Marie Curie

Care and support through terminal illness

The vicious cycle of fuel poverty and terminal illness

Contents

Introduction

Despite welcome progress in tackling fuel poverty, millions of households in the UK today still struggle to afford to heat their homes properly.

Anyone can experience fuel poverty, but among the groups most vulnerable to the damaging consequence of living in cold housing are older people, those with chronic illnesses or long-term conditions, and people with low or declining incomes. Many people who are terminally ill fall into several, if not all, of these categories.

Terminally ill people may experience a vicious cycle of fuel poverty. Their deteriorating health means they have to spend a lot more to heat their homes sufficiently, which some may struggle to afford due to depleted incomes and the other significant costs associated with their illness. However, the consequences of living in a cold home can be severe. It can lead to new infections, make existing symptoms flare up or become worse, affect their mental wellbeing and, in the worst cases, even hasten their death.

After receiving a terminal diagnosis, people should be able to concentrate on the things that matter – making the most of the time they have left, creating new memories with loved ones and putting their affairs in order. They shouldn't have to worry about whether they can afford to keep their house warm.

It is clear that urgent action is needed to tackle fuel poverty among terminally ill people. It is unacceptable that any dying person should spend the end of their life in cold, damp and uncomfortable conditions – deprived of the best possible quality of life because of unaffordable heating costs.

The scope of this report

This report provides an overview of some of the drivers and impacts of fuel poverty among people living with terminal illnesses. It sets out the case for change and makes a number of policy recommendations that would help reduce the number of dying people who can't afford to heat their home.

Marie Curie provides care and support for people affected by terminal illnesses. We are not an energy company or a housebuilder, so this report does not attempt to comment on these policy areas which, while absolutely critical to tackling fuel poverty, are outside of our expertise. Other organisations with expertise in these areas have a lot of important things to say about addressing fuel poverty, and we have signposted to them in the appendix of this report on page 20.

We began writing this report before the global coronavirus pandemic. The outbreak has, and will continue to have, significant implications for fuel poverty – not least because of the extra time people are spending at home, which will increase heating bills, and the impact job losses will have on household income. These implications are not yet fully understood, however, so we have not addressed them in this report.

What is fuel poverty? Definitions and scale in the UK

Different definitions of fuel poverty are used by governments across the UK. In England, the 'Low Income, High Cost' indicator is used, which defines a household as fuel poor if:

- they have required fuel costs that are above average (the national median level); and
- were they to spend that amount, they would be left with a residual income below the official poverty line.

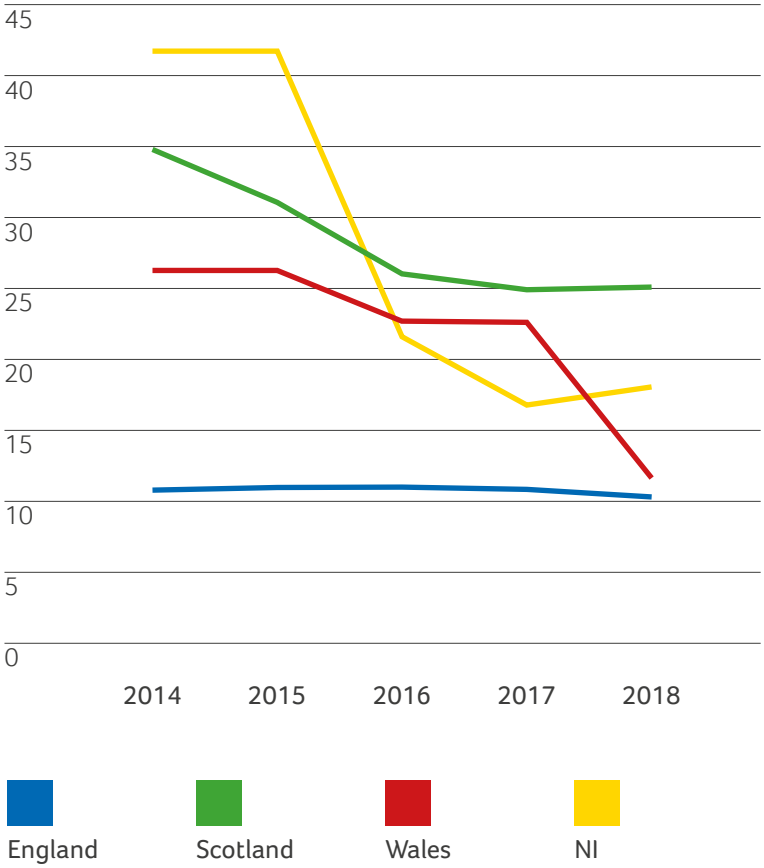
Wales and Northern Ireland use a largely similar definition, where a household is considered fuel poor if it needs to spend more than 10% of household income to maintain a satisfactory heating regime.

