

Royal Berkshire
NHS Foundation Trust

Haemodialysis at home

Kidney care information for patients and
relatives/carers

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Philosophy of care for our renal patients

- We believe everyone has the right to holistic-based care and the right to be treated as an individual.
- We aim to involve family and friends in your care (with your agreement).
- We believe in the multidisciplinary team approach to your care, and welcome comments and feedback from all involved.
- We accept individual values and cultures and will do our best to respect individual needs.
- We believe in assisting each of you to achieve the optimum level of functioning and well being that we can possibly obtain with your help.
- Dialysis care is a partnership between you and the staff. We need to work together to keep you fit and well.

Haemodialysis at the Royal Berkshire NHS Foundation Trust

We have 2 haemodialysis units at the Royal Berkshire Hospital, Benyon, and Huntley and Palmer. We also have 3 Satellite units based in Bracknell, Newbury and Windsor. As part of our expanding home therapies unit, we offer home haemodialysis, using a smaller HD machine requiring minimal home conversion. Selection onto this programme will require individual patient review, not all haemodialysis patients will be suitable. This involves a period of training both in the Haemodialysis unit and at the home environment.

Understanding your treatment

For Haemodialysis (HD) treatment to be successful, a partnership between the nursing staff and you is necessary. Unfortunately, with kidney disease there are restrictions and guidelines that you need to follow to keep well, but we try hard to minimise these and make your days as free as possible.

Information related to dialysis can be complex so please do tell us if you don't understand our explanations. It always helps to know why you have to take all the drugs etc, and we want you to be as informed as possible so that you can keep healthy and understand how your body works.

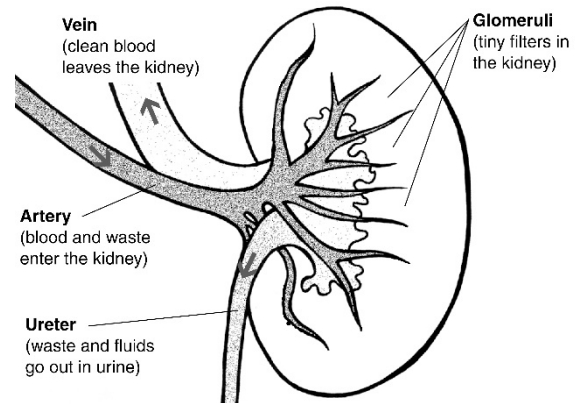
Who are the Renal team?

Dr Emma Vaux – Consultant Physician & Clinical lead	Haemodialysis 0118 322 7968
Dr Mobin Mohteshamzadeh – Consultant Physician	Transplant 0118 322 6532
Dr Nitin Bhandary – Consultant Physician	Transplant 0118 322 6532
Dr Oliver Flossmann – Consultant Physician	Kidney Care/CAPD 0118 322 7967
Dr Bassam Alchi – Consultant Physician Dr Rabya Sayed – Consultant Physician Dr Harry Wakefield – Consultant Physician Dr Carolyn Amery – Consultant Physician Dr Carolina Canepa – Consultant Physician	Haemodialysis 0118 322 8408 Kidney Care Home Haemodialysis & Transplant Haemodialysis Haemodialysis / Kidney Care
Angela Clarke – Renal Matron Bernice Boore – Lead Nurse Victoria & RBH	Tel: 0118 322 8395
Riz Wiles – Lead Nurse – Satellite sites	Tel: 0118 322 7199
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Jennie Cadiz HHD Nurse Rodante Canson – HHD Nurse	Mobile: 07386 699463 Mobile: 07501 644690
Laura Kabambe – Sister Victoria Ward	Tel: 0118 322 7963/7521
Jaya Abbi – Acute Dialysis Sister	
Renal Social Workers	Tel: 0118 322 8772
Renal Dietitians	Tel: 0118 322 7117 bleep 709
Benyon Dialysis Unit	Tel: 0118 322 8360/6807
Bracknell Dialysis Unit	Tel: 01344 662961/2963
Enborne Dialysis Unit	Tel: 01635273640/3638
Huntley & Palmer Dialysis Unit	Tel: 0118 322 8518/8519
Windsor Dialysis Unit	Tel: 01753 866008
Victoria Ward	Tel: 0118 322 7476/7462

Kidney and dialysis basics

Function of the kidneys

The main function of the kidneys is to clean the blood and make urine. Blood is pumped by the heart to the kidneys. Each kidney has a filtration and drainage system to remove toxins. The waste is then taken from kidney to bladder and removed as urine.



