

PALLIATIVE CARE FOR PEOPLE WITH SICK KIDNEYS



THIS BOOK WILL:

- Help you to understand your journey with kidney disease.
- Help you, your family and your community on this journey.
- Help you to understand how the health care team can support you on this journey.
- Help you and your family plan for when you will finish up.

TOPICS:

1. What is palliative care
2. Important decisions
3. Things to think about
4. I'm not sick, I feel ok
5. I don't feel so good anymore
6. Medicines
7. Nearly ready to pass away
8. Just before I pass away
9. Carers need support too

Aboriginal Interpreter Service



If there is anything you do not understand about your kidney story and what will happen to you ask the health clinic to get an interpreter and tell your story again.

What is Palliative Care?



Palliative Care is for people that have a sickness that can not be cured or fixed and they will finish up soon.

What is Palliative Care?

What can Palliative Care do for me when I get sick?



The Renal team, Health Clinic and Palliative Care team will work together to help your family and community look after you when you get too sick to take care of yourself. They will help with medicines and equipment to make you feel comfortable.

They can help you finish up where you want.



Important decisions

When your kidneys get really sick they will stop working and you will pass away. You will need to make some important decisions about whether or not you want dialysis.



Dialysis can help to make you feel better and help you to live longer.

But to have dialysis you will need to move to town to learn how to do it. You may need to live in town for ever.

If you don't want dialysis then you can stay at home and finish up in your community close to your family.



Important decisions

People with kidney disease often have other illnesses.



