

# An Introduction to Kidney Disease Treatment Options



*Prevent, Detect, Support.*

**Acknowledgements:**

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Royal North  
Shore Hospital



An Introduction to Kidney Disease  
Treatment Options  
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**Disclaimer**

Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or other health professional's advice. All care is taken to ensure that the information contained in this booklet is accurate at the time of publication.

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# Foreword



***An Introduction to Kidney Disease Treatment Options* is designed to provide you with information about the different types of treatment for kidney disease.**

Topics that are covered in this booklet include transplantation, haemodialysis, peritoneal dialysis and supportive care.

If you are reading this for the first time, it may be that you have just received news that you need to consider kidney disease treatment options, or you may be supporting a loved one in this situation.

Kidney Health Australia is here to support you throughout your journey and our fully qualified team of nurses and allied health professionals are only a phone call away should you wish to speak to someone confidentially.

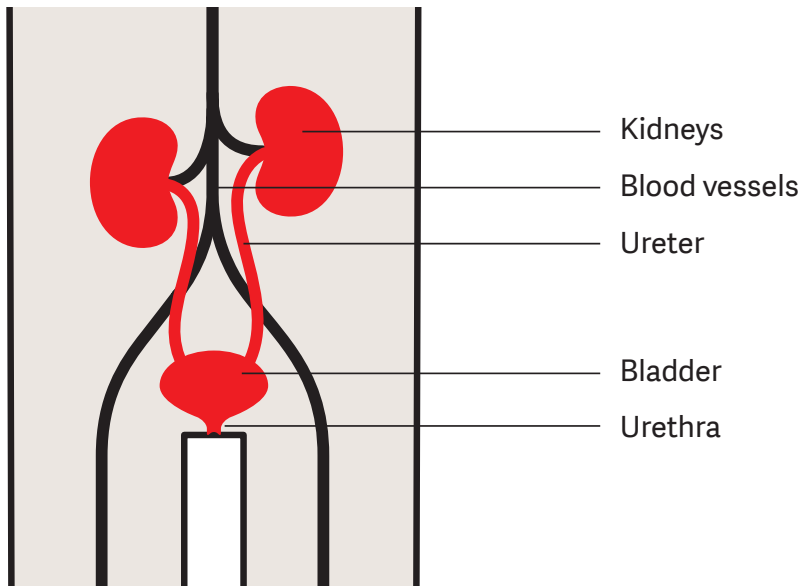
Welcome to Australia's kidney community; please keep in touch so that we may be able to provide you with whatever support and assistance you require.

**Mikaela Stafrace**  
CEO  
Kidney Health Australia

# What are kidneys?

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

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

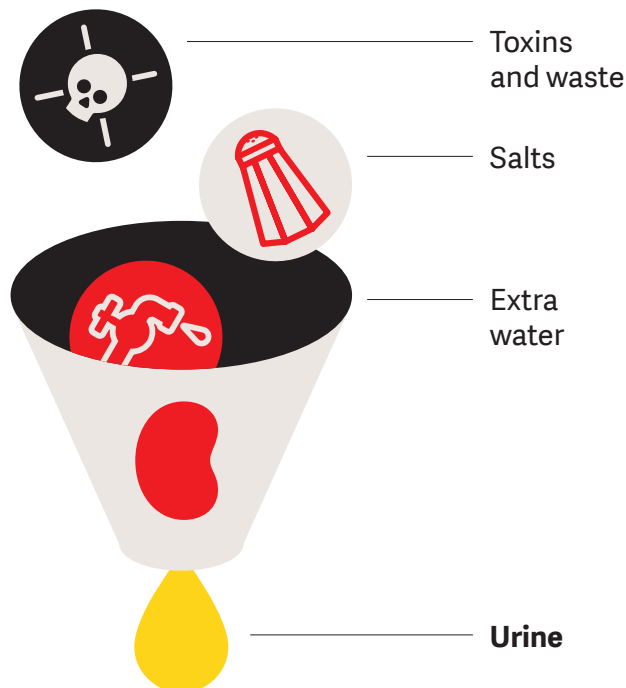


## What do healthy kidneys do?

Kidneys are the unsung heroes of the body.

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

- Extracting excess fluid to make urine (wee)
- Controlling blood pressure
- Filtering waste products from the blood
- Controlling body fluids
- Stimulating the production of red blood cells
- Controlling potassium, calcium and phosphorus levels
- Regulating vitamin D



## What happens when the kidneys don't work properly?

Sometimes kidney function can change 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, illness or infection. A sudden change in kidney function is called **acute kidney injury**. This is often temporary but can occasionally lead to lasting kidney damage.

More often kidney function worsens over a number of years – it is a chronic, or ongoing, condition. **Chronic kidney disease** (also referred to as CKD) is called a *silent disease* as there are often no warning signs. Sometimes people lose up to 90 per cent of their kidney function before getting any symptoms.

## Symptoms you may experience

- Retention of fluid causing breathlessness and swelling
- Tiredness
- Headaches
- Poor memory and concentration
- Irritability
- Sleep disturbances
- Feeling washed out
- Itchiness
- Nausea and loss of appetite
- Weight loss
- Altered sexual function

## Treatment options

When you have end stage kidney disease your body cannot get rid of extra water and waste products. If this becomes dangerous to your health you will need to make some decisions about the kind of kidney disease treatment that you want. This could include dialysis, preparing for a kidney transplant, or choosing supportive care. Your kidney function will need to be replaced by either a kidney transplant or dialysis.

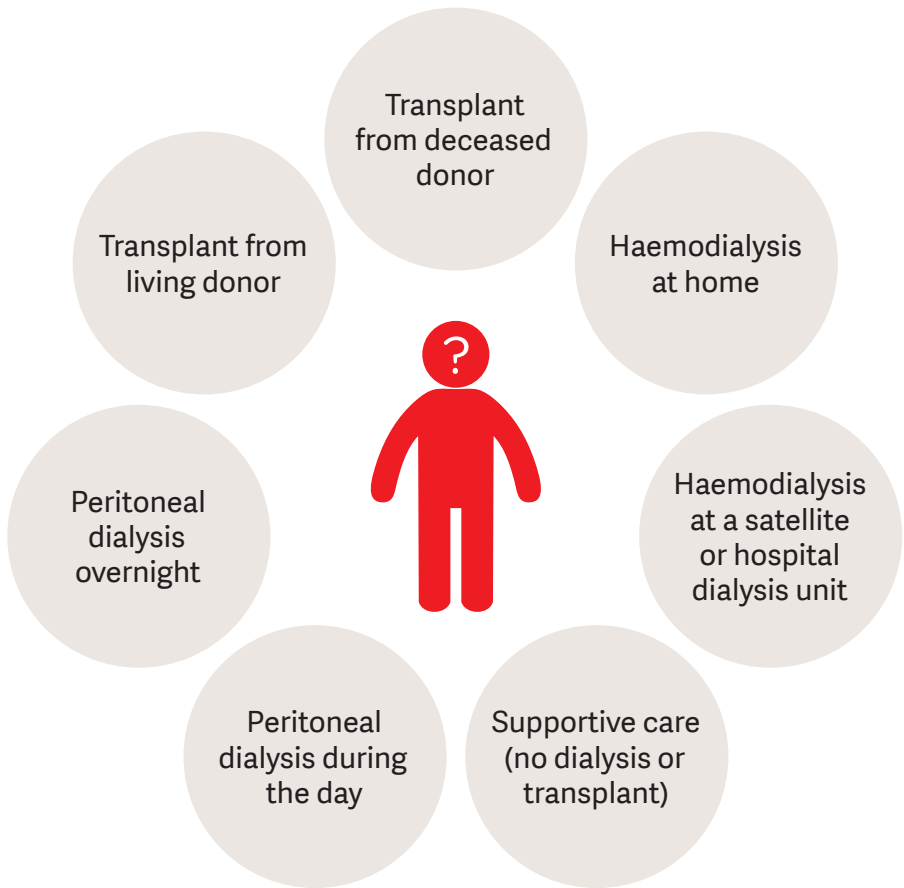
Dialysis has a number of options, which include home dialysis (either peritoneal dialysis or home haemodialysis) and centre-based haemodialysis (in a satellite dialysis unit or a hospital dialysis unit).