In Scotland, a new definition was introduced in 2019, whereby a household must fulfil both the following criteria to be considered fuel poor:

- Its required fuel costs must be more than 10% of household net income after deducting housing costs.
- The remaining household net income after the payment of fuel costs and childcare costs (if any) must also be insufficient to maintain an acceptable standard of living for the household.

Analysis of fuel poverty trends across the UK shows that under the respective definitions, the overall proportion of fuel poor households in England has remained in the 10–12% range consistently over the recent years, while it has fallen in each of the other nations.

Proportion of households in fuel poverty (%) according to the respective definitions in each jurisdiction.



Overall, in 2018, approximately 2.4 million households in England,[1] 155,000 households in Wales,[2] 619,000 households in Scotland,[3] and 131,000 households in Northern Ireland[4] were living in fuel poverty.

National Energy Action (NEA) – the charity working to end fuel poverty in England, Wales and Northern Ireland – estimate that the cost of treating morbidity associated with cold homes from 2012 to 2016 was over £5 billion.[5]

Layton Thompson/Marie Curie

28%

28% of Marie Curie nurses who responded to our survey said they've cared for a dying patient who struggled with heating costs.

Because data on fuel poverty rates among terminally ill people is not available, we sought to shed a light on the scale of problem among the people cared for by Marie Curie. We surveyed our community nursing workforce and, among those who responded, just under a third (28%) have provided care to a dying patient during the last five years who said they were struggling with the costs of heating their home.[A]

This is not to suggest that this proportion of all terminally ill people are fuel poor, but it does provide an interesting insight in lieu of wider data.

Our findings would seem to reinforce other evidence that those with advanced or life-limiting illnesses are particularly vulnerable to experiencing fuel poverty. For instance, households with someone with a long-term illness or disability account for over 40% of all fuel poor households in England.[1] While the average UK household spends £1,214 on energy bills each year, it is estimated that over a quarter of households with a disabled person spend more than £1,500 per year – with nearly 20% of these households spending over £2,500 per year.[6]

It is likely that actual rates of fuel poverty among terminally ill people are even higher than all of this data suggests, as some households may feel embarrassed that they are struggling with heating costs, creating a reluctance to raise or acknowledge the problem.

[A] The survey was conducted among Marie Curie's community nurses across the UK. There were 204 responses to the survey, which represents 11% of our community nursing workforce.

Drivers of fuel poverty among terminally ill people

This chapter explores two drivers which contribute toward fuel poverty among dying people: the impact of a terminal illness on someone's physical health, which makes them more likely to feel the cold and build up higher heating bills; and the financial impact of dying, which leaves some people unable to afford these costs.

In cases where someone was already living in fuel poverty and was then diagnosed with a terminal condition, the impacts explored in this chapter are only likely to exacerbate their struggle to afford sufficient heating.

Physical health

There are a number of connections between the physical effects of different terminal illnesses, feeling cold and higher fuel costs.

For people with cancer, treatments like chemotherapy or radiotherapy and the wider impact of the disease means many patients experience weight and hair loss, poor circulation, reduced energy levels and side effects like neuropathy, all of which may make them feel colder.

The symptoms of neurodegenerative conditions like dementia will often restrict physical activity, slowing body heat generation and conservation. This immobility leads to a lowering of metabolic rate and, consequently, the need for a higher ambient temperature.[7]

Parkinson's disease affects the nervous system, which controls body temperature, leaving some patients more sensitive to the cold.[8] Around 40–50% of people with Parkinson's will experience this sensitivity or other symptoms such as cold limbs, which is often accompanied by pain.[9]

People with chronic kidney disease, especially at the more advanced stages, are more likely to experience anaemia. This is when there are too few red blood cells to carry oxygen around the body, and one of the common symptoms of which is feeling cold.[10]

More broadly, people who are terminally ill are more likely to spend more time at home due to their declining health. Research has found this to be a common issue in conditions like motor neurone disease. In the earlier stages of the condition, patients may be too tired to leave the house for activities like work or leisure, and may eventually be unable to leave at all as the disease progresses.[11]

This issue, which may affect people with numerous different terminal conditions, increases both the need for their house to be heated for longer and the risks to their health if they can't afford the resulting high heating cost. As the National Institute for Health and Care Excellence (NICE) states: "living in a cold home may have a greater effect on people who have to spend longer than an average amount of time at home. This could include those with chronic health conditions *(including terminal illnesses)* or disabilities" (emphasis added).[12]

The symptoms of someone's illness may also require them to take action which inadvertently makes their living environment colder. Qualitative evidence from our Marie Curie Nurse survey highlighted that patients with conditions like lung cancer and COPD may often keep windows in their house open, despite cold temperatures outside, because the fresh air helps with their breathing.

