

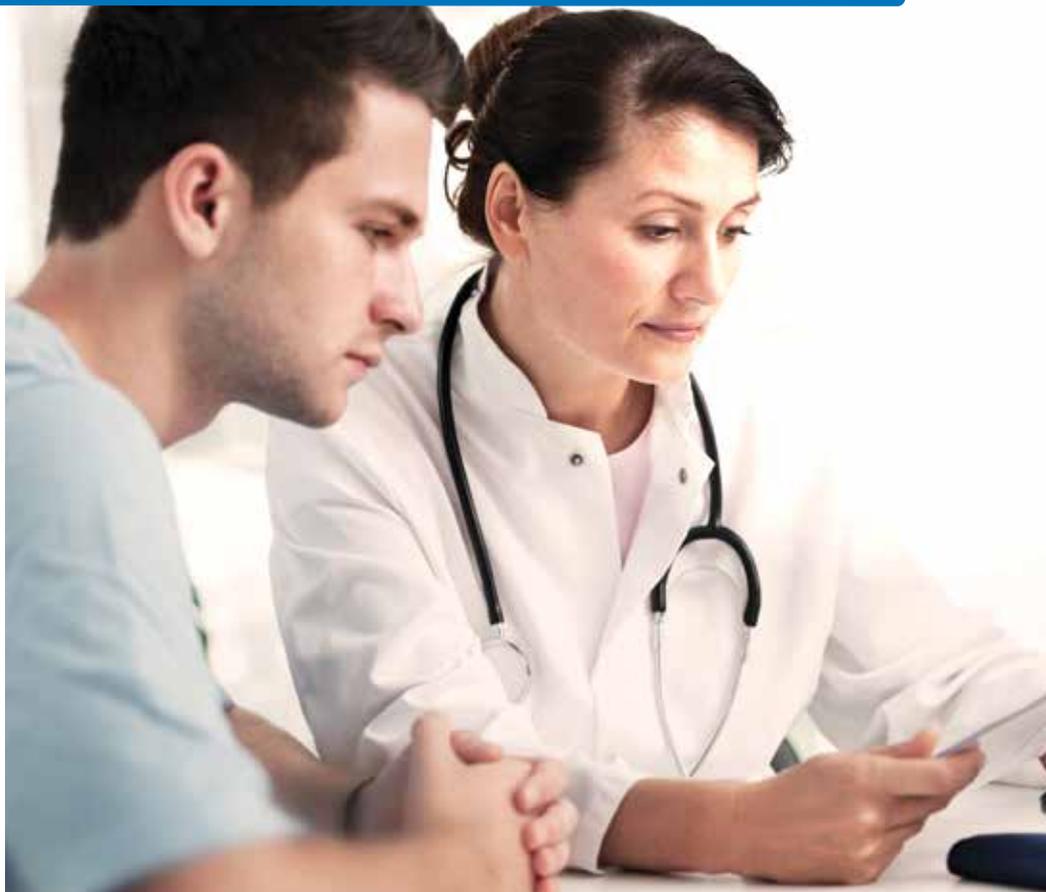
Choosing not to have dialysis

Patient Information



Working together for better patient information

One of the options for treating advanced kidney disease is to manage your symptoms and not have dialysis. This leaflet provides information about the option of choosing not to have dialysis. This leaflet is aimed at adults over the age of 18.



Do I have to have dialysis?

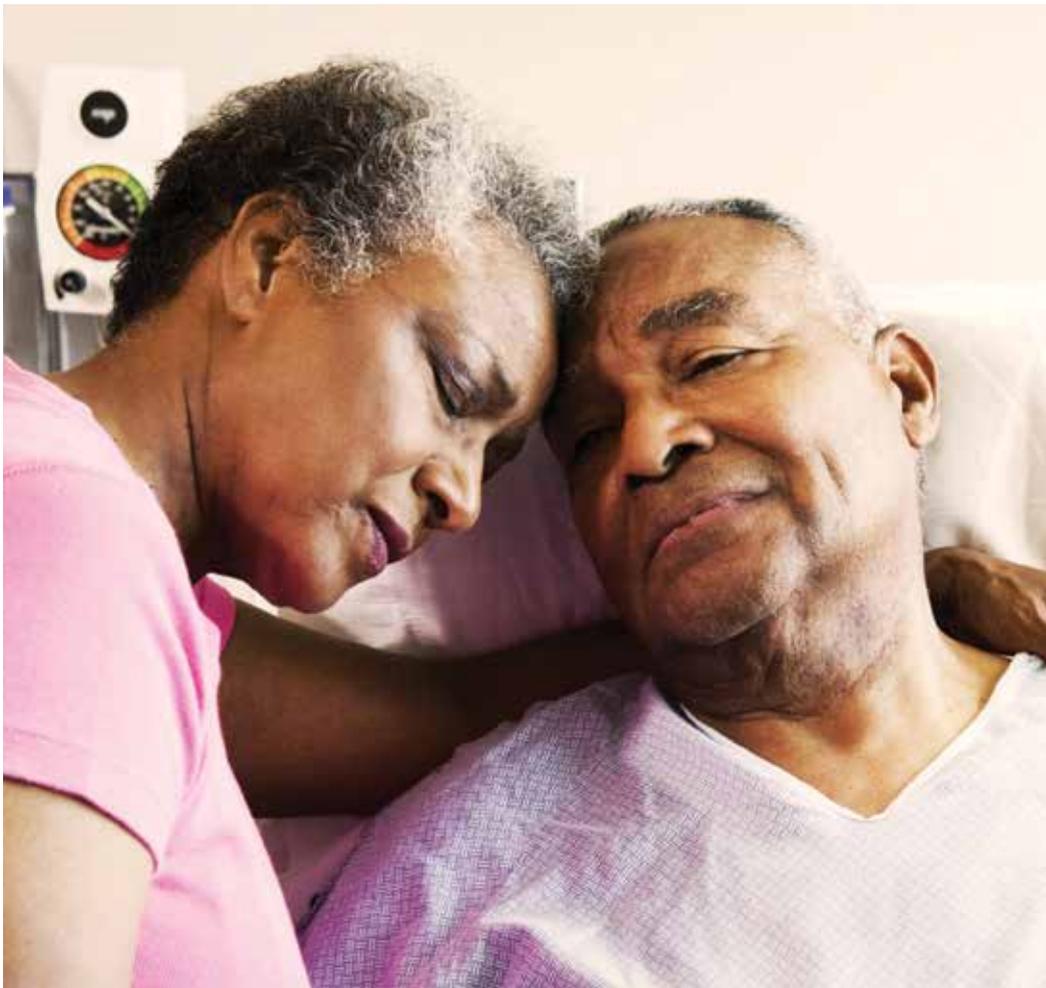
No. This is your choice. As your kidney function gets worse, your kidney team may talk to you about the different treatments that are available for when your kidneys fail. They will also tell you about the option of not having dialysis at all. This is sometimes called 'conservative' or 'supportive' kidney management.

