Home Dialysis Decision making support



Overview

This document is designed to complement the Home Dialysis Webinar. It includes:

- Key questions to ask your renal healthcare team about home dialysis
- Frequently Asked Questions (FAQs) about home dialysis
- Useful links to resources to help you make an informed decision and provide clarity and support.

To watch our previously held webinars on topics such as; holiday dialysis, diet and nutrition, and current research. Please use the link below to head over to our YouTube channel.



Click here for our YouTube Channel.

Questions to Ask Your Renal Worker

- How can home dialysis work for me?
- How will I be reimbursed for the extra cost of dialysis?
- How will my payments be made?
- Can I get any other support with the costs?
- How often will delivery of stock be?
- What if i don't have space for stock?
- What if I am on a water meter?
- What if i need support at home on dialysis or have a problem with my machine?



FAQ's

Do you need a big house/entire spare room for home dialysis?

Definitely not. Storage can be very creative including using a shed/garage for supplies if needed. A Kidney Wales grant can be used to buy a shed for storage.

Can you dialyse at home living alone? - Yes

absolutely if clinically stable.

Can you dialyse on HHD with a line rather than a fistula? - Yes

Can you travel on home dialysis?

Yes! If on PD or NxStage you can take it with you, or if on a standard HD machine you can just book into a clinic at your destination. You can find out more from your renal team.

Do you have to do 4 hours 3 times a week on HHD?

No, however you should consult with your renal team on what works best for you as you may need more or less.





Home Dialysis Reimbursement Information Fact Sheet

Page 1: What is home dialysis / why consider reimbursement?

The different dialysis treatments available at home (PD)

Page 2:

The different dialysis treatments available at home continued (HDD)

What is reimbursement? Are reimbursement payments taxable?

Ensuring that the costs reimbursed are as reasonable as possible

Page 3:

Ensure you receive all the benefits to which you are eligible

How is electricity usage calculated for home dialysis?

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How is water usage calculated for HHD?

Dialysis prescriptions and how they will be used for utility reimbursement

What about the rising energy costs?

<u>How will payments be</u>

made?

What other support is available to help me with my energy bills?



For people whose kidney failure is treated by home dialysis

What is home dialysis and why do I need to think about reimbursement?

Home haemodialysis machines use electricity and water, and peritoneal dialysis uses electricity to heat the bags or run the overnight machine. The additional electricity and water used for your dialysis will increase the cost of your utility bills. Reimbursement is repayment for the additional costs relating to your dialysis. This fact sheet will explain more about the electricity and water costs relating to dialysis, and how you can be paid back by the NHS to help you with these additional costs.

Dialysis is a treatment that removes toxins and excess fluid from blood when kidneys have failed. Home dialysis offers an effective alternative to unit based dialysis with patients reporting that it fits in well with their lifestyle, they feel better and much healthier. As you are dialysing at home you will need to use your own electricity and possibly water to use the equipment provided. The amount of electricity and water you use will depend on the type of dialysis and your prescription. There are two types of dialysis treatments available at home; Peritoneal Dialysis (PD) and Haemodialysis (HD). PD uses electricity, but not your water supply. HD uses both electricity and your water supply.

Peritoneal Dialysis (PD)

There are two ways of carrying out PD. Continuous Ambulatory Peritoneal Dialysis (CAPD) and Automated Peritoneal Dialysis (APD). Each method will require you to use your electricity for the dialysis equipment although the amount used depends on which type of PD you are using:

• CAPD does not require a machine to carry out dialysis. Usually CAPD is performed manually during the daytime. The number of times you do this each day will be shown on your prescription. A bag warmer is provided to warm up the dialysis fluid to the right temperature before each time you carry out the treatment. Electricity is required for the bag warmer.

 APD is a machine that carries out dialysis automatically, usually during the night whilst asleep. Electricity is required for the APD machine for the whole duration of the treatment. Home Haemodialysis (HHD)

HHD can be performed either during the day or during the night whilst you are asleep. HHD requires you to use your own electricity for the dialysis machine and your water supply. The amount of electricity and water you use will depend on your prescription and the cleaning required to keep your equipment safe;

 The Haemodialysis machine is a machine that removes toxins and excess fluid from the blood through a dialyser (acting as an artificial kidney when your own kidneys have failed). It requires electricity and water throughout the treatment and for any disinfecting/cleaning cycles as required.

Water Reverse Osmosis (WRO) is a machine that purifies tap water for haemodialysis treatment, and requires
electricity and water throughout the treatment and for any disinfecting/cleaning regimes as required.

What is reimbursement?

In simple terms it is repayment for out of pocket expenses. In relation to home dialysis, the out of pocket expenses are the additional amounts of electricity and water that you use for the purpose of carrying out your dialysis treatment in your own home as prescribed by your renal team.

The reimbursement money paid to you by the NHS needs to be calculated fairly, using the most efficient method and be equally available to all people who dialyse at home in Wales.

Are my reimbursement payments taxable?

No. This is because you are simply being reimbursed for money you have already spent. So, if your tax is paid by your employer (Pay As You Earn known as PAYE) you do not need to do anything. If you pay your tax by completing a tax return (known as self-assessment) you do not need to include the reimbursement payments as taxable income.





I am using HD at home, how can I help with ensuring that the costs I need to be reimbursed are as reasonable as possible?

Water, is by far the most expensive part of any reimbursement claim, simply because so much of it is used as part of your treatment and to keep your equipment safe.