A kidney transplant involves the transplantation of one kidney into your body from either a living or deceased donor. If you are suitable for a kidney transplant, this is the most effective treatment for kidney failure. Compared with other kidney failure treatment options, transplantation could increase your life expectancy and improve your quality of life.

Some people choose not to have dialysis or a transplant and instead choose supportive care. With this option, medications and diet are used to manage the symptoms of end stage kidney disease.

It is also important to know that many people start on one treatment type and then transfer to another for many different reasons.









Depending on your health some or all of these treatment options will be available to you. Your doctor and clinical nurse specialists can advise you about the 'medical' advantages or disadvantages and availability of each treatment option.

It is important to remember that it is your decision to make and your health care team will help to provide you with as much information as possible to make the decision.



#### RESOURCES

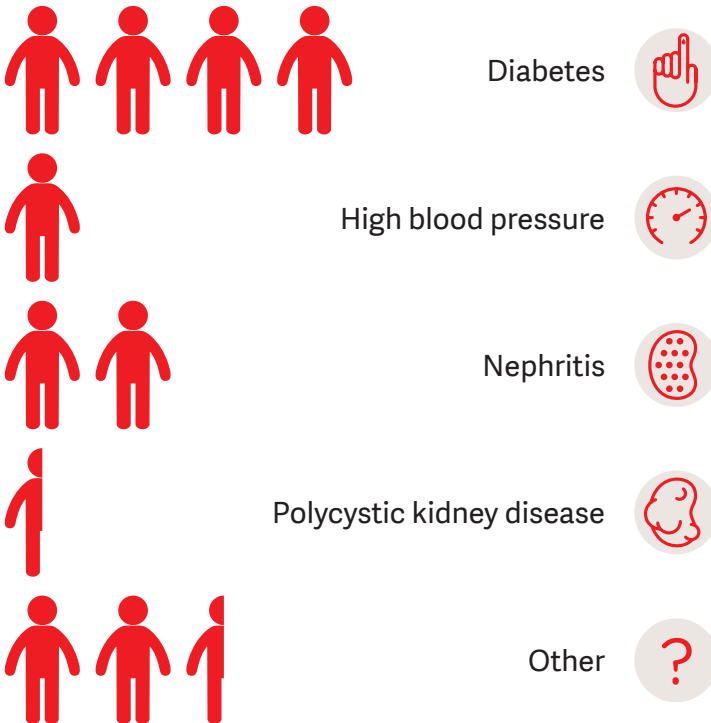
-  Kidney Health fact sheets (translated versions available)
-  Kidney Health Australia booklets: An Introduction to Haemodialysis, An Introduction to Peritoneal Dialysis; An Introduction to Home Dialysis, An Introduction to Supportive Care of Advanced Kidney Disease  
Kidney Health Australia book: Living with Kidney Failure
-  [www.kidney.org.au/your-kidneys/support](http://www.kidney.org.au/your-kidneys/support)  
[www.kidney.org.au/your-kidneys/support/  
kidney-disease/treatment/choosing-your-treatment](http://www.kidney.org.au/your-kidneys/support/kidney-disease/treatment/choosing-your-treatment)
-  Kidney Health Information Service (KHIS) **1800 454 363**

## You are not alone

In Australia:

- Over 2,000 people start dialysis or receive a transplant every year
- There are currently 21,000 people in Australia on dialysis or living with a transplant

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



# Peritoneal dialysis (PD)

## How peritoneal dialysis works

Peritoneal dialysis (PD) is the oldest form of dialysis, and was first used in 1923. In Australia approximately 20 per cent of all people on dialysis use PD.

PD works inside the body using your natural **peritoneal membrane** which allows impurities to be drawn out of the blood. The peritoneal membrane lines your abdominal (peritoneal) cavity, and covers organs such as your stomach, liver, spleen and intestines. The peritoneal membrane (also called the peritoneum) is **semi-permeable**. This means that it naturally allows some substances to pass through, but not others.

For PD to work there has to be permanent access to the peritoneal cavity. This is achieved by a soft tube (called a peritoneal catheter) which extends through a small incision in the tummy into the peritoneal cavity. The insertion of the peritoneal catheter requires a short hospital admission. The catheter provides a pathway through which dialysis solution (dialysate) can be placed into the peritoneal cavity. Dialysate is a liquid that usually contains glucose (a type of sugar) but also contains substances that are similar to those in your blood.

Once the dialysate is inside the peritoneal cavity, the cavity acts as a reservoir holding the dialysis solution. Your body's waste products pass from your bloodstream across the peritoneal membrane and into the dialysate. After a set number of hours, the used dialysate, with the impurities from your blood, is drained from the peritoneal cavity and replaced with fresh solution and the process commences again. every day at home either during the day using manual bags or at night using a machine.

### **The basic PD cycle (exchange)**

The PD cycle once established is: drain, fill, dwell. Each time this cycle is repeated, it is called 'an exchange'.

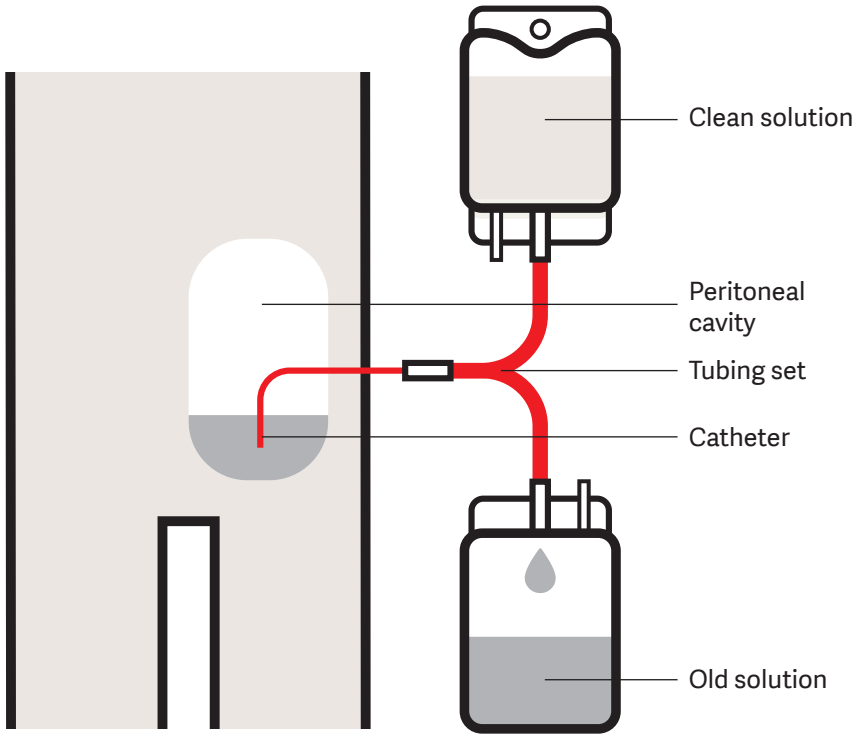
**Drain:** First you connect your tube to the PD set and drain out the old dialysate which has been in the peritoneal cavity for the prescribed length of time (often 4-8 hours).

