

# 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.

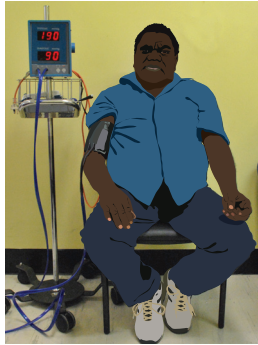
But to have dialysis you will need to move to town to learn how to do it. You may need to live in town for ever.

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



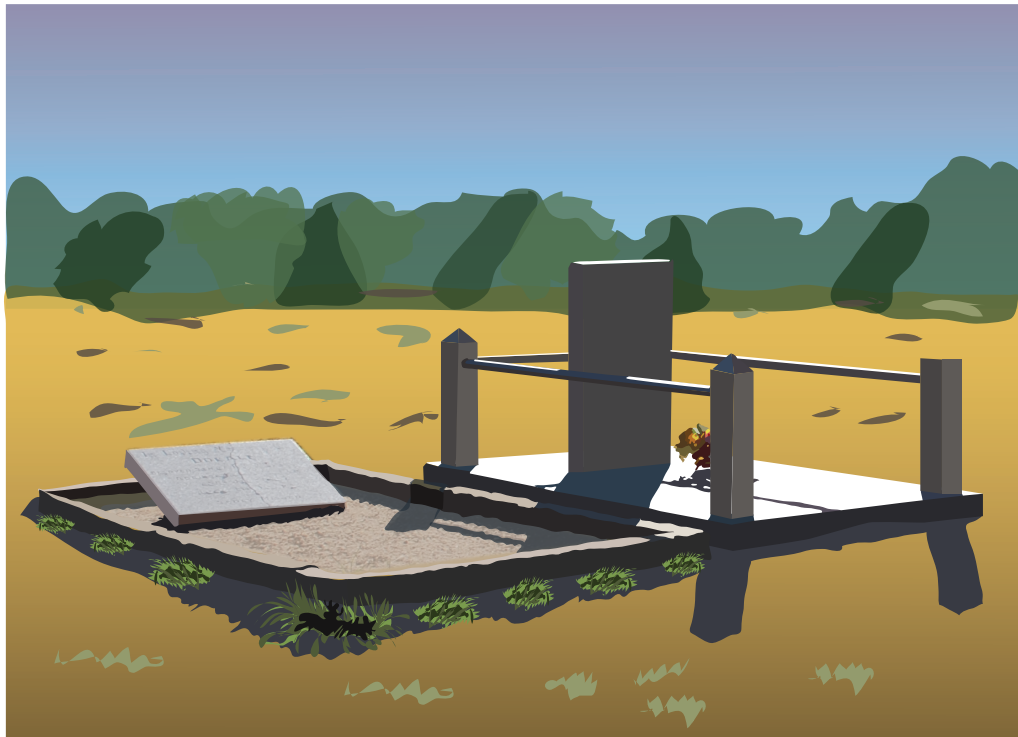
- Heart or lung problems

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

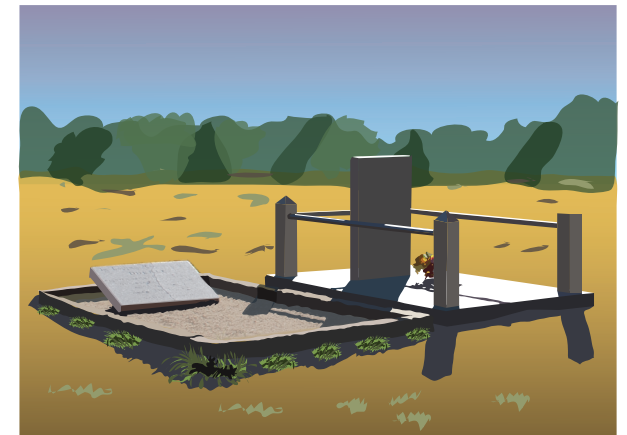
## Important decisions



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



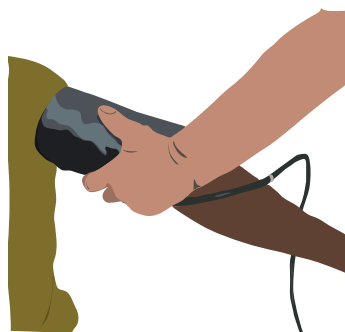
If you decided not to have dialysis you may be able to change your mind and start dialysis.

