A decision aid for the treatment of kidney disease

My Kidneys
My Choice

HOME DIALYSIS

Kidney Health NEW ZEALAND
Prevention • Support • Research

KIDNEY HEALTH AUSTRALIA

Why am I here?

You have been given this decision aid tool because your kidney care team has determined that your kidneys are damaged and likely to deteriorate in the near future.

While you may feel relatively healthy now, when kidney function drops below 15% of that of a healthy kidney (called 'kidney failure'), there is usually a dramatic fall in health and wellbeing.

Kidney failure affects more than 22,000 people and their families in Australia and New Zealand.

A kidney transplant is generally the best treatment for people with kidney failure, but it is rarely immediately available and may not be suitable for everyone. That's why understanding your other treatment options is vitally important.

Unlike with many other medical conditions, you play a significant role in choosing your treatment for kidney failure. Your kidney care team will discuss the options available and help you make an informed decision to deliver the best possible outcome for you.

This decision aid has been especially designed to guide you through making that choice.

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 and your options, ask your kidney care team for further information. To learn more about kidney health, visit:

www.kidney.org.au

www.kidneys.co.nz

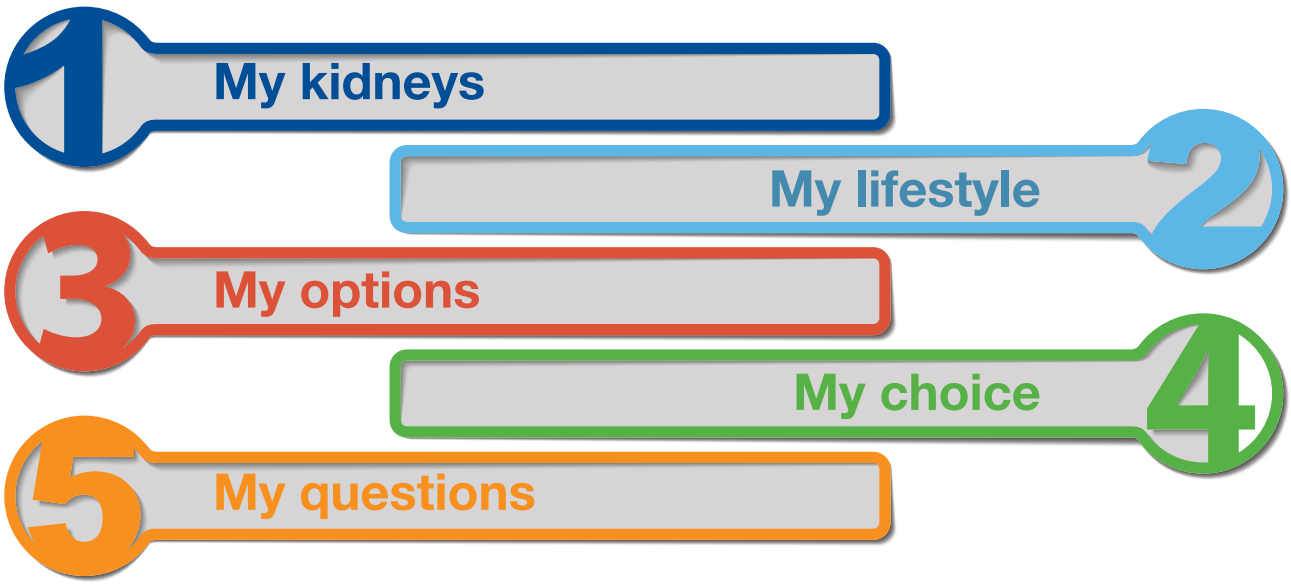
www.homedialysis.org.au

How do I use this tool?

Each section of this tool addresses a different factor that may affect your decision. It is important to go through the sections one by one, as each draws on information and thoughts you need to acknowledge.

Use this tool to help you make a decision in the way that suits you best – whether alone, with a loved one or with your healthcare professional.

Remember to bring this decision aid to your next appointment with your kidney care team. Having it at hand may be useful when discussing your treatment options.



Disclaimer:
This decision aid tool is intended for use in conjunction with the advice of your healthcare professionals. This tool does not account for individual variation among patients or purport to suggest any particular course of medical treatment. Use of this decision aid tool is voluntary.

