NHS
Royal Berkshire
NHS Foundation Trust

Choosing not to have dialysis: What happens next?

This leaflet is for patients who decide not to have dialysis for kidney failure. It explains how we monitor you and help you to control your symptoms.

Introduction

Deciding not to dialyse is an important decision that will have taken you time to make. You should have had several discussions with various members of the renal team and the appropriate members of your family, resulting in you feeling comfortable with your decision.

What happens now?

Providing you are feeling well, you will continue to attend clinic appointments, and carry on taking the prescribed medication. We will monitor your blood tests regularly and amend your medication to control your symptoms and keep you feeling well for as long as possible. As your kidney blood tests decline, we will see you in clinic more frequently to make sure that any symptoms you may have are well controlled.

As your kidneys reach the point of doing very little, it may become increasing difficult for you to come into the hospital. If this does happen, please cancel your appointment but you must telephone the kidney care nurses to let them know, and if necessary, we can arrange a home visit to make sure you are as comfortable as possible. At this point, we will have already been in contact with the professionals in the community that are linked to your GP, and the social workers to ensure the care is increased to a level that you require. We will then continue to keep in touch by telephone and visits, ensuring we keep up with your care needs.

If you are unable to come into the hospital, we will hand a lot of your care over to your GP and their team. They have had the training needed to enable them to control your symptoms and care for your renal failure. However, your care will always be overseen by the hospital renal team.

Not having dialysis

It is important that you understand that having chosen not to have dialysis, you will still be treated actively with medication. The treatment aims are to protect the kidneys, maintain their function for as long as possible, while treating the symptoms of renal failure.

Measures to preserve your remaining kidney function

A small amount of kidney function can go a long way to keeping you feeling well and free of major symptoms. The kidneys will naturally tend to get worse as time goes by, but the rate of this varies from patient to patient, and may even be reduced with good management. The most important of these is **good control of the blood pressure**. Already damaged kidneys are more susceptible to further damage and some 'over the counter' drugs can cause major problems. One example of these are non-steroidal anti-inflammatory painkillers, such as Ibuprofen (Brufen or Nurofen). It is always advisable to check with the renal team before taking any new medications. **It is also important to avoid dehydration**, especially during illnesses within the family, such as diarrhoea and vomiting.

Treating anaemia

Anaemia is very common in renal patients and can manifest itself quite early on. Fortunately, the hormone that is usually produced by the kidney to help manufacture red blood cells can be given in the form of an injection. You may also be iron deficient, which will contribute to anaemia. This can be corrected by having iron given to you, either into your vein (IV) or by taking tablets. Anaemia accounts for many symptoms of renal failure, particularly tiredness and weakness. Fortunately, this is usually easily managed.

Is there a need for a special diet?

We recommend a healthy balanced diet. It is important that you enjoy what you are eating but some dietary modifications may help. It is useful to reduce your intake of salt, as too much of this can cause retention of fluid. We also advise to reduce the intake of foods that contain a lot of potassium, such as bananas, chocolate and citrus fruits. In some circumstances, it may help to reduce the protein intake but this depends on the individual patient and should be discussed with the renal dietitian.

Is there a need for fluid restriction?

Restricting salt can help prevent the build-up of fluid in the in the body. Diuretics (water tablets) are often used if fluid retention becomes a problem. If these diuretics become less effective, it may be necessary to limit your fluid intake. Again, this should be considered during discussions with your renal consultant.

Other symptoms

As kidney failure progresses, other symptoms will occur. The doctors will prescribe various medication to try to control these, for example, anti-emetics will be prescribed for nausea and anti-pruritics to alleviate itching. Many symptoms can be treated and it is important to realise that renal failure does not usually cause pain.

Will I have the choice of where I die?

Many people prefer to die at home, where they feel more comfortable and can be in familiar surroundings. This is especially so when there is help from family and friends, who are being supported by the community care team. If it is becoming difficult to care for you at home, it may be possible to care for you in a nursing home. It is important to ensure that the particular nursing home is accessible by family and friends so that they can visit. Hospice care is quite restricted but could also be available if help is needed controlling symptoms. A hospital admission may also be an option for some people. These options should be discussed with the specialist nurses and doctors so that plans can be made to support your wishes and those of your family.

Should I write down what I want to happen?

It is often useful to write down your plans; it can then be copied into your health records so that all the medical team are clear of your wishes. The doctor will reassess the plan periodically with you to make sure you do not want to change anything.

Will there be support for my family?

The family of a dying patient are always considered as part of the care package; your family will have as much support as they need while caring for you. The amount of care you need often depends on the physical ability and the psychological needs of the carer.

Is there anything else I should know or do?

Many of us do not like to think about arrangements that need to be made before we die; however, it can make the last few weeks less stressful for both you and your family if decisions have been made about the following.

- Making a will.
- Make a list of names addresses and telephone numbers of those who need to be informed of your death.
- Make a list of important contacts, banks insurance policies, financial accounts, pension plans and solicitors.
- Write a plan for you funeral arrangements.
- Gather any written messages you would like to leave to loved ones.

What if I have further questions?

It is likely that all sorts of questions will arise; there is always someone to ask.

- If you have medical concerns, please talk to the doctors or kidney care nurses.
- If you have legal worries, such as making a will, you need the advice of the solicitor.
- If you have concerns about the support provided to you and your family, please contact any member of the renal team involved in your care.

Thinking about dying can be difficult and sad, but with the appropriate support, we hope to make your end of life care as comfortable as possible.

Contact us

Department of Renal Medicine (Kidney Care Team) telephone: 0118 322 7969
or email rbb-tr.renal.enquiries@nhs.net

Out of Hours / Bank Holidays – Victoria Renal Ward 0118 322 7476

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

Department of Renal Medicine, April 2025. Next review due: April 2027.