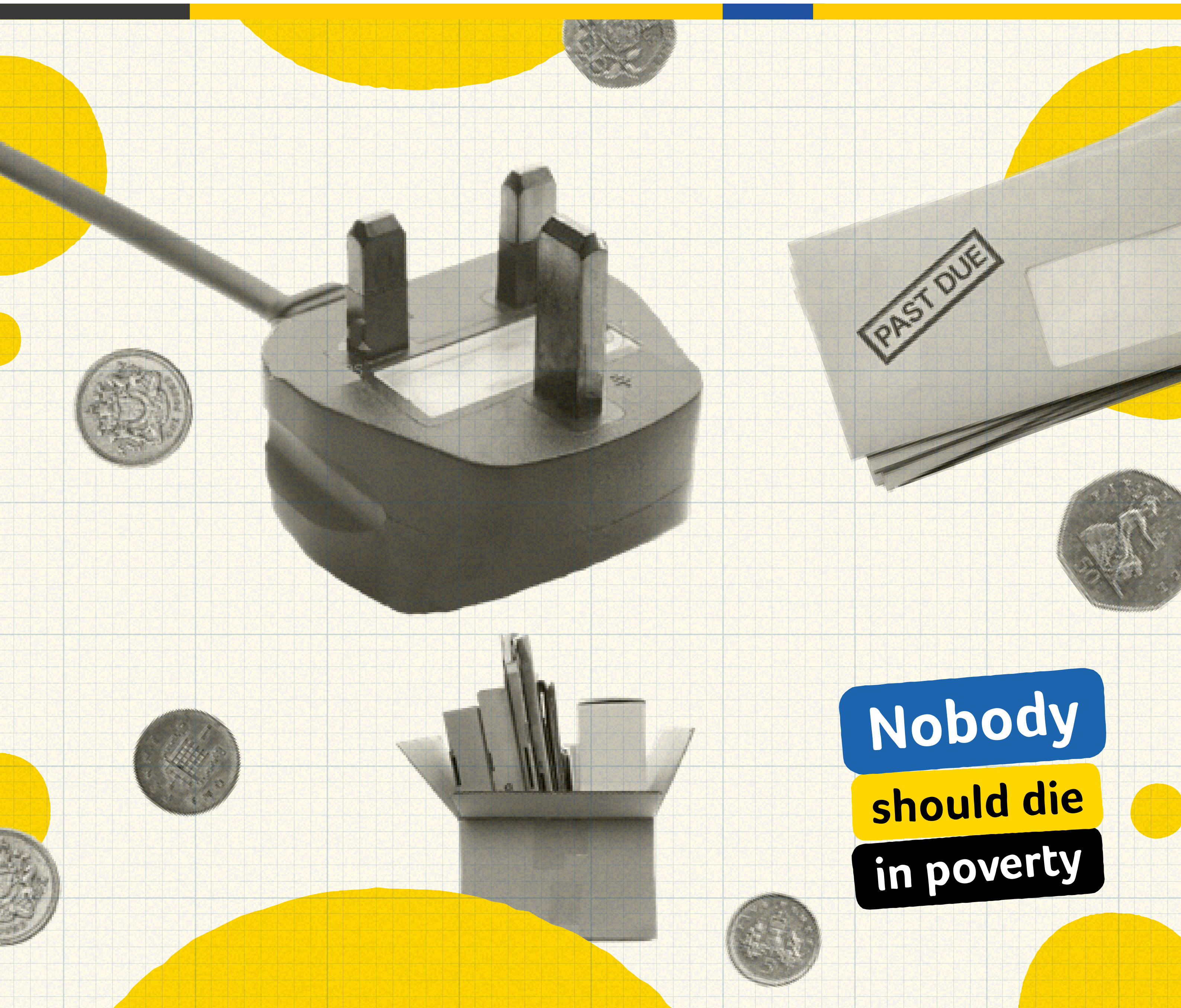
One charge too many

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



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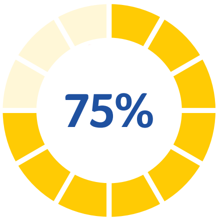
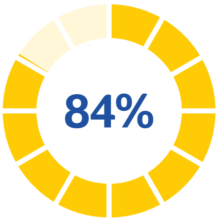


A terminally ill person's energy bill can rise by **75%** after their diagnosis.

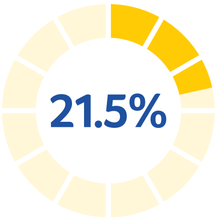
Average UK energy bills rose above **£2,000 for the first time** in 2022 – meaning a person with a terminal illness could be paying as much as **£3,500 a year** for energy.



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**.

Around **150,000 people** die at home in England and Wales each year from conditions that are commonly treated with medical devices.



21.5% of excess winter deaths can be attributed to living in a cold home.

The average cost of an NHS inpatient palliative care bed is **£349 per day** – more than **five times the cost** of running most medical devices for a month.

Executive summary

The financial impact of terminal illness can be devastating – from lost income to increased costs caused by the condition, in the aftermath of a terminal diagnosis many people face drastically changed financial circumstances and an increased risk of financial insecurity. Every year across the UK, more than 90,000 people die in poverty.

In addition to new costs like paying for medications, travel to hospital appointments and the cost of care, perhaps the sharpest cost that many families affected by terminal illness face is rising energy costs. New and higher energy needs brought on by terminal illness – the need to keep the home warmer or cooler for longer in order to stay comfortable and healthy, using mobility aids and assistive technology, or storing medications at the right temperature – can lead to a dramatic increase in the energy bills of people living with a terminal illness, and their households.

Even before the cost of living crisis, and the historically high energy prices which the UK has experienced in recent years, many families affected by terminal illness were struggling to afford the cost of energy. With the average UK energy bill rising above £2,000 a year for the first time in 2022, people with a terminal illness – who have higher energy needs than the average household – have been hit particularly hard.

A person's energy bill can increase as much as 75% after a terminal diagnosis, compared to before they were diagnosed – meaning many terminally ill people could have been paying as much as £3,500 a year for energy last year. This increase often comes just as people are forced to give up work due to their condition and have less money coming in, and as they may have new costs to pay as well as a result of their illness.

For many people living with a terminal illness, even receiving the care and treatment they need comes at a cost. Those who rely on at-home medical devices – such as ventilators, oxygen concentrators, dialysis machines or other devices – to manage their condition and symptoms at home, often find that the cost of powering these devices is significant. Compared to an average household, powering these devices alone might add anywhere from 13% to 32% onto the cost of a terminally ill person's energy bill.

Estimating the number of people using at-home medical devices in the UK is challenging – Marie Curie has found a concerning lack of data is held by NHS Trusts on the number of their patients using common medical devices. As an alternative we have considered the number of people who die at home from conditions where common care and treatment includes at least one common medical device; in England and Wales last year nearly 150,000 people died at home from these conditions – and it is likely that many more people who ultimately die in hospital or a hospice will be cared for at home for some time before they die. Further research in this area should be a priority.

