



Kidney failure

What choices do I have?

Emotional and

practical support

Kidney failure: what choices do I have?



Being diagnosed with kidney failure can be a very worrying time for patients and their families. It changes people's lives and throws up so many questions about treatments. This booklet provides an insight into your treatment options.

One of the best things that you can do before making any decisions about your treatment is to find out as much as you can about what choices are available to you locally, what choices will suit the way you live your life and whether you want to travel for holidays. Everyone's choices are personal and depend on many things besides their kidney disease – such as whether you're working or retired and whether you want to be involved in your own care or like to be cared for in a hospital setting.

The sooner you find out about what choices are available to you, the better, as it gives you more time to talk through your decisions with the kidney care team and your family. It's really important to get to know all the kidney care team at your hospital, as they are the ones best placed to help you choose which treatment is right for you and your lifestyle.

You will be given a personal care plan by your kidney care team, and this is planned between you and the team. It lists all personal choices and the stages of your individual treatment and care over the following months.

Kidney failure

Approximately one in eight of us has some abnormality with our kidneys leading to Chronic Kidney Disease (CKD). For most of us, this can be monitored by our GPs in the community without ever visiting a hospital. However, around 10% of people with CKD may reach a stage that is known as established renal failure when the kidneys can no longer work well enough to keep us healthy and alive, and support from dialysis treatment or a kidney transplant is considered.

Remember it's never too late to review your choice of care and you can even change your treatment. Always talk to your kidney care team for the right advice for you.



Choice

There are lots of factors that might affect your treatment decisions, including the cause of your original kidney problem, the lifestyle you enjoy, work, home, family and other influences. Many of the choices lie with you and if your kidney unit cannot provide every treatment option, you may want to think about your place of care or what compromises you are prepared to make.

Treatment choices



Kidney transplant

Transplantation is the best treatment for the majority of patients with established kidney failure. Transplantation extends life expectancy, improves quality of life and offers freedom from dialysis.



Dialysis

Dialysis is an artificial way of removing waste products and unwanted water from your blood.

You can choose between:

- **Haemodialysis**

where blood is washed through a machine either at home or in hospital.

- **Peritoneal dialysis**

where fluid is passed into your abdomen up to four times a day, or overnight at home.



No dialysis

Some patients choose a path called conservative treatment rather than treatment with dialysis. This may suit people with other medical conditions who feel dialysis is not for them.

Kidney transplant

This is the most successful treatment for kidney failure. Donated kidneys come from two sources: the national deceased (cadaveric) donor pool, or from a living donor. Kidneys from living donors offer the best chance of success overall and prevent the need to join the national transplant waiting list. One in three kidney transplants in the UK is now performed from a living donor, either between close family members (blood relatives) or between non-blood relatives, including partners and friends.

It is important to talk about living donation with your friends and family. If you have someone willing to donate a kidney, but they cannot be matched to your blood group and tissue type, there is now a national scheme called 'paired donation' which aims to match living kidneys across transplant centres around the UK. Some units are also developing methods which allow transplantation despite differences in blood groups. Some units can offer treatment to remove the antibodies from the blood in order to make an incompatible transplant possible between a donor and recipient.

A kidney transplant before starting dialysis (known as a pre-emptive transplant) is the gold standard of choice, as patients can avoid the need for dialysis altogether and the kidney is likely to last longer.



One in three kidney transplants in the UK is now performed from a living donor.

If you are interested in finding out more about living donation, it is best to talk to a transplant coordinator who will explain the processes and options to you. Donors can also talk in confidence to members of the transplant team before committing to donation.

Unfortunately not everyone is suitable for renal transplantation, particularly those with multiple other medical conditions, or people of advanced age. All patients have to have tests to ensure they are fit enough to receive a transplant, and some may need particular medical conditions to be treated, or (in addition) they may need to lose some weight, before they are able to receive a kidney transplant.

