

# Home Dialysis Energy Reimbursement in Scotland

September 2023



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## Introduction

Kidney Care UK have been campaigning for the full, fair and timely reimbursement of the additional energy costs which arise as a result of having home dialysis.

The ongoing cost of living crisis has seen energy costs soar. This has hit individuals on home dialysis hard and in many different ways, most critically because home haemodialysis (HHD) and automated peritoneal dialysis (APD) machines use additional electricity which increases the cost of rising utility bills.

The increasing energy costs of maintaining the environment, particularly the heating of the room where home dialysis takes place to ensure that the dialysis machine operates properly and that dialysis can be undertaken in a comfortable and warm environment to support a person's health and wellbeing, also adds to these additional costs.

## Reimbursement of additional energy costs for home dialysis in Scotland

Scotland, unlike England and Wales, has no national guidelines for the reimbursement of the additional energy costs for those on home dialysis, it is therefore at the discretion of each of the fourteen NHS Health Boards to decide if, what and how they reimburse. In order to obtain a comprehensive overview and understanding of the reimbursement of the additional energy costs of home dialysis in Scotland Kidney Care UK, during Spring – Summer 2023, undertook an information gathering exercise to ascertain:

- If each Health Board reimburses people with kidney disease on home haemodialysis (HHD) or automated peritoneal dialysis (APD) for their additional energy costs of having dialysis at home.
- What the rate of reimbursement is.
- How the reimbursement rate is calculated.
- How often the reimbursement rate is reviewed.
- The process and frequency of reimbursement.
- If each health board considers the heating of the room or cabin where home dialysis takes place in their reimbursement rate.

This information was obtained via a combination of freedom of information requests to each Health Board and communication with key individuals within health board finance and renal departments. A less formal information gathering exercise was also conducted in the Winter of 2022 in order to begin to obtain an understanding of the home dialysis reimbursement situation and process in Scotland. The findings of both exercises have and will continue to be used to inform our policy campaigns on this issue in Scotland.

## Section 1: Background

### 1.1 An overview of kidney disease in Scotland

An estimated 607,000 people in Scotland are currently living with all stages of chronic kidney disease (CKD) with this figure projected to rise to over 634,00 in the next decade<sup>1</sup>. 273,000 people in Scotland are currently estimated to be living with CKD stages 3-5<sup>2</sup> with around 2,123 people on dialysis in Scotland<sup>3</sup>. In the region of 245 people with kidney disease in Scotland are thought to be on home dialysis with around 46 people on home haemodialysis (HHD), 131 on automated peritoneal dialysis (APD) and 68 on continuous ambulatory peritoneal dialysis (CAPD)<sup>4</sup>. The number of people on dialysis in Scotland in the next decade has the potential to increase significantly with projections of as many as 10,000 people receiving dialysis in Scotland by 2033<sup>6</sup>.

### 1.2 Types and frequency of home dialysis

There are three types of home dialysis: home haemodialysis (HHD), automated peritoneal dialysis (APD) and continuous ambulatory peritoneal dialysis (CAPD) (See appendix point 1). These treatments can be undertaken by adults or children. HHD is normally undertaken three times a week for three to four hours or longer. APD is normally undertaken daily during the night while asleep; the process lasting 8–10 hours. CAPD, which does not require a machine, is carried out four to six times a day every day and takes at least 30-40 minutes each time.

### 1.3 Home dialysis machines: room temperatures

Home dialysis machines have ambient operating temperatures to ensure that they operate properly (see appendix point 2).

## Section 2: Home dialysis energy reimbursement findings

### 2.1 Reimbursement of the additional energy costs for people on home haemodialysis (HHD) in Scotland

#### 2.1.1 Reimbursement of HHD by NHS health boards

Half (7) of the health boards in Scotland have an HHD energy reimbursement policy in place with ten health boards in total stating that those on HHD residing in their health board are financially reimbursed.