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



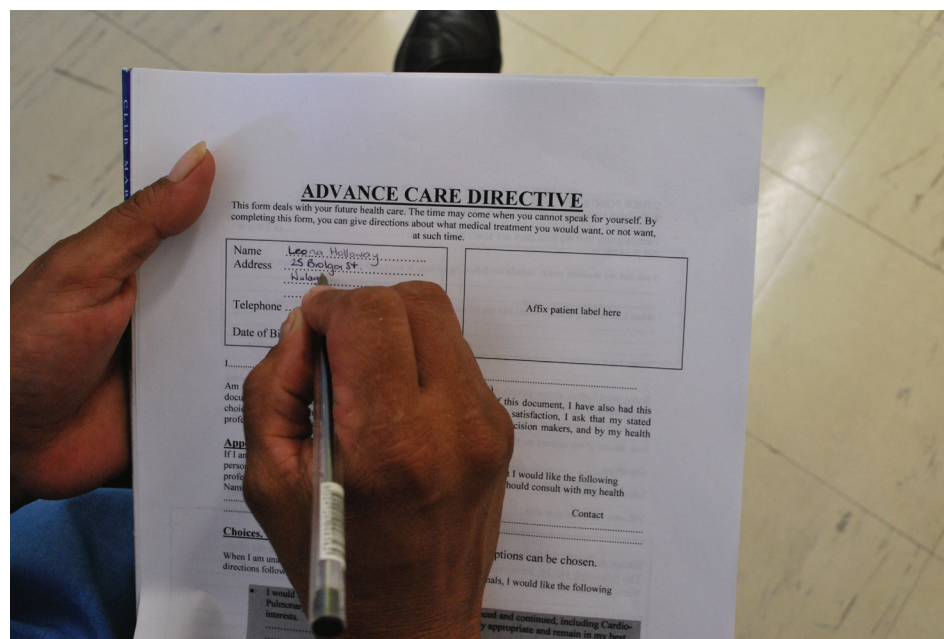
You need to talk about all of these things with:

- 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"

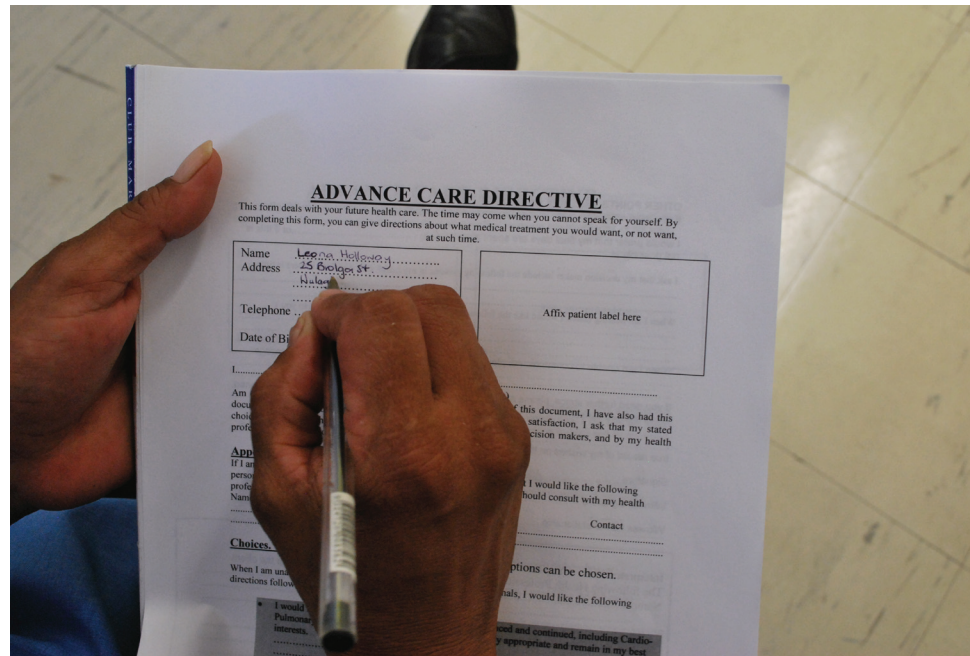


The Advanced Care Directive tells the doctors and family what you want when you are really sick and can not speak to tell your story.

