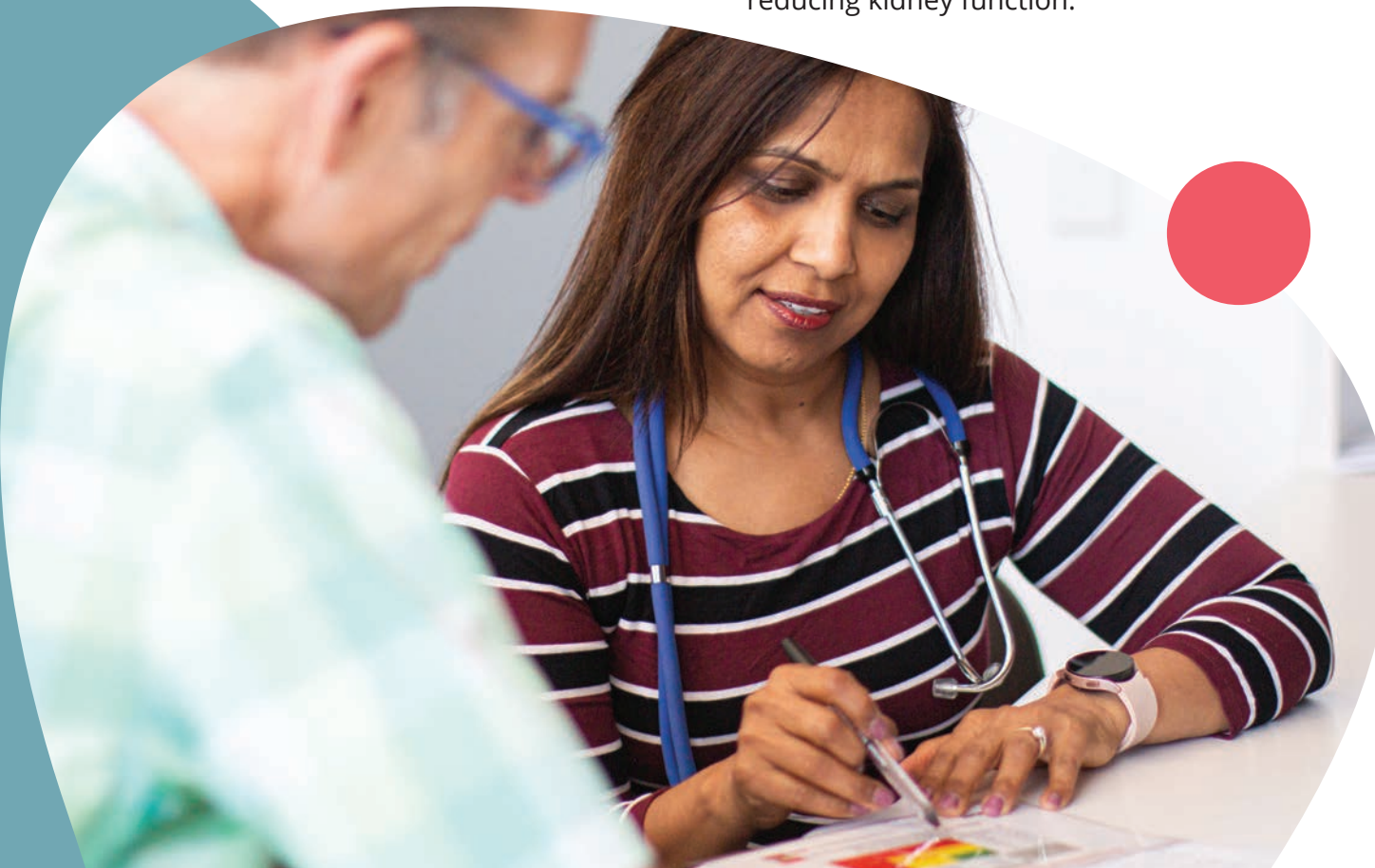
Understanding the different kidney failure treatments and how they can impact on your life, will be helpful for discussing your options with your healthcare team. Your healthcare team will listen to your wishes and situation, so that you can make an informed decision together. The overall aim is to achieve the best possible outcome for you.

Education is important!

