

Help!

I've got kidney failure

Your introduction to  
**Kidney Failure** and its treatment

Third Edition

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Kidney Care UK is the UK's leading kidney patient support charity working to improve the quality of life for kidney patients and their loved ones. The charity provides financial, practical and emotional support, invests in improvements to care services and represents patients' interests at a national level.



# Introduction

This booklet is an introduction to kidney failure and its treatment. It includes general information which will apply to most people. However it is important to know that everyone is different and each person has different circumstances and needs. Therefore, you should discuss your own condition and treatment with your team of healthcare professionals at your hospital.

At the end of the booklet there is lots of useful information including a 'jargon busting' section to help explain medical terms, and a guide to further information in books and online.

## Contents

<b>What is Chronic Kidney Disease? Is it the same as kidney failure?</b> .....	<b>2</b>
What happens to the body in kidney failure?.....	3
Treatment starts early.....	3
Hints and tips about tablets and other medication.....	4
<b>How do I get involved in making decisions?</b> .....	<b>5</b>
<b>Dialysis</b> .....	<b>6</b>
When choosing where to have dialysis .....	8
<b>Peritoneal dialysis (PD)</b> .....	<b>9</b>
<b>Haemodialysis</b> .....	<b>10</b>
Home haemodialysis.....	19
How does it fit together? .....	11
Dialysis table.....	12
<b>Kidney transplants</b> .....	<b>14</b>
<b>Choosing not to have dialysis or a transplant</b> .....	<b>16</b>
<b>Living life</b> .....	<b>17</b>
<b>Living with kidney failure</b> .....	<b>20</b>
Smoking.....	20
Exercise.....	20
Holidays and travel .....	20
Work.....	20
Insurance and mortgages.....	20
Sex.....	21
Having babies.....	21
<b>What next?</b> .....	<b>22</b>
How long will someone with kidney failure live?.....	22
<b>Jargon busting (glossary)</b> .....	<b>23</b>
<b>Important addresses</b> .....	<b>24</b>

# What is Chronic Kidney Disease? Is it the same as kidney failure?

**Chronic kidney disease (CKD) is a common and serious problem. It is estimated that 1 in 10 adults have CKD. When someone has CKD the kidneys are less able to do their normal work permanently. After a time, the kidneys may stop working almost completely – a condition known as kidney failure.**

The vast majority of people with CKD do not develop kidney failure and for most their kidney function remains at a stable but reduced level. However, in some people the function of the kidneys falls and may result in kidney failure. The term 'kidney failure' means that the kidneys are working at less than about 10% of normal but people may have symptoms before that. This can be life threatening as the kidneys have a crucial role in keeping you well. This happens to about 1 in 1000 of the general population. In the UK about 55000 people are having treatment for kidney failure.

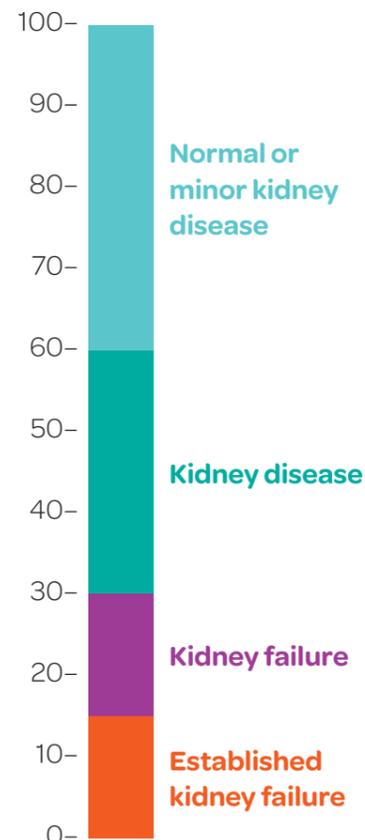
So, in short, CKD is when kidneys have reduced function and kidney failure is when they have stopped working almost completely.

In health, the main role of the kidneys is to remove waste products and excess fluid (made up of salt and water) from the blood. When the kidneys stop working, wastes and fluid can build-up in the body. The effects can be subtle but as the problem progresses it can cause vomiting, itching, tiredness and swelling. Because the body is no longer able to get rid of waste products and look after the fluid balance, untreated kidney disease can shorten your life.

The kidneys do some other very important jobs too such as controlling blood pressure, keeping bones healthy and making red blood cells. You can see a cartoon showing the role of the kidney at [www.thinkkidneys.nhs.uk/campaign/](http://www.thinkkidneys.nhs.uk/campaign/).

Even with advanced kidney failure, the fluid that is passed as urine may look normal, but blood tests will show there is a build-up of wastes, chemicals and excess fluid in the blood. This is important since it means you will need regular blood and urine tests to monitor your condition.

People who develop kidney failure will need treatment to take over the work the kidneys. The treatment is either a kidney transplant or dialysis.



## Some causes of kidney failure

- Diabetes
- High blood pressure (often with hardening and narrowing of the arteries to the kidneys)
- Inflammation in the kidneys (nephritis, or glomerulonephritis)
- Polycystic kidney disease (a disease that runs in families)

## What happens to the body in kidney failure?

**Chemical imbalance.** The levels of essential chemicals in the blood can get too high if the kidneys can't control them.

**Fluid overload.** The kidneys control the amount of fluid in the body. When they stop working, fluid can build up in the body.

**High blood pressure.** The kidneys normally control the blood pressure in the body. So, having kidney failure often means a person also has high blood pressure.

**Anaemia.** The kidneys play a role in making red blood cells, so when they stop working patients often get anaemic.

**Weak or damaged bones.** The kidneys also help maintain healthy bones. People with kidney failure are therefore prone to bone damage.

All this can lead to symptoms. In the early stages of chronic kidney disease, there may not be any symptoms. But, symptoms may develop from the kidney failure itself or from the complications of kidney failure and may result in any of the following:

- itching;
- weakness or tiredness;
- loss of appetite;
- poor concentration;
- restless legs;
- leg cramps;
- swollen ankles;
- shortness of breath;
- poor sleeping;
- low sex drive;
- feeling cold.