**Fill:** Your peritoneal cavity is filled with the new dialysate. Once your peritoneal cavity is full you will disconnect from the tubing and bags.

**Dwell:** The dialysate remains in your cavity for a period of time. Waste and extra fluids are drawn out of the blood vessels and through your peritoneal membrane into the dialysate during this time.

At the start of each exchange, you will carefully connect your catheter with a tubing set that includes a bag of new dialysate and a drain bag. The connecting tubing set, and bags for the new and old solution (dialysate) are only connected when the dialysate is being changed. In between these exchanges, the catheter and a small 'extension' tube at the end of it are the only visible parts and are taped gently against your tummy.

This is the basic PD cycle. Later in this booklet you will read about two different types of PD. One type involves doing four cycles like this during the day. The other type of PD uses a machine to do the cycles for you while you sleep.

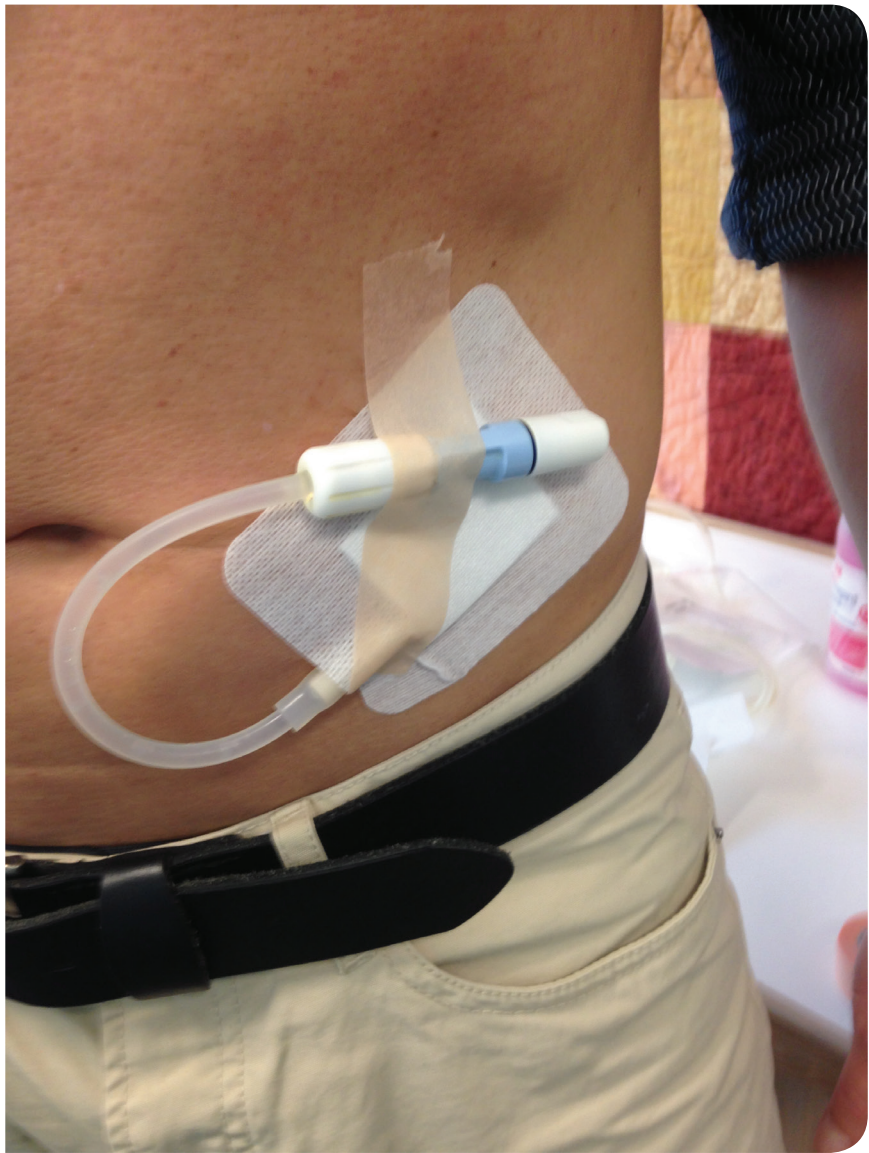


### **How peritoneal dialysis affects your body**

During PD the average adult comfortably holds 2-3 litres of dialysis solution in their peritoneal cavity. Although this seems to be a large amount of fluid to hold in your abdomen, little or no discomfort should be experienced. The fluid moves between the two layers of the peritoneum, which results in only a minor increase in the width of your waist. You may initially be aware of the extra fluid, but this feeling will decrease over time. In children the volumes are much smaller and tailored to the size of the child.

The peritoneal catheter is your access for dialysis. It is permanent and is about 30cm long. The point at which the peritoneal catheter leaves your abdomen is called the **exit site**. It is important that the exit site is kept clean to prevent infection. You will be shown how to check and clean your exit site every day. The catheter will be securely taped to keep it in position and prevent it from moving around.





*Peritoneal catheter supported with tape*

## Different types of peritoneal dialysis

There are two different ways of doing PD, which suit different lifestyles.

### **Continuous Ambulatory Peritoneal Dialysis (CAPD)**

With CAPD you always have dialysate in your body so your blood is constantly being cleaned. Usually four exchanges are done each day. Each exchange takes about 30-45 minutes and can be done almost anywhere, with a few sensible precautions. In between exchanges you are free to go about your daily activities. Overnight you have a long dwell while you sleep. Exchanges are typically done on waking, at lunch time, at dinner-time and prior to going to bed. Some flexibility is available for busy days.

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



*PD bag exchange*

### **Automated Peritoneal Dialysis (APD)**

During APD a machine called a cycler automatically does the exchanges for you. Each night your catheter is attached to the tubing of the cycler. It does several exchanges, moving the clean and used dialysate in and out of your body while you are asleep. APD is done every night and usually takes between 8–10 hours. You are connected to the machine during this entire process. During the day some dialysate is usually left in your body so that dialysis continues. In the evening the dialysate is drained out automatically by the cycler.



