



There's no place like Home!

An introduction to
Home Haemodialysis

Second Edition

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Meet the Experts

Several people have helped to bring this book to life with their own accounts of home haemodialysis, many thanks to them. The best people to listen to about what it is like are other patients and their family, along with the professionals who will look after you. Their quotes will be found throughout the book.

Arthur and his wife **Julie** do his home haemodialysis together, as seen in photographs of the machine in their house.

Jag works in business, and has had peritoneal dialysis, hospital haemodialysis, home haemodialysis and two kidney transplants.

Anthony works as a window fitter, and lives at home with his wife **Fran** and two children. He started dialysis at the age of 13 and over the years has also had a kidney transplant.

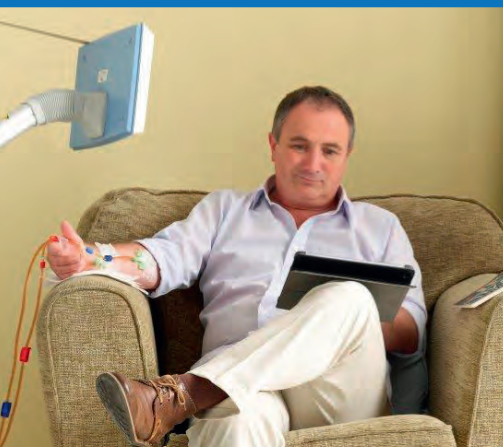
Chris is a retired engineer and school governor. He wants to dialyse at home and to be able to visit his family abroad.

Lesley is a nursing sister working in a home haemodialysis training unit.



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 book is an introduction to home haemodialysis. Haemodialysis is a treatment for kidney failure that uses a machine to filter the blood through an artificial kidney. Haemodialysis can be done in hospital or renal unit, but there are many differences between home and hospital treatments and different things to think about. So this booklet is to give you and your family more information about having dialysis at home. This can be useful to allow you to be involved and in charge of making choices about the type of dialysis you might have.

To understand the information here fully, it's good to know a bit about kidney failure dialysis first. There are other places where you can get information; some of these are listed near the end of the book.

Contents

Why do I need dialysis?	2
What are the different types of dialysis?	3
Some differences between the types of dialysis	4
Learning how to do it	6
Fistulas for home haemodialysis	7
What is a fistula and can I do my own needling?	7
What if I cannot have a fistula?.....	7
Taking care of a fistula	7
Your worries answered by a dialysis nurse	8
Dialysis and your lifestyle	10
How normal a life can I lead on home haemodialysis?	10
Is my home big enough?	10
What about diet and fluid intake?.....	11
Can I go on holiday?	11
Sports and hobbies.....	11
What about sex and pregnancy?	11
Help at Home	12
Will I be safe at home? Does someone else have to be there?.....	12
How much help should be family give me?.....	12
Types of home haemodialysis?	13
Home Haemodialysis	14
What are the benefits of home haemodialysis?	14
How many years can I stay on dialysis?.....	14
What about any problems I may have with home haemodialysis?	14
Can I still have a kidney transplant?.....	14
Jargon busting (glossary)	15
Other sources of help and advice	16

Why do I need dialysis?



Minor kidney disease is often called as chronic kidney disease or CKD. It is very common; up to 1 in 10 of the population have it. In a few people the kidneys get worse and they develop 'established kidney failure'; this is when the kidneys work at less than 15% of the normal rate. It happens to about 1 in 1000 people.

Healthy kidneys remove waste and excess water or fluid from the blood. When the kidneys stop working, wastes and fluid build up in the body. This can cause vomiting, itching, tiredness and swelling. If kidney failure isn't treated, it will eventually lead to death. The kidneys do other jobs too such as controlling blood pressure, keeping bones healthy and making red blood cells.

Dialysis is an artificial way of doing some of the work of the kidneys. It removes waste products and balances the chemicals in the blood, and it also removes excess fluid from your body from food or and drink. People with kidney failure also need medications to help with the other problems of kidney failure – anaemia, bone problems and high blood pressure.

Although a successful kidney transplant is the best treatment for kidney failure, many people who have kidney failure cannot have a transplant. For some people, it is that they are just not well enough to have a transplant while for others the wait can be long. Unfortunately, there is a shortage of kidneys available for transplant, so even people who are suitable may have to wait for one. What is more, transplants don't last forever and dialysis will be needed. So, it's really important that people find the type of dialysis that suits them the best at each stage of their life.



