

Left out in the cold

Report 2023

Foreword

People who have kidney failure typically have a kidney function of around 10% or less. They will be experiencing symptoms including, but not limited to:

Swelling of the feet, ankles and legs

Shortness of breath

Brain fog

Extreme fatigue

Frequent nausea

Dialysis is a treatment that does some of the work of your kidneys, and this can be done in a number of ways, including having dialysis sessions at home. The main benefits of home dialysis include:

- **People can control the hours they receive dialysis**, allowing them to fit this treatment around their day-to-day commitments including employment.
- **They are more in control of their treatment and their lives**, giving them more independence, which can lead to improved emotional, psychological and social wellbeing.
- **They can benefit from an improved quality of life** by being able to spend more time at home with their loved ones.
- **There is less exposure to Covid-19 and other infections** because people do not regularly need to attend hospital for treatment.
- **Longer, slower dialysis helps to increase kidney function** and may lead to longer life.

Guidance from the National Institute for Health and Care Excellence (NICE) advocates home dialysis as a more cost-effective treatment than hospital dialysis and one which benefits and empowers people. The [Getting it Right First Time \(GIRFT\) programme](#)¹ recommends a target of 20% of people on dialysis for home dialysis, which could save the NHS £5m per year. Not only is home dialysis better for many people but it is also more cost effective for the NHS and reduces pressure on renal units.

People who need dialysis should be able to choose the treatment that is right for them, no matter where they live or their financial circumstances. However, through our campaigning work for better support and care for kidney patients through the cost of living crisis and beyond, we are seeing a postcode lottery of where this support is and isn't being consistently applied. It is simply not good enough. If you want to have home dialysis then you should be supported to have it, without the fear of how much it will cost.

“We love having the freedom of home dialysis BUT if we don't get more help we will have to consider going back to a unit.”

Home haemodialysis can save the NHS around £10,000 per patient, per year when compared with hospital-based dialysis. Yet, according to our research, hospitals only reimburse around £10,000 each year, on average, to ALL their home dialysis patients.

In December 2022, Kidney Care UK contacted all NHS trusts in England with renal units to ask them about their transport and energy reimbursement responsibilities. Those who did not respond (which was sadly the vast majority) were sent freedom of information requests. In conjunction, the charity ran a survey for people with kidney disease to complete in February and early March 2023. This report combines the findings.

Cold homes, empty pockets

People on home dialysis need to ensure that the temperature of the room that they are having their treatment in is comfortable because dialysis machines need to function at a specific temperature (above 18°C). In addition, haemodialysis involves removing blood from the body, filtering it and returning it, during which time the blood cools. This inevitably makes people feel uncomfortably cold during the procedure. Warm dialysis rooms are therefore a medical necessity, not a luxury.

The following anonymous testimonials were received in response to our survey:

“I do not have the heating on in the room I use for dialysis, I use blankets to keep warm. It appears the cold room may be making my pressures unstable.”

“My dialysis machine didn’t work one night; I contacted the dialysis company who told us the bedroom was too cold at 15 degrees and that it should be around 19 degrees.”

“My machine alarms constantly when the room is too cold and I have to turn up the temperature of the dialysate to maximum, (thus using more electric). I phoned the helpline and was told the optimal temperature was 21 degrees, but the current temperature of the room was below 17 degrees.”

The annual cost of running a dialysis machine at home can be as much as £1,000 or more, depending on type, frequency and duration of treatment.

As utility prices remain at an all-time high, and only 26% of dialysis patients are in employment because of their condition and the burden of treatment, thousands are being pushed further into hardship because of utility bills they cannot afford.