## Treatment for kidney failure

### Treatment starts early

If you have CKD, you may not feel ill, but the body is being affected in many ways. The team looking after you will be deciding on how to slow down the decline in your kidney function, treat any symptoms or complications of CKD and, if required, talk to you about options for the treatment of kidney failure. There are many things that can be done to prevent symptoms and slow down the rate at which the kidneys fail. These include:

**Preventing build-up of chemicals.** Because the kidneys can no longer balance chemicals in the body, it may be necessary to eat a special diet so that dangerous chemicals don't build up. The dietitian will give individual information and advice for each patient. Diet in kidney failure is not just about avoiding certain foods. It is important to keep enjoying eating, and to eat well because poor nutrition can also cause problems.

**Reducing fluid in the body.** When kidneys stop working, they are often less able to remove excess fluid from the body. This will mean that you may need to drink less (tea, coffee, water, juice and alcohol) and have less salt so that the excess fluid doesn't build up in your body. Remember that fluid is water and salt together.

**Controlling blood pressure.** High blood pressure is known to speed up kidney failure. Keeping the blood pressure low (consistently 130/80 mmHg or less) can delay the need for dialysis by years. Some people with kidney failure have a large amount of protein in the urine. Blood pressure tablets called "ACE inhibitors" or "angiotensin 2 antagonists" are often used by kidney doctors to treat high blood pressure in people with CKD, especially if they have high protein levels in the urine.

**Treatment for anaemia.** The symptoms of anaemia can make you feel very tired and breathless, so getting treatment for this can make you feel much better. This treatment is often by injection that can be given once or twice a week. The injections are known as ESAs (which stands for Erythropoiesis Stimulating Agents).

**Slowing down the cause of kidney failure.** Rarely, the cause of the kidney failure may be directly treatable. Relieving blockages to the drainage, treating inflammation within the kidney or using drugs to stop cysts growing in polycystic kidney disease are some examples.

**Preventing damage to bones.** Renal bone disease can start in the early stages of kidney disease; a long time before dialysis or a transplant is needed. Calcium, phosphate and vitamin D are needed to keep bones healthy. Because the kidneys control all 3 of these substances, when they fail it has an impact on the bones. Doctors often prescribe drugs to help keep bones healthy in the early stages of kidney failure such as vitamin D supplements and phosphate binders.

So, many different types of tablets and other medications are required by most people with kidney failure, each doing a different job. These can be very effective in controlling the effects of kidney failure, but it is also very important to understand as much as possible, and to get into the habit of taking them regularly and at the right times.



## Hints and tips about tablets and other medications

1. Carry a list of all medicine, and check with the hospital and your GP that the list is correct
2. When a new drug is started:
  - understand why it is being given
  - find out what side effects might occur
  - make sure it does not react with any of the other treatment being given
3. If any side effects develop, ask a doctor or the Renal Pharmacist for advice
4. Don't stop medication without telling anyone
5. Store all tablets in their original containers, in a cool dry place out of the reach of children
6. Use a 'pill organiser' to help you remember to take your tablets at the right time. You can buy 7-day pill organisers which you fill up once a week with the correct dose of tablets
7. Order new supplies of tablets in good time: most tablets are prescribed by the GP, some may come from the hospital.

### Isambard's story

At first it was difficult to make the transition from being a fit and healthy person (so I thought) who can come and go at will, to becoming the focus of such oppressive concern at home. It almost drove me insane.

My family – very much involved in keeping me alive – also took time to get the measure of the illness. I met the disease at every turn: in my pills, in my diet, in bodily function, in my family's attitude, and in my limited ability to socialise. I was hemmed in. Just as initially I resented the idea of being dependent on medication for the rest of my life, so I resented my dependence on people around me for food, shelter and support.



Having kidney failure does not mean you have to stop enjoying life

## How do I get involved in making decisions?

Having a good understanding of your kidney problems, what causes them and how they are treated is very important. People who develop their knowledge, get the right skills to look after themselves and are more confident about their own healthcare often feel much more in control and tend to be happier. It is also more likely that having a better understanding of your health will help you to make better choices about your health, treatments and manage your condition more effectively.

There are two ways of treating kidney failure: a kidney transplant or dialysis. There is currently no cure. In other words, dialysis or a kidney transplant can replace some of the functions of the kidneys but does not get rid of the kidney disease.

Making choices about the treatments for kidney failure is complicated and daunting for everyone. These choices need thought and time but being involved and in charge of your own decisions generally results in better choices for you and your family. Don't be afraid to ask questions.

So, three questions to consider:

- First, am I suitable for a kidney transplant?
- Second, is dialysis right for me?
- Third, what sort of dialysis do I want? Remember, even if you are suitable for a kidney transplant, you need to think about dialysis. Transplants aren't always available.



### Maureen's story

The words 'you have kidney failure' are perhaps one of the most dreaded things you are going to hear. From that day forward you start a 'new life' of blood tests, diet and visits to a renal consultant who keeps you up to date with how your kidneys are functioning.

My first reactions were 'This isn't happening to me' and 'It will get better'. But of course it was, and it doesn't.

In my case there was a deterioration over years. The terrible tiredness and nausea were the most distressing, then the high blood pressure and finally I started to carry a lot of fluid. I got so exhausted and breathless that dialysis was the next step.

Now I had read about dialysis in a magazine and I for one wasn't having any part of that, thank you very much. But the dreaded day eventually arrived and I turned up at the Renal Unit very tired, breathless and scared. I was taken to the unit, the nurses explained what was going to happen and before I had time to think I was connected up. I was really surprised it wasn't anything like I had imagined. And when I came off, 'wonderful', I could really breathe properly again. Everyone was helpful and friendly.

Health professionals will be ready to answer your questions (photo ©Kidney Care UK).

# Dialysis



If you need to start dialysis, it will be important to think about the long term as well as how dialysis will affect your life right now when deciding on which sort of dialysis to have first. So the order of when you have each type of dialysis can be important to get the best quality of life and the most health benefit. For example, there is evidence that shows having PD as your first treatment has benefits.

Dialysis is an artificial way of doing some of the work of the kidneys. It removes waste and balances the chemicals in the blood, and it

also removes excess fluid from your body from food and drink.

There are two main types of dialysis either peritoneal dialysis (PD) which is done at home, or haemodialysis (HD) which can be done either in hospital or at home.