Chris

I started with hospital haemodialysis, then had a year of peritoneal dialysis. When peritoneal dialysis wasn't working I knew I wanted to have haemodialysis at home.



Jag

I would definitely recommend home haemodialysis, though a transplant is better.



You need to find the type of dialysis that suits you best, at whatever stage you are in your life. (photo ©Kidney Care UK).

What are the different types of dialysis?

There are two different types of dialysis: peritoneal dialysis (also called PD and is done at home), and haemodialysis (also called HD and can be done at home or in the renal unit).

PD and HD work in similar ways: the blood is filtered through a very thin membrane known as the dialysis membrane. The excess fluid and wastes pass into a special liquid called dialysis fluid or dialysate so that they can easily be removed from

the body. The dialysis membrane has tiny holes, which means it can act like a sieve, keeping the important parts of blood but allowing fluid and wastes to pass across it.

The membrane in peritoneal dialysis is the natural lining of the abdomen, so dialysis takes place inside the body. In haemodialysis an artificial membrane is used, called a dialyser, and blood is taken out of the body using a machine and filtered through the dialyser.

PD is generally undertaken at home, by either the patient or a carer. HD can be done in a centre (normally a hospital clinic) or at home.

Home haemodialysis doesn't suit everyone on dialysis, but its flexibility and the higher quality of waste removal are the main advantages. This leads to a quality of life that can be much better than is possible with hospital-based haemodialysis.

Anthony and Fran's Story

Anthony works as a window fitter, and lives at home with his wife Fran and two children. He started dialysis at the age of 13 and over the years has also had a kidney transplant.



Anthony

Honestly, home haemodialysis is the best way. If you want to look after your own life, go home.

I worked doing windows and always dialysed at home in the evenings. I wouldn't have had a job if I had been on hospital dialysis.

Home haemodialysis was better for the kids – they were 11 and 13 at the time. They knew I was here and knew what I was going through, why I was often so tired. They used to come and read to me when I was on dialysis, and helped me clear up and clean after the treatment.



Fran

It's better for family life, dialysis times are flexible.

The children adjusted really well. They needed to be clean in the dialysis room, but we had a television and Xbox in there for them. Dialysis became normal, even to their friends.

Even if he could dialyse by himself at home, I would worry in case anything might happen. Not that anything did happen that really needed my help. There's an alarm bell in the dialysis room, if I touch it by accident the dog goes mad, even though Anthony has been transplanted for over a year.

Some differences between the types of dialysis

	HOME HAEMODIALYSIS	UNIT HAEMODIALYSIS	PERITONEAL DIALYSIS
Where does dialysis happen?	At home	In a hospital or clinic	At home
Will I need to have an operation?	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.
Will I need space at home?	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.
How often do I need to have dialysis?	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.
What time of day does the dialysis take place?	When you decide.	At the appointment time given by the unit.	When you decide.
How strict is the diet?	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
How strict is the fluid restriction?	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.
Can I go to work?	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.
Are holidays possible?	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.
What are the main complications?	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.



I want home haemodialysis. How do I learn how to do it?

If you are thinking about home haemodialysis, it's worth talking to other patients as well as the Home Dialysis team in your renal unit. Ask for an appointment with the nurse or doctor in charge of the programme. They can talk to you about how home haemodialysis might fit into your lifestyle and you will have an opportunity to ask questions. You may wish to write a list before your appointment, so you don't forget anything.

It might be useful to ask a patient who is on home haemodialysis the following questions:

- How do you feel?
- How does dialysing at home affect your family and family life?
- How easy was it to learn?
- How do you manage putting the needles in your arm yourself?
- Do you work?
- Have you been away on dialysis?
- How much space does the machine take up in your home?
- What impact has storing all the supplies had on your home?

These questions might be good to ask the doctor or the nurse:

- How long will it take me to learn to do home haemodialysis?
- Do I need to have anyone with me at home when I am on dialysis?
- Who organises plumbing the machine into my house?

- How often will the supplies be delivered to my home?
- Will I get any financial help for the electricity and water use?
- Will I be able to carry on working?
- Where can I travel to with home haemodialysis?
- How heavy is the machine?
- Can I transport the dialysis machine on holiday?
- Will I need to take the dialysis supplies with me when I go away?

There may be other things you want to ask. Just add them to the list before you have your appointment.