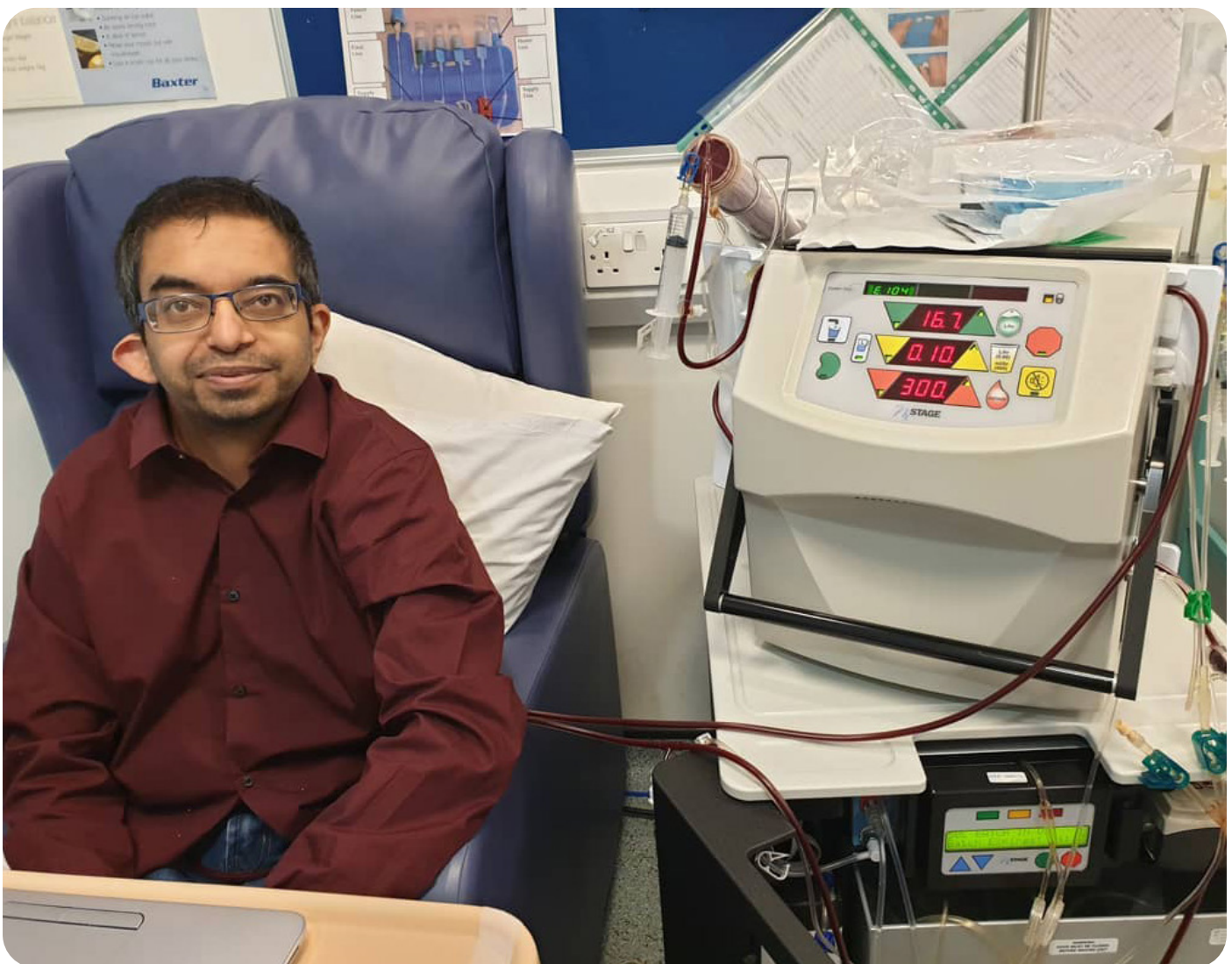
Many people on home dialysis are having to choose between life-sustaining treatment, heating or eating.

Full, fair and timely reimbursement

At Kidney Care UK, we believe everyone receiving home dialysis should be receiving full, fair and timely reimbursement for the energy they use to run their home dialysis equipment, irrespective of where they live and which type of dialysis they receive.

Under rules set out in the [NHS England home dialysis service specification](#)², there is an entitlement for people to receive reimbursement from their NHS trust for the additional utility costs incurred by home haemodialysis treatment, “which may include electricity, water, gas and telephone.” Trusts, who are already receiving funds from NHS England to cover the costs of these reimbursements within the National Tariff, are also being asked to reimburse for the costs of peritoneal and paediatric dialysis.

To assist healthcare professionals in making fair reimbursement calculations, the UK Kidney Association (UKKA) has released guidance, developed by the Welsh Kidney Network, including a [reimbursement calculator](#)³, based on a standard energy tariff of 35p per kilowatt hour. However, despite this clear-cut policy, many people still tell us that they are not receiving payments.



² NHS England home dialysis service specification: <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/a06-serv-spec-haemodialysis-renal-failr-home.pdf>

³ Reimbursement calculator: <https://ukkidney.org/renal-association/news/reimbursement-additional-utility-costs-patients-receiving-home-dialysis-%C2%A0>

Where is the money?

We ran an online survey between 1 February 2023 and 13 March 2023, and over 1,000 people (1,005) told us about their experiences.



37% of respondents on home haemodialysis told us they are not receiving any reimbursement for energy costs from their trust.



Even among people doing a similar amount of dialysis, reimbursement payments vary hugely, between £160 and £1040 per annum.



80% of people on home dialysis who do receive reimbursement felt it didn't cover all the costs their treatment incurs.