Karen's dad Patrick, from Barnsley, had terminal lung cancer and other co-morbidities:

"Dad was always an outdoorsman – a strapping big guy. He loved looking after the garden and wouldn't really have been bothered by the temperature. He'd have been happy sitting in a pair of shorts and t-shirt in the house no matter what time of the year. But once he got sick, he lost a lot of weight and really started to feel the cold more. If he was watching TV or in bed, he'd need to be wrapped up in multiple layers just to be comfortable. Towards the end, the heating was on pretty much non-stop, so the bills absolutely sky rocketed. It probably didn't help that the house was quite old."

Research has sought to measure the real monetary impact of advanced illnesses on fuel bills. Macmillan estimate that between 2014 and 2016, people with cancer spent an additional £15.7m a year on energy bills.[13]

Elsewhere, survey research from Demos in 2017 showed that energy bills (gas, heating and electricity) were the single biggest enhanced cost faced by people with motor neurone disease (MND) as a direct result of their condition. On average, energy bills for those surveyed nearly doubled.[11]

Financial wellbeing

Two-thirds of households affected by terminal illness in the UK experience financial strain as a result.[14] What this means is that at the same time as many are facing significantly higher heating bills because of their health condition, their financial resources are also seriously depleted. There are a number of reasons for this.

The impact of their condition may mean that people with terminal illness have to pay for expensive equipment or home adaptions – for example, wheelchair ramps, stair lifts and accessible wet rooms – to allow them to remain in their own home and maintain a decent quality of life. They will also likely experience additional costs for things like specialist food, travel for medical appointments, and higher phone and broadband bills. On average, these additional costs may be as high as £3,300 per patient per year.[14]

If they are of working age, people who are terminally ill will have to reduce working hours at some point in their disease trajectory and eventually leave their job entirely. For example, almost a third of people with cancer experience loss of income as a result of their diagnosis of £860 a month on average.[15] This is a stark figure when we consider that it is over 2.5 times larger than the average fuel poverty gap in England in 2018, and nearly twice as large as the fuel poverty gap in Wales.[1] **[B]**

This issue doesn't just affect patients themselves. In 2018, over a fifth of informal carers of palliative or end of life patients also reported having to reduce their working hours to provide care.[16]

[B] The fuel poverty gap (FPG) is the average reduction in fuel costs that a fuel poor household would need to escape fuel poverty. In 2018, the average FPG was £334 in England and £431 in Wales.

Response to our community nurse survey:

"On numerous occasions over the five years I have experienced different levels of fuel poverty. The pressure carers have when faced with less income and the additional cost of having to purchase [things like] incontinence items results in choosing between heat in the home and patient dignity. Patients can be very agitated, especially when experiencing end stage pain [and] body temperature changes. Some families would rather have them laden with covers than put the heating on for fear of the winter bill or increased fuel costs."

In the context of these financial pressures, the support provided by the social security system can be a lifeline for terminally ill people and their loved ones. Research suggests that as many as 60% of people living with some terminal illnesses, such as neurodegenerative conditions, rely on benefits as their main source of income. [17] However, accessing this support is not always straightforward for dying people.

Many welfare benefits have a fast-track application process for claimants who are terminally ill – known as the 'special rules for terminal illness'. This allows them to access their payments quickly, without the need to go through intrusive assessments or fill in as many forms. But under current social security law, only people who can prove they have less than six months to live are eligible to apply for benefits via the special rules.

This results in many terminally ill people being excluded from the fast-track process because of the unpredictable nature of their conditions. They will have to apply for welfare support through the normal rules, which includes significantly more bureaucracy and, crucially in the context of fuel poverty, much longer waits for payments.

For instance, between 2013 – when the Personal Independence Payment (PIP) was introduced – and July 2020, the average clearance time in Great Britain for new claims under the normal rules was 16.5 weeks, compared to less than seven working days for new special rules claims.[18] A delay like this can have a massive impact on people who are facing significant additional costs as a result of their health problems and are struggling to afford to heat their home.