- High blood pressure and blood circulation problems



- Problems with diabetes



- Weak bones



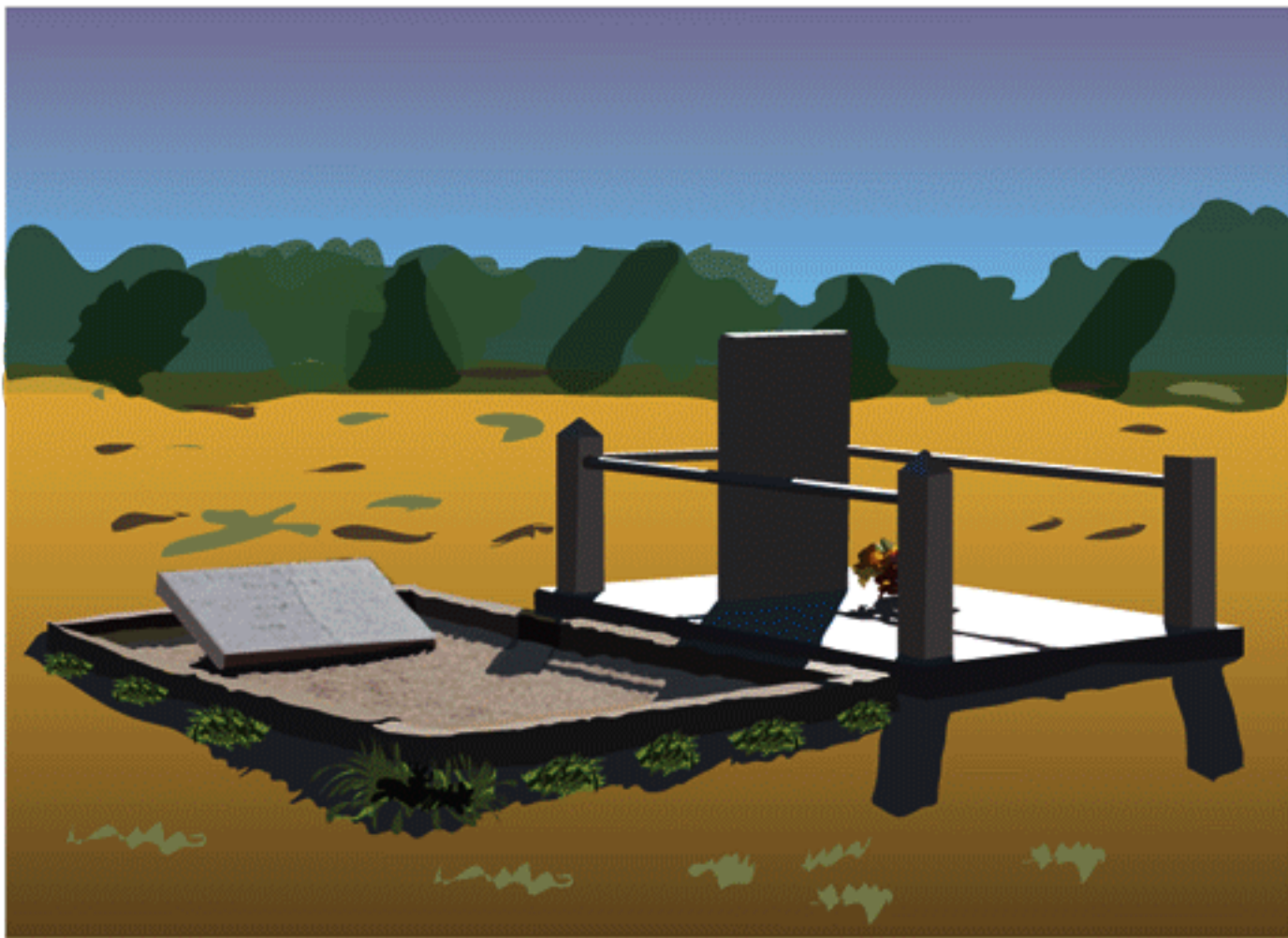
- Heart or lung problems

Talk to your doctor and health care team about dialysis.



Important decisions

It is important to understand that no one really knows when you will finish up.



Finishing up can happen quickly or you may feel well and stay strong for some time. No one can tell, it is different for every person.

Important decisions

You can decide where you want to finish up.



- At home



- At the hospice



- At the hospital

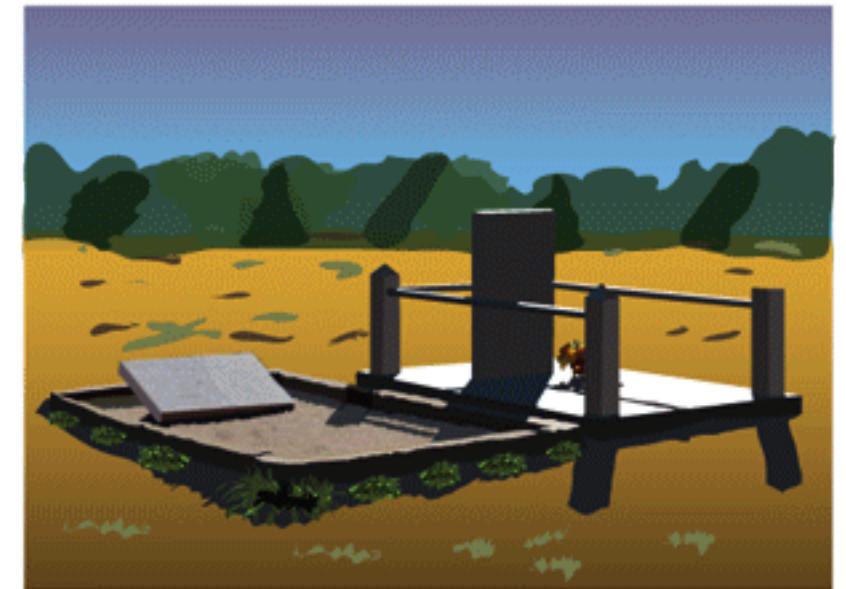
Important decisions



If you start dialysis you can change your mind and stop dialysis.



Stopping dialysis means you will finish up within a few weeks. The renal team will tell you how long it might take. It will depend on other sicknesses you may have and how long you have been doing dialysis for.



Important decisions



If you decided not to have dialysis you may be able to change your mind and start dialysis.

Sometimes your body is too weak and dialysis won't help.

The renal team will be able to do some tests to tell you if you can do this.



