



Cost of staying alive

Report 2022

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Why kidney patients are disproportionately impacted by the cost of living crisis

The cost of living crisis is creating a situation where millions of people across the UK are having to make very difficult choices.

For the 3.5 million people living with chronic kidney disease (CKD), particularly those with kidney failure, these choices are becoming increasingly impossible.

When you're struggling to deal with chronic kidney disease, the additional pressures of trying to make ends meet and keeping your utilities on can make life incredibly difficult. If your kidneys aren't working properly, you are likely to feel the cold much more than the average person and the effect of energy price increases will be particularly acute.

The support package put in place by Government provides limited help for some to cope with rising costs but does not address the specific needs of people who face significant additional costs because of their health condition.

It simply isn't good enough.

Last year we gave over £549,000 in grants to more than 1,100 patients and their families. In September and October 2022, the charity has seen an increase of 240% in demand for grants to help people pay their heating bills and an increase of 51% in demand for £300 emergency assistance grants.

There is only so much that the charity can do. We need others to step up and take action now.

We're sharing this report now to encourage action because the kidney community can no longer wait. As every day passes, kidney patients are spending more on fuel or utilities to simply stay alive. Empty promises won't power dialysis machines to keep patients alive, fuel cars or keep houses warm.

Enough is enough.



3.5 million people in the UK have chronic kidney disease (CKD), compared to **3 million people** living with cancer



68,000 people in the UK have kidney replacement therapy and many **feel the cold more** due to anaemia



Of these 68,000, **30,000 people** are on dialysis and **5,000** of them dialyse at home



People on home dialysis **pay more for their water and electricity** because the dialysis machine is very **energy and water intensive**



Home dialysis uses as much as **7502 litres of water per week**. That is the equivalent of **taking 80 showers every 7 days**



It currently costs around **£1,000 per year in electricity** just to run a home dialysis machine. This is **on top of your average home energy costs**

What our community needs to get through this crisis

Ultimately, the government needs to ensure that no kidney patients are disproportionately impacted by the cost of living crisis.

We are calling for:

- The Government to urgently establish an emergency fund providing immediate financial support to cover the costs of running medical equipment at home and the costs for travelling to dialysis treatment this winter.
- The Government to mandate current guidance so that NHS trusts have a straightforward, accessible reimbursement system in place to ensure anyone on any form of home dialysis is reimbursed now for the additional costs of utilities.
- All NHS England Trusts to ensure that they are following Non-Emergency Patient Transport Services (NEPTS) guidance so that everyone who travels to and from hospital for life-sustaining dialysis receives timely and sufficient reimbursement for fuel costs or access to free and reliable patient transport.
- Targeted financial support preventing excessive energy costs for people who use more energy because of chronic kidney disease, once the Energy Price Guarantee comes to an end in April 2023.
- A commitment from the Government to develop longer term protection for vulnerable energy customers, with consideration given to social tariffs and/or schemes similar to WaterSure, which caps costs for vulnerable higher users.

- The Government to honour its commitment to increase benefits in line with inflation and to bring forward that increase so that benefits are better able to cover existing costs of essentials, rather than waiting until April 2023.

Getting cold is a real risk to health for people with kidney disease and without any support, too many will be cold this winter.

We are also calling on utility companies to do more to ensure they are supporting their most vulnerable customers. It's important that kidney patients are signed up to the Priority Services Register¹, a free support service offered by suppliers and network operators, which allows the utility companies to tailor their services to support their customers' specific needs. This means ensuring kidney patients are on the best tariffs and are prioritised for support (such as alternative water or heating sources) and re-connection when there are any planned or emergency power outages.

However, when we asked patients in our survey, only 33% were already signed up to the Priority Services Register and 34% had never heard of it.

1. The Priority Services Register is a free support service, offered by energy suppliers and network operators, to help people in vulnerable situations. Find out if you are eligible, and how to register for the service: <https://www.ofgem.gov.uk/information-consumers/energy-advice-households/getting-extra-help-priority-services-register>

Kidney Care UK and Anglian Water partnership



In June 2022, Kidney Care UK announced a partnership with Anglian Water. We joined forces to ensure those living with CKD receive additional support from both organisations. Approximately 10,000 patients in the Anglian region rely on dialysis, be that in their homes or in hospital.