This isn't the only time-related issue in the welfare system that has a bearing on fuel poverty. Under Universal Credit, a dying claimant will still have to go through the five-week wait for their first payment regardless of whether they qualified through the special rules or not. The Trussell Trust has argued that the five-week wait is creating destitution among claimants, one aspect of which is the inability to afford heating costs.[19]

Support is available in Great Britain through the Warm Home Discount Scheme (WHDS), which provides a £140 discount on electricity or gas bills for people who either receive the Guarantee Credit element of Pension Credit or who are on a low income and receive certain means-tested benefits. NEA has described the WHDS as a 'lifeline' for people struggling to heat their home,[20] however calls for terminally ill people to automatically qualify,[21] or for the eligibility criteria to be extended to support more vulnerable households,[6] have not been heeded.

Phil Hardman/Marie Curie

The Extra Cost Commission also found that 40% of disabled people were unfamiliar with the Warm Home Discount Scheme in 2015,[22] suggesting greater action is needed to raise awareness of the support available through the scheme.

Elsewhere, Winter Fuel Payments provide help with meeting the cost of fuel bills, but are only available to those aged over 65. Campaigners have advocated for extending the programme to support non-pensioner households in need,[23] but this, again, has not been implemented.

Ultimately, access to welfare support and other associated schemes is still not a guarantee that terminally ill people will have the money they need for essentials like heating. Nearly 40% of families in the UK where at least one person is disabled and receives disability benefits are in poverty.[24] This has a direct impact on the affordability of essentials like heating. Indeed, research from Citizens Advice in 2018 showed that a staggering 87% of households that couldn't afford to keep their prepayment energy meters topped up were in receipt of welfare benefits.[25]

These financial pressures may leave terminally ill people unable to afford to heat their home or relying on a number of coping measures to get them through the day. Research has identified common strategies that some people deploy to cope with fuel poverty, including:

- cutting back on electricity use and reducing spending on essentials like food to leave more money available for heating (see page 14)
- putting newspaper over windows to try to boost insulation
- 'energy rationing', for example self-disconnecting the home energy supply or only heating one room in the house.[26]

In 2019, nearly 30% of carers for a person with dementia who responded to the Carers Northern Ireland State of Caring survey said they were struggling to make ends meet financially. Of these, nearly a quarter reported trying to cope by cutting back on essentials, including heating.[27]

Sian, from Surrey, is living with incurable cancer:

"As a side-effect of the chemotherapy, I suffer with neuropathy in my hands and feet. It feels like really severe pins and needles, and the colder I get the worse it becomes. Sometimes my hands get so numb I can't even lift milk out of the fridge because it's so painful. The extra cold makes it impossible. I start dropping things, and I can't walk, I can't change the duvets on the bed, or even think about driving.

"That's why it's so important I keep warm. Already I'm spending about £45 each on gas and electricity per month during the summer, so I dread to think what the winter fuel bills will be. I'm expecting to spend well over the £100 mark on each, and when you're living on benefits that doesn't go far.

"My partner has had to move in with me, so they took £200 away. He gets £69 per week in Carer's Allowance because he had to give up work, but that doesn't stretch. I'm genuinely worried about how we're going to cope. I dread to imagine what the bills will be come the height of winter. With things as they are, we'll have to rob Peter to pay Paul, you know. It's going to be a real stretch."

The vicious cycle of fuel poverty and terminal illness

Dying people may experience a **vicious circle of fuel poverty**. Their deteriorating health means they have to spend a lot more to heat their homes sufficiently, which some can't afford, but the consequences of living in a cold home can cause their health and wellbeing to get even worse.

38%

38% of Marie Curie Nurses who have cared for patients in fuel poverty believe it made the person's physical health worse.

Cold, damp conditions in the home can be breeding grounds for mould, which may make infections more likely. While this might have only a minor impact on a healthy person, the effects can be severe for someone with advanced cancer or chronic kidney disease whose immune systems may already be weakened due to the impact of their condition or the effects of treatment like chemotherapy or radiotherapy.

Pain is another important factor and evidence has shown that pain experienced by cancer patients can be triggered or worsened by feeling cold.[28]

Elsewhere, evidence shows that exposure to the cold suppresses the immune system of people living with chronic lung conditions like COPD, while cold air can further diminish their lungs' capacity to fight infection, leading to an increased risk of bronchitis and pneumonia.[29]

There is a strong link between hospital admissions for people with COPD and the viral infections caused by cold, damp conditions,[30] with some research suggesting that the likelihood of hospital admissions for people with COPD increases four-fold during the winter.[31]

The impact may even be fatal, with research showing significantly higher 30 and 90-day mortality for COPD patients hospitalised with pneumonia.[32]

More broadly, cold and damp conditions can increase the risk of arthritic symptoms, impacting on strength and dexterity, which may make falls more likelyfor frail patients with conditions like dementia.[36] Cold temperatures may also result in rising blood pressure and increased risk of stroke or other circulatory problems.

