

Information about the
haemodialysis process

I need haemodialysis – what happens now?



The Outpatient Haemodialysis Unit

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Eğer bu bilgiyi bir başka dilde istiyorsanız lütfen bağlantı kurunuz:

Jeśli chcesz uzyskać te informacje w innym języku skontaktuj się z:

0141 211 2178

Name	
Dialysis days**	
Consultant**	
Registrar**	
Named Nurse**	
Dietician**	
Pharmacist**	

** If you change dialysis shift, this information will change. Additionally, the registrars change every 6-12 months.

This booklet contains information on:

- Staff that you may meet
- What is haemodialysis and why do I need it?
- How is blood removed to be cleaned?
- How long will I be attached to the machine for?
- How will I feel during and after dialysis?
- Will dialysis keep me well?
- Fluid management
- Potassium and Phosphate
- Anaemia
- How will I be monitored?
- What if I have medical problems?
- Who can I talk to?
- Will I be able to continue with my job or studies?
- Can I claim Social Security benefits?
- Will I be able to go on holiday?
- Will I need dialysis for the rest of my life?
- Appendix 1: Cutting down on potassium in your diet
- Appendix 2: Cutting down on phosphate in your diet

Welcome to the outpatient haemodialysis unit.

This booklet gives you information about the haemodialysis (HD) process and the people who will help to manage your dialysis. It gives you a brief overview of the HD process but does not cover every aspect in detail. Staff will be happy to answer any additional questions you might have.

Some of the information in this booklet has been adapted from The National Kidney Federation website:

<http://www.kidney.org.uk/Medical-Info/haemodialysis.html>

There are many other online sources that provide useful information including:

The Edinburgh Renal Unit website: <http://www.edren.org/pages/edreninfo/haemodialysis-hemodialysis.php>

The Kidney Patient Guide:

<http://www.kidneypatientguide.org.uk/site/contents.php>

Staff whom you may meet

- Doctors – a consultant and a registrar are responsible for your care and although not based in the unit will monitor your laboratory results and will review your care as necessary.
- Dieticians – staff who specialise in helping you with your diet
- Pharmacists – staff who help you with your medication
- Nurses – staff who care for you in the unit. The Senior Charge Nurse is the person in Charge of the unit and staff nurses will work with you and help you with your dialysis.

What is haemodialysis (HD) and why do I need it?

HD is a method for removing waste products from the blood stream. It is necessary when the kidneys do not work effectively and the body is unable to remove toxins. When these toxins build up in the blood stream they can make you feel very unwell and cause a variety of symptoms, including loss of appetite, sickness and lethargy.

You need HD because your kidneys are not working and are unable to filter and 'clean' your blood effectively.

HD takes over the role of the kidneys; it does not cure kidney failure. HD is one of three methods of kidney replacement therapy. Peritoneal dialysis and transplant are not covered in this booklet.

How is blood removed to be cleaned?

During the HD process, blood is removed from the body and passed through a machine where it is 'cleaned' and waste products are removed. This involves using a filter with a membrane; blood flows up one side of the membrane in the machine and dialysis fluid flows down the other. Waste products cross the membrane from the blood into the dialysis fluid and the 'clean' blood is then passed back into the body. The machine is also able to remove some excess fluid from the body. During this process, certain vitamins are also removed and so at the end of each dialysis session, you will be given tablets (folic acid and vitamin B) to take which replace these.

In order for blood to be removed and returned, we need to access the blood stream (vascular access). This is achieved in one of three ways:

- temporary line
- tunnelled line ('permcath')
- fistula

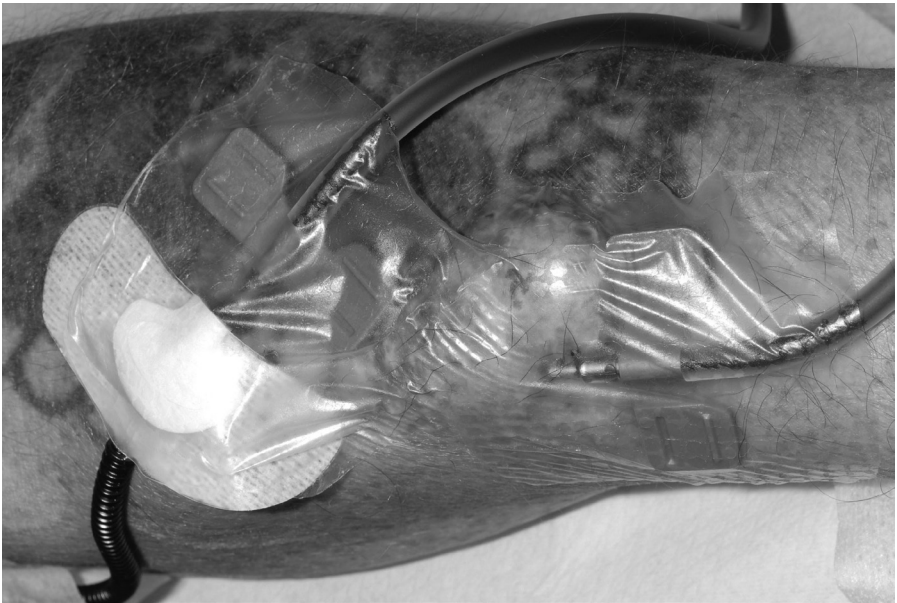
A temporary line is only a short term measure; it involves placing a plastic tube in a vein in either the neck or the groin.