Removing toxin wastes

During digestion food is broken down into substances that can be carried around the blood. These useful substances provide the body with the energy required to carry out growth, repair and cell functioning.

The body produces waste products from these processes. This waste is toxic to the body and needs to be constantly removed.

When this waste reaches the kidneys these toxins are filtered out. In people with kidney failure this filtering process is impaired so the levels of toxins build up in the bloodstream.

Removing excess water

The second most important function of the kidney is to remove excess water from the body. All fluid drunk and eaten is absorbed into the bloodstream. Healthy kidneys regulate the amount of water in the body and any excess water is removed as urine. This is impaired in kidney failure.

Other kidney functions

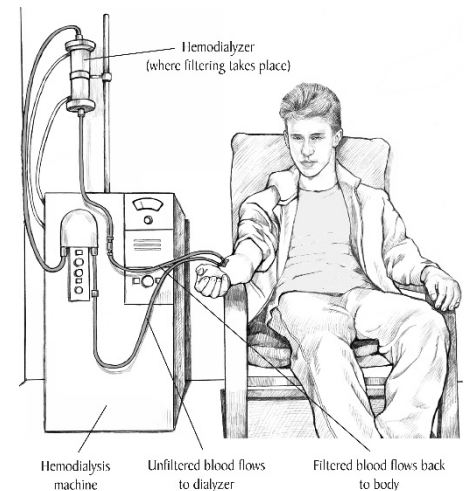
1. Blood pressure control
2. Manufacture of red blood cells
3. Keep bones healthy

What is dialysis?

Dialysis is an artificial way of doing the work of the kidneys.

Haemodialysis (HD) and how does it work?

The process of HD takes place outside of the patient's body. It is done by pumping your blood through a special filter called a dialyser (or artificial kidney) removing toxins and excess water, then returning the cleansed blood to your body.



How do we access your bloodstream?

Before you can start haemodialysis, we need to have access to your bloodstream. This can be done in two ways:

Ideally, you will start haemodialysis with a fistula (or AVF), which will have been created in your wrist area or upper arm, above your elbow, some weeks or months before you need to start. This procedure is performed by the Churchill Hospital, in Oxford, under local anaesthetic. It involves joining an artery to a vein. The increased blood flow in the vein causes it to become enlarged and then needles can be inserted into it accessing the bloodstream.



Alternatively, a temporary or semi-permanent catheter (called a tunnelled dialysis catheter or line) can be inserted into a large vein in your neck.



Traditionally, HD is performed 3 times a week, for 4 hours per session in a dialysis unit.

Home haemodialysis is a more frequent treatment received 4, 5 or 6 days a week depending on the patients individual needs. The increased frequency improves fluid and toxin removal and mimics normal kidney function more than traditional hospital haemodialysis. The frequent treatments enable home haemodialysis to be gentle and more cardio-vascularly stable.

Care of your access

Your fistula or line is very precious and needs to be looked after carefully. If you are waiting to have a fistula created, you will be asked to 'save' an arm. It is usually the arm of the hand that you don't write with. This means do not let anyone take blood tests or do a blood pressure on this arm. Avoid watches, tight sleeves, and carrying heavy shopping across on your fistula arm. This avoids unnecessary damage to the blood vessels. Please avoid carrying anything heavy with this arm. Take care in the garden that you don't scratch your arm or get your fistula dirty.

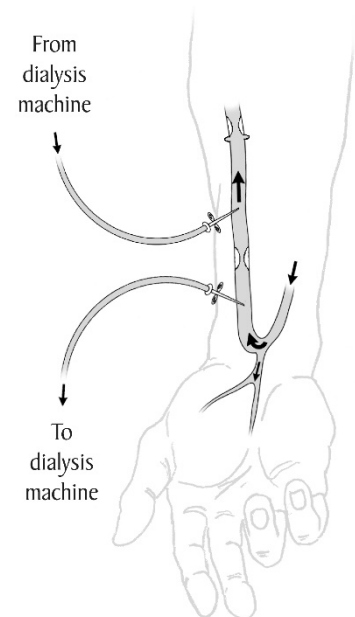
Fistula care

Buttonhole is currently the method used by our patients on home haemodialysis, and ideally you will create your own buttonhole sites. This involves using a sharp fistula needle over a couple of weeks following the same angle and depth each time. This forms a tract in the skin. You will then be able to use a blunt needle, following the same tract for the subsequent treatments.