Taking all of this into account, it is no surprise that, among those Marie Curie Nurses who have cared for patients struggling with heating costs (see page 6), 38% believe it made the patient's physical health worse.

Beth is a Marie Curie Healthcare Assistant working in Greater London:

"Caring for patients in the winter months presents its own challenges, particularly when you're working in houses that are freezing cold with no central heating and you have to find ways to keep the patient warm. I remember one night I spent with a patient and it was freezing... It was a struggle to go through the night, but I made sure the patient was fully covered. They had two electric heaters, so I put them by the patient to make sure they were warmer than me."

Excess winter deaths

There is an important link between cold homes, fuel poverty and heightened mortality rates among people with terminal conditions. Governments across the UK monitor excess winter deaths (EWDs) – the number of extra deaths occurring during the winter months (December–March) compared to other times of the year. Crucially, the World Health Organization (WHO) estimates that 30% of EWDs are attributable to living in cold, damp housing.[43]

Between 2014/15 and 2018/19, there were 175,240 EWDs in England and Wales,[33] 16,500 in Scotland[34] and 4,835 in Northern Ireland.[35] **[C]**

Respiratory diseases, circulatory diseases and dementia have consistently been among the leading underlying causes of EWDs in every nation in the UK. When we apply the WHO's 30% calculation, this suggests that nearly 42,000 deaths from these conditions were attributable to cold, damp housing in England and Wales between 2014/15 and 2018/19 – nearly 12,000 from circulatory diseases, over 19,100 from respiratory conditions and nearly 10,900 from dementia.

This same concerning picture exists in the other nations. Between 2014/15 and 2018/19:

- over 710 deaths from chronic lower respiratory diseases and 930 deaths from dementia were attributable to cold, damp housing in Scotland.
- over 475 deaths from respiratory diseases and nearly 280 deaths from dementia were attributable to cold, damp housing in Northern Ireland.

It is also notable that EWDs predominantly affect older people, with 74% of EWDs in England being among those aged 75 and over. This is also the group that accounts for the most deaths from terminal conditions, indicating the vulnerability of terminally ill people to fuel poverty and the health consequences of cold housing.

These trends would seem to be reinforced by our survey findings, as nearly a fifth (17%) of those Marie Curie Nurses who have cared for patients struggling with heating costs believe it hastened their deterioration.

10,900

Nearly 10,900 excess winter deaths among people with dementia in England and Wales were attributable to cold housing between 2014/15 and 2018/19.

17%

Nearly a fifth of Marie Curie Nurses who have cared for patients in fuel poverty believe it hastened the person's deterioration.

[C] At the time of publication, figures for the 2019/20 winter were available in Scotland and Northern Ireland, but not in England or Wales. This report focuses on the period up to 2018/19 to allow for comparisons to be made across the UK.

40%

40% of Marie Curie Nurses who have experienced patients in fuel poverty believe it made the person's mental health worse.

Quality of life

There are a number of other, less visible ways that fuel poverty may impact on the health, wellbeing and quality of life of dying people and their loved ones.

Unsurprisingly, cold homes have been linked to increased levels of anxiety and depression[36] while people living in fuel poverty are also 2.5 times more likely to report high or moderate stress than those able to afford their heating costs.[29]

Response to our community nurse survey:

"It [fuel poverty] is extra stress for vulnerable patients who [are] already going through a traumatic time."

Social isolation may also increase among people in fuel poverty, especially older people, because their high fuel bills may mean they can't afford to go out, or they may be reluctant to invite loved ones to visit because their house is cold.[36]

The impact of these factors on mental wellbeing is clear. Among those Marie Curie Nurses who have cared for patients struggling with heating costs, 40% believe it made the patient's mental health worse.

Shockingly, fuel poor households may even be forced into what has become known as the 'heat or eat dilemma' – having to reduce spending on food, both in terms of quantity and quality, in order to afford heating costs. As well as impacting on their quality of life, this also risks relative malnutrition and weight loss – both of which may lead to a deterioration in their condition and, cruelly, make them feel even colder.[37]

Another common coping mechanism of people living in cold homes is going to bed early to stay warm,[38] which has a clear negative impact on quality of life, particularly for those who may not have long left to live.

NICE guideline NG6

In 2015, the National Institute for Health and Care Excellence (NICE) published guideline NG6 on 'Excess winter deaths and illness and the health risks associated with cold homes'. The guideline, which covers England and Wales, but not Scotland or Northern Ireland, makes a number of recommendations to Health and Wellbeing Boards (HWBs), health and social care professionals and other relevant stakeholders to help combat the damaging impact of fuel poverty and cold housing conditions.

