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
- Blury 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 Rivotrill. 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
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.healthinfonet.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

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