All-Party Parliamentary Group
for Terminal Illness

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No place like home?

Report of the All-Party Parliamentary Group for Terminal Illness inquiry into housing and fuel poverty at the end of life

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Foreword

Drew Hendry MP,
Chair of the APPG for Terminal Illness

For many of us, a 'good' death would include the option to spend the end of our lives in our own home. More than two-thirds of us say this is what we would prefer – and being able to choose where we die is a vital source of solace for those living with terminal illness. Even if we do not die there, most of us will spend most of our final months and years at home.

However, there is often a stark difference between the ideal and the reality that many people face at the end of their lives. Living in poor quality, overcrowded or unsuitable housing, difficulties obtaining much-needed home adaptations or struggling to meet the costs of energy can mean that for many, home can be far from a good place to die.

These struggles can leave people living with terminal illness vulnerable to social isolation, worsening physical and mental health and make it harder for them to be cared for at home. They can also lead to significant financial hardship as the additional costs of living with a terminal condition make it still harder for families to afford their housing and heating costs.

Shamefully, those most likely to experience these unacceptable conditions are the poorest in our society. People on the lowest incomes are the least likely to die at home, even if they wish to, and are more likely than those on higher incomes to be living in poor quality housing or to struggle with housing and energy costs.

For those who are homeless, these troubles are even more pronounced. It is doubly difficult to provide palliative care to somebody who does not have a suitable place to spend the end of their life, and too often the complex needs of people experiencing homelessness mean that they are likely to die in unsuitable environments or in distressing circumstances.

The scourge of poverty affects too many people throughout their lives. It is a scandal that it also means that many people's experience at the end of life is needlessly difficult, painful, and stressful – and denies many the chance to die at home if they wish.

The APPG for Terminal Illness's report proposes a new deal for dying people. One document confirming their diagnosis should ensure the needs of people with terminal illness are treated as a priority and that they are made eligible for support through benefits, systems and services on a fast-track basis. Everybody deserves the best possible end of life experience – removing barriers to this basic right must be an urgent cross-party ambition.

I wish to pay tribute to my fellow members of the APPG for Terminal Illness for their support of this inquiry, to Marie Curie for organising the inquiry and collating this report, and to those organisations, charities, experts and health and social care professionals who gave written and oral evidence to the APPG.

Drew Hendry MP
June 2021

Introduction

All-Party Parliamentary Group for Terminal Illness

The All-Party Parliamentary Group (APPG) for Terminal Illness is a cross-party group of MPs with an interest in issues around terminal illness. Its purpose is to raise awareness of issues around terminal illness in Parliament and promote links between Parliament, individuals and families affected, charities, scientists, health professionals and decision makers.

The Group includes Members of Parliament from across the political spectrum who are keen to discuss, improve and share knowledge of end of life care.

The APPG meets several times a year to discuss topics surrounding terminal illness with individuals and organisations involved or interested in this area.

APPG for Terminal Illness membership:

- **Drew Hendry MP** – Chair
- **Jeffrey Donaldson MP** – Vice-Chair, Secretary
- **Liz Saville-Roberts MP** – Vice-Chair, Treasurer
- **Jessica Morden MP** – Vice-Chair
- **Imran Ahmad-Khan MP** – Vice-Chair
- **Jim Shannon MP** – Vice-Chair
- **Owen Thompson MP** – Vice-Chair
- **Lord Dykes** – Vice-Chair
- **Gavin Newlands MP** – Member
- **Alison Thewlis MP** – Member
- **David Linden MP** – Member

Secretariat

Marie Curie supports the work of the APPG for Terminal Illness through providing its secretariat.

Marie Curie is the leader in end of life experience in the UK. It works to provide a better life for people living with a terminal illness and their families. It offers expert care across the UK in people's own homes and in its nine hospices.

Last year, Marie Curie supported more than 50,000 people across the UK at the end of their lives. Its free information and support services give expert care, guidance and support to families so they can have something that really matters to them – time to create special moments together.

Marie Curie is also the largest charitable funder of palliative and end of life care research in the UK and campaigns inside and outside Parliament for the policy changes needed to deliver the best possible end of life experience for all.

About this inquiry

In this inquiry the APPG set out to explore how housing poverty and fuel poverty impact upon end of life experience.

More than two-thirds (67%) of us say we would prefer to die in our own home, and one of the key objectives of palliative and end of life care is to support people to die where they choose. Even those who choose not to die at home are likely to spend much of the final period of their lives at home. However, assumptions about the suitability of the home environment for providing care may not always be true for people experiencing poverty.

This inquiry explores the extent to which housing and fuel poverty affect the experience of people living with terminal illness, their families and carers – including their ability to die at home should they wish to.

The inquiry was conducted between March and May 2021 and its objectives were to:

- Hear from a wide range of experts, professionals and people who have experienced housing and fuel poverty at the end of life, or people who have worked with them.
- Understand how the experience of living in a cold or unsuitable home impacts a person's experience at the end of their life.
- Provide recommendations to policymakers and practitioners on ways to improve the experience of people facing housing and fuel poverty at the end of life.

Thirteen organisations, professionals and individuals with expertise across the housing, fuel poverty and end of life sectors responded to the inquiry's call for evidence. The call for evidence was followed by three oral evidence sessions with experts in these fields. More information on the organisations who contributed to this inquiry can be found at the end of this report.

This report is the second in a series of reports by the APPG for Terminal Illness. The first inquiry focused on the legal definition of terminal illness in benefits law, and can be read at:

https://www.mariecurie.org.uk/policy/appg-for-terminal-illness/legal-definition-of-terminal-illness

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Executive summary

> *"Fast-track access to housing, benefits and support with energy costs at the point of diagnosis, would make a huge difference to the lives of everybody who is affected by terminal illness."*
>
> Liz Allam, Association of Palliative Care Social Workers

One of the central goals of palliative and end of life care is to support people to die in the place of their choosing – and more than two-thirds of us say that we would prefer to die in our own home[1]. Even those who wish to die elsewhere will spend much of their final months and years of life living and being cared for at home.

But for those who are living with a terminal illness in an unsuitable environment, who are experiencing poverty, or who are homeless, there are often significant barriers to providing them with end of life care and a good end of life experience.

People who are experiencing poverty or are on lower incomes face health inequalities throughout their lives – they are more likely to have long-term health conditions, face barriers accessing healthcare services and have lower life expectancy than those on higher incomes[2]. Ill-health is also a driver of poverty – half of all individuals who live in poverty live in a household where somebody is disabled, and a quarter of unpaid carers live in poverty[3].

These inequalities in outcomes persist all the way to the end of a person's life. People experiencing poverty are more likely to live in homes which are not conducive to providing good-quality palliative care and, as a result, even if they would prefer to die at home, they're less likely to do so and more likely to die in hospital[4].

This report examines how housing and fuel poverty, and the experience of homelessness, impact on the end of life experience of those living with terminal illness – on their ability to and experience of dying at home, but also on their physical, mental and emotional wellbeing, financial situation, and the impact upon family members and carers.

It considers:

- the particular challenges of supporting people who are homeless at the end of life
- the health and wellbeing impacts of experiencing fuel poverty and living in a cold home at the end of life
- the difficulties providing end of life care in poor-quality or unsuitable housing
- the difficulties terminally ill people face in meeting their housing and energy costs.

The APPG found that each of these issues can have a profound impact on a person's experience at the end of their life, meaning that they are less likely to be able to die at home – or, if they do, that this experience is needlessly stressful, painful, or undignified.

Evidence to the APPG highlighted that people living with terminal illnesses often find themselves needing to spend more money on heating their homes, putting them at greater risk of fuel poverty. Many people on low incomes at the end of life are trapped in older, energy-inefficient homes or forced to pay for their energy through expensive prepayment meters, which only increases their energy costs and worsens fuel poverty.

Living in a cold home risks physical and mental health impacts that can exacerbate the symptoms of terminal illnesses and leave people isolated and miserable. For many terminally ill people, the need to keep their homes warm to stay healthy

Half of all individuals who live in poverty live in a household where somebody is disabled.

forces them into the impossible dilemma of having to spend less money on food or other costs to be able to heat their homes, or cutting back on energy use and risking their health further.

At the same time, many of the poorest people in the UK spend the end of their lives in poor quality, inaccessible or overcrowded housing, often with little security or protection from eviction. Adapting the home to meet the changing needs of a person with terminal illness is often needlessly difficult, and witnesses to the APPG's inquiry explained that providing good quality palliative care in an unsuitable home environment can be almost impossible.

Even where a person's home is unsuited to being cared for at the end of life, it is often extremely difficult to find alternative housing for them quickly. For many, the long and arduous local authority housing process makes it impossible, so they remain in a home environment where care cannot be provided easily, or have to be, against their wishes, cared for elsewhere.

