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Report of the All-Party Parliamentary Group for Hospice and End of Life Care

Inquiry into the financial impact of a terminal diagnosis

HospiceUK

Marie Curie

Sue Ryder

Because no one should face death or grief alone

Contents

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Foreword

Paulette Hamilton MP and Baroness Finlay of Llandaff

Co-Chairs, All-Party Parliamentary Group on Hospice and End of Life Care

A diagnosis of a terminal illness always comes with difficulty and uncertainty. How long will I live? Will I be in pain? How will I tell people? What will happen after I am gone?

But for too many people across the UK, another question looms: how will I afford it?

The costs of living with a terminal illness vary, but the evidence we have received makes clear that they can run into the tens of thousands of pounds. Additional electricity and heating costs alone can reach several thousand pounds a year on top of regular bills. Then there is the cost of travel to appointments, the cost of specialist food, the cost of local authority social care – and all of this while dealing with the physical and psychological impacts of knowing that your life will soon end.

While additional support is available, such as through the Special Rules for Terminal Illness and fast-track NHS Continuing Healthcare, many people are unaware of this. And even when that support is accessed, it is also clear that the costs can far outstrip the support currently available from the NHS, local authorities, and the Department for Work and Pensions, and it is unrealistic to expect the third sector to plug the gap, despite the excellent work that goes on.

And all of this comes at a time when, particularly for working-age people, your income has fallen. Many people need, or understandably choose, to work less after a diagnosis, and often their partner also reduces their working hours to take on caring responsibilities.

These twin pressures of higher costs and lower income can push even households that were previously comfortable into a difficult financial situation. You might have been able to keep up with your rent or mortgage previously – but those costs are still there after you're diagnosed. This is of course not good for your mental health, but it can also have physical impacts if people cannot eat well or keep their house warm, or miss appointments due to the cost of travel.

The evidence submitted to this inquiry, and the oral evidence sessions we have held, lays bare the stark reality. It has also demonstrated how the financial impact of a terminal diagnosis has effects beyond the person affected to their wider family and friends, and beyond the person's death.

We are also deeply concerned that terminally ill people have not been properly recognised in the recent Pathways to Work Green Paper and forthcoming changes to Universal Credit, which have been a missed opportunity to take action to improve support for terminally ill claimants.

This APPG believes that there are practical steps that Government can and should take to both bring down the costs for people with terminal illness and increase their incomes. These include:

- Reviewing the current levels of financial support available to people living with a terminal illness
- Ensuring that someone of working age with a terminal illness has an equivalent income at least equivalent to someone of pension age in the same situation
- Introducing a social tariff for energy for people living with a terminal illness
- Providing up-front financial support for the costs of running medical devices for the care needed for a person in their own home

The prospect of people dying in financial hardship is concerning at any time. Yet at a point at which Parliament is considering the legalisation of assisted dying, it is even more important that the material needs of people at the end of life are fully met, to ensure that no one faces any pressure to choose an assisted death because of financial concerns.

We would like to place on record our thanks to all those who submitted evidence to this inquiry. While we have not been able to include every point raised in this final report, everything we heard has been invaluable in informing this report.

We would like to especially thank the frontline palliative care professionals and people with lived experience of terminal illness, either directly or from caring for a loved one, who provided evidence. The stories we have heard have been powerful, shocking, and heartbreaking – and even more so when there are clear ways to address these issues. They have only strengthened our resolve to act to ensure that a terminal diagnosis is not also a devastating financial blow.

The final period of life should be a time to make memories, not to worry about your bank balance. A terminal illness will always bring additional costs. The challenge we set for parliamentarians is to take on the recommendations in this report and ensure that the support provided by government is equal to those costs.

We hope that you find this report as informative as we found undertaking the inquiry, and we look forward to working with Government to make these recommendations a reality.

Introduction

All-Party Parliamentary Group for Hospice and End of Life Care

The All-Party Parliamentary Group for Hospice and End of Life Care (the APPG) is a cross-party group of parliamentarians with an interest in issues around hospice, palliative and end-of-life-care.

The APPG's purpose is to raise awareness in Parliament of hospice, palliative and end-of-life-care, 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 these issues. The APPG meets several times a year to discuss topics surrounding hospice and end-of-life care with individuals and organisations involved or interested in this area.

APPG Co-Chairs and Officers

Paulette Hamilton MP – Co-Chair

Baroness Finlay of Llandaff – Co-Chair

Paul Holmes MP – Officer

Luke Taylor MP – Officer

Secretariat

Hospice UK, Marie Curie, and Sue Ryder support the work of the APPG through jointly providing its secretariat.