- Blood test



- Blood pressure

- Urine sample



Important decisions



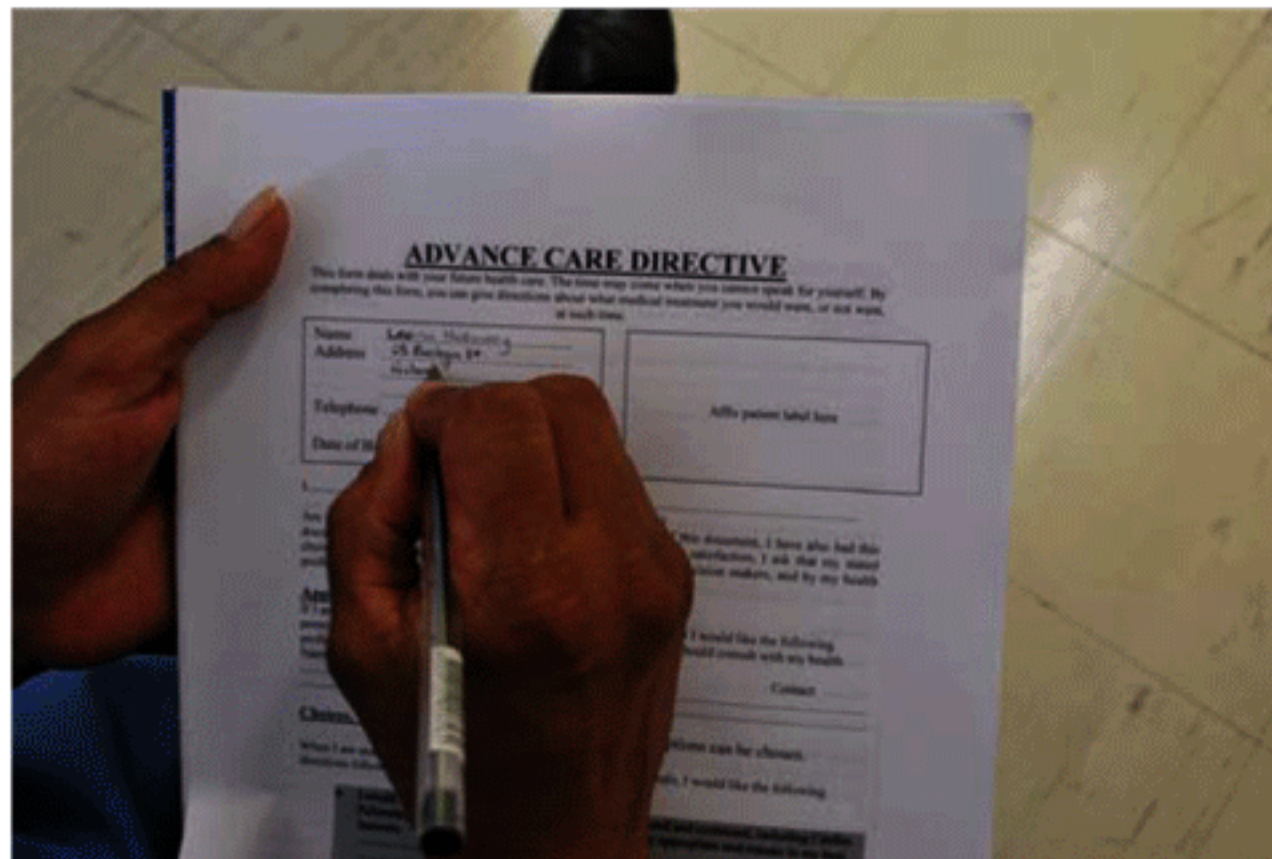
You need to talk about all of these things with:

- your family
- your health clinic
- the renal team
- the palliative care team

Talking with these people will help you and your family make the right decisions to manage your sick kidney journey.

Important decisions

When you and your family have made a plan about how to manage your kidney disease the renal team or health clinic can write your story on a form. This is called an "Advanced Care Directive"