Each time you needle, you will first remove your scabs that form over the buttonhole site, using a sterile pick that is provided. Monitor these sites for signs of infection - any redness, pain or pus around the site and you will need to see a doctor

immediately, so call your home dialysis nurse or HD unit out of hours.

You must only try to needle your fistula twice and if you have 2 failed attempts and you have a 3rd buttonhole site, use this. If you are able to use a sharp needle then you can use this to go into a different area of fistula away from your buttonhole site. You should never use a sharp needle on an established buttonhole site.



Fistula problems and troubleshooting

It is important to regularly check the 'buzz' or thrill in your fistula, get to know it and let your dialysis nurse know of any changes. Also if you are dehydrated following a bout of diarrhoea, or in that rare British heatwave, or if it feels faint, call for advice.

Monitor for signs of clotted fistula, e.g. dark blood in the circuit or if you are unable to establish a flow in the needles, then you need to come in and be seen. Call your dialysis nurse or out of hours dialysis unit.

Maintain good hand hygiene to prevent infection. Make sure you wash your arm with soap and water before you put your needles in.

If your fistula arm becomes red and inflamed, you need to call your dialysis nurse or dialysis unit if out of hours.

Do not take blood pressure readings or allow bloods to be taken, or the administration of intravenous drugs through your fistula.

If extended bleeding post-dialysis is longer than 15 minutes, you need to call your dialysis nurse or out of hours dialysis unit for advice. Apply a clean milk bottle top hollow side down towards your arm and press very firmly. Ring 999 to obtain help and then you MUST come in to A&E.

Home HD and your machine

Although there are many home dialysis machines available on the market, Fresenius Nxstage and B Braun Physidia are the machines that have been chosen by our NHS Trust.

The Nxstage is made up of 2 parts – the main unit which is called a *Cycler*, and the *Pureflow* is the part that is plumbed in to mains water supply. This makes up and holds the Dialysate fluid that you need for each treatment.

Plumbing of the machine is the responsibility of the renal department with the guidance of the home dialysis nurse. It does not require a water reverse osmosis unit to be installed like a traditional machine would, making NxStage more compact, requiring minimal home conversion.



The Physidia is the newer, more modern machine that offers optimal dialysis each session. This machine cannot be plumbed in and only allows a max of 3 hours per session.

Your prescription for home dialysis for either machine is tailored to you and your needs depending on several factors. We will discuss your medical and social needs to determine the number of days and the amount of hours you require. The minimum time on the machine is 3 hours, this would mean both Nxstage and Physidia can be suitable for you. However, if it is decided that you need more than 3 hours a session depending on blood results and your BMI – then Nxstage will be the machine for you.

There is a set up time like with any machine, you must also factor an additional 40 minutes for this.

Training is intensive and takes place over 3 weeks, the first 2 weeks will be in a training area within the dialysis unit and the 3rd week at home. Again, this is tailored to you – all we ask in return is the commitment and the willingness to learn.

Trial sessions are offered to ensure patients are able to make an informed decision without committing to the service.



(Nxstage)



(Physidia)



Travelling with your HHD machine

The Nxstage machine can be taken away with you anywhere in the UK for staycations or abroad depending on the list of destinations available. The machine weighs 33kg and we will provide a travel case for you to use.

As you can see from the photo you have pre-made Dialysate in the form of bagged fluid that you use when away from home, instead of the plumbed in part of the machine.

It is your responsibility to take your machine with you when going on holiday. We will

organise sending the supply of bagged fluid to your chosen destination.

We will supply you with letters for customs and the airline, to support you taking the machine on medical grounds. Some airlines may charge for the weight of the machine so please check with your airline first and obtain confirmation.

Please talk to your nurse before booking a holiday to discuss if the destination is possible, and also to check the amount of time it takes to get fluid there, as this varies. UK is 4 weeks minimum notice, Europe 6 weeks minimum, rest of the world is 8 weeks minimum. This may well change, so please check first, changes in world affairs can affect these delivery time frames and availability.

Important things to remember when booking your holiday are to have a comprehensive travel insurance policy and if travelling within the European Union (EU) to carry an EHIC card for claiming treatment in EU countries.

For unforeseen problems with your machine, you will not be able to get a replacement and therefore you need a backup plan to access a local haemodialysis centre. You will need to organise this and we will provide letters and recent bloods/swabs. We will discuss in more detail when you are planning your holiday.