While rebate and reimbursement schemes exist for oxygen concentrators and dialysis machines in the UK, the administration of these schemes is inconsistent between the UK nations and across individual nations, and often leaves people out of pocket for months until refunds are paid. For those who rely on other devices at home there is no rebate scheme at all.

The impact of high energy bills on people with a terminal illness and their families can cause significant financial strain, leading to families running down savings and going into debt to keep their homes warm and vital medical devices powered. For some, meeting these costs can force them into choosing between heating their homes and eating or paying other expenses, and building up a 'debt legacy' for their loved ones when they are gone.

In addition to this financial burden, the impact on people's health and wellbeing at the end of life is also stark – being unable to afford to keep their homes warm can leave people with a terminal illness at risk of increased pain, infections and other complications, as well as increased levels of stress, anxiety and depression. In the most extreme cases it may even hasten their death – as many as 21.5% of excess winter deaths each year are directly attributable to the impact of living in a cold or damp home; more than 3,000 across the UK in the last year alone.

For many, being unable to afford their rising energy bills can mean that they are unable to be cared for or die at home – where two-thirds of us would prefer to die. Healthcare charities have warned that the cost of powering medical devices may cause more patients to seek treatment in hospital instead of at home. While the health and wellbeing impacts of living in a cold environment could lead to more people with a terminal illness experiencing unplanned hospital admissions – at a cost to the NHS of £349 per day, according to the latest research from the Centre for Health Economics.


Helena Reynolds uses a prescribed intravenous nutrition feeding device in her home. Read more about her experiences on pages 7-8.

Too often, people with a terminal illness find that they are unable to access sufficient financial support to meet the rising energy costs they face. Those who are of working age are ineligible for the Winter Fuel Payment and can face difficulties accessing the Warm Home Discount scheme, while emergency cost of living support from the UK Government via the Energy Bill Support Scheme and the Energy Price Guarantee has now been withdrawn – without a targeted replacement for terminally ill people and other vulnerable people.

Even as energy prices fall from their peak at the end of last year, the cost of living crisis has not gone away for people with a terminal illness. For many, their energy costs remain unaffordable. It is clear that targeted support with the cost of energy would significantly ease the financial burden that high energy bills place on people with a terminal illness and their families – it may also help allow people to be cared for at the end of life in their own homes, reducing pressure on NHS hospitals. With energy prices remaining historically high, action in this area should be a priority.

Nobody should die in poverty – and nobody should spend the end of their life stuck in a cold home, worried about the health risks of turning the thermostat down to save money, or the cost of powering the vital medical equipment they need. Taking action to make energy bills affordable for people with a terminal illness 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.

This report aims to start a discussion with government and policymakers on the impact of high energy costs among people with a terminal illness and what can be done to better support them with these costs, as well as suggesting action to improve to existing rebate schemes for the cost of running at-home medical devices. Due to data limitations, this report makes recommendations only in relation to England, however we hope its findings will also be of interest to policymakers considering these issues in the rest of the UK.

Summary of recommendations

1. 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.

2. 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.

Helena’s story

Helena Reynolds, living in Essex, uses a prescribed intravenous nutrition feeding device in her home. Here she shares her experience managing the cost of running these devices.

I’ve got Crohn’s disease, and I’ve only got 50 to 70cm of small colon left after having 26 surgeries. My bowel at the moment is incompatible with life. And they’ve told me that they are going to try and do another operation, but it might not work. I might not survive it, but either way I won’t have a chance if I don’t try to have this operation.

I’m on TPN [Total Parenteral Nutrition] right now, 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 while I’m not on my machines the next day. My scooters have to be charged as well, for when I go out, because I can’t walk very far.

Financially, TPN has had a massive impact. My electricity has gone through the roof because of everything I’m having to charge up, and also because the amount of baths I’m having to have. I have to keep warm and I can’t get cold because if I get too cold I can’t function, I get really tired and I’m up in pain. But I don’t have any choice, I have to do that otherwise they’ll find me dead in bed because I won’t wake up. It’s as simple as that.

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, because I’m on a special diet. I have to make my own soups and stews and I have to have full cream milk, full cream yoghurts and butter. I’m not allowed anything else because my body doesn’t absorb everything, but it takes a little bit at times when it’s working.

So I make all my own foods, and then I have to blend it into baby food. So the cost of living’s really hit me hard. So what I’ve done today, I’ve been and bought some ham shanks and I’ve made soup and I’ll blend that and I’ll put it in the freezer and I batch cook, so I’ve got a meal for when money’s not available.

I bought an air fryer to try and see if I could

> *“I have to keep warm and I can’t get cold because if I get too cold I can’t function.”*

save money on things like that. I just do what I have to do but I'm on my own. I worry about families who've got disabled family members and children. How on earth are they coping? I've no idea.

The Government's given us this little bit of £301, but that's gone away for my trips to and from the hospital and all the other expenses that I need. I can't use that on anything else. So, you know, it's really hard. I don't go anywhere, I don't go out with friends, I don't go out for drives anymore, because I just can't afford it.

My mental health really suffers and sometimes I think maybe I'd be better off not being here. It just makes me feel like I'm a burden on the state. When I've gotten stuck, my daughter would always help me. She's a nurse prescriber up in Lancashire, she said, "Mummy, I don't want you cold, I don't want you struggling, you know, promise you'll call me". I'm constantly watching the smart meter, constantly watching what I'm using every day. And I really don't know what's going to happen in the future.

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 we can plan for the future, that there is some hope out there, that we're not just being left or forgotten.

> *"I'm constantly watching the smart meter, constantly watching what I'm using every day. And I really don't know what's going to happen in the future."*

Higher energy bills at the end of life

Households that include a person with a terminal illness typically have higher energy needs than households that are not affected by terminal illness, leading to energy bills that can be substantially higher than an average household. While estimates vary, one study estimated that people with some terminal illnesses **may see their energy bills go up as much as 75% compared to before they were diagnosed[13].**

Additional heating and cooling needs

Many terminal illnesses, and the treatments for them, can make patients more susceptible to changes in temperature and especially to the cold. Exposure to cold conditions can lead to numerous effects which negatively impact the health and wellbeing of people living with terminal illness, including:

- causing additional pain, stiff joints, and neuropathy and exacerbating arthritic and rheumatic pain[14]
- constricting the airway, leading to breathlessness and reduced resistance to infection in people with respiratory conditions[15]
- encouraging damp and mould to grow, leading to allergies and upper respiratory tract infections[16]
- increasing blood pressure and plasma fibrinogen levels, leading to an increased risk of hypertension, thrombosis, heart attacks and strokes[17]
- increased levels of anxiety, depression, and stress[18].

While an increased risk of infection or complications might be relatively manageable for a healthy person, for somebody living with a terminal illness – who may already have lost weight or have a weakened immune system due to their condition or treatments such as chemotherapy – these risks can be dangerous[19]. Terminal illnesses can also lead to reduced mobility and activity, slowing body heat generation and conservation[20], meaning people with a terminal illness feel the cold more, and are more at risk of the above complications in a cold environment. Finally, living in a cold home has been associated with slower recovery following a discharge from hospital[21].