## 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.

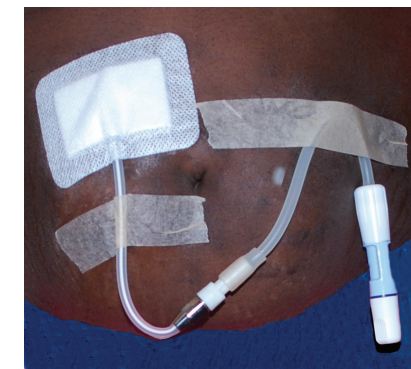


## I'm not sick, I feel OK



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.

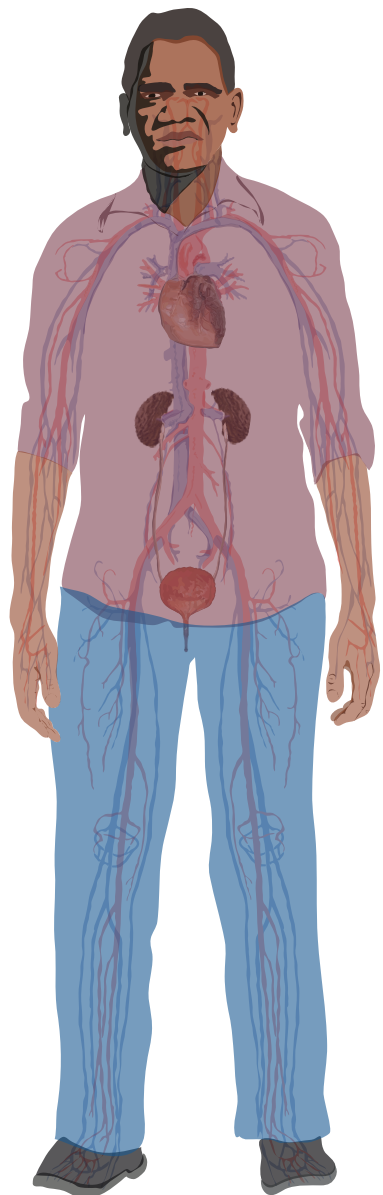


It gives you a choice.



## I don't feel so good anymore

What happens when I get really sick and my kidneys don't work at all?



## I don't feel so good anymore

You will have feelings of sickness called "symptoms", because your kidneys are not working.