Frequently, these issues are exacerbated by financial insecurity. Witnesses explained that terminal illness triggers a range of additional and enhanced costs that can leave individuals and families struggling to meet their housing, energy, and other costs. These costs often arise just as a person with terminal illness, and in many cases a family carer, are forced to reduce working hours or give up work entirely, meaning that even people who were previously comfortable can find themselves suddenly facing poverty.

While the benefits system can be a lifeline for people living with terminal illness, obtaining support is often unnecessarily difficult. Recent reforms to disability benefits have widened the gap between the level of benefits people receive and the support that people with terminal illness need to afford a decent standard of living, while support for people struggling with housing costs has fallen in value relative to housing costs and is often difficult to access.

When a person is homeless at the end of life, witnesses told us that the challenges of providing good-quality care are exacerbated by the fact that they have no secure place to call home. The complex needs of many of the homeless population – including early onset ageing, increased prevalence of long-term health conditions and barriers to accessing healthcare – make identifying and providing palliative care very difficult. Witnesses to the APPG's inquiry identified a frequent lack of coordination between homelessness services and those providing end of life care, which leads too many people to fall through the cracks in their final months of life.

While hostels and other temporary accommodation provide excellent support to people who are homeless, they are often not suitable for people at the end of life. Yet, too often, people cannot be placed in suitable, alternative accommodation before their deaths. Even where housing is made available, this is often inappropriate for the needs of somebody with a terminal illness.

Across each of these areas, the APPG's inquiry found a common theme. Too often, the benefits, systems and services available to support people who are homeless, people who are struggling to meet their housing and energy costs, or who are trapped in unsuitable housing, are needlessly inflexible. Dying people are frequently treated no differently to any other person and expected to fit in with rigid approaches instead of support being flexible enough to meet their needs. This leads to many individuals and families facing unnecessary hardship because they cannot access the support that would help them.

The recommendations in this report, as summarised on the next page, aim to address this and recognise the importance of ensuring support is quickly made available to people who have a limited time left to live and are often extremely vulnerable.

Introducing more flexibility – in the benefits system, in schemes targeting people experiencing poverty, and in the housing system – would ensure people living with terminal illness are treated as a priority and can quickly access the support they need.

Several of these recommendations focus on ensuring terminally ill people can be fast-tracked through processes and systems to get the support they need quickly and without facing delays. In order to facilitate this, the APPG has an initial and overarching recommendation:

1. **The UK Government should work with local authorities to introduce a ‘fast-track passport’ for people who have a diagnosed terminal illness that entitles them to access all relevant benefits and services on a fast-track or priority basis.** This should be a single document which is made available to all people with a diagnosed terminal illness, regardless of their prognosis.

This ‘passport’ would represent a new deal for terminally ill people experiencing poverty at the end of their lives, unlocking:

- Eligibility for help with the costs of energy and interventions to ensure they do not have to live in a cold home (Chapter One).
- Support with home adaptations they may need – or to be moved to a more suitable home (Chapter Two).
- Additional support to address the financial impact of terminal illness and the difficulties many face in meeting their housing and energy costs (Chapter Three).
- Priority support for housing in accommodation that is suitable for their needs if they are experiencing homelessness (Chapter Four).

The APPG believes that everybody has the right to end their life in a safe, warm and secure home if they wish to. The recommendations in this report will help ensure that everybody in our society, not just those who are better off, has the right to make that choice.

Summary of recommendations

Executive summary	1. The UK Government should work with local authorities to introduce a 'fast-track passport' for people who have a diagnosed terminal illness that entitles them to access all relevant benefits and services on a fast-track or priority basis.
Chapter one The impact of fuel poverty on people with terminal illness	2. Require Health & Wellbeing Boards and Integrated Care Systems to audit their compliance with NICE's NG6 recommendations on the health risks associated with cold homes. 3. The Department for Work & Pensions should introduce a 'vulnerability component' to the Winter Fuel Payment. 4. Energy providers should prioritise those with a terminal illness for switching from prepayment meters to credit or smart meters. 5. The Department for Business, Energy & Industrial Strategy should make terminally ill people automatically eligible for a payment under the Warm Home Discount Scheme 'core group'. 6. The Department for Business, Energy & Industrial Strategy should prioritise terminally ill people for intervention under energy efficiency schemes such as the Energy Company Obligation.
Chapter two Facing the end of life in unsuitable housing	7. Fast-track the processing and payment of Disabled Facilities Grants by local authorities for people diagnosed with a terminal illness. 8. Require local authorities to consider the outgoings of applicants for Disabled Facilities Grants as well as income and assets. 9. Require local authority housing departments to make direct housing offers to people diagnosed with a terminal illness. 10. Ensure local authority housing services have designated housing officers to deal with the needs of people with terminal illness. 11. The UK Government must act on its commitment to end Section 21 evictions.
Chapter three Difficulties affording housing and energy costs	12. The UK Government must scrap the six-month rule in benefits law. 13. The UK Government should not take the £20 per week uplift to Universal Credit. 14. The Department for Work & Pensions should introduce a new 'self-care element' to Universal Credit. 15. Local authorities should prioritise people with a terminal illness for Discretionary Housing Payments. 16. Fast-track payment of Support for Mortgage Interest loans to people with a terminal illness.
Chapter four Supporting people who are homeless at the end of their lives	17. Local authorities should adopt a 'housing first' approach to people experiencing homelessness at the end of life. 18. Health and social care professionals should adopt more flexible advance care planning models for people experiencing homelessness. 19. A duty should be placed on local authorities to consider the appropriateness of temporary accommodation for a person's health and care needs. 20. Local authority homelessness departments should have dedicated officers to deal with the needs of people with terminal illness.

Chapter one

The impact of fuel poverty on people with terminal illness

"Towards the end, the heating was on pretty much non-stop, so the bills absolutely skyrocketed. It probably didn't help that the house was quite old."
Karen, from Barnsley, whose dad Patrick had incurable lung cancer

Living in a cold home can have a severe impact on a person's end of life experience. Not only can it be bad for the health of those living with many terminal conditions, but the added costs of needing to heat homes to a higher temperature can drive many families into poverty. For many, this will mean they are faced with the impossible choice of choosing whether to pay for food or meet other bills, or heat their home.

Despite progress in tackling fuel poverty in recent years, many people remain in cold housing or struggle to heat their homes properly. According to the latest estimates in each nation, 10% of households in England, 12% in Wales, 18% in Northern Ireland and 24% in Scotland were classified as fuel poor[5].

People living with terminal illnesses are among the groups most vulnerable to falling into fuel poverty. In England, households that include somebody living with a long-term illness or disability account for 40% of all fuel-poor households[6], while households with at least one person categorised as vulnerable are one-and-a-half times more likely to be fuel poor than those without[7].

The health and wellbeing impact of living in a cold home at the end of life

Impacts on physical health

Many terminal illnesses, and the treatments for them, make people more susceptible to the cold[8]. If people cannot afford to heat their home sufficiently, they will spend the end of their lives living in a cold home. Feeling cold can exacerbate physical symptoms such as breathlessness and cause people additional pain[9].

For patients living with chronic obstructive pulmonary disease (COPD), for example, exposure to cold conditions suppresses their immune system, diminishes their lung capacity, and leads to an increased risk of bronchitis and pneumonia[10]. Research indicates that the likelihood of hospital admission for people with COPD increases fourfold in the winter months[11].

Cold, damp conditions in the home are a breeding ground for mould, which makes infection more likely. Such infections might be relatively minor for a healthy person, but for somebody living with a terminal illness – who may have a weakened immune system due to their condition or treatments like chemotherapy – they can be very dangerous[12].

In England, households that include somebody living with a long-term illness or disability account for 40% of all fuel-poor households.

"We had a gentleman who came into our hospice - he was living in private rented accommodation which wasn't badly maintained but within the bathroom had a lot of black mould. We got in touch with environmental health who actually condemned the property and said he couldn't return because it was a health hazard for him."

Samantha Moss,
Sue Ryder Manorlands Hospice

Mental health and wellbeing

Less visibly, living in cold housing can also have a severe impact on the mental health and wellbeing of people reaching the end of life. Cold housing is linked to increased levels of anxiety and depression[13], with studies showing a direct correlation between lower average temperature in the home and depression[14]. People living in fuel poverty are two-and-a-half times more likely to report that they feel high or moderate stress, compared to those who can comfortably afford their energy costs[15].

