

Choosing to stop dialysis

This leaflet is for kidney patients receiving long term dialysis who are considering discontinuing their dialysis treatment. If you have any questions or concerns about anything mentioned in this leaflet, please speak to your supportive care nurse.

Why might I decide to stop my dialysis treatment?

There may come a time when you feel you want to stop dialysis treatment. You may feel that dialysis is no longer maintaining or improving your quality of life. If this happens, it is important to know that you have the right to stop dialysis. However, before making this decision, it is essential that you discuss it carefully with your loved ones and your kidney team.

There are a number of reasons why you may consider stopping dialysis:

- You may feel that your quality of life on dialysis has become unbearable or that dialysis is no longer improving your quality of life.
- You may be finding that it is becoming increasingly difficult to travel to the dialysis unit.
- You may feel that dialysis is no longer maintaining or improving your health because you are unable to live independently or enjoy a certain quality of life.
- You may be experiencing difficult symptoms.
- Your health may be deteriorating due to other health conditions as well as your kidney failure.
- You may consider stopping dialysis for personal reasons related to your individual circumstances.
- Your kidney team may discuss the option of stopping dialysis with you.

What should I consider before deciding to stop dialysis?

You have the right to consider stopping dialysis if you wish. People think about stopping dialysis for many reasons. However, it is very important that you discuss this with your family or friends and with your kidney team. Your kidney team can offer you help and support while you are making your decision.

Discussions about stopping dialysis can take place in the hospital, the dialysis unit or in the outpatient clinic with members of your family or friends present, if you wish. In some cases it may be appropriate to discuss the options in your own home.

It is essential that you let your kidney doctor or nurse, or another member of the kidney team know that you are considering stopping dialysis. This is so that we can arrange for discussions about stopping dialysis to take place. In some instances you may wish to discuss this first with your GP.

You may feel unable to talk to your loved ones about stopping dialysis because you are afraid of how they might react. A member of your kidney team can be present to help you discuss this with your family and friends, if this is what you would like.

Deciding to stop dialysis can be a very difficult decision to make and you may benefit from talking to one of our kidney psychologists or counsellors who will be able to offer you emotional support at this difficult time. Your kidney doctors, kidney nurses, social workers and the chaplain are also available for support and discussion.

What happens when I stop dialysis?

For the first few days after stopping dialysis you may feel no different and continue to eat and drink as normal. Without dialysis, toxic waste products and fluid will build up in your body. You may start to develop some symptoms such as feeling sick, itching, shortness of breath, feeling restless, and general tiredness. It is unlikely that these symptoms will develop all at once, but they may all appear gradually.

If these symptoms occur, medication can be given to help control them and keep you as comfortable as possible.

How long will I live once I've stopped dialysis?

There is no definite answer to this question and this can vary considerably between individuals. Once dialysis stops, survival is usually between a few days and a few weeks.

Dying from kidney failure is usually painless and medication can be given to relieve any symptoms.

Where will I be cared for once I stop dialysis?

Talking about stopping dialysis allows you time to discuss your wishes and preferences for end of life care with your family, friends and your kidney team.

Depending on your wishes and preferences, you will be cared for by your kidney team, GP, district nursing team, carers and local palliative care or hospice services, all of whom will provide support for you and your family. We will talk to you and your family about these options in more detail.

We understand that you may change your mind about where you wish to be cared for as you become more unwell. The important thing is that you discuss this with your family, friends and your healthcare team so that they can help with this.

Is stopping dialysis considered to be suicide?

Stopping dialysis is not suicide. Nor is it euthanasia or assisted dying. Suicide occurs when a person takes action to cause death. When somebody stops dialysis, the cause of death is kidney failure.

Many religions teach that individuals have the right to stop treatment, including dialysis, if they feel it has become more of a burden than a benefit.

If you have concerns about this, you may wish to discuss it further with your religious or spiritual advisor. Alternatively, we can refer you to our chaplaincy services here at the hospital.

Is there anything else I need to know or should do?

Many of us are reluctant to think about arrangements that need to be made in the event of our death. However, if you make the decision to stop dialysis, you might like to think about:

- discussing your thoughts with family, friends, a member of your kidney team, or your religious or spiritual advisor
- when you would like to stop dialysis
- making a will or checking that your existing will is up to date
- letting people know your wishes and preferences for where you would like to be cared for at the end of your life
- making funeral arrangements.

If you have any further questions, please speak to a doctor or nurse caring for you.

Contact us

Your dedicated renal supportive care nurses can give you help and advice regarding stopping dialysis and the care that will be available to you. You can call them on **020 7188 5720** or **020 7188 7548** (9am to 5pm, Monday to Friday).

Alternatively, you can speak with your local palliative care service via your GP.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and Accessible Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

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