

Information for patients about advanced kidney disease Dialysis and non-dialysis treatments

DOCUMENT PREPARED FOR

This information is to help you understand some key issues about dialysis; it is designed to give you information so that you can make an *informed consent to receive dialysis or not to receive dialysis*. It is not intended to replace information given to you by your doctors and nurses so please ask questions at any time. This document will provide you information about:

- Treatment options for advanced (Stage 5) kidney disease
- What dialysis does, its potential benefits and risks
- Likely survival with or without dialysis
- The process of making an informed choice about dialysis
 1. Understanding the information in this document
 2. Remembering this information
 3. Being able to relate this understanding back to your doctors and nurses

What can you expect now that your kidney disease has advanced?

You have advanced kidney disease and you now need to make a decision about your choice of treatment together with your doctors, nurses and family. The choice you make now does not have to be permanent; some patients will move through several different treatments. Decisions take time, and important decisions should not be rushed. This is why you may have been provided with information about different treatments and why we have encouraged you to consider your options.

YOUR KIDNEY FUNCTION IS AT%

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

Treatment choices for someone with Stage 5 kidney disease are:

1. Dialysis – usually needed when kidney function is less than 10%
 - a. Home dialysis – peritoneal dialysis or haemodialysis
 - b. Hospital dialysis – haemodialysis only
2. Kidney transplantation

Not every patient is suitable for dialysis or kidney transplantation.

Brief overview of dialysis

Dialysis replaces some but not all of the work of your kidneys; it is not a cure for kidney failure but is a good treatment for many people. Dialysis is the process of cleansing the blood and removing excess fluids. There are two forms of dialysis treatment: peritoneal and haemodialysis.

Peritoneal Dialysis

Before peritoneal dialysis can be performed a tube (catheter) is placed into the abdomen, and will stay there permanently. Special fluid goes into the abdomen through this catheter and then is drained. This allows the body to get rid of some of the waste products that build up when the kidneys don't work.

There are two ways to perform peritoneal dialysis: continuous ambulatory peritoneal dialysis (CAPD) which is performed 4 times a day, and automated peritoneal dialysis (APD) which uses a machine every night. You can do this at home by yourself, with or without a support person.

What are the risks with peritoneal dialysis?

- Catheter exit site infection, catheter blockage or malfunction
- Peritoneal dialysis machine malfunctions
- Infection (called peritonitis)

Pleasingly we have low rates of these risks at St. George and Sutherland Hospitals.

The peritoneal dialysis process tends to fail over time, either because of infection or because the inside lining of the abdomen stops being efficient at clearing the waste products. After 3 years about 40% still have successful peritoneal dialysis and after 5 years this figure is only 20%.

At this stage some patients transfer to haemodialysis, some are fortunate enough to have a transplant, and others withdraw from dialysis and have non-dialysis conservative management.

Haemodialysis

The haemodialysis process uses a machine and an artificial filter to get rid of waste products and excess fluid when kidneys don't work. To do this a fistula is usually created; this is a joining of an artery and a vein in your arm, done by a surgeon. This is permanent.

To undertake haemodialysis, the blood stream is accessed by putting needles into your fistula - or by direct connection to a tube called a vascath. The blood circulates through this machine, generally for 4-6 hours, at least 3 times a week. Haemodialysis can be done at home or in the hospital.

What are the risks with haemodialysis?

- Headaches, dizziness, cramps, blood pressure changes or heart palpitations during or after the dialysis session
- Feeling 'washed out' the day after the dialysis
- Clotting or infection of the fistula or vascath tube

Why do we encourage patients to do home dialysis?

Home dialysis has the best outcomes of the different dialysis treatments

Research tells us that people who are on home dialysis will generally live longer.

