

Dear Mr Hunt

I am writing to you in my capacity as Director of Policy at Kidney Care UK, the UK's leading kidney patient support charity, to share Kidney Care UK's new [Cost of Staying Alive](#) report which issues a stark warning that thousands of kidney patients' mental, physical, and financial health is at risk, unless Government takes immediate action. We believe the forthcoming Autumn Statement represents a key opportunity to address these issues.

Our survey of over 1,000 UK kidney patients found:

- 88% of respondents are worried they will have to turn off the heating over winter.
- 87% of survey respondents report that having CKD increased their costs, even before the cost-of-living crisis
- 83% are worried about how they will cope mentally
- 68% are worried they won't be able to feed their family
- 44% of patients had already missed meals

The cost-of-living crisis is affecting everyone, but people living with long term conditions such as kidney disease are particularly at risk. Their condition means they frequently have to spend more on keeping homes warm (many people with kidney disease feel cold all the time), eating a special diet and regular travel to hospital appointments. This is often on a limited income, because maintaining full time employment while living with kidney disease can be very difficult. Some of the highest costs are faced by **people who run life maintaining medical equipment at home**. Only 35% of our respondents on home dialysis received any reimbursement and are therefore paying to run the equipment themselves.

The £150 which the Government provided in its package of support for the additional costs of disability was welcome, but for many this is simply not enough to cover the additional costs they must bear because of their health condition. The energy price guarantee has also helped but will end in April 2022 and vulnerable customers need some reassurance of ongoing support.

Kidney Care UK is therefore issuing the following calls for action:

- Targeted financial support that prevents people who use more energy because of CKD, facing intolerably high energy costs, 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 they may cover the essential costs individuals face now, rather than waiting until April 2023.
- The Government to establish an emergency fund providing immediate financial support to cover the costs this winter of running medical equipment at home and travel to dialysis treatment centres.



- The Government to mandate current guidance that NHS trusts have a straightforward, accessible reimbursement system in place as a matter of urgency so that anyone on any form of home dialysis is reimbursed fairly and promptly 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.

We would be very happy to meet to discuss further or supply further information.

Yours sincerely

Fiona Loud
Policy Director