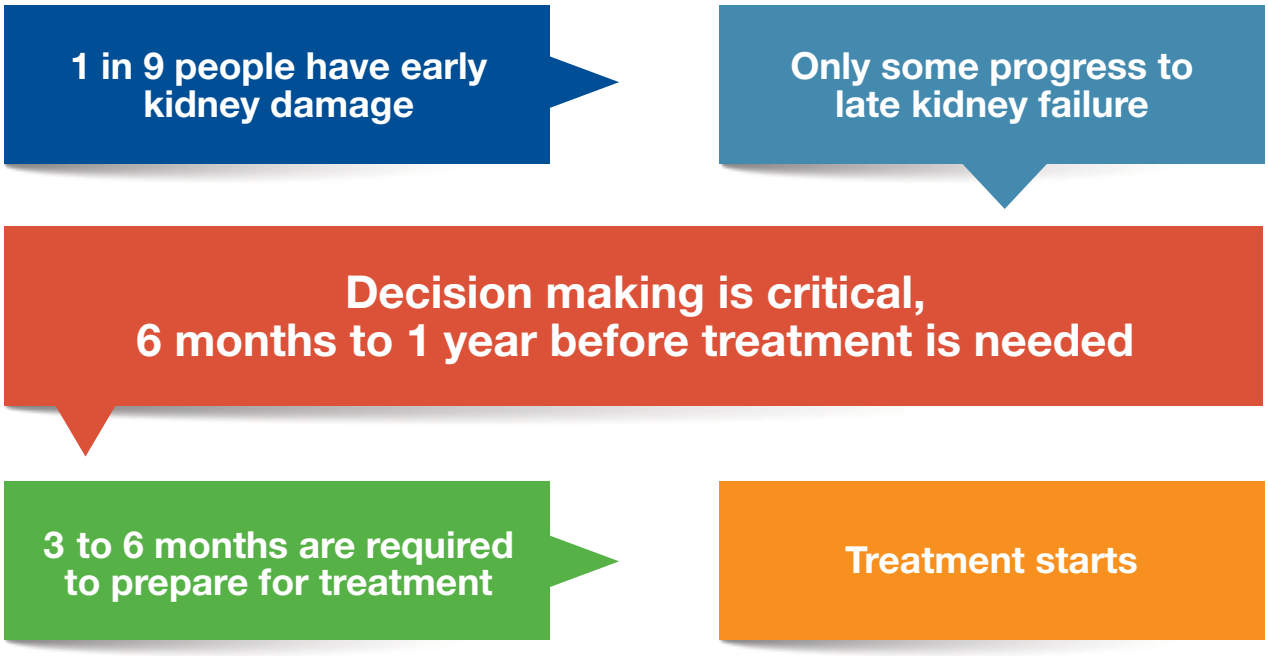
My treatment journey

If your kidney specialist says your kidneys may fail within six months to one year, NOW is the time to decide on a treatment.

If you have not decided on a treatment and your kidneys fail, emergency dialysis may become necessary. This means your life is at risk, and the choice of treatment will be taken out of your hands. It may mean more time in hospital and less time enjoying your life.

So plan ahead. The sooner you start preparing for treatment, the better the outcome. Talking to family and loved ones can also help you make the best decision for you.

The best choice of treatment for any condition is one you have made with a good understanding of the treatment itself, consideration of how it will affect you and your lifestyle, and one your doctors and nurses believe is suitable for you.



2. My Lifestyle

My Kidneys My Choice

Use this guide to help you think about specific areas of your life and how the different treatment options for kidney failure may change them. Weighing up these factors can help you make an informed decision on treatment.

Write down your thoughts under each area below.

Here is an example:

My life now	My thoughts
My leisure activities and hobbies Playing bridge with friends	I always play bridge with friends on Tuesday. It's something I'd really miss.

What is important to ME?

My life now	My thoughts
My work or study	
My relationship with my family at home	
My relationship with my other family and friends	
My leisure activities and hobbies	
My sporting activities and exercise	
My travel or holidays away from home	

2. My Lifestyle

How I feel about myself	My thoughts
Being in charge of my own life	
Being able to do things for myself	
Having a reason to be alive	
Needing others to look after me	

My life in the future	My thoughts
Finding time for treatment	
Travelling to a centre for treatment	
Being in my own home for treatment	
Storing treatment equipment in my house	
Not having treatment	
Explaining my choice to my family	

Main types of kidney failure treatment

There are three main ways of treating kidney failure. Your feelings about which choice is best for you may change over time, so it is good to be aware of all the options.