A tunnelled line is more permanent and involves placing a plastic tube under the skin into a vein in the upper chest; this is performed in the X-ray department.

A fistula involves a small operation, often performed under local anaesthetic, attaching a vein to an artery in the forearm. This allows the vein to thicken so needles can be placed into it easily to allow the dialysis process to take place. A fistula needs to mature (develop) after it has been created and before it can be used. This can take about 8 weeks.



A tunnelled line or 'permacath'.



A fistula in the forearm with dialysis needles inserted.

With a temporary or a tunnelled line, nursing staff will attach you to the dialysis machine using two plastic tubes. One of these tubes allows blood to be pumped out of the body and into the machine and the other tube allows blood to be pumped back into the body once it has been cleaned. With a fistula, two needles are placed into the fistula with a plastic tube attached to each to allow blood removal and return.

Of these three methods of vascular access (accessing the blood stream), a fistula is the best. It allows for a better quality of dialysis and poses less risk of infection than either a tunnelled line or a temporary line. However, in some patients creating a fistula is not possible in which case a tunnelled line is the preferred option.

Whichever form of access you have, you will always be connected and disconnected from the dialysis machine in a sterile fashion to minimise the risk of infection.



A patient connected to a haemodialysis machine via a tunnelled catheter.

How long will I be attached to the machine for?

A standard HD session lasts for 4 hours and takes place three times per week. The length of time on the machine can vary from person to person and some people need to stay on it for 4.5 or 5 hours for waste products and fluid to be removed effectively. You will get to know how long it takes for you.

How will I feel during and after dialysis?

HD affects everybody differently. Some people feel well and experience no symptoms, others complain of feeling tired, having a headache or just feeling 'washed out'. HD is not a painful process. If you dialyse using a fistula, at first the needle insertion can be uncomfortable but after the first few sessions, this will settle.

We recommend that when you start HD, you do not drive to and from sessions until you know how HD will affect you. If you are very tired afterwards, it would be sensible to arrange alternative transport or to use hospital transport.

Fluid is often removed during HD. Most patients on HD pass little or no urine. Although you might pass urine initially, usually within 6 months of starting HD, this will have tailed off.

Removing too much fluid or removing it too quickly can cause side effects including low blood pressure, fatigue, chest pains, leg-cramps, nausea and headaches. These symptoms can occur during HD and may persist afterwards. The severity of these symptoms is usually relevant to the amount and speed of fluid removal. However, this often varies from person to person and day to day.

These side effects can be avoided or be less severe if fluid intake is limited between HD sessions (see below).

Will dialysis keep me well?

HD is not a perfect substitute for healthy kidneys and it is likely that you will not feel as fit and well as you did before developing kidney failure. You can optimize your treatment to keep as well as possible by taking care of the 3 Ds - dialysis, diet and drugs.

The HD diet can be quite strict and involves limiting the intake of fluid and certain foods which are high in salt, potassium and protein. This is not as bad as it sounds and with a little effort and imagination, it is possible to prepare meals which are both nourishing and taste good! Going out for meals is possible as long as you are careful. (More information in the sections below)

HD patients often have to take a variety of medicines; these

include vitamins after HD, medicines to bind phosphate and substances to boost the blood count.

There will be times when you will feel exhausted which unfortunately happens with most chronic illnesses. If you stick to the advice you are given and you pace yourself, you should be well enough to do most normal activities.

Fluid management

Most patients on HD are asked to limit their salt (sodium chloride) and fluid intake.

When the kidneys stop working they produce less urine, this can cause fluid to accumulate in the body. This may be referred to as “fluid overload”. In mild cases, ankle swelling or feeling bloated can be symptoms of fluid overload. In extreme cases fluid overload can cause shortness of breath as fluid collects in the lungs (we call this ‘pulmonary oedema’). Fluid overload also causes high blood pressure.