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<sup>1</sup> <https://www.kidneyresearchuk.org/about-us/influencing-change/health-economics-report/>

<sup>2</sup> <https://www.kidneyresearchuk.org/about-us/influencing-change/health-economics-report/>

<sup>3</sup> <https://www.kidneyresearchuk.org/about-us/influencing-change/health-economics-report/>

<sup>4</sup> Scottish Renal Registry

<sup>5</sup> The data we collected in spring-summer 2023 while incomplete, suggests that these numbers have now risen.

<sup>6</sup> <https://www.kidneyresearchuk.org/about-us/influencing-change/health-economics-report/>

Two of the ten health boards informed us that they do not have a reimbursement policy for those on HHD residing in their health board as all those on HHD living in their board are cared for and reimbursed by another health board:

**“We xxx [health board] do not have any haemodialysis patients who dialyse at home as all our home haemo patients are taken over by xxx [hospital] in xxx [another health board].”** NHS Health Board

From the information we received, at least one of these two health boards is invoiced by the health board who cares for their HHD patients for the reimbursement sum:

**“I can advise that NHS xxx [health board] has made no payment in the last financial year to reimburse patients on home dialysis. NHS xxx [health board] bill NHS xxx [health board] for the patients who live in xxx [region] but carry out home haemodialysis through NHS xxx [health board].”** NHS Health Board

One of the ten Health Board states that they currently do not have a HHD home energy reimbursement policy in place but have recently adopted another health boards policy to reimburse an individual on HHD:

**“NHS xxx [health board] do not have a current policy in place however the process of reimbursing is based on xxx [hospital in another health board] information.”** NHS Health Board

Of the health boards (4) who currently do not reimburse any energy costs for those on HHD, one attributed this to them not having anyone on HHD in their health board and said that they would put a future policy in place if this were to change:

**“We have no policy as we have had no patients - if this would be required in future we would put this in place.”** NHS Health Board

Another health board informed us, at time of contact, that they are currently finalising their reimbursement policy for HHD:


**“We can advise that the process is being finalised with implementation to be back dated, this will be for home therapies (HHD and PD).”** NHS Health Board


### 2.1.2 HHD Reimbursement Rate

Rates of reimbursement for HHD vary considerably between health boards in Scotland with the lowest rate of reimbursement being a set payment of £30 per month and the highest rate being set payments of between £127.14 - £206.67 per month.

The variation in HHD reimbursement rates between health boards can be attributed to the way in which each rate is calculated and what is considered and included in that rate. Table 1 below and on the next page lists, in descending order, the HHD energy reimbursement rates, the way in which we have been informed these are calculated and if the health board states they take into account the heating of the room or cabin where HHD takes place.

**Table 1: HHD Energy Reimbursement Rates**

Rate ranking	Number of NHS health boards	Rate per month	How rate is calculated: direct quotes from health boards	Inclusion of heating the room/cabin in rate
Highest rate of reimbursement	1*	£206.67  Alternate day HHD in a cabin**	“The amount covers the electricity costs for both the running of the HD machine and heating the room/cabin. This is based on factors such as how many times a week patients dialyse and where, i.e. cabin or room. This was calculated using the treatment time, disinfect time and power consumption of each dialysis machine.”	Y
	Same health board as above	Around £175  3x week HHD in a cabin**, and 5x week HHD in a room in the house	“The amount covers the electricity costs for both the running of the HD machine and heating the room/cabin. This is based on factors such as how many times a week patients dialyse and where, i.e. cabin or room. This was calculated using the treatment time, disinfect time and power consumption of each dialysis machine.”	Y
	Same health board as above	£127.14  3x week HHD in a room in the house	“The amount covers the electricity costs for both the running of the HD machine and heating the room/cabin. This is based on factors such as how many times a week patients dialyse and where, i.e. cabin or room. This was calculated using the treatment time, disinfect time and power consumption of each dialysis machine.”	Y