If you're not sure of your current kidney function level, or you don't feel you know enough about your condition, ask questions, and speak with your healthcare team to see what information they can share. Kidney Health Australia is also here to help. We have a large range of educational information and support services that can help you understand kidney disease and kidney disease treatments.



For more information on kidney disease and treatments, scan the QR code or visit [kidney.org.au/treatment](https://www.kidney.org.au/treatment)



How to use this guide?

1. My kidneys
2. My life
3. My options
4. My choice
5. My questions

Each section addresses various factors that may affect how you feel about different treatment options. It is important to go through the sections one by one, as each provides information and thoughts you may want to acknowledge. Your kidney doctor or nurse will advise you prior to completing this guide, which treatment options are available to you. Not all treatment options are suitable for everyone, as your health and overall situation needs to be considered.

Use this guide to take control and form an understanding of which available treatment options might be right for you. You can do this on your own, or together with someone, such as a family member, friend or healthcare professional.

Remember to bring this decision-making guide to your next appointment with your kidney team. Having it at hand will be useful when discussing your thoughts and deciding on your treatment together with your healthcare professional.



1.

Over **2 million** Australians live with kidney disease.



Kidney disease can progress to **kidney failure** over time.



If you have been told that your kidneys are likely to fail within 6 months to 1 year, now is the time to **decide on your treatment.**



Ideally a few months are required to **prepare for treatment.** However, treatment can start urgently, if needed.



Treatment starts.

My kidneys

If your doctor says that your kidneys may fail within six months to one year, **NOW** is the time to decide on a treatment. It is best to decide on a treatment before your kidneys stop working. This is important, so emergency dialysis and lengthy hospital stays may be avoided, and to leave you with as much treatment choice as possible.

So, **PLAN AHEAD.** Typically, the sooner you start preparing for treatment, the better the outcome. Talking to family and friends can also help with making the best decision for you.

The best choice of treatment is one you make with a good understanding of the treatment itself, consideration of how it will affect you and your lifestyle, and by taking into account your healthcare team's advice.

Treatments available to you

Not all treatment options are suitable for everyone. Based on your health and overall situation, your kidney failure treatment options currently include: *(healthcare team to complete)*

- Kidney transplant
- Peritoneal dialysis
- Home haemodialysis
- Centre-based haemodialysis
- Comprehensive conservative care

Please note that you can change your mind. Talk to your healthcare team if you would like to change the type of treatment you are receiving, e.g. from centre-based to home haemodialysis.

2.

My life

Here is an example:

Treatment may affect:	How do I feel about it?
My leisure activities and hobbies.	I like to go and watch my team play on Saturdays with my friends. It's something I'd really miss.

Completing this section will help you think about specific areas of your life and how the different treatment options may change or affect them. Weighing up these factors can help you make an informed decision on treatment.

My lifestyle

Treatment may affect:	How do I feel about it?
The time I can spend on household activities and with people at home.	
My relationships with family, friends, and community.	
My work or study.	
My leisure activities and hobbies.	
My sporting activities and exercise.	
My travel or holidays away from home.	

2. My life



Pictured: Emmy

My independence

Treatment may mean that I need to:	How do I feel about it?
Be actively involved in the management of my condition.	
Do things for myself.	
Reach out for help if needed.	
Have people supporting me with my emotional wellbeing.	
Weigh up whether to have treatment to prolong my life or manage my symptoms to feel better.	

2. My life

My situation

Treatment may mean that I need to:	How do I feel about it?
Balance the time between treatment and other commitments.	
Travel to a centre for treatment.	
Store treatment equipment in my house.	
Be in my own home for treatment.	
Talk about my treatment with family, friends, and people at work.	

3.

My options

Main types of kidney failure treatment

There are three main ways of treating kidney failure: dialysis, kidney transplant and comprehensive conservative care. Your thoughts on which one is best for you may change over time, so it is good to be aware of all the options. Please remember, your healthcare team is there to provide support and help with managing your disease and treatment, no matter which treatment you choose.

Dialysis

With dialysis, special equipment does the job of cleaning your blood. There are several types of dialysis, and the following sections will help you think about which would suit you best. Dialysis is the most common type of treatment for kidney failure.