Physidia technically don't offer holiday dialysis as such – but you can order extra stock and arrange for machine and consumables to be taken to your UK destinations. Unfortunately, you cannot travel abroad with this machine as the company don't offer customer support or insurance.

Hand washing technique

There are thousands of bacteria living on your hands all the time. While they are on your hands, they do not cause any problems, but if they are allowed to get elsewhere in the body they cause an infection.

This means that before you do your dialysis, you must wash your hands using an anti-bacterial solution such as Octenisan soap, which will remove a large proportion of the bacteria.

When washing your hands you must:

- Use running water.
- Ensure all surface of hands have been thoroughly scrubbed.
- Hand washing should take at least 30 seconds.
- Hands are rinsed thoroughly.
- Paper towels are used to dry hands.



Once you have washed your hands it is important to remember that you must not touch anything other than your dialysis equipment, i.e. no touching nose, hair, clothes etc. otherwise you will have to wash your hands again.

It is a good idea to use hand cream at times to help keep your skin healthy.

Fluid balance

Dialysis is not as efficient at fluid removal as healthy kidneys, therefore the amount of fluid that is taken in through drinking and food needs to be restricted.

During your training you will be given a 'dry weight'. This will be the weight that you need to maintain on dialysis. At this weight, your blood pressure should be within normal limits and you must have no signs of either too much fluid (overloaded) or too little fluid (dehydrated).

The more fluid there is the harder your heart has to work, causing high blood pressure and a strain on your heart.

Your weight and fluid balance

Your total weight is made up of two parts:

- Flesh weight
- Fluid weight

Flesh weight – this remains fairly constant. Any gain in flesh weight is gradual. It may fall if you have been unwell and haven't been eating very well, or increase if you're eating better.

Fluid weight – this is affected by the amount of fluid you take in by eating and drinking. What goes in must come out somewhere! If you don't pass much urine anymore then you may be relying on dialysis to remove it.

Any sudden change in your weight will be due to an INCREASE or DECREASE in the amount of fluid in your body.

- Not enough fluid – weight DECREASES – This is *DEHYDRATION*
- Too much fluid – weight INCREASES – This is *OVERLOADED*
- The right amount of fluid will maintain your * DRY WEIGHT*

Overloaded

Fluid overload is too much fluid in your body. This could be due to drinking too much, including hidden fluid! Symptoms might include:

- Increased weight.
- Swollen feet and ankles or legs.
- Shortness of breath, particularly when lying down in bed.
- Puffy eyes or face.
- Raised blood pressure.

What should you do?

You may need to drink less and take a look at what you are eating.

Eating too much salt may lead to you becoming overloaded and make you thirstier. Your dry weight may need to be reviewed.

Contact your home haemodialysis nurse if you have had any of the above symptoms.

Dehydration

Dehydration is too little fluid in the body. It may be due an episode of diarrhoea and vomiting. It can also occur if you are over cautious with your fluid restriction and in hot weather if you perspire more.

Being dehydrated may cause your fistula to work less well or in extreme situations stop working altogether.

Symptoms of dehydration

- Weight reduced.
- Cramps.
- Low blood pressure, which can cause dizziness.
- Thirst and dry mouth.
- Tiredness.
- Nausea and possibly vomiting.
- Keep a close eye on your fistula, check the buzz and if at all concerned, ring in.

What should you do?

You may need to drink a little more than usual. You will need a reassessment of your dry weight by your home haemodialysis nurse.

Blood tests: what do they mean?

Renal profile – provides valuable information on how your treatment is going. This includes dialysis and medications.

Full blood count – measures haemoglobin (HB) red blood cells monitoring for anaemia.

Iron levels - monitoring the iron stores in the body, you require a good iron store for Epo to work. These both help to maintain your haemoglobin level.

Parathyroid hormone (PTH) – a hormone excreted by the parathyroid gland found in the neck. PTH assists the body in maintaining blood calcium levels.

KT/V – this allows us to look at removal of waste, an equation which shows the clearance during dialysis of specific substances. You will be given a target range for a weekly KT/V to ensure adequate dialysis.

Cholesterol – A fatty substance needed for normal body function, but too much can lead to increased risk of heart disease. This level is checked six monthly as a random test. If found to be high you may require a tablet to help lower your cholesterol.