Rate ranking	Number of NHS health boards	Rate per month	How rate is calculated: direct quotes from health boards	Inclusion of heating the room/cabin in rate
	1	£75	Method of calculation was not provided.  "The payment amount (£225 per quarter) is a round figure with the aim of ensuring that patients carrying out haemodialysis at home are not out of pocket and can be used to pay for electricity, heating or any other costs produced by dialysing at home."	Y
	1	£69.63	"Calculation is based on how many hours for treatment and disinfection are required on a weekly basis and how many units of energy are used. The average cost per kW of energy is applied to calculation."	N
	1	£50	"Based on patients' average electricity usage on dialysis days."	Y
	3***	£43	X1 health board: "This is based on the electricity used by one of our first HHD patients. Installation of an additional meter and the bill came directly to the board."  X2 Health Board: "Home dialysis reimbursement costs were calculated from the power use of each machine and the average kWh electricity cost in April 2022."	N
	Lowest rate of reimbursement	1	£30	"This is calculated on the electrical consumption of our machines based on a typical hour per week of dialysis."

\*This health board is also responsible for the care and reimbursement of people on HHD in two other health boards.

\*\* The cost to heat a cabin will generally be higher than the cost to heat a room in a home

\*\*\* One of the three health boards state that they are using the reimbursement policy of another health board hence the same rate.

### 2.1.3 Process and frequency of HHD reimbursement

HHD energy reimbursement payments are most frequently made via bank transfer on either a monthly, or quarterly basis.

### 2.1.4 Review of rate of HHD reimbursement

The frequency with which the HHD energy reimbursement rate is normally reviewed varies between Health Boards, from annually (2)<sup>7</sup>, bi-annually (1), when a significant energy price change occurs (1), or a combination of the later and annually (1):

“The rate was calculated in April 2022, again when the energy costs increased in October 2022. This will be reviewed again in October 2023.” NHS Health Board

“Last review April 2022, next review 2024.” NHS Health Board

“[The rate is reviewed] if [there is a] significant change in market price.” NHS Health Board

One health board states that they have “no firm process” for reviewing their HHD reimbursement rate, while another states that they do review their HHD rate of reimbursement but failed to state how frequently they do this. Only one health board who has an HHD energy reimbursement policy in place failed to provide us with this information.

## 2.2 Reimbursement of the additional energy costs for those on automated peritoneal dialysis (APD) in Scotland

### 2.2.1 Reimbursement of APD by NHS health boards

While there are more people with kidney disease in Scotland on APD (131) than HHD (46), only 4 (28%) of the 14 Health Boards in Scotland currently have an APD energy reimbursement policy in place. One health board is in the process of finalising their APD reimbursement policy and another health board is currently reviewing if they should introduce such a policy.

### 2.2.3 APD reimbursement rate

Rates of APD energy reimbursement vary between the four health boards who currently have a policy in

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<sup>7</sup> One of these health boards is responsible for HHD patients residing in two other boards as well as their own.



place. Three of the health boards have a fixed reimbursement rate, the highest rate being in the region of £20 per month<sup>8</sup>, closely followed by £18.60 per month, then £7.80 per month. The remaining health board with an APD energy reimbursement policy states that the amount they reimburse is dependent on the electric bill an individual submits for the running of their APD machine.

## 2.2.4 Calculation of the reimbursement rate

How rates for APD energy reimbursement are calculated varies between health boards:

“PD patients’ rate is worked out on their tariff and how many hours they are on PD ... PD patients have their land line cost reimbursed also... Calculation at standard rate tariff x 0.006 by the number of hours plus 5%VAT.” NHS Health Board

“Costs were calculated from the power use of each machine and the average Kw/hour electricity cost in April 2022.” NHS Health Board

“Calculation Based on manufacturer’s estimated monthly running cost” NHS Health Board

“Power used by machine 6 days a week.” NHS Health Board

Only one health board states that they have considered the cost of heating the room where APD takes place in their rate.