It is important to inform the renal team as soon as possible that the property is on measured/metered water. You will be supported and advised on how to access water affordability caps that are available for homes that use a significant amount of water. Any difficulties in accessing the water affordability caps must be reported back to the renal team as soon as possible.

https://www.dwrcymru.com/en/support-with-bills

How do I ensure I am getting all the benefits I am eligible for?

You should consider applying for Personal Independence Payments (PIP) or Attendance Allowance (AA) if over state pension age – check pension age at <u>https://www.gov.uk/state-pension-age</u>

PIP/AA are 'non- means tested' benefits paid to help with additional costs of longterm illness or disability. PIP/AA are paid regardless of income, savings or National Insurance Contributions; they can be paid working or studying. Check eligibility at https://www.gov.uk/pip/eligibility

PIP/AA (&DLA) are 'non-means tested' benefits that may allow you to qualify for help described above. https://www.gov.uk/pip

https://www.gov.uk/attendance-allowance/how-to-claim

How is water usage calculated for HHD?

Fixed water & sewage rates

For homes that are on fixed water and sewerage rates, there is no additional financial burden as the additional use associated with HD is absorbed within the fixed rates.

Measured/metered water

If you don't want to apply for PIP or have any other means to access the Welsh Water affordability cap, an annual review of the main water providers is undertaken on an all Wales basis. This gives an average water per hour cost which is used for the purpose of the home dialysis reimbursement.

The NHS will continue to reimburse you for your water usage until such times as you have accessed the water affordability cap. We would strongly recommend that you do and this is a far better use of NHS resources. Ask your renal team if you need more information about PIP or water affordability cap.

What is a dialysis prescription and how will it be used for utility reimbursement?

A dialysis prescription in relation to the reimbursement of utility costs will be based on the frequency (how many times per week), duration (hours) and any cleaning regimes associated to the dialysis equipment. It is important to inform the kidney team of any changes to dialysis prescription that will affect the utility reimbursement. Any changes will be adjusted, communicated and documented accordingly.

How is electricity

There are two steps in calculating

home dialysis?

HHD).

usage calculated for

electricity costs for home dialysis (PD and

1. An annual review of the main energy

providers is undertaken on an all Wales

basis. This gives an average kilowatt per

hour cost which is used for the purpose

of the home dialysis reimbursement.

2. The renal technical services have

standardised dialysis machine which is

used to calculate the energy for the

purpose of the home dialysis

reimbursement.

provided the usage of energy for

What about the rising energy costs?

A revision to the reimbursement rate came into effect in April 2022 which accounts for the unprecedented rise in electric costs in 2021/2022. The Renal Network will continue to monitor the situation closely.

How will payments be made?

The home dialysis team will explain the process on how home dialysis utility reimbursement payments will be made. You will be asked to provide bank account details so that payments can be paid directly to you.

What other support is available to help me with my energy bills?

 A household with medical equipment should be registered with the energy supplier as a priority service user. This ensures that support is provided should the continuity of supply be disrupted and support offered if you are struggling to meet the cost of the energy needs. Energy suppliers have some flexibility to write off short term energy debt.

 'Nest' offers free, impartial advice and, if eligible, a package of efficiency improvements such as a new boiler, central heating or insulation. This can lower energy bills.
 www.nest.gov.wales or call 0808 808 2244.

Advice from the Welsh Kidney Charities



Our expert advocacy team work across the whole of the UK and take action on behalf of kidney patients.

The team are available to listen and to answer your questions about benefits, housing, transport, dialysis, work, treatments and managing day-to-day life when you are living with kidney disease.

As part of our advocacy service we can organise a free Welfare and Benefits Health Check with a benefits and debt management advisor. We will make sure you are maximising your income through all the benefits and schemes available to you.

Email info@kidneycareuk.org or call us now on 01420 541424 to be put in touch with your local Kidney Care UK advocacy officer.

More information on making the most of your money can be found at: https://www.kidneycareuk.org/get-support/cost-living-hub.

As well as emotional support Paul Popham Fund provide financial advice and grants of up to £150 that can be used towards the cost of energy bills/debts.



Please contact us for more information via Email <u>support@paulpophamfund.co.uk</u>, Telephone 0800 038 8989 or visit our website: <u>www.paulpophamfund.co.uk</u>

What are financial assistance grants from Kidney Wales?

Our financial assistance grants are to help support kidney patients when they are experiencing financial hardship, related to or resulting from the burden of Chronic Kidney Disease (CKD). Each application will be reviewed by staff and trustees to assess fit with our mission and to determine if the request meets our requirements for a grant award.

Who can apply for a Kidney Wales grant?

Applications will only be accepted from health care professionals, submitted on behalf of patients, using a registered NHS/Health Board e-mail address. Applications are expected to be submitted primarily by Renal Social Workers or Clinical Psychologists, but applications from other members of the patient's kidney care team may also be considered.

For more information or support, please visit our website: <u>https://kidneywales.cymru</u> or contact us via Email <u>team@kidneywales.cymru</u> or Telephone 02920 3433940

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Helpful Resources

<u>Kidney Wales financial assistance g</u>rants

Kidney Wales information Webinars

<u>Kidney Wales and Anglesey Council collaboratively</u> <u>supporting home dialysis patients</u>

<u>Kidney Wales - New home dialysis reimbursements</u> <u>scheme</u>

NKF Home dialysis the advantages

NKF Home dialysis films

Welsh Kidney Network

KCUK Home dialysis booklet

