

# Dialysis and endstage renal failure

**This information is aimed at people who have been told that their kidneys are failing and that they may need dialysis or transplantation to stay alive. We have produced it in a question and answer format and hope you will find it useful and informative.**

Like most people, you've probably taken your kidneys a bit for granted. Realising that you have serious problems is never easy. We believe that if you have a good understanding of the function of your kidneys, of what can go wrong, and of what can be done to help you, this will help.

## **Kidney failure - what is it?**

Our kidneys, we have two usually, have many functions. They remove waste products from the blood and also remove excess fluid. They do this by acting as a filter, thus producing urine. They also help control our blood pressure, the level of minerals in our bones and the production of red blood cells.

If the kidneys fail the filtering must be done artificially and your blood pressure may have to be controlled by medication. **End stage renal failure (ESRF)** is when kidney function is so bad that you are likely to die within weeks or months unless special treatment such as dialysis or transplantation is given. Some recent documents use 'established renal failure' (ERF) too. This is maybe because they don't like the sound of 'end stage'.

You will also find that your diet will have to be modified, as will the amount of fluid you drink. No treatment can fully compensate for natural kidney functioning.

## **Why have I got it?**

About 1 in 10,000 people in Scotland start dialysis for end stage kidney failure each year. There are many causes. More information on many of the causes of kidney failure is available in our [EdRenINFO](#) section.

## **What are the treatments for kidney failure?**

In the early stages of kidney failure, long before dialysis is required, **conservative** (medical) treatment is sufficient to keep you fit and well. This form of treatment involves drugs and a special diet. Many people never need more than

this. See our page on [chronic renal failure and its progression](#).

There may be a time, however, when this is not enough and **renal replacement** treatment needs to be considered. This can be by dialysis, or for some people a kidney transplant is also a possibility. Others choose to have none of these - see below.

With advances in treatment and drugs you can look forward to a fairly good lifestyle, working and enjoying family life and most leisure activities as before - but this depends on your age and general health too.

While the renal team will do all they can to help you cope with your condition, you have a major part to play. A little motivation, a positive outlook and a bit self-discipline go a long way!

Treatment occurs at special kidney centres, or renal units. These have teams of specially trained staff knowledgeable in kidney disease, transplantation and dialysis. They are made up of doctors, nurses, dietitians, social workers, pharmacists, technicians and others.

## **What are the treatment choices?**

There are several different options. More information on each of these is available by following the links below. Individual units will always have information on these, and will be able to help with which ones may be more suitable for you.

- [Peritoneal dialysis \(CAPD, APD\)](#) - treatment that can usually be carried by you in your own home or at work. >[More info](#)
- [Haemodialysis](#) - treatment that can usually be carried by you in your own home or at work. [More info](#)
- [Kidney transplant](#) - The best treatment by far if it is suitable for you. [More info](#)
- [No dialysis](#) - The best option for some people may be **not** to have dialysis. [More info](#)

## **Your treatment before end stage**

Usually kidney failure develops slowly, and at first you may not have noticed anything. Gradually most people begin to feel tired, lose their appetite and may start to itch. Some get swollen ankles or develop high blood pressure. You may

have to get up several times during the night to go to the toilet. If you have concerns about any of your symptoms please do not hesitate to ask a member of the team.

Initially, you will be treated **CONSERVATIVELY**. The aim is to keep you feeling well, and to delay or even prevent the need for dialysis. This form of treatment uses drugs and diet. You may find that you are prescribed a number of different drugs - see [Chronic renal failure and its progression](#) for information on some of these.

More detail on prevention is available from our information on [Chronic renal failure and its progression](#).

### **When will dialysis be needed?**

Dialysis is started when the symptoms of kidney failure become too troublesome and when blood tests show that waste products are at a level where problems are likely.

Staff will monitor you carefully and advise you of when dialysis is likely to be needed. The average eGFR for starting dialysis in the UK is about 8. You may need it sooner or manage till later. Planning needs to be done well in advance of this though.

### **How will dialysis affect me and my family?**

Many people feel much better after they start dialysis, but it does involve some change in routines at home and at work.

You will probably find that some thought will have to be given as to how to manage your time in order to accommodate the treatment. It is important, however, to keep things in perspective - life does go on!

