

Dialysis Unit

A patient's guide to haemodialysis

We have compiled this booklet, with the help of patients, which deals with some of the most frequent questions and problems that patients encounter when undergoing haemodialysis. It may not answer all of your queries. Please ask staff if you are worried or puzzled about anything. There are always plenty of people in the multi-disciplinary team here to help you.

We cannot cover all aspects, there are booklets available on particular topics, and some people explore the Internet for more general information. A list of available leaflets can be found at the end of this booklet along with some useful websites and books.

Haemodialysis

Haemodialysis is a treatment to remove waste products and fluid from your blood when chronic kidney disease (CKD) has progressed to a point when your own kidneys can no longer do this. It is one (very important) aspect of your care, but it is only part of your total treatment, and your involvement is an integral part of that treatment.

The kidneys have a very important function in the body. They balance our fluid and body chemicals and get rid of potentially harmful waste products. To a large extent this function can be taken over by dialysis, which 'washes' your blood of impurities and waste products, and removes excess fluid. There are many other functions of the kidney including blood pressure control and production of enzymes which influence our bones and blood production.

The standard dialysis regime is three to four hours of dialysis three times a week. There are occasional exceptions but they are rare. It is important to attend for haemodialysis regularly to prevent build up of waste products and fluid which can make you unwell.

Each person is different and your treatment is tailored to your specific needs by the specialist renal doctors.

Access

This is the term we use to describe the means of getting blood from your body to put through the dialysis machine and back.

A **fistula** is a join between an artery and vein created by a surgeon, usually in the arm. This thickens up the vein so that a needle can be inserted. Most of our patients use this method. Usually the needles cause no problems but if you find this painful, a cream with local anaesthetic called **emla** can be applied before you come for treatment or a small injection of local anaesthetic can be given.

You will be told how to check that your fistula is working (feeling a buzz) – it is particularly important first thing in the morning or if you have low blood-pressure. If you cannot feel the buzz you must **contact the unit straight away**.

Please **never ever** allow blood samples and/or blood pressure measurements to be taken from the fistula arm. Try also to avoid any injury to that hand or arm, and do not carry heavy weights for approximately the first two months until the fistula is well healed. Be scrupulous about hygiene and report any infection in that arm.

You must be guardian of the fistula, as many nurses and doctors in other departments and hospitals will not be familiar with it.

Some patients are dialysed by a tube called a **permacath** inserted into a large vein, usually in the neck. However the permacath is then tunneled under the skin and appears below the collar bone.

This exit site needs to be kept clean and dry and you will be advised how to do this. In most cases this is a temporary measure, as the blood flow and therefore clearance of waste products may not be as good as with a fistula.

Ask your nurse for a leaflet about how to care for your fistula or permacath if you do not already have one.

The haemodialysis unit – what to expect

Transport

Patients may drive themselves, or be brought by family or friends to dialysis. There are designated free parking spaces close to the Unit for which you will need a permit from the ward clerk. We would encourage you to travel independently if possible as it will be more convenient and you will not have to spend time waiting for transport.

If you are not able to bring yourself up to the unit we will arrange hospital transport for you. Hospital transport drivers need to convey other patients from the same area so you will be sharing the transport. You will be given a pick-up time. Please be ready in good time and listen out for the doorbell. If you need to make any changes to your usual transport arrangements please tell the Haemodialysis ward clerk at least 48 hours in advance. Never turn the driver away or make your own way in without sufficient notice.

Waiting

We understand that everyone wants to start dialysis promptly once they have arrived in the Unit. However machines must be sterilised, which takes forty-five minutes, and equipment prepared. We cannot skip procedures and they must be done between every dialysis session.

Returning home after dialysis often involves a wait too. If you are sharing transport you may have to wait for your travelling companion(s). They may dialyse for a different length of time than you or they may be delayed by being unwell or difficulties with their machine.

In the unit

Before you start your dialysis you will be weighed and have your blood pressure checked. Most patients sit in a reclining chair while they dialyse. Occasionally if this is too uncomfortable or you are unwell a bed will be available. You need to wear loose clothing so that we can easily reach your access.

Drinks and sandwiches are provided but you may prefer a snack of your own choice. If you are prescribed phosphate binders, for example Calcichew, Phosex, Renagel or Fosrenol to help lower your phosphate level then please remember to bring them with you for your snack. Very occasionally we may advise you not to eat while on the machine, particularly if you have problems with low blood pressure (as the blood supply goes to your stomach rather than pushing around to your brain which makes you dizzy).