Marie Curie identified a number of recommendations from the guidance that could potentially play a critical role in helping to address fuel poverty among terminally ill people. We contacted HWBs in England to get an understanding of how these recommendations are being enacted in their areas. It should be noted that not every recommendation in guideline NG6 is the responsibility of HWBs, although they do provide a valuable source of information on relevant plans, policies and procedures in their area.

We received information regarding at least one of the recommendations from 109 HWBs (85% of the HWBs we contacted in England). This chapter provides an analysis of our findings.

NICE NG6 recommendations that are the responsibility of Health and Wellbeing Boards

Recommendation: Health and Wellbeing Boards should ensure a local single-point-of-contact health and housing referral service is commissioned to help vulnerable people who live in cold homes.

Living with a terminal illness inevitably means dealing with a wide range of different health and social care professionals and other support services. Coordinating care and support among these groups can be a time-consuming and stressful process for patients and carers, so a single-point-of-contact health and housing referral service would seem to offer an effective way for dying people to access support if they are struggling with heating costs, without significantly adding to their coordination burden.

Analysis by NEA in 2016 found that 30% of HWBs had some form of health and housing referral service in place.[39] When we asked them about this recommendation, 57% of those that provided an answer said that such a service, or something similar, was in place.

While more HWBs seem to be acting on this recommendation than in 2016, it still means that more than two-fifths (43%) of the areas for which we received information do not have a single-point-of-contact service in place. Many of these HWBs did highlight separate services to address the respective housing, energy and health-related elements of fuel poverty, but they don't operate under the single-point-of-contact referral system as recommended by NICE.

Recommendation: Health and Wellbeing Boards should develop a strategy to address the health consequences of cold homes.

This recommendation is important for ensuring fuel poverty and cold housing is recognised and addressed properly at the strategic level in localities across England.

Measuring the effectiveness of each locality's strategy is outside the scope of this report, but when we asked about this recommendation, 60% of HWBs that provided an answer mentioned a strategy or action plan to tackle fuel poverty, excess winter deaths or cold housing.

While it is encouraging that a greater proportion of HWBs seem to have taken action on this NICE recommendation, our findings still show that over one-third (40%) of them don't have a cold homes strategy or plan in place. Action is needed to ensure much higher levels of compliance.

Other recommendations in NICE NG6

Recommendation: Those responsible for arranging and helping with someone's discharge from a health or social care setting should assess whether the person is likely to be vulnerable to the cold and if action is needed to make their home warm enough for them to return to.

Dying people will experience frequent admissions to different health and social care settings throughout the course of their illness, especially as they approach the end of their life. This could include admissions to hospital or use of hospices and care homes for a temporary period of care or respite. In 2016 alone, there were over 1.6 million emergency admissions to hospital among people in their last year of life in Great Britain.[40] The discharge process therefore presents a vital opportunity to assess patients' holistic needs, including the heating situation in their home.

When we asked Health and Wellbeing Boards about this recommendation, it revealed that lots of areas across England have plans, policies or procedures in place to prevent vulnerable patients being discharged to cold homes, although this isn't universal.

Some also mentioned obligations under the Care Act 2014 – specifically, the requirement that local authorities carry out holistic assessments of patients' needs, including the suitability of their home environment. While some people living in fuel poverty will undoubtedly have been identified through these assessments, the very existence of NICE guideline NG6 would seem to suggest that the Care Act alone is not sufficient to ensure everyone who needs support with a cold home at the point of discharge receives that support.

Recommendation: Primary health and home care practitioners should, at least once a year, assess the heating needs of people who use their services, whether during a home visit or elsewhere, taking into account the needs of groups who are vulnerable to the cold.

The financial circumstances facing terminally ill people and their carers may change at short notice. For example, if they are working age, they may be able to continue working for a while after receiving their diagnosis, but then have to reduce their hours or leave their job entirely once their symptoms worsen. If they are older, they may have built up savings before receiving their diagnosis, but find themselves having to spend this on expensive equipment or home adaptions as their condition deteriorates.

This means that essentials like heating may be affordable at one stage in a person's journey with terminal illness but unaffordable in others, so regular heating needs assessments from health and social care professionals can be a valuable tool in identifying dying people who have slipped into fuel poverty.

After asking Health and Wellbeing Boards about measures to implement this recommendation in their areas, it is clear that a lot of good work is being done across the country, with numerous areas providing local solutions to help identify households experiencing fuel poverty and deliver the support they need. Again, this isn't universal and it would also seem that some of the services that are in place do not have the regular annual assessment element that is recommended by NICE, which could make such a difference to dying people as their condition progresses.