Viral screen – monitors lots of different viruses in the body e.g. Hepatitis B and C, CMV, HIV. This is a routine 6 monthly test required by all patients having dialysis or prior to travelling to another unit for holiday dialysis.

Would you like to:

- Find out your latest test results?
- Read online information about your kidney condition and treatment?
- Read letters about you from the Renal Unit?
- Read about renal diets?
- Check the Transplant List?
- Find any other information about kidney disease?

If you answered YES to any of these questions, you should take a look at Patient Knows Best (www.patientknowsbest.com) you can log in via the NHS app. Ask your dialysis nurse for more details.

Medications

Phosphate binders e.g. Calcichew, Renagel, Phosex

Phosphates from the diet, pass out in urine in people with healthy kidneys. In renal failure the phosphate levels build up in the blood causing itching, and if left uncontrolled can result in bone disease. In order to prevent complications, binders must be taken with food, they will bind with the phosphates and allow it to be passed out in stools.



Note: Calcichew must be taken with the first mouthful of food.

Intravenous iron. In order to produce healthy red blood cells our bodies require a good iron store, in renal failure this store needs to be increased, to correct this, an intravenous infusion or 'drip' may be required. If you require this treatment we will arrange it and notify you by post.

Erythropoietin (Eprex). A hormone produced in healthy kidneys. The hormone assists the body to produce new red blood cells. In kidney failure the hormone may need to be artificially replaced, not all patients require it.

Alpha Calcidol also known as One Alpha. It is a vitamin D supplement which is given to help keep bones strong. It is usually taken 3 times per week, at night, changed depending on your blood results.

Anti-hypertensives. Given to lower blood pressure. Hormones, which normally control blood pressure, do not always work efficiently in kidney failure. Therefore help is sometimes needed in the form of drugs such as Lisinopril, Amlodipine and Doxazosin.

MRSA / MSSA kits/swabs

If you have been told you are positive once, then you will not be swabbed again, but in fact you will receive a kit which consists of Hibiscrub wash and a nasal cream every 3 months for decolonisation. Please use the scrub for 5 days from top to toe – the nasal cream will be used 3 times a day for 5 days. If you are negative – you will be swabbed every 3 months to ensure you are still negative.

General information

Clinics:

Clinics will take place in the out patients clinic at the Royal Berkshire Hospital or Bracknell Unit on a 2 monthly basis. You will be required to take a blood test 2 weeks before this clinic.

Home visits

During the first month of your training, your home Haemodialysis nurse will do weekly visits, then monthly. Your regular transonic measurements will be carried out during a home visit. Regular Transonic measurements are carried out to look at the flow within your fistula to check how effectively it is working.

Running costs for your machine

As a patient using a space to dialysis in your own home, many patients are eligible for a reduction in their council tax. You will need to contact your local council to enquire/inform them you are dialysing at home.

Running costs of the machine

In the first instance, the costs of water and electricity will need to be met by the patient. It costs approximately the same price per week as leaving a light bulb on constantly. However, recently the Trust have put in a reimbursement service for all patients to help towards their bills. During your training programme you will be asked to fill out a bank details form – an amount is determined using a reimbursement calculator, then the reimbursement is then paid straight into your bank account. Please ask your HHD nurse for more information.

Holidays with Nxstage

Before booking any holiday you need to be deemed clinically fit to travel by the home HD consultant.

After clinical review and agreement contact your home HD nurse for them to arrange delivery of your holiday bagged fluid and make sure it is delivered to your destination.



Blood tests

You will be given guidance on what blood tests are required on a monthly basis. You will then need to take your blood samples to your GP or nearest satellite/HD Unit.

Useful information

NKF – National Kidney Federation www.kidney.org.uk Tel 0845 601 0209

Tell us your views

If you wish to discuss any aspect of your treatment and care, please speak to a senior member of staff or to the nurse looking after you. The matron is also available during normal working hours and welcomes your views.

You can also pick up a copy of the Trust leaflet called 'Patient Advice and Liaison Service (PALS)', which explains how you can raise concerns or give feedback on your experience at the hospital.

Friends and Family Test

Whatever your experience you can give feedback by answering the Friends & Family test question – 'Overall, how was your experience of our service?' – by going online www.royalberkshire.nhs.uk/patients-and-visitors/friends-and-family-test/ or using the link sent to you in an SMS text message.

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Photographs by kind permission of patients from the Berkshire Kidney Unit and Diagrams from the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health.

For more information about the Trust, visit our website at www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

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