As part of the partnership, a dedicated phone line was set up. **If you are one of the 870,000 kidney patients who are Anglian Water customers, you can reach their dedicated support team on 0800 232 1962.**

We call on other utility companies to work with Kidney Care UK to take action now and support their vulnerable customers.

"I just feel that I need a break from the house, since Covid-19 and now with the cost of the bills. I don't know if I will ever get away from here... maybe death will come first."



This is no longer just a cost of living crisis for kidney patients - this is a cost of staying alive crisis

Between 15 July and 31 August 2022, 1,042 people responded to our online survey. The views in this report represent a significant proportion of the kidney community, particularly of the 68,000 being treated for kidney failure.

Of the 1,042 people who responded to our survey:

32% were on dialysis

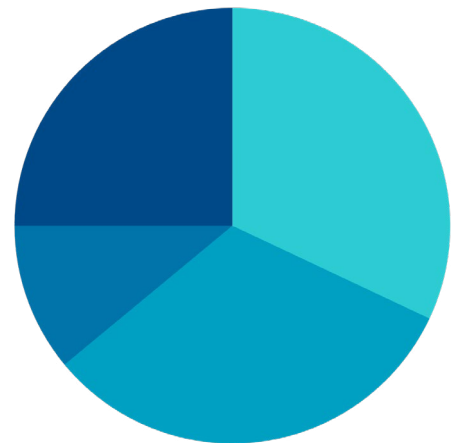
32% were transplanted

25% had earlier stage kidney disease

11% were in kidney failure but not on dialysis

Of those on dialysis: 20% were on in-centre dialysis, 8% were on peritoneal dialysis and 7% were on home haemodialysis.

Just over a third (35%) of patients on any form of home dialysis told us that they receive any payments from their Trust to cover additional utility costs.



Graham



Graham, 52, has stage 4 chronic kidney disease (CKD). He is a former long-distance lorry driver whose job has changed as a result of the pandemic. Combined with his health problems, this has affected how much he is able to spend every month.

“I find it incredibly difficult to heat my home and the recent hikes have more than trebled the cost. I’m concerned about how getting ill could affect my kidney function, which is already low. I’ve started to use thermal curtains and keep the blinds closed in an attempt to keep as much heat in as I can, but it’s a losing battle. It’s a very difficult time for everyone, but every time I hear that energy prices are rising again, I know my battle has just got even harder. **I’m not sure how much fight I have left.**”

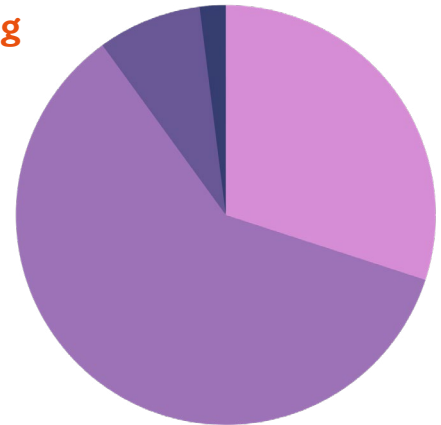
*Graham is a real patient but does not wish to be pictured in this report.

Nearly every kidney patient we asked told us they were worried about rising costs

98% of people are worried about the rising cost of living

60% of those people are worried about it all the time
30% of those people are worried about it sometimes
8% of those people worry about it a little bit

The cost of living increases are clearly having a detrimental impact on the physical and mental health of people already living with the challenges of CKD and there are fears this will get worse.



Nearly 8 out of 10 people (79%) report that the rising costs of living are now having an impact on their physical health, with 1 in 10 (11%) of those people saying this is impacting them every single day.

Nearly 9 out of 10 people (87%) report that the rising costs of living are currently having an impact on their mental health, with 1 in 6 (15%) saying this is impacting them on a daily basis.



"I am scared to do anything due to the costs."



Responding to rising prices

Unsurprisingly, the vast majority of people in our survey (87%) have seen their energy bills already increase in 2022, with many reporting that their bills have doubled or increased by hundreds of pounds. Because of this, people have already made significant cutbacks to the basic necessities of life in response to the cost of living increases:



87% have **turned down the heating** in their homes



65% have **not replaced shoes or clothes** when they have become worn out or too small



44% have **missed meals**, with 1 in 10 saying they have **skipped meals regularly**

No one should be missing meals because they cannot afford food, but doing so can be particularly risky for the health and wellbeing of people with kidney disease.