At Kidney Care UK, we have been campaigning on this issue since March 2022 as part of our [Priced Out of Existence campaign](#)⁴. Alongside this survey, we wrote and made freedom of information requests to all NHS trusts in England to get a clearer picture of how home dialysis reimbursement is taking place (or not). Specifically, we asked each trust:

- How much they reimbursed each person
- How many people they had reimbursed
- The total they had spent on reimbursement

This research and our discussions with units has identified that now – and following our campaigning – the majority of trusts have reimbursement policies in place, and many are making payments with a considerable number of trusts already using the UKKA reimbursement calculator. While we are very pleased to hear this, we are concerned that many dialysis patients are still receiving very little or, in some cases, no reimbursement at all. This is simply not good enough.

There are too many kidney patients who are eligible for reimbursement but who are not receiving it. It's vital to identify and overcome the barriers within trusts that are preventing people on home dialysis receiving the payments to which they are entitled. **Reimbursement is not something they should have to fight for, it should be something all home dialysis patients receive automatically. This begs the question, if virtually everywhere has a policy, why aren't people getting the money?**

⁴ Kidney Care UK's Priced Out of Existence campaign: <https://www.kidneycareuk.org/get-support/your-stories/i-am-being-priced-out-existence/>

Our freedom of information request findings

The good

Twelve (29%) of the 42 NHS trusts we wrote to confirmed they are reimbursing patients for electricity used to power their home dialysis machines, using a tariff of 35p/kWh (pence per kilowatt hour) similar to the current unit price limit within the Energy Price Guarantee.

A further four trusts confirmed they reimbursed at the rate charged by the patient's energy supplier.

In addition to reimbursing for domestic energy usage, eight trusts (19%) also told us they are making payments for metered water.

Five trusts (12%) said they are keeping their policies under regular review or will start to review them. We welcome this approach and ask other trusts to follow their example.

Two trusts (5%) make contributions towards heating an individual's dialysis room.

We are asking all trusts to do this; it is worrying that 95% of NHS trusts do not contribute to increased heating costs.





The bad

One of the 42 trusts who responded to us reported that they pay only 15p/kWh and another has only recently increased its rate from 14p **despite the domestic cost being far higher since the beginning of the energy crisis.**

Trusts **must ensure they are reimbursing at or above the domestic rate.**

Three of the trusts that responded to us said they were actively making reimbursement payments, but did not tell us about the rate at which they did so, and therefore **we have no assurance of whether they are paying the accepted rate.**

The ugly

One trust shockingly responded to our request to say they "do not reimburse energy bills for renal home dialysis". **This is despite the fact that all NHS trusts are receiving the funds to cover the costs of reimbursements and that there are clear rules set out in the NHS England home dialysis service specification, outlining that patients should receive reimbursement from their trust.** We have raised this and shared details of this trust directly with NHS England.

Eight trusts (19%, almost 1 in 5) did not respond to our freedom of information request at all, which means that **we have no understanding of whether they are properly reimbursing for the extra utility costs.** This also raises a concern about whether those trusts are aware of their responsibility to properly reimburse.

The mental burden faced by people with kidney disease during the cost of living crisis

Our survey found that almost three quarters (73%) of people who do their dialysis at home have been worried about the costs this winter. Almost half (43%) of home haemodialysis patients are considering going back to hospital/unit based dialysis.

“I have to have both the central heating and an electric heater on, despite recently having the loft insulated – which I did knowing I would be reimbursed [for my home dialysis energy costs]. Now I won’t [be], and my energy tariff is about to change. I don’t know what to do.”

“I keep asking [my] dialysis unit about the bills and they keep fobbing me off... [I’ve] been on dialysis at home for over one year and not had a penny off them. [I’m] really worried over bills making me more ill. It is now affecting my mental health.”

“I’m stuck in bed 24/7 because I live in a very old house, and it costs too much to get warm and to keep it warm.”



The physical impact on the health of people living with kidney disease in the cost of living crisis

When we asked people with kidney disease if they had kept their homes colder than they would like this winter due to worries about the costs, we saw that 95% of people had done so at some point (42% all the time, 29% often, 17% sometimes, 7% very rarely, 5% never).

People with long term conditions need to keep homes sufficiently warm to maintain their health and wellbeing – this is particularly true for people living with kidney failure who receive dialysis to stay alive.



As Dr Sunil Daga, consultant nephrologist, explains: “Colder temperatures can result in net fluid gain in patients on dialysis which in turn affects blood pressure and increases risk to their health. Patients on dialysis often have multiple long term health conditions which can also deteriorate due to colder temperatures. It is important that patients are supported to stay warm.”