*Connecting to the APD machine*

## How will peritoneal dialysis affect my lifestyle?

Levels of activity and lifestyle choices vary across stages of life and from person to person. What is important to you may be less important to other people. You may work, be retired, travel, play sport or have a family to care for.

### **Diet and fluid**

As PD provides continual dialysis most people do not need to change their diet and fluid intake to keep their blood chemistry normal. You will be advised of any changes to your diet that are needed based on your blood results, your well-being and how well you are balancing your fluid levels in your body.

## **Employment**

Your work routine (days that you work and hours that you work) may play a large part in your decision about which form of dialysis will suit you best. People using PD can usually schedule their dialysis exchanges around work commitments or use APD and do the exchanges at night. Depending on your work place and the type of work that you do, it may also be possible to do the PD exchanges during the day at work.

## **Finances**

If your ability to work changes, this may impact on your income and your household finances. See the *Patient & carer support* page at [kidney.org.au](http://kidney.org.au) for more information.

When you have PD at home there is no charge for your PD machine and supplies. These are delivered to your home once a month. Some people choose to buy special storage items to help organise their supplies, and you may notice that you use extra hand soap and paper towels.

Some prescription medications may also be needed for your PD. Some dialysis units assist with the cost of buying digital scales (to weigh yourself), a blood pressure machine and any other equipment or resources you may need. This does vary, so please check with your dialysis unit.

## Sport and exercise

Continuing sport and exercise is encouraged for everyone on PD. With PD you are more likely to have the flexibility to fit your dialysis routine around your exercise. If you play a contact sport, it is important to make sure your peritoneal catheter is protected. If you swim, you need to pay careful attention to the advice of your **healthcare team** about water quality and safety.





## Travel and holidays

With careful planning you can travel and go on holidays while on PD. It may involve making arrangements to have supplies sent to your destination. You will need to organise this before your trip, and you may have to pay some costs.

More detailed information on peritoneal dialysis is available in the booklet 'An Introduction to Peritoneal Dialysis' and other resources shown below.



### RESOURCES

-  Kidney Health Australia fact sheets:  
Peritoneal Dialysis – A Treatment Option
-  Kidney Health Australia booklets:  
An Introduction to Peritoneal Dialysis
-  **Kidney Health Australia book: Living with Kidney Failure**  
**[www.kidney.org.au/your-kidneys/support/dialysis/peritoneal-dialysis-home](http://www.kidney.org.au/your-kidneys/support/dialysis/peritoneal-dialysis-home)**
-  Kidney Health Information Service (KHIS) **1800 454 363**

# Haemodialysis

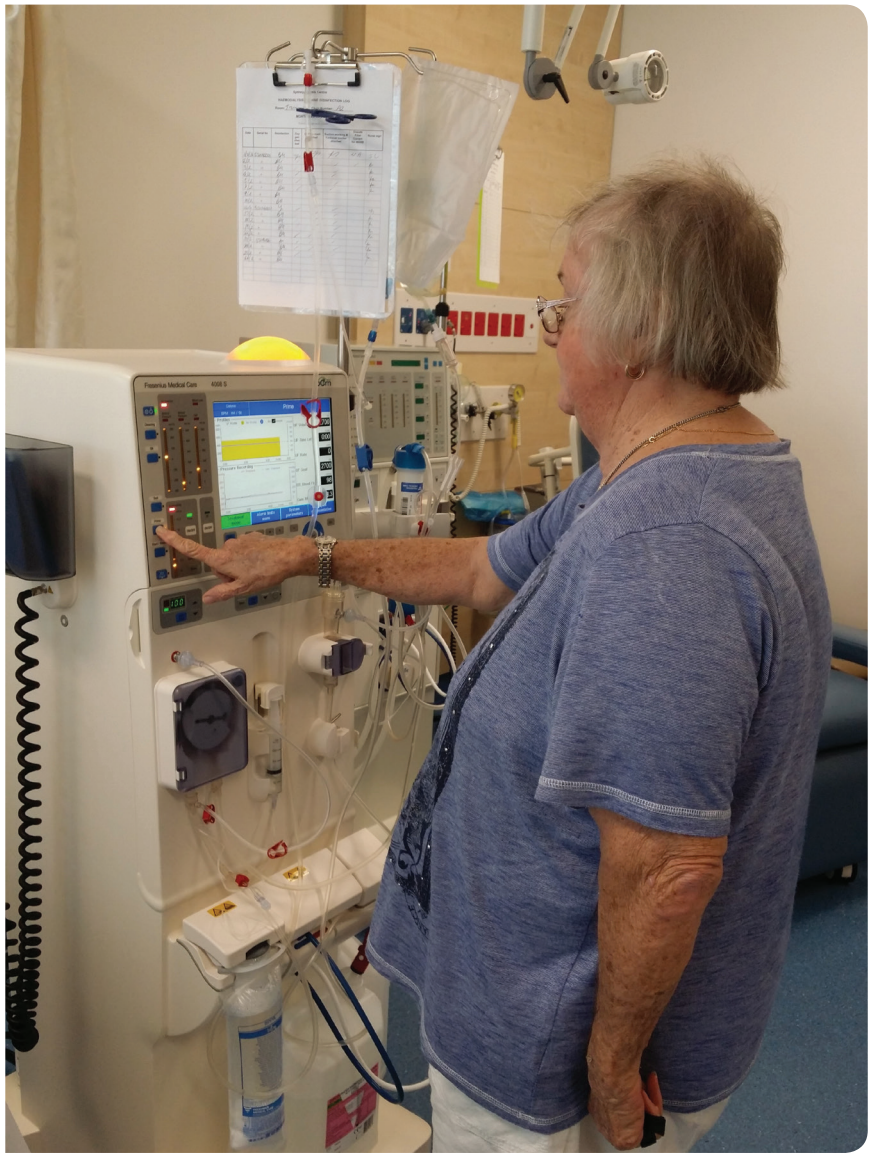
## How haemodialysis works

All haemodialysis requires **vascular access**, a dialysis machine, and a dialyser. Your blood flows from your vascular access and is pumped through lines before and after the dialyser on the dialysis machine, and the clean blood is returned to your body.

### **The dialysis machine**

The dialysis machine is the engine that runs and controls your dialysis. The dialysis machine is prepared with lines, **dialysate** and a dialyser. It also has safety features to detect air and blood clots.