Many people living with a terminal illness also suffer from comorbidities such as arthritis, which are exacerbated by cold conditions – even simple tasks like making a hot drink can be made more difficult when the cold affects their dexterity. Many end up relying on others to help with these tasks, with the associated loss of independence affecting their wellbeing[16].

Experiencing fuel poverty can also increase social isolation. Increased fuel bills may mean that somebody cannot afford to go out, or they may be reluctant to invite loved ones to their home because it is cold[17]. For people already living with terminal illness, social isolation and loneliness, coupled with their condition, can be debilitating[18].

The challenges of living in a cold home with a person living with a terminal illness can also impact family carers. Where a person with terminal illness is struggling to afford their heating costs, family members will often compromise their own needs to ensure that they can afford to keep the heating on for their loved one, which can then impact their own health and wellbeing[19].

Case study

An elderly couple who were mostly housebound.

The husband was living with dementia, prone to infection and feeling the cold, which would affect his already low appetite.

He would only settle in the conservatory, watching the birds or listening to the radio, which he might decide to do at any time of day or night. His wife was buying less food for herself and making other financial sacrifices so that she could afford to keep the heater in the conservatory on 24 hours a day.

Source: St Mary's Hospice

Inadequate implementation of NICE guidelines in England & Wales

The National Institute for Clinical Excellence (NICE) has issued guidelines which make a number of recommendations to Health & Wellbeing Boards (HWBs) in England and Wales to help them identify and combat fuel poverty and the impacts of living in cold housing[20].

These recommendations include ensuring that HWBs have strategies in place to address the health impacts of cold homes and commission local single-point-of-contact health and housing referral services to support vulnerable people in cold homes. NICE also recommends that those responsible for arranging discharges into the home assess whether patients are likely to be vulnerable to the cold and take action if needed.
However, implementation of these recommendations is patchy. 43% of HWBs in England do not have a single-point-of-contact referral service in place, 40% do not have a cold homes strategy in place, and assessment of patients' heating needs is far from universal[21]. The structural landscape at local level is also rapidly changing, with many of the functions of HWBs overlapping with Integrated Care Systems[22].

The vicious cycle of fuel poverty and terminal illness

How high energy costs can worsen health

The average energy bill of a person living with some terminal illnesses doubles after their diagnosis[23]. As a person's health deteriorates, many spend more time at home and need to heat it to higher temperatures for longer, further increasing energy bills. This can force terminally ill people into the 'heat or eat dilemma' – having to reduce spending on food to afford heating costs, which risks malnutrition and weight loss. This, cruelly, can make terminally ill people feel even colder and force them to spend even more on energy[24].

This vicious cycle can, in the worst cases, be fatal. The World Health Organisation estimates that 30% of excess winter deaths are directly attributable to living in cold, damp housing[25]. Between 2014-15 and 2018-19, cold housing may therefore have been responsible for:

- over 19,100 deaths from respiratory conditions and nearly 10,900 deaths from dementia in England and Wales[26]
- over 710 deaths from chronic lower respiratory diseases and 930 deaths from dementia in Scotland[27]
- over 475 deaths from respiratory diseases and nearly 280 deaths from dementia in Northern Ireland[28].

The World Health Organisation estimates that 30% of excess winter deaths are directly attributable to living in cold, damp housing.

Layton Thompson/Marie Curie

Challenges obtaining support to meet energy costs

The Winter Fuel Payment (WFP) provides support to households struggling with their heating costs, but it can be difficult for many households experiencing fuel poverty to access this support. While the WFP is available to anybody aged over 65, it is unavailable to those aged under 65 even if they are experiencing fuel poverty or are otherwise vulnerable, meaning that people younger than 65 who are diagnosed with a terminal illness are excluded.

For those who are eligible, the WFP can only be applied for before 31 March of the year for which the claim is made and is then not paid until the winter, with payments often not received until the following March. If a terminally ill person does not fall ill during the period for which claims are open, they will be unable to claim until the following year and may die before they can benefit[29].

Given that terminally ill people often need to heat their homes to a higher temperature throughout the year and are at risk of severe health and wellbeing impacts from living in a cold home, the design of the WFP means many people living with terminal illness are denied a vital form of financial support.

The role of energy providers and retrofitting older homes

“The energy sector has been effective in its efforts to retrofit existing homes and make them more energy efficient - however, there is no doubt about it, there is still a long way to go.”

Daniella Weduwer, Energy UK

Prepayment meters

Witnesses highlighted that many terminally ill people from low-income households pay for energy via prepayment meters. Most households using prepayment meters are on low incomes[30], yet energy costs for prepayment meters are often higher than for those different energy tariffs[31]. It is therefore unsurprising that those on the lowest incomes can spend up to 30% of their income on fuel costs, compared to as little as 3% among non-fuel poor households[32].

60% of terminally ill people rely on benefits as their main income[33] and are less able to absorb the higher cost of energy on a prepayment meter. Even adding credit to the meter can be a challenge, with people often too unwell or lacking the mobility to get to a shop[34].

As prepayment meters require a standing charge – a daily fee for being connected whether any energy is being used or not – patients will often return to their home after a lengthy hospital or hospice admission to find a debt on their meter, causing further financial hardship as they must pay this off before adding further credit[35].

Up to 16% of prepayment meter customers 'self-disconnect' each year – not topping up the meter when it runs out of credit[36] - often going without power for days or weeks[37]. For terminally ill people, who may have medical equipment in the home that requires power, the impact of self-disconnection can be severe and even life-threatening.

While tenants have the right to request a credit meter, suppliers often require a credit check or a deposit before they will install one[38]. As many people on low incomes have poorer credit, and most families living with terminal illness rely on benefits as their main source of income, many will be unable to switch to a credit meter – only around one in ten attempted switches is successful[39].

Support from energy providers

Some statutory support for customers having trouble with their energy bills is available through the Warm Home Discount Scheme (WHDS), which gives those who are eligible £140 off their energy bill between October and March.

While those receiving the Guarantee Credit element of Pension Credit are automatically eligible for a payment under the WHDS (the 'core group'), the criteria for the so-called 'broader group' vary between providers[40], making it difficult for people to know whether they qualify.

Payments to the 'broader group' under WHDS are discretionary and frequently paid on a first come, first-served basis. They are limited by an energy provider's allocation; meaning that people who may benefit but do not know they are eligible or do not come forward quickly enough often lose out[41].

There have been multiple calls from charities for terminally ill people to be automatically eligible for a WHDS payment as part of the 'core group'[42] or for the eligibility criteria to be extended to more vulnerable households[43], however these calls have not been acted upon.

Older and energy inefficient housing

Only 30% of homes in the UK currently meet Energy Performance Certificate (EPC) band C[44] - households living in less-efficient homes deemed to be in fuel poverty according to the UK Government's measure[45]. An increasing proportion of lower-income people and people who rent are living in converted[46] or older properties[47], which are more energy inefficient and more expensive to heat[48]. As the UK's population ages, many more people are at risk of growing older in energy-inefficient homes and facing fuel poverty at the end of life.

These challenges can be particularly acute in rural areas, where a higher proportion of homes are off the gas grid and households are more likely to heat their homes using more expensive fuels[49] and 12.5% of rural families are in fuel poverty[50]. Fuel poverty is also twice as 'deep' in rural areas, with the average rural fuel poor family needing to save £600 a year to make their energy affordable, compared to £300 for an urban fuel poor family[51].

A range of measures have aimed to improve the energy efficiency of homes in the UK, with some – such as the Energy Company Obligation (ECO) – being targeted at low-income households[52]. The ECO scheme will extend until at least 2025[53], however there is no requirement on energy companies to make it available to people living with a terminal illness unless they are already in receipt of a WHDS payment or certain relevant benefits[54].

> *"Programmes like these have led to a higher proportion of energy efficient, warmer homes that meet a better standard - but many of those programmes have now come to an end, particularly in England."*
>
> Rachel Casey, Joseph Rowntree Foundation

Recommendations

Terminally ill people deserve to live the end of their lives in a safe, warm home – it is not right that they are among the groups most vulnerable to falling into fuel poverty, with many falling into a cruel cycle of higher energy costs, financial distress, and worsening health.

The health and wellbeing impact of a cold home is clear and well-understood; local services must do more to identify those people who are the most vulnerable to the cold and support them to be comfortable at home at the end of life, should they wish to be cared for there.

While support schemes exist in the benefits system and the energy sector for people who are experiencing fuel poverty, many of these are insufficiently targeted or flexible to benefit many terminally ill people. Terminal illness can affect a person at any time of their life and at any time of year – limiting financial support to those of a certain age or in certain circumstances, or to certain times of year, means that terminally ill people who desperately need support are denied assistance.