Overall, our analysis suggests that important progress is being made in implementing key recommendations from NICE guideline NG6, but this isn't universal. Further action is needed to ensure that all areas in England have the strategies, plans and procedures in place to meet the NICE recommendations and protect local populations, as far as possible, from the health consequences of cold housing. Mechanisms to share best practice across areas may be helpful in this context.

Where applicable and appropriate, the measures recommended by NICE should also be implemented and prioritised in other parts of the UK, as advocated for by the likes of the Northern Ireland Fuel Poverty Coalition[41] and NEA Cymru.[42]

Conclusion and recommendations

Terminally ill people may experience a vicious cycle of fuel poverty. Their deteriorating health means they have to spend a lot more to heat their homes sufficiently, which they may be unable to afford, but the consequences of living in a cold home can cause their health and wellbeing to get even worse. For some, the impact may even hasten their death – cutting further the time they have to spend with loved ones and make memories.

We have made a number of policy recommendations to reduce, as far as possible, the number of dying people who can't afford to heat their home properly.

Financial assistance to support dying people suffering from fuel poverty

Delays and barriers to accessing financial support, including welfare benefits, make it even harder for some terminally ill people to afford heating costs. Changes are needed in the administration and delivery of a number of existing support programmes to help mitigate this.

- The six month rule in social security law should be scrapped so that terminally ill people can get fast-track access to the benefits they need, when they need them.
- People who claim Universal Credit under the special rules should not be subject to a five week wait for payments, which has been shown to result in destitution. In the short term, advance payments of Universal Credit should be changed to non-repayable grants.
- People diagnosed with a terminal illness should automatically qualify for support under the Warm Home Discount Scheme.
- The UK Government should add a 'vulnerability' component to the eligibility criteria for Winter Fuel Payments. This would recognise that people with terminal illnesses, of all ages, are at risk of being fuel poor, and help to ensure as many dying people as possible can access support to keep their home warm when they need it.

While there would be financial implications of these recommendations, it is reasonable to assume that this would be significantly offset by a reduction in the cost to the health service of treating morbidity associated with cold homes, which was estimated at over £5 billon between 2012 and 2016.[5]

Ben Gold/Marie Curie

Action to ensure greater implementation of NICE NG6 recommendations

Our analysis shows that, despite welcome improvements over the last few years, there is still work to be done to deliver universal action on the recommendations in NICE's guideline on 'Excess winter deaths and illness and the health risks associated with cold homes'.

- All relevant health and social care bodies in England should undertake an audit to measure their compliance with the NG6 recommendations, identify any gaps that exist and develop an action plan to address these gaps.
- Equivalent health and social care stakeholders in other jurisdictions of the UK should also audit their policies and strategies for tackling the health effects of cold housing and align them with the NICE recommendations.

Public health messaging on staying warm when you are terminally ill

As one of the groups most vulnerable to the effects of the cold, terminally ill people need as much information and advice as possible on staying warm during the winter months and cold periods.

In advance of the winter months, governments across the UK should run awareness-raising campaigns to deliver tailored information and guidance on staying warm to all people who are known to be terminally ill or approaching the end of their life. This should include automatic signposting to where they can get help if they are struggling with heating costs – including how to access programmes like the Warm Home Discount Scheme and Winter Fuel Payments.

Tools like palliative care registers, Key Information Summaries and GP records could be used to identify those who fall into these categories and may require support.

Appendix

Information and advice on fuel poverty from industry experts:

National Energy Action
www.nea.org.uk

Energy Action Scotland
www.eas.org.uk/

End Fuel Poverty Coalition
www.endfuelpoverty.org.uk

Fuel Poverty Coalition Northern Ireland
www.endfuelpoverty.org.uk

Citizens Advice
www.citizensadvice.org.uk

Age UK
www.ageuk.org.uk

The Consumer Council
www.consumercouncil.org.uk

References

1. Office for National Statistics (2020). Annual fuel poverty statistics in England, 2020 (2018 data).
2. Welsh Government (2019). Fuel poverty estimates for Wales: 2018.
3. Scottish Government (2020). Scottish house condition survey: 2018 key findings.
4. Northern Ireland Housing Executive (2019). Estimates of fuel poverty in Northern Ireland in 2017 and 2018.
5. National Energy Action (2016). Cold homes claiming needless lives and costing every local Health and Wellbeing Board in England over £27,000 each day. Available at: www.nea.org.uk/media/news/260216-01/
6. Scope (2018). Out in the cold.
7. George, M et al (2013). The energy penalty: Disabled people and fuel poverty.
8. Parkinson's U.K.
9. Kataoka, H and Ueno, S (2016). Severe cold lower limbs in patients with Parkinson's disease during the summer. Neurology International, 8 (4).
10. Oxford University Hospitals NHS Foundation trust. Chronic kidney disease.
11. Demos (2017). MND costs: Exploring the financial impact of motor neurone disease.
12. National Institute for Health and Care Excellence (2015). Guideline: Excess winter deaths and illness and the health risks associated with cold homes.
13. Macmillan Cancer Support (2016). Cancer patients risk being left out in the cold this winter. Available at: www.healthmatters.org.uk/history/cancer-patients-risk-left-cold-winter/
14. Marie Curie (2019). The cost of dying: The financial impact of terminal illness.
15. Macmillan Cancer Support. Cancer's hidden price tag: Revealing the cost behind the illness.
16. Carers UK (2018). State of caring 2018.
17. Kochovska, S et al (2018). Impacts on employment, finances and lifestyle for working age people facing an expected premature death: a systematic review. Palliative & Supportive Care, 16 (3).
18. Department for Work and Pensions. Personal Independence Payment: Official statistics to July 2020.
19. Trussell Trust (2019). #5WeeksTooLong: Why we need to end the wait for universal credit.
20. National Energy Action. Protect the Warm Home Discount. Available at: www.nea.org.uk/protect-warm-home-discount/#:~:text=As%20well%20as%20providing%20rebates,new%20boiler%20or%20central%20heating
21. 'Charities call for terminally ill patients to be given energy rebate'. The Guardian, 02.01.2011. Available at: www.theguardian.com/society/2011/jan/02/fuel-bill-discount-for-terminally-ill
22. Scope. Evidence to the National Assembly for Wales Climate Change, Environment and Rural Affairs Committee inquiry into fuel poverty. Available at: business.senedd.wales/documents/s95777/FP%2026%20Scope.pdf

23. National Energy Action and Npower (2011). Valuable to the vulnerable: Consumer perspectives on the Winter Fuel Payment.
24. Joseph Rowntree Foundation (2020). U.K. poverty 2019/20: Social security.
25. Citizens Advice (2018). Switched on: Improving support for prepayment consumers who've self-disconnected.
26. National Energy Action. Dangerous strategies people in fuel poverty adopt to cope. Available at: www.nea.org.uk/wp-content/uploads/2018/12/Infographic.pdf
27. Data gathered through the Carers NI State of Caring survey 2019. It should be noted that this data is not representative of all dementia carers in Northern Ireland, and only reflects the views of those who responded to the State of Caring survey.
28. Macmillan Cancer Support (2011). Facts and figures: Fuel poverty. Available at: http://www.macmillan.org.uk/documents/aboutus/newsroom/2013factsheets/fuelpovertyfactsandfigures050813(2).doc
29. Department of Health (2009). Annual report of the Chief Medical Officer.
30. British Lung Foundation (2017). Out in the cold: Lung disease, the hidden driver of NHS winter pressure.
31. National Energy Action (2018). Under one roof: Health and housing sectors tackling fuel poverty and cold-related ill health together.
32. Restrepo, M I et al (2006). COPD is associated with increased mortality in patients with community-acquired pneumonia. European Respiratory Journal, 28.
33. Office for National Statistics (2019). Excess winter mortality in England and Wales: 2018 to 2019 (provisional) and 2017 to 2018 (final).
34. National Records of Scotland (2020). Winter mortality in Scotland 2019/20.
35. Northern Ireland Statistics and Research Agency (2020). Excess winter mortality in Northern Ireland.
36. Marmot Review Team (2011). The health impacts of cold homes and fuel poverty.
37. Lakasing, E and Johnson, J G (2019). Fuel poverty: Significant cause of preventable ill health. GM Journal.
38. Citizens Advice Bureau (2011). A cold house for everyone? Fuel poverty in Northern Ireland.
39. National Energy Action (2016). Get warm soon? Progress to reduce ill health associated with cold homes in England.
40. Marie Curie (2018). Emergency admissions data briefing.
41. Northern Ireland Fuel Poverty Coalition (2019). A manifesto for warmth.
42. National Energy Action (2020). A new fuel poverty strategy for Wales.
43. World Health Organisation (2011). Environmental burden of disease associated with inadequate housing: A method guide to the qualification of health effects of selected housing risks in the WHO European region.

For more information:

Craig Harrison
Policy and Public Affairs Manager, Marie Curie

E: **craig.harrison@mariecurie.org.uk**

Marie Curie

Care and support through terminal illness

Thank you to everyone who supports us and makes our work possible. To find out how we can help or to make a donation, visit our website **mariecurie.org.uk**

Charity reg no. 207994 (England & Wales), SC038731 (Scotland) F407