The unit is air-conditioned. Some people feel cold even in summer; bring a rug or warm jacket to pop over you.

Some like to bring their own cushion or pillow. Televisions are at each position or bring a book, newspaper, or laptop.

As an outpatient area both sexes are dialysed together, however if you wish to dialyse in a single sex area, we will try to accommodate this. Please ask a member of the nursing staff.

If the nurses give your erythropoietin (EPO) please bring it with you.

Unit Staff

Nurses

The Unit is staffed by highly trained nurses. You will have a named nurse who will take a special interest in your well-being, even though you may not see him or her at every visit. They check your results and notify the medical staff if there are any concerns. They will also see you every month to discuss your blood test results and any treatment problems.

Nursing staff work different shifts and so you do not see the same people at every visit. If you have a problem please speak to any of the nurses on duty and they will pass the message on. If you are worried that you have not had a response, please ask again but remember to tell us whom you spoke to the last time. An instant answer is not always possible as we may have to wait for a reply from another department.

Doctors

There is not a doctor in the department at all times, but during most of the day sessions there will be one available. The doctors carry out a monthly ward round to check on your progress and give you the opportunity to raise any concerns.

In an emergency a doctor will be called from the ward. You can also request to see a doctor by appointment or an earlier clinic date can be arranged. Your own GP will continue to care for you as usual and will prescribe your regular medication. The doctors may adjust your medication and leave a message for you and your GP.

Dietitian

Dialysis cannot remove waste products as well as normal functioning kidneys can. In order to reduce the amount of waste products in your blood it may be necessary to make changes to what you eat. If you need to make changes the dietitian will see you to help plan which foods you need to avoid and make sure you are managing to eat a good variety of foods. The dietitian will also see you if you are not eating well or if you want to lose some weight, for example in preparation for a kidney transplant.

Anaemia nurse

The anaemia nurse will check your blood results to see if you are anaemic. If these results show that you are anaemic, they will discuss treatment options with you. This may involve having some intravenous iron either on the haemodialysis machine or at an outpatient appointment within the hospital. Other treatment may involve small injections to replace a hormone (which helps your body to make red blood cells) that your kidneys may no longer be producing. The anaemia nurse will also discuss any changes to your treatment which may be necessary from time to time.

Counsellor

Having a chronic condition, especially one which is restrictive, and needs frequent hospital visits is stressful to you and your family. There is a renal counsellor with whom you can talk through emotional and relationship problems in total confidentiality. This is available to close family members too. Members of the Chaplaincy Team are also available if wished.

Renal welfare officer

The welfare officer works for the Addenbrooke's Kidney Patient Association and is happy to assist with contacting the DSS or Citizens Advice Bureau for advice on benefits and pensions as well as help with applying for Disability Living and Attendance allowances.

Medication

We need to know what medicines you are taking. Please bring a current list for your named nurse when you begin dialysis or when any changes are made. It is also a good idea to keep a current list of your medication with you also, for example a copy of your GP repeat prescription request. You may find that the dose of a medicine you have taken for some time needs to be adjusted when you start dialysis. Usually your GP will continue to prescribe your medicines for you, but the hospital doctor may liaise with your GP to change or add to them.

It is important to take your medicines regularly and never to run out of them. Please give plenty of notice to your GP to renew prescriptions.

Common dialysis medication

Blood pressure pills. High blood pressure is a common problem in people with kidney disease. A combination of fluid balance and medication is usually required to keep the blood pressure in the normal range. **For your first haemodialysis session do not take your blood pressure tablets that morning but bring them with you and we will advise you on the best time to take them.**

Erythropoietin (EPO) is a substance that stimulates the bone marrow to make red blood cells, but is low or absent in kidney failure. It may be injected either under the skin or into the bloodstream through the dialysis machine. Some patients feel confident to give their own injection, others bring in their EPO and the nurse will give it. The anaemia specialist nurses will organise your prescriptions or write to your GP when there are changes in the dose. It is important to have your EPO injections regularly.

Phosphate binders are medicines which help to reduce the level of phosphate in your blood and should be taken at the same time as food. They work by mixing with the food and sticking to the phosphate so that it cannot get into your blood stream.

Iron is a component of blood cells and we may need to give you some on dialysis. You may have been taking iron pills before you started dialysis. If so you can stop them as we find it is more effective to give the iron into your bloodstream. We will check you iron levels regularly and you may be given intravenous (IV) iron at different frequencies depending on the results.

Diuretics may be prescribed and if you still have some urine output you should continue to take them. If your urine output stops then please let us know.

