

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 of the different treatments through their kidney disease. 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%

Treatment choices for someone with Stage 5 kidney disease are:

1. Dialysis – usually needed when less than 10% kidney function left
 - a. Home dialysis – peritoneal dialysis or haemodialysis
 - b. Hospital dialysis – haemodialysis only
2. Kidney Transplantation
3. Supportive care (this is NO dialysis or conservative management)

Not every patient is suitable for dialysis or kidney transplantation.

Ask your nephrologist to circle ALL OPTIONS that are appropriate for you and in your best interest:

HAEMODIALYSIS	PERITONEAL DIALYSIS	TRANSPLANTATION	SUPPORTIVE CARE
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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.

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 or filtering the blood and removing excess fluids. There are two forms of dialysis treatment: peritoneal and haemodialysis.

Home dialysis has the best outcomes of the different dialysis treatments

Research has shown that home dialysis treatment has the best outcomes and in some people survival on home haemodialysis is as good as receiving a kidney transplant. If you are considered a suitable patient for dialysis then you will be encouraged to undertake dialysis at home. We believe this will give you better quality of life than hospital based dialysis and generally associated with longer survival. However, for a variety of reasons, not everyone can undertake dialysis at home.

Provided there is no medical reason why one form of dialysis is more suitable than another for you, your choice of which type of home dialysis will only be influenced by your personal circumstances and lifestyle.

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

Some other information about dialysis

- Dialysis generally, but not always, reduces symptoms from kidney failure; your doctors, nurses and the renal supportive care team can help if symptoms persist despite dialysis.
- Most people will have a stable quality of life and be able to integrate home dialysis into their lifestyle; if you receive hospital or satellite unit 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 likely 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.
- We may ask you and your family to develop an Advance Care Plan if this has not already been undertaken.

Peritoneal Dialysis

Before peritoneal dialysis can be performed a tube (catheter) is inserted into the abdomen. This is done either by a kidney specialist or a surgeon. This tube is permanent and will stay in the abdomen. Special fluid is run into the abdomen through this catheter and then 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.

Are there any risks with peritoneal dialysis?

- There are certain risks associated with peritoneal dialysis. Pleasingly we have low rates of these risks at St. George and Sutherland Hospitals. The main ones are:
 - Catheter exit site infection, catheter blockage or malfunction
 - Peritoneal dialysis machine malfunctions
 - Infection (called peritonitis)
- 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 from the body. 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 with our Renal Supportive Care team.

Haemodialysis

The main function of dialysis is to filter the blood of unwanted toxins, chemicals and fluid which is the job that kidneys normally do. The haemodialysis process uses a machine and an artificial filter. 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 inserting 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. The blood is cleaned of toxins and excess fluid in the body during that time.

Are there any risks with haemodialysis?

- There are some risks with haemodialysis. The main ones are:
 - Headaches, dizziness, cramps, low blood pressure or heart palpitations during the dialysis session

- Feeling 'washed out' the day after the dialysis
- Clotting or infection of the fistula or vascath tube

If you would like more information regarding peritoneal and/or haemodialysis further education can be organised at your request.

What happens if I don't have dialysis?

- Every patient with kidney failure has the option **not** to have dialysis.
- Research increasingly shows that survival on dialysis may not be any longer than without dialysis for patients in the following two categories:
 1. **Age 75 years or older AND coronary (heart) disease**
 2. **Over age 80 years, with or without heart disease**
- Research has also shown that dialysis may not increase the length of life for some patients particularly if they fall into the following category:
 3. **Patients 75 year or older who have two or more of the following:**
 - other health problems (such as heart, lung, vascular disease or strokes)
 - dementia
 - frailty
 - poor functional state on a day to day basis
 - poor nutrition

Renal supportive care without dialysis is a treatment plan often given to 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 supportive 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 patients of an average age 82 with advanced kidney disease live on average 16 months without dialysis.

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

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 until a transplant occurs, if you are a suitable patient for a kidney transplant.
- Unfortunately, people on dialysis do not live as long as the general population. We have listed below the 'average' survival time on dialysis for different age groups. Some patients will live longer than these times and some for a shorter period. We realise that this is confronting information but we believe it is best that you have all the available data at hand. 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>

Age at start of dialysis	Average % chance of surviving 1 year	Average % chance of surviving 2 years	Average % chance of surviving 5 years
0-24	98	96	94
25-44	96	93	85
45-64	93	87	69
65-74	88	78	50
75-84	83	69	33
85+	72	54	20

- Below are the 'median' survival times on dialysis for different age groups. Median survival is the number of years that 50% of people in each age group are expected to survive after commencing dialysis. Your doctor will discuss this with you.
(* data not yet available). <http://www.anzdata.org.au>

Age at start of dialysis	Median, years
0-24	*
25-44	*
45-64	6.5
65-74	4.6
75-84	3.5
85+	2.2

- Some patients begin dialysis then decide they no longer wish to continue; that is a choice that your doctors and the renal team will support you with. We have specific treatment plans in place for this situation and you will be supported by the Renal Supportive Care team.

Advance Care Plan

We encourage all patients over the age of 75 years of age 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.

You may be offered an opportunity to make an advance care plan with your doctor or nurse. This can be a difficult but important conversation. In doing this, we hope we will help you to:

- Live well, tell us your priorities, and receive good healthcare in accordance to your preferences at all stages of an illness, including good care at the end of life
- Have more autonomy, or more control over what happens to you when you are sick
- Ease emotional burdens on your family and loved ones when you get sick
- Understand more about your health, illnesses, and treatment options

This process will allow us to understand you, and provide the best medical care possible for your circumstances. We are hoping that for you and your family, talking about important personal values and end of life issues will be life affirming, provide hope, and strengthen your relationships.

Summary

The decision to commence 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.

Take this with you to discuss with your doctors, nurses or social workers at any time. We hope this helps.

The Renal Team at St. George and Sutherland Hospitals - September 2017

What are my values?

Deciding about dialysis can be a very difficult decision. If you are still undecided, it is helpful to think about your values, and talk to your nephrologist or nurse about which option best fits your values?

Rate the following: **1 (not true) to 5 (very true)**

I want to spend time with my family	1	2	3	4	5
I have many hobbies and they are an important part of my life	1	2	3	4	5
I have fulfilled my goals in life and want my kidney disease to run its natural course	1	2	3	4	5
I like to be independent, and not rely on help from others, even my own family	1	2	3	4	5
I want to live as long as possible, no matter what	1	2	3	4	5
I like to spend as little time as possible in hospital	1	2	3	4	5
It is difficult for me to travel to and from hospital on a regular basis	1	2	3	4	5
I want to avoid having needles	1	2	3	4	5
I feel too overwhelmed and want someone trained to do my dialysis	1	2	3	4	5
I feel I can live with being on dialysis	1	2	3	4	5
I have lots of family and support; people are willing to help out with dialysis and transport	1	2	3	4	5