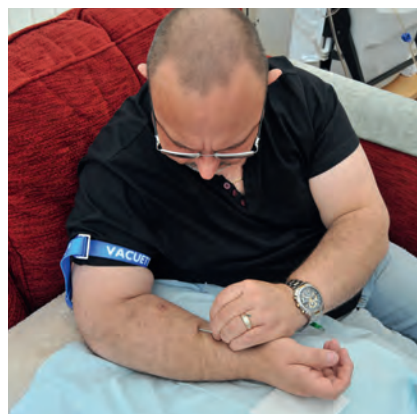
Before starting home haemodialysis, a visit to your home from nurse and technician will be arranged. This visit helps you (and them) decide the best place for you to have your machine, where to store your supplies and to check that your water, waste and electricity supplies are satisfactory.

The next step is for you to be trained. Many renal units have a specialist home training unit where you can go to continue treatment whilst learning how to do your own dialysis. This can take between 3 and 12 weeks, depending on how many dialysis sessions you do a week and how quickly you learn. There is no pressure and no rush. Training will be just at your own pace.

During the training period, the technicians will arrange to have the dialysis equipment installed into your house. This can sometimes take a few weeks to organise, so the earlier it's started the better.

Once you feel ready, and the nurses and doctors are also confident that you can manage, you will be able to start your dialysis at home.

The home dialysis team of doctors, nurses and technicians do not forget about you once you are at home; there is 24 hour availability in case of problems, and you'll have regular home visits to check how you are. Monthly blood tests will be required, and you will still need to come into the renal unit for clinic check-ups.



Arthur: After a good handwash and cleaning of the skin, the needle is inserted into the fistula. It's important to wash your hands and sterilise the trolley before each session of dialysis.

Fistulas for home haemodialysis

What is a fistula

To have haemodialysis, you need to get a lot of blood from your body through the dialysis machine and back into your body. Don't worry – it is not all taken out at once. You have about 5 litres of blood in your body, but at any one time about 200 mL are in the machine. Blood is taken out and put back in at about 400 mL every minute so all your blood will go through the machine every 12.5 minutes and 20 times in total during a standard session of 4 hours. The blood vessels in your arms are not usually strong enough to cope with the rate at which the blood needs to be removed. So an artificially enlarged blood vessel is formed, which is bigger and stronger than the normal veins in your arm. This is called a fistula. Fistulas are usually made in the arm.

The fistula is made during a short operation by a surgeon who joins an artery and a vein together. This makes the blood flow through the vein much quicker and stronger than usual and causes it to get bigger. It usually takes about 2 months for it to be fully formed and strong enough to cope with the needles and blood flow used for dialysis.

Can I do my own needling?

Many people on home haemodialysis use something called a 'buttonhole technique', which involves putting the dialysis needles through the same hole every time you have dialysis to create a track. With this you can use blunt needles and people think there is less discomfort. It works just like ear piercings – so getting the needles in can become much easier.

Learning how to put the two needles into your fistula for dialysis can be a bit daunting. The nurses are very experienced in teaching people how to do this and have lots of tips and tricks to help. It can also be helpful to share experiences with other patients.

Most people find once they have learnt how to do this, it is not difficult and usually feel they can needle their own fistula better than anyone else! But it is very, very important to follow all the steps meticulously to reduce the risk of damage to the fistula or introducing infection into your bloodstream.

What if I cannot have a fistula?

Some people cannot have a dialysis fistula, they may have one which does not work. If this happens, they will need to have dialysis using a plastic tube (called a 'line' or 'catheter' or 'cannula') that passes through the skin and into a large vein in the neck or the groin. Lines can get blocked and are prone to infections, so they are not the first choice for haemodialysis. Although in some people lines work well for years with no problems, and it should be possible to have home haemodialysis if you have a line.

Taking care of a fistula

Keeping a fistula safe and functioning is important. A good fistula is the lifeline for anyone having haemodialysis, whether at home or in hospital. It is important to keep the skin clean and report any redness or infections near the fistula.

The nurses will teach you how to keep your fistula healthy and working well, and what to look out for in case of problems.

The fistula needs to be prevented from physical injury. Fistulas can bleed, although this is very rare. Your team will train you in what to do (this is important even if you have haemodialysis in hospital).


The British Renal Society have published a guide to help you care for your fistula (*see page 16 for details*). It is a medical document, so talk to your team about it.

If you enjoy contact sports or have a manual job, a leather or plastic guard over the fistula may reduce the risks of any injury.

Chris' Story

I wasn't worried about working the haemodialysis machine, as I had already used a peritoneal dialysis machine. The manual was well written and easy to understand. Patient to patient education is the most valuable and important.