Why would I choose not to have dialysis?

Dialysis can be a life changing treatment. Dialysis helps some people to live longer and improves many of the symptoms of kidney disease but for others it may not.

Dialysis is a demanding treatment and it can make life challenging. In all types of dialysis there are restrictions to your life which are part of the treatment. If you have many medical conditions and you are in poor health, dialysis itself may be an additional burden for your body. Dialysis may not improve the symptoms of any other medical conditions and it is possible that it may even make some medical conditions worse. You may spend a large amount of time in hospital having dialysis or being treated for its complications. It is important to weigh up these factors when thinking about dialysis.





What will happen if I choose not to have dialysis?

Your doctors and nurses will continue to work hard to keep you as well as you can be. The following are ways that your kidney team can help:

- Protect your kidney function by ensuring your blood pressure is controlled
- Treating anaemia which is common in advanced kidney disease
- Advise you about your diet and fluid intake
- Treat the symptoms of kidney failure
- Support you and your family when your health gets worse

What else can I do to stay as well as possible?

- When you have advanced kidney disease, your kidney function will gradually get worse over time. Although you can't prevent this happening, you can try and protect your kidneys from further damage. You now need to be very careful when you buy medicines at the chemist. Always tell your doctor and pharmacist that you have kidney disease and check that the medication you are given is safe to take.
- Eat a healthy diet. If you are unsure about what is good and bad to eat in kidney disease, have a chat with your doctor, nurse or dietitian. You might need advice about avoiding diets high in salt, potassium and phosphate.
- Make sure that you get treatment for any other illnesses early. Your kidneys are vulnerable if you get unwell and can get worse quickly.
- When you have a long term illness like kidney disease you are more likely to get other illnesses. You can protect yourself by having your winter flu vaccine and make sure you ask your doctor about the vaccine against pneumonia.





How long will I live without dialysis?

It is difficult to be accurate about life expectancy, as this depends on your individual medical conditions, general level of health and the speed that your kidney disease has progressed.

If I die of kidney failure, what should I expect?

Generally, the symptoms of kidney failure get worse slowly over time. You may notice that you become sleepy and gradually weaker and have other symptoms such as losing your appetite, feeling sick and itchy skin. Your team of doctors and nurses will be able to support you and your family.

What support and help will there be as my kidney function gets much worse?

Your doctor or nurse may suggest talking to specialists in end of life care.

These doctors and nurses are known as the palliative care team and they will talk to you about how you would like to be looked after as your kidney function declines. These discussions are known as Advanced Care Planning. They may involve your GP, your family and staff from your local hospice.

Some things you may wish to think about include:

- Making or checking your Will, and considering a Power of Attorney so that someone can make decisions on your behalf
- Making funeral arrangements and decisions about organ and tissue donation
- Thinking about a Living Will and discussing this with your GP who can support you to ensure that your wishes are respected.
- Making a list of important contacts, financial accounts, insurance plans, pensions and other legal papers.
- You may also need advice from a social worker to help with housing, social and financial issues.

It can be daunting to think about this. Your GP, the palliative care team and your kidney team are here to support you.



Where can I find out more information?

- NHS Choices website - End of life care: www.nhs.uk/planners/end-of-life-care/pages/end-of-life-care.aspx
- Kidney Research UK – Dialysis Decision Aid: www.kidneyresearchuk.org/file/health-information/KR-decision-Aid-print-friendly.pdf



 www.kidneycareuk.org

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