- Itchy skin

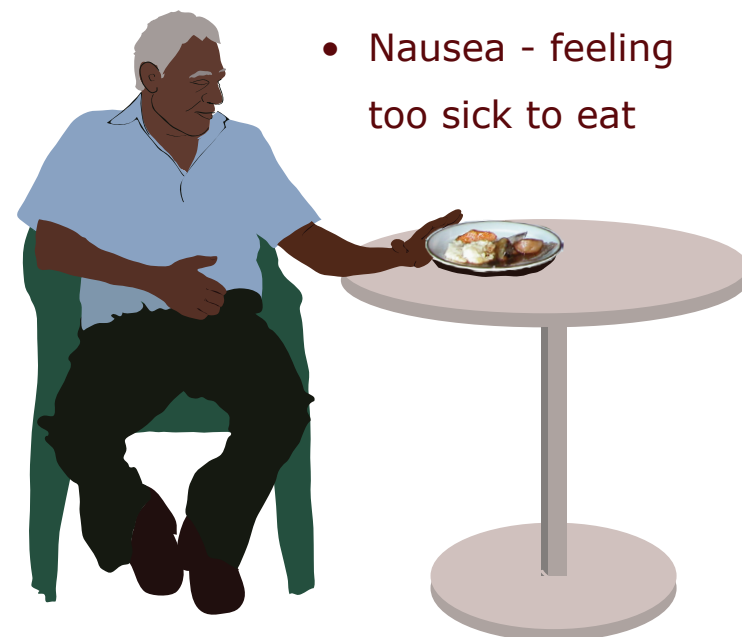


- Confusion

- Twitching - shaking hand



- Short wind



- Nausea - feeling too sick to eat

## I don't feel so good anymore



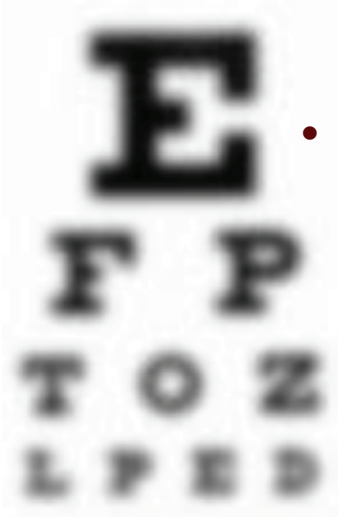
- Tired and weak



- Very sleepy



- Sadness or worry



- Blurry vision



- Puffy legs and tummy

## I don't feel so good anymore

The health clinic, renal and palliative care teams will look at things that everyone can do to help you and your family.



Renal, palliative care and the health clinic do this by talking over the phone so everyone hears the same story.

## I don't feel so good anymore

The health clinic and palliative care teams may be able to help you with some equipment such as wheelchairs, beds and shower chairs.

These can help you and your family keep you comfortable at home.



Health clinic staff can visit you at home and bring any medicines that you may need.

## I don't feel so good anymore

Things that may help you feel strong when you are unwell:

- Family visit



- Visiting country



- Pastor and church groups

- Telling stories



- Passing on important information



- Bush medicine and bush tucker



## Medicines



You might want to use traditional medicine and healers as well as the clinic medicines.



## Medicines



One medicine is given through a sticky patch that goes on your skin. The patch helps to take your pain away.

It takes about half a day for it to work and you will keep it on for 3 days.



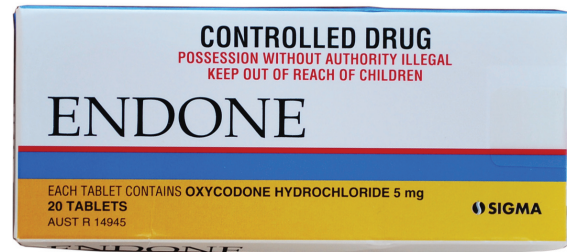
After 3 days the clinic staff will change it for another one.

## Medicines

These are examples of some other medicines used in palliative care.



Some medicines in your drops. Like Clonazepam or Rivotril. These drops can go under your tongue - you don't have to swallow anything. This medicine helps with feelings of worry; it helps you relax.



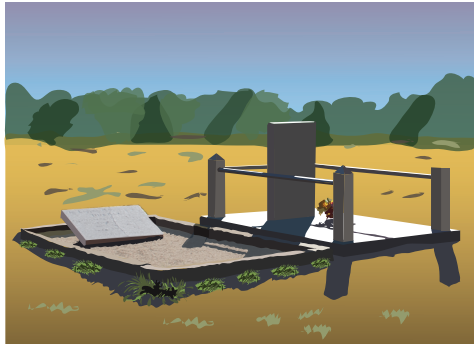
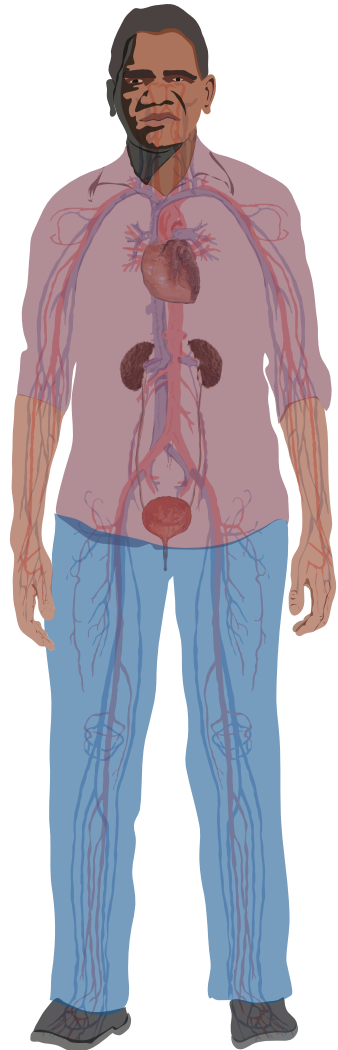
Other medicines are tablets, like Oxycodone or Endone. These help with pain and keep you comfortable. They are strong tablets; you might feel sleepy after taking them.