PD and HD work in similar ways:

- Waste products are cleared from the blood and the chemicals are brought into balance.
- Excess fluid (remember fluid = salt and water) is removed from the blood.
- The wastes and fluid pass into a special liquid called the dialysis fluid or dialysate so that they can easily be removed from the body.
- The dialysis actually takes place through a thin layer, known as the dialysis membrane, which keeps the dialysis fluid and blood from mixing together. This membrane has tiny holes which means it can act like a sieve, keeping the important parts of blood but allowing water and wastes to pass across it.



Dialysis is an artificial way of doing some of the work of the kidneys (photo ©Kidney Care UK).

## Nikki's story

I can sympathise with anyone who has kidney failure, particularly young people.

I was diagnosed at age 20. I was a dancer, had just left stage school and taken all my major exams. I had lots of dreams and ambitions and felt that my life was just beginning. I ate really healthily and many people said I was the healthiest person they knew.

A month after I'd left college the bomb dropped. To cut a long story short, I ended up in hospital and after many tests was told what I'd got. I can't really express how I felt. Shock, numbness, confusion and a number of other emotions, but most of all an overwhelming feeling that my life and career were over before they'd begun.

The most difficult things to get through were choosing which type of dialysis to go on, and understanding the illness and why it all happens. With the great support of family, friends and the wonderful hospital staff I went onto CAPD [Continuous Ambulatory Peritoneal Dialysis] and gradually started to feel better, accept it all and try to get on with my life.

A year and a half later I had a transplant from my Dad, I now have my own dancing school and feel very fortunate. It is very easy to feel negative and feel down and upset but I think that all of this has made me a stronger person who doesn't have to take things for granted any more. And I always remember that there are people worse off than me.



Nikki with her father, Graham, 'treading the boards' during one of their annual fundraising cabarets. Nikki is able to lead a full and active life, following her dreams.

## When choosing where to have dialysis, think about:

**Where you would like to have dialysis.** You can have dialysis at home or in a clinic or hospital.

**How much of the dialysis you would like to do for yourself.**

You can get as involved as much as you like with the dialysis treatment. This is true if you have your dialysis in hospital or at home. Most people who have dialysis at home do the dialysis themselves, but there is also support available for people who can't manage everything.

**If you would like the dialysis to be able to fit around your life.**

Having dialysis in the renal unit usually means that patients have fixed treatment appointments three times a week for four hours each. This enables patients to have four days 'off' dialysis every week. Dialysis at home is more flexible, but is done more frequently.

**Would you like to continue to work or go back to work?**

Fixed dialysis schedules in hospital can be altered to accommodate work patterns; however those on home dialysis find it much easier to continue their employment.

**If you decide to have your dialysis in the unit, how will you travel to the dialysis unit?**

It may be possible for transport to be provided by the hospital,

or you might be able to make your own way there. The time taken to travel to and from the dialysis centre should be taken into account as well as waiting in the unit to start your treatment. Sadly, hospital transport is not always reliable or there can be problems with your treatment that delays you heading home. This can mean that having hospital based dialysis takes up most of the day.

**If you decide to have dialysis at home, where you will store the supplies?**

Most home dialysis patients will need to store about one month's supplies. The equipment can be stored in the garage, a shed, in the cupboard under the stairs or a spare room. Space also needs to be set aside for the dialysis to be performed. This may need to be in the bedroom if night-time dialysis is chosen.

**Do you still want to go on holidays and travel?**

PD patients can have their supplies delivered to their destination. Although this requires forward planning, travel for holidays, family events or business can usually be arranged to most parts of the world within a few weeks (or days in an emergency). More planning is usually required for haemodialysis patients as they need to find a centre in which they can have their treatment while they are away from home.

**How much contact would you like with other patients?**

People who have HD in the renal unit have regular contact with other patients. People on home based

treatments will meet patients if they attend clinics, patient groups or are admitted to hospital.

**How much contact would you like with healthcare professionals?**

Having HD in the renal unit means that there are nurses nearby during each dialysis session. People who have dialysis at home will have regular contact with nurses during home visits, by telephone and at regular clinic visits. Some home dialysis machines connect to the internet so that the nurses and doctors can keep an eye on your treatment. This can give patients a lot of reassurance. Everyone who has home dialysis will be trained and educated about all aspects of their treatment.



Grace chose home haemodialysis to give her the flexibility she needed while studying art. She went on to have a successful transplant.

# Peritoneal dialysis (PD)



In PD, dialysis fluid sits inside the tummy and the membrane is the lining of the tummy. This membrane is called the peritoneum.

In PD, dialysis is happening all the time. This is because the dialysis fluid is always in contact with the dialysis membrane. PD can be done by hand (CAPD) or by using a machine (APD).



Once you have been taught how to use the PD machine, you will be able to set it up at home (photo ©Kidney Care UK).

## Isambard's story

### Isambard chose CAPD.

In my case, the CAPD option offered independence from hospitals, and less in the way of fluid restrictions. A permanent line was inserted into my tummy, and I was taught the rigorous sterilisation techniques that accompany each exchange of dialysis fluid.

By the time I got home, boxes of dialysis bags had already arrived complete with all the attendant paraphernalia of iodine, dressings and sterilising fluid.

It took about five months to get the hang of dialysis. The morning rigmarole of changing the dressing on the catheter exit site, sterilising everything and then doing an exchange makes getting up a long-drawn out process.

Thus, suffering from what they call in the business 'problems of self-image', I returned with trepidation back into the pool of sexual activity. My first experience, however, gave me a rare insight into middle age: trying to make love with a protruding stomach, shortness of breath and a defective erection.

Thankfully things did get better. There were two bouts of peritonitis (an infection – due to my sloppiness in sterilising the area where I was doing exchanges – that causes stomach cramps and vomiting) which resulted in a dressing-down from the consultant.

At times there was a feeling of entrapment; for example, waking up at night and feeling perpetually connected to dialysis bags. When I tired of giving myself pep talks, or relapsed from focusing on the good things in life, from time to time a wave of sadness seized me.

The best experience for me, psychologically, was when I returned to work for two weeks in London (one of the marvels of the organisation that supplies the dialysis equipment is that, given enough time, it can deliver world-wide) and discovered that I could cope with doing dialysis at work.