The APPG recommends:

2. **Require Health & Wellbeing Boards and Integrated Care Systems to audit their compliance with NICE's NG6 recommendations on** the health risks associated with cold homes, identify any gaps in compliance that exist and develop an action plan to urgently address these gaps.
3. **The Department for Work & Pensions should introduce a 'vulnerability component' to the Winter Fuel Payment** so that vulnerable people, including those with a diagnosed terminal illness, are eligible for the payment even if they are under 65 years old. Claims under this component should be paid on a fast-track basis and be able to be claimed throughout the year.
4. **Energy providers should prioritise those with a terminal illness for switching from prepayment meters to credit or smart meters** and allowing people with a diagnosed terminal condition to switch away from a prepayment meter without being required to pay a deposit.
5. **The Department for Business, Energy & Industrial Strategy should make terminally ill people automatically eligible for a payment under the Warm Home Discount Scheme 'core group.'** It is not right that those living with a terminal condition are required to apply for support on a first come, first-served basis.
6. **The Department for Business, Energy & Industrial Strategy should prioritise terminally ill people for intervention under energy efficiency schemes such as the Energy Company Obligation.** Where a person has a diagnosed terminal illness, they should be automatically eligible for efficiency measures under these schemes, which should be carried out on a fast-track basis.

Chapter two

Facing the end of life in unsuitable housing

"It's often the case that people don't achieve their wish of dying at home because of their housing conditions."
Carolyn Walker, St Christopher's Hospice

Two-thirds of us would prefer to die in our own home and community[55], and one of the key objectives of palliative care is to support people to die at home should they wish to do so.

People who are better-off are more likely to die in their own home than people who are poorer, who are more likely to die in hospital[56] – with studies showing a person's home environment is a key determinant of whether or not they are able to die at home[57].

Living in a home that is unsuitable for end of life care creates significant challenges. For many, it means they are denied the opportunity to die at home even when it's their preference, and for others, it means their experience of dying at home is stressful, painful and isolated.

1.8 million people in the UK have an accessible housing need.

Trapped in inaccessible housing

"I worked with a young man with end-stage bowel cancer, who had no toilet on the floor he was on, sharing a tiny bedroom. His family watched him suffer up and down, a young man with so much dignity in himself, but he would struggle up and down those stairs. We had been trying for over a year to get him rehoused but it was impossible. The impact on not only him but his family was needless."
Pippa Dean, Association of Palliative Care Social Workers

1.8 million people in the UK have an accessible housing need[58], but at least one in six households with an identified housing need do not have all of the accessibility features they require[59] - meaning that thousands of people living with disabilities and terminal illnesses remain in inaccessible housing. Many others who would benefit from specialised housing are unable to access it - two-thirds of people living with dementia, for example, live in mainstream housing[60].

Challenges caused by inaccessible homes at the end of life

For people living with terminal illness, housing needs are multidimensional – people may need adaptations such as handrails, stairlifts or walk-in showers, in addition to space for equipment such as hospital beds, oxygen supplies and hoists[61].

It is often particularly difficult to fit such equipment in small, cramped rooms, or on the higher floors of flats with poor access. This is a particular challenge in high density areas like London[62].

Without adaptation, many patients with mobility issues cannot manage stairs. For those living on higher floors, this can be a significant challenge which not only impacts their quality of life – for example if toilet facilities are unavailable on the floor they are on – but presents a real risk to their life in the event of a fire[63].

Poor accessibility increases the risk of social isolation and restricts social participation, increasing the burden on informal carers and family members[64]. In the worst cases, accessibility challenges can lead to patients being unnecessarily confined to their homes, or even to one room or a bed at the end of their lives[65].

A lack of space in the home can also present difficulties for care workers. Carers need a certain amount of room around a bed in order to provide care safely; if this is unavailable then providing care at home can be impossible. Witnesses explained that as a result, in some cases agencies can be reluctant to provide care in such environments[66].

It is not unusual for discharges from hospital or inpatient hospice units to be delayed due to these accessibility challenges, which can lead to patients ultimately dying in an inpatient unit despite their preference to die at home. Waiting for equipment and adaptations accounted for 51,328 lost hospital bed days in 2017/18[67], while studies have suggested that adaptations in the home can help delay entry to residential care by four years[68].

> *"If you're in unsuitable housing, a lack of space for equipment to be kept can mean a lack of space for other family members in the home, and if you've got carers coming in to deliver personal care, they need space to move around safely. It limits your choices about where you can be cared for."*
>
> Sharon Cole, Sue Ryder Manorlands Hospice

Case study

A woman in her 50s who lived in a second floor flat in a building with no lift. She had cancer, which caused weakness in her legs and affected her mobility – she eventually became confined to her flat, missing out on seeing her family and engaging in social activities she would otherwise have been able to do in her wheelchair.

She was supported by a palliative care social worker to apply for a transfer to a level access property but there was none available; eventually after a year of being isolated at home she was moved. She died a month later.

Source: Association of Palliative Care Social Workers

Problems obtaining home adaptations

> *"We need to meet the growing accessibility needs of the population, which will continue to increase as we have more people living to an older age with disability and comorbidity. The demand for accessible housing is only going to increase and if we don't make much better strides in adapting existing housing stock, then we won't be able to meet those demands."*
>
> Alex Massey, Motor Neurone Disease Association

The UK's ageing population means that accessibility needs will only increase in future – by 2040, nearly one in seven people is projected to be aged over 75[69]. There is an urgent need to ensure that a far greater proportion of the UK's housing is accessible, or in future decades many more people will be facing the last years of their lives in housing that is unsuitable for their care needs.

While improving the proportion of new-build housing that is built to high quality and accessibility standards is important, it will not be sufficient. Around 85% of the homes we will live in in the year 2050 have already been built[70] - meaning that many people with long-term health conditions are already living in, and will continue to live in, housing that already exists.

It is imperative that action is taken to adapt existing housing stock to ensure it will meet the accessibility needs of the population in future. It is therefore worrying that witnesses to the APPG's inquiry raised serious concerns about the ability of people at the end of life to obtain the home adaptations they need.

The cost of home adaptations is often significant – schemes like the Disabled Facilities Grant (DFG) exist to provide financial support to people who need to adapt their homes but are unable to do so. However, the DFG scheme is beset by slow delivery timescales which cause problems to people at the end of life. In 2016/17, two in five local authorities in England failed to pay all approved DFGs within one year[71].

Such delays are an additional source of stress for patients and their families, who must cope with living in un-adapted housing while waiting for payments[72]. In many cases, by the time a DFG is eventually paid, a terminally ill person will have deteriorated beyond the point that adaptations can help them, or they may have died while waiting for it to be paid[73].

In addition, support for the DFG is means-tested. While the means test takes assets and income into account, it does not consider the real costs of living with a terminal illness, while means test thresholds have not kept pace with inflation and housing costs[74]. In practice, this means many terminally ill people are denied the financial support to make their home accessible despite not having the means to pay for it themselves.

Providing end of life care in overcrowded or non-decent housing

Living in poor quality housing at the end of life

"I worked with a young man in his early 30s who was sharing a flat above a pub with another person, he didn't know the other person's name, but they had all facilities shared. The other person was quite obstructive to carers coming in to look after him. The housing team tried very hard and acted as fast as they could, but unfortunately he still died before they could move him to more suitable accommodation."

Liz Allam, Association of Palliative Care Social Workers

Witnesses to the APPG's inquiry agreed that it can be extremely difficult to provide good-quality end of life care in poor or unsuitable housing, and so it is often the case that people do not achieve their wish of dying at home because of their housing conditions[75].

Many older people, and people living with chronic health conditions or disabilities, are living in poor, inadequate or non-decent housing[76 77]. This has significant impacts on health and wellbeing, and in the most extreme cases can be potentially life-shortening[78].

19% of homes in England and 14% in Wales are classified as non-decent[79], while in Scotland, 45% of dwellings failed to meet the Scottish Housing Quality Standard in 2016[80]. The risk of living in poor quality housing is much higher for people experiencing poverty; more than a fifth (23%) of the poorest fifth of households in England live in non-decent housing, compared with 16% of the richest fifth[81].

23% of the poorest households in England live in non-decent housing.

It is not uncommon for palliative care workers to visit a patient at home and find the accommodation to be cold, damp and mouldy, or in a poor state of repair[82]. For patients with lung or respiratory illnesses, or who have a weakened immune system, this represents a serious risk to their health.

Overcrowding is also much more prevalent among lower-income households, affecting 7% of people in the poorest fifth of households in England, compared with less than 0.5% of those in the richest fifth[83]. People from Black & Minority Ethnic (BAME) backgrounds are also more likely than White British households to be living in overcrowded housing[84].