Alfa-calcidol/one-alpha may be given orally or IV on the dialysis machine. It helps to balance your calcium levels and control your parathyroid hormone (PTH) level to help keep your bones strong and healthy.

Over-the-counter medicines or herbal remedies should always be checked with the dialysis unit as some may be harmful to dialysis patients. **Antacids** and **indigestion tablets** can upset the calcium levels in your blood. If you are troubled by indigestion we will recommend an appropriate medicine. Some regular remedies such as cold cures, cough mixtures and non-steroidal anti-inflammatories are not suitable for kidney patients.

Insulin dose changes may occur for diabetic patients when they start dialysis and so you should liaise with your diabetic specialist nurse and the dialysis Unit. Be sure to have breakfast despite an early start if you dialyse in the morning.

The **Renal Pharmacist** is happy to discuss your medication with you if you have any queries or concerns.

General health

It is important to attend your dialysis sessions even if you feel unwell. You can then talk to a doctor in the dialysis unit.

If you become unwell quickly, call your GP. It may be necessary for you to be sent to a local hospital or to Accident and Emergency at Addenbrooke's. Never delay seeking advice.

Contact with your GP is important as you will continue to see them for problems that are not directly associated with dialysis.

Immunisations

For your safety, we require that all patients are immunised against Hepatitis B. We will contact you and your GP to arrange this if it has not already been done.

Other immunisation against, for example influenza and pneumonia are recommended and should be discussed with your GP.

Care of the skin

Care of the skin is important as it may be fragile and easily broken and also slow to heal. Keep it well moisturised with a non-perfumed lotion or cream such as E45 or baby preparations.

It is wise to use high-factor sun-block preparations and cover up as much as possible due to the increased danger of skin damage, especially if you have had or plan to have a transplant.

Feet

Any scuffs or patches which do not heal quickly should be reported. Even if you have seen your GP, we like to know too. You may be advised to have foot care by a chiropodist/podiatrist.

Teeth

Please visit your dentist regularly. If you require any treatment it must be carried out with antibiotic cover. If you do not have a dentist please register with one as soon as possible.

Problems associated with chronic kidney disease

Some of the problems dialysis patients cope with include:

Anaemia. Kidney patients are often anaemic (a low haemoglobin). There are a number of reasons for this so we keep a close check on your haemoglobin, at least every month, and treat if necessary. At times a blood transfusion is needed. A low haemoglobin makes you feel tired, cold, washed out and often breathless. It adds a strain on your heart which needs to work harder to carry oxygen around the body. Please let us know if you have had nose bleeds, unexpected bruising, pass blood in your urine or in your stools or bleed for more than 20 minutes after the needles have been removed after dialysis.

Itching can be caused by a specific problem with levels of certain substances in your blood, including a high phosphate level, high PTH or low iron level. Sometimes it may be due to a non specific problem related to toxins in the blood. Treatment can be given for all of these causes, please let us know if it is a problem.

Constipation can be a problem for dialysis patients. The usual solutions such as drinking more fluid or increasing fruit or fibre are not suitable for you. Regular use of laxatives may be needed and advice will be given on which one is most appropriate for you.

Diarrhoea may also be a problem. In the first instance loperamide (which is available over the counter or from your GP) can be used. Please inform staff if you have diarrhoea (ideally before you arrive in the dialysis unit), as we need to take measures to reduce the risk of passing it on to other patients.

Restless leg syndrome is common in kidney patients. If this is troublesome for you then please speak to the doctors and they can advise on which medications you can take to ease this problem.

Indigestion. Avoid antacids. We will prescribe the appropriate medicine.

Infectious diseases. If you develop any infectious disease such as coughs or shingles, or have been in contact with one, please try to tell us before you arrive at the unit. Infections can develop more quickly in dialysis patients and take longer to clear. Seek help from your GP or tell us promptly.

Sleep disturbance may also be a problem for some people on dialysis. If the problem persists then please discuss with the dialysis doctors.

Help to keep infection at bay by always using the alcohol rub or hand washing to clean your hands on arriving and leaving the dialysis unit and prompt your visitors and others to do the same.

Fluid

You will be advised of your 'target' or 'dry' weight, This is the weight which you should be when you finish a dialysis session. This is what the doctor considers to be the weight of your body when it is not retaining the extra fluid which your failing kidneys are not able to remove. Determining this is difficult and will depend on physical examination and monitoring of your blood pressure. Your target weight is likely to change over time relating to changes in your general health and wellbeing. You will be advised of these changes depending on your results.