# Haemodialysis



Haemodialysis uses a man-made membrane. Blood is pumped out of the body and across the membrane using a machine. At the same time dialysis fluid is pumped across the other side of the membrane.

## Maureen's story

### Starting dialysis.

So now I've entered another stage of my life. 'Dialysis and me'. I am now on a different diet, as I'm allowed to eat more protein because the machine does some of the work of my kidneys.

I receive my treatment and meet lots of other people with the same problems as myself. We talk and swap news and have a laugh.

The machine is my lifeline and because of it I am reasonably well and lead a good life, certainly a lot better than I did before I received dialysis, and I look healthier too.



Arthur dialyses himself five times a week at home. Arthur and his wife Julie can choose the time of day they want to be treated, and the machine takes under half an hour to set up.

## How does it fit together?

The order of when you have each type of dialysis is important to get the best quality of life and the most health benefit. There are benefits to having PD as your first treatment.

Doing PD when your kidneys are still working a little bit can keep them going for longer. The other advantage of doing PD as the first treatment is that you don't need to take blood from the body to do the dialysis. The means that you can preserve your blood vessels, in case you need to have haemodialysis in the future.

Deciding on a dialysis option can be difficult. However it is important to remember that you can change your mind and swap between treatments if the one you choose doesn't suit you. As your life changes you may want to change the type of treatment you have. It is really important to make your wishes known to the doctors and nurses in hospital.

Jonathan has had both dialysis and a transplant, and has been able to maintain a good quality of life (photo ©Kidney Care UK)

## Some differences between the types of dialysis

Where does dialysis happen?	At home	In a hospital or clinic	At home
<b>Will I need to have an operation?</b>	Yes. A short operation will be needed to enlarge a blood vessel in your arm so that the blood can be taken from your body. This is called a fistula. This is done about 2 months before you start dialysis.	Yes. A short operation will be needed to enlarge a blood vessel in your arm so that the blood can be taken from your body. This is called a fistula. This is done about 2 months before you start dialysis.	Yes. A short operation to put a tube into your abdomen will be needed so that the dialysis fluid can go in and out of the body. This is usually done about 2 weeks before you start dialysis, however, it is possible to use the tube within a few days of the operation if needed.
<b>Will I need space at home?</b>	Yes. You will need quite a large area where the dialysis machine and water purifier can be plumbed in, although the newer machines are getting smaller. You will also need a large storage area for supplies of dialysis equipment.	No storage required.	CAPD can be done anywhere such as the living room, dining room or bathroom. The APD machine fits on the bedside table. You will also need a large storage area for supplies of dialysis equipment.
<b>How often do I need to have dialysis?</b>	Lots of different 'regimes' if you do it during the day it can be three to six times a week, 3-5 hours each session. Home Haemodialysis can also be done overnight while you are asleep, lasting about 7-8 hours and done between 3 and 6 times every week.	Normally three times a week, 4-5 hours a session. You will also spend time travelling to and from the dialysis unit, which may not be local.	Every day. There are 2 methods of PD. CAPD is done 4 times a day, each 'exchange' takes 20 - 30 minutes. APD uses a machine to do the 'exchanges' while you are asleep overnight.
<b>What time of day does the dialysis take place?</b>	When you decide.	At the appointment time given by the unit.	When you decide.
<b>How strict is the diet?</b>	There may be some restrictions, but these may be less if you have dialysis more than 4 times a week. Your dietitian can advise you.	There are strict restrictions on certain types of food; especially food high in potassium or phosphate. Your dietitian can advise you.	There may be some restrictions on certain types of food; especially food high in potassium or phosphate. This may be less if you have some remaining kidney function. Your dietitian can advise you.

	HOME HAEMODIALYSIS	UNIT HAEMODIALYSIS	PERITONEAL DIALYSIS
<b>How strict is the fluid restriction?</b>	There may be some restrictions, but these may be less if you have dialysis more than 4 times a week.	Most hospital HD patients are restricted to about 500mls of fluid a day. This will be more if you pass any urine.	There may be some restrictions, but these may be less if you have some remaining kidney function.
<b>Can I go to work?</b>	Yes. Home haemodialysis can be done outside of work hours.	Yes, however you need to attend dialysis at your exact appointment times so this may restrict the work you can do. It may be possible for dialysis to be arranged for evenings if you work during the day.	Yes. APD is done overnight, leaving you free during the daytime. If you have CAPD, you can fit the exchanges around your working day. It is possible to do a CAPD exchange almost anywhere there is a clean and convenient place.
<b>Are holidays possible?</b>	Yes. You will need to book into a dialysis unit near to your holiday destination. This can be arranged by your own renal unit. Some Home HD machines are transportable in a car so may be taken with you.	Yes. You will need to book into a dialysis unit near to your holiday destination. This can be arranged by your own renal unit.	Yes. The dialysis equipment will be delivered to your holiday destination. PD supplies can be delivered to most parts of the world.
<b>What are the main complications?</b>	Some people feel tired after each session although this is not as much as a problem if you do it overnight. Problems with the fistula or dialysis access may lead to blood infections.	Tiredness after each treatment. Sudden fall in blood pressure can make you feel very dizzy and weak. Fluid overload can cause swelling and may lead to problems breathing. Problems with the fistula or dialysis access may lead to blood infections.	Fluid overload can cause swelling and may lead to problems breathing. Infections inside the abdomen if strict hygiene rules are not followed.



# Kidney transplants

A kidney transplant involves removing a healthy kidney from one person (the donor) and giving it to another person (the recipient). Transplant kidneys may come from a person who has given a kidney after their death or from a living donor.

A successful kidney transplant is the most effective treatment for kidney failure compared to either peritoneal dialysis or haemodialysis. This is because a well-functioning transplanted kidney can do all the jobs of the kidney, whereas dialysis only really replaces a couple of functions. However it is not a cure for kidney failure.

Only about 30% of people with kidney failure are suitable for a kidney transplant, if the right donor kidney can be found. Anyone with serious heart or lung disease, or who have been diagnosed with cancer may not be suitable for a kidney transplant.

## Isambard's story

### Isambard had a transplant from a deceased donor.

The call for a transplant came at 2.30 a.m. eight months after I had started on dialysis. I did not really feel in the mood for a major operation and, although trying to share the transplant co-ordinator's sense of joy on the telephone, I was terrified. I left within half an hour.

