

## Fact sheet

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# Non-dialysis Supportive Care

## What is non-dialysis supportive care?

Non-dialysis supportive care (also called supportive care) is the treatment choice for kidney failure if you have decided that dialysis and transplant are not right for you. This might be because you are already very frail and do not want complex treatments. You may have tried the other treatments for a while and now want to stop.

With supportive care you will still be supervised and supported by health professionals. You may have medications and a special diet to improve your quality of life. Supportive care will not extend your life when your kidneys fail completely. If you are currently frail, your life-span with supportive care is similar to that with dialysis.

For more information about all the treatment options for kidney failure see the *Kidney Failure Treatment Options* fact sheet and visit <http://kidney.org.au/your-kidneys/support/kidney-disease/treatment>

## Can I decide to have supportive care?

You can decide that supportive care is the best treatment for you. This will allow you to die peacefully when your kidneys completely fail.

This decision may be difficult as your family may feel that you should have every possible treatment. Although you can consider the feelings of others and think about other options, it is important to remember that you make the final decision.

It is easier to make a decision about treatment when you have all the information you need. Hospitals offer education sessions about dialysis, transplantation and supportive care. These sessions give you and your family time to ask questions and talk to others in a similar situation. Talking to a social worker, counsellor or your spiritual adviser can also be helpful.

## Why choose to have supportive care?

Many people can enjoy full lives while on dialysis or living with a transplant. It is possible to work, study, care for a family, play sport, travel, and spend time with friends.

However, both dialysis and transplantation have limitations. Transplantation is not always available, or it may not be successful. Transplanted kidneys may eventually fail.

Dialysis requires you to commit to regular treatments, either at home or by attending a dialysis centre. Dialysis may require diet and fluid restrictions. If you also have other medical conditions, including having had a stroke or a heart attack, a lack of independence and poor health may make life on dialysis seem unbearable. Whatever the reasons, you may get to the stage where you feel that dialysis is a struggle. You may not start dialysis because you feel that you do not want a complex treatment to extend your life.

When making a decision about treatment, it is important to remember that it is your choice and that supportive care is one option. If you are not sure, it is always possible to try dialysis to see how things go.

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## What if depression is affecting my ability to make a choice?

Depression can affect 1 in 5 people with kidney disease, and 1 in 3 people on dialysis.

It is normal to feel angry, sad and upset when you are diagnosed with kidney failure. However, this feeling should last for a limited time. If it continues, then you have may depression.

If you think you are depressed it is important to talk to someone, as there are many treatments available.

For more information about depression talk to your doctor, call **beyondblue** on 1300 22 4636 or visit **www.beyondblue.org.au**.

You may also wish to purchase the *SANE Guide to Good Mental Health for People affected by Kidney Disease* booklet available from Kidney Health Australia.

If you have depression, it is important to deal with this before making any decisions about your treatment for kidney disease.

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## Who will look after me if I choose supportive care?

Your general practitioner, a kidney specialist (nephrologist), specialist nurses, a social worker, a dietitian, and a palliative care team are some of the health professionals who may be involved in your supportive care. The palliative care team are doctor and nurse specialists who support you with pain and symptom management. Seeing a palliative care team does not change your lifespan but may increase your quality of life.

Kidney failure symptoms can include itchy skin, restless legs, and general pain. The palliative care team supports you and your family to live independently and in comfort. Some people visit a palliative care team for many years

## What should you do if you decide to have supportive care?

The first step is to talk to your family and your health care team. If you all understand each other and work together, you can make sure that you have the best quality of life until your kidneys fail completely.

It is a good idea to make sure that your affairs are in order, for example:

- Make sure you have a Will
- Think about appointing a Medical Power of Attorney (see [www.australia.gov.au/content/powers-of-attorney](http://www.australia.gov.au/content/powers-of-attorney))
- Consider making an Advanced Care Directive (see [www.advancedcareplanning.org.au/](http://www.advancedcareplanning.org.au/))
- Make a list of your financial records including bank accounts, real estate, insurance policies
- Provide contact details of people who will be helping to settle your estate, e.g. solicitor, accountant and the executor of your Will
- Let people know about your choices for funeral services

Your health care team, Palliative Care Australia [palliativecare.org.au/](http://palliativecare.org.au/) or the Office of Public Advocate/Guardianship in your state can also provide more information.



### THINGS TO REMEMBER

- The decision to have supportive care will allow you to pass away peacefully when your kidneys fail completely.
- The final decision must be yours after you have all the information you need and have spoken to your health care team and family/friends.
- A palliative care team will support you with pain and symptom management which will not change your lifespan.

## What does that word mean?

**Depression** - While we all feel sad, moody or low from time to time, some people experience these feelings intensely, for long periods of time (weeks, months or even years) and sometimes without any reason. Depression is more than just feeling low. It is a serious condition that affects your physical and mental health. There are a range of treatments, health professionals and services available to help with depression, as well as information on what you can do to help yourself. For more information about depression talk to your doctor, call beyondblue on 1300 22 4636 or visit [www.beyondblue.org.au](http://www.beyondblue.org.au).

**Dialysis** - A treatment for kidney failure that removes waste products and excess fluid from the blood by filtering the blood through a special membrane.

**Lifespan** - How long you have left to live.

**Palliative care** - Care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness.

**Transplant** - a treatment for kidney failure where an organ or tissue is removed from the body of one person (the donor) and put it into the body of another person who is very ill (the recipient). Organs that are suitable for donation include kidneys, heart, lungs, liver, intestines and pancreas. Tissues that are suitable for donation include heart valves and tissues, bone and tendons, skin, and eye tissue.

For more information about kidney or urinary health, please contact our free call Kidney Health Information Service (KHIS) on 1800 454 363.

Or visit our website [kidney.org.au](http://kidney.org.au) to access free health literature.

This is intended as a general introduction to this topic and is not meant to substitute for your doctor's or health professional's advice. All care is taken to ensure that the information is relevant to the reader and applicable to each state in Australia. It should be noted that Kidney Health Australia recognises that each person's experience is individual and that variations do occur in treatment and management due to personal circumstances, the health professional and the state one lives in. Should you require further information always consult your doctor or health professional.



If you have a **hearing or speech impairment**, contact the National Relay Service on **1800 555 677** or **relayservice.com.au**

For all types of services ask for 1800 454 363