In addition, there are also the following benefits:

- **Flexibility.** If you are working, or a carer for someone, a flexible dialysis schedule will more likely fit around your other work and family commitments.
- **Time.** Hospital-based haemodialysis will be more time consuming than home haemodialysis, because of the time you need to travel to and from hospital. Once you get to the hospital, you will often need to wait your turn for the nurse to put you on and take you off dialysis.
- **Schedule.** Whilst we will attempt to accommodate your preferences, the location and time of hospital dialysis will depend on our availability, and may change at short notice even after you commence dialysis.
- **Cost.** Home dialysis will not cost you anything extra. The equipment is provided free of charge and the government will provide subsidies for water and electricity. Hospital dialysis is also free, but there will likely be additional costs for transport to and from dialysis.

However, for a variety of reasons, not everyone can undertake dialysis at home.

Almost every patient is initially worried about undertaking dialysis at home but these worries are generally overcome during the training period and outcomes are very good.

You and your family do NOT need to be medically trained, or fluent in English, to be able to dialyse at home.

Some other information about dialysis

- Dialysis does not always reduce symptoms from kidney failure; your doctors, nurses and the renal supportive care team can help if symptoms persist despite dialysis.
- Most people will be able to integrate home dialysis into their lifestyle; if you receive hospital-based haemodialysis, there may be inconveniences to you or your family such as transporting you to and from the dialysis centre at specific times three days per week; parking is also a difficulty for these patients.
- You will be required to follow specific dietary and fluid restrictions and will need to take the medications ordered by your kidney specialist.
- Regular blood tests will be taken to monitor the effect of the dialysis treatments.

Your medical team wants you to be involved in your treatment planning and self-management to the best of your ability. We ask you to notify your nurse or kidney specialist if you have concerns about your dialysis treatments.

What happens if I don't have dialysis?

Every patient with kidney failure has the option **not** to have dialysis.

- Research increasingly shows that patients in the following categories may not live any longer on dialysis than without dialysis:
 1. **Patients 75 years or older who have two or more of the following:**
 - other health problems (such as diabetes, coronary heart disease, vascular disease or strokes)
 - dementia
 - frailty
 - poor functional state on a day to day basis
 - poor nutrition
 2. **Patients 80 years or older**
 - Some patients younger than 75 years but have serious other health problems may also not benefit from starting dialysis. If this is the case, your doctor will discuss this with you.
 - Research also shows patients in these categories are likely to become more dependent on their family and carers in their day to day life time if they started dialysis

Conservative or supportive care

Conservative or supportive care without dialysis is a treatment plan often chosen by patients who are unlikely to survive for a long time even if they have dialysis or, are likely to have a poor quality of life on dialysis. Renal Supportive Care involves a team of doctors, nurses, social workers and dieticians who focus on maintaining control of symptoms from kidney failure and a good quality of life without dialysis.

Some people choose conservative care because they feel that the burdens of dialysis may be more overwhelming than the potential benefits, and prefer to spend their remaining life with friends and family rather than on dialysis.

Our data at St. George and Sutherland Hospitals shows that WITHOUT dialysis, patients of an average age 84 with live on average 15 months when kidney function is <15%, and on average 8 months when kidney function is <10%.

How long will I live if I do have dialysis?

Although dialysis is a life-sustaining procedure it is not a cure for kidney failure. This means that you will be dependent on dialysis for the rest of your life or for those suitable, until a transplant occurs.

Unfortunately, people on dialysis do not live as long as the general population. We realise that this is confronting information but we believe it is best that you have all the available data at hand. Below is Australian data about your likely survival on dialysis.

Age at start of dialysis (years)	Average % chance of surviving 1 year	Average % chance of surviving 5 years
0-24	98	94
25-44	96	85
45-64	93	69
65-74	88	50
75-84	83	33
85+	72	20

Below are the 'average' survival times after starting dialysis. It means half of people in each age group are expected to longer and half shorter.

- Please note that these survival times reflect patients who are medically and functionally healthy enough to receive dialysis. They are NOT a reflection of expected survival in kidney failure patients who are too sick (with other health problems) to do dialysis.