Now, over a year after the operation, all is going smoothly. With only the pills to take daily and three monthly check-ups, life has changed beyond all recognition.

The feeling of well-being, both physical and psychological, is astounding. More energised, healthier, and freed from the shackles of dialysis, I feel human again. A day does not pass without feeling gratitude towards the donor's family.

I can only hope that it might be of some minor consolation to them that the transplant has given me the opportunity to lead a full and unfettered life once more. A miraculous second chance.



(photo ©Kidney Care UK)

## Pam's story

### Pam became a 'living kidney donor'.

Would I still say 'Yes'?

Absolutely. Although I am not sure that I ever made such a conscious decision. It was more a series of small steps which eventually led to the day when two teams of skilled medical staff removed my left kidney and transplanted it into my brother.

I spoke to my family and arranged to have the first of a series of tests to determine the level of compatibility. No-one willingly undertakes a major operation without some misgivings. I remember feeling frustrated at how little information was available about the procedure, even though I was assured of the routine nature of the exercise.

Once the issue of compatibility had been resolved the team then focused on my own kidneys. What was their 'plumbing' like? Which one would be the easiest to remove? Were they both in good condition? More 'Yeses'.

Then there were further consultations with both clinical and psychological specialists. How would I have felt had the operation proceeded, but failed? Not very happy, but the question had to be asked and answered. Another 'Yes'?

The final rush to the actual operation is something for which you cannot really prepare. The calm professionalism of the medical staff is a valuable stabiliser.

I am not sure that I can recall the few days immediately after the operation. It is a major procedure and there are a few missing days in my life. My family and the nursing staff kept me comfortable and in no time at all my brother was trundling his drips into my ward!

Now, six months on, I am still aware that I underwent surgery and that it may take a few more months to return to my original fitness level. But I only have to see my brother fit and well and able to contribute to his family life to know that I made the right decision. The worry I had over my brother's ill health and discomfort has been replaced with a deep sense of satisfaction that I have been able to help him to overcome that sort of circumstance.

And yes, I would still say 'Yes'.



# Choosing not to have dialysis or a transplant

conservative and end-of-life care

It is important for patients and their families to understand that dialysis is not compulsory.

If you do not wish to receive treatment, you should discuss this with the staff at your renal unit. Not having dialysis when your kidneys have failed means that your life would probably be shortened compared to if you had dialysis. But for some people, treatment may be a burden and even shorten their life due to the strain the dialysis puts on the body. For example, people whose lives are seriously restricted by other illnesses may decide that they would rather not to start dialysis treatment. This approach is called **'conservative care'**.

This is not the same as **'end of life care'**. This term is used to refer to the period and care needed when someone's life is coming to an end. It may be someone who has decided not to have dialysis at all. For others, it may be they have had dialysis for many years but become frail or disabled and have decided that the time has come to stop treatment and die with dignity. At that time, it is important to have a care plan agreed with the person and their team. Having a care plan can also help patients to decide where they would like to die; either at home, in hospital or in a hospice. Everyone involved will then make every effort to make sure that the patient's wishes are met and that their death is pain free, dignified and in the place of their choosing.



*I've learnt to stay independent, by asking for the help I need.*

Help from Marjorie enables Ernest to have dialysis in his caravan on holiday



# Living life

Everyone's emotional state has a major impact on their physical well-being. The way you feel will influence the way you behave. If you have kidney failure, the way that you behave can have a direct effect on your health. For example, you may become less careful about your diet, forget to take your tablets, or abandon fluid restrictions – all of which put additional strain on an already poorly body.

## Some of the stresses that commonly affect people with kidney failure are:

- Having to make decisions about things they have never even thought about before;
- taking in strange information, to enable them to understand a complex medical subject;
- learning about themselves and the ways they cope with things;
- needing to ask for support to manage their treatment;
- seeing themselves as a complete person, not just as a disease or condition;
- learning to live differently for the rest of their life; and worrying about the future.



Enjoying life with his family gives Andrew huge pleasure (photo ©Kidney Care UK)



*Living with kidney failure has made me realise how much I value my family*

People use different strategies to help them cope with long-term illness. Many kidney patients find the following strategies helpful:

- 1. Denial.** In the early stages, it can be very useful to deny the situation or not to take it seriously. This helps people escape from the feeling of being overwhelmed by the disease. It also allows time to organise other, better ways of dealing with the situation.
- 2. Information seeking.** People often find it helpful to seek information about their disease and its treatment. Becoming expert in a subject may give you a sense of control over it. There is also a great deal of other information available, from books and websites. The quality of this information does vary but all the sources listed on pages 24 and 25 have been looked at by the authors and have been found to be reliable.
- 3. Disease management.** Many patients gain a sense of control over their disease by becoming involved- including being responsible for taking medicines and doing their own dialysis at home. PatientView (see below) is an excellent way to manage the information about your care.
- 4. Goal setting.** A very useful coping strategy for many people. Goals might include exercising or going out, or getting back to work.