“No matter what stage of kidney disease you are at, it is vital that you eat a varied, regular and healthy diet. When your kidneys start to fail, you may have to choose different foods to the ones you normally eat. This can mean that the choices and options that were available to you before are now less viable.

“If people are already having to restrict the foods they are eating due to costs, then this further change may impact their health. **Eating a healthy and nutritious diet is vital for maintaining kidney function and basic wellbeing; no-one should be forced to have to miss meals or alter their diet because they are having to choose between heating or eating.**”



Angeline Taylor

Chair of the British Dietetic Association Renal Nutrition Specialist Group

Roxy



Roxy, 36, was diagnosed with lupus, a long-term autoimmune disease that can lead to various different health problems, when she was 18 years old. She currently does dialysis at home and is very concerned about the increase in the cost of living and the impact that it will have on her treatment.

“It stresses me out. I get some help towards electric but there’s a big gap that I’m trying to fill myself. When you’ve got a disability you often feel left out of things with your friends. You can’t go everywhere and eventually the invites stop coming. You can feel quite isolated. If you add to that the cost of everything rising, you become even more limited and isolated. My gas and water bill needs to be paid before anything else because I need to survive. I can’t afford to miss an electric bill and be put on a prepaid meter, which could cut out while I’m doing my dialysis. It’s those things that are at the front of your mind all the time.”

The cost of living crisis risks increasing the social isolation of people living with kidney disease. Many have made the difficult choice to not have time with friends and family or to cancel activities that bring enjoyment and fulfilment to their lives.

- 73% (more than two thirds) have **stopped going out and seeing friends and family**
- 25% (one quarter) have **avoided attending important family events**
- 68% (more than two thirds) have **cancelled holiday plans**
- 24% (almost one quarter) have **stopped playing sports or going to the gym**
- 38% (over a third) have **stopped their hobbies due to the cost**
- 9% (almost 1 in 10) have **cancelled taking further education classes**



Concerns about the colder months ahead

When anticipating the impact of the cost of winter 2022, people are worried they may have to make even more significant changes than they already have.



88% are worried that they will have to **switch the heating off** over winter



82% are worried they will **become physically unwell**



83% are worried about **how they will cope mentally**



68% are worried that they **won't be able to feed their family**



84% are worried that they **won't be able to pay the bills**



70% are worried they **won't be able to buy Christmas presents**

"I get so cold but I have tried to only have the heating on for one hour in the morning and one hour at night"





The struggle to keep warm

Many people are making the difficult decision to not heat their homes as much as they would like this year. People with late stage kidney disease can feel cold all the time, often due to anaemia or the process of dialysis, but keeping homes sufficiently warm is simply unaffordable this winter. As well as the discomfort of being cold, this puts the health and wellbeing of kidney patients at risk.

“The economic downturn and unprecedented major increase in cost of living is a substantial challenge to us all but the consequences fall disproportionately and have a greater impact on those with lower incomes and those patients with chronic disease. This adversely affects those severe chronic kidney disease (CKD) patients requiring dialysis treatment and recipients of a kidney transplant (over 80,000 in the UK).

“Intolerance of the cold is a widely reported symptom of CKD/ dialysis and the ability to maintain adequate winter heating is crucial to patient wellbeing. Cold also increases the risk of serious infection, to which kidney patients are already prone. We recognise home dialysis treatment as the gold standard of treatment for suitable patients. With this comes additional electricity, water and heating requirements.

“I fear that kidney patients will suffer disproportionate deprivation and risk ill health as a consequence of the cost of living increases, both current and anticipated.”



Graham Lipkin

Consultant Nephrologist at Queen Elizabeth Hospital Birmingham and
Trustee of Kidney Care UK and the UK Kidney Association

Fez



Fez, 36, is a qualified youth worker currently volunteering as a patient advocate for organ donation and kidney health. Fez has had three kidney transplants, including one from his father, and had to leave university due to kidney failure.

“I currently live off my benefits and my Personal Independence Payment (PIP). I get about £500 per month and half of that goes on the gas bill, which is about £230 – and they haven’t even raised it for the winter yet! That’s half of my PIP gone. I have to use the rest to cover council tax, food, general living costs and putting petrol in my car.