Some medicines come by a needle, like Fentanyl or Sublimaze. This is a strong medicine for very bad pain. You can use these instead of tablets.

## Medicines

I am not sure about those medicines?  
Some people say they will make me pass away quicker.



This is NOT true.

The kidney sickness is what will make you pass away not  
the medicines.

The medicines are to help you if you have pain.  
They will help to take the pain away and make  
you feel more comfortable.



## Medicines

When someone is passing away they might be very sleepy due to the illness and medications.



If this worries you or your family the clinic staff can help.

## Nearly ready to pass away



If you are finishing up at home the health clinic staff can visit you in your house or special place and see how you are. They will talk with family to let them know what is happening. They can check if you have any worries or questions.

## Nearly ready to pass away

As you get closer to passing away the symptoms might get worse.



You may have short wind because of more fluids in your chest, which makes it harder to breath.

The health clinic can give you some medicine to help with this.

## Nearly ready to pass away

If you don't want to finish up at home you can go to the hospital or hospice.



The health staff will help take care of you and your family can be with you.



## Nearly ready to pass away



If you are at the hospital and want to pass away at home the health team may be able to help you to go home and finish up with your family.

## Just before I pass away



It is OK to pass away  
at your home and  
community.

## Just before I pass away

Most people become very sleepy and pass away quietly in their sleep.



## Carers need support too

Sometimes looking after someone who is passing away is the job of one person. They might feel:

- Tired
- Responsible
- Unappreciated
- Afraid of payback



It is important for that person to look after themselves and to be supported by other family members and the community.

## Carers need support too

If you are a carer these are some things you might want to think about:



- Tell your work that someone in your family is going to pass away and you will be helping to look after them.

- Talk with Centrelink about carers allowance and pensioner entitlements.



- Do you have other family or children who will help you while you are caring for your relative?

- Are there any respite services in your community that may be able to help you?

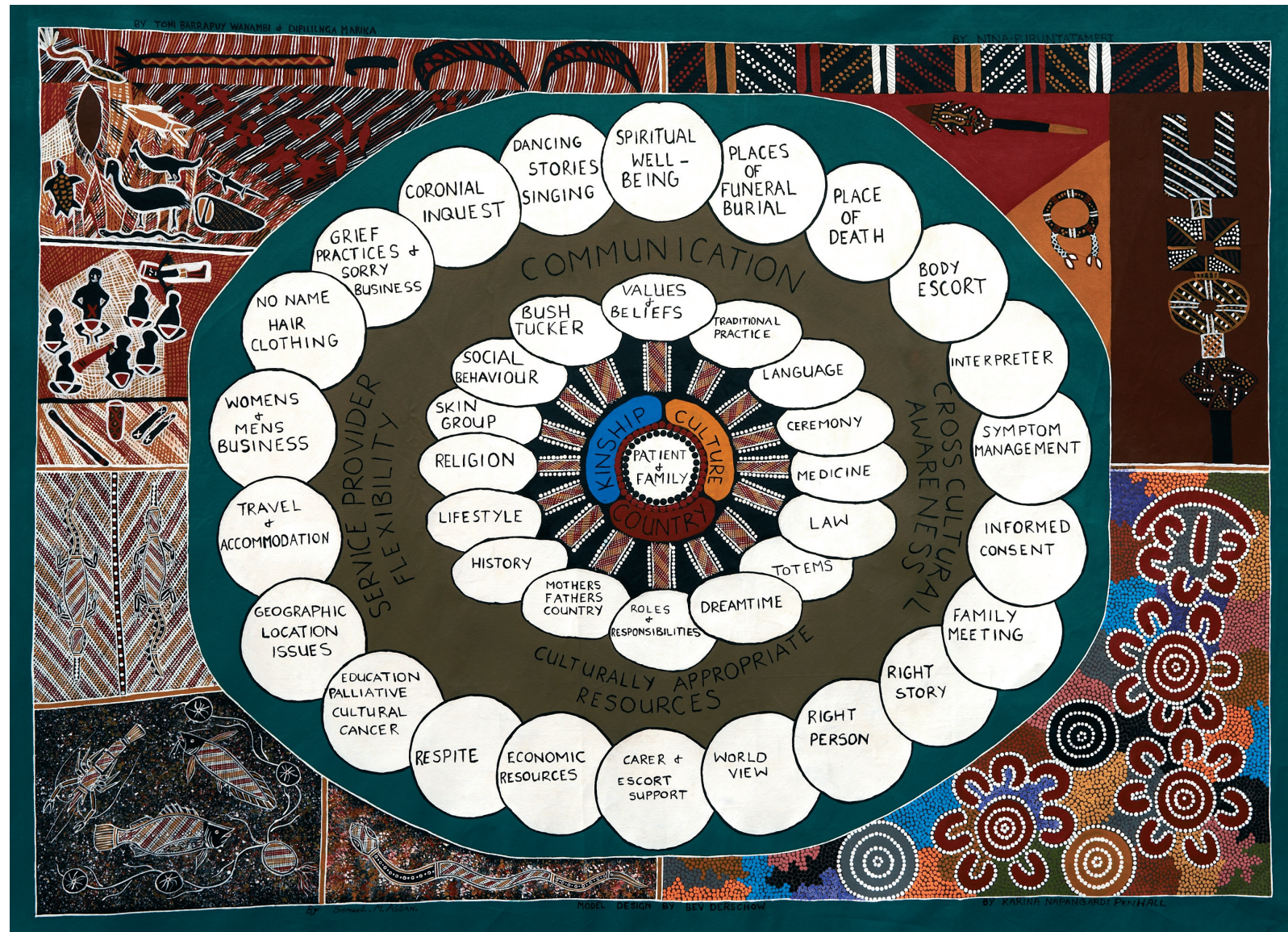
- You might be able to go to Darwin or Alice Springs for some respite if you get too tired or need a break.