Witnesses identified numerous cases of providing palliative care to people in overcrowded housing – often with whole families sharing one room. This presents significant challenges in the delivery of the care that patients need and can act as a barrier to having important conversations with the patient about their care, due to the lack of private space[85].

Challenges finding suitable housing

“It’s a sad fact of life that often patients will die before they’re rehoused or won’t be able to be cared for at home. We often will make a rehousing application and get a standard letter back saying that this person doesn’t meet the requirements for a transfer on medical grounds. So that begs the question, if somebody is at the end of life and they don’t meet the requirements, who does?”
Carolyn Walker, St Christopher’s Hospice

Even where people who are living in unsuitable, poor-quality, or overcrowded housing have a terminal illness, witnesses highlighted that it is often very difficult for them to be rehoused to a more suitable property that might be more conducive to receiving end of life care. Fewer than a quarter of local authorities in England report that their housing department works closely with social care services in relation to end of life support[86].

Making a successful rehousing application is often a long and arduous process. For many patients there is very little hope of being rehoused in their lifetime, with many unable to be cared for at home altogether and ending up being cared for in a hospice or nursing home[87].

Palliative care social workers have experienced cases of people losing out on properties simply because they were unable to ‘bid’ on suitable properties at the specific time they are released by local authorities – often due to clashes with necessary medical treatment or hospital appointments[88].

Witnesses also highlighted that housing officers at local authority housing services teams or housing associations are often unfamiliar with the specific needs of people at the end of life and their specific housing needs[89]. Where good practice does exist among local authorities, this is often where palliative care teams or social workers have built ad-hoc relationships with individual housing officers in local authorities, as opposed to robust processes[90].

Hospices will often make a rehousing application on behalf of a patient but be told the patient does not meet the minimum requirement for a transfer on medical grounds[91]. Assessments against these criteria are often made based on the patient’s circumstances at the point they apply, without consideration of how their condition may change over time[92].

While housing departments can make direct offers to people in certain conditions, bypassing the bidding system, this is done at the discretion of the local authority and there is no requirement for a person’s health circumstances to be considered when determining whether to make a direct offer.

“Some social workers have better experiences than others. There’s a lack of understanding about a person’s needs in the processes involved - for example they expect us to be bidding on houses and they don’t take into account the fact that a person might be too unwell to bid, or they might be in hospital. The systems and processes to access housing are tricky, but fundamentally this comes down to the fact that there’s a lack of housing stock.”
Liz Allam, Association of Palliative Care Social Workers

Layton Thompson/Marie Curie

A growing number are growing old in private rented homes

Facing the end of life in rented housing

Pensioner households are the fastest-growing household type in the UK and the proportion of pensioner households living in poverty has risen over the last decade[93]. With shortages of social housing and many people unable to afford to own their own home, more people will grow old in the private rented sector.

As a result, the number of people who are renting the home they are living in at the time they develop complex health problems that ultimately need palliative care, will grow in future.

In 2019, nearly a quarter (23%) of privately rented homes did not meet the Decent Homes Standard, compared to 16% of owner-occupied homes[94], and the rate of improvement has slowed markedly over the last decade[95]. Similarly, just 11% of homes in the private rented sector are accessible[96].

Patients living in private rented accommodation can face particular challenges arranging necessary home adaptations, with private landlords often reluctant or slow to respond to such requests[97]. These delays often mean that patients die while waiting for works to begin[98].

Private tenants who receive benefits can also face discrimination from landlords in the sector[99] – more than half of landlords

(57%) report that they are unwilling to let to people who claim Universal Credit[100]. This is of particular concern as an estimated 60% of people living with a terminal illness rely on benefits as their main source of income[101].

Lack of security in the private rented sector

Private renters also have far less security of tenure than social renters and move more often, which can be costly and lead to disruption and stress – especially for those living with terminal illness and disability. This lack of security is encapsulated by the continued threat of tenancies being ended through a 'no-fault' eviction under Section 21 of the Housing Act 1988. As the private rented sector has grown in size, the use of no-fault evictions has correspondingly increased markedly[102]. While the UK Government has committed to ending no-fault eviction, no legislation has yet been brought forward to end the practice[103].

There is nothing to prevent a landlord serving a notice to quit on somebody who has been diagnosed with a terminal illness, and a person's recourse to challenging such an eviction may be extremely limited[104]. There is little protection from a no-fault eviction for renters in arrears due to delays in benefit payments, as judges are not required to take this into consideration.

Given the concerns with how terminally ill people are treated by the benefits system, many families living with terminal illness are at risk of falling behind on rent due to delays in benefit payments – and then face the prospect of losing their home.

This lack of security means that private renters often do not want to raise issues with their landlords – including such issues as possible home adaptations, problems with damp or mould, or difficulties affording rent. Nearly half (45%) of renters do not feel comfortable speaking to their landlord about issues they are having[105].

Recommendations

Many people living with a terminal illness are trapped in housing that is inaccessible, unsuitable or of poor quality. For many, this will mean they are unable to die at home should they wish to; for others, their experience of dying at home will be unnecessarily stressful, isolated and undignified due to their housing conditions.

The fact that schemes designed to support people to adapt their homes are often failing to meet the needs of terminally ill people, and that people living with terminal illness face long and arduous processes before they can be moved out of non-decent housing, are significant concerns. The APPG is deeply concerned that nothing prevents a private landlord from evicting a tenant who is living with a terminal illness, and that there is little legal recourse for the tenant if they do.

Everybody living with a terminal illness should be able to expect a safe, secure and suitable home at the end of life so they can focus on their health, not their housing situation.

The APPG recommends:

7. **Fast-track the processing and payment of Disabled Facilities Grants by local authorities for people diagnosed with a terminal illness,** so that people with a limited time to live are not required to wait for months before knowing whether they will receive support to adapt their home, or before receiving that support.
8. **Require local authorities to consider the outgoings of applicants for Disabled Facilities Grants as well as income and assets** when means-testing eligibility for the grant. As outlined in Chapter Three, the high level of additional costs faced by people living with terminal illness mean that a means test which does not consider these costs risks unfairly denying terminally ill people support for home adaptations.
9. **Require local authority housing departments to make direct housing offers to people diagnosed with a terminal illness,** bypassing the bidding system. Where properties are available, those with a terminal illness should not be required to bid for suitable housing in which to spend the end of their lives.
10. **Ensure local authority housing services have designated housing officers to deal with the needs of people with terminal illness.** Housing services should ensure that designated housing officers, who understand the needs of people with life-limiting and terminal conditions, are available to support the housing needs of people at the end of life, from adaptation to rehousing.
11. **The UK Government must act on its commitment to end Section 21 'no-fault' evictions.** Given the importance of a secure home environment to people at the end of life, it is unacceptable that people with a terminal illness continue to have no protection from no-fault eviction.

Chapter three

Difficulties affording housing and energy costs

Two-thirds of households affected by terminal illness face financial strain as a result.

"I dread to think what the bills will be, come the height of winter – with things as they are, we'll have to rob Peter to pay Paul, it's a real stretch."

Sian, from Surrey, who is living with incurable cancer

Financial hardship can have a direct impact on a person's ability to meet their housing and energy costs at the end of life. Facing significant one-off, additional and enhanced costs at precisely the point that one or more wage earners may have been forced to leave the workforce can leave households living with terminal illness facing an impossible financial situation – and unable to pay even previously affordable bills.

Families and individuals on lower incomes and those who rent are the hardest hit, but the combined impact of higher costs and lower income after being diagnosed with a terminal illness can drive even people who were previously comfortable into poverty.

The high cost of dying in the UK

"Being in poverty worsens insecurity - not knowing whether you're going to be able to cover your bills or put food on the table... whether your landlord is going to evict you because they can. This is the experience for many."

Rachel Casey, Joseph Rowntree Foundation

In the UK, two-thirds of households affected by terminal illness face financial strain as a result[106]. Following a diagnosis of terminal illness, families face a range of changing circumstances that can have a significant impact on their finances – one or more members may need to reduce their hours, take on caring responsibilities or give up work entirely, and outgoings due to bills and additional costs may rise just as their income is falling.

Additional costs

People living with terminal illness face three types of additional costs[107]:

- One-off costs such as housing adaptations or an adapted vehicle.
- Regular costs such as care costs or paying for extra assistance around the home.
- Enhanced costs that would likely have been incurred anyway but which are higher as a result of illness, such as energy bills or travel.

The cost of home adaptations is by far the largest one-off cost most families living with terminal illness face. The adaptations somebody may need range from relatively inexpensive additions such as grab rails or wheelchair ramps, to far more extensive adaptations to the home such as installing an accessible bathroom or a stairlift. Major adaptations can be expensive – the average cost of home adaptations is £16,000[108] and over 95% of respondents to one survey said that the costs involved were a major barrier to adapting their home[109].