Kidney transplant

When you have kidney transplant surgery, a kidney from another person is placed (transplanted) into your body. Kidneys for transplantation come from living donors or deceased donors. Living donors are usually donors who know the person with kidney failure. Having a living donor may mean you can have a transplant before you start dialysis (called pre-emptive transplantation). Deceased donors are people who die with organs that are suitable for transplantation. To receive a kidney transplant from a deceased donor, you will need to be added on the kidney transplant waitlist first and this usually happens after starting dialysis.

Comprehensive conservative care

You may decide not to have dialysis or a kidney transplant and choose comprehensive conservative care instead. Comprehensive conservative care focuses on treating symptoms through medication, diet, and other supportive ways to allow you to live as well as possible for as long as possible. Comprehensive conservative care cannot stop the decline of your kidney function.



Pictured: Kaitlyn

3. My options

	Dialysis	Kidney transplant	Comprehensive conservative care
Summary	Treatment of your kidney failure will include the use of special equipment to remove waste products from your blood.	You receive a kidney from another person. They may be a living or deceased donor.	You will manage your kidney failure with medication, diet and other types of support to live as independently and in as much comfort as possible.
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.	Your treatment will be based on continued visits to your specialist doctor and kidney team, who will help manage your symptoms through medication, diet, and other supportive ways.
My suitability for this treatment	Most people with kidney failure are suitable, unless you have serious illness affecting other body systems.	A transplant is generally best suited to patients without serious health issues besides kidney disease.	This is suitable for all patients. However, people often select this treatment option, if the burden and discomfort of dialysis or kidney transplantation outweighs the potential benefits for them. Other reasons include spiritual, cultural, or personal beliefs.
My life and work	There are different types of dialysis. Home treatments are more flexible than others. However, any type of dialysis may impact your availability to work.	Most people are able to resume normal activities and work within 3–6 months after transplant.	As your health declines with time, you may find it difficult to work.
My diet and fluids	There are some things you may need to limit and avoid, but it depends on the type of dialysis, ability to pass/make urine (wee), and other health factors.	There may only be a few restrictions on what you can eat and drink, but it is important to continue to eat healthily. Medications to look after your new kidney may increase your appetite.	There are some things you may need to limit or avoid.

3. My options

	Dialysis	Kidney transplant	Comprehensive conservative care
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 in advance. International travel is not advised within 12 months of your transplant.	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 be costs to set up plumbing for home dialysis. You may be eligible for rebates on electricity and water if you have dialysis at home. Check with your kidney team and/or health insurance provider regarding additional dialysis options and support.	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 likely not as good as 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 your life after the operation to help your body accept the new kidney. Transplant medications can have different side effects, which your healthcare team will discuss with you. Transplant operations can have complications, like any surgery.	You will likely need to take medication, make some changes to your diet, and use other supportive ways to allow you to live as well as possible for as long as possible.

3. My options

	Dialysis	Kidney transplant	Comprehensive conservative care
My body	You have an initial operation on your arm or tummy, that allows your body to have dialysis treatment. Which operation you need will depend on the type of dialysis you choose.	You have a 2–3 hour operation and will stay in hospital for 1–2 weeks. There will be daily blood tests for one month after your operation. If you are from a regional or remote area, you will need to stay near the hospital for up to 3 months.	You have no operations or changes to your body.
My home	If you choose home dialysis, you will have to store equipment and supplies at your home. You may also have to make some modifications to your plumbing. If you choose in-centre treatment, you will not need to have supplies at home. You will need to attend a dialysis centre multiple times per week.	No changes/impact at home.	No changes/impact at home.



3. My options

The difference in dialysis – which is suitable for me?

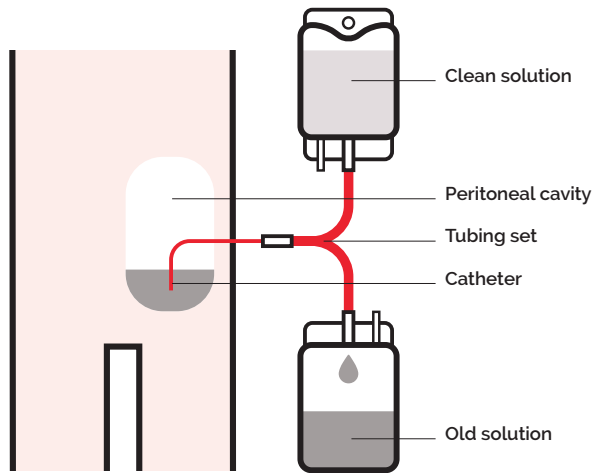
The tables (on Page 15 and 16) summarises different types of dialysis and their effects on various aspects of your life, to help you decide which is best for your situation. However, it's important that you seek further information and education as recommended by your healthcare team. Remember, you may not be suitable for every kind of dialysis or any.



