

If I choose to stop Dialysis – Why, How and What next?

Sussex Kidney Unit



Information for patients and families

Choosing to stop dialysis

You have the right to make informed choices about your treatment for kidney failure. That means you can choose to start and to stop dialysis. We will give you all the relevant information in order that you can make an informed decision.



This leaflet seeks to inform you, your family and carers of what it means to stop dialysis.

Why would I choose to stop dialysis?

Living with an illness like kidney failure can be physically challenging and emotionally painful. Dialysis is meant to improve your quality of life, not cause harm and suffering. Stopping dialysis is a personal decision based on how you perceive your quality of life and future prospects.

It is important that you are sufficiently well informed to make a decision to stop dialysis and that you have the capacity to appreciate the consequences. Capacity is the ability to make decisions for yourself. Please also be mindful that your health care team can help you address other factors that weigh on your decisions.

Examples are: depression and the burden of excessive dialysis that could be changed to improve your perceived quality of life.

What would happen to me if I stopped dialysis?

If you stop dialysis your health may deteriorate quite quickly and will ultimately end in your death. Each person reacts differently and at a different pace when dialysis is stopped, depending on their medical conditions.

Without dialysis treatment, fluid and toxic wastes would build up in the body, making you feel increasingly drowsy possibly leading to unconsciousness. It is normal to experience loss of appetite and you could experience some breathlessness that would be treated with medication to maintain physical comfort.

What type of food and drink could I have?

If you choose to stop dialysis there is generally no reason to continue to follow your renal diet. Restricting your fluid and salt intake can help lessen any discomfort experienced due to shortness of breath. Your doctor and dietician would be able to answer specific questions you may have about diet and fluid intake.



How do I talk about this with my family and friends?

The decision to stop dialysis can be a very difficult and painful choice to make and to share with those close to you. If you are considering the decision it is important to talk with your loved ones as you will need to help them to understand how you are feeling. Although you may find it hard at first, the best approach is to discuss your feelings openly. It may be that you are finding your quality of life is not as you would wish it to be, this may be due to reasons other than your renal failure. If you become too unwell to make your own decisions your family may have to make treatment decisions for you. For this reason you need to share your feelings with them. A good way to do this is to complete an Advance Care Plan where you can document any specific requests. The renal counsellor and other members of your health care team can help you prepare for this difficult conversation and to provide you with the Advance Care Plan, which if you choose to complete it will outline your wishes for end of life care.

What kind of support can I get?

If you are considering stopping dialysis you should talk with your healthcare team about what kind of help may be available to you in the hospital or in the community. Every community is different and every patient's needs are different.

What can be done if I have any pain or discomfort?

Any symptoms you may experience can be treated with medication to relieve the pain and to help you relax. These can be given in the community as well as in the hospital. If you are no longer able to take medication by mouth they can also be given by injection or patches. With excellent symptom control, your death should be peaceful and pain free.

How long will I live if I choose to stop dialysis?

This varies from person to person and may be as little as a few days to a few weeks depending on the kidney function you have left and your overall medical condition. Your doctor may be able to give you some indication of how long you may have.

Can I choose where to die?

We are committed in honouring people's wishes about where they want to die. Many people choose to die at home; in familiar surroundings where they are more comfortable. We will do all that we can to ensure your wish is followed. A nursing home, hospice or a hospital are other options which may be more appropriate depending on your personal needs. Please speak to the nurses or doctors who look after you on the dialysis unit about any wishes you may have.



Can I change my mind and go back on dialysis?

The simple answer is that yes you can go back on dialysis. This should be discussed with your doctor, who may suggest that the treatment of symptoms may be more suitable for you instead of returning to dialysis.

What else do I need to have in place?

Whether you choose to consider stopping dialysis or not, we recommend that you organise the following:

- Making of a Will,
- Deciding on a Power of Attorney (Health and Welfare and Property and Finance)
- Completing an Advance Care Plan.



These documents give you the opportunity to outline your wishes for your personal care and funeral preferences.

Questions to ask your healthcare team:

Will my healthcare team still look after me?

If you choose to stay at home your overall care will be transferred to the community. If you move to a nursing home or hospice, you will be cared for by their staff. But there will always be a renal doctor available to answer any questions there may be around your medications, fluid management or any other concerns you or your carers may have. If you choose to stay or come into hospital, we would strive for admission to a ward which is familiar to you and your family and the renal team would continue to oversee your care.

Who will be there to support my family?

Wherever you choose to be when you are dying, your family will be supported by the doctors and nurses looking after you at the time. You may be aware that we also have renal counsellors who can offer support to your family.

Where can I find further sources of information?

British Kidney Patients Association

www.britishkidney-pa.co.uk

Telephone: 01420 541424

Useful numbers

Angela Cole Lead Nurse Dialysis

01273 696955 extension 67598

Renal Outpatient Department 01273 664559

Main Dialysis Unit 01273 696955 extension 64605

Renal Ward 01273 696955 extension 64057

Renal Counsellors 01273 696955 extension 64097

Chaplain specialising in renal care:

Brighton 01273 696955 extension 64122

Princess Royal Haywards Heath 01444 441881 extension 8232

If you require this document in a language other than English please inform your interpreter or a member of staff.

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Se precisa deste documento noutra língua por favor informe o seu interprete ou um membro do pessoal.

Disclaimer

The information in this leaflet is for guidance purposes only and is in no way intended to replace professional clinical advice by a qualified practitioner.