When you arrive in the department you will be weighed to measure the amount of fluid you have gained since your last dialysis session. An assessment of how much fluid to be removed will then be made. Other factors can influence the decision such as your blood pressure, or if you have not been eating well which means your 'target' weight has fallen.

Most patients need to ration the amount of fluid they drink. The amount of fluid you can safely drink is usually 500ml plus the volume of your previous day's urine output.

If you pass 750ml in 24 hours you can drink: $750\text{ml} + 500\text{ml} = 1250\text{ml}$ per day.

If you are not passing any urine we recommend you limit the amount you drink to 500ml (roughly one pint) per day. Remember, this includes all your fluid whether from food or drinks. Please ask the dietitian for more information if you need it.

The consequences of drinking too much are:

- Increase in blood pressure.
- Shortness of breath.
- Strain on your heart.
- Swelling of ankles or face.

It also means that we need to remove more fluid with the dialysis machine. This may take longer and make you feel more washed out.

To avoid drinking you could try chewing gum, sucking a boiled-sweet or an occasional ice-cube instead of a glass of drink. Ask your doctor for an artificial saliva spray. Use a smaller cup or glass; put that mug out of reach!

Avoiding salty foods, particularly ready-meals, will help make you less thirsty. Do not use salt substitutes such as 'Lo-Salt' or 'Pan-Salt' because they contain potassium. Ask the dietitian for further advice.

You are in control of fluid.

Diet

The renal dietitian will personally monitor your blood test results. These will determine if any changes are required in your diet. Helpful tips, ideas and recipes are available from the dietitian to help you with your diet.

You need to keep **potassium** in your blood within our target range 3.5 to 6.5mmol/l. The consequences of a high potassium level are very serious. It can affect the heart rhythm causing the heart to stop. Most patients will get no warning of this so it is very important to keep your potassium level within the target range.

Phosphate is another element in the bloodstream which may be high in renal failure. It can cause you to itch and have red eyes when levels are high. The long-term effects of a high phosphate level are weakening of your bones as calcium is drained out and damage to your blood vessels. If you have been prescribed phosphate binders please remember to take them with your meals. If you need further information you can ask the renal dietitian.

Salt should be limited (see the fluid section above). Do not add salt to your food at the table. If necessary, add a little only during cooking.

The dietitian will give you advice and information to keep the levels of harmful products within normal limits and advice on eating a healthy diet or losing weight. Diet sheets and recipe ideas can also be provided.

Work

We encourage everyone who is able, to work and will do all we can to support you if you want to work.

Some employers may be concerned about risks in the work place. We will be happy to speak to them to explain or reassure them of your suitability to continue working. There are very few reasons why you may not continue to work.

The renal welfare adviser is also available to advise you on work and benefit issues.

Dialysis Clinic

Most patients will see a doctor monthly on the dialysis unit but it is also important to attend your dialysis clinic appointment as this is a valuable opportunity to discuss any problems with your care in private with the doctor, nurse and dietitian. It also gives the doctor the opportunity to examine you thoroughly which is not possible when you are on the dialysis machine. Adjustments to your treatment and medication can be planned, or alternative options such as peritoneal dialysis and transplantation discussed, if appropriate. It is in your interest to attend, particularly if you are dialysed on the twilight shift and may not often get the opportunity to see other staff.

Keeping appointments

You may be given appointments for other tests or other clinics on the same day as your dialysis treatment. Please inform the dialysis ward clerk so that your transport and dialysis time can be amended if necessary. Please do not cancel other outpatient appointments without checking with us.

Holidays and leisure

We encourage patients to lead as normal and active a life as possible, with participation in sport and hobbies.

For special occasions we always try to adjust your dialysis times, if sufficient notice is given.

Christmas and other special occasion food recipes can be obtained from the dietitian. Ask for a recipe book.

We recognise how important it is to have a break, and are pleased to help to arrange this; holidays can be arranged both in this country and abroad. At present it is easier to find places abroad than in the UK, but ask for advice. You will see posters on the notice board and there are further lists of holiday destinations available from the holiday co-ordinator. Usually the host centre like you to be stable and settled on dialysis for at least six months before they accept you for holiday dialysis. Tell staff your plans well in advance so they can make contact with a dialysis unit at or near your holiday destination.

Please do not book flights or accommodation until dialysis sessions have been confirmed by the holiday co-ordinator.

It is necessary to have blood tests and swabs taken at least four weeks before your holiday to ensure you are in good health.