Pictured: Mark

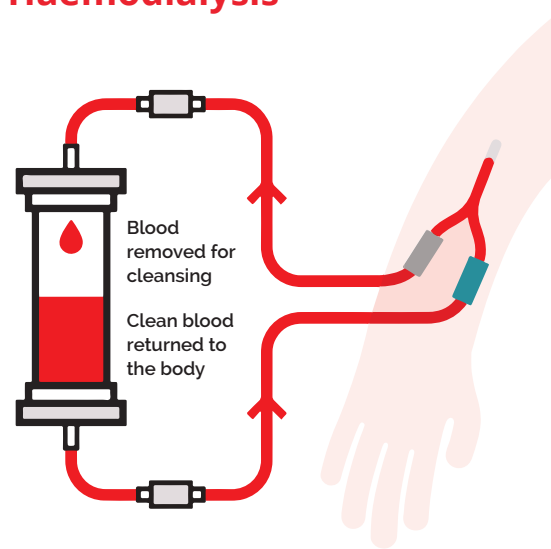
3. My options

Peritoneal Dialysis



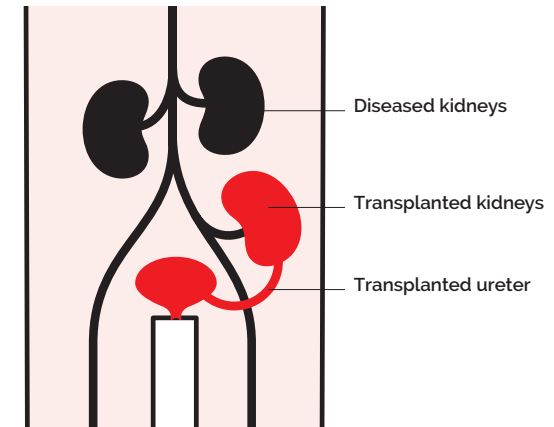
This picture shows how peritoneal dialysis works. The clean solution (dialysis fluid) goes into your tummy via a tube. Once in, it extracts (takes out) wastes and extra water from your blood. The old solution then comes out of your body via the tube and flows into a bag.

Haemodialysis



This picture shows how haemodialysis works. When you have haemodialysis, you are hooked up to a machine that cleans your blood. Your blood is moved from your body through the machine to remove wastes and extra water. The cleaned blood flows back into your body.

Kidney transplant



This picture shows a body with a kidney transplant. Usually, a person's own kidneys are left in the body and the kidney from the donor is added. Sometimes it is necessary to remove the failed kidneys, e.g. if they were very large because of polycystic kidney disease.

If you would like to read more about treatment options visit [kidney.org.au/treatment](https://www.kidney.org.au/treatment) or download resources including the below, at [kidney.org.au/resources](https://www.kidney.org.au/resources):

- An Introduction to Peritoneal Dialysis
- An Introduction to Home Dialysis
- An introduction to Haemodialysis
- An Introduction to Kidney Transplantation
- An Introduction to Kidney Donation by Living Donors.