### **What about work?**

Everyone's work situation is different, but starting dialysis does not necessarily mean you have to stop work. Indeed, unless you have a particularly heavy job, we would almost certainly encourage you to continue. Most employers are understanding and helpful.

### **Schooling?**

You should be able to continue as normal.

### **Should I exercise?**

This is important. Exercise and keeping fit improves your health and sense of wellbeing.

You should do as much exercise as you feel comfortable with. Generally speaking, however, contact sports should be avoided if you have a fistula, shunt or neckline. Swimming may be permissible for people on PD, but please ask for advice.

### **Can I drive?**

Under most circumstances you may continue to drive, although we do suggest for the first two months of haemodialysis you do not drive immediately after your treatment.

If you have an HGV or PSV licence you should discuss your condition with medical staff before returning to driving. (HGV and PSV licences are for driving trucks and buses in the UK)

### **Sex life?**

You should be able to continue as normal.

Patients with kidney failure can have a full sexual relationship with their partner. However, some patients may feel tired or low in mood which may affect their sex drive. Medication and altered blood chemistry can also contribute to this. Female patients may also notice significant changes in their menstrual cycle.

There are ways we can help you cope with sexual problems, so please try and discuss them with the medical staff or social work staff if you are in any way concerned.

Longer discussion of these issues can be found from the [NKF\(UK\) pages on sex problems with renal failure](#), and the [NKF\(USA\) pages on sexuality in CKD](#) (but they mean dialysis and transplant, not earlier CKD stages) and [pregnancy on dialysis and after transplantation](#).

### **Holidays?**

Everyone enjoys a holiday, and there is no reason why you cannot continue to have a break, but they will require some extra planning. Holidays can be arranged both in this country and abroad, and should be arranged some months before you intend to go. Patients on haemodialysis usually have to be on treatment for 6

months before they can be considered.

If you are on peritoneal dialysis and wish to take a short break or a longer holiday, providing you are well, this is usually possible. Your supplies will be delivered to your destination as long as you give a little bit of notice.

If you are on Haemodialysis it is more complicated. It depends on there being space in a unit where you are going, unless you are going to a dialysis holiday centre (yes there are some). There will be local policies on blood testing and safety for such visits. [www.globaldialysis.com](http://www.globaldialysis.com) is useful for international travel.

### **Smoking?**

Smoking damages your heart and lungs. You cannot afford the extra risk so you should try to stop. It is even more important for you to try to stop smoking if kidney transplantation is being considered. Smoking damages the blood vessels and this could affect the future success of a transplanted kidney.

### **Alcohol?**

Alcohol is quite permissible in certain forms but must be counted within your normal fluid allowance and diet. Ask for advice about this.

### **Coping with end stage renal failure**

There is an old saying that the fear of something is often worse than the reality and this is frequently the case with renal failure.

All of us have our life planned out in our minds. There are the immediate things which we know we will be doing in the next few hours, days and weeks. There are the things we plan to do over the next few months - the family wedding, the annual will do once we have the time!

When something as life threatening such as renal failure comes along to rock our boat, it is natural that we feel anxious, afraid and worried over what the future holds for us. All of a sudden, there is a big question mark over the life we had planned and an uncertainty over what will replace it.

There is much research to show that no matter what we lose, be it our keys, someone close to us, part of our body or body function, we, as humans, respond in the same way.

Initially, when the loss is discovered, there is a sense of numbness which may last for a few seconds, hours or even days and then we often go through a period of denial - you; know the feeling, "maybe if I really stick to the diet my kidneys: will get better".

Eventually the reality sinks in, however - this is for real - this is happening to me. Some of us continue the denial, go about life as if nothing has changed, some of us panic, seek reassurances that all will be well and many of us just take each day as it comes and decide to worry about it when "tomorrow" comes.

All this is fine and part of the adjustment process, but eventually we have to move on because all too often "tomorrow" does come, and we are faced with the reality that change is inevitable and life will never be quite the same again.

Some of us become sad, some angry, and a few of us become very controlled and decide to keep our feelings to ourselves. Once again, this is fine - it's all part of the adjustment process, but remember, it's not only you, the patient, who feels the effects of approaching renal failure, all the uncertainties, worries and anxieties. These are also felt by those nearest to you. They also worry about you and how this will affect their future. Change is around for everyone.