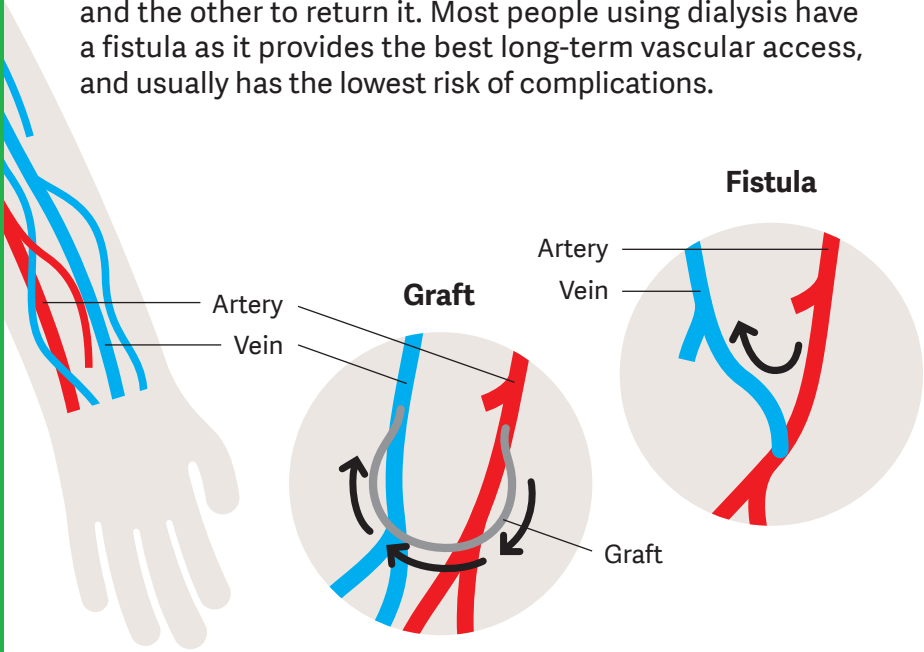




*Operating a dialysis machine*

### Vascular access with a fistula

A **fistula** is the name for joining an artery to a vein. This is usually surgically created at the wrist area of your non-dominant forearm (the arm you don't write with). With a fistula, blood flows quickly from the artery and makes the vein wider. This provides the good blood flow in your arm, which is needed for dialysis to work. The fistula is where you put in the needles for the dialysis. Two needles are required, one to remove the blood and the other to return it. Most people using dialysis have a fistula as it provides the best long-term vascular access, and usually has the lowest risk of complications.



### Vascular access with a graft

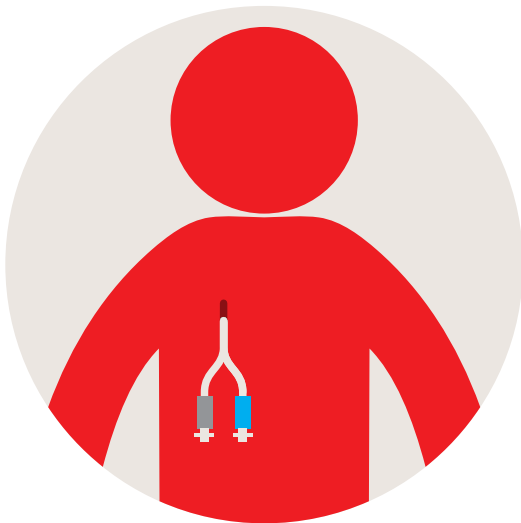
If your veins are too small or delicate for a fistula to work then vascular access with a **graft** may be needed. This is an artificial tube which is placed in an arm or leg, one end is attached to an artery and the other end is attached to a vein. The needles for dialysis are put into the graft.

### **Vascular access with a central venous catheter**

Sometimes it is not possible to create a fistula or a graft. In these cases vascular access is with a **central venous catheter**. This is also known as a dialysis catheter. A central venous catheter is a soft plastic tube that is placed into a large vein in the chest. This then splits in half to take the two needles for the dialysis.

Unlike a fistula, a central venous catheter can be used straight away. Some people may have a temporary central venous catheter while they are waiting for their fistula to be ready.

Central venous catheters can work well, but they do have an increased risk of infection if not managed carefully. They also have a higher incidence of getting blocked, and are usually not suitable for long term use.



## The Dialysis Routine

The time spent on haemodialysis varies. On average the treatment will be three times a week for four to five hours, every week of the year. You will also need to allow time for preparing and completing the treatment.

Routines in a dialysis unit do not change. The staff at the dialysis unit will help you to find a routine that fits in with your lifestyle, but there can be limitations to appointment times.

An advantage of doing haemodialysis at home is that you can change your dialysis routine to suit you.

For example:

- increase to alternate days (every second day), or even four, five, six or seven times per week
- increase or decrease the hours of each dialysis session as long as the target number of dialysis hours is reached each week
- do the dialysis overnight (can be up to eight hours)
- do the dialysis on a public holiday when dialysis units are closed

The advantages of additional hours of dialysis are discussed later in this booklet. They include more energy, better blood test results, a longer life-span and less diet and fluid restrictions.

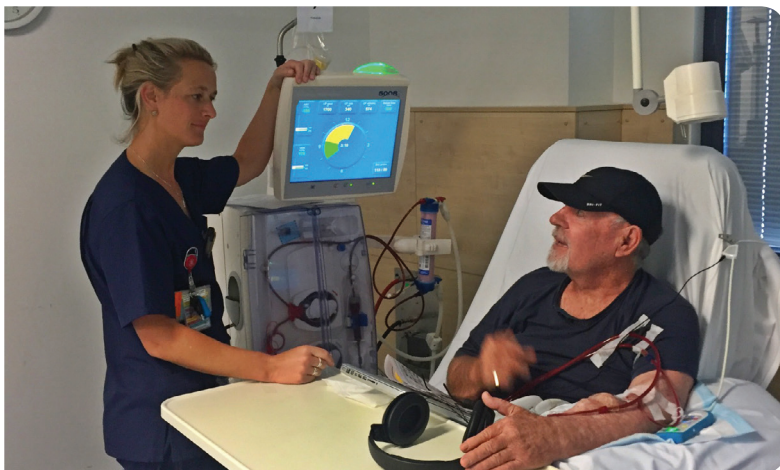
How many hours of haemodialysis you have each week should be a shared decision between yourself and your health care team based on your blood results and general well-being.

## What are the differences between home haemodialysis or unit based haemodialysis?

Haemodialysis can be performed at home or at a centre. Centre-based dialysis can occur in either a satellite dialysis unit or a hospital dialysis unit.

- **Home** – you are trained by nurses to manage your dialysis in your own home
- **Satellite dialysis unit** – these units are located in the community, and you can manage your dialysis yourself or with the help of nurses
- **Hospital dialysis unit** – these units are located at a hospital. They are staffed by nurses and are usually for people who require extra medical support

Your health care team will advise you of the available treatment options for you, and will help you choose the best dialysis that fits with your lifestyle and wishes.



*Unit-based haemodialysis*

## **There are many benefits to having your haemodialysis at home:**

- Less time spent in hospital
- Less time spent travelling to and from hospital
- More frequent haemodialysis means you will feel better
- Flexibility to fit haemodialysis around your work and family commitments
- Flexibility to fit haemodialysis around your lifestyle

Many people comment that doing haemodialysis at home gave them back their life.

## **Some things that people like about having haemodialysis at a satellite or hospital dialysis centre are:**

- The haemodialysis is supported by a nurse but many units encourage you to help with your own dialysis
- You will often meet the same people when you go in for haemodialysis and you can share experiences
- Home and haemodialysis are kept separate

## How will haemodialysis affect my lifestyle?

Levels of activity and lifestyle choices vary across stages of life and from person to person. What is important to you may be less important to other people. You may work, be retired, travel, play sport or have a family to care for.

