

Other leaflets to help you with your diagnosis of end stage renal disease are :

Frequently Asked Questions

Introduction to Haemodialysis

Home Dialysis - the advantages

What is Peritoneal Dialysis

Introduction to Peritoneal Dialysis

Are there different types of Peritoneal Dialysis

Peritoneal Dialysis - Frequently Asked Questions

New Patient Support pack

Care of your Fistula

The NKF have over 150 titles in our Kidney Matters Series relating to chronic kidney disease, kidney diseases, diet, transplantation and living donor.

Please call our [free Helpline number 0800 169 0936](tel:08001690936) for more information and to see if we can help you.

The National Kidney Federation cannot accept responsibility for information provided. The above is for guidance only. Patients are advised to seek further information from their own doctor.

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www.kidney.org.uk

*The NKF - the largest Kidney Patient charity in the UK
A federation of more than fifty patient charities, supporting kidney patients & carers*

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KIDNEY MATTERS

Information from The National Kidney Federation supporting kidney patients, their friends & family

HOW TO COPE WITH END STAGE RENAL DISEASE

- **What is end stage renal disease?**
- **Getting support and coping strategies**
- **Making choices**
- **Treatment for end stage renal disease**

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HELPLINE 0800 169 09 36



What is end stage renal disease?

End stage renal disease is loss of kidney function to a point where this becomes life threatening. Less than 1 in 10 people with kidney disease get kidney failure. Established renal failure is also called end stage kidney failure (or, in the USA, end stage renal disease).

End stage renal disease usually develops slowly, as **chronic kidney disease (CKD)** progresses over a period of months or years. However, very few people with CKD ever develop renal failure. In some people kidney failure can develop suddenly, which is called acute kidney injury. Also, someone with CKD may get acute kidney injury if they develop a severe infection or other unexpected illness.

How to cope with end stage kidney disease

If this is a new and sudden diagnosis, most people will feel shocked, even if they already know they have some kidney disease. It is totally normal to be upset and confused, and at first to try and deny what is happening.

Many centres have special clinics to support people who are getting close to end stage kidney disease.

Getting support and coping strategies

People often find it a challenge to manage end stage kidney disease on their own, support from family, friends or hospital staff is important. No-one wants to be a burden on anyone else, but hiding feelings from family and friends may make it more difficult in the long term.

If you think you may need help from social services, or be entitled to financial allowances, talk to the social worker attached to your kidney unit.

People cope with end stage kidney disease and have enormously successful lives, but it is not easy and everyone has to overcome problems from time to time. Every person copes in a different way; there is no 'formula' to make it easy. Some coping strategies that can be helpful include having an activity (eg a hobby) to turn to; setting goals (eg I will go to that wedding!); keeping up as many normal routines as possible, understanding your disease and taking an active part in your treatment helps.

Making choices about dialysis and transplantation

Every person with end stage kidney disease will make choices about the type of treatment that is best for them. It is best to plan in advance. Putting off decisions until the last minute may mean more complications or a longer stay in hospital than is necessary.

Planning in advance does mean having to commit to a particular line of treatment, which can be very daunting. Information, support and having time to make the best choices will be enormously helpful. As well as seeing a doctor in clinic, it can be helpful to talk to nurses on the kidney unit (many units have a nurse who specialises in 'pre-dialysis care'), and to someone who has had dialysis, who can be contacted through the kidney unit at the hospital, or through the local kidney patients' association.

Treatment for kidney failure

To keep as well as possible, everyone should stop smoking, lose weight if they are overweight, keep active and eat a healthy balanced diet, with advice as

appropriate from their renal dietitian. It is important to control **blood pressure** and **cholesterol** should be well controlled, and the levels of **phosphate** in the blood should be regulated by diet and drugs as necessary. If someone is **anaemic**, this should be treated.

There are 4 main types of treatment available for end stage kidney disease These are:-

Haemodialysis

Blood is washed through a machine, normally in three sessions a week. Can be given in hospital as an outpatient, in a local 'satellite' unit, or at home.

Peritoneal dialysis

Uses a tube in the tummy. Fluid is passed in and out of the tummy four times a day at home, or overnight at home using a machine.

'Supportive', or 'conservative' care

Some people may choose not to have dialysis at all. This may suit people with other medical problems and slowly progressive kidney failure.

Kidney transplant

The best treatment for kidney failure in those fit enough for the operation. The best type of transplant, if possible, is from a living donor, given just before dialysis would be needed.