

Welcome to haemodialysis

Information for patients

Welcome to haemodialysis

Welcome to haemodialysis at the Royal Free London. The purpose of this booklet is to welcome you to the service and to help prepare you to start haemodialysis.

In this booklet, we cover most of our commonly asked questions, take you through an average haemodialysis treatment and give you some information on each of our units and the other services offered.

We have four satellite dialysis units, along with a unit at the Royal Free Hospital – we aim to provide services as close to your home as possible and these include:

Barnet Dialysis Unit

Edgware Kidney Care Centre

St. Pancras Kidney and Diabetes Centre

Tottenham Hale Kidney and Diabetes Centre

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Haemodialysis

1A: What is HD?

One role of your kidneys is to filter out waste products and remove excess fluid and salts from your blood. HD helps to do this when your kidneys are not working properly.



- HD can be done in a dialysis unit by nursing staff or we can teach you to do it by yourself either in the unit or at home.
- HD involves small amounts of blood being drawn out of your body by either a needle or plastic tube which is inserted into your blood vessels.
- Your blood then travels through plastic tubes to a dialysis machine where it passes through a filter and the waste products are cleared.
- After that the tubes then return the blood back to your body. Only a small amount of blood is removed at one time.

1B: How often will I need HD?

- Usually people have HD **three times a week on a fixed schedule**. Either on a Monday, Wednesday and Friday or a Tuesday, Thursday and Saturday; there are no slots on a Sunday.
- The dialysis itself **lasts for around 4 hours**, but this is different for everyone and waiting times and travel can mean it will take more time than this out of your day. See section 2 for more information on a typical day on dialysis.

Section 1

- Dialysis **slots are available in the morning, afternoon and evenings (twilight)**, but are subject to availability – **talk to your named nurse if you have any queries.**
- If you need to change you session as a one off because of a family event or appointment please contact your named nurse.
- Dialysing at home gives you full flexibility.

AM	7.30am
PM	1.30pm
Twilight	6pm

1C: Are there any side effects or complications?

Does it hurt?

At first putting the needle into your fistula may hurt, but this will lessen over time. The process of HD is not painful.

Tiredness

Some people feel tired after HD – you can reduce this by having the full treatment time recommended by your nurse and following advice you have been given about diet and fluid intake.

Fluid overload

Fluid can build up in your body because you may not be able to pass urine and the liquids you consume (including things such as gravy, yoghurts and soup) will stay in your tissues and lungs which can cause you to develop pneumonia. Sticking to your fluid restriction will help avoid this.

Low blood pressure

This may cause you to feel dizzy or to get cramps. If this happens, your nurse may give you extra fluids to help you feel better. Sticking to your fluid restriction will help to avoid these problems as this reduces the amount of fluid that has to be removed during dialysis.

Infection

Lines, grafts and fistulas can all become infected. This is often serious and can lead to the development of infections in your heart and spine; one in five (20%) of these types of cases are fatal.

Infection rates with lines are 10 times higher than with fistulas so we would always encourage you to have a fistula formed for your long term dialysis access wherever possible.

We regularly monitor for serious bacteria on your skin and nose. We have strict infection control policies in place to deal with this and staff will inform you of what to do. More information about infection prevention and control at the Royal Free London can be found on our website: www.royalfree.nhs.uk/patients-visitors/advice-and-support/infection-prevention-and-control/



Bleeding from your fistula or graft

It is normal to bleed a little when your fistula needles are removed. This is controlled by applying pressure to your fistula at the end of dialysis to stop the bleeding. Sometimes this takes a long time to stop. If this happens, we will ask the vascular surgeons to see you to arrange a scan and treat the problem.

Section 1

1D: Self-care HD

We know that patients who take part in their own care have better than those who do not. We will teach you to carry out some, or all, of your own HD as you are able to. Anyone can do it, but you need to be willing to learn! We have special self-care areas at all of our units. If you decide to carry out some or all of your own HD:

- you will receive personalised training which will last as long as you need until you feel comfortable and confident
- a friend or family member can also be trained to help.

Please speak to your named nurse for more information about how you can take part.