I did have reservation about a fistula. First, I didn't want holes carved in a perfectly good left arm. Then when I first had to needle myself, I was shitting bricks! But even the first time that I did needle myself, it was less painful than when the nurses did it. Now it works well and I am happy with the fistula and the needling.



Your worries answered by a dialysis nurse

Lesley gives the low down on home haemodialysis



We don't look after the machine, we look after the patient.

And we don't just look after the patient, we look after the whole family.



Who is suitable for home haemodialysis?

Anyone is suitable for home haemodialysis unless it's shown they cannot manage. Certainly there's no age limit. Some manual dexterity is required to set up and to use the machine. The most important factor is 'do you want to do it?'

What are the benefits of home haemodialysis?

Home haemodialysis gives people more energy and better lives. They can eat more – sometimes the blood phosphate levels are even too low if dialysis is going really well. A low phosphate isn't a huge problem. It just means that you don't need to take phosphate binding tablets and can eat a more normal diet.

Compared to having dialysis in a hospital or satellite dialysis unit, there will be less travelling time, but to make the most of home haemodialysis the hours on the machine will need to be longer overall than in a hospital or satellite unit.

How long does it take to train for home haemodialysis?

Usually 2–10 weeks. If someone is already fully self-caring and needling themselves on their dialysis unit, the training can be really quick.

People training for home haemodialysis worry most about putting needles in their fistula. But it's less painful to do it yourself than to have a nurse do it for you. If someone is really worried we can refer to a psychologist, but usually the most useful thing is for someone to talk to other patients who have learnt to needle themselves.

Will I be safe at home?

You can dialyse at home using a plastic line, though a fistula is better. There is a risk of infection if the end of the line is touched or if procedures are not fully sterile at the start and end of haemodialysis, so it may be better if someone is at home to help in people with lines.

If something goes wrong the machine will alarm. Everyone is trained in how to respond to the alarms and correct the machine, or a kink in the plastic tubes carrying the blood. If the worst happens it is easy to shut off the machine and keep yourself safe.

Low blood pressure can occur, but is less common than when people dialyse in a hospital or satellite dialysis unit. If you are prone to low blood pressure, the machine can be set up so that it is easy to give yourself some extra fluid to bring the blood pressure up.

Can I sleep during home haemodialysis?

Nocturnal dialysis means dialysing all night. There are no special precautions to take if you go to sleep while on home haemodialysis.

An additional sensor is used to detect needles becoming dislodged.

It can take a few weeks to get used to the machine but after that people normally sleep well.

What are you going to do with that extra time and the opportunity to alter dialysis days?

Dialysis and your lifestyle

How normal a life can I lead on home haemodialysis?

If home haemodialysis is working well, it is possible to lead an almost normal life. You can fit the sessions into your day when it is convenient, and many people continue to work.

Many people find doing dialysis overnight is best way of managing a full time job, but doing it during the day can work as well. Manual jobs are certainly possible if you have enough energy and physical strength. Work that requires a lot of travel may be a challenge. However, if only a couple of nights away from home are needed, this can be fitted in easily.

For longer trips away, haemodialysis would need to be arranged at a dialysis unit near to the destination, unless you have one of the smaller,

transportable machines. For longer trips there are more challenges, but it is possible to have haemodialysis in most parts of the world.

Family life is bound to be affected by having kidney failure, and you may be reluctant to have a dialysis machine at home. However, for most people and their families, it is better to be at home rather than spending hours travelling to and from hospital. You should discuss the effects of dialysis with your whole family, and talking to other people having home dialysis will be helpful.

Is my home big enough?

If you are thinking about home haemodialysis, you will need to set aside some space for the dialysis machine and the water purifier. This will need additional plumbing

and drainage. You will also need a small trolley for the dialysis equipment you need at each session (dialysis tubing, the needles, sterilising equipment).

Most home HD machines are less than 3 feet tall. The water purifiers are about the size of a bedside table.

You will also need space to store the supplies. These will include the dialysis fluid concentrate solutions, dialysis filters, blood lines, needles, cleaning products and accessories. The supplies will be delivered to your house at least once a month. The nurses at the hospital will be able to give you advice on where you can store your supplies.



Chris

I knew I wanted to have haemodialysis at home, but there wasn't enough room in my bedroom for one of the large machines they use on the unit. Then I saw the small home haemodialysis machine and knew I could find the space for this in my house.

The new compact haemodialysis machines can fit into most homes. (photo ©Kidney Care UK).



