

Choosing not to have dialysis

Conservative kidney management



One of the options for treating advanced kidney disease is to continue managing your symptoms and focusing on maintaining your quality of life. This leaflet provides information about the option of choosing not to have dialysis.



What is the alternative treatment to dialysis?

As your kidney function gets worse, your kidney team will talk to you about the different treatments that are available for when your kidneys fail, such as dialysis.

They will also tell you about the option of not having dialysis. This is called **conservative kidney management**.

Why would I choose conservative kidney management?

Dialysis is a life-changing treatment. It helps some people to live longer and improves many of the symptoms of kidney disease.

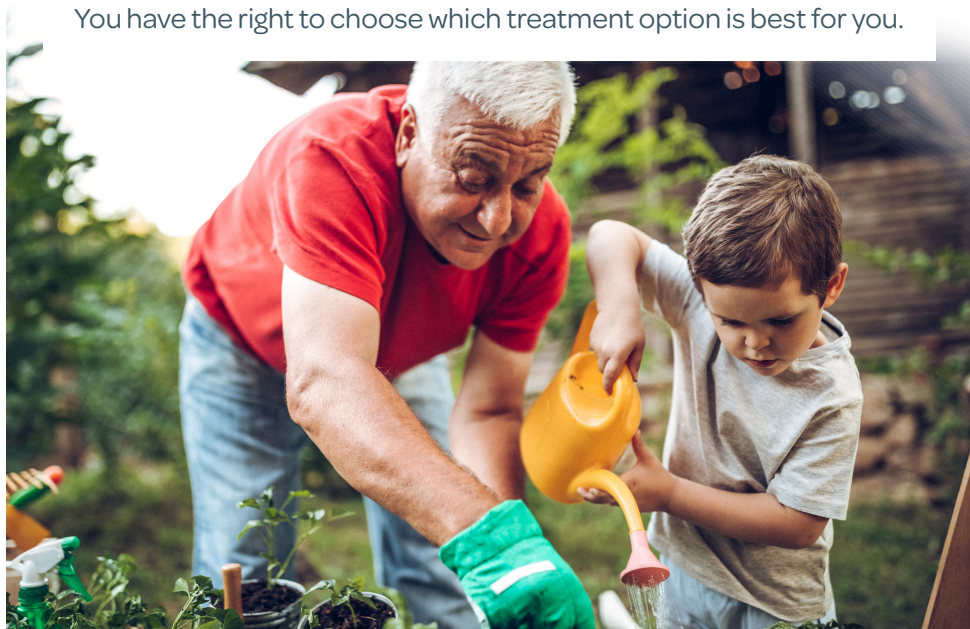
However, dialysis will not cure your kidney failure. Once you start dialysis you will need to continue with it for the rest of your life, or until you receive a kidney transplant.

If you are older, or have other medical problems that limit your ability to do everyday activities, dialysis may be an additional burden for your body. Dialysis may not improve the symptoms of other medical conditions and it may even make some of them worse.

People who choose dialysis spend more time in hospital than people receiving conservative kidney management. Dialysis may therefore limit your ability to do the things you enjoy in life.

However, dialysis helps to keep you alive so choosing conservative kidney management will shorten your life.

It is important to consider these factors when thinking about whether to choose conservative kidney management or dialysis. You have the right to choose which treatment option is best for you.



What will happen if I choose conservative kidney management?

Your doctors and nurses will continue to work hard to keep you as well as you can be. Treatment for conservative kidney management includes:

- Regular appointments with your kidney team.
- Monitoring and controlling your blood pressure to protect your kidney function.
- Treating anaemia – a shortage of red blood cells in your body.
- Providing advice about your diet and fluid intake.
- Treating any symptoms of kidney failure like itching.
- Helping you to make plans for the future and supporting 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 completely, there are things you can do to protect your kidneys as much as possible.

- **Eat a healthy diet.** Some foods that are high in salt, potassium and phosphate can be harmful to your kidneys. A dietitian can give you specialist advice on how you can adapt your diet.
- **Take regular exercise.** This can be as simple as increasing the amount of walking that you do each day. Doing any amount of exercise is better than none. Your kidney team can give you advice about how to exercise safely.
- **Give up smoking.**
- **Give up or cut down on your alcohol intake.**
- **Keep up to date with your vaccinations.** When you have kidney disease, you are more likely to get other illnesses and take longer to recover. This can make your kidney function worse, so it is important to get treatment early. Ask your GP about having flu, pneumonia and Covid-19 vaccinations.
- **Some over-the-counter and prescription medicines can make your kidney disease worse.** Always tell your doctor and pharmacist that you have kidney disease and check that the medication you are given is safe to take.

How long will I live if I have conservative kidney management?

It is difficult to predict how long you will live if you choose to have conservative kidney management. It will depend on your age, general level of health, any other medical conditions and how quickly your kidney disease is progressing.

If you have very little kidney function left, it is likely you will die within a few weeks or months. Some people with end stage kidney failure will die as a result of another illness, such as cardiovascular disease or cancer.

What will happen if I die of kidney failure?

Generally, the symptoms of kidney failure get worse slowly over time. During the last few weeks of life, you will become weaker and more sleepy. You may lose your appetite, feel sick and have itchy skin.

Your kidney team will keep you as comfortable as possible. They will support you and your family to ensure that your treatments and care are carried out according to your wishes.

During the last days of life, you will become more drowsy and eventually fall into a coma (unconscious) and then die.

This is usually peaceful and free of suffering.

Is not having dialysis the same as suicide?

No. Dialysis is a medical treatment and you always have the right to decide not to accept medical treatment. You may wish to discuss this further with a religious or spiritual advisor. Your kidney team can help with this.



What support is available as my kidney function gets worse?

Your kidney team can refer you 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 gets worse. These discussions are known as **advance care planning**.

They may also include your GP, your family and hospice staff. You may want to think about:

- **Expressing a preference** for where you would like to be cared for and where you would like to die. This may be at home, in a hospice or in hospital, for example.
- **Expressing a preference** for the types of medication and treatment that you would like to receive, such as pain medication.
- **Making or checking your Will.**
- **Consider making a lasting power of attorney (LPA)** so that someone can make decisions on your behalf. Please note that an LPA can take up to 20 weeks to register.
- **Making funeral arrangements** and decisions about organ and tissue donation.
- **Making a list of important contacts**, financial accounts, insurance plans, pensions and other legal papers.
- **Letting a family member or close friend have access to your social media accounts** to either close them or leave them as a memorial after you die.
- **Getting advice from a social worker** to help with housing, social and financial issues.

It can be very hard to think about these things. However, having a plan in place means your kidney team and family know your preferences for the type of care that you would like to receive at the end of your life.

Where can I find out more information?

- **Kidney Care UK** Treatments – www.kidneycareuk.org/treatments
- **Dialysis Decision Aid** – www.kidneyresearchyorkshire.org.uk/yorkshire-dialysis-and-conservative-care-decision-aid
- **Marie Curie** Planning ahead checklist – www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/start-planning-ahead
- **NHS Choices: end-of-life care** – www.nhs.uk/conditions/end-of-life-care

Contact us to see how we can support you

Call free on
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If you have feedback about this leaflet, please let us know at: **feedback@kidneycareuk.org**

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