3. My options

		Summary	My time on dialysis	My training and support	My life and activities	My diet and fluids
Home dialysis	Continuous Ambulatory Peritoneal Dialysis (CAPD)	Dialysis fluid goes in and out of your tummy through a tube. You change the fluid usually four times a day.	Dialysis usually takes 30 minutes, 4 times every day, can be adapted to suit your lifestyle. You change the dialysis fluid that goes in and out of your tummy.	Training will take up to 1–2 weeks, with ongoing and after hours support from the clinic.	Dialysis equipment is portable, and treatment is relatively simple. You can do it in most places.	There may be a few things you should not eat or drink.
	Automated Peritoneal Dialysis (APD)	A machine controls dialysis fluid which goes in and out of your tummy through a tube overnight whilst you sleep.	Dialysis usually happens for 6–10 hours while you are asleep and can be adapted to suit your lifestyle.	Training will take up to 1–2 weeks, with ongoing and after hours support from the clinic.	Dialysis happens while you are asleep. There are fewer changes to your daytime activities.	There may be a few things you should not eat or drink.
	Haemodialysis	Your blood is cleaned by a special filter attached to a machine.	Dialysis usually happens 3–5 times a week and takes 4–6 hours. You can choose your dialysis times to suit your lifestyle, including overnight.	Training will take 6–12 weeks, with ongoing and after hours support from the clinic.	Dialysis can be done at home and can be arranged around your activities.	There may be a few things you should not eat or drink, but the more dialysis you do, the fewer restrictions.
Centre-based dialysis	Haemodialysis	Your blood is cleaned by a special filter attached to a machine.	Dialysis typically takes 4–5 hours, 3 times a week, usually at set appointment times. There will also be travel and waiting time involved at your expense.	You do not need training. Medical staff will control the dialysis at the clinic.	You need to go to the clinic for your treatments. Daytime activities will need to be scheduled around your treatments.	There will be many things you should not eat or drink.

3. My options

		My body	My home	My treatment costs	My travel and holidays
Home dialysis	Continuous Ambulatory Peritoneal Dialysis (CAPD)	You will have an operation to put a small tube in your tummy. This needs to be kept clean.	You will need a suitable space at home to keep and set up your dialysis equipment.	The main dialysis equipment is free and delivered to your home. You may need to pay for some medications and occasional small supplies. Check what your clinic provides.	You can travel, as long as there is the possibility to arrange supplies. Overseas travel is often possible.
	Automated Peritoneal Dialysis (APD)	You may feel some fullness in your tummy, and some people gain a little weight.	You will need a suitable space at home to keep and set up your dialysis equipment.	Electricity rebates are available for the APD machine.	You can travel, as long as there is the possibility to arrange supplies and the machine. Overseas travel may be possible.
	Haemodialysis	You will have an operation on your arm to form a fistula for the dialysis needles that connect to the machine. Some people need a tube in their neck or chest instead of a fistula.	You will need a suitable space at home to keep and set up your dialysis equipment. Electrical and plumbing work will be necessary for your dialysis machine.	Water and electricity rebates are available for the Home Haemodialysis machine.	You may be able to travel, but it must be planned in advance, and it depends on availability of a dialysis centre close to your destination. Overseas travel is possible but can be very expensive and there may be issues with infection control.
Centre-based dialysis	Haemodialysis		No equipment is stored at your home.	There may not be availability at your preferred location. You may need to pay for travel to the clinic, accommodation, and some medications. Check what your clinic provides. Country patients should get travel assistance.	You may be able to travel, but it must be planned in advance, and it depends on availability of a dialysis centre close to your destination. Overseas travel is possible but can be very expensive.

4.

My choice

By the time you reach this section, you should have some understanding of the treatment options for kidney failure, including that of comprehensive conservative care, and how you feel about each one. If you feel you still need support to understand your options, please ask your healthcare team for more information. Use the section below to write down your thoughts on the different treatment options available for you. Remember, your feelings and preferences may change over time.

My thoughts:

Am I considering a transplant?

YES

NO

Am I considering dialysis?

YES

NO

Am I considering comprehensive conservative care?

YES

NO

	My thoughts	Pros	Cons
Continuous ambulatory peritoneal dialysis (CAPD)			
Automated peritoneal dialysis (APD)			
Home haemodialysis			
Centre-based dialysis			
Comprehensive conservative care			

4. My choice



Am I ready to make a choice?

- Do I understand all the options available to me?
- Have I spoken to my healthcare team for their input?
- Have I spoken to my family and friends for their input?
- Do I still have questions to help me make a choice?
*(jot them down in the **My questions** section below)*

If you have a preferred option for a treatment available to you, write it below. Remember, you can change your mind!

Date	My preferred option	Reason

5.

My questions

Write down any questions you may still have that you want to discuss with your healthcare team.

1.
2.
3.
4.
5.