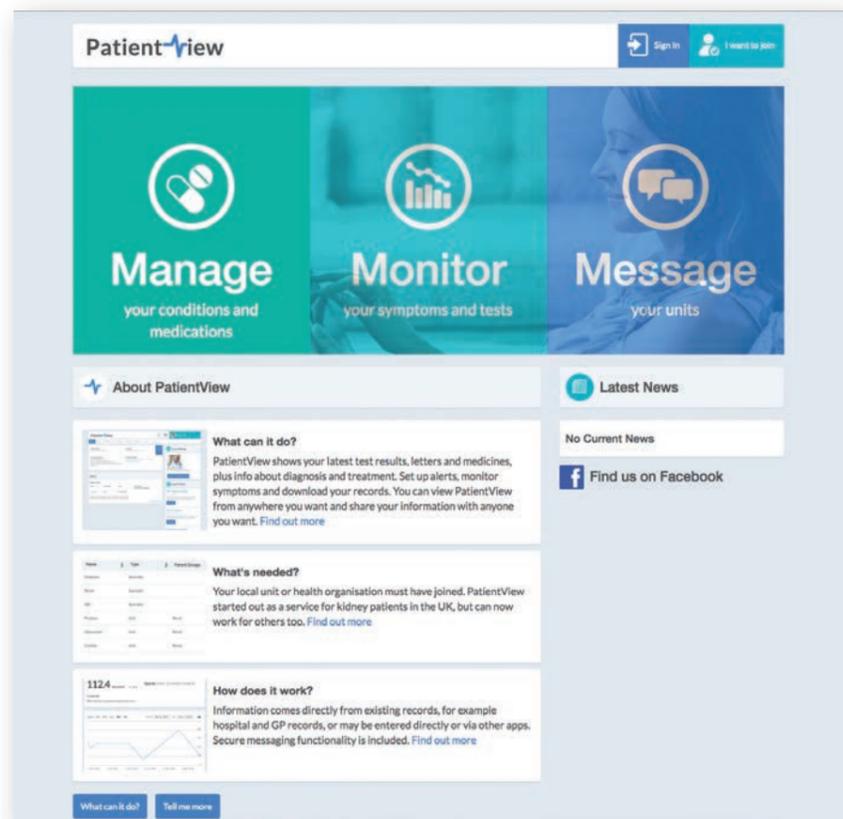
## Isambard's story

In renal units, one sees people who have had all manner of complications from an early age, such as people with diabetes who have had amputations. Most of them are not putting on brave faces, but in fact have a genuine reserve of cheerfulness.

In this place of extremes I found what lay ahead worrying at first. But then, seeing how others managed, I found it easier to understand my own predicament.



*I look at life differently now*



The PatientView website is an excellent way to manage the information about your care.



# Having kidney failure doesn't mean you need to stop enjoying life!

Top: Being on haemodialysis does not affect Maddie's speed on the ski slopes.

Above left: Vivienne enjoys the gentler, but no less competitive, world of bowls.

Above middle: Andy enjoys being outdoors and on the water.

Above right: If you are on APD, you may be able to take the machine on holiday.

# Living with kidney failure

## Smoking

Smoking tobacco carries a risk of damaging blood vessels and having a heart attack. Smoking also causes lung cancer.

Because kidney failure increases the risk of heart attacks and diseased blood vessels, even in non-smokers, continuing to smoke with kidney failure carries an extremely high risk. Ask for help if necessary, because giving up an addiction to tobacco is not easy.

## Exercise

General health benefits from regular exercise. This does not have to be vigorous – people should work to their limits while making a point of being active and mobile. This keeps muscle strength up, and helps the heart.

Some people find it helpful to take part in organised exercise at gyms or health clubs. Ask one of the doctors for advice before starting an exercise programme.

## Holidays and travel

People with kidney failure visit all parts of the globe. But do bear in mind that some remote places will have few facilities for dealing with kidney failure. Most of the world, though, has well-developed kidney failure services and can be visited quite safely.

Ask for advice well in advance of a holiday. It may be necessary to pay for each haemodialysis session, depending on where you are travelling. Many Renal Units will pay for a limited number of sessions a year of holiday dialysis. Up to date recommendations on vaccinations and other precautions such as malaria prevention are given on the Department of Health and British National Formulary websites. Advice on which vaccinations and drugs are suitable for kidney failure patients is given in the 'drugs' section of the Medical Information zone on the NKF website (see 'Important addresses' on page 24).

In some parts of the world, including India and the Middle East, there is a high risk of developing hepatitis if you have haemodialysis on dialysis units, and there may be a risk of catching one of these liver viruses. Travel insurance should include cover for illnesses that are linked to kidney failure. It is important that you tell the insurance company that you have kidney failure before you travel, as you may not be covered if you don't.

## Work

Many people with kidney failure are in full-time work, and have better sickness records than their 'healthy' friends. Most employers are very helpful to their employees with kidney failure, but may be concerned at first. Staff at your Renal Unit can write reports for your occupational health department at your place of work.

## Insurance and mortgages

Kidney failure has to be declared for most new mortgage applications and life or employment insurance policies. Provided you are generally fit apart from kidney failure, it should be possible to get a mortgage or insurance but a report from the specialist is often required. If there are problems getting a policy, ask for advice from your local kidney patients' association or the NKF as there are brokers and companies who are used to helping people with kidney failure.

## Sex

Sexual problems are common for men and women who have kidney failure. Not only are emotional problems more likely to occur, but also there are a number of medical conditions that can affect sexual function, in both men and women. Research has shown that people of all ages may have sexual problems, but these are more frequent in the mid-40s and later. Some people worry that sex may not be possible when they are receiving dialysis treatment. However, dialysis need not stop them from having an enjoyable love life.

Sexual problems are made worse by anaemia, and treatment with EPO may help some people. Problems with getting or sustaining an erection in men may be treated with Viagra or other similar drugs. More information on addressing sexual problems for both men and women can be found on the NKF website (see 'Important addresses' on page 24 for details).

Although some doctors may be uncomfortable about giving advice about sexual problems, most kidney units have access to a local specialist, so it is helpful to ask one of the doctors or nurses to make a referral. In some areas, however, there may be rather a long wait.

## Having babies

Kidney failure reduces fertility, particularly in women. Men are likely to have a reduced sperm count but are usually able to father children. By contrast, women who are on dialysis may stop ovulating and having periods. This is not always the case so proper means of contraception should be used if pregnancy is not planned.

Pregnancy for a woman on dialysis is usually complicated, though can be successful in some cases. It is usually better to plan a pregnancy well before dialysis is needed, or a year or so after receiving a successful kidney transplant.

Whatever the plans for pregnancy might be, it is best to discuss these with your Renal Unit team. Some Renal Units have special clinics where a kidney doctor and an obstetric specialist work together, advising women before pregnancy (some drugs must be changed before you get pregnant), and looking after women during pregnancy.