Before and after each HD session, you will weigh yourself. With your input, we will set what is called an ‘ideal’ or ‘dry weight’ with you. This is an educated guess of what your weight would be if your kidneys were producing the right amount of urine. We use this as a guide to how much fluid should be removed during each HD session.

As the kidneys produce less urine weight gain between dialysis sessions will tend to increase. Occasionally people may continue to pass a lot of urine and will not experience weight gain between HD sessions. Usually however you will be asked to limit your fluid intake to minimise weight gains between HD sessions. Large weight gains are dangerous and increase the risk of fluid collecting in the lungs. If large weight gains continue long term, this can contribute to heart problems.

Gaining or losing fat and muscle might mean we need to alter your ideal (dry) body weight. Your weight will be reviewed frequently to try to ensure we do not remove too much or too little fluid during a HD session. Please tell your dialysis nurse if your appetite changes.

Taking excess salt will cause you to feel more thirsty and will therefore lead to fluid overload. We will ask you to follow a “no added salt diet” and choose lower salt foods. Similarly if you have diabetes mellitus and your blood sugar levels are high this too can make you feel thirsty. Controlling your diabetes is therefore very important.

Potassium and Phosphate

Potassium and phosphate are minerals naturally present in the body; they are not waste products. When the kidneys are not working these minerals can build up and need to be removed through dialysis. Unfortunately these minerals are often not fully removed during dialysis. High levels of both of these minerals can be dangerous and contribute to heart problems. It is therefore very important that potassium and phosphate blood levels are controlled.

Potassium and phosphate are present in many foods in our diet. To reduce your blood levels of phosphate and potassium we often ask you to reduce your dietary intake of these minerals by making different food choices and or limiting certain foods.

Sometimes changing the way food is cooked can make a difference to its potassium content. Additionally patients on HD are often on medication to lower blood phosphate levels. These are called phosphate binders. These medicines work by joining to phosphate in foods resulting in less phosphate going into the blood.

Not all patients who are on HD need to limit their intake of potassium and/or phosphate and you should only do so if we discuss this with you.

We have provided a guide at the end of this pamphlet of foods containing high quantities of potassium and/or phosphate with some alternatives as a guide (appendices 1 and 2). The National Kidney Federation supply a free (£1 for p&p) recipe book via the website called 'Food with Thought'; this contains some recipe ideas. www.kidney.org.uk/books

This is not a substitution for a consultation with our dietician. Our dietician will speak to you regularly and address your personal dietary requirements/ queries, as these will be individual to you and may vary over time.

Anaemia

The kidneys contribute to the process of blood making. When the kidneys do not work, the blood count often drops; a condition called anaemia. To combat this you might be prescribed iron and darbepoetin (similar to a hormone normally produced by the kidneys which boosts blood count). These medicines are given through the HD machine.

How will I be monitored?

Nursing staff will see you at each of your HD sessions and you can discuss any problems with them. They will continually monitor your blood pressure and your weight as well as any problems with the HD process.

During the first week of every month we take blood samples from the machine and send them to the laboratory – we call this 'the monthly bloods'. This includes a measure of the adequacy of dialysis, potassium and phosphate levels and

haemoglobin (blood count). We have a multi disciplinary team meeting where we discuss each patient, any specific problems and look at the results of these tests to decide if changes should be made to patient treatment.

You may want to look at the results of these tests on the internet by registering for Renal Patient View (<https://www.renalpatientview.org/>). If you are interested in this please ask your dialysis nurse to give you an information pack (this contains the registration form).

What if I have medical problems?

If you have new symptoms that you think might relate to your kidney condition and dialysis tell the dialysis nurse about it. Depending on the problem they may recommend that you make an appointment with your GP or may contact one of the medical team to ask them to see you.

If you have been started on new treatment by your GP or another specialist please let the dialysis nurse know so that we can check that we don't need to modify your HD treatment. Similarly if your GP or another specialist arranges for you to come to hospital for any investigations or treatment please let the dialysis nurse know so that we can plan any necessary changes. For example sometimes we need to change the days of HD sessions to allow investigations to take place.

Who can I talk to?