What you are feeling right now is a natural reaction to what you have been going through for the past weeks, months or maybe years. There is much uncertainty around, uncertainty that we somehow have to learn to live with. Some patients feel they have lost control of their lives and that suddenly someone else is "pulling the strings".

Try not to keep things to yourself. A problem shared is a problem halved. Often with a little bit of information many things suddenly fall into place and we begin to see that little bit of sunlight.

So ask. Speak to the doctor at the clinic; ask to see one of the Unit social workers, anyone you feel at ease with. All of us have many years experience working with kidney patients and there are few situations we have not coped with before. Share your concerns and we will do our best to help.

## **What support can I get while on dialysis**

As mentioned previously, the aim is for you to be able to lead a fairly normal life. Most patients see dialysis as a necessary nuisance! They dialyse to live, not live to

dialyse.

There may be times, however, when you want an arm to lean on, and there is quite a bit of support around for both you and your family. The type of support will vary locally, although there are also national patient support organisations (some are listed below).

**Edinburgh patients (but note that similar support is available in most Renal Units)**

**Renal PatientView** - read your test results, letters to your GP from the Renal Unit, and information links for your diagnosis and treatment online. Ask for a login when you come to clinic or to the dialysis unit, or email us: [renal@ed.ac.uk](mailto:renal@ed.ac.uk)

**Preparing**

You will be seen by the Community Dialysis Team, which is a small team of nurses knowledgeable in all aspects of the treatments available. They will give you information and help you prepare for whichever treatment is best for you. This will happen ideally over a period of time and may involve information sessions both at the Renal Unit and in your home. Family are encouraged to take part and, if you feel it is appropriate, close friends are welcome to participate as well. In addition, one of the Unit social workers may visit you at home to explain how the treatment will affect your day to day life and answer any other questions you may have.

**Medical Staff**

The staff in the Renal Unit are specialised in this area of medicine. They will be happy to explain kidney failure and its implications and treatment, and answer any questions you may have.

It is often a good idea to jot down questions when they are fresh in your mind. Please feel free to talk to them.

**Nursing Staff**

We have a fully trained and experienced nursing staff in the dialysis units, in the Renal Wards and the PD Training Unit. They carry out prescribed treatment and train, advise and help you to carry out the particular type of dialysis chosen. As time goes on, you will get to know each other well!

**Dietitian**

Our dietitians will give you a personal diet sheet, tailored to your needs. They are available to discuss your diet with yourself and your family and can offer many helpful suggestions. Very worthwhile having a chat to!

**Renal Social Worker**

There are specially trained social workers based in the Renal Unit, who are there to offer you and your family support and advice in coping with all aspects of your illness and your day to day life.

In many cases they will visit you at home prior to your treatment starting, in order to get to know you and your family better, and to answer many of the questions which you are sure to have. They are there to support you and your family throughout the period of your illness. Once again, they are there to help. Please feel free to use them.

**Pharmacist**

Often a number of medications are needed to treat the causes of kidney failure and to prevent complications. The pharmacists on the Renal Unit are available to help you with any problems or questions you may have. For instance, they can suggest ways to assist with the taking of your medicines and can talk through any concerns you may have on side effects. Please do not hesitate to call us.

**[South East Scotland Kidney Patient Association \(SESKPA\)](#)**

This local Association, made up of patients and their families just like yourselves, meets monthly to offer support and advice and to fund-raise for kidney patients in this area. Advice and information on this is available from the Unit social workers.

## Further information

Links to further information on dialysis and transplantation is given in the [EdRenINFO](#) sections on

- [Peritoneal dialysis](#)
- [Haemodialysis](#)
- [Transplantation](#)

The [EdRenINFO](#) page on [Chronic renal failure and its progression](#) may also be relevant to you.

The [British Kidney Patient Association](#) is a national association concerned with the welfare of kidney patients. BKPA, Bordon, Hampshire GU35 3JZ. Tel: 01420 472021/22.

[Kidney Research UK \(KRUK\)](#) funds research into kidney disease.

Further excellent links to valuable sources of information for patients are reachable from our [Other links](#) page.



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