What about diet and fluid intake?

Dialysis can't completely take the place of healthy kidneys and so watching what you eat and drink is very important. Restrictions on your food and drink aren't usually as strict for people who do home haemodialysis as they are for people on three times a week dialysis in hospital. This is because people on home haemodialysis can do more frequent treatments than is possible for people who go to hospital for dialysis.

Watching what you eat is important so that dangerous substances don't build-up in the blood. This usually means eating food that doesn't contain much potassium and phosphate. Your dietitian can give you advice on which food to avoid if necessary. You might also be asked to eat less salt. You can do this simply by not adding salt to food or when cooking, and avoiding processed food with high levels of salt. It is also important to eat a healthy and well balanced diet.

Healthy kidneys do a great job at controlling levels of fluid (which is made up of salt and water) in your body, no matter how much or little you drink. When kidneys stop working, they lose this function and so dialysis is needed to remove excess fluid. Having too much fluid inside your body can be dangerous. It causes swelling, breathlessness and can lead to serious heart problems.

Removing large amounts of fluid from the body during dialysis will leave you feeling drained out, dizzy and would put a large strain on the heart. So, it's best not to let too much fluid build-up. You can do this by restricting the amount of fluid you drink, and by having dialysis at least every other day.



I had the space to have the larger machine and everything else in one room, a 'mini-hospital'

Can I go on holiday?

Holidays are a great way to relax. Unfortunately, a holiday from dialysis isn't possible. Talk to your unit about how holiday dialysis is organised. Some people can organise their sessions to get a day or two away, but long gaps off dialysis can be dangerous as fluid and toxins build up in your body.

For longer breaks you will need to have dialysis away from home. You can be booked into a haemodialysis unit near your destination.

Sports and hobbies

One of the advantages of home haemodialysis is the extra flexibility that it offers, allowing people to 'do their own thing' more freely.

Perhaps the biggest concern might be the worry of damaging the dialysis fistula (see page 9). So it is important not to do any activities that might risk injury to your dialysis fistula, such as robust contact sports. You can get a fistula guard (a piece of moulded leather or plastic that fits over the arm) which can be worn during sport.

If you like to swim, this is a great form of exercise and is unlikely to damage the fistula. However, you will need to make sure that there is no risk of bleeding, so it's best to wait for about 24 hours after dialysis before swimming.

What about sex and pregnancy?

Having kidney failure can reduce sex drive and fertility for both men and women. However, having a really good quality of dialysis can help improve the situation. It is rare for women who have hospital dialysis three times a week to get pregnant, but there have been many cases of successful pregnancies among women who have more frequent home haemodialysis.

If a woman who is on dialysis does get pregnant they will need to be very carefully looked after. The chances of getting pregnant are lower than the general population but not zero. Indeed, women on home haemodialysis who are doing it either overnight or more frequently increase their chances of falling pregnant. However, being pregnant on dialysis has a lot of risk to baby and mum. So, most people will be advised to wait until they have a transplant. However, outcomes are getting better. During the pregnancy, it is likely that dialysis will need to be done every day and the best solution is to dialyse overnight for as long as possible.

Many kidney units have a specialist clinic where the maternity and kidney doctors work together. These clinics can also give advice to women planning to get pregnant, and review their treatment, in order to ensure that they are as healthy as possible before they conceive.

Some men with kidney failure have problems getting or keeping an erection. This can be the case even if they are having a good quality of dialysis. If this happens, there are things that can be done to help so it's definitely worth talking to your doctor. For example, the doctor can make sure that you are not anaemic and stop any medications where impotence is a side effect. Viagra may be effective, but you should always talk to your doctor before taking it to make sure your blood pressure is at a safe level.

Help at home

How safe will I be at home? Does someone else have to be there?

Home haemodialysis is very safe. Yes, it looks very 'high technology' and a bit scary, but the machines have huge amounts of safety equipment and the training given before someone dialyses at home is very thorough.

Equally importantly, there is 24 hour support in case of technical problems. If there is a machine fault that cannot be fixed immediately at home, you will have been taught how to respond to emergencies during your initial training period. The machine will then be repaired the next day and you can have an extra dialysis session if necessary to catch up.

Apart from problems with the machine, the main safety issue at home is getting low blood pressure with faintness during dialysis. You will be trained to deal with this, and also how to prevent the problem (which is usually due to removing too much fluid too quickly during dialysis).

Some people worry about the needles falling out. Again, this is rare, but patients get carefully trained to reduce this risk and there are detection systems used to give you a warning if a needle dislodges.

