

Kidney Care UK: Parliamentary Briefing: Cost of living increases and home dialysis, April 2022

"We have to put effort in just to stay alive. I genuinely believe that the rising cost of living will tip some people over the edge and will cost lives." Person living with kidney disease, UK

Soaring energy costs are 'pricing people out of existence':

- People with chronic kidney disease (CKD), for which there is no cure, already experience financial difficulties due to barriers to employment and additional costs of disability. Kidney Care UK is increasingly receiving calls from people extremely anxious about paying for basic necessities. Kidney patients cannot wait any longer for action.
- People receiving dialysis at home are at particular risk from soaring energy costs, due to the high energy consumption of dialysis machines which are keeping them alive.
- The [NHS Service Specification](#) advises that NHS Trusts reimburse additional costs of home dialysis, but reimbursement is inconsistent across the country and many patients receive none or very little financial support to pay for the additional costs of treatment.
- For most home dialysis patients, the £200 repayable relief on energy bills and council tax deduction will not be adequate. The Spring Statement was a missed opportunity. Consistent reimbursement, longer term capped tariffs for vulnerable groups and immediate financial support are urgently needed.

Key statistics:

- People receiving renal replacement therapy in the UK are more likely to experience deprivationⁱ. Almost half (47%) are in the two most deprived quartiles of the populationⁱⁱ.
- Barriers to employment for people on dialysis (frequency and length of treatment, physical toll of treatment, intense fatigue associated with dialysis and CKD) compound financial insecurity for this group. International studies show employment rates of 18-33% among people on dialysis (no UK specific data available).ⁱⁱⁱ
- There are about 30,000 people with kidney failure on dialysis in the UK^{iv}; many frequently feel excessively cold due to anaemia and the process of dialysis.
- 5,000 people receive dialysis treatment at home, which adds between £593 and £1,454 to utility costs per year (this is before the predicted 54% energy bill rise this year).^{iv}
- A typical household would have to have 75 baths per week (more than ten every day) to consume the same amount of water as a person who has nocturnal dialysis at home.

Home dialysis benefits many patients and the NHS, and increased use is a key aim NHS renal policy programmes:

"[Home dialysis] enabled me to carry on with my A level's, do dialysis at home, socialise with friends and family, and meant minimal time spent at hospital or in the car travelling to and from hospital. It even allowed me to go away for weekends or stay at friends' houses, allowing me to have those normal teenage years..."

[Home haemodialysis patient](#), UK

It is also a cost-effective use of NHS resources. Achieving the Getting it Right First Time ([GIRFT](#)) target of 20% prevalence rate for home dialysis could save the NHS £5m per year.

Home dialysis impacts household utility bills: The additional power and water depends on the dialysis prescription (how much dialysis received), but Kidney Care UK calculates that the annual utility costs of haemodialysis at home are between £593 for 3 sessions a week at 4 hours a time and £1,454 for 5 sessions a week overnight, which is found by many to be the gentlest and most effective treatment. This cost is before the energy cost increases in April and October 2022.

Reimbursement guidance exists but is not applied consistently:

UK Kidney Association [guidance on reimbursement](#) for home therapy is available to support Trusts. The renal service [commissioning specification](#) states that “It is recognised that there may be circumstances when it is appropriate to make a contribution towards a utility bill if:

- A patient is running specialised equipment at home, which would usually be operated in a hospital setting AND;
- There are additional costs of running the equipment over and above the patient’s usual utility bills; AND
- The specialised equipment is the commissioning responsibility of NHS England. In the case of home dialysis, NHS England will meet (through the payment of the national tariff to the patient’s usual dialysis provider) the additional direct utility costs (which may include electricity, water, gas and telephone) by way of a reimbursement to the patient. These costs should be based on documentary evidence such as copies of utility bills before and after the specialised equipment was introduced. The costs should be agreed between the provider and the individual patient.”