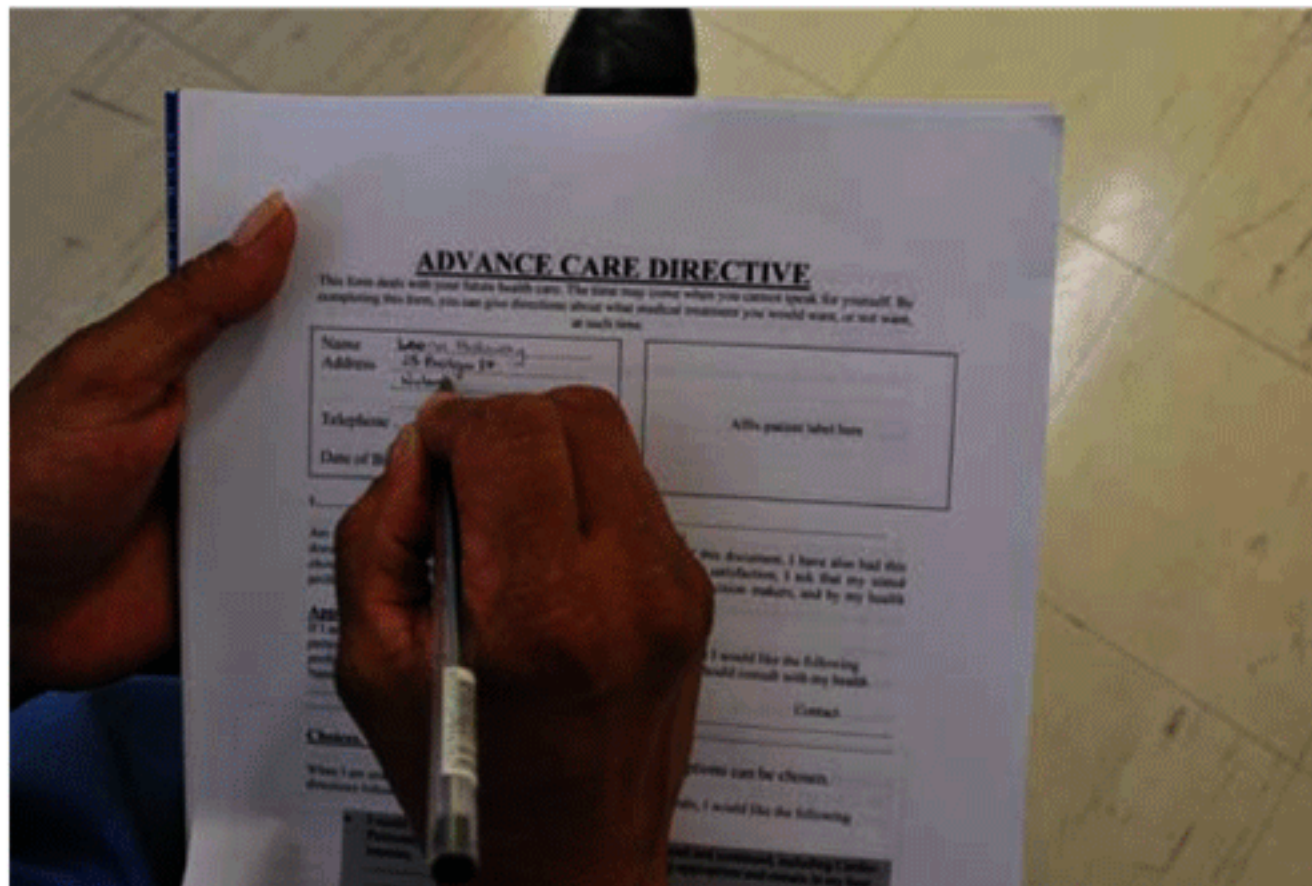


The Advanced Care Directive tells the doctors and family what you want when you are really sick and can not speak to tell your story.

Things to think about

Who are the important people in your family and community that need to know if you want to have dialysis or not?

Do they understand your story? Do they know where you want to finish up?



Does your family really understand the story on your advanced care directive?

Things to think about



If you have decided to stay at home are your family happy to look after you when it comes time to finish up?

Things to think about

You may want to think about somewhere outside your home, like your favorite place, so that your family don't have to move out after you pass away.



You and your family could find a place for you to pass away where family can be with you to keep you company and sing and tell stories.

Things to think about

- Fixing up your bank account.



- Do you need to make a will?



- Do you have any superannuation?



- Funeral and ceremony money?



- Do you have any things you want to buy?



- Get a letter from the health clinic to give to Centrelink. This will explain to them what is happening to you.



I'm not sick, I feel OK



I have kidney disease but
I feel well and I don't want
dialysis.

I'm not sick, I feel OK



Still go to the health and renal clinics. They will help you stay strong for as long as possible.

Still have blood tests when you need them.



I'm not sick, I feel OK

Take medicine daily and eat good food. This will help you to be more active and stay stronger for longer.



I'm not sick, I feel OK

Keep being active and doing the things that make you feel happy and strong.



I'm not sick, I feel OK



It may be good idea to talk about getting a fistula and catheter. Dialysis works much better if your fistula has been done for a few months.

Having a fistula and catheter does not mean you have to have dialysis.



It gives you a choice.