Sadly, we heard from a number of people on home dialysis whose health has been impacted by the cost of living crisis:

“With keeping the heating on a lower temperature, I’ve needed seven courses of antibiotics for chest infections and most recently I’ve caught pneumonia. It’s so hard to get better, your immunity is lower with the treatments you’re on and then you can’t afford to put the heating on as much as you’d like. With the electricity I’m still currently getting the government support and dread what it’ll be when that ends. Our income used to allow us a comfortable lifestyle but now we have to be more careful and count the pennies.”

“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.”

“I’m on nocturnal dialysis and find it hard to sleep because I’m too cold.”

“My body temperature drops on dialysis but when you can’t heat your home as well as doing dialysis it’s horrible. My body hurts from the cold.”

Our survey also found that 17% (almost 1 in 5 people) have pre-payment meters installed, including seven of our respondents who were on home dialysis. [Ofgem rules state that suppliers can’t fit a prepayment meter to help manage debts if it is not safe for people to have one](#)⁵ (such as people using a dialysis machine at home). We believe that the guidance should go further and specify that home dialysis patients can rightfully expect their existing pre-payment meter to be removed if they wish.

Simply not good enough

The freedom of information responses we have received show just how much variation there is across England in the reimbursement support received. Trusts are already receiving the funds to cover the cost of reimbursement for additional utility costs which is a right under the home dialysis service specification, and it should not be a postcode lottery.

It’s simply not good enough that some trusts who are reimbursing are either paying below the standard tariff or are not able to say whether they are paying at that rate. **All NHS trusts must ensure that they are meeting their reimbursement obligations in full.**



Kidney Care UK is calling for

- All NHS trusts in England to inform and then consistently reimburse people on home dialysis, fully, fairly and quickly, for the additional utility costs incurred. Policies are in place but too many people are not receiving the money they are eligible to receive. This isn't good enough and it must change immediately.
- NHS trusts, in accordance with the [longstanding home haemodialysis service specification](#)⁶, to ensure their reimbursement policies provide for all additional costs incurred by dialysis treatment, including for extra water consumption and heating. Too many people on home dialysis do not know how they are going to pay their bills. This is not a cost of living crisis, it's a cost of staying alive crisis.
- NHS trusts to keep their home dialysis reimbursement policies and reimbursement rates under review to ensure no one is out of pocket due to them receiving their life saving dialysis at home. If home dialysis is the best treatment for them, then where they live or what their financial circumstances are should not be a factor. This is supported by the first two guiding principles of the NHS: the NHS provides a comprehensive service, available to all and access to NHS services is based on clinical need, not an individual's ability to pay.
- The government and energy companies to work on developing longer term protection for energy customers with long term conditions like kidney disease, including a [new social tariff](#)⁷ to help vulnerable people heat their homes. This should be a protected tariff, cheaper than the price of the cheapest available energy tariff, and targeted at those living in fuel poverty, on a low income or dependent on medical devices.

What you can do about your utility reimbursement

Kidney Care UK is in regular contact with the NHS England team who are leading on reimbursement policies. We are raising specific concerns on behalf of people who are not receiving payments which cover the energy costs of running their machines, or in some cases, are not receiving any payments at all.

If you need more information or support about reimbursement you can:

- Read our reimbursement information at www.kidneycareuk.org/reimbursement
- Speak to your NHS trust to ask them about their reimbursement policies
- If you need support speaking to your trust, one of our Patient Support & Advocacy Officers can help – please contact us on 01420 541 424 or info@kidneycareuk.org
- If your trust is not responding to your questions, you can write to your MP and ask for their support in engaging with your trust. [You can find the details of your MP here.](#)
- You are also welcome to share your trust's reimbursement responses with us via policy@kidneycareuk.org. Using the information we've built up on each trust's reimbursement policy, we will lobby your trust on your behalf

⁶ NHS England home dialysis service specification: <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/a06-serv-spec-haemodialysis-renl-fair-home.pdf>

⁷ The case for a new social tariff: <https://www.nea.org.uk/news/solving-the-cost-of-living-crisis-the-case-for-a-new-social-tariff-in-the-energy-market/#:~:text=A%20social%20tariff%20is%20a,or%20on%20a%20low%20income>

Kidney Care UK's work to support people through the cost of living crisis

Kidney Care UK showcased the acute challenges faced by kidney patients in the face of the pandemic and the rising cost of living crisis by launching the Priced Out of Existence campaign in March 2022.

[We created a film](#) – which was later shortlisted in the Charity Film of the Year category at the Third Sector Awards – and shared this with the media and across social media. The film was viewed thousands of times and helped the charity secure hundreds of pieces of media coverage. This included news stories across the BBC network on multiple occasions, ITV news, all major UK national print newspapers and a front cover story in *The Guardian*.