Where families have to pay for regular costs such as care and support at home, these costs can run into the thousands of pounds over time – the average hourly rate for a carer is around £20 and a live-in carer can cost a family around £650 a week[110].

The largest enhanced cost families living with terminal illness face is for energy. People living with terminal illness are often particularly susceptible to the cold and so need to heat their homes more continuously and to higher temperatures[111]. The cost also increases because of the need to use some medical devices – such as electric adjustable beds – which may need to be on 24 hours a day.

In 2014-16 alone, people with cancer in the UK spent an additional £15.7 million per year approximately on energy bills[112], while the average energy bill of a person with motor neurone disease can double after diagnosis[113].

The combined impact of these additional costs is significant – witnesses to the APPG's inquiry estimated that the total cost of living with a terminal illness can be between £12,000 and £16,000 per year on average, with this average concealing significant variation[114].

Housing costs

Meeting housing costs can be a significant struggle for families facing terminal illness. Those who rent or have a mortgage are more likely to struggle to keep up with their housing costs if they develop a terminal illness than those who own their home outright, with additional costs and falls in income making even housing costs which were previously affordable suddenly more difficult to afford.

On average, owner-occupiers in England spend around 18% of their income on housing costs, compared to 27% for social renters and 32% for private renters[115]. With the proportion of household income spent on costs related to terminal illness ranging from 16% to as high as 98% depending on income[116], the impact of a terminal illness can suddenly render housing costs unaffordable for many families.

People in rural areas may have particular struggles in meeting their housing costs after a terminal diagnosis. Affordable housing can be scarce in rural areas, with homes on average 25% more expensive than in urban areas, while there is much less social and affordable housing to rent in rural areas for those unable to buy[117].

42% of private renters and 65% of social renters have savings of less than £500[118] – given the scale of additional costs incurred by families living with terminal illness, these savings are likely to be quickly exhausted and result in further strain on a family's ability to meet their housing costs.

Case study

A man in his 40s who had always lived and worked in the City of London had a well-paid job which had comfortably covered his rent before he fell ill. When he fell ill with cancer, he had to give up work – his rent was so high it was not fully covered by Housing Benefit. All of his benefits went on rent and his savings were being eaten away by the month.

He would keep his heating on low as he was the only one in the property – he was undergoing chemotherapy and tired from this, yet he was not resting as he should've been or as warm as he should've been. He was also suffering from depression due to his financial situation and ill-health.

Source: St Mary's Hospice

Barriers to employment and inadequate welfare support

Income loss

> *"People's lives can change overnight - usually they will have to give up work at some point, so there is a huge income drop. Not only do they have to give up work, but often their spouse or partner may give up work to care for them, so the knock-on effect on a family's income can be massive, and that can happen quite quickly."*
>
> Samantha Moss,
> Sue Ryder Manorlands Hospice

The impact of these costs often hits at exactly the point a household's income is severely reduced. People living with a terminal illness will likely have to reduce their working hours, and eventually give up work entirely, due to their deteriorating health. More than four in five advanced cancer patients, for example, report income loss as a result of their condition[119].

Similarly, more than a fifth of unpaid carers report having to reduce their working hours to provide care[120]. The impact of two or more earners in a household being out of work at the same time can create a 'double burden' on household finances, making it even harder for families to meet the higher costs they face as a result of terminal illness.

For people who are retired, additional costs are likely to come at a time when their income has already fallen, or they are on a fixed income from pensions or other savings. This can mean they are less able to absorb new costs and may struggle financially as a result[121].

The six-month rule

The benefits system can be a lifeline for families living with terminal illness. However, the 'six-month rule' – that requires dying people to prove they have less than six months to live to access the Special Rules for Terminal Illness (SRTI) and get fast-track access to benefits – is unfit for purpose. It excludes many terminally ill people with unpredictable conditions, forcing them to endure long delays to get the support they need or being rejected for benefits entirely.

Nearly two years on from the Department for Work & Pensions (DWP) announcing a review of this system, the Department has yet to publish the results of this review and bring forward proposals to change the law as recommended by the APPG in 2019[1].

Universal Credit

The move to Universal Credit has led to further gaps between the amount of benefits people receive and the financial support that those with terminal illness need for an adequate standard of living.

In particular, the move to Universal Credit raises concerns for people living with terminal illness who are living alone and don't have a carer in receipt of Carer's Allowance to look after them. While they may have been eligible for a 'Severe Disability Premium' (SDP) under the Employment and Support Allowance (ESA) legacy benefit, the SDP is being abolished for new Universal Credit claimants.

The SDP provides critical support for the additional costs of care incurred by severely disabled people living alone, and the loss of this premium could leave new claimants as much as £44-£84 worse off each week[122]. This is likely to lead to many people with life-limiting illnesses facing higher costs, and additional social isolation, as a result of struggling to afford private care support[123].

Phil Hardman/Marie Curie

Similarly, the five-week wait for Universal Credit applies to all claimants, regardless of whether they applied through the Special Rules or not, and has been shown to result in destitution – specifically, in the inability to afford essential household bills[124].

Other social security benefits

> *"The number of pensioners living in the private rented sector and in poverty after housing costs has increased. This is likely because of rising rents that the Local Housing Allowance isn't keeping up with - there is evidence that constraints on Local Housing Allowance mean that pensioners are having to use State Pension or disability benefits to cover their rent."*
> Rachel Casey, Joseph Rowntree Foundation

Witnesses to the inquiry highlighted numerous other examples of the value of social security benefits often not being enough to help families living with terminal illness to afford their living costs, and often not covering all of the costs they are supposed to cover.

Local Housing Allowance (LHA) rates – used to work out Housing Benefit and the Universal Credit housing element for people renting in the private sector – were not enough to cover the rents of 715,000 households in November 2020[125]. LHA rates have been falling further and further behind average rent prices and have recently been frozen again following a temporary reset in response to the Covid-19 pandemic[126].

The trend of increasing social rents, along with welfare reforms such as the Removal of the Spare Room Subsidy (RSRS or 'Bedroom Tax') as well as the overall benefit cap, have impacted some social renters' ability to meet their housing costs. One in five households on Universal Credit with a housing entitlement receive an average monthly reduction of £70 due to the RSRS[127]; for somebody living with a terminal illness and facing other enhanced costs, this may be the difference between being able to make ends meet or getting into arrears.

A Discretionary Housing Payment may be paid by local authorities to people struggling to meet their housing costs due to the RSRS or if the LHA is insufficient to meet their rent. However, as the name suggests, Discretionary Housing Payments are made at the discretion of the local authority and there is no requirement for local authorities to consider whether a person is terminally ill before deciding whether or not to award a payment.

Homeowners may be able to access support via the Support for Mortgage Interest (SMI) scheme, but this scheme is insufficiently flexible to meet the needs of people living with terminal illness. People may be eligible for SMI if they are in receipt of Universal Credit or Employment & Support Allowance – but unless they are also in receipt of Pension Credit, they must be in receipt of these benefits for nine months before an SMI loan will begin and there is no fast-track process for those with a terminal illness[128]. This excludes dying people under Pension Credit age who need support but do not live long enough to qualify, and leaves others facing a long wait to receive support with their housing costs.

The shortfall between benefit payments received and a household's outgoings often leaves households living with disability facing higher deprivation than those on a similar income who are not living with terminal illness and disability[129]. On average, people living with disability face costs of £583 each month to sustain the same quality of life as a non-disabled person – even after disability benefits have been received[130].

People living with disability face costs of £583 each month to sustain the same quality of life as a non-disabled person.

Recommendations

Dying people and their families should not face cripplingly high costs and inadequate support from the benefits system at the end of their lives.

The APPG is deeply concerned that many of the social security benefits that are supposed to provide the lifeline of financial support to families living with terminal illness are insufficient to meet the costs they face or are too inflexible to provide the support they need.

This is driving many families and individuals into poverty and destitution at a time when they should be able to focus on their health and making the most of the limited time they have left together.

The APPG recommends:

12. **The UK Government must scrap the six-month rule in benefits law** so that all terminally ill people can get fast-track access to the benefits they need, when they need them.
13. **The UK Government should not take £20 away from dying people by cutting Universal Credit this October.** Abolishing the uplift in September 2021, as planned, would leave the poorest fifth of households £350 worse off across 2021-22[131], impacting the ability of many terminally ill people and their ability to afford housing and heating costs.
14. **The Department for Work & Pensions should introduce a new 'self-care element' to Universal Credit** to replace the Severe Disability Premium. This should be available to those who meet the eligibility criteria to have somebody receive Carer's Allowance or a carer element to look after them, but do not.
15. **Local authorities should prioritise people with a terminal illness for Discretionary Housing Payments** to help them meet their housing costs if they are affected by the Removal of the Spare Room Subsidy, or if the Local Housing Allowance is insufficient to meet their housing costs.
16. **Fast-track payment of Support for Mortgage Interest loans to people with a terminal illness** if they meet the criteria to receive one, even if they are not in receipt of Pension Credit. It is wrong that people with a limited time to live must face a nine-month wait before they can receive support.