### **Diet and fluid**

Usually kidneys get rid of many wastes and extra minerals from food that your body does not need. When you are on dialysis the treatment does this, but cannot always remove enough wastes. However everyone is different when it comes to diet restrictions and haemodialysis. People who have longer or more frequent haemodialysis, such as every second day or overnight, are less likely to have to make changes to their diet and fluid.

When you are on haemodialysis, knowing what you can eat can be a challenge. Most people need help from an **Accredited Practising Dietitian** experienced in kidney disease (often called a **Renal Dietitian**) to set up a personalised meal plan. Nurses at the dialysis units can refer you to a dietitian.

When you are on haemodialysis, fluid is removed during the dialysis process. For some people they still pass urine and get rid of fluid that way, but many do not. Therefore most people on haemodialysis need to limit the amount of fluid they have each day. Fluids are liquids that you drink, and any foods that are liquid at room temperature. This includes ice cream, yoghurt and ice cubes. Fluid is also contained in foods like cooked pasta and rice, salad ingredients, soup and watermelon.

If you do frequent haemodialysis at home you should have better fluid control and improved freedom with what you can eat and drink. An accredited practising dietitian or your nursing team can help you to sort out the fluids that you can have each day.

### **Employment**

Haemodialysis takes up many hours each week. You can work with all types of haemodialysis but you may need to adjust your working hours, particularly when you first start dialysis and your body is adjusting. Your work routine (days that you work and hours that you work) may also play a large part in your decision about which form of dialysis will suit you best.

### **Finances**

If your ability to work changes, this may impact on your income and your household finances. See the Patient & Carer support page at [kidney.org.au](http://kidney.org.au) for more information.



## **Sport and exercise**

Continuing sport and exercise is encouraged for everyone on haemodialysis. With home haemodialysis you are more likely to have the flexibility to fit your dialysis routine around your exercise. If you play a contact sport, it is important to make sure your fistula is protected. If you swim, you need to pay careful attention to the advice of your health care team about water quality and safety.

You can also exercise during your haemodialysis sessions. The options include:

- Cycling on a portable pedal machine
- Zumba on dialysis
- Resistance exercises with a stretch band

Talk to your health care team to see which options for exercise on dialysis are available for you.





## Travel and holidays

With careful planning you can travel and go on holidays while on haemodialysis. It may involve making an appointment to have your haemodialysis at another facility. You will need to organise this before your trip, and you may have to pay some costs.

More detailed information on haemodialysis is available in the booklets '*An Introduction to Haemodialysis*', '*An Introduction to Home Dialysis*' and other resources shown below.



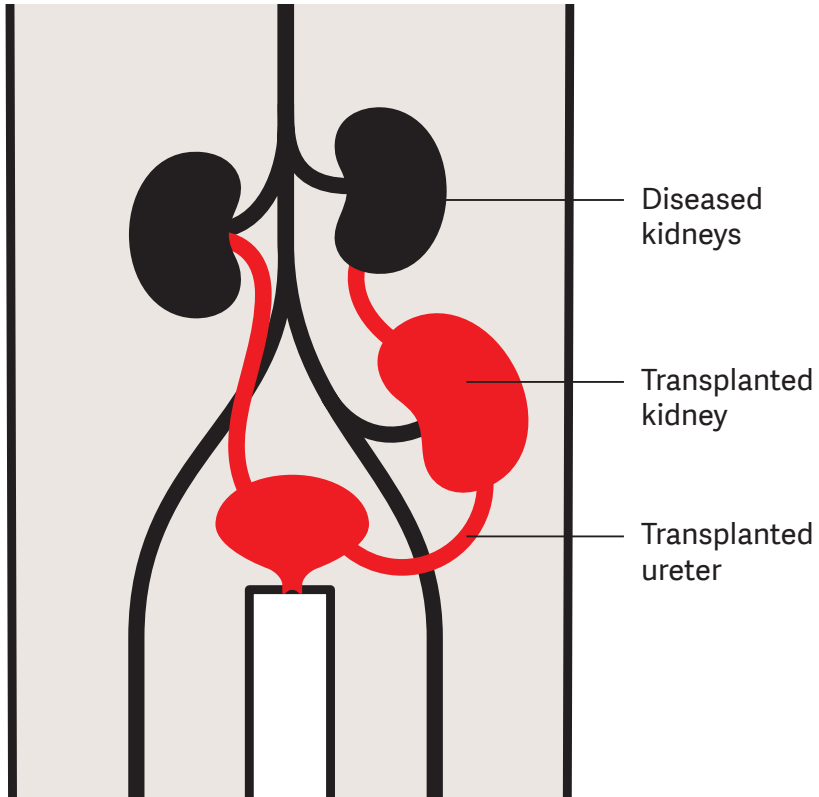
### RESOURCES

-  Kidney Health Australia fact sheets:  
Haemodialysis–A Treatment Option  
Home Haemodialysis–A Treatment Option
-  Kidney Health Australia booklets: An Introduction to Haemodialysis; An Introduction to Home Dialysis  
Kidney Health Australia book: Living with Kidney Failure
-  [www.kidney.org.au/your-kidneys/support/dialysis](http://www.kidney.org.au/your-kidneys/support/dialysis)
-  Kidney Health Information Service (KHIS) **1800 454 363**



# Transplantation

A kidney transplant is treatment for kidney failure but it is not a cure. A transplant offers a more active life, without needing dialysis. However, the new kidney requires ongoing care. You will need to take medications to stop your body rejecting the kidney (anti-rejection) for as long as you have the transplanted kidney.



*Kidney transplant anatomy*

### **Are kidney transplants successful?**

Kidney transplants are very successful. On average, 95 per cent of transplants are working one year later. In Australia, around four in every ten kidney transplants are still working 15 years later. Some people have had kidney transplants that have lasted more than 30 years.

If the transplant works well for the first year, the chances are good that it will function very well for many years. Success rates are higher with living donor kidneys than for deceased donor kidneys.

How long your transplanted kidney will work can depend on many factors. If a kidney transplant stops working, dialysis treatment will be necessary again. Another transplant may also be possible at a later time.

### **Who can have a kidney transplant?**

Kidneys can be donated by living donors or deceased donors. Having a transplant from a living kidney donor means you will have better outcomes. If you have a transplant from a living donor it usually means you will not have to wait as long for your transplant.

You can be given the option of transplantation if you are considered to be medically suitable by the kidney transplant team. Unfortunately a transplant is not suitable for everyone, as the risks are sometimes too high. The transplant team may decide that the risks of the operation or the medications may make your health worse.

However, it is everyone's right to be considered for a transplant.

You will need to speak with your **nephrologist** for further information about your circumstances if you are regarded as not being suitable for a kidney transplant.

Factors affecting your suitability for a kidney transplant include:

- Agreement with the idea of transplantation and acceptance of the risks involved
- Your general health, apart from kidney failure
- Willingness to go through with the tests and the transplant surgery
- Willingness to take the anti-rejection medications

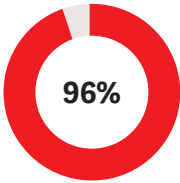
Most metropolitan cities have a hospital that performs kidney transplants. If you live in a regional or rural area of Australia, or in a city that does not have a transplant hospital, you will need to travel to the closest transplant hospital for your evaluation and tests, and for the transplant procedure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

### Are kidney transplants successful?

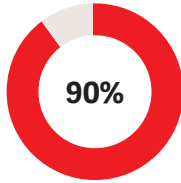
Kidney transplants are very successful. On average, 95 per cent of transplants are working one year later. If the transplant works well for the first year, the chances are good that it will function very well for many years.