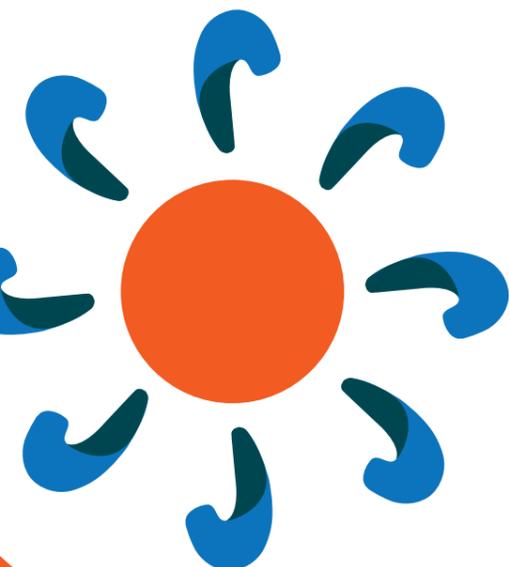
## Deborah's story

The issue of having children is also affected by renal failure. I know of many healthy children successfully conceived post-transplant, and indeed of many healthy children carried into early stage renal failure.

I do believe that my inability to sustain a successful pregnancy is directly attributable to years of nerve damage in diabetes followed by renal failure. This is an area of great regret for me and I believe deprived me of exploring a side of me that is quintessentially 'female'. This then is another area a woman will need to address in the early stages of renal failure. She needs to be clear on where she stands on these issues and be made aware of what opportunities are available to her for her future.



Sarah's father gave her one of his kidneys, and the successful transplant ensured baby George a good start in life.



# What next?

## Deborah reflects

A woman having dealt with the time spent in renal failure, followed by the period surrounding a transplant and all that journey entails, will still be left with the burning question of how much to tell people about her 'condition' and, more importantly, when. For my part, the moment I am within a 'medical' environment I am happy to tell all. Outside of this I have got it so wrong too many times to venture an opinion on how to deal with specifics in this issue. Suffice to say it is very easy to become a 'medical bore' and to put people off their food! I guess that maintaining links with good friends throughout renal failure is vital for several reasons. For a start it eliminates a large part of the problem of how much of your 'history' is required in order for people to gain an opinion of you; and it gives a fairly accurate indicator of how much involvement the people closest to you want. Talking to fellow (single) female transplant recipients it has dawned on me that we appear to have acquired an unrealistic 'this is my problem and I don't expect anyone else to deal with it' approach to our future. That's a shame because life is too short and everyone has their own form of 'baggage'. Everybody is a product of how they have dealt with what life has thrown at them. To conquer renal failure and live with transplanted organs has got to be a source of admiration!

## How long will someone with kidney failure live?

**How long someone will live when they have kidney failure depends on problems in the heart and other parts of the body, as well as on the success of the dialysis or transplant. Each of these factors varies from person to person and an individual assessment needs to be made. Even then, it is not possible to predict anyone's survival accurately. Indeed, many people will die from other causes entirely.**

Some people who develop disabling or painful conditions ask to have their dialysis stopped. Death from kidney failure then takes place in 1-3 weeks.

Any sickness or agitation can be treated with drugs. Stopping dialysis is clearly a major and irreversible decision, but is not illegal or regarded as a form of suicide. The renal team will discuss the motives someone might have for stopping dialysis, but will support anyone who makes this difficult decision.

The outlook for people on dialysis and following transplantation has improved markedly over the last 20 years, and recent updated statistics are available on the websites for United Kingdom Transplant ([www.uktransplant.org.uk](http://www.uktransplant.org.uk)) and the Renal Registry ([www.renalreg.com](http://www.renalreg.com)). The average survival four years after starting dialysis in people aged 18-64 is about 75%, though this is better in younger ages (90% aged 18-34), and lower in those who are older (30% for ages over 75 years). These figures have been compiled by the Renal Registry (*for more details see page 24*). A successful transplant increases survival compared to dialysis. However these are only average figures. You are an individual – you are not average.



Whatever stage your kidney failure has reached, you deserve individual care and assessment (photo ©Kidney Care UK).

## Jargon busting

**Acute** Short-term and of rapid onset, usually requiring a rapid response.

**Anaemia** A shortage of red blood cells in the body, causing tiredness, shortage of breath and pale skin. Anaemia is measured by the haemoglobin level (see below).

**APD** Abbreviation for automated peritoneal dialysis – a form of peritoneal dialysis that uses a machine to drain the dialysis fluid out of the person and replace it with fresh solution. APD is usually carried out overnight while the person sleeps.

**Arteries Blood** vessels that carry blood from the heart to the rest of the body.

**BP** Abbreviation for blood pressure.

**CAPD** Abbreviation for continuous ambulatory peritoneal dialysis. A continuous form of PD in which a person performs the exchanges of dialysis fluid by hand. The fluid is usually exchanged four times during the day, and is left inside the person's body overnight.

**Catheter** A flexible plastic tube used to enter the interior of the body. Different types of catheter may be used for haemodialysis, peritoneal dialysis or to drain urine from the bladder.

**Cells** The tiny units from which all living things are built up. Cells in different parts of the body look different from each other and perform different functions (for example, skin cells are very different from blood cells).

**Chronic** Long-term and of slow onset, not usually requiring immediate action.

**CKD** An abbreviation for 'chronic kidney disease'. This includes both chronic kidney failure and milder forms of kidney disease.

**Clearance** The removal of the toxic waste products of food from the body. Clearance is one of the two main functions of the kidneys. In kidney failure, clearance is inadequate and toxins from food build up in the blood.

**Creatinine** A waste substance produced by the muscles when they are used. The higher the blood creatinine level, the worse the kidneys (or dialysis or a kidney transplant) are working.

**CRF** Abbreviation for 'chronic renal failure', in which the kidneys are working at less than one third (30%) of normal.

**Dialysis** An artificial process by which the toxic waste products of food and excess water are removed from the body.

**Diastolic blood pressure**

A blood pressure reading taken when the heart is relaxed. It is taken after the systolic blood pressure and is the second figure in a blood pressure measurement.

**Donor** A person who donates (gives) an organ to another person (the recipient).

**End-stage renal failure (ESRF)**

A term for advanced chronic kidney failure. People who develop ESRF will die within a few weeks unless they are treated by dialysis or transplantation. These treatments control ESRF but cannot cure it.

**EPO** Abbreviation for erythropoietin.

**Erythropoietin** A hormone made by the kidneys, which stimulates the bone marrow to produce red blood cells.

**ESA** An abbreviation for 'Erythropoiesis Stimulating Agent'. This term is sometimes used instead of EPO and means essentially the same thing, but some of the new injections used to boost Hb are not strictly speaking EPO.