Chapter four

Supporting people who are homeless at the end of their lives

> *"There is a huge gap in provision - there is nowhere for people who have high care and support needs to go at the moment, they often end up in temporary accommodation or hostels without adequate support."*
> Dr Caroline Shulman,
> University College London

The challenges faced by people at the end of their lives are intensified when somebody has no permanent place to call home, since they may be unable to access the services they need or unable to find a suitable place in which to spend the end of their lives.

People who are homeless have a much higher likelihood of having a long-term health condition. Early onset of frailty is more common[132], as is cancer[133] and early prevalence of cardiovascular disease[134]. As a result, the average age of death for people who are homeless is 46 for men and just 43 for women[135] – this reduced life expectancy brings further challenges at the end of life.

While palliative and end of life care support people to die in the way – and in the place – they wish to, for it to be most effective a person's care should ideally be planned in advance wherever possible. Many people who are homeless are unable to access palliative care until very late in their illness if at all. As a result, options for care are often extremely limited, and their deaths are more likely to be perceived as traumatic and undignified[136].

Challenges delivering health and social care to people who are homeless

The complex needs of people experiencing homelessness

Many homeless people have multiple and complex health and care needs throughout their lives, in some cases compounded by substance dependency and addiction. Difficulties often stem from adverse experiences and complex trauma, often during childhood, that can result in lifelong challenges in developing trusting relationships and emotional regulation; this can result in impulsive behaviour[137], difficulties navigating systems[138] and poorly managed addictions and mental ill health[139].

These difficulties can lead to behaviours that present as 'challenging' to palliative care and other professionals on a ward or in a community. Previous negative experiences can mean that people are reluctant to engage with professionals and do not feel comfortable discussing their health concerns[140]. Addiction-driven behaviours can also make the provision of palliative and end of life care more challenging[141].

The prevalence of premature frailty among the homeless population means that people frequently have advanced ill-health and high support needs and may be experiencing cognitive impairment at a far younger age than the general population. While nursing homes provide excellent care for people with such needs, admissions criteria are often oriented towards those over 65 years old.

The average age of death for people who are homeless is 46 for men and just 43 for women.

Recognising the need for palliative and end of life care in the homeless population

Often, people experiencing homelessness who have a terminal condition are unable to access palliative care until very late in their illness, if at all. They may already face barriers to regularly engaging with healthcare services, meaning detection of deterioration and management of symptoms can be challenging[142]. This can be a particular problem when affected by illnesses with an uncertain prognosis, complicated further by addiction[143], which along with the often young age of people experiencing homelessness can be a barrier to initiating conversations about end of life care[144].

It can be particularly difficult for people experiencing homelessness to have conversations with professionals expressing their wishes and priorities for end of life care (known as 'Advance care planning (ACP)'). ACP is predicated on choice, but the choices many have are restricted and many of the options available to the general population are unavailable – not least the choice of where they would like to die.

A more flexible 'parallel planning' approach – where plans are developed that allow for unpredictability in a patient's condition – has value for people who are homeless. Under this approach, concerns about a person's deteriorating health are used to trigger conversations about their care needs and preferences – rather than a definitive diagnosis which may be impractical or impossible to obtain[145]. This can help facilitate conversations about a person's health and what may improve their quality of life, which are often easier to have with a person who is homeless than a conversation about death and dying[146].

Challenges providing care in hostels and temporary accommodation

> *"Temporary housing is often staffed by people who have no medical or clinical background. They're housing staff, and they often end up carrying this huge and heavy burden of trying to support somebody as their health deteriorates - often that stress comes from the fact that the accommodation is not designed to help people with these health needs and there's often no more suitable place for them to go."*
>
> Niamh Brophy, St Ann's Hospice

Many homeless people with advanced or terminal ill-health will stay in a hostel as their condition deteriorates[147]. For many, a hostel is the only stable home they will ever know[148] - but while hostels provide crucial support, they are not designed to be a place of care for people with terminal illnesses[149].

Hostels are often noisy and chaotic environments and rarely have significant space for the equipment that somebody at the end of life may need[150]. The environment can leave patients experiencing distress and leads to many being unable to have family members visit them at the end of their lives[151].

The support provided by hostels usually has a recovery focus; for example, supporting people to transition from street homelessness into more stable accommodation, or supporting people away from substance misuse. Staff typically have no palliative care or nursing background and supporting people with a terminal illness as their health deteriorates is a burden they are not trained to take on but are forced to shoulder as there is often no other place for people to go[152].

Care settings such as hospices often have zero-tolerance policies towards substance misuse. If a terminally ill person still has substance dependency issues, they may be denied a place, meaning that hostels or other forms of temporary accommodation can end up being the default place of care even if this is not the person's choice[153]. Patients who are reliant on medication for their condition can also struggle, as many sites are not registered to store controlled substances, which presents a practical barrier for people who need access to their medicine on site. The inquiry heard that in a small number of instances, residents with substance dependency issues can present risks to other patients, including those who are terminally ill[154].

> *"Staff are understandably quite nervous if suddenly you have a lot of controlled drugs on site and for people with addictions, they might be quite attractive - so risk levels increase. I've had a gentleman who was attacked because he had a fentanyl pain patch on his body, it was taken off him."*
>
> Niamh Brophy, St Ann's Hospice

Challenges securing appropriate housing at the end of life

Difficulties making homelessness applications

Despite the inappropriateness of hostels and much temporary accommodation for the care and support needs of a person reaching the end of life, witnesses to the APPG's inquiry highlighted that there are rarely mechanisms in place to prioritise people with higher needs in the homelessness system.

Homeless people with palliative care needs are treated like everybody else making a homelessness application – there is no duty on services to fast-track them or to use additional criteria when assessing applications[155].

It is often important to terminally ill people that they are near relatives or other people who can offer support. However, people who are homeless often have very little choice about where temporary accommodation is and it is often not possible to get local authorities to accommodate them near to relatives in a specific place[156].

Additionally, a local authority only has a duty to house somebody if they are not deemed to be 'intentionally' homeless. This definition extends to people who have been evicted from their previous accommodation – even under Section 21 'no-fault' eviction[2]. People who are made homeless are often very vulnerable and face significant difficulty challenging a ruling that they have become 'intentionally' homeless[157].

Housing quality

> *"I'm aware of people who are very sick making homelessness applications and ending up in very unsuitable accommodation. If people are in overcrowded or unhygienic accommodation, they may be denied chemotherapy or surgery, for example, until they are in a place where it is deemed safe enough to give them that treatment."*
> Dr Caroline Shulman,
> University College London

Beyond a duty to provide flat level or self-contained accommodation, if medical evidence of need is provided, local authorities have no duty to find terminally ill people anything other than the emergency temporary accommodation that they would provide anybody else – often this is far from ideal for people who are living with a terminal illness[158]. This is often a question of the lack of suitable properties and appropriate housing stock[159], but even where suitable properties are available, terminally ill people are not prioritised for this accommodation.

Accommodation often lacks out of hours access, which presents challenges for people who may need to have carers or clinicians visit them as part of their treatment. Similarly, properties may be unsuitable for people who are bed-bound or have limited mobility; for example, being located on the higher floors of buildings without a lift[160]. It can also be extremely difficult to get permission for even minor adaptations to be made to increase safety such as hand-rails, or key safes to enable carers to visit.

Temporary accommodation is often shared, which can present difficulties for people at the end of life. Witnesses to the inquiry identified cases of other residents being obstructive to carers[161], as well as circumstances where shared kitchen and bathroom facilities presented infection control risks to immunocompromised patients, and insufficient space for medical equipment[162].

Even where self-contained accommodation is available it is often poor quality, with conditions that are unhygienic, cold, or

Case study

A 58-year-old woman with a diagnosis of pancreatic cancer with metastases. She needed self-contained accommodation and was placed by the local authority into accommodation that was in a basement. It was extremely small, dark with no natural light. She was extremely depressed and stressed by this as there was no space for her to unpack a suitcase and no room for a chair for anyone to visit. She remained isolated and was too ill to visit her family. There were mice and the heating wasn't working. When this poor standard was challenged by the homeless team, the local authority sent someone to fix the heating and the infestation but refused to consider any reason to move her; as the property was self-contained their duty to her was fulfilled.