Why self-care?

Self-care gives you increased flexibility, independence and freedom. It saves time and gives a sense of personal satisfaction. Here is what some of our self-care patients have to say:

“We support and help each other while we learn.”

“The self-care unit is bright, fresh and clean.”

“You don’t need to wait for a nurse to get you set up and then help you off when you’re finished, by the time someone would be there to help you off the machine you have already left.”

“The responsibility that comes with self-care creates a sense of satisfaction...”

“It makes my life much easier, having flexibility with slots.”

Section 1

1E: Home HD

This involves you or a relative/carer performing your HD at home. **If you're interested, let your nurse or doctor know.**

Why home HD?

- You will have more **independence and flexibility** to fit dialysis around work, family and life.
- You **do not have to come to hospital, except** for your clinic appointments.
- You have the freedom to dialyse more often or for longer meaning you will feel better and have **fewer restrictions on what you can eat or drink.**

How is home HD arranged?

You don't need a lot of room to do this and we will visit your home to work out how best to do it. Usually people use their bedroom, lounge or spare room for their dialysis. We supply the equipment and advise of any changes needed to your home. There is no charge for supplies or reasonable adjustments to your home.

What training will I receive?

Either you, a relative or a carer will receive training. The aim of our training is to make you feel comfortable. You will be trained by our expert HD nurses. Training usually takes 6-8 weeks.



Section 1

1F: FAQs

Can I drive?

Being on HD doesn't stop you from driving unless there's another medical reason why you cannot.

Can I drink alcohol?

Yes, but only after advice from your doctor or dietician as certain types of alcohol are not recommended for some patients. You should also stick to your fluid restriction.

Will the unit arrange transport for me?

We encourage all patients to make their own way to dialysis if they are able to. Your transport needs will be assessed and you will have transport if suitable.

Will I be able to work or continue my studies?

Once you are established on HD you should feel well enough to go back to your job. Talk to your nurse and they will try to arrange a slot.

Can I go on holiday?

It is easier to go on holiday if you are on peritoneal dialysis but it is usually possible to arrange haemodialysis if you want to go on holiday in the UK or abroad. Depending on where you go there may be a fee to pay. Talk to your named nurse who can help point you in the right direction.

Will HD affect my sex drive?

HD does not mean you have to stop having sex. As long as you feel comfortable, you can continue as normal. For information about starting a family, contraception or erectile dysfunction, talk to your GP or consultant.

A day on HD

If you are new to dialysis you will be told on your letter where and when your slot is (see section 1 for time slots).

We encourage all patients to make their own way to dialysis, if they are able. All patients transport needs are assessed and you will have transport if you need it.

If you arrive early you will be asked to wait until your dialysis area and machine have been cleaned. Wash your hands thoroughly and weigh yourself – someone can help you if needed.

Once you are settled in the dialysis chair your nurse will check your blood pressure and see if you have any fluid that needs removal.

You will then be connected to the machine via your access so your blood can be cleaned and filtered by the dialysis machine and returned to your body. You'll be able to see your blood going through the tubing and the machine.

The process takes 3-4 hours – it varies for each person. Your blood pressure will be checked intermittently and you may hear the machine bleep occasionally.

Many patients sleep, read, work, use their laptops and watch TV during the treatment to pass the time. Some refreshments such as a cup of tea and biscuits are available. WiFi is also available via 'The Cloud'.

When the dialysis is complete, the needles are removed and pressure applied until bleeding stops. You can then weigh yourself. Providing you feel well enough you can then make your way home. If you feel unwell after, the nurses may keep you until you feel better.

The equipment is then cleaned and disinfected to stop the spread of infections, ready to be used by the next patient.

How to look after your dialysis access

3A: Fistulas and grafts

Do's

- **Exercise your hand regularly:** Squeezing a soft ball for three to five minutes, three or four times a day increases blood flow through the fistula/graft and hand.
- **Check your fistula/graft daily:** If it becomes red or tender contact your dialysis unit. If the buzzing/vibration sensation has changed or disappeared, contact your dialysis unit or if they are closed contact the Royal Free Hospital renal unit.
- **Check your hand:** If it becomes very painful, blue or swollen, contact the Royal Free Hospital.