This high profile coverage led to the specific issues raised by the film being referenced directly by the then Prime Minister in his Good Morning Britain interview in May. The Campaign was also raised directly by Sir Keir Starmer at PMQs on 18 May. Furthermore, we wrote to every MP, meeting and raising parliamentary questions with MPs from all parties. We were instrumental in and [attended a Westminster Hall debate in May](#)⁸ sponsored by Jim Shannon MP where our work was cited repeatedly, and we were subsequently able to brief the relevant Minister, Gillian Keegan. Our work is also covered in the [Parliamentary library](#)⁹.

As a result, Kidney Care UK met with the Department of Health and Social Care in July and

secured a commitment from them that they would ask NHS England to speak to every NHS trust to confirm their reimbursement arrangements. We also received confirmation that NHS Grampian would reimburse patients following our actions raising the issues faced by George, a patient under their care.

In September, we held a cost of living webinar featuring guests from Anglian Water and Citizens Advice. We also ran a survey across the summer months to understand how the issues were affecting the kidney community.

More than 1,000 people shared their experiences with us, which enabled us to create our [Cost of Staying Alive report](#)¹⁰ which we published in November. The findings of this report secured more media coverage and also enabled us to approach utility companies to highlight how the cost of living crisis was disproportionately affecting people with kidney disease. In fact, our fundraising team were able to raise £1m more in 2022 than the year before in recognition of our efforts to explain why the kidney community are acutely impacted by rising utility and food costs.

In the last 12 months, we have secured numerous partnerships with utility firms, including Wales & West Utilities, Anglian Water, Southern Water and Electricity North West. These partnerships enable us to train their staff to better understand how kidney disease impacts their customers, and



Anglian Water have set up a dedicated phone line (0800 232 1962) for people with kidney disease in their supply area to help them ensure they are on the most appropriate tariff. Kidney Care UK is also able to use utility partners' communications with their millions of customers to raise awareness about kidney disease across the UK.

The demand for the emotional, financial and practical support services that Kidney Care UK provides has never been greater. As we witnessed the fear and uncertainty of living through a pandemic being compounded with the biggest cost of living crisis in a generation, we are proud

to have been able to reach and support more patients, their families and carers in 2022 through our patient support services.

This report focusses on the situation in England. Kidney Care UK is actively engaging with nursing staff, NHS leaders, and most importantly people receiving home dialysis across the devolved nations, to lobby for full, fair and timely reimbursement policies and practices.

If you would like to share your experiences with our Policy team for those countries, please contact us on policy@kidneycareuk.org.

We supported 3,028 people in 2022 (an increase of 14% compared to 2021)

180 individuals were supported through our free telephone counselling service in 2022

We gave financial support to 1,499 people through our patient grants, an increase of 26% on the previous year

We saw almost three times as many requests for support with heating and utility bills than in 2021

In 2022, we gave £748,166 in financial grants to help to improve the quality of life of people with kidney disease, and 50% of applications were from people who had not asked for our support before

Sadly, demand for our emergency assistance grants (a £300 one-off payment to meet an immediate need for food, clothing and other essentials) has risen by 78% over the last three years

In the first two months of 2023, we have already seen 48% more applications for financial support compared to the same period in 2022

¹⁰ Cost of Staying Alive report: <https://www.kidneycareuk.org/news-and-campaigns/news/cost-living-crisis-pushing-thousands-kidney-patients-brink/>

When Tracey and her husband both fell ill (her husband with bronchial pneumonia, requiring hospitalisation, and Tracey with a nasty chest infection which lasted six weeks), their monthly electricity bill jumped from £150 to £500 after they needed to heat their home above 7°C. Tracey contacted us:

“[When the bill arrived] I was in shock and had no idea how could pay this. For a few weeks I was in a very anxious state and trying to work out how the hell I was going to pay... I ummed and ahed, called several phone numbers given to me by my electricity supplier, but all they could offer was not going to settle the bill.

“I bit the bullet and contacted Kidney Care UK, hopeful for any help and advice they could give me, and I am so thankful I contacted them, they helped me with £300 towards my bill, which was a massive relief and weight lifted from my mind.

“I really don’t know what or where we’d be without this, I’m extremely grateful and thank Kidney Care UK and all the people who donate and fundraisers who do their magic to enable others to reach out for help and advice when we need it the most. You are all angels in disguise.”

If you are struggling and need support please contact us. You are not alone.



www.kidneycareuk.org | info@kidneycareuk.org

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