In other cases, the symptoms of terminal illness can lead to fever and sweating, making people with a terminal illness feel hot. Many cancers, for example, cause neoplastic fever which leads to sweating[22], while treatments such as opioids or hormone therapies can also lead to problems with temperature regulation. In such cases, patients may need to use air conditioning or fans to stay cool and keep their temperature down.

People living with a terminal illness therefore often find that to stay healthy and comfortable they need to heat and/or cool their homes to a greater degree, and for longer than before, as their condition progresses and their health deteriorates. The importance of ensuring that they stay at the right temperature also means that people with a terminal illness are less able to 'ration' their use of heating and cooling than an average household might be, in response to increasing energy prices.

> *"I use a stair lift to get around my home, an electric wheelchair, a small refrigerator for my meds and I need extra heaters and fans. My bills have doubled and that made it a very hard winter. I spent most of the winter in bed, and my hospital admissions increased. I was even in hospital over Christmas."*
>
> **- Emma**

Other additional energy requirements

Living with terminal illness can lead to other needs that require higher energy use than an average household's, and therefore lead to further pressure on energy bills.

Many people with a terminal illness who are being cared for at home will need to store medicine in the home. Most medication must be kept at a specific temperature – typically between 2°C and 8°C – to maintain its stability and effectiveness[23]. Maintaining a constant temperature for stored medication is critical – even a short period at either room temperature or sub-zero temperatures can degrade medications and make them less effective. For this reason, and to prevent the risk of cross-contamination by food, many people who take medication at home store it in a separate refrigerator, which must be powered constantly to ensure that their medicine always remains within a specific temperature range.

People living with many terminal conditions will also find that they need to use washing machines and tumble dryers more frequently, to ensure that their clothes and bedsheets are clean, and also use more hot water to wash and clean themselves more frequently. This may be due to kidney or bladder dysfunction caused by their illness, or to reduce the risk of germs being transmitted if their immune system is compromised by their condition.

The symptoms of many common terminal illnesses include reduced mobility and increased frailty, especially as conditions progress[24]. In order to remain at home and be as independent as possible, many people with a terminal illness will have adaptations made to their homes to help them deal with these mobility issues – such as stairlifts, hoists to help them get in and out of bed or the bath, or alarms to alert a carer or healthcare provider in the event of a fall. These adaptations are not only often expensive to install, but need to be powered constantly once they have been installed.

> *"My electric wheelchair, nebuliser and powered hospital bed make my mobility so much easier to deal with, but we have had to really cut back on other things, such as food, to pay for the increased cost."*
>
> **- Jacqueline**

Many people living with a terminal illnesses who find that their mobility is affected will also spend more time at home than before. As well as their additional heating requirements, they may find that they are increasingly using electrical devices such as televisions, computers, and mobile phones for leisure and to stay connected with family and friends, whereas before they might have participated in other activities[25].

Finally, many people living with a terminal illness will need to use assistive devices to help them stay in their homes and remain independent. These may range from 'smart home' technology to help people with disabilities or mobility issues to control their lighting, heating, and other household needs, to devices that support with speech and communication for people who struggle to communicate due to their condition[26]. Again, these devices often need to be constantly powered or regularly charged.

Challenges managing higher energy costs

Often, the additional energy needs brought on by terminal illness come just at the point that a person with a terminal illness and their household become less able to meet the increased cost of these needs.

For those who become terminally ill at working age, the combined impact of increased costs and income loss leads to a 'double burden' on household finances that leaves many households struggling to make ends meet. Four in five people living with some terminal illnesses experience income loss because of their condition[27], and two in three people with a terminal illness rely on welfare benefits as their main or sole form of income[28]. For retired people, the additional expense of higher energy bills may come at a time when their income has fallen compared to when they were working, or they are on a fixed income from pensions or other savings, meaning they are unable to absorb this additional expenditure.

As Marie Curie's report Dying in Poverty, based upon research from the Centre for Research in Social Policy at Loughborough University, found in 2022, these impacts can drive families affected by terminal illness below the poverty line. 90,000 people in the UK die in poverty each year – one in four of those who die within working age and one in six of those who die in retirement spend the last year of their lives in poverty[29]. Coming out of the workforce – and coming to rely on the benefits system for income as costs rise due to illness – was found to be the single biggest predictor of a fall below the poverty line in the aftermath of a terminal diagnosis.

> *"My powered hospital bed helps to position me so I am not in pain. I'm terminally ill so we rely on my husband's wage now, and we have struggled with the bills going up."*
>
> **- Vicky**

Energy costs are not the only new, or enhanced, cost that people with a terminal illness face. The cost of paying for necessary medications, travel to hospital and other medical appointments, and paying for help with care, are all significant new expenditures for many people with a terminal illness and can lead to significant financial strain on a household's budget[30]. Other household costs may also go up – such as food and grocery costs if a person's condition requires them to eat a special diet to stay healthy. These additional costs can put further strain on a household's budget and mean that higher energy costs are even more difficult to endure.

The cost of meeting the additional heating and cooling needs many people with a terminal illness have will be exacerbated if they are living in older or energy-inefficient housing. Only around 30% of UK homes meet Energy Performance Certificate (EPC) band C[31], with less well-performing homes being more energy inefficient and more expensive to heat, leading to households paying higher energy bills. These challenges are particularly acute in rural areas, where a higher proportion of homes are less energy efficient and are more likely to be using 'off-grid' fuel sources[32]. People with a terminal illness who are living in older, rural, or otherwise energy inefficient homes, may find that as their energy needs go up due to their condition, their energy costs rise even faster than they do amongst other groups.

The cost of running medical devices at home

Many thousands of people living with a terminal illness rely on medical devices that they use at home. Medical equipment – such as oxygen concentrators, ventilators, home dialysis machines, 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.

For many, being able to receive treatment for their condition at home is the critical deciding factor in whether they can stay at home at the end of life – where two-thirds of people say they want to spend the end of their lives[33] – or have to go into hospital or another acute care setting.

More often than not, however, the cost of running these devices falls on people with a terminal illness and their household, rather than on the NHS. While people who use some medical devices (such as oxygen concentrators[34] and some forms of dialysis[35] in England, Wales and parts of Scotland) receive a rebate or reimbursement for their costs, those who use other medical devices do not receive reimbursement for the cost of running them.

> *"Without this equipment my husband would not have been able to spend his last days at home with his family, but we had to cut back on other things as the gas and electric prices increased so much."*
>
> **- Gail**

How much does running medical devices cost?

The cost of running these devices can be a significant additional burden on a household's energy bill – in addition to the other factors that affect terminally ill people's energy costs as outlined earlier in this report. While it is challenging to comprehensively determine the cost of running a medical device for an individual, as this will depend upon their usage of the device and their energy tariff, we are able to make indicative estimates – Table 1 estimates the potential monthly cost of using some common at-home medical equipment, based on typical UK energy prices and usage assumptions for those devices.