Don'ts

- **Wear tight fitting** clothes, bracelets or watches on your fistula/graft arm.
- **Use your arm for carrying/lifting** heavy objects.
- **Let anybody take blood samples**, insert a cannula or measure blood pressure on your fistula/graft arm.

3B: Line care

Do's

- **Make sure your line is covered with a dressing and secured in place** at all times. The less your line is able to move the less likely it is to become infected.
- **Wash your hands** first if it is necessary to touch your line.
- **Immediately report any swelling, tenderness, fever or oozing from the exit site** to your dialysis unit.
- **Immediately report any bleeding from the exit site** to your dialysis unit and apply pressure to the exit site.
- **Call 999 if the bleeding is heavy or doesn't stop after pressing.**

Don'ts

- **Get your dressing wet.** Keeping it dry avoids infection.
- Make sure your bath is waist level and do not submerge your dressing. Do not shower or swim.
- **Replace the dressing if it becomes dislodged.** Contact your dialysis unit for advice.
- **Play contact sports.** If you do play sports ensure your line is securely taped to your chest and the clamps are closed. Ask your nurse for advice.
- **Allow your line to be used for anything other than dialysis,** unless it's an emergency.

For more information:

Always feel free to speak to the doctors, surgeons or nurses who are looking after your haemodialysis treatment. We are here to give you all the advice and support that you may need.

Your dialysis unit

4A: Who is who?

Below are a few pictures of the different colour uniforms all our staff wear, just to help you know the different roles of staff at your dialysis unit.



Matron: This is the head nurse across all of our dialysis units.



Clinical nurse specialist: Specialises in different aspects of kidney care. Usually in the clinic areas.



Nursing assistant: Assist nursing staff and patients with preparation for treatment.



Practice educator: Provides support, education and training to staff and patients.



Sister/charge nurse: This is the unit's senior nurse. They manage the unit on a daily basis. They also carry out your dialysis treatment.



Junior sister: May be your named nurse. Deputises to the sister/ charge nurse in their absence, a team leader and carries out your dialysis.



Staff nurse: May be your named nurse and carries out your dialysis.



Domestic staff: Provide cleaning and catering services in your unit.

4B: Your named nurse (NN) is:

All dialysis patients are assigned a named nurse (NN) who acts as their care co-ordinator. All other staff will be happy to help you too.



During your first dialysis treatment your NN will **introduce themselves and welcome you** to the unit. If you are not sure who your NN is, please ask or look at the staff picture boards.

Your NN will encourage you to take an active part in your own care and monitor your own results using PatientView (www.patientview.org); this is an online system used by our dialysis patients and enables you to view your latest test results, letters and medicines.

Your NN will **review you at least once a month** to see how you are, and assess your dialysis. You'll have an opportunity to ask any questions about your dialysis care. They can also refer you to the other services we offer if needed (eg the access team, psychology service or citizens advice bureau).

Every month your NN will monitor your blood test results alongside your consultant and renal dietician and discuss this with you.

Please tell your NN if you have:

- a change in any of your medicines,
- any admissions to hospital or other hospital appointments
- any tests or investigations coming up.

Section 4

4C: Consultant cover

Consultants visit the units one to two times a week to coordinate care with the team – they run weekly clinics at a specific time. You will be seen by your dialysis consultant in clinic within two weeks of starting HD and then every six months.



Your consultant will meet with your named nurse before your clinic to discuss any dialysis related problems.

Extra appointments can be scheduled if needed, for example if you have been in hospital.

The dialysis unit is an out-patient area and a consultant is not always present. If you would like to see a consultant in clinic to help with a dialysis related problem, please speak to your NN.

4D: Medical advice

- If you feel unwell while in the unit, your nurse will assess you and seek advice from the renal team at the RFH.
- If you are too unwell to attend dialysis, please call your unit for advice or visit the RFH emergency department.
- If you do need to visit an emergency department for a dialysis-related problem, please do still try to come to the RFH emergency department.
- For less urgent health problems, or if you are running out of some of your medications, please visit and speak to your GP.