## WORDS TO UNDERSTAND:

- palliative care
- pass away
- kidney disease
- interpreter
- renal team
- health care team
- palliative care team
- comfortable
- dialysis
- fistula
- catheter
- blood pressure
- diabetes
- hospice
- hospital
- blood test
- urine sample
- sick kidneys
- advanced care directive
- symptoms
- equipment
- patch
- respite

# The Northern Territory Aboriginal Palliative Care Model



This model was developed and designed by Beverley Derschow to illustrate a holistic approach to the Palliative Care System. The model was supported by artwork from Indigenous artists from the Northern Territory. Available as a poster from [www.healthinonet.ecu.edu.au](http://www.healthinonet.ecu.edu.au)

# PALLIATIVE CARE FOR PEOPLE WITH SICK KIDNEYS

## RESOURCE TOPICS:



*THE WORK OF YOUR KIDNEYS*



*WHEN YOUR KIDNEYS GET SICK*



*LIVING WITH KIDNEY DISEASE*



*DIET AND KIDNEY DISEASE*



*TREATMENT OPTIONS & PATHWAYS*



*PERITONEAL DIALYSIS*



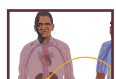
*HAEMODIALYSIS*



*FISTULA AND CATHETER*



*PALLIATIVE CARE FOR PEOPLE WITH SICK KIDNEYS*



*TRANSPLANT BOOKS 1 - 4*

NT Renal Services would like to thank all the renal patients and others who donated their time in posing for the photos that were used to make the illustrations in these resources.

### **Producer**

Gillian Gorham

### **Project Management**

Suzanne Stewart

### **Art work**

Michael Roseth

### **Content Development**

NT Palliative Care

### **Consultants**

Renal patients, NT Renal Services, PEPA Program, NT Preventable Chronic Disease Program, NT Aboriginal Interpreter Services, NT Aboriginal Services Support Unit, NT Aboriginal Workforce Development, Western Desert Nganampa Walytja Palyantjaku Tjutaka, Congress, Danila Dilba Health Service, Katherine West Health Board, Jeannie Devitt

### **Border art work**

From NT Palliative Care Model

Design by Bev Derschow

Painting by Barrapuy Wanambi, Dipililnga Marika, Wayalwanga Marika, Samuel M Assan, Nina Puruntatameri, Karina Napagardi Penhall

Proudly supported by  
**Northern Territory  
Government**



**Australian Government**  
**Department of Health and Ageing**

**Northern Territory  
Renal Services**