“I’m lucky enough to live with my mum and brother but when winter comes and costs increase again, it’s going to be really tough. My mum’s almost at retirement age so her income won’t be coming in and we will basically have her pension, my benefit and my brother’s income. She is thinking about carrying on working, which is really difficult to think about. It’s quite frustrating as well; surely we can be doing more as a society to protect the vulnerable. We know these changes are going to happen, so we should prepare support for people in socially deprived areas, those with chronic illnesses or disabilities and the elderly – the people that will suffer the most. This winter people will likely die because they can’t afford to heat their homes. Something needs to be done now, why wait?”

“It’s the winter I am worried about. Our house costs a fortune to keep warm, how am I going to find the money?”



The additional financial costs of chronic kidney disease

Having a long term condition like chronic kidney disease (CKD) results in additional costs which are compounded by the cost of living crisis. Our survey highlighted that:

- 83% of people reported that **having CKD brings additional costs**
- 6 out of 10 people (60%) **said it increased their energy usage**

The most commonly reported additional costs were:

- The need for extra heating to keep warm
- The cost of eating a special diet
- The travel costs to get to and from appointments

Other themes that emerged in the survey comments were:

- Having to warm up dialysis bags
- The need to do extra washing
- Using utilities more due to spending so much time at home
- Costs caused by the Covid-19 pandemic, such as being at home or avoiding public transport.

Costs of travel

Meeting the cost of travelling to and from medical appointments is becoming a significant concern for some. Regular medical appointments are a fact of life for many people living with kidney disease and this increases at specific treatment points, such as the period post-transplant, and is particularly acute for people who travel to a hospital or unit for their three or four sessions of dialysis a week (up to 416 journeys per year).

After working with NHS England as expert advisers to their transport programme, we secured confirmation in May 2022 that the NHS will provide a universal commitment to transport support for all journeys to and from in-centre haemodialysis in England. Trusts have until April 2023 to implement this. **We are still hearing from far too many patients that they cannot access reimbursement and some Trusts are not paying enough to cover the actual costs.** There is further variation across the UK; patients in Wales able to access reimbursement for travel costs to and from dialysis, but in Northern Ireland and Scotland policies vary with some people having to cover the cost themselves. With the average cost of filling a tank around 15% more than it was a year ago for petrol cars and 29% more for diesel, many people are finding it difficult to afford other activities because they have to spend so much on their travel to and from their life sustaining treatment.

Progress is being made in some areas; for example the Midlands network are updating their transport reimbursement policies and working with Kidney Care UK Advocacy Officers to make sure patients get the money to which they are entitled. However much more needs to be done. We are happy to speak to any unit or network about implementing the new guidance.

Costs of home dialysis

Thousands of people running dialysis equipment at home face some of the highest additional energy costs just to stay alive; some say they can no longer sustain this with the current price rises. This is despite home dialysis being recommended by kidney specialists and the NHS as an excellent option, enabling patients to receive longer and slower dialysis which can improve health, wellbeing and long-term outcomes. The flexibility offered by home dialysis also makes it easier for patients to continue with employment or study and it can save the NHS money. However, the cost of running a home dialysis machine could now be over £1,000 per year and, of survey respondents on any form of home dialysis, only 35% told us they receive payments from their Trust to cover additional utility costs.

After we raised these issues through our Priced out of Existence campaign, we secured a commitment from NHS England to ensure that all NHS Trusts provide reimbursement payments to cover the additional energy costs of home dialysis patients. However, these do not cover the whole of the UK or all patients in need of support; for example peritoneal dialysis policies are still in development, as are policies for children on any form of dialysis). Reports from people with kidney disease and Kidney Care UK Advocacy Officers indicate that where reimbursement policies exist, implementation systems may not yet be in place and people are not yet receiving the money they need to cover costs. Even within the same Trust, patients are having different experiences of reimbursement.

Some units are working hard to make it easy for patients to receive their reimbursements. In Salford, they are surveying their patients and have produced comprehensive information to explain what people are entitled to. In Wales, the Clinical Network has provided a spreadsheet so that units can calculate the amount to be reimbursed to patients. The UK Kidney Association have now made this calculator available to all units in England. Although this is a helpful step, it does not include the additional cost of heating the dialysis room. This gap in support needs to be addressed, particularly given the intense cold many feel whilst on dialysis.

Phoenix



Phoenix dialyses overnight five times per week, every week. This year, due to the rising costs, he and his family have effectively turned the heating off at home.

“There’s no escaping the fact that our energy costs will rise even higher – and I’m reimbursed a fraction of the amount it costs to run my machine at home. It shouldn’t be up to charities to help disabled people survive, and some will feel pushed to the edge. Rising fuel costs are making just staying alive even harder and it feels like we’re being priced out of existence.”