Kidney patients are prone to infection

Patients with kidney disease tend to be more prone to infection and are less able to fight it than other people. Infection is now one of the biggest problems for renal patients; they can be serious and even fatal.

To protect you against infection we advise:

- Having a fistula rather than a line to perform HD.
- Cutting down on salt and fluid if your nurse or doctor has told you to as this will help avoid infections in the chest.

We also advise you to have the following vaccinations every year:

- Hepatitis B
- Influenza (flu)
- Pneumovax® (only required once).

Myth buster

Some people are worried about getting flu after having the flu vaccination; this is not possible because it does not contain any live flu viruses. You may have a tender area where the vaccine was given as the body develops immunity to this years' virus, which will protect you from what can be a life threatening illness for renal patients.

Holiday dialysis

We all need a holiday! If you decide to go on holiday, you need to identify where you want to dialyse too. Contact the unit you want to dialyse in and they will explain their procedures to you. Your named nurse will help get all the information together that the holiday unit needs for you to arrange your dialysis. When you return, you may need to dialyse in isolation for eight weeks and we may suspend you from the transplant list to ensure you have not picked up an infection while abroad.

Section 4

4E: What else do we do?

Dietitians

This is a team of specialised renal dieticians. They're here to help you make any changes to your diet necessary to help manage your kidney disease. If your nurse or doctor feels you would benefit from our services they will refer you. However if you think you would benefit, please ask your named nurse for more information.

Psychology service

This service is for patients with psychological issues arising from their kidney disease and its treatment. It aims to help patients adjust to the emotional stresses and strain. They are unable to prescribe any medications, but are able to provide a brief therapy service. Nursing staff and doctors can refer you, or you can contact them on: rfh-tr.RFH-RenalPsychology@nhs.net or 020 7794 0500 ext 37571.

Citizen's Advice Bureau

Camden CAB run clinics at our Tottenham, Edgware and St Pancras sites. It is available to all renal patients who wish for advice on various issues such as debt, benefits, housing issues, employment and immigration. To make an appointment please contact 020 7397 0673 or: renal@camdenservice.org.uk.

Royal Free Hospital Kidney Patients Association (RFHKPA)

This is a charity for the benefit of RFH renal patients. They champion issues on behalf of patients, provide support and organise social events. A newsletter is published on a quarterly basis. You can contact them by emailing: rfhkpa@gmail.com or visit their website: www.royalfree.nhs.uk/services-a-z/kidney-services/royal-free-hospital-kidney-patients-association/

Renal Patient View (RPV)

An online resource that allows you to securely access some of the information found in your notes, such as blood test results, allowing you to become more involved in your care. Talk to your named nurse if you're interested.

4F: Patient transport

Transport eligibility

We encourage all patients to make their own way to dialysis.

The NHS has universal eligibility criteria for transport that you will be assessed against to make the process fair and safe. All patients transport needs are assessed and you will have transport if you need it.

The transport team will be responsible for assessing if you meet the criteria within the first two weeks of dialysis.

If you meet the patient transport criteria

Your transport will pick you up before your dialysis treatment and drop you home afterwards. The type of transport that you get will depend on your current mobility and health which will change over time.

Most patients will share transport, so there will be delays in the journey as several are picked up and dropped off. The patient transport service is provided by an external company. The transport provider's aim is to pick you up within 60 minutes of your treatment time.

If you don't meet the patient transport criteria

You will need to make your own way to the dialysis unit. All of our units are accessible by public transport, as detailed later on. Other alternatives include driving yourself or asking a friend or relative to escort you.

If you feel one of our other units would be easier for you to travel to, speak to your named nurse.

If you are on a lower income you may be eligible to have your travel fees refunded; ask your named nurse for more information.

