

One charge too many

The impact of rising energy costs on people at the end of life.

Across the UK, thousands of people living with terminal illnesses rely on medical devices that they use at home. Medical equipment – including ventilators, suction machines, and powered hospital beds – plays a vital role in preserving people’s health, comfort, and dignity in their own homes towards the end of their lives.

However, the cost of running these devices typically falls on terminally ill people and their household, rather than the NHS. Although people who use some medical devices (such as oxygen concentrators, and some forms of dialysis in England) receive a rebate or reimbursement for their costs, those who use other medical devices do not receive any help at all.

Marie Curie research has uncovered the huge financial impact of terminal illness, with 90,000 people dying in poverty in the UK every year. The cost of running essential at-home medical equipment is yet another expense for those already under serious financial pressure. After the cost of running medical equipment, and their other increased heating and power needs,

dying people’s energy bills can be 75% higher than the average household’s.

A household that includes a terminally ill person who is using a common medical device may see their monthly energy bills rise 7% above the average household if they have an electric bed, 16% if they are receiving at-home dialysis, 21% if they are on a ventilator, and as much as 38% more if they are receiving oxygen concentration. People using multiple devices will see these running costs stack up to more significant charges.

“My nebuliser is essential to help with my breathing, but I am on a prepayment meter, so when I can’t afford to top up my electricity I can’t use the heating, lighting or my nebuliser.”

- Darren, Lincoln

A terminally ill person’s energy bill can rise by **75%** after their diagnosis.

84% of Marie Curie staff have cared for patients who were struggling with the cost of energy.



The cost of running an oxygen concentrator can be **£65 per month**, a dialysis machine **£27 per month** and a ventilator **£35 per month**.



Most terminally-ill people receive no support to run at-home medical equipment, so could experience increased risk of unplanned hospital admission. The average cost of an NHS inpatient palliative care bed is **£349 per day** – more than five times the cost of running most at-home medical devices for a month.

Helena's Story

"I've got Crohn's disease, and I've only got 50 to 70 cm of small colon left after having 26 surgeries. My bowel at the moment is incompatible with life.

"I'm on TPN (Total Parenteral Nutrition), which gives me the vitamins, minerals and nutrients that I need to survive. I'm on it four nights a week for 12 hours at a time, and then I have to charge everything up the next day. My scooter has to be charged as well, because I can't walk very far.

"My electricity has gone through the roof. I'm constantly watching the smart meter, constantly watching what I'm using every day.

"Because my TPN is expensive to run on top of everything else, I have had to cut back severely in other areas. Mainly on food.

"The Government's given us this little bit of £301, but that's gone on my trips to and from the hospital and all the other expenses that I need. I don't go anywhere, I don't go out with friends because I just can't afford it.

"If people in my position did get a little financial support for things like this, it

would just take a lot of pressure and a lot of worry away, knowing that there is some hope out there, that we're not just being left or forgotten."

With UK energy prices having risen substantially in the last few years and continuing to be historically high, we are concerned that some households affected by terminal illness are struggling to meet these unavoidable running costs.

This is leaving some with an awful, and potentially life-threatening decision – do they cut back on other essentials like heating and food, or do they ration their use of their prescribed equipment?

Without targeted support, people with a terminal illness could experience:

- **increased need for treatment in hospital** if they can no longer afford to power equipment at home
- **increased risk of unplanned hospital admission** if their condition has deteriorated due to limiting the use of their equipment, or heating and food
- **an impact on their health and wellbeing** if they can't use the equipment they need, are forced to cut back on other expenses like heating and food, or become stressed due to rising bills and debt.

In most cases, the costs of powering at-home medical devices are paid for by patients themselves. Limited rebate schemes exist across the UK for oxygen concentrators and dialysis machines, but without a consistent nationwide policy in place, eligibility for reimbursement can be a postcode lottery.

Only 23% of Trusts in England were able to return data to Marie Curie on patients using devices such as nebulisers, oxygen concentrators and ventilators. There is no national policy in place to record these numbers and there are no rebate or reimbursement schemes for most of the at-home medical equipment. This leaves patients struggling to afford to charge their electric wheelchair or using their oxygen concentrator only when absolutely necessary in order to keep energy bills as low as possible while struggling with a terminal illness.

This can mean that even those who may be entitled to some reimbursement of their costs may not see the full amount returned, and many patients will be left out of pocket for months before they are paid back in arrears.

We are also concerned that many NHS Trusts have been unable to provide any data to Marie Curie on the number of patients in their area using medical devices in their homes.

What is Marie Curie calling for?

Nobody should die in poverty – and nobody should spend the end of their life worried about the cost of powering the vital medical equipment they need.

Taking action to make energy bills affordable for terminally ill people will ensure that instead of worrying about making ends meet, they can focus on what matters most – making memories with their loved ones and living as well as they can for as long as they are able.

Improving support with the cost of running medical devices

- The Department of Health and Social Care (DHSC) should improve how the cost of running medical devices is refunded to terminally ill patients so that this cost is met by the NHS in England and not patients themselves.
- The DHSC should look to extend rebate schemes to other medical devices and explore how terminally ill patients can be credited upfront for the energy their devices will use
- NHS Trusts should be required to record and report information on the number of patients in their area who are using medical devices at home.

A Social Tariff on energy prices

- The Department for Energy Security and Net Zero and Ofgem should consider the introduction of a Social Tariff on energy prices for those most in need.
- All households including a person living with terminal illness must be eligible for a Social Tariff – to recognise the additional costs they face as a result of their condition.

“Without the oxygen concentrator and nebuliser my wife would have passed away sooner, but there was a major increase in my household bills. The cost of keeping her alive came out of money that was meant to help her quality of life.”

- Paul, St Ives

Marie Curie is the UK’s leading end of life charity. We work hard to provide a better life for people living with any terminal illness, and those closest to them.

We offer expert, hands-on care across the UK in people’s own homes and in our nine hospices. Last year, we supported more than 50,000 people across the UK at the end of their lives.

Our free information services provide practical information and expert support on all aspects of life with terminal illness, dying and bereavement – including benefits and finances.

We are the largest UK charitable funder of palliative and end of life care research, and we campaign inside and outside Parliament for the policy changes needed to create a better end of life for all.

Want to know more?

Read our full report on terminal illness and energy costs.

mariecurie.org.uk/povertyreports