Based on the average UK electricity bill, capped by the Ofgem price cap, of £172.88 per month (£2,074 per year)[36], and depending on the medical device they are using, a household that includes a person with a terminal illness may therefore see an additional monthly energy cost equivalent to **6.9%** over an average household if they have an electric bed, **15.8%** if they are receiving at-home dialysis, **20.6%** if they are on a ventilator, and as much as an extra **37.8%** more than the average household if they are receiving oxygen concentration.

Table 1. Common medical device running costs

Device	Energy consumption per day (kWH)[a]	Assumptions[b]	Monthly Energy Cost (£)[c]
Electric wheelchair	0.36	Used for four hours each day. Fully charged batteries expected to hold a charge for several hours, with a potential range of approximately 10-20 miles.	3.56
Ventilator	3.60	Ventilators run for 24 hours a day for most patients.	35.64
Oxygen Concentrator	6.60	Wattage depends on size, usually falls between 275 and 600 watts. Long-term oxygen therapy improves the prognosis for people with COPD when given for 15 hours a day or more.	65.34
Haemodialysis machine	2.76	Performed six or seven days a week for about two hours each time.	27.32
Nebuliser	1.00	Dose is given as a single administration, or as two 1mg doses separated by 30 minutes. Repeated every 12 hours for a maximum of 36 hours or until clinical improvement.	9.90
Body drier	3.30	Most mid-size dryers are around 2500 watts.	32.67
Electric beds	1.2	An electric hospital bed typically consumes 50 watts of power. The bed is plugged in constantly to lift the patient as needed.	11.88

If a person with a terminal illness needs to use more than one medical device – for example, they may require an electric bed and an electric wheelchair as well as an oxygen concentrator or ventilator, depending on their condition and their symptoms – then the costs of running multiple devices will stack up and leave them with even more significant costs.

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a. Power rating (watts) of the device x Amount of time (hrs) device is used ÷ 1,000.

b. Analysis conducted on behalf of Marie Curie by KPMG

c. Based upon electricity price of £0.33 per/kWh – Department for Energy Security & Net Zero. Policy Paper: Energy Price Guarantee. May 2023.

> *"My son's suction machine, electric wheelchair, powered hospital bed and ventilator gave him the independence to live his life. But the financial impact was very hard, as our bills were excessive compared to other families."*
>
> **- Christine**

The impact of paying to run vital medical equipment on the affordability of energy bills for people with a terminal illness is substantial. A recent survey of Marie Curie's Caring Services staff found that 84% of our frontline staff have cared for patients who were struggling to afford the cost of their energy bills in the last year, 28% of staff having observed patients having difficulty affording the cost of running at-home medical equipment[37].

With UK energy prices having risen substantially in the last few years and continuing to be historically high[38], the cost of running vital medical equipment in the home has risen sharply for people with a terminal illness and is likely to continue to be a significant financial burden for households affected by terminal illness in the future.

How many people with a terminal illness are using medical devices at home?

Finding reliable and comprehensive data on the number of people who are using common medical equipment in the home in the UK is difficult. As an example, the National Kidney Federation estimates that around 30,000 people receive dialysis in the UK every year with one in five (approximately 6,000) choosing to dialyse from home[39] – however, comprehensive estimates of the number of people using other medical devices are not readily available.

In March 2023, Marie Curie submitted Freedom of Information requests to NHS Trusts, requesting data on the number of patients in each Trust area who were using common medical devices in their homes. However, most Trusts were unable to provide this data – only 23% of NHS Trusts in England were able to provide even partial data, typically on a limited number of devices (commonly oxygen concentrators) with most Trusts reporting that this information was either not held or could not be provided without incurring significant cost.

This lack of data is concerning – it means that most NHS Trusts are unable to report on the number of patients using at-home medical devices in their area and, therefore, estimating the size of this population is a significant challenge. As an alternative, Marie Curie has considered Office for National Statistics (ONS) mortality data to make an indicative estimate of the number of people with a terminal illness who may have been using medical devices at home before they died.

Table 2 shows the number of people who died at home in England and Wales in 2021 of key conditions (data is available at the level of ICD chapter) where common care and treatment includes the use of one or more of the medical devices listed in Table 1 – assuming that if these patients died at home, they were likely to have been cared for at home for some time in the months leading up to their death. Table 2 reflects the latest year for which ONS figures are available for key condition and place of death; figures for Scotland and Northern Ireland are not available in this context.

Table 2. Deaths at home from selected medical conditions, England and Wales, 2021

ICD chapter	Key conditions included	Deaths at home, 2021[d]
II Neoplasms	Cancers	61,534
V Mental and behavioural disorders	Dementia	6,874
VI Diseases of the nervous system	Alzheimer's, MND	8,276
IX Diseases of the circulatory system	Heart disease, cerebrovascular disease	47,963
X Diseases of the respiratory system	Emphysema, COPD, CLRD	13,859
XI Diseases of the digestive system	Cirrhosis, liver disease	5,203
XIV Diseases of the genitourinary system	Kidney disease, renal conditions	1,749
XXII Codes for special purposes	Covid-19	4,462
	Total	149,920

The numbers indicated in Table 2 are indicative and are unlikely to be exhaustive – for example, many people who ultimately die in hospital, in a hospice or another care setting will not be recorded in this data but will have spent a significant period being cared for at home in the months leading up to their death and potentially using a medical device during this time. Further research is needed to establish a comprehensive estimate of the number of people with a terminal illness using at-home medical devices as part of their care and treatment.

However, this data indicates that many tens of thousands of people every year in England are spending the last phase of their life at home with conditions where medical devices are commonly used to manage their symptoms and keep them comfortable – and in many cases, they will be paying out of pocket to power them.

How effective are rebate schemes for the cost of running medical devices?

As outlined above, despite the substantial cost of powering at-home medical devices for the people who rely on them, in most cases these costs are borne out of pocket

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d. Office for National Statistics. Deaths registered in England and Wales, 2021 (refreshed populations). January 2023.

by patients themselves. Many thousands of people with a terminal illness– and others who rely on these devices whose conditions are not terminal – who are using ventilators, nebulisers, powered beds and body driers at home, face the prospect of paying hundreds of pounds each year to keep this vital equipment powered.

At present, a national rebate scheme exists for the cost of running oxygen concentrators in the UK[40]. A meter reading is taken from the concentrator device itself, recording the number of hours that the concentrator has been used, which is used by the supplier of the device to calculate the electricity that has been used to run the concentrator – which is then reimbursed to the patient by the device supplier on behalf of the NHS[41].

The fact that oxygen concentrators, unlike most medical devices, have an hours-used meter enables the cost of running the device to be reimbursed to patients actively and in full. However, the rebate is only paid by the device supplier every three months[42], meaning that patients must pay the upfront cost of the energy used themselves until their rebate is received – and as outlined above, based on Marie Curie's analysis, oxygen concentrators are the single most expensive at-home medical device to power.

The only other common medical device for which a reimbursement scheme exists is dialysis – however practice is significantly less consistent than for oxygen concentration. In England, reimbursement is offered only for home haemodialysis but not for peritoneal dialysis[43].