Source: Dr Caroline Shulman, University College London

Phil Hardman/Marie Curie

damp[3]. Witnesses felt that local authorities do not appear to check whether the accommodation they are providing is suitable for a person's needs before placing them there[163].

Lack of coordination between services

> *"Experience is quite varied - I've had some local authorities where I've jumped up and down feeling so grateful that they've been so compassionate, but you shouldn't be relying on compassion for suitable housing. It should be a basic right. Often it comes down to a basic lack of understanding and a lack of awareness about the lived experience of people in these environments."*
> Niamh Brophy, St Ann's Hospice

Witnesses explained that a homeless person's experience at the end of life can be made more challenging by poor coordination between homelessness services and the other services they may be engaged with, such as a hospice team or palliative care social worker. This leads to people falling through the gaps between services, with no single service being the lead organisation in a person's care[164].

Where a person has been evicted, local authorities require an eviction to reach its final stage – bailiffs arriving at the home to execute the eviction – before emergency accommodation can be offered. People must present at their local authority's offices on the day of the eviction to be given emergency accommodation – often with all of their possessions with them. This is extremely distressing, and inappropriate for terminally ill people who are dealing with severe symptoms or mobility issues, and whose possessions may include medical equipment[165].

Housing officers and hostel staff often have a lack of understanding of the particular needs of terminally ill people, especially when a person is living with a less well-understood condition such as motor neurone disease or multiple sclerosis. This can lead to insensitivity to people's needs, for example the perception that terminally ill people will all go to hospital or a hospice and that there is no need for them to apply for accommodation[166].

Emergency measures introduced during the Covid-19 pandemic aimed at getting people off the streets and into accommodation have improved much of this. Local authority homelessness services have demonstrated more flexibility regarding the documentation they require to process applications and have introduced telephone consultations rather than requiring people to present at local authority housing departments. This shows that improvement is possible – however there is a risk that after the pandemic local authorities return to 'business as usual' and poor practice resumes[167].

Recommendations

Everybody deserves to spend the end of their life in a secure and safe environment, where they can receive the care and support that they need. People experiencing homelessness are no different, however the APPG's inquiry has found that for many who do not have a permanent home, their experience is often poor.

Due to the complex needs of people experiencing homelessness, providing palliative and end of life care is a significant challenge – this challenge is exacerbated when a person is in an unsuitable environment such as a hostel or temporary accommodation. While hostels provide crucial support, they are often not a suitable place to receive end of life care.

It is therefore a significant concern that local authorities do not treat people with terminal illness differently to any other person experiencing homelessness. This inflexibility, and a lack of coordination with palliative and social care services, means that too many dying people are forced through inappropriate and burdensome processes, or housed in unsuitable accommodation.

The APPG recommends:

17. Local authorities should adopt a 'housing first' approach to people experiencing homelessness at the end of life[168]. This approach should prioritise getting people quickly into suitable homes on a fast-track basis, and then addressing any other support needs they may have through coordinated support.

18. Health and social care professionals should adopt more flexible advance care planning models for people experiencing homelessness. Approaches such as the 'parallel planning' model, that allow for unpredictability in a patient's condition, will support professionals to have better conversations about care preferences with people experiencing homelessness.

19. A duty should be placed on local authorities to consider the appropriateness of temporary accommodation for a person's health and care needs. People with a terminal illness should not be placed in unsuitable accommodation and housing departments should take this into consideration when placing people or reviewing accommodation where needs have changed. People with a terminal illness should also be prioritised for appropriate accommodation if it is available.

20. Local authority homelessness departments should have dedicated officers to deal with the needs of people with terminal illness. These officers should provide a single point of contact for professionals and patients to fast-track applications and coordinate with care services to provide the most suitable support for a person with terminal illness's specific needs.

Conclusion

> *"We need to create a stronger social security system that provides security for every member of our society, one that can be relied on to unlock the constraints of rising costs, care needs and health conditions."*
>
> Rachel Casey, Joseph Rowntree Foundation

Being able to die in the place of our own choosing, with dignity, is one of the most important elements of a good death – most of us would prefer to die in our own home and community, and even those of us who do not die at home will spend much of our final years there. For many people, however, the triple challenge of high housing and heating costs, unsuitable or insecure housing, and inadequate support from the benefits system means that for too many, a death at home is a difficult experience – and, for many, unachievable.

Witnesses to the APPG's inquiry have highlighted that for people experiencing poverty and homelessness who have a terminal illness, the end of their lives are often difficult, painful and distressing. For many, these unbearable circumstances can worsen their physical and mental wellbeing, and even hasten their death.

Shockingly, the APPG's inquiry has also found that for many, terminal illness itself can be a cause of poverty. Even people who were comfortable before receiving the diagnosis of a terminal illness can be driven into poverty by the sudden wave of additional and enhanced costs they face as a result of their condition.

Dying people should not be forced to spend the precious time they have in their last months of life living in a cold or unsuitable home, paying unaffordable housing and energy costs, or facing housing insecurity and homelessness.

Many of the solutions to these problems already exist – however, at present they do not work for people living with terminal illness. Dying people face an intolerable situation – they are expected to fit in with rigid service models, instead of those services being flexible enough to adapt to their particular needs. For people with a limited time to live, this is inexcusable and leads to unnecessary stress, hardship and ill-health at a time when they are already struggling with the devastating impact of being diagnosed with a terminal illness.

The recommendations in this report would address these inflexibilities – in the benefits system, in schemes targeting people experiencing housing and fuel poverty, and in the housing and homelessness system – by introducing more flexibility and ensuring the needs of people who have a terminal illness and a limited time left to live are treated as a priority.

How we treat those who are dying is a measure of the compassion of our society – this inquiry has revealed that too often, in too many areas, we are falling short. It is imperative that we urgently address these failings by putting the needs of dying people who are at risk of poverty where they should be – at the centre of systems and support services – so that those reaching the end of life, and their families, are able to focus on what really matters – living as well as they can, and having the best end of life experience.

Inquiry terms of reference and witnesses

The APPG launched a call for evidence in March 2021, seeking evidence from organisations, stakeholders and individuals with relevant expertise and experience of the issues caused by housing and fuel poverty at the end of life.

The terms of reference for this call for evidence were:

1. The challenges of providing end of life care at home to people with a terminal illness who are living in older, overcrowded, or unsuitable housing.
2. The extent to which fuel poverty and living in a cold home affects the health and wellbeing of people living with a terminal illness.
3. The difficulties faced by people living with terminal illness in affording the costs of housing, including heating costs, particularly for those living in rented accommodation or who require home adaptations due to disability.
4. The challenges of providing end of life care to people who are homeless, living in temporary accommodation or experiencing housing transience.
5. The particular challenges faced by people experiencing housing and fuel poverty in rural areas and urban areas of the UK.
6. Potential legislative, policy or practice solutions that would improve the experience of people experiencing housing and fuel poverty who are living with terminal illness, their families and carers.

The APPG heard oral evidence from the following witnesses:

Tuesday 20 April

Alex Massey, Policy Manager at the Motor Neurone Disease Association

Samantha Moss & Sharon Cole,
Family support social workers at the Sue Ryder Manorlands Hospice

Tuesday 27 April

Dr Caroline Shulman, General Practitioner in Homeless and Inclusion Health, Honorary Senior Lecturer at University College London

Carolyn Walker, Welfare Team Lead at St Christopher's Hospice

Niamh Brophy, Homeless Palliative Care Coordinator at St Ann's Hospice

Liz Allam and Pippa Dean,
Palliative care social workers representing the Association of Palliative Care Social Workers

Tuesday 4 May

Rachel Casey, Housing Policy & Partnerships Officer at the Joseph Rowntree Foundation

Daniella Weduwer, Policy Manager at Energy UK

Steve Crabb, Chair of the Energy UK Vulnerability Commitment

The APPG also received expert written evidence from the following organisations and individuals:

Association of Palliative Care Social Workers; Dying in the Margins, University of Glasgow; Energy UK; Dr Clare Gardiner, University of Sheffield; Joseph Rowntree Foundation; Marie Curie; Motor Neurone Disease Association; Dr Caroline Shulman, University College London; St Ann's Hospice; St Christopher's Hospice; St Mary's Hospice; Sue Ryder.

Written evidence submissions are available on the Marie Curie website at www.mariecurie.org.uk/appg-for-terminal-illness

Unless otherwise stated, all references, quotes and statistics in this report are from evidence submitted to the APPG's inquiry. Where an organisation is cited in this report, this is taken from written evidence; where a named individual is cited, this is taken from oral evidence.

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