Not all centres in the UK offer renal transplant at their hospital. All centres are, however, linked to hospitals where transplants take place so it is essential you ask your kidney doctors where your local transplant hospital is and whether transplantation is an option in your case.

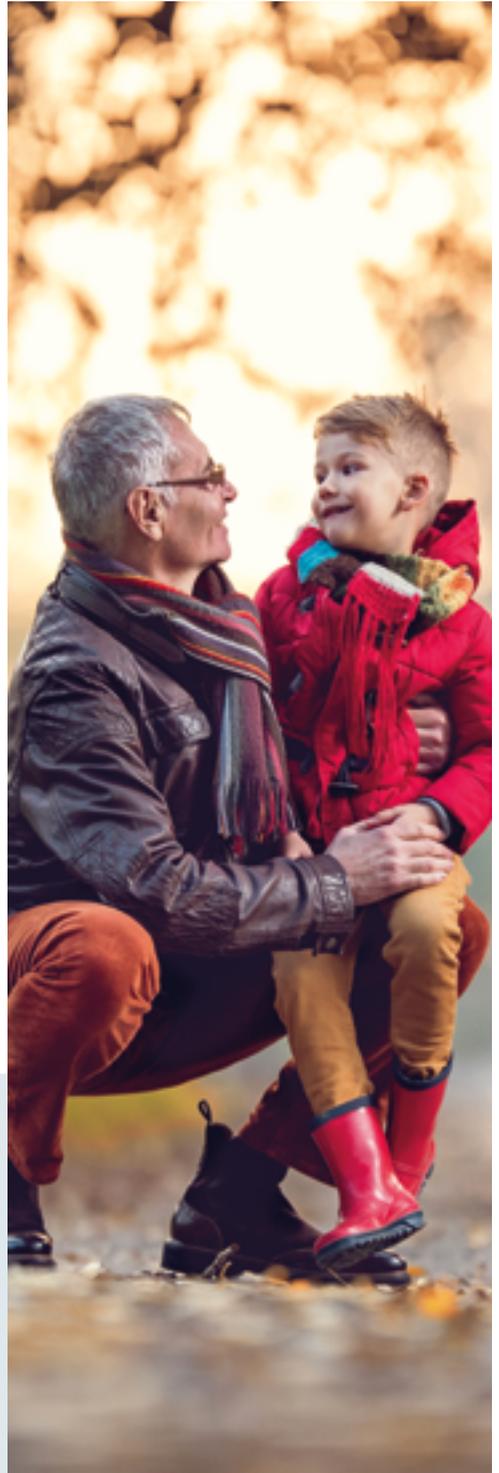
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Haemodialysis

During haemodialysis, blood flows out of your body, round a dialysis machine, through a dialyser (artificial kidney) which cleans it and it is then returned to your body. This can be done at home, in a 'satellite' haemodialysis unit near your home, or in a dialysis unit in a main hospital. You will need a small operation to create a 'fistula', which is where an artery is joined to a vein, so that the vein can be made bigger to allow dialysis needles to reach your bloodstream. This is usually done six months before you start dialysis, to give it time to enlarge although they can usually be used safely after about six weeks if necessary. If you need dialysis before a fistula is made, you may have a temporary dialysis line (a small plastic tube) put into a large vein in your neck.

Standard haemodialysis is for four hours three times a week on alternate days. A growing number of patients are now opting for self-care dialysis within the unit as well as home haemodialysis which can offer more independence, either with daily nocturnal dialysis or conventional three times weekly home dialysis.

Patients are trained for home haemodialysis by the kidney care team to manage their own treatment, and technical support is always available if it is needed. Patients who do home haemodialysis insert the dialysis needles into their fistula themselves, or have a spouse/relative/partner trained to do it for them.



