

What is non-dialysis care?

This leaflet explains about not choosing dialysis for kidney failure – known as ‘non-dialysis care’ – what it means for you and how your condition will be managed without dialysis.

Does everyone choose dialysis?

For many people with advanced kidney disease, dialysis treatment can extend and greatly improve their quality of life. However, the treatment can be demanding and time-consuming and it is necessary to make lasting changes to life style. Although it is possible for these people to adjust and still lead a fulfilling life, dialysis is not a cure all treatment. The treatment replaces some of the functions of the kidney but does not benefit other health problems. Because of this, dialysis may not improve the quality of life for some people. The need to change lifestyle can also be an added burden that some patients with other serious medical conditions or the generally frail would not be able to manage.

Deciding not to have dialysis

The decision not to dialyse cannot be undertaken lightly. This decision is reached after you have had discussions with various members of the renal team and your family. When all forms of treatment have been discussed, we can then decide together which form of treatment would be the most appropriate for you.

Who can I talk to about making this decision?

Within the Renal Unit, there is a team of health care professionals who are qualified and experienced in discussing the issues surrounding the choice of dialysis. They are the consultants, the renal nurses and a social worker. All of these people are available to talk to you with or without your family. These meetings can be initiated from your routine clinic appointment.

Will the doctors be supportive if I choose not to have dialysis treatment?

Yes. Although it is initially assumed that all patients will have dialysis treatment, the doctors recognise that it is not always the most appropriate form of treatment, and is not always what the patient would prefer. You will still be seen in the Low Clearance Renal Clinic and you will still be cared for and supported by the kidney care nurses, who can liaise with other members of the team when necessary. Your blood tests will still be monitored regularly, and you will be prescribed the necessary drugs to treat any symptoms that occur.

What if I change my mind?

Nothing is set in stone, it is quite common for people to change their minds and the renal service is always prepared for this. If you have decided not to have dialysis treatment, and at any point in the future, you are unsure about this decision, please contact the renal nurses or consultants and we can discuss the issues surrounding your doubts. It may be that you just need some reassurance in your choice or that we need to start planning for dialysis.

What if I cannot decide?

It is sometimes hard to decide whether dialysis treatment would have any benefit to you or actually make your quality of life poorer. In this situation, it may be appropriate to start dialysis. If at any point in the future you are still unsure about the decision, you will be able to discuss it with the nurses and doctors caring for you.

I find it hard to talk to my friends and family

It is always difficult to discuss sensitive issues with loved ones. People are often worried that they will be upset or are not sure how they will react. With difficult discussions, it is often best to be honest and open. It may be useful to involve the renal team whilst having these conversations. The kidney care nurses are available to talk to either here at the hospital or if preferred in your own home.

Is deciding not to have dialysis, suicide?

Dialysis is a treatment not a cure and everyone has the right to refuse treatment, if they feel it will not be of any benefit. You may wish to speak to a senior member of your religious organisation if you have one, for guidance in this issue.

Choosing not to have dialysis

It is important that you understand that by not having 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 possibly be reduced with measures other than dialysis. **The most important of these is to ensure 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. Examples of these are non-steroidal anti-inflammatory painkillers, such as 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 if there are any 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 in kidney disease. 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 or by taking tablets. Anaemia accounts for a lot of the symptoms of renal failure, particularly tiredness and weakness. Fortunately, this is usually easily managed.

Is there a need for a special diet?

The overall aim is to 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. It is also a good idea 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 amount of protein you eat, but this depends on the individual patient and should be discussed with the renal dietitian, before making any changes.

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 discussed with your renal consultant.

Other symptoms

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

How long will I live without dialysis?

This varies from person to person, and depends on many factors. If a person has another serious medical condition, the outcome may not be affected by the decision to dialyse or not. The other main factor to affect the length of a person's life is the amount of kidney function that is left when the decision is made. If the decision is made early, with the right attention, the function may go on for a number of years. However, if the patient has very little function, then the survival is likely to be less. This question should be discussed with the consultant or specialist nurse at one of your appointments.

And finally...

Non-dialysis care is a valid form of care that is more suited to some renal patients than others. As a team of renal professionals, we are here to help you explore the issues surrounding dialysis and renal failure, enabling you to make the appropriate decision for you as an individual.

Contacting us

Kidney Care Nurses 0118 322 7899

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, February 2023

Next review due: February 2025