Despite this, Kidney Care UK’s Advocacy Team, who offer direct support to people with kidney disease, report that in some NHS Trusts reimbursement schemes are neither discussed nor available to people considering home dialysis.

In addition, the level of reimbursement payments can be insufficient to meet additional annual costs. We are supporting patients who have made the difficult decision to return to dialysis in the unit purely because reimbursement payments are too low to cover the energy costs of home dialysis. This will strain the capacity of already stretched dialysis services.

Inadequate financial support increases stress and removes choice:

The added costs of home dialysis, amid a backdrop of rising costs in many areas of life, renders it an unviable option for many if adequate reimbursement policies are not available. This is in direct opposition to the first two guiding principles of the NHS:

- The NHS provides a comprehensive service, available to all
- Access to NHS services is based on clinical need, not an individual’s ability to pay

On 31st March 2022, when asked about Government plans to mitigate the potential effect of rising energy costs on health inequalities for people with kidney failure receiving home dialysis treatment, Rt Hon Greg Hands MP referred to the energy price cap, the £200 loan and £150 council tax discount for some households, as well as schemes such as the Warm Home Discount, Winter Fuel Payments and Cold Weather Payments. This support will provide limited help for some to cope with rising energy bills, but does not address the specific needs of people who face significant additional costs because they are paying to run life-saving medical equipment at home. The loss of the Warm Home Discount for many people receiving certain disability benefits will further increase the financial stress this winter for people living with a disability, particularly in light of further price hikes in October 2022.

Kidney Care UK calls for Government and NHS Trusts to act urgently:

- NHS trusts should ensure a straightforward, accessible system is in place to enable people on home dialysis to be reimbursed for additional cost of utilities, as set out in UK Kidney Association guidance.
- NHS Tariff payments for home dialysis must be sufficient to cover all associated costs, including reimbursement for additional utilities usage.
- Government should work with energy companies to develop capped tariffs for people on medical treatments at home such as dialysis for many hours a week. The precedent is set by the WaterSure scheme, which caps water bills for people in receipt of certain benefits who are high water users because of medical need.
- The Government response to cost-of-living increases and predicted energy costs rises must consider the impact on people with long term conditions who receive medical treatment in their own homes, and ensure any solution meets their specific needs. We recommend the 'Extra Costs Taskforce' addresses the disproportional impact of rising energy costs on this group as a matter of urgency.
- Government should also develop additional targeted support for vulnerable energy customers, such as social tariffs and crisis financial support, prior to the additional energy price increases due in October 2022.

In 2021, Kidney Care UK gave £549,000 in grants to more than 1,100 patients and their families. We saw an increase in demand of 47% for our immediate hardship grants of £300. We are expecting a significant increase in requests for hardship support this year; many patients have raised concerns on social media about how they will be able to cope. Having listened to our beneficiaries, we have made a conscious decision to do more to support more patients at a time when our community needs more help than ever. No one should face a choice of heating or eating, or feel excluded from home dialysis because they cannot afford it.

Our online hub provides guidance and support – please share with your constituents
<https://www.kidneycareuk.org/get-support/cost-living-hub/>

For more information about any of the issues raised in this briefing and to discuss how you can help, please contact: Fiona.loud@kidneycareuk.org or visit our website at www.kidneycareuk.org

References:

ⁱ Guthrie G & Bell S. Deprivation and kidney disease—a predictor of poor outcomes. *Clinical Kidney Journal*, 2020, 13 (2) 128–132, <https://doi.org/10.1093/ckj/sfz151>

ⁱⁱ <https://ukkidney.org/audit-research/data-portal/demographics> (accessed 210422)

ⁱⁱⁱ Hallab A & Wish J. Employment among patients on dialysis. *CJASN*, 2018, 13 (2) 203-204; <https://doi.org/10.2215/CJN.13491217>

^{iv} <https://ukkidney.org/audit-research/annual-report/23rd-annual-report-data-31122019> (accessed 210422)