All units throughout the World insist on screening for MRSA, Hepatitis and HIV as well as routine blood samples to know your usual results.

Remember that medical treatment abroad is expensive so be sure to have adequate medical insurance cover.

The holiday co-ordinator can advise on companies with a competitive premium. Make sure you have a EHIC (formerly E111) if treatment is in EC.

We hope this will help you to find your feet and get to know us all.

A list of useful numbers:

Dialysis Unit Ward Clerk:	01223 217832
Addenbrooke's Main Switchboard:	01223 245151
Renal Welfare Officer:	01223 714425
Counsellor:	01223 274544
Anaemia Nurse:	01223 257195
Dietitian:	01223 216655
Dialysis Holiday Co-ordinator:	01223 217827
Dialysis Unit Manager:	01223 217830

Useful websites

Addenbrooke's Hospital: www.addenbrookes.org.uk

Addenbrooke's Kidney Patient Association: www.akpa.org.uk

Baxter Support and Resources for People with Kidney Disease: www.renalinfo.com

Kidney Patient Guide: www.kidneypatientguide.org.uk

Kidney Research UK: www.nkrf.org.uk

Nephrology at your fingertips: www.nephronline.org

UK National Kidney Federation: www.kidney.org.uk

Books:

- *Kidney Dialysis and Transplants* by Dr Andy Stein and Janet Wild.
- *Eating well with kidney failure. A practical guide and cookbook* by Helena Jackson, Annie Cassidy and Gavin James.
- *Kidney failure the facts* by Stewart Cameron.

Patient Information Leaflets:

- Central Venous Catheters (Permacaths)
- Renal Services, dialysis
- What is a fistula



We are currently working towards a smoke free site. Smoking is only permitted in the designated smoking areas.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169

Help with this leaflet:



If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or patient.information@addenbrookes.nhs.uk

Polish

Jeżeli chciałbyś uzyskać te informacje w innym języku, w dużej czcionce lub w formacie audio, poproś pracownika oddziału o kontakt z biurem Informacji Pacjenta (Patient Information) pod numerem telefonu: 01223 216032 lub pod adresem patient.information@addenbrookes.nhs.uk

Portuguese

Se precisar desta informação noutra língua, em impressão de letras grandes ou formato áudio, por favor peça ao departamento que contacte a secção de Informação aos Doentes (Patient Information) pelo telefone 01223 216032 ou através do e-mail patient.information@addenbrookes.nhs.uk

Arabic

إذا كنت تود الحصول على هذه المعلومات بلغة أخرى، بالأحرف الكبيرة أو بشكل شريط صوتي، يمكنك أن تطلب من القسم الاتصال بمعلومات المريض على الرقم: 01223216032 أو عبر البريد الإلكتروني: patient.information@addenbrookes.nhs.uk

Cantonese

如您需以另一語言版本、特大字體或錄音形式索取本資料，請要求部門聯絡病人諮詢服務：電話 01223 216032，電郵地址 patient.information@addenbrookes.nhs.uk

Turkish

Eğer bu bilgileri başka bir dilde veya büyük baskılı veya sesli olarak isterseniz, lütfen bulunduğunuz bölümdeki görevlilere söyleyin Hasta Bilgilendirme servisini arasinlar: 01223 216032 veya patient.information@addenbrookes.nhs.uk

Urdu

اگر آپ کو یہ معلومات کسی دیگر زبان میں، بڑے الفاظ میں یا آڈیو طریقہ سے درکار ہوں تو برائے مہربانی اس شعبہ سے پیشینٹ انفارمیشن سے ذیل کے ذریعہ رابطہ کرنے کی درخواست کریں: 01223 216032 یا patient.information@addenbrookes.nhs.uk

Bengali

আপনি যদি এই তথ্য অন্য কোন ভাষায়, বড় অক্ষরে বা অডিও রেকর্ডিং পেতে চান তাহলে 'প্যাশেন্ট ইনফরমেশন' এর সঙ্গে 01223 216032 নম্বরে ফোন করে বা patient.information@addenbrookes.nhs.uk ঠিকানায় ই-মেইল করে যোগাযোগ করার জন্য ডিপার্টমেন্টটিতে অনুরোধ জানান।

Document history

Authors	Clare Parslow
Department	Cambridge University Hospitals NHS Foundation Trust, Hills Road, Cambridge, CB2 0QQ www.cuh.org.uk
Contact number	01223 216655
Publish/Review date	January 2010/January 2012
File name	Haemodialysis
Version number/Ref	2/PIN1800