Age at start of dialysis (years)	Average survival (years)
45-64	6.5
65-74	4.6
75-84	3.5
85+	2.2

Your doctor and nurses are very happy to discuss your particular case with you. If you wish to read more about this it is available on the ANZDATA website that reports kidney patient outcomes in Australia. <http://www.anzdata.org.au>

Can I stop dialysis?

Patients all have the option to stop (or withdraw from) dialysis. Sometimes this happens when people become very sick with another serious health problem. Other times, people may start dialysis and enjoy good quality of life, but as they get older, the burdens of dialysis or other health problems become more overwhelming.

The decision to stop is not uncommon in Australia (see <http://www.anzdata.org.au>) but always a hard thing to think about. Your doctors and nurses are always available to discuss this and help you and your family through the process.

Advance Care Plan

We offer all patients with kidney failure (<15%) to prepare an Advanced Care Plan with their families so their wishes and plans can be respected

Advance care planning involves thinking about what medical treatments you would or would not want if you were to become seriously ill and unable to make decisions. It is a record of your preferences, goals and values. This is a difficult but important conversation, and we offer this to all of our patients with kidney failure. In doing this, we hope we will help you to:

- Understand more about your health, illnesses, and treatment options
- Have more control over what happens to you when you are sick, and ease emotional burdens on your family and loved ones

Research tells us that talking about important personal values and end of life issues is life affirming, enhances hope, and can strengthen your relationships.

Summary

The decision to start dialysis, or not, can be a difficult one. We hope that the information in this document is a useful starting point for you and your family. We encourage you to talk to your doctors, nurses, social workers and family members.

If you decide to pursue dialysis, you will be asked to sign a consent form. This is to reflect that we have provided this information, that you feel you have understood, and are making a voluntary decision to do so.

The Renal Team at St. George and Sutherland Hospitals - 2021

Comparison of treatments for advanced kidney disease

	Haemodialysis	Peritoneal dialysis	Supportive Care
What does this involve?	Blood pumped outside your body into an artificial kidney machine which "cleans" your blood.	Using the natural membrane in your abdominal cavity to exchange waste products, which is then drained out.	Medications and dietary advice to address symptoms of kidney failure.
Is this done at home?	Some people can do this at home, after a period of training. People also do this in the hospital.	This will be done at home by yourself. Sometimes people need assistance from their family	You will be at home.
Time commitment	4-5 hours, 3 times per week on dialysis or 7-8 hours, 3 times per week overnight. If you do this in hospital, you will also need waiting and travel time to and from hospital 3 times per week.	CAPD. 30-45min for each exchange of fluid. Usually 4 times per day. APD. 8-10 hours every night while sleeping.	There will be no time taken up by dialysis
What procedure do I need?	A surgical procedure on the blood vessels of your arm to create an arteriovenous fistula.	A surgical procedure to place a peritoneal dialysis catheter, usually to the side of your belly button.	There will be no surgical procedure involved.
What are the benefits?	<ul style="list-style-type: none"> • May extend your life, especially if you have no other major health problems • Some patients can do this at home. • If you do this in a hospital trained staff are available 	<ul style="list-style-type: none"> • May extend your life, especially if you have no other major health problems • You can be at home. • Less stringent diet restrictions. • More flexible times and able to travel • No needles 	<ul style="list-style-type: none"> • Able to spend time in the way you want, doing what's important to you, rather than doing dialysis. • No side-effects or problems caused by dialysis • Quality of life may be better for some people than on dialysis
What are the risks/harms?	<ul style="list-style-type: none"> • For people with many other health problems, it may not extend life. • Side-effects can include low blood pressure, muscle cramps, severe infections, and frequent needles • Time-consuming and may reduce quality of life • May involve frequent travel to and from treatments • Restrictions on fluid intake and diet 	<ul style="list-style-type: none"> • For people with many other health problems, it may not extend life. • Side-effects include infections in the abdominal cavity. • The dialysis may be hard for some people to do by themselves • After a period of time, usually months to years, it may not work any more 	<ul style="list-style-type: none"> • Your life may be shorter than if you start dialysis, especially if you have no other major health problems