Success rates are higher with living donor kidneys than for deceased donor kidneys.

### Percentage of people alive after five years who received a kidney from a:



Living donor

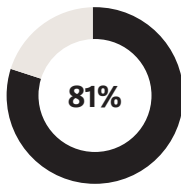


Deceased donor

### Percentage of transplanted kidneys working after five years from a:



Living donor



Deceased donor



## Kidney donors

Kidneys for transplantation come from either living donors or deceased donors.

**For every 10 kidney transplants performed in Australia:**



**three**

involve kidneys from  
living kidney donors

**seven**

involve kidneys from  
deceased kidney donors

The surgery and pre-surgical care for you will be the same whether your transplanted kidney is from a living or deceased donor. It is recommended that you discuss your situation with your health care team, to make sure you understand your options.

## How will transplantation affect my lifestyle?

### **Diet & fluid**

You should follow a healthy diet when you have a kidney transplant. There are no actual restrictions and usually you are encouraged to drink plenty of fluids. An accredited dietitian can advise if there are any restrictions you should make, or help with controlling your body weight, if this is difficult for you.

### **Employment**

You will need to allow time off work for your surgery (usually about 6 weeks). You will also need to schedule time for medical appointments and tests before your surgery. These will reduce considerably around 3 months after your surgery.

### **Finances**

The transplant surgery is done as part of the usual health care system in Australia. The medications you need are available on the usual PBS system. If you have a living donor from overseas you may need to check if they will incur any costs.

### **Sport and exercise**

Gentle exercise is recommended during your recovery from surgery. Once you have recovered from surgery, check with your doctor if you can resume active sport. You should avoid any contact sport that can damage the transplant kidney.





## Travel and holidays

You can travel with some sensible precautions to ensure you always have access to your special medications. Travel insurance may be difficult to secure. See fact sheet on travel and transplant.

More detailed information on kidney transplantation is available in the booklet 'An Introduction to Kidney Transplantation' and other resources shown below.



### RESOURCES

-  Kidney Health Australia fact sheets: Haemodialysis–A Treatment Option (translated versions available)
-  Kidney Health Australia booklets:  
An Introduction to Kidney Transplantation  
Kidney Health Australia book: Living with Kidney Failure
-  [www.kidney.org.au/your-kidneys/support/kidney-transplant](http://www.kidney.org.au/your-kidneys/support/kidney-transplant)
-  Kidney Health Information Service (KHIS) **1800 454 363**

# Supportive care

**Supportive care** (also called non-dialysis supportive care or conservative care) is the treatment choice for kidney failure if you have decided that dialysis and transplant are not right for you. This might be because you are already very frail and do not want complex treatments. You may have tried the other treatments for a while and now want to stop.

With supportive care you will still be supervised and supported by health professionals. You may have medications and a special diet to improve your quality of life.

Choosing supportive care means that you accept that your loss of kidney function will progress and there is a high chance that this will lead to your death. However, if you are frail and in poor health with other medical conditions as well as kidney disease, choosing dialysis may not lead to any longer survival.

### **How supportive care works**

Your general practitioner (GP), a kidney specialist (nephrologist), specialist nurses, a social worker, a dietitian, and a **palliative care** team are some of the health professionals who may be involved in your supportive care. These health professionals will all support you with pain and symptom management.

Kidney failure symptoms can include itchy skin, restless legs, and general pain. Your supportive care team will help you to live independently and in comfort. Some people can survive with supportive care for many years.



## **Why would I choose supportive care?**

Supportive care may be an appropriate choice for you when dialysis is very unlikely to improve the quality or length of your life.

Many people can enjoy full lives while on dialysis or living with a transplant. It is possible to work, study, care for a family, play sport, travel, and spend time with friends.

However, both dialysis and transplantation have limitations. Transplantation is not always available, or it may not be successful. Transplant kidneys may eventually fail.

Dialysis requires you to commit to regular treatments, either at home or by attending a dialysis centre. Dialysis may require diet and liquid restrictions. If you also have other chronic medical conditions, a lack of independence and poor health may make life on dialysis seem very difficult.

Whatever the reasons, you may get to the stage where you feel that dialysis is a struggle. Or you may not want to start dialysis because you feel that you do not want a complex treatment to extend your life.

When making a decision about treatment, it is important to remember that it is your choice, and that supportive care is one option. If you are not sure, it is always possible to try dialysis to see how things go.

## **How will supportive care affect my lifestyle?**

If you choose supportive care, your health care team will continue to provide ongoing treatment to manage the symptoms of reduced kidney disease. How this impacts on your lifestyle will depend on the frequency and severity of your symptoms.

Many people who choose supportive care live for months or even years. The goal during this time is to have the best quality of life that you can.

Your health care team may suggest changes to your diet or fluid intake to help you to feel better. Your ability to work or travel will depend on how well you feel. Community home care and nursing services are available to help you remain independent in your own home for as long as possible.





It is wise to make sure your financial arrangements are in order while you are able to think clearly and make your wishes known. This may include preparing or updating your Will, writing an Advanced Care Directive, and appointing a Power of Attorney.

Your health care team, Palliative Care Australia [palliativecare.org.au](http://palliativecare.org.au), or the Office of Public Advocate/Guardianship in your state can also provide more information.

More detailed information on supportive care is available in the booklet 'An Introduction to Supportive Care of Advanced Kidney Disease', and other resources shown below.



#### RESOURCES

-  Kidney Health Australia fact sheets:  
Non Dialysis Supportive Care–A Treatment Option
-  Kidney Health Australia booklets:  
An Introduction to Supportive Care of Advanced  
Kidney Disease  
Kidney Health Australia book: Living with Kidney Failure
-  [www.kidney.org.au/your-kidneys/support/  
kidney-disease/supportive-care](http://www.kidney.org.au/your-kidneys/support/kidney-disease/supportive-care)
-  Kidney Health Information Service (KHIS) **1800 454 363**



# How do I make the choice?

The choice between a kidney transplant, dialysis and supportive care depends on factors such as your age, health and lifestyle. Your health professionals can help you make a choice. They are experts in treatment. However you are the expert in your life and you have to live every day with your decision. If you make the decision about 6-12 months before you need treatment then you will have plenty of time to prepare.

## **The process of decision making**

You already make decisions every day. What shall I wear, which car should I buy, where should I go at the weekend?

Here are some facts about making decisions:

- Some decisions are bigger than others but the process is the same
- Some people are happy to make decisions with very little knowledge, some want to know it all
- Some people prefer a health professional or their family to make a health decision, some people like to make it themselves
- Some people change their minds lots of times, others stick to the first choice
- Some people like to make decisions early, others leave it to the last minute

There is no right or wrong as long as you are happy with the result. What sort of decision maker are you?

Here are some easy steps to making your treatment decision.