Section 4

You may also be eligible for a 'Freedom Pass' which entitles you to free travel around London. Find out more here:
www.londoncouncils.gov.uk/services/freedom-pass

Section 4

4G: How to get here – Tottenham Hale Kidney and Diabetes Centre

5-7 Daneland Walk, Hale Village, Ferry Lane, London, N17 9FE
Tel: 020 7830 2747

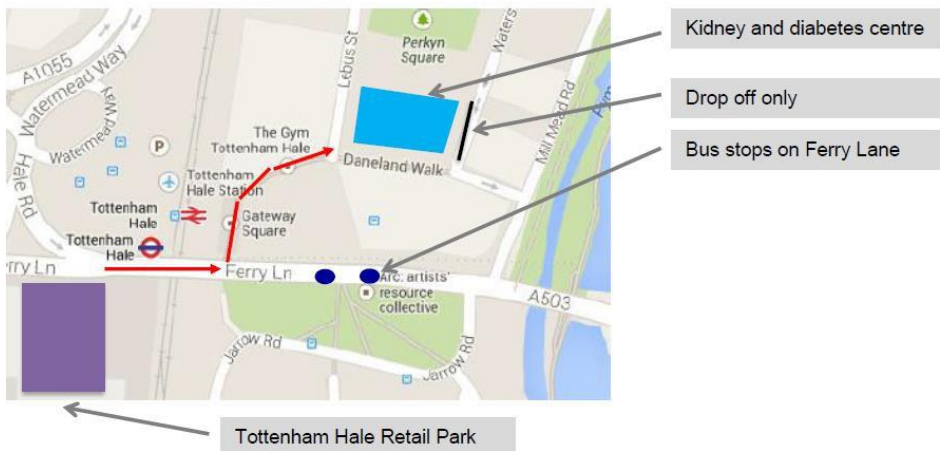
Tube: Victoria Line to Tottenham Hale.

Train: West Anglian Mainline between Liverpool Street and Stanstead Airport, Cambridge, King's Lynn and Hertford East. All trains run between Liverpool Street and Tottenham Hale.

Bus: 192, 41, 123, 230, W4, N73 and N41. These are all accessible via the new bus terminal at Tottenham Hale.

Parking: Free parking is available for all dialysis patients. Talk to our unit receptionists about parking permits.

Walking route from Tottenham Hale Station/retail park: Turn left on to Ferry Lane and follow the footpath over the railway bridge. Take the first left into Hale Village, walk past Tesco express and the unit is on the left on Daneland walk.



Section 4

4G: How to get here – St. Pancras Kidney and Diabetes Centre

St Pancras Hospital
4 St Pancras Way
London, NW1 0PE
Tel: 020 3758 2030

Opening hours:
7.30am-1am (the following morning).

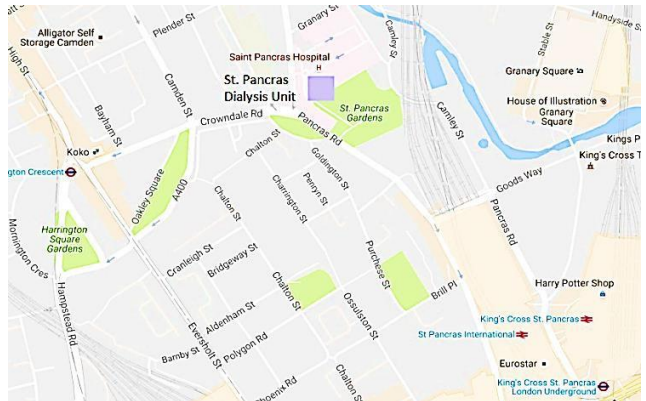
Tube: Mornington Crescent (Northern line) and King's Cross St. Pancras (Victoria, Northern, Hammersmith and City, Circle and District lines) are both a short walk.

Train: King's Cross St. Pancras is the nearest Overground station.

Bus: 46 and 214 stop nearby on St. Pancras road.

Patient parking: We have limited parking available and would recommend using public transport. Ask reception staff for a permit.

Walking from King's Cross St. Pancras: Walk onto St. Pancras Road, continue onto Camley Street and turn left on Granary Street. St. Pancras Hospital and the dialysis unit is on the left.



Section 4

4G: How to get here – Edgware Kidney Care Centre

Edgware Community Hospital Burnt Oak Broadway Edgware, HA8 0AD

Tel: 020 8732 4164/5

Opening hours: 7.30am-1am (the following morning).