Furthermore, in practice, the level of reimbursement that dialysis patients can expect to receive varies significantly depending on where they live. Without a consistent nationwide policy in place, while some NHS Trusts fully cover the cost of running home dialysis equipment, others only part-cover these costs, potentially leaving patients hundreds of pounds out of pocket every year in order to receive this vital treatment[44].

With only limited rebate or reimbursement schemes in place, many thousands of people with a terminal illness in England who rely on at-home medical devices to treat their symptoms and sustain their quality of life, are faced with a significant financial impact as a result. Even those who may be entitled to some reimbursement of their costs may not see all of their costs returned, or may have to wait a substantial period of time before they receive this.

> *"My mother used an oxygen concentrator, but only received the rebate after her death. It didn't come quickly enough."*
>
> **- Susan**

This financial burden, in addition to the other factors driving higher energy bills among people with a terminal illness, can cause significant financial strain and impacts not only on their financial circumstances, but also on their health and wellbeing at the end of their lives.

The impact of high energy costs on people with a terminal illness

The high energy needs – and inability to easily 'ration' their use of energy – faced by many people affected by terminal illness, mean that they are particularly vulnerable to fuel poverty. The combined impact of enhanced needs for 'everyday' energy use and the particular cost of running vital at-home medical devices can leave families with substantially higher bills – impacting not just their financial situation but their health and wellbeing as well.

Financial impacts

A terminally ill person's energy bill can increase by as much as 75% over what they were paying before they were diagnosed[45] and be substantially higher than the average UK household's bill. This added expenditure, in addition to other new costs brought on by terminal illness, like medication or home adaptations, as well as the potential for lost income, can lead to significant strain on a household's finances. For many, this will force them into fuel poverty[46].

Two-thirds of households affected by terminal illness experience financial strain as a result[47], with those families who are already the most disadvantaged being most likely to experience financial distress after a diagnosis[48]. This strain can lead to families rapidly running down whatever savings they may have, or accumulating debt in order to make ends meet – with many people with a terminal illness building up a 'debt legacy', with their surviving family members left to meet those costs after they are gone[49].

> *"Medical equipment helped my husband to be more comfortable and to die at home, five weeks after his diagnosis. However, I was left struggling financially with my seven-year-old son due to huge bills after my husband passed."*
>
> **- Morag**

The high cost of meeting their energy needs – which has only grown more challenging during the cost of living crisis in the UK – can force people with a terminal illness into the dilemma of having to choose between heating their homes and powering vital medical equipment, or eating and paying other bills[50]. In 2022, more than one in five of Marie Curie's frontline Caring Services staff reported caring for patients who were struggling to afford suitable food for themselves or their families[51].

We are increasingly concerned that these pressures may drive families affected by terminal illness to ration their use of energy

– despite the difficulty people with a terminal illness face in doing so and despite the risks to their health and wellbeing this poses – especially as UK energy prices continue to be at historic highs. The UK's energy suppliers have reported that households have cut back their energy consumption by as much as 10% compared to recent years due to high prices[52], while as many as 16% of customers who use prepayment meters 'self-disconnect' every year – not topping up their meter when it runs out of credit[53]. For people with a terminal illness, who may have specialist medical equipment in the home and for whom keeping at the right temperature is vital to their wellbeing, the impact of energy rationing or self-disconnection can be severe and could even be life-threatening.

Impacts on health and wellbeing

As outlined earlier in this report, exposure to conditions that are too hot or too cold can lead to several negative impacts on a person with a terminal illness' health, from increased risk of infection to additional pain, neuropathy, and higher blood pressure. Being unable to keep the home environment at the right temperature because of the rising cost of energy or the cost of running medical devices, or having to choose heating over eating and not having sufficient nutrition, risks making terminally ill people's conditions worse and reducing their quality of life.

In Marie Curie's recent survey of our Caring Services workforce, more than a third (37%) of our staff reported witnessing impacts on the physical health of their patients, with nearly one in four (23%) also reporting that this had hastened the deterioration of some of their patients' conditions.

The impacts on people's mental health are also significant – people living in fuel poverty are more than two times as likely as those who are not to report moderate or high stress levels[54], with studies also having shown a direct correlation between lower temperatures at home and depression[55]. Many people with a terminal illness who are struggling to afford the cost of energy and other essentials also find that they cannot afford to go out or may be reluctant to invite loved ones to their home because it is cold[56]. This can increase a sense of social isolation that many people living with terminal illness already feel and which, coupled with their condition, can be debilitating[57].

> *"A feeding pump, nebuliser, powered hospital bed and suction machine kept my husband alive during the latter stages of his illness. Costs were an issue, and on top of the emotional impact of caring for someone you love who is terminally ill, the financial situation was really beyond words."*
>
> **- Mavis**

Marie Curie's recent Caring Services staff survey found that nearly four in five (78%) of our staff have witnessed impacts on the mental health and wellbeing of their patients due to the rising cost of living, with two in five (41%) reporting that financial difficulties had increased patients' social isolation.

In extreme cases, being unable to afford to keep a home warm could even hasten somebody's death. University College London and the Institute of Health Equity estimate that as many as 21.5% of excess winter deaths are directly attributable to cold homes[58]. Based on this measure, across the UK in 2021-22 as many as 3,240 excess deaths in the UK could have been attributable to living in cold conditions[59] – many of these excess deaths are likely to have been people living with pre-existing terminal illnesses.

Increased risk of hospital admission

While two-thirds of us wish to die at home and just 7% of us would prefer to die in hospital[60], across the UK fewer than half of people who die do so in their own homes – more people continue to die in hospital than in any other setting[61].

Despite the fact that people's preference for a home death does not change regardless of their financial or economic circumstances[62], those who are better off are more likely to die at home and those who are worse off or struggling financially are more likely to die in hospital[63]. Studies have shown that a person's home environment, including how warm it is, is a key determinant in whether somebody is able to die at home[64].

Being unable to afford the cost of powering medical equipment in the home may push people with a terminal illness to have their treatment in hospital – the National Kidney Foundation, for example, has warned that the rising cost of energy could force more patients to return to receiving dialysis in hospital[65]. Not only is this not where most people at the end of life wish to be cared for, but the cost to the NHS of providing care in hospital is higher than providing treatment at home[66].

> *"Without multiple medical devices, my partner wouldn't be able to stay at home and I wouldn't be able to care for him. All the utilities have gone up, but the highest one is definitely the electric."*
>
> **- Elizabeth**

People living with a terminal illness who are unable to afford to heat or cool their homes adequately are at higher risk of hospital admission[67] due to the risk of developing the health complications outlined earlier in this report. People can typically expect on average to have between one and two separate unplanned admissions to hospital in their last year of life, totalling around eight days in hospital. Although the number and duration of admissions varies depending upon a person's age, condition and health and can be much higher[68]. Recent cases of patients losing access to overnight NHS care because they cannot afford to heat their homes raise the prospect of more people with long-term and terminal illnesses being unable to remain at home and forced to receive care in hospital[69].

People with a terminal illness who are discharged from hospital into cold homes that they cannot afford to heat are also likely to recover more slowly[70] and to be at a higher risk of further, repeat admissions back to hospital[71], not only causing them and their families significant distress and disruption, but also putting additional pressure on NHS hospitals. These pressures can be significant – in England, around 5.5 million bed days annually are currently required by people in their last year of life[72].