The nurses, doctors, dieticians and pharmacists attached to the unit are happy to answer any questions. Starting HD is often difficult particularly in the early stages and it is natural to feel upset, angry and resentful. Thousands of patients have successfully passed through these difficult early stages

of kidney failure and sometimes talking to someone who has 'been there' can really help. The National Kidney Federation (NKF) helpline (0845 601 02 09, charged at local call rate, UK only, or e-mail: helpline@kidney.org.uk) can answer questions and put you in contact with your local Kidney Patient Association. From September 2010, there will be a group of patients locally who will form an 'informed patients group' and they will have received training to allow them to address many of the common concerns and questions; again the NKF can put you in contact with this group.

Will I be able to continue with my job or studies?

In most cases, yes you will be able to continue with your job/studies. Some people adjust their working hours; others fit dialysis into evenings and weekends.

Can I claim Social Security benefits?

Patients who dialyse at home at least twice per week can claim disability living allowance (attendance allowance if you are over 65). Other benefits are assessed on individual medical and financial circumstances. If in doubt you should contact your social worker, local welfare rights officer or citizen's advice bureau.

Will I be able to go on holiday?

Yes. Arrangements can be made to dialyse at other units at home and abroad – provided they can fit you in. The NHS pays for 6 HD sessions per year (January to December) in a private clinic. (It is perfectly possible to stay for longer but you would have to pay after the 6 sessions). At an NHS clinic/site or at a clinic which accepts the EHIC card, you can have as many HD sessions as you want. Staff can give you more

information and help organize this. It is best to give as much notice as you can to allow necessary arrangements to be made. Under certain circumstances on return from holiday, you may have to have your HD sessions in a single room for 3 months. This is not always the case and we can advise depending upon your individual circumstances.

Will I need dialysis for the rest of my life?

As long as you have no kidney function you will need some form of kidney replacement treatment. Some patients can have a kidney transplant but this is not a suitable option for everyone; your doctor will be able to discuss this with you. If you have a successful transplant then dialysis treatment will cease but there will still be medicines to take.

Sister chats with a patient during dialysis.



Appendix 1-

Cutting down on potassium in your diet

High Potassium (Limit or Avoid)

- Drinks** Fruit and vegetable juices
Coffee – up to 1 cup per day
Milk – up to ½ pint per day
Pure fruit juices
Beer, cider, lager, sherry or wine
- Fruit** All dried fruit, bananas, avocado, melon, papaya, rhubarb, fresh grapefruit, fresh pineapple
- Veg.** Plantain, mushrooms, aubergine, sweet potato
- Cereals** All bran, muesli other cereals containing nuts or dried fruit
- Sweets** Chocolate, toffee, liquorice, black treacle, marzipan
- Snacks** All nuts and potato crisps, Bombay mix, peanut butter
- Potatoes** Baked or roast potatoes, chips (unless parboiled – partially boiled before making chips)

**** Avoid all salt substitutes e.g. Lo-salt as they contain mostly potassium. ****

Lower Potassium Alternatives

- Drinks** All fizzy drinks, cordial and squashes, except high juice, tea, fruit tea, spirits
- Fruit** Apples, pears, tinned fruit (drained of juice), small slice of melon, small kiwi

- Veg.** All boiled vegetables, onion, carrot, turnip, cabbage, cauliflower, lettuce, cucumber, celery, broccoli, courgette
- Cereals** Porridge, weetabix, shredded wheat, corn flakes, rice krispies
- Bread** All breads
- Sweets** Boiled sweets, mints, fruit pastels, chewing gum, jam, honey, syrup
- Snacks** Snacks made from wheat, corn or rice (e.g. doritos, wotsits, skips, popcorn)
- Potatoes** Boiled potatoes, rice, pasta, noodles, bread

Appendix 2 -

Cutting down on phosphate in your diet

High Phosphate (Limit or Avoid)

Drinks: Ovaltine, horlicks, bovril, lassi, cola

Cereals: Branflakes, all bran, muesli and cereals containing nuts or chocolate

Snacks: Scones, potato scones, rye crispbread

Meat: Liver, kidney, liver and chicken pate

Fish: Scallops, sprats, whitebait, kippers, smoked fish

Miscellaneous: Nuts, peanut butter, marmite, chocolate

Your dietitian will discuss milk, cheese, yogurt and egg quantities with you.

Lower Phosphate Alternatives

Drinks: All other fizzy drinks, cordial and squashes, except high juice, tea, fruit tea, spirits

Cereals: Porridge, weetabix, shredded wheat, corn flakes, rice krispies

Snacks: Cream crackers, water biscuits, digestives, rich tea, shortcake, pancake, crumpet, chewy fruit sweets, pastilles, peppermints, marshmallows

Meat: Beef, lamb, chicken, pork, turkey

Fish: All white fish. (Once per week: pilchards, fresh herring, mackerel, trout)



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