Without urgent action from the NHS to make sure home dialysis patients are reimbursed, kidney patients like Phoenix will be putting their health at risk this winter to maintain their life-sustaining dialysis treatment.

Paul



Paul, 60, from Norfolk, is a self-employed, semi-retired car mechanic who has suffered from renal reflux most of his life. He needs to be on dialysis three times per week and, as a result, can no longer work full time. Paul spends roughly 18 hours per week receiving treatment at his local dialysis unit, often feeling tired and run down in the hours afterwards.

“The rising cost of living is impacting everything we do. I drive myself back and forth to the unit because it gives me a bit of independence, but the journey has gone from costing me £30 per month to £60. Due to my health, I’m restricted on what foods I can eat. The increase in food costs, particularly for food that is more expensive anyway, is having a negative impact on my life and health. I can’t work as much as I did, so all of these increases have a big impact. I’m also concerned about the potential increases over winter. As we move into shorter nights, we’ll need to have lights on for longer and have the heating on more and I will start to feel the cold more because of my treatment. It takes you a while to recover after dialysis and your body reacts to the cold.”

The impact of the Covid-19 pandemic

Whilst we didn’t specifically ask people about the pandemic in this survey, the impact it continues to have on our community was clear in the comments we received, with 14% of people directly referencing the fact that they were still ‘shielding’ in their comments.

Fiona Loud, Policy Director at Kidney Care UK, said, “The Covid-19 pandemic continues to affect the lives of kidney patients. There are now increased costs from staying at home and this winter’s energy price rises will highlight this anxiety even further.”

A number of other comments reflected behaviours linked to lockdown, for example ordering food online to avoid going into shops, working from home and avoiding public transport/travel. This mirrors the data released in May 2022, from the Office of National Statistics, highlighting that 13% of immunosuppressed individuals were still following shielding advice.

Unbalanced budgets - higher costs and limited incomes

People with kidney disease often have to meet the additional costs of their condition from a budget that is already overstretched. Kidney disease is more common among people in lower socioeconomic groups and data shows that the employment rate for people on dialysis is just 26%. Around a third of people who responded to our survey were unable to work (33%).

Despite this, our survey showed:

- 63% do not receive means-tested benefits, such as Universal Credit, Income Support, income based Jobseekers Allowance (JSA) or income-based Employment and Support Allowance (ESA)
- 40% do not receive means-tested benefits (like PIP, Disability Living Allowance (DLA) or Attendance Allowance)

This reinforces our experience that people with kidney disease can find it difficult to access disability benefits. Research by our Advocacy Officers shows that in 21 recent cases, only two people were granted PIP (at the standard rate) after initial assessment. After appealing with support from Kidney Care UK, this increased to 13 people being awarded at the standard rate, with a further six awarded the enhanced rate.

Kidney Care UK has joined the widespread call for the Government to honour its commitment to increase benefits in line with inflation and to bring forward that increase so that benefits are better able to cover existing costs of essentials, rather than waiting until April 2023. Unless the benefits uprating is brought forward, including benefits to cover the additional cost of disability, many will be unable to cover the cost of essentials this winter and risk spiraling into debt.

Whilst the Government has put in place a package of support to help people with the cost of living increases, the majority of support is for cost increases affecting the whole of the UK population. There is also a £150 one-off payment for people on certain disability-related non-means tested benefits. However, **40% of our survey respondents were not receiving these benefits and would not be eligible for this one-off payment, despite having chronic kidney disease.** Furthermore, this £150 is not sufficient. Kidney patients are facing additional costs on top of the general increases, and for many, the £150 will not meet these price rises.

The deficit that is left has the potential to leave people already living with the challenges of kidney disease facing impossible choices and going without daily essentials just to meet the costs of staying alive.