Support with energy costs

As outlined earlier in this report, while some rebate or reimbursement schemes exist in the UK for the cost of running medical devices, these are inconsistent – patients who are using devices other than oxygen concentrators or dialysis machines at home do not see any reimbursement for their costs, while costs for oxygen concentrators are only rebated in arrears after three months and arrangements for dialysis reimbursement vary significantly across the country.

> *"My late wife needed oxygen assistance 24/7, which the in-home oxygen concentrator provided. The cost of electricity increased by 66%, although the running costs were refunded three months in arrears. It was another stress along with my wife's illness, and I could understand that a three-month refund delay could be critical to some households."*
>
> **- James**

For people with a terminal illness who are using other medical devices at home, or who are otherwise facing substantially increased energy bills due to additional heating or cooling requirements or other needs related to their condition, support with the rising cost of energy can be a lifeline.

Despite their high energy needs and particular vulnerability to fuel poverty, however, many people with a terminal illness and their families find that they receive inadequate government support with their energy costs. Too often, support is based upon the requirements of a household with average energy needs and is insufficient to meet the added costs a household affected by terminal illness will experience, while in other cases people with a terminal illness find that they are ineligible for financial support.

Marie Curie's recent Caring Services staff survey found that six in 10 (60%) of our frontline staff found government assistance with the rising cost of living had been 'somewhat supportive' for their patients, but just 15% felt it had been 'supportive' and only 6% felt it had been 'very supportive' – and, concerningly, nearly one in five (19%) thought the support had not been helpful for their patients[73].

Winter Fuel Payment and Warm Home Discount

The Winter Fuel Payment (WFP) provides eligible recipients between £250 and £600 (inclusive of a Pensioner Cost of Living Payment of between £150 and £300 in winter 2022-23 and 2023-24) to meet their heating costs over the winter; it is typically paid automatically in November or December[74].

However, it is only available to those who are over the age of 65 – meaning a person with a terminal illness who is of working age will not receive WFP under any circumstances even if they are at risk of fuel poverty.

Similarly, the Warm Home Discount (WHD) – a one-time £150 discount on electricity or gas bills between October and March – is only automatically available to older people who are receiving the Guarantee Element of Pension Credit or, as of 2022, people on low incomes (receiving certain benefits or tax credits) and whose homes are likely to be hard to heat[75]. While recent changes to the WHD are positive and will enable many more people with a terminal illness to claim support from the scheme, others – such as older people who do not receive Pension Credit or working age people who are not receiving Universal Credit – will not automatically qualify.

Other people may qualify for the WHD but must apply to their energy provider for the scheme – eligibility criteria vary between providers, and while a person with a terminal illness may be eligible based upon other criteria, such as the receipt of certain benefits, no provider currently includes terminal illness as an eligibility criterion in its own right.

Furthermore, the number of payments a provider makes under the WHD is limited by their allocation; in practice, they are often allocated on a first-come, first-served basis, meaning that people with a terminal illness who may be eligible but do not know about the scheme, or apply too late, are at risk of losing out[76].

Energy Bill Support Scheme and Energy Price Guarantee

During the winter of 2022-23, the UK Government gave every household an automatic £400 discount on their energy bills; for those on credit or smart meters this came in the form of an automatic deduction while for those on prepayment meters this came in the form of a voucher[77].

While the Energy Bill Support Scheme (EBSS) was a welcome measure to support households with historically high energy bills due to the cost of living crisis, the level of support provided by the scheme – approximately £66 per month over six months – was designed to support households paying an average UK energy bill. For those living with a terminal illness, who may have had vital at-home medical equipment to power and substantial additional heating and other energy needs over the winter, the scheme is unlikely to have covered all the additional costs they experienced due to rising energy bills over that winter.

In addition to the EBSS, the Energy Price Guarantee provided a 'support rate discount' on energy bills after the Ofgem price cap rose above £2,500 in autumn 2022 – effectively reducing the cap to a level where the typical household would not pay more than £2,500 annually for energy[78].

The EBSS concluded at the end of March 2023 and was not replaced; while the energy price cap will fall to £2,074 from July 2023 (and the Energy Price Guarantee will therefore fall away)[79], UK energy prices remain historically high and EBSS, the price cap and Energy Price Guarantee are based upon a typical household's energy use. People with a terminal illness, who have ongoing higher energy needs than an average household, will continue to require targeted support with their energy costs as their bills will be substantially higher – based upon an estimate that their bills can be as much as 75% higher than the average household's, many may still be paying more than £3,500 a year for energy – and they are likely to be significantly less able than most households to afford ongoing high energy prices.

Household Support Fund

The UK Government has also made additional support available via the Household Support Fund (HSF), which was introduced in October 2021 and has been extended until March 2024. More than £2 billion has been made available to local authorities via the HSF, to support the most vulnerable people with the cost of living – including paying for essentials and meeting energy costs[80].

The HSF is administered directly by local authorities and each authority decides how to run its scheme – there are differences between areas in eligibility criteria, whether or how people must apply to receive support and how money from the fund is ultimately paid. While some local authorities provide support directly to residents, others have distributed it through charities or local community groups[81].

As with the Warm Home Discount, the differing eligibility criteria and requirements between local authorities mean that many people with a terminal illness may find that they are ineligible to receive support from their council's HSF.

Conclusion and recommendations

Even before the cost of living crisis, households affected by terminal illness were struggling with rising energy bills. In the aftermath of a diagnosis, many people with a terminal illness see their need for energy rise – as they spend more time at home, as they need to store medications safely, as they come to rely increasingly on assistive technologies, as staying warm becomes more important and as they need to power at-home medical devices as part of their care and treatment.

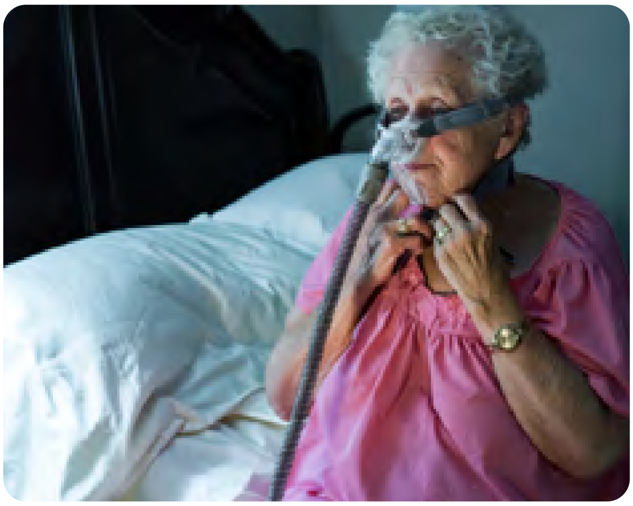
Powering these vital medical devices can add significant additional costs to a terminally ill person's energy bill – yet in many cases they are forced to pay substantial sums themselves, effectively paying for their own treatment, and in the few cases where rebate or reimbursement schemes exist, they are inconsistent and often leave terminally ill people out of pocket for months. The lack of comprehensive data available on the number of people using at-home medical devices makes estimating the size of this problem challenging, but it is likely that many tens of thousands of people are in this position every year. Further research is needed to comprehensively determine how many people with a terminal illness are using medical devices in the home as part of their care and treatment.