Dialysis

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

Kidney transplant

For some people, surgery can be done to transplant a kidney from another person into their own body. Although a transplant is seen as the best option when feasible, it is rarely immediately available when someone develops kidney failure.

Conservative care

Some people decide not to have dialysis or a kidney transplant, and instead choose conservative care. This choice lets kidney failure run its natural course and focuses on treating symptoms. Conservative care aims to preserve kidney function for as long as possible through dietary management and medications, but cannot stop the decline in kidney function.

Conservative care is often chosen by people with other medical conditions who feel the burden and discomfort caused by dialysis or a kidney transplant outweigh the potential benefits.

	Dialysis	Kidney transplant	Conservative 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 when needed for 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 currently suited to younger patients without serious health issues besides kidney disease	This is suitable for all patients, however is usually chosen if you have a poor quality of life or life expectancy, often due to illness affecting other body systems
My life and work	There are different types of dialysis. Home treatments are more flexible than others	Most people are able to resume normal activities and work within 3–6 months after transplant	Your health will deteriorate, so your life expectancy will decrease

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Main types of kidney failure treatment (cont.)

	Dialysis	Kidney transplant	Conservative care
My diet and fluids	There are some things you may need to limit and avoid, but it depends on the type of dialysis	You can eat and drink anything, but it is important 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
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 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 your life after the operation, to help your body accept the new kidney. Transplant operations can have complications	You will manage symptoms from kidney failure through diet and medication. Your life expectancy will be decreased
My body	You have an operation on your arm or tummy, depending on the type of dialysis	You have a 2–3 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 changes/impact at home	No changes/impact at home

The differences in dialysis – which is suitable for me?

This table 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 kidney care team. Remember, you may not be suitable for every kind of dialysis.

		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, and 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 simple. You can do it in most places	There may be a few things you should not eat or drink
Home dialysis	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 less changes to your daytime activities	There may be a few things you should not eat or drink
Home dialysis	Haemodialysis	Your blood is cleaned by a special filter attached to a machine	Dialysis usually happens 3–5 times a week, and takes 5–6 hours. You can choose your dialysis times to suit your lifestyle	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 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

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The differences in dialysis – which is suitable for me? (cont.)

		My travel and holidays	My treatment costs	My body	My home
Home dialysis	Continuous Ambulatory Peritoneal Dialysis (CAPD)	You can travel, as long as supplies can be arranged. Overseas travel is often possible	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 will have an operation to put a small tube in your tummy. This needs to be kept clean. 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
Home dialysis	Automated Peritoneal Dialysis (APD)	You can travel, as long as supplies and the machine can be arranged. Overseas travel is often possible	Country patients should get travel assistance. Electricity rebates are available for the APD machine.		You will need a suitable space at home to keep and set up your dialysis equipment
Home dialysis	Haemodialysis	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	Water and electricity rebates are available for the HHD machine	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 rather than 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
Centre-based dialysis	Haemodialysis	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	You may need to pay for travel to the clinic and for some medications. Check what your clinic provides		No equipment is stored at your home

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 conservative care, and how you feel about each one. If you feel you still don't understand your options, ask your kidney care team for more information before you make your choice.

Use the section below to write down your thoughts on the different treatment options available for kidney failure. 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 conservative care? ☐ YES ☐ NO

	My thoughts	Pros	Cons
Continuous ambulatory peritoneal dialysis (CAPD)			
Automated peritoneal dialysis (APD)			
Home haemodialysis			
Centre-based dialysis			
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 health care team for their input?
- ☐ Have I spoken to my family for their input?
- ☐ Do I still have questions to help me make a choice?

  (Jot them down on the next page.)

If you have a preferred option for treatment at this time, 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 kidney care team.

1. _____

_____

2. _____

_____

3. _____

_____

4. _____

_____

5. _____

_____

6. _____

_____

7. _____

_____

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 kidney care team. You will likely spend a significant part of the meeting discussing which choice of treatment is best for you, so this resource will help ensure you have thought through all your options.

http://www.homedialysis.org.au

http://www.kidneys.co.nz

http://www.kidney.org.au