

Conservative Treatment

Does everyone choose to have dialysis treatment?

You have the right to make your own choices about how you are treated for kidney failure. That means you can choose not to start dialysis. It is important for you to have all the information you need to make this decision.

People with complete kidney failure will die as a consequence of this if they don't have treatment with <u>dialysis</u> or a <u>kidney transplant</u>.

- Dialysis treatment can greatly improve the quality of life of many people with kidney failure.
- · However, dialysis treatment is demanding and time-consuming and requires lasting changes to lifestyle.
- Many people on dialysis are able to make these adjustments and still lead a fulfilling life, but dialysis is not a cure-all.
- Dialysis may not improve the quality of life for some people, particularly if they have other serious health problems such as heart disease or cancer.

Some people decide to have 'conservative' treatment (also called, palliative or supportive care) rather than have dialysis or a transplant.

What is conservative treatment?

The aim of conservative treatment is to manage the symptoms of kidney failure without using dialysis or transplantation.

Conservative treatment includes medical, emotional, social, spiritual and practical care for both the person with kidney failure and their family/whanau.

Although many people who choose conservative treatment are elderly, old age is not the only reason to choose this option.

If you choose to have conservative treatment, your kidney unit will continue to look after you for as long as you wish. You may also wish to be cared for by another service such as Hospice/ Palliative Care (in collaboration with your family doctor).



Why might somebody decide not to have dialysis treatment?

There are a number of reasons why somebody might decide to have conservative treatment for their kidney failure.

- They have been advised that they have other serious illnesses that will shorten their life, and that the burden of dialysis treatment would be greater than any likely benefits.
- They consider the dialysis treatment so demanding and time consuming that it will change their lifestyle
 so that they will have a very poor quality of life. They are being treated with dialysis, but now have another
 serious physical illness such as severe or worsening heart failure that will shorten their life.
- They are being treated with dialysis, but consider that their quality of life has become very poor.

Can I decide not to have dialysis treatment?

Yes. You have the right to decide not to start dialysis if you feel that the burden would outweigh the benefits and reduce your quality of life. You also have the right to stop dialysis at any time after starting dialysis. Only you know what it is like for you to live with kidney failure.

It is very important that you have plenty of time to discuss the issue thoroughly with those close to you and with members of the renal team looking after you.

The kidney care team will ensure that you receive the necessary information to make a good decision and will support you.

What does conservative treatment involve?

This treatment involves a team of people from the hospital, the community and your home. Your medical care will normally be managed by your kidney doctors together with your family doctor.

Doctors, nurses and other people in the kidney care team will make sure that you have:

- Medicines to protect your remaining kidney function for as long as is possible and appropriate. This will include advice on preventing further kidney damage by avoiding drugs such as Brufen, Neurofen and Voltaren
- Advice on the right diet. But, as your kidney failure worsens and your appetite deteriorates, sticking to a rigid diet will become progressively less important and feasible.
- Advice on how to avoid dehydration which may worsen your kidney failure. Dehydration can develop during illnesses that cause diarrhoea and/or vomiting.
- Remember to have your annual 'flu jab. If you know that your time is limited, however, this may not be appropriate.
- Medicines to treat other symptoms of kidney failure, such as feeling short of breath, nausea, <u>anaemia</u> (low blood count), poor appetite or itchy skin.
- · Adequate community support, such as home help and district nursing.
- Referral to a local Palliative Care service. The aim of <u>palliative care</u> is to keep you active and independent for as long as possible as well as supporting you in the final stages. Palliative Care focuses



on support and comfort and works alongside your family doctor

- Adequate information on where to get financial support, assistance with making of a will and, if
 necessary, the completion of an Advance Directive if you have particular wishes about end of life care
 that you want to be respected.
- Adequate support for your family/whanau. Counselling for family members is sometimes needed to cope with the prospect of losing a loved-one. You may also need help to inform and support your family about your decision.
- Ultimately, once you have died, your family may wish to receive bereavement support. Your family
 doctor and/or Palliative Care Service can coordinate this if need be.

What if I cannot decide?

Sometimes it is difficult to decide whether dialysis will be worthwhile.

In this case, your kidney doctor may suggest you have a trial period of dialysis; usually a few weeks. Embarking on such a trial is very arduous so ensure that you discuss it fully. During this time you, your family and the kidney care team will see how dialysis is affecting you, both medically and psychologically. The doctor and other members of the team will then be able to talk with you and decide together whether it is in your best interests for dialysis to continue.

Talking to a trusted family doctor might help you come to the right decision for you.

How long will I live if I don't have dialysis?

This varies from person to person, and depends on many factors. An accurate prediction is very difficult to make as each situation is different.

Important factors are:

- · How much kidney function remains
- · How sick you are from other serious illnesses
- · How determined you are to reach milestones or special events

Chronic ill health affects both your physical and emotional strength – sometimes it is just too hard to fight anymore. If this is the case then it may mean that you deteriorate more quickly than anticipated.

It is reassuring to know that most people who die of kidney failure are able to be kept very comfortable and pain free. Other troublesome symptoms during this time will also be managed and your family/whanau will receive specific support to help them cope.

You have the right to re-visit your decision about dialysis at any time. Any concerns that you have will be addressed promptly by your kidney care team.

This is a sensitive and emotional issue. If you are worried about how you will cope, you can talk it though with a member of the team that you trust.



Will I have a choice of where I die?

Many people would prefer to die at home, where they feel more comfortable and can be in familiar surroundings. This is especially so when there is help from family, friends or carers. Support from community services and your family doctor will be arranged before discharge.

In many areas, Hospice care or Palliative Care is available and in this case you may wish to receive such support. Hospices are not just for cancer patients and it may be possible for you to receive such care if you wish.

A hospital admission may be another option for some people.

You should discuss these issues with the kidney team. The priority is to support you and your family as much as we can

Is deciding not to have dialysis the same thing as taking my own life?

No. No one should feel obliged to receive treatments that are not right for them and ethically you do not have to have life-prolonging treatments if that is not your wish. Each person should be encouraged to make their own decisions regarding their health and this should be respected.

Most religions believe that people have the right to decline medical treatment, including dialysis, if they feel it will not help them.

You may wish to speak with your religious advisor if you have any concerns about this.

If you have other questions or concerns, feel free to ask your kidney team or your family doctor.



DIALYSIS

The process of cleaning wastes from the blood artificially. This job is normally done by the kidneys. If the kidneys fail, the blood must be cleaned artificially with special equipment. The two major forms of dialysis are hemodialysis and peritoneal dialysis.

◀ KIDNEY TRANSPLANT

When a healthy kidney is taken from one person and surgically placed into someone with kidney failure. The kidney can come from a live or deceased donor. It is important to remember that a transplant is a treatment not a cure for kidney disease.

ANAEMIA

A reduction in the number of red blood cells. People with anaemia can suffer from tiredness and lack of energy. Anaemia in people with chronic kidney disease is usually caused by a lack of iron or a hormone made by the kidney called erythropoietin.

PALLIATIVE CARE

Palliative care is the care of people who are dying from active, progressive diseases or other conditions that are not responsive to curative treatment. Palliative care embraces the physical, social, emotional and spiritual elements of wellbeing—tinana, whanau, hinengaro and wairua — and enhances a person's quality of life while they are dying. Palliative care also supports the bereaved family/whanau.