Tube: Edgware tube (Northern Line) is a 10 min walk away or you can get the 288 bus from the station which takes around 10 minutes. Burnt Oak Station is also nearby – 15 minute walk and 10 minute bus ride (302 and 305).

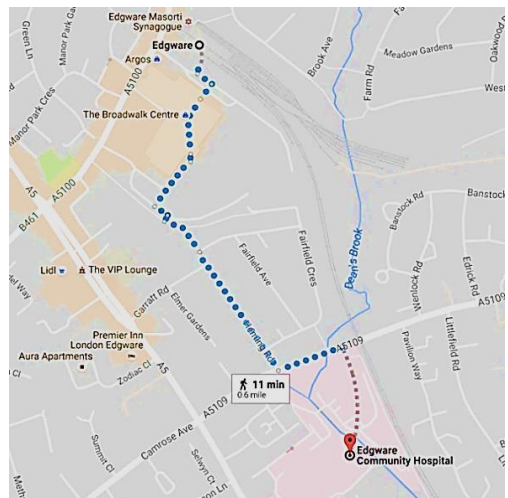
Train: There are no mainline train stations near this unit.

Bus: 32, 142, 204, 288, 251, 292, 614, 644, N5 and N64 all stop outside Edgware Community Hospital on Burnt Oak Broadway.

Parking: There is free parking for all dialysis patients. Please talk to our unit receptionists if you need a parking permit.

Walking from Edgware tube:

This takes about 11 minutes. Exit the station and walk through the Broadwalk Centre, exit onto Church Way. Walk along and turn right onto Heming Road, then turn left onto Deansbrook Road, the hospital is on your right.



Section 4

4G: How to get here – Barnet Dialysis Unit

Barnet Hospital Wellhouse Lane Barnet, EN5 3DJ

Tel. 020 8216 4955/6

Opening hours: 7.30am-1am (the following morning)

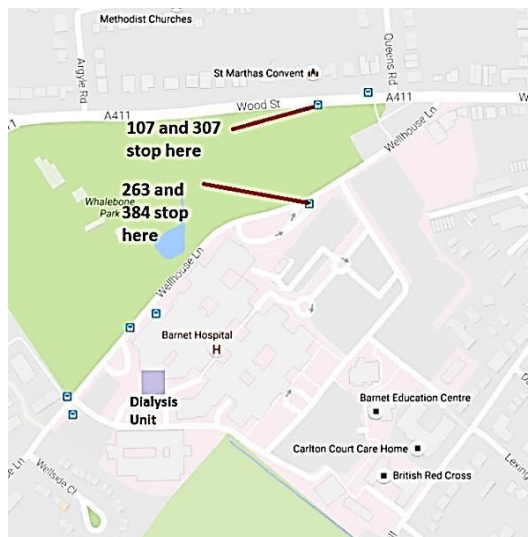
Tube: High Barnet station on the northern line is the nearest station. From there it is a 30 min walk or 10 min bus ride on 263, 107 or 307.

Train: New Barnet is the nearest train station, on the Thameslink railway line from Moorgate to Welwyn Garden City. It is a 10 minute bus ride from here using 107 or 384, 307 stops nearby.

Bus: A number of buses to the hospital, bus routes 384 and 263 stop at the hospital. 107 and 307 stop on Wood Street which is nearby.

Parking: Free parking is available for dialysis patients.

Please speak to staff at reception for a permit.



4H – Contact numbers

Royal Free London switchboard

Tel: **0207 794 0500** followed by extension:

- **Barnet Dialysis Unit: Ext 64955**
- **Edgware Kidney Care Centre: Ext 24160**
- **St. Pancras Kidney and Diabetes Centre: Ext 82030**
- **Tottenham Hale Kidney and Diabetes Centre: Ext 50500**

For more information about the kidney services we offer at the Royal Free London, please visit our website:

www.royalfree.nhs.uk/services/services-a-z/kidney-services/

For a full list of references for this leaflet, or to give us feedback on it, please contact: rf.communications@nhs.net.

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please ask a member of staff.

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