## 2.2.5 Process and frequency of APD reimbursement

APD energy reimbursement payments are made on either a monthly or quarterly basis. In the case of one of the four health boards this payment is made via bank transfer and in another health board the option of a bank transfer or cheque is given. Two of the four health boards who have an APD energy reimbursement policy failed to specify how these payments are made. Two health boards also indicated that an individual must provide their electric bill to be recompensed:

“Electricity invoice is submitted to unit, signed off by consultant and sent to finance for payment.”  
NHS Health Board

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<sup>8</sup> Rate was due to be discussed again.

“Patient reimbursed quarterly upon receipt of their electric bill.” NHS Health Board

### 2.2.6 Request to be reimbursed for APD

While four health boards have an APD energy reimbursement policy in place, this does not necessarily mean that everyone on APD within that health board automatically receives the payment they are entitled to. In some cases it appears that people have to ask and opt in to the reimbursement process:

“As yet, no pd patients have requested any financial assistance.” NHS Health Board

“Not all patients ask for this [APD reimbursement].” NHS Health Board

### 2.2.7 Review of APD reimbursement rate

Three of the four health boards with a APD energy reimbursement policy state that they review their rate of reimbursement, with the fourth health board stating that they ‘did not know’ if the rate was regularly reviewed. In terms of the frequency with which the APD energy reimbursement rate is reviewed, responses from each of the health boards were as follows:

“Regularly.” NHS Health Board

“If a significant change in market price [occurs].” NHS Health Board

“To be discussed at a [forthcoming] PD meeting.” NHS Health Board

## Section 3: Summary

Half (7) of the health boards in Scotland have an HHD energy reimbursement policy in place, with ten health boards in total stating that those on HHD residing in their health board are financially reimbursed. However, while HHD energy reimbursement policies might be in place there are evident disparities between health boards in their rate of reimbursement, how that rate is calculated and what it includes and how often that rate is reviewed. While all dialysis machines need to operate within certain ambient temperature ranges only three health boards in Scotland state that they consider the cost of heating the room where HHD takes place in their reimbursement rate, with only one health board in Scotland indicating that they consider the difference in the cost of heating a cabin versus a room in a person’s house where HHD takes place in their reimbursement rate. HHD energy reimbursement payments are most frequently made via bank transfer on either a monthly, or quarterly basis.

While there are more people in Scotland on APD (131) than HHD (46), significantly fewer health boards (4) have a home energy reimbursement policy in place for this. As with reimbursement rates for HHD, rates of reimbursement for APD vary between health boards as does the way in which these rates are calculated. It should also not be automatically assumed that because a health board has an APD energy reimbursement policy in place that all people on APD within that health board automatically receive the payment they are entitled to.

## Section 4: Conclusion and recommendations

In the absence of national guidelines in Scotland to reimburse the additional energy costs of home dialysis, if, what, how and when this is reimbursed is wholly dependent on the Health Board a person on home dialysis resides in.

The information Kidney Care UK has collated demonstrates that there is a clear need in Scotland for national home dialysis energy reimbursement policy guidelines. This would end the post-code lottery and ensure that all health boards have a policy in place for this purpose. Everyone living with kidney disease, on all modes of home dialysis, should be fully and fairly reimbursed, without complication and in a timely manner, for the additional energy costs of having dialysis at home.

We recommend that a national policy in Scotland should:

- Be an opt out, not an opt in policy to ensure that all people in Scotland on all modes of home dialysis, who wish to be reimbursed, are financially recompensed for their additional energy costs.
- Require relevant kidney health care professionals to proactively inform each individual with kidney disease, prior to commencing dialysis, about their right to be reimbursed for their home dialysis energy costs.
- Regularly review the rate of reimbursement.
- State that the process of reimbursing individuals on home dialysis should be timely, clear and straightforward to ensure ease of reimbursement.
- Reflect the number of days and hours an individual dialyses at home.
- Consider the type of dialysis and dialysis machine a person uses.
- Include the additional operational energy costs of using a home dialysis machine such as the set up and disinfectant time and for those on APD the heating of the fluid bags prior to dialysis.
- Consider the additional energy costs of maintaining the environment where home dialysis takes place, particularly the heating of the room or cabin where home dialysis takes place to ensure that the dialysis

machine operates properly and that the health of the person on home dialysis is maintained.