**Established renal failure (ERF)** Another term for end stage renal failure or ESRF.

**Fistula** An enlarged vein, usually at the wrist or elbow, that gives access to the bloodstream for haemodialysis. The fistula is created by a surgeon in a small operation. This increases the flow of blood through the vein and causes it to enlarge, making it suitable for haemodialysis needles.

**g/l** An abbreviation for grams per litre, the units used for the concentration of Hb in the blood.

**Haemodialysis** A form of dialysis in which the blood is cleaned outside the body, in a machine called a dialysis machine or kidney machine. Each dialysis session lasts for three to five hours, and sessions are usually needed three times a week.

**Haemoglobin (Hb)** A substance in red blood cells that carries oxygen around the body. Blood levels of haemoglobin are measured to look for anaemia. A low Hb level indicates anaemia.

**Hormones** Substances that act as chemical messengers in the body. Hormones travel around the body in the blood and control how other parts of the body work.

**Hypertension** High Blood Pressure.

**Kidneys** The two bean-shaped body organs where urine is made. They are located at the back of the body, below the ribs.

**mmol/l** Abbreviation for millimoles per litre. A unit used to measure the blood levels of many substances. Creatinine is measured in smaller units called micromoles per litre (amol/l).

**amol/l** An abbreviation for micromoles per litre, the units used for the measurement of creatinine in the blood.



## Nephrology

The study of the kidneys.

**PD** Abbreviation for peritoneal dialysis.

**Peritoneal cavity** The area between the two layers of the peritoneum inside the tummy. The peritoneal cavity contains the abdominal organs, including the stomach, liver and bowels. It normally contains only about 100 ml of liquid, but expands easily to provide a reservoir for the dialysis fluid in peritoneal dialysis.

**Peritonitis** Inflammation of the peritoneum, caused by an infection. People on peritoneal dialysis risk getting peritonitis if they touch the connection between their PD catheter and the bags of dialysis fluid. Most attacks are easily treated with antibiotic drugs.

**Phosphate** A mineral that helps calcium to strengthen the bones. Phosphate is obtained from foods such as dairy products, nuts and meat. In kidney failure, phosphate tends to build up in the blood.

**Potassium** A mineral that is normally present in the blood, and which is measured in the biochemistry blood test. Either too much or too little potassium can be dangerous, causing the heart to stop.

**Recipient** In the context of transplantation, a person who receives an organ from another person (the donor).

**Red blood cells** Cells in the blood which carry oxygen from the lungs around the body.

**Renal** Relating to the kidneys.

**Satellite haemodialysis unit** A place where some patients go for haemodialysis away from the main hospital renal unit. These units tend to be more friendly and less frantic than most main hospital buildings.

**Sodium** A mineral that is normally present in the blood that comes from salt (sodium chloride), and which is measured in the biochemistry blood test.

## Systolic blood pressure

A blood pressure reading taken when the heart squeezes as it beats. The systolic blood pressure is measured before the diastolic blood pressure and is the first figure in a blood pressure measurement.

**Transplant kidney** A kidney removed from one person (the donor) and given to another person (the recipient). Transplant kidneys may be either cadaveric transplants, living related transplants or living unrelated transplants.

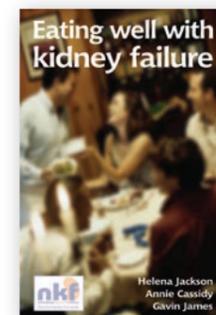
**Urine** The liquid produced by the kidneys, consisting of the toxic waste products of food and the excess water from the blood.

**Veins** Blood vessels which carry blood from the body back to the heart.

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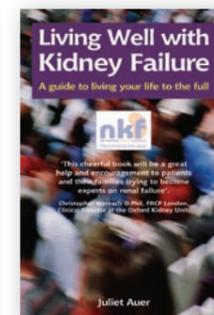
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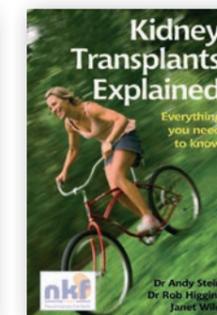
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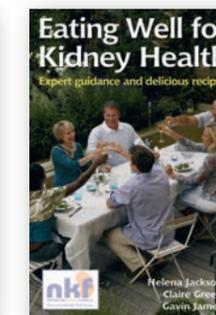
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## Important addresses

### Kidney Care UK

3 The Windmills  
St Mary's Close  
Turk Street  
Alton  
Hants GU34 1EF

Tel: 01420 541424

Email: [info@kidneycareuk.org](mailto:info@kidneycareuk.org)

[www.kidneycareuk.org](http://www.kidneycareuk.org)

### National Kidney Federation

The Point  
Coach House  
Shireoaks  
Worksop  
Notts S81 8BW

Tel: 01909 544999

Fax: 01909 481723

Helpline: 0800 169 0936

[www.kidney.org.uk](http://www.kidney.org.uk)

### Kidney Research UK

Nene Hall  
Lynch Wood Park  
Peterborough  
PE2 6FZ

Tel: 0300 303 1100

[www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)

### British Heart Foundation

Lyndon Place  
2096 Coventry Road  
Sheldon  
Birmingham B26 3YU

Helpline: 0300 330 3311

[www.bhf.org.uk](http://www.bhf.org.uk)

### Diabetes UK

Wells Lawrence House  
126 Back Church Lane  
London E1 1FH

Tel: 0345 123 2399

Fax: 020 7424 1001

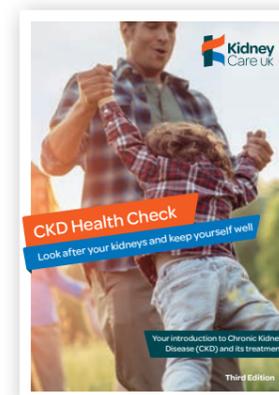
Careline: 0345 123 2399

[www.diabetes.org.uk](http://www.diabetes.org.uk)

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## Text by Dr Richard Fluck and Janet Wild RGN



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Janet Wild has been a Renal Nurse since 1988 and is now Market Access and Therapy Development Manager at Baxter Healthcare Ltd.



# Supporting everyone affected by kidney disease

We understand that living with kidney disease can be demanding and we are here to help patients and their loved ones with practical help and support:

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