The new energy needs they face can see people with a terminal illness and their households paying as much as 75% more to their energy provider than they were paying before they were diagnosed. If they become ill during working age, this new cost will come just as they may have been forced to give up work, and if they become ill later in life this cost must be met out of a fixed income from pensions and savings.

Rising energy prices have only made the challenge of affording the cost of energy harder for people with a terminal illness and their families. While measures to support families through the cost of living crisis are welcome, government interventions on energy prices have typically not been targeted – they have not been sufficient to stop many families affected by terminal illness, who are particularly vulnerable to fuel poverty, from desperately struggling with historically high energy bills and being forced into impossible dilemmas about whether to heat their homes or put food on the table.

The financial strain this causes is not the only impact of high energy prices on people with a terminal illness – in many cases it can have a direct impact on their health and wellbeing as well. From increased stress and anxiety due to worrying about how to make ends meet, to risking infections or other complications if they turn the thermostat down to save money, to ultimately being unable to remain at home for their care and treatment due to the cost of running medical equipment, the financial burden associated with energy costs can have a direct and devastating impact on people's health, care and experience at the end of their lives.

Nobody should die in poverty, yet more than 90,000 people each year in the UK spend the last year of their life below the poverty line



– for many, the high cost of energy will be a significant contributing factor to the financial strain they face at the end of life.

Instead of being able to focus on what matters – their health, and making memories with their loved ones – for too many people the final stage of their life is spent stuck in a cold home, worrying about the cost they are incurring from running the equipment they need to stay healthy and comfortable, terrified at the prospect of their next energy bill.

This report aims to start a discussion among government and policymakers about ways to better support people with a terminal illness and their families with the high costs of energy they face. Addressing these challenges, and taking action to improve the availability of data in this area to understand the real scale of this problem, should be an urgent priority. Due to the data challenges already identified, this report only makes recommendations in relation to England – however, we hope that its findings will also be useful for policymakers considering these issues in the rest of the UK.

Recommendations

1. Improving support with the cost of running medical devices

The founding principle of the NHS is that care should be free at the point of use. For many people receiving care at home, however, the cost of powering medical devices – and inconsistencies in how these costs are rebated or refunded – means that they are effectively paying out of pocket for their own treatment. People with a terminal illness, and others who rely on medical devices to manage their conditions and symptoms, face bills that can run into hundreds of pounds a year to run the vital equipment that keeps them healthy and comfortable.

For some, these costs will drive them into financial difficulty at a time when they may have a reduced income or be reliant on benefits – for others, this financial burden may drive them to seek treatment in hospital even if they would prefer to be cared for at home.

Marie Curie believes that 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.

Existing rebate and reimbursement schemes for the cost of running oxygen concentrators and dialysis machines often leave people with a terminal illness out of pocket for months before they are paid back in arrears, while the reimbursement scheme for dialysis is inconsistently administered across England. We are also concerned that many NHS Trusts were unable to provide any data to Marie Curie on the number of patients in their area using medical devices in their homes.

The DHSC should look to extend rebate schemes to other medical devices and explore how terminally ill patients could be credited upfront for the energy their devices will use, rather than being paid in arrears, as well as a nationally-administered rebate scheme to address inconsistencies in administration. This could, for example, be calculated based upon the cost of running the device (the estimated energy consumption in kWh of the device, multiplied by the unit cost of electricity at the Ofgem price cap). It should also be acknowledged that any additional funding required to deliver this approach would have Barnett consequentials for the rest of the UK that should be protected to support the NHS in each nation to consider similar approaches.

Estimating the number of people who would be covered by this approach – and therefore the cost to the DHSC and NHS – is challenging without comprehensive data on the number of people using at-home medical devices; however, under the current approach, to rebate the costs faced by individuals of running medical devices can be substantial and lead to significant financial strain for families affected by terminal illness. To address the lack of comprehensive data identified in this report and to enable the consideration of more detailed policy proposals, NHS Trusts should be required to record and report information on the number of patients using at-home medical devices in their area.

Not only would improving support with the cost of medical devices help reduce the financial burden on families caused by the cost of high energy bills, ensuring that at-home medical devices are free at the point of use for patients may also reduce the likelihood of patients opting to be cared for in hospital or the risk of hospital admissions.

With the average cost of an inpatient palliative care bed at £349 per day[82], financially supporting patients to receive their care and treatment at home would help reduce pressure on NHS hospitals by reducing bed days and enable people at the end of life to be cared for where they want to be.

2. A Social Tariff on energy prices

People with a terminal illness, and others who have particularly high energy needs, are among the hardest hit by rises in energy prices. Already facing bills many hundreds of pounds a year higher than the average UK household, historically high prices are leaving many families struggling to make ends meet. This can have a devastating impact not only on terminally ill people's finances but on their health and wellbeing as well.

As the Energy Bill Support Scheme is withdrawn and the Energy Price Guarantee falls away, a more permanent and targeted solution to the high cost of energy faced by the most vulnerable in society is urgently needed.

In addition to support with the cost of medical devices, Marie Curie believes that 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, to ensure that energy remains affordable for people with a terminal illness and others who are the most exposed to high prices and most vulnerable to fuel poverty.

We are supportive of the model proposed by Age UK[83], which would ensure that a Social Tariff would:

- provide a discount on energy of 50% of the market rate or a price cap to eligible households
- be mandatory for all energy suppliers and automatically enrol eligible households
- provide equal benefit to those on prepayment meters and using alternative fuels.

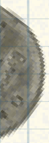
Given their particular vulnerability to fuel poverty, Marie Curie believes it is vital that all households including a person living with terminal illness are eligible for a Social Tariff, to recognise the additional costs they face as a result of this condition.

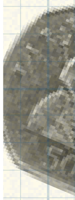
Introducing a Social Tariff, and ensuring that all people with a terminal illness can benefit from it, would support people to stay warm and comfortable at home at the end of their lives. It will ensure that nobody with a terminal illness is forced to risk their health and wellbeing by rationing energy, and provide peace of mind to people with a terminal illness and their families – allowing them to focus on what matters most to them at the end of life rather than worry about their bills.