It is also possible to dialyse yourself at home on your own, with no-one else around. The machines are so safe that most units are happy to support you if you want to go solo. There may be extra training though, to make sure you can manage.

How much help should my family give me?

How much your family wants to get involved with the dialysis is entirely up to you. It is possible to do everything without any help. On the other hand, it is possible for someone in the family to do everything for you.

Either of these extremes is potentially stressful and in most families the jobs required for dialysis are shared. The best solution is what works in a particular family.



Anthony

Needling was quite easy. I was never nervous doing it at home. The first time I tried, though, I could only get the needle half in and bled a bit.



Arthur and his wife Julie: Setting up the machine; the cassette of plastic tubes has been clamped into the machine, the tubular object on the near side of the machine is the artificial kidney. You can set the machine up on your own, but sometimes a team effort is quicker and more fun.

Types of home haemodialysis

There are several different types of machine and dialysis fluid available for home haemodialysis.

You can have dialysis at home on a machine that has been especially designed for use at home, or on one of the larger machines that are also used in hospitals.

Many machines need to be 'lined' before dialysis, that is, the disposable plastic tubing for the blood needs to be put onto the machine. This can be a little fiddly and takes a few minutes. The newer generation of small machines have the lines built into a plastic cassette, and this can be clamped into the machine much more quickly.

Haemodialysis requires a mixture of ultrapure water and a salt solution. This dialysis fluid can be made by a machine called an RO (Reverse Osmosis) machine using water from a domestic tap. The machine is about the size of a bedside cabinet.

Waste fluid from the dialysis machine can be disposed of down the domestic drains.

One type of machine or fluid delivery system is not by itself better than another, and many units offer a choice of systems. A choice can be made during the home training process.



Lesley

People training for home haemodialysis worry most about putting needles in their fistula. But it's less painful to do it yourself than to have a nurse do it for you. If someone is really worried we can refer to a psychologist, but usually the most useful thing is for someone to talk to other patients who have learnt to needle themselves.



Jag's Story

I had the space to have the larger machine and everything else in one room, a 'mini-hospital'.

All the time I was on dialysis, I carried on working full time; coming to the hospital for dialysis straight after work was difficult, and I didn't spend much time with my family.

Once I was on home haemodialysis, I was able to spend quality time with my wife and kids.

It took a few weeks to settle in at home. My family panicked when my BP went low, but I sorted it out myself.

The blood pressure was more stable at home than dialysing in hospital.

At hospital I was dialysing three times a week, at home I did every other day. This made me feel better, I didn't have the weekend build up of fluid and chemicals.

I used to hate the cleaning and rinsing the machine every month. I didn't use the small machine, they had just come out and I wasn't sure they would give me enough dialysis.

Home Haemodialysis

What are the benefits of home haemodialysis?

Haemodialysis in a hospital or clinic is usually three times a week, but many people at home do their dialysis five or six times a week.

It isn't a rule that people at home have to do more dialysis sessions, but they usually find that more sessions means the control of fluids and wastes in the blood is much better. This means that they can be much less strict with diet and fluid restrictions.

Home haemodialysis is also much more flexible than hospital dialysis. There is no travelling to and from the dialysis unit and no waiting around for the machine to be ready. You can have your dialysis at a time that suits you, even if that's different every day.

There is some evidence that people who develop their knowledge, gain 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. Taking control will help you feel much better, both physically and emotionally.

How many years can I stay on dialysis?

Haemodialysis can be a successful long-term treatment. There are people who have had the treatment for over 30 years. The success of haemodialysis depends firstly on the access for dialysis, and a good fistula is the best. Next, keeping a regular healthy diet and fluid intake keeps the body as stable as possible with as little strain on the heart. Good blood pressure control and not smoking also reduce the risks of heart disease.

Many people will also change from one type of treatment to another over the years, perhaps starting with peritoneal dialysis, then having a transplant, and then haemodialysis if the transplant fails.

As well as medical treatments, keeping a positive attitude, having support from friends and family and coping strategies when there are problems is important.

What about any problems I may have with home haemodialysis?

Something will almost certainly happen at some point that makes home haemodialysis more difficult. Not necessarily a major medical problem, but maybe something as simple as redecorating at home. There may be some family issues and the responsibilities of home haemodialysis may be an extra pressure.

Many people on home haemodialysis spend periods of time having their dialysis in the unit. This isn't a failure, but something that happens and dialysis units expect to have some people from home having dialysis in the hospital unit from time to time.

