

What happens if I choose not to have dialysis?

Information for patients from the Kent Kidney Care Centre

The aim of this leaflet is to let patients and their relatives know about the care that is available when dialysis is not advisable or wanted.

When your kidneys are working effectively, they filter out waste products that build up inside your body. The kidneys also balance the body's fluid content and produce urine. When your kidney is no longer working properly, these waste materials and fluid collect in your blood. The effects of the unwanted waste and fluid in your body cause many **symptoms** and you may start to feel unwell. Some symptoms can be relieved by medication and/or by dialysis treatment.

Patients may experience severe symptoms of kidney failure, which affect normal daily life because the levels of toxins and/or water in the body are high. Dialysis is then needed to remove the toxins and control fluid levels in the body. Dialysis is not a cure for kidney failure but it can relieve some of the symptoms.

For many people with kidney failure a life with dialysis can be a full and rewarding time. However, there are some people that feel they would not wish to live with the limitations imposed by the treatment. When the need for dialysis approaches, those people whose lives are seriously restricted by other illnesses or who are elderly, may decide that they would rather allow nature to take its course. What is important to remember is that you do not have to have dialysis.

We do not know if dialysis will prolong your life, but research has shown that for those who have complex medical/terminal illnesses it does not. It is possible that in these cases dialysis may even shorten their lives. Even in circumstances where life is prolonged a little, their quality of life may be poorer than if they had not started dialysis. Only you can judge whether your quality of life is acceptable in your discussions with medical and nursing staff about whether to start dialysis or not.



Making a choice: is dialysis right for me?

During your clinic visits the doctors and nurses will explain to you what dialysis involves and what it means not to have dialysis. We also talk about this at the patient information sessions. We want to give you the full picture so you can make an informed, rational choice about whether you want dialysis or not.

You will be given time to think and discuss your options with your family, and the medical and nursing teams. You may not feel that you could cope with the difficulties involved with dialysis or you simply do not want it. If you decide not to have dialysis, it is important that you understand you can change your mind in the early stages.

What will happen if I decide not to have dialysis?

You will be referred to the conservative management team. The team is available to meet the needs of those who do not wish to have dialysis. The team includes:

- a medical consultant
- a nurse consultant
- renal nurses
- a renal care navigator
- a renal counsellor.

These people have specialist skills to help and support you and your family. The team will help to:

- control unpleasant symptoms
- keep you as comfortable as possible
- help you in dealing with your feelings
- help you get appropriate care in the community
- keep your GP informed of any changes in treatment
- liaise with the palliative care team, including hospice specialists.

How long will I live if I do not have dialysis?

This varies from person to person and is very difficult to predict. It depends on the extent of kidney damage and on your overall medical condition. There is no set time.

How will I feel?

The way you feel reflects the symptoms that you have and it varies from person to person. Some people have many symptoms while others have few. It is important that you tell the consultant and the nurses how you feel, as you can be given medication to try and control these symptoms.

Some of the symptoms include:

- excessive tiredness
- nausea (feeling sick)
- feeling out of breath (breathlessness)
- a lack of appetite
- itchy skin
- agitation
- irritability
- confusion.

Nausea is caused by the build-up of waste products in your body that are usually removed by your kidneys. There are several drugs available that can be used to reduce or prevent it.

Breathlessness is generally due to heart failure or the build up of excess fluid that is usually removed by your kidneys. Drugs and suction treatment can be used to keep your lungs clear and reduce breathlessness. Some of the drugs used to treat nausea, pain, breathlessness, and agitation can cause drowsiness, but careful administration of drugs can increase comfortable feelings and reduce feelings of distress.

You may experience some **pain** in your body which is difficult to define. Please discuss this with the doctor or nurse when you see them.

Planning ahead

You may wish to prepare for the future, to think about, talk about, and write down your preferences and priorities for care at the end of your life. You do not need to do this unless you want to. If a time comes when, for whatever reason, you are unable to make a decision for yourself, anyone who has to make decisions about your care on your behalf will have to take into account anything you have written in your plan.

You may find that your feelings about your care change over time, this is completely normal and simply reflects that different things become more or less important at different times, we do not always cope or respond as we expect in a given situation. You should make sure that any plans you make are kept as up to date as possible.

There are specific documents available to help you make your choices and decisions and the conservative management team will be there to advise you of these.

Who will look after me?

You and your family will be given time to discuss this with members of the conservative management team, all of whom are there to support you.

If you wish to be at home, a member of the conservative management team will come and visit you, as well as your GP and the community nurse, should you need them. You can still come to clinic as long as you feel able.

You may need help with your daily care needs and our Renal Care Navigator can help to organise this for you.

Support from the local hospice team is also available and they can see you at home if you wish.

Who will support my family and friends?

Everyone in the team is there to support your family and friends in whichever way they would like. This could be giving them time to talk in clinic, at home, or via the telephone. The renal counsellor is available to help people express and manage their thoughts and feelings.

Useful phone numbers

- | | |
|---|---|
| • Karen Jenkins, Renal Nurse Consultant | Telephone: 01227 86 41 42 |
| • Advanced Kidney Care Team Nurses | Telephone: 01227 78 30 19 |
| • Amanda Bevin, Renal Counsellor | Telephone: 01227 86 43 80 |
| • Hazel Hood, Renal Care Navigator | Telephone: 01227 61 27 34
(Monday to Thursday) |

This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhuft.nhs.uk/patientinformation