With the continuing cost of living crisis and another winter closely falling upon us, people with kidney disease on home dialysis should not have to worry about whether they can afford to turn their heating on or up to a temperature where their dialysis machine works properly so that they can successfully have this life-saving treatment. The quotes below are illustrative of the harsh reality that some kidney patients on home dialysis faced last winter:

**“We have found a few of our patients are sitting in the cold whilst dialysing, which has consequences for their health, as well as their equipment” Renal nurse**

**“My dialysis machine didn’t work one night; I contacted the dialysis company who told us the bedroom was too cold and that it should be around 19 degrees.” Home Dialysis Patient**

**“My machine alarms constantly when the room is too cold...” Home Dialysis Patient**

**“Basically, my living room became too cold for the special liquid – dialysate – to flow through the machine and pull toxins from my blood.” Home Dialysis Patient**

**“I would cut my time on the machine short to save energy and because I would get so cold due to not putting on the heating.” Home Dialysis Patient**

Kidney Care UK believe that no one with kidney disease should have to pay for the additional energy costs of having lifesaving treatment at home.

With an ever-growing number of individuals on dialysis in Scotland and an ongoing cost of living crisis, Kidney Care UK believe it is imperative that the issue of the reimbursement of the additional energy costs of having dialysis at home are addressed as a matter of urgency.

## Appendices

### 1. Types of home dialysis

#### A. Haemodialysis (HD)

When someone’s kidneys don’t work properly, toxins and excess fluid build up in their blood stream. HD works by taking blood from the body and ‘cleaning it’ in a dialysis machine to remove the toxins. Blood is taken out of a person’s body and run through a filter. Toxins are removed from the blood into the dialysis fluid, which is then disposed of.

#### B. Peritoneal Dialysis (PD)

Peritoneal dialysis (PD) became an alternative to haemodialysis in the 1980s. In PD, a soft tube called a catheter is used to fill the abdomen with a cleansing liquid called ‘dialysis solution’. The abdominal cavity is lined with a membrane (layer) called the peritoneum. The waste products and extra fluid (and salt) pass through the peritoneum from your blood into the dialysis solution, attracted by its high sugar (dextrose) content. They then leave the body when the dialysis solution is drained. This used solution is thrown away. The process of draining and filling is called an ‘exchange’ and takes about 30–40 minutes. The period the dialysis solution is in the abdomen is called the ‘dwell time’.

One form of PD, continuous ambulatory peritoneal dialysis (CAPD), doesn’t require a machine and it is possible to walk around with the dialysis solution in the abdomen. CAPD is carried out four to six times a day every day and takes at least 30-40 minutes each time. Another form of PD, automated peritoneal dialysis (APD), requires a machine to fill and drain the abdomen; performing three to five exchanges during the night every night while asleep; the process lasting 8–10 hours.

### 2. Ambient operating temperatures for a number of Fresenius and Baxter home dialysis machines

Manufacturer	Type of dialysis	Machine	Ambient operating temperature
Fresenius	APD	SleepSafe Harmony System	Non-paediatric: 15-35°C Paediatric: 20-35°C
	HHD	5008S HD system	15-35°C
	HHD	6008 HD System	15-35°C
	HHD	NxStage System One machine*	15-37°C
Baxter	HHD	AK98 Home Haemodialysis machine	18-35°C
	APD	Homechoice Claria APD	15-36°C

\*Users are requested to ensure that the cyclor unit, treatment cartridge and any pre-mixed dialysate are exposed to the target ambient temperature for one hour before use (for example after transportation or storage).



Kidney Care UK is the UK's leading kidney patient support charity, providing practical, financial and emotional assistance for kidney patients and their families throughout the UK. We believe that no one should face kidney disease alone.

For further details of all the support we provide to people living with kidney disease, please visit our website [www.kidneycareuk.org](http://www.kidneycareuk.org) or call us on 01420 541 424.

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