Example questions:

Here some questions that people often ask their healthcare team:

1. *How will the treatment make me feel?*
2. *How long will I need treatment for?*
3. *Can I change my treatment?*
4. *Can I continue working?*
5. *When do I need to start treatment?*

What happens next?

Now that you've considered your treatment options and recorded your thoughts on each one, take along this resource and your notes the next time you visit your healthcare team. You will likely spend a significant part of the meeting discussing which choice of treatment is best for you. This resource will help ensure that you have received detailed information about the different kidney failure treatment options.



Pictured: Hayley

Notes

A series of horizontal dotted lines for writing notes.

What does that word mean?

Catheter – A plastic tube that is used to take fluid in or out of your body.
(See *Vascular access catheter*)

Dialysate / Dialysis Fluid – Special fluid that is used during dialysis to help clean the waste and excess fluid from your blood.

Dialysis machine – A machine used in dialysis that filters your blood to remove excess water and waste products when your kidneys are damaged, dysfunctional, or missing.

Donor – A person who gives a body organ, such as a kidney to another person.

Fistula – Produced when a vein and an artery in your arm or leg are joined together in an operation to make it easier to move blood in and out of your body during haemodialysis.

Kidney failure – The stage of kidney disease when your kidneys have stopped working, so treatment such as dialysis or a transplant is needed to sustain life. Previously referred to as end stage kidney disease (ESKD); end stage kidney/renal failure (ESKF or ESRF), or stage 5 CKD.

Kidneys – Most people have two kidneys, each about the size of an adult fist and weighing 150 grams. Inside each kidney there are about one million tiny units called nephrons. The nephrons are the part of the kidney that filters 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. Most of the water returns to the blood and the waste products collect in the bladder then leave the body as urine (wee). Most kidney diseases attack the nephrons.

Kidney transplant – A treatment for kidney failure where a kidney is removed from the body of one person (the donor) and put into the body of the person with kidney failure.

Living kidney donation – Where a living person donates one of their kidneys to be transplanted to another person, usually a family member or close friend.

Polycystic kidney disease (PKD) – An inherited kidney disease where many fluid filled sacs (cysts) grow on the kidneys.

Pre-emptive transplant – When someone receives a kidney transplant before beginning dialysis.

Urine – The name for excess fluid and waste products that are removed from the body by the kidneys. Commonly called wee.

Vascular access – Access to the blood stream for haemodialysis.

Vascular access catheter – A special tube, which is surgically inserted into your neck, collarbone or top of your leg to allow access for haemodialysis. Also called a central venous catheter.

Vein – A blood vessel that returns blood to your heart.

Where to go for more information and support



At Kidney Health Australia, we're passionate about Healthy Kidneys for all Australians. As the recognised voice for chronic kidney disease in Australia, we're driving awareness and earlier detection of chronic kidney disease and championing best practice care to slow disease progression and improve health outcomes.

We support people living with chronic kidney disease, their healthcare teams, and the research community to achieve better outcomes. Through advocacy, programs, and partnerships we're changing the paradigm from kidney failure to kidney preservation.

Pictured: Amanda

Our support services:

- Educational resources on kidney health and kidney disease, covering diagnosis, treatment options and management: [kidney.org.au/resources](https://www.kidney.org.au/resources)
- Evidence-based fact sheets, books, and educational videos about kidney disease.
- A large range of self-management resources including recipe books and nutrition resources.
- Renal unit locations: [kidney.org.au/ways-we-help/find-a-dialysis-unit](https://www.kidney.org.au/ways-we-help/find-a-dialysis-unit)
- Big Red Kidney Buses in VIC, NSW and QLD for free holiday dialysis sessions: [kidney.org.au/bus](https://www.kidney.org.au/bus)
- Peer-to-peer support groups like the Kidney Buddies program and private Facebook group, KidneySpeak.
- Monthly eNews: register at [kidney.org.au/subscribe](https://www.kidney.org.au/subscribe)
- Free Kidney Helpline: **1800 454 363**



Connect with us

Freecall 1800 454 363

kidney.org.au

@kidneyhealth



Thank you to our community of kidney heroes for sharing their photos with us, contributing to this important resource.



If you have a hearing or speech impairment, contact the National Relay Service on **1800 555 677** or relayservice.com.au
For all types of services ask for **1800 454 363**