You can get lots of support from the home haemodialysis team, who know they aren't just there to train people and to send them home, but to support people through the whole dialysis journey.

Can I still have a kidney transplant?

Yes, there is nothing about home haemodialysis that stops you having a transplant. Indeed, if you are fitter and healthier a transplant is more likely to be successful.



Jargon busting

Anaemia

A shortage of red blood cells in the body, measured as haemoglobin levels or red blood cell count. Anaemia may be treated if the haemoglobin level is below 110 g/L.

Arteries

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

Blood Pressure (BP)

The pressure in the arteries measured by a cuff and a sphygmomanometer. High blood pressure is associated with heart attack and stroke and low blood pressure may reduce the healthy functioning of the kidneys.

Calcium

Mineral important throughout the body, especially in bones. Blood level may fall as the kidneys fail to produce activated vitamin D in CKD Stages 4 and 5.

Catheter

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

Chronic

Present for a long time – in CKD for at least 3 months and of slow onset, not usually requiring immediate action.

CKD

Abbreviation for chronic kidney disease.

Clearance

The removal of the toxic waste products of food from the body. Clearance is one of the main functions of the kidneys. In CKD, clearance is reduced and toxins from metabolism, and also medications, built up in the blood.

Creatinine

A waste substance produced by the muscles. The higher the blood creatinine level, the worse the kidneys are working. The blood creatinine level is used to calculate the eGFR, an estimate of kidney function.

Dialysis

An artificial process by which the toxic waste products of food and excess water are removed from the body. This can be directly from the blood as in haemodialysis, or from the lining of the abdominal cavity (peritoneal dialysis). It usually needs to be performed several times each week over several hours. Dialysis improves symptoms but is not a cure.

Established renal failure

(ERF) A term for advanced chronic kidney failure, which is also Stage 5 CKD. People who develop ERF may die within a few months unless they are treated by dialysis or transplantation. These treatments control ERF but cannot cure it.

Fistula

An enlarged vein that can be used for dialysis. A small operation near the elbow or wrist joins together an artery and a vein, making the vein large enough for a needle to be inserted.

Graft

If a fistula fails or is not possible, a length of woven plastic tubing is placed between an artery and a vein, and needles can be passed through the skin into the graft to take blood in and out of the body for dialysis.

Haemoglobin

(Hb) A substance in red blood cells that carries oxygen around the body. A low Hb level indicates anaemia.

Hypertension

High blood pressure, usually over 140/90.

Kidneys

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

Line

A plastic tube used to remove blood from the body, and then to return it after it has passed through the dialysis machine. The line goes into a large vein in the neck or the groin. This is also sometimes called a catheter.

Nephrologist

A doctor who specialises in kidney disease, dialysis and transplantation.

Peritoneal

A medical name for the interior lining of the tummy, which can be used for dialysis.

Phosphate

A mineral that helps calcium to strengthen the bones. Phosphate is obtained from foods such as dairy products, nuts and meat. In CKD Stages G4 and G5, phosphate tends to build up in the blood and the intake in the diet may need to be restricted.

Potassium

A mineral that is normally present in small amounts in the blood. Either too much or too little potassium can be dangerous, causing the heart to stop. People with CKD will have their potassium level measured when the eGFR is checked, and will be advised if the level of potassium is abnormal.

Protein

An important building block in the body. Carried around the body in the blood, appears in the urine in some people with CKD.

Renal

Relating to the kidneys.

Sodium

A mineral, normally present in the blood, that comes from salt (sodium chloride). Sodium retention exacerbates high blood pressure, and most people with CKD will benefit from reducing the sodium in their diet.

Tunnelled line

A plastic tube (or catheter) used for taking blood out of the body for dialysis and returning it to the body. Instead of coming out through the skin near the vein, the line 'tunnels' under the skin for 3–5 cm. This makes the line more comfortable and creates a barrier to infection.

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.