## **Step 1**

### **Identify the decision**

In the case of treatment for kidney disease these are the common decisions:

- Is transplantation suitable for me?
- If yes, will it be a living donor or a deceased donor?
- Is dialysis suitable for me?
- If yes to dialysis, which type seems to fit my lifestyle best?
- Would I prefer not to have a major treatment and let nature take its course with supportive care?

## **Step 2**

### **Identify your priorities**

If it is a big decision you should think about what is important to you. This will help you focus when you start to learn about your options.

This might include:

- Your family or pets
- Your work, study or a hobby
- Freedom to go on holiday or trips away
- Finances
- Social life or daily routine

### **Step 3**

#### **Find out what your options are.**

Write all your options down and discuss them with your family and significant others.

### **Step 4**

#### **Knowledge is power.**

Learn as much as you can about the options that you are interested in. This may take a few weeks and involve many sources of information.

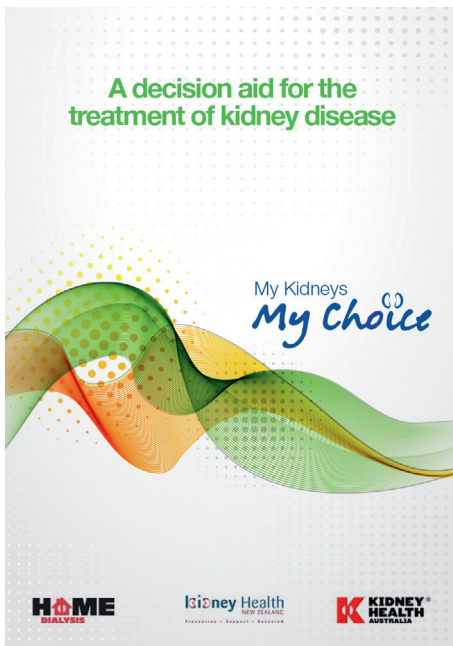
Remember to consider “would this option affect the things in life that are important to me?”

Take advantage of the nurses and social workers who offer group and individual education sessions. Use booklets (like this one), good quality websites, videos, and consider talking to other people in the same position. Your health care team can offer advice on any possible reasons why a particular treatment may not be possible due to current or previous health issues.

Record all your information for each option. Sometimes seeing information on paper can make a decision easier.

## Step 5 Compare the options and make a choice.

*My Kidneys, My Choice* is a useful decision aid that will help you to make your choice. It contains a check-list of issues that you should consider when making your choice. The decision aid is available from the *Treatment for kidney disease > Choosing your treatment* page at [kidney.org.au](http://kidney.org.au).



## Step 6 Chat to your health care team and discuss the way forward.

# What if I am struggling to cope?

It is normal to feel anger, despair, fear and other negative emotions during the journey of kidney disease diagnosis and treatment. These feelings usually improve with time. If the impact of kidney disease treatments and the changes to your lifestyle are overwhelming you, then it is important that you talk to someone.

The nurses, social worker or doctor at your renal unit are the best place to start. Social workers are employed in renal units to provide professional counselling to patients and their family members. They are very familiar with the issues you are experiencing. There is no need to feel embarrassed or ashamed or to suffer in silence.

You can also see your GP who can arrange a referral to a psychologist or social worker in your community. These services can be accessed through Medicare.



## RESOURCES

- Organisations such as *beyondblue* ([beyondblue.org.au](https://beyondblue.org.au) or call **1300 22 4636**) provide a confidential telephone information and advice helpline



**If you find yourself feeling low, please ask for help.**

# Where can I get more information?

This booklet contains information about kidney disease treatment options. Other booklets in this series cover home dialysis, haemodialysis, peritoneal dialysis, transplantation, and supportive care.

We encourage you to read all the booklets so you can make an informed decision about your treatment.



## RESOURCES

-  Living with Kidney Failure booklet 8th edition, Kidney Health Australia  
Community newsletter
-  [www.kidney.org.au](http://www.kidney.org.au)
-  Connect with us on Facebook, Instagram and Twitter
-  Social groups – Kidney Club
-  Kidney Health Information Service **1800 454 363**  
TelEconnect **1800 454 363**

# What does that word mean?

## A

### **Accredited practising dietitian**

Accredited Practising Dietitians (APDs) have the qualifications and skills to provide expert nutrition and dietary advice.

### **Acute kidney injury**

A loss of kidney function that happens quickly which may or may not be permanent.

### **Automated Peritoneal Dialysis (APD)**

A type of PD where a special fluid is put into the peritoneal cavity through a soft plastic tube, then drained out of your body continuously for a few hours by a machine, usually at night. See also CPD.

## C

### **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.

### **Chronic kidney disease (CKD)**

A term used widely to describe kidney damage or reduced kidney function (irrespective of the cause) that persists for more than three months. Sometimes CKD leads to kidney failure, which requires dialysis or a kidney transplant to keep you alive.

### **Continuous Ambulatory Peritoneal Dialysis (CAPD)**

A type of PD where a special fluid is put into the peritoneal cavity through a soft plastic tube, then drained out a few hours later. This is usually done three or four times each day. See also APD.

## D

### **Dialysate**

A special fluid used in dialysis to remove waste and extra fluid from the blood.

### **Dialyser**

The part of a kidney machine which acts like a filter to remove waste from your body.

### **Dialysis**

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

### **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.

## E

### **Exit site**

The point where the peritoneal catheter exits your abdomen.

## F

### **Fistula**

Produced when a vein and an artery in your arm or leg are joined together to make it easier to move blood in and out of your body during haemodialysis. Also known as an arterio-venous fistula.

## G

### **Graft**

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



## H

### **Haemodialysis**

A treatment for kidney failure. Your 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 your body.

### **Health care team**

Living with kidney disease means that you will have contact with many health professionals. In addition to your nephrologist (kidney specialist), your health care team will also include renal nurses, renal dietitian, renal social workers, your GP, and other health professionals depending on your circumstances.

## N

### **Nephrologist**

A doctor who specialises in kidney function.

## P

### **Palliative care**

Doctor and nurse specialists who support you with pain and symptom management. Seeing a palliative care team does not change your lifespan but may increase your quality of life. Some people visit a palliative care team for many years.

### **Peritoneal dialysis (PD)**

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

### **Peritoneal membrane**

The membrane that lines your peritoneal cavity and covers organs such as your stomach, liver, spleen, and intestines.

## R

### **Renal**

Another word for kidneys.

### **Renal Dietitian**

A Dietitian experienced in kidney disease who can help develop an eating plan needed as part of the management of kidney disease.

### **Renal Nurse**

Nurses who are trained in kidney disease treatments.

### **Renal social worker**

Social workers who are trained in providing people with kidney disease and their families with the support needed to cope with kidney disease.

## S

### **Semi-permeable membrane**

A thin lining that allows some things to pass through it, but blocks others.

## T

### **Transplant**

A surgical procedure to place a kidney from a live or deceased donor into a person whose kidneys no longer function properly.

## U

### **Urine**

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

## V

### **Vascular access**

Access to your blood stream for haemodialysis.

**Connect with us**  
**[www.kidney.org.au](http://www.kidney.org.au)**  
**Freecall 1800 454 363**