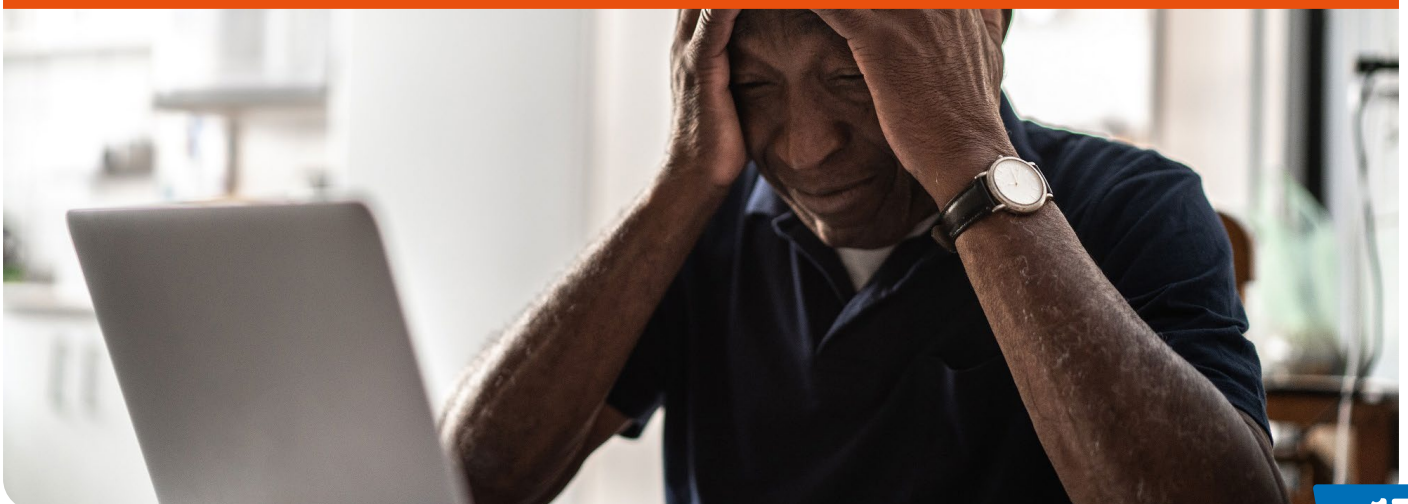
Amit



Amit is 45 years old and lives in Croydon. He has been on home dialysis since 2016 as a result of kidney failure. Amit currently works in London, but he is only able to work part time due to his health. He lives with his retired parents and his wife, who also works part time. They don't receive Universal Credit to help towards rent and bills, but Amit receives some money in the form of Personal independence Payment (PIP) to help manage costs. However, PIP is not enough to cover all costs and necessities. Amit receives just £160 every year from his Trust to cover the costs of dialysis. His latest electricity bill forecast (25 October 2022) was £5,095.86 per year, or £425 per month.

"It has come down to heating, eating or home dialysis – an absolutely impossible choice and one nobody should have to make. I'm also worried about the impact the extra stress is having on my kidney function. I'm concerned that it will come to the point where I won't be able to afford dialysis at home. I fear the hospital will cut back on treatments due to costs and they'll give me two sessions instead of three. That's not good because if I have reduced treatment I could be left unable to cope physically anymore."

"I am no longer able to live in my own home, and have had to move back in with my parents."



The impact of the cost of living on treatment options and patient choices

Kidney Care UK is extremely concerned by reports from people with kidney disease that the cost of living crisis may limit their choice of treatments. Treatments that would be best in terms of health, wellbeing and quality of life may no longer be feasible because of affordability.

Dialysing at home can be the best choice for some people in terms of kidney health and quality of life, but people are now having to consider the financial implications of a choice that would otherwise make a huge difference to their wellbeing. A kidney transplant is the best possible treatment for kidney failure, but we are increasingly hearing from people who are worried about the impact time off work as they recover will have on their ability to pay their bills.

No one should be forced to make decisions that are detrimental to their health and wellbeing due to fears about the rising costs of living.

Dawn



Dawn, 59, has kidney failure and has been on home dialysis for the last eight years. Four years ago, Dawn's hospital spoke to her about doing home haemodialysis because it was found to be more medically beneficial to her health: she would be able to do 20 hours per week, instead of just 12 at the hospital. She was also told that it would save the NHS money and free up more beds and staff. However, despite constant chasing from Dawn and support from her Kidney Care UK Advocacy Officer, as of August 2022 she is still waiting to receive the backdated and current reimbursement she is entitled to for her home dialysis.

“With the increase of cost of electricity and my husband as my full-time carer, we are now finding it extremely hard to cover the extra electricity that we have to use as a result of my dialysis. I know that dialysing at home with my husband keeps me in the best of health while waiting for a transplant, as well as saving the NHS money. But without the help with electricity, myself and others may be forced to move back to having our dialysis in hospital, only receiving a maximum of 12 hours. I hope this doesn't need to happen, as this would be bad for my health.”