References

1. Marie Curie. Dying in Poverty: Exploring poverty at the end of life in the UK. May 2022.
2. All-Party Parliamentary Group for Terminal Illness. No place like home? Report of the APPG for Terminal Illness inquiry into housing and fuel poverty at the end of life. June 2021.
3. Marie Curie 2022 *Op. Cit.*
4. BBC News. Cost of living crisis: 'Our lives are at risk because of energy costs.' 13 May 2022.
5. iNews. 'I can't sleep if I owe money': Terminally ill people are dying worrying about the cost of living crisis. 17 April 2022.
6. Office for National Statistics. Consumer price inflation, UK: December 2022. January 2023.
7. Ofgem. Latest energy price cap announced by Ofgem. November 2022.
8. Marie Curie. Marie Curie data briefing: The Cost of Living: A survey of Marie Curie Caring Services staff. March 2023.
9. NatCen Social Research. British Social Attitudes Survey 30.
10. Office for National Statistics. Deaths registered in England and Wales: 2021. July 2022.
11. National Records of Scotland. Deaths registered weekly in Scotland, 2022-23. June 2023.
12. Northern Ireland Statistics & Research Agency. Weekly Death Bulletins 2022. January 2023.
13. Vibert S. MND Costs: Exploring the financial impact of Motor Neurone Disease. Demos, Motor Neurone Disease Association. 2017.
14. Liddell, C. and Morris, C. Fuel poverty and human health: a review of the recent evidence. Energy Policy. 38, pp. 2987-97. June 2010.
15. Public Health England. Local action on health inequalities: Fuel poverty and cold home-related health problems. Health Equity Evidence Review 7. September 2014.
16. Fisk W, Lei-Gomez Q and Mendell M. Meta-analyses of the associations of respiratory health effects with dampness and mold in homes. Indoor Air 17 (4) pp.284-96. 2007.
17. London School of Hygiene & Tropical Medicine, Public Health England, University College London. Evidence Review & Economic Analysis of Excess Winter Deaths for the National Institute for Health and Care Excellence (NICE). Review 1: Factors determining vulnerability to winter- and cold-related mortality/morbidity. January 2014.
18. Marmot Review Team. The Health Impacts of Cold Homes and Fuel Poverty. May 2011.
19. All-Party Parliamentary Group for Terminal Illness 2021 *Op. Cit.*
20. El-Ansari W and El-Silimy S. Are fuel poverty reduction schemes associated with decreased excess winter mortality in elders? A case study from London, UK. Chronic Illness, 4(4), pp.289–294. December 2008.
21. Preston I, Moore R and Guertler P. How much? The cost of alleviating fuel poverty. Centre for Sustainable Energy. 2008.
22. Zell JA, Chang JC. Neoplastic fever: a neglected paraneoplastic syndrome. Support Care Cancer. 13(11), pp 870-7. November 2005.
23. Care Inspectorate. Health Guidance: The Temperature Requirements for Medicines Storage. March 2016.
24. Marie Curie. Living with a terminal illness: Loss of mobility.

25. Vibert S 2017 *Op. Cit.*
26. Jamwal R, Jarman H et al. Smart home and communication technology for people with disability: a scoping review. Disability and rehabilitation. Assistive technology 17(6), pp 1-21. September 2020.
27. Marie Curie. The cost of dying. December 2019.
28. Marie Curie 2022 *Op. Cit.*
29. Ibid.
30. Marie Curie 2019 *Op. Cit.*
31. Green Alliance. Reinventing retrofit: how to scale up home energy efficiency in the UK. February 2019.
32. Energy Saving Trust. Why outside the grid does not mean outside of help. November 2020.
33. NatCen Social Research *Op. Cit.*
34. Citizen's Advice. Grants and benefits to help you pay your energy bills.
35. 35 Kidney Care UK. Home dialysis reimbursement: a guide for patients.
36. Department for Energy Security & Net Zero. Policy paper: Energy Price Guarantee. May 2023.
37. Marie Curie 2023 *Op. Cit.*
38. House of Commons Library. Research briefing: Domestic energy prices. March 2023.
39. National Kidney Foundation. National Kidney Foundation's call to action on home dialysis postcode poverty. 2022.
40. Citizen's Advice *Op. Cit.*
41. BOC Healthcare. Oxygen Concentrators: A User Guide.
42. Ibid.
43. 43 Kidney Care UK *Op. Cit.*
44. National Kidney Federation *Op. Cit.*
45. Marie Curie 2022 *Op. Cit.*
46. Marie Curie. The vicious cycle of fuel poverty and terminal illness. November 2020.
47. Marie Curie 2019 *Op. Cit.*
48. Azzani M, Roslani AC, Su TT. The perceived cancer-related financial hardship among patients and their families: a systematic review. Support Care Cancer 23(3), pp. 889-98. March 2015.
49. Marie Curie 2019 *Op. Cit.*
50. APPG for Terminal Illness 2021 *Op. Cit.*
51. Marie Curie 2023 *Op. Cit.*
52. The Guardian. UK households have cut energy consumption by 10%, say suppliers. 27 November 2022.
53. Citizen's Advice. Switched on: Improving support for prepayment consumers who've self-disconnected. 2018.
54. APPG for Terminal Illness 2021 *Op. Cit.*
55. Marmot Review Team *Op. Cit.*
56. Ibid.
57. Marie Curie. Connected communities – Tackling loneliness and social isolation. January 2019.
58. Institute of Health Equity. Fuel poverty, cold homes and health inequalities in the UK. 2022.
59. End Fuel Poverty Coalition. Excess winter deaths and fuel poverty. January 2023.
60. NatCen Social Research *Op. Cit.*
61. Marie Curie. Better End of Life 2021: Dying, death and bereavement during Covid-19. April 2021.
62. Marie Curie. A Place for Everyone: What stops people from choosing where they die? 2020.
63. Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? Soc Sci Med 47(5), pp. 565-79. September 1998.





64. Wales J, Kurahashi AM, Husain A. The interaction of socioeconomic status with place of death: a qualitative analysis of physician experiences. BMC Palliative Care 17(87). June 2018.

65. National Kidney Federation *Op. Cit.*

66. Singh S et al. Is comprehensive geriatric assessment hospital at home a cost-effective alternative to hospital admission for older people? Age and Ageing 51(1). January 2022.

67. The Housing and Ageing Alliance. Policy Paper: Health, Housing and Ageing. 2013.

68. Marie Curie. In and out of hospital: Emergency hospital admissions and A&E attendances in the last year of life in England. July 2021.

69. The Guardian. Disabled boy loses overnight NHS care because parents cannot afford heating. 4 January 2023.

70. Preston I, Moore R and Guertler P 2019 *Op. Cit.*

71. The Housing and Ageing Alliance 2013 *Op. Cit.*

72. Marie Curie July 2021 *Op. Cit.*

73. Marie Curie 2023 *Op. Cit.*

74. Gov.uk. Winter Fuel Payment: Overview.

75. Gov.uk. Warm Home Discount Scheme.

76. APPG for Terminal Illness 2021 *Op. Cit.*

77. Gov.uk. Help with your energy bills.

78. Department for Energy Security & Net Zero 2023 *Op. Cit.*

79. Ofgem. Customers to pay less for energy bills from summer. May 2023.

80. Department for Work & Pensions. Household Support Fund extended from today to help families in need. April 2023.

81. Gov.uk. Get help with the cost of living from your local council.

82. Personal Social Services Research Unit, Centre for Health Economics. Unit Costs of Health and Social Care 2022 Manual. 2023.

83. Age UK. Keeping the lights on: The case for an energy social tariff. March 2023.

For more information:

Mark Jackson
Senior Research & Policy Manager, Marie Curie

E: **mark.jackson@mariecurie.org.uk**

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