Peritoneal dialysis

This type of dialysis involves putting a small, soft, plastic tube called a catheter into your abdomen (tummy area), which allows dialysis fluid to be drained in and out of what is called your peritoneal cavity. Waste products are passed from your blood and are absorbed by the dialysis fluid. When the fluid is drained out it takes the waste and extra fluid out of your body. This can be done either by hand four times a day via a process called CAPD (continuous ambulatory peritoneal dialysis), or by machine overnight and known as APD (automated peritoneal dialysis). CAPD takes about 20–30 minutes to drain the fluid in and out and needs to be done four times a day. APD takes place for eight hours overnight and needs 30 minutes to set up and clean the machine before and after each treatment.

Peritoneal dialysis	Haemodialysis
At home.	Usually in hospital, but increasingly possible at home with proper training and support.
Four times a day or overnight.	Three sessions per week of four hours.
Needs a catheter inserting in your abdomen two months before starting.	Needs small operation to make a fistula for inserting dialysis needle six months before a planned start on dialysis.
Slightly less restrictive on fluid and diet intake.	More restriction on fluid and diet intake.
Risk of infection (peritonitis).	Possible complications with fistula in the arm and tiredness after treatment.

The best way to make a choice about which dialysis treatment will suit you is to talk to the staff and to other patients about their decisions and what they like and don't like about their treatment choice. It is usually possible to change your type of dialysis if you want to after some planning.



There is some variation in the proportions of people who do haemodialysis and peritoneal dialysis throughout the UK at different centres. Neither treatment is proven to be superior in terms of either quality of dialysis or life expectancy and it really is a question of which will suit you best. Decisions are based on personal preference and medical advice in a shared manner, taking into account personal circumstances related to your work, life, health, leisure activities, aspirations, fears and anything else you feel important.

Choosing not to have dialysis

Some patients decide not to have any treatment for their kidney failure and many units now have a dedicated team of nurses who are able to provide support and care for these patients and their families. It is important to remember that dialysis and transplantation is not for everyone and that people have the right to choose not to have dialysis.

Patients who choose not to have dialysis are usually managed in the same way as other patients with CKD until the point at which the kidney fails where the priority of care changes to relieving the symptoms of kidney failure and managing its complications.

Summary

There are no hard and fast rules about when you may need to start dialysis or have a kidney transplant and the timing will depend on many things, including the speed of decline of your kidney function and the symptoms you may develop from kidney failure related to build up of toxins. These are often referred to as 'symptoms of uraemia' and may include, itchiness, nausea, vomiting, fatigue, weight loss, loss of appetite, confusion and occasionally pains in the chest. The time you will need to 'start' dialysis or receive a transplant will depend on how these symptoms are affecting your life and are judged by you and the kidney doctors and nurses looking after your care.

Information for patients

There are lots of helpful materials that provide information about different types of treatment and its impact on health and lifestyles and these are available from charities like Kidney Care UK, as well as from your kidney unit. There are also useful DVDs, information leaflets and sources of NHS information on the internet such as NHS Choices. Some units also have 'peer support' groups where you can speak to other patients who have been through similar experiences. Some units have counsellors from whom you can get advice.

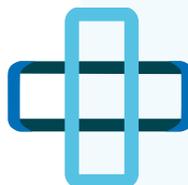
Kidney Care UK has a counsellor who is available for telephone consultations:

Call 01420 541424

Help in making choices

Treatment for kidney failure is a means to live life as fully as you can: the choices that you make must, as far as possible, let you manage your kidney disease around your life, rather than allowing your life to revolve around your kidney disease.

It is impossible to manage on your own, and support from your kidney care team, your family and your friends is really important.



Please visit
www.kidneycareuk.org
if you'd like to find additional sources of helpful information.

**Kidney Care UK is the leading
kidney patient support charity**



**Kidney Care UK provides support, advice,
counselling and financial help for kidney
patients and their families.**

We fund the improvement of renal equipment, services and specialist staff. We also invest in research and help to influence government and NHS policy. To access our full range of services, please use the contact details below.

Visit our website at **www.kidneycareuk.org**
Call us on **01420 541424**

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