Patients' Associations

Kidney Care UK

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

Tel: 01420 541 424
Fax: 01420 89438

www.kidneycareuk.org

National Kidney Federation

The Point
Coach Road
Shireoaks
Worksop
Notts S81 8BW

Tel: 01909 544 999
Fax: 01909 481 723
Helpline: 0800 169 0936

www.kidney.org.uk

Kidney Research UK

Nene Hall
Lynch Wood Park
Peterborough PE2 6FZ

Tel: 0300 303 1100
or 0800 783 2973

www.kidneyresearchuk.org

Diabetes UK

Wells Lawrence House
126 Back Church Lane
London E1 1FH

Tel: 0345 123 2399
Fax: 020 7424 1001

www.diabetes.org.uk

The Internet

As well as the websites listed, there are many more which you may find useful. Here are some suggestions:

www.aakp.org

The American Association of Kidney Patients

www.bhf.org.uk

The British Heart Foundation

www.bhsoc.org

The British Hypertension Society

<http://britishrenal.org/wp-content/uploads/2016/10/Recommendations-for-Managing-LTH-of-AVF-and-AVG-1.pdf>

British Renal Society Guide on Fistula Management.

www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Renal/fs/en

Department of Health publications for the NHS on kidney diseases.

www.edren.org

The website of the Edinburgh Renal Unit. For general information go the EdRenInfo link at the top of the home page.

www.jbs3risk.com

Risk calculator for the prevention of cardiovascular risk, devised by the Joint British Societies.

www.kidney.org.uk/Medical-Info/drugs/vacc2.html

The section of the NKF website giving information about medicines and vaccinations that can and can't be used for people with kidney transplants.

www.kidneypatientguide.org.uk

Information for people with kidney failure, and those who care for them.

www.nephron.com

Exhaustive information on everything to do with kidney diseases.

www.nice.org.uk

National Institute for Health and Care Excellence, produces clinical guidelines for the NHS, which include treatment of anaemia in CKD, treatment of diabetes, and treatment of high blood pressure. CKD guidance was updated in 2014.

www.patient.co.uk

Provides a wide range of patient leaflets including information on prescribed drugs.

www.patients-association.com

Provides advice on patients' rights.

www.renal.org

Renal Association, the UK national body of kidney specialists. Has a useful section on CKD, with information on how eGFR is calculated and links to national guidance.

www.patientview.org

Enables patients in some UK kidney units to view their own results and care pathways on the Internet.

www.thinkkidneys.nhs.uk

The NHS campaign to improve the care of people at risk, or suffering from, AKI.

www.uktransplant.org.uk

National Health Service site giving information about transplantation and organ donation.

To order these books, please call our Order Line 01752 202301 or go to www.classhealth.co.uk

Further Reading

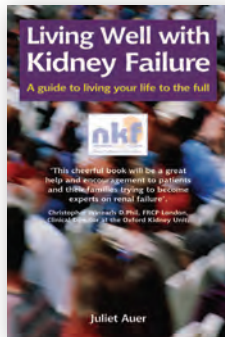
For enquires please email: info@class.co.uk

BOOKS



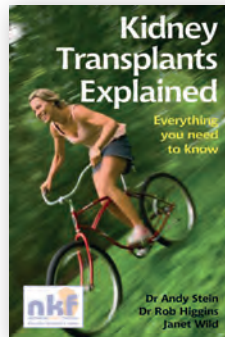
Eating Well With Kidney Failure

Helena Jackson, Annie Cassidy and Gavin James (ISBN 978 185959 116 1)
RRP £19.99



Living Well With Kidney Failure

Juliet Auer (ISBN 978 185959 112 3)
RRP £17.99



Kidney Transplants Explained

Dr Andy Stein, Professor Rob Higgins and Janet Wild (ISBN 978 185959 193 2)
RRP £19.99



Eating Well for Kidney Health

Helena Jackson, Claire Green and Gavin James (ISBN 978 185959 204 5)
RRP £19.99



Kidney Failure Explained

Dr Richard Fluck and Janet Wild (ISBN 978 185959 792 7)
RRP £24.99

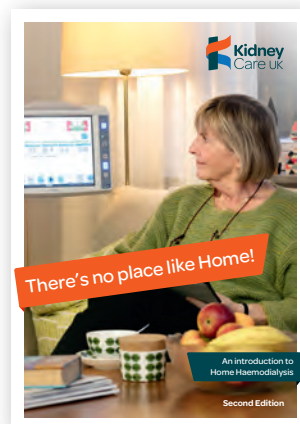
Further copies of these booklets are available from Kidney Care UK. Please call 01420 541424.

BOOKLETS



CKD Health Check

Dr Richard Fluck and Janet Wild RGN (ISBN 978 185959 649 4)



No Place Like Home

Janet Wild RGN and Dr Richard Fluck (ISBN 978 185959 651 7)



Help! I've got kidney failure

Janet Wild RGN and Dr Richard Fluck (ISBN 978 185959 647 0)

Text by Dr Richard Fluck and Janet Wild RGN



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