*Dawn is a real patient but does not wish to be pictured in this report.

Variation and inequalities

The cost of living crisis impacts kidney patients no matter where they live. Area differences will be influenced by housing stock, prevalence of homes without a gas supply and necessity of car use. There are also differences between UK nations in key policy areas affecting people with kidney disease, particularly those on dialysis. Whilst commitments are in place, we know from patients themselves that this varies and more needs to be done to ensure that there is a lack of inequality and variation across the UK.

Northern Ireland

Dialysis transport costs: support varies depending on Trust. In some areas free volunteer drivers are available and in some areas, only people on certain benefits are reimbursed.

Home dialysis reimbursement: support varies depending on Trust.

Prescriptions: prescriptions are currently free of charge.

Wales

Dialysis transport costs: everyone on dialysis should be able to access transport, whether that is using non-emergency patient transport or receiving reimbursement for fuel costs, regardless of income.

Home dialysis reimbursement: Everyone on home haemodialysis should receive reimbursement for additional utility costs.

Prescriptions: prescriptions are currently free of charge.

Scotland

Dialysis transport costs: support for patient transport varies depending on Trust. In some areas, free volunteer drivers are available and in some areas, only people on certain benefits are reimbursed for transport costs.

Home dialysis reimbursement: support varies depending on Trust.

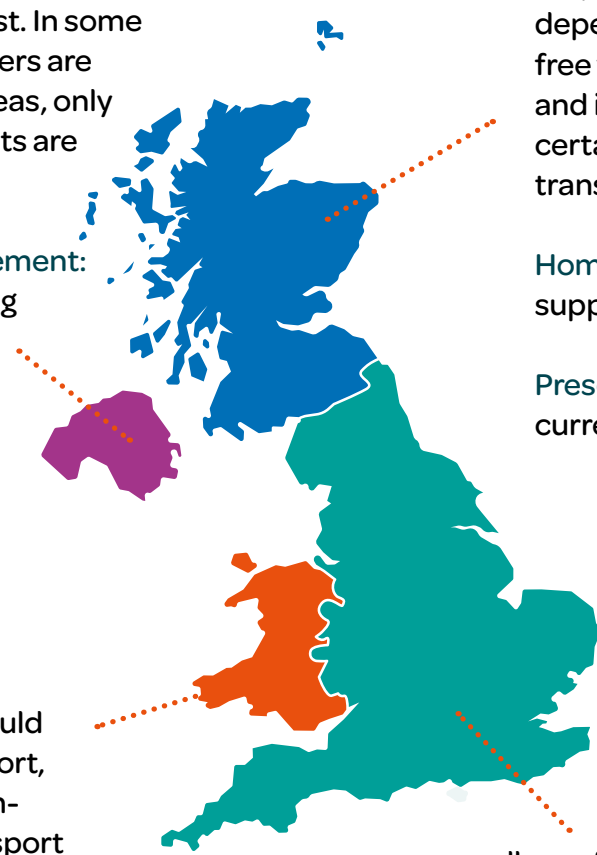
Prescriptions: prescriptions are currently free of charge.

England

Dialysis transport costs: By April 2023, everyone on dialysis should be able to access transport, whether that is using non-emergency patient transport or receiving reimbursement for fuel costs, regardless of income. Some Trusts are already reimbursing patients, but not all.

Home dialysis reimbursement: Everyone on home haemodialysis should receive reimbursement for additional utility costs. This is now being extended to peritoneal and paediatric dialysis. But we know that this is not happening fast enough.

Prescriptions: prescriptions are not free but there are exemptions. Some people on dialysis are exempt from prescription charges, but the guidance is unfairly open to interpretation and people with a kidney transplant must pay for their prescriptions.



“I just feel worthless and helpless. I physically can't work, and I am stuck on benefits. I am barely surviving, and I just don't know where the extra money is going to come from.”

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.

If you would like to speak to your nearest Advocacy Officer, apply for a patient grant or speak to us about our free telephone counselling service you can find out more at www.kidneycareuk.org or call us on **01420 541424**.

Other sources of support

Samaritans: www.samaritans.org

The Trussell Trust: www.trusselltrust.org

Citizens Advice: www.citizensadvice.org.uk

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

www.kidneycareuk.org | info@kidneycareuk.org

01420 541424 | Lines open 9am - 5pm, Monday–Friday

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