Choosing to stop dialysis

Conservative kidney management







Patient Information Forum



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One of the options for treating advanced kidney disease is to stop dialysis and focus on managing your symptoms and maintaining your quality of life. 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.

Over time, however, dialysis may no longer allow you to have the quality of life that you want.

You may experience symptoms that are not getting better. It might become more difficult to travel to and from your dialysis sessions. Or you might have other health conditions that are getting worse.

Talk to your kidney team if you are finding dialysis difficult to cope with. You may be able to switch to a different type of dialysis or reduce the number or length of dialysis sessions that you have each week.

Another option is to stop dialysis all together and move to conservative kidney management.

Dialysis helps to keep you alive so choosing conservative kidney management will shorten your life.

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.





• **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 a 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 choosing to stop 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 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/



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Publication date 11/2023 Review date 11/2026



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