About Hospice UK

Hospice UK is the national champion for hospice care. We represent a community of more than 200 hospices from across the UK, delivering services to adults and children.

About Marie Curie

Marie Curie is the UK's leading end of life charity. We are here for anyone with an illness they're likely to die from, and those close to them. We bring 75 years of experience and leading research to the care we give at home, in our hospices and over the phone.

About Sue Ryder

Sue Ryder is here to make sure everyone approaching the end of their life or living with grief can access the support they need. There is no one size fits all when it comes to how we cope and the help we need, but with our support, no one has to face dying or grief alone. We are there when it matters.

Executive Summary

The end of someone's life should be one of peace and stability, allowing people focus on what really matters.

Yet evidence suggests that, for too many people, it is in fact a time of considerable financial difficulty on top of the health and psychological impacts of a terminal diagnosis. Research has found that more than 300 people a day die in poverty in the UK[1], while the cost of living has hit households containing someone living with a terminal illness especially hard, as energy costs remain high by historical standards.

It is this context that led the All-Party Parliamentary Group for Hospice and End of Life Care to launch this inquiry into the financial impact of a terminal diagnosis. The inquiry received evidence from a wide range of organisations and individuals, and held three evidence sessions in the House of Commons, and ran a survey of professionals and people with lived experience.

All of this evidence has been highly valuable in demonstrating the significant gaps that remain in the financial support provided to people at the end of life.

Put simply, there is insufficient protection in place against the spiralling costs that many households face after a terminal diagnosis – and the income provided by the state is not sufficient to meet them. This crisis affects all age groups, but working-age people in particular, and the recent legislation around Universal Credit was a missed opportunity to rectify this.

Key evidence

- Costs, particularly for energy and transport, can increase dramatically after a terminal diagnosis – in some cases by over £10,000 a year
- At the same time, particularly for working age households, income often drops due to the effect of illness and caring responsibilities – creating a double shock to a household's finances
- Existing government support is not enough to meet these costs, and there is an unsustainable reliance on under-pressure voluntary support
- The working-age benefits system in particular does not provide adequate support for people facing terminal illness
- All of this causes significant and long-lasting financial and emotional impacts on the terminally ill person and those around them, and in some cases worsens health, leading to additional costs to the NHS and local authorities

Key recommendations

- The Government should ensure that a household receiving Universal Credit in which a claimant qualifies under the Special Rules for End of Life, or the Severe Conditions Criteria, has an income equivalent to that of a pension-age household
- The Pensions Commission should explicitly consider how access to the State Pension can be provided early for working-age people with terminal conditions.
- The Department of Health and Social Care should ensure that there is a single, simple and comprehensive, scheme providing up-front support with the costs of medical devices provided by the NHS
- The Department of Energy Security and Net Zero should introduce a social tariff for households in which someone has a terminal illness.

Chapter 1

How terminal illness affects finances

Income

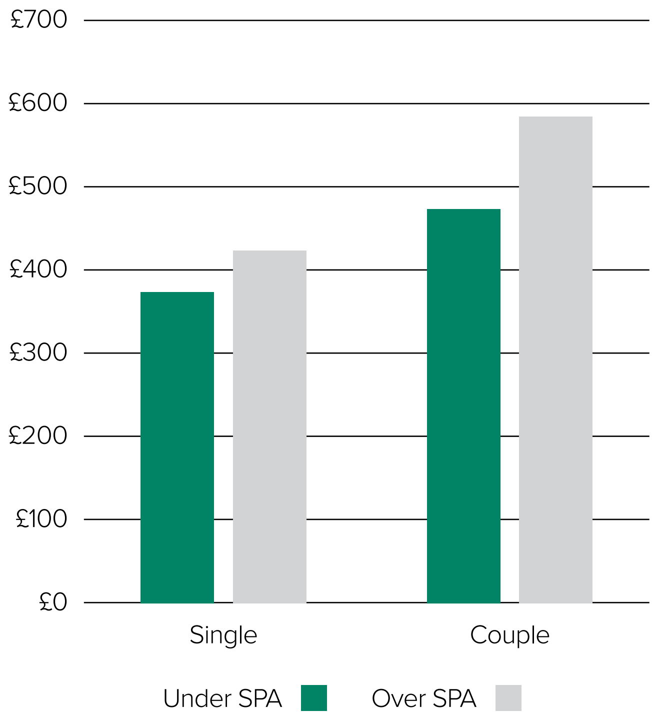
When people think about a terminal diagnosis, they usually think about the profound medical and emotional impacts that learning you have a limited time to live brings. Those are of course critical, but it is clear from the evidence we heard as part of this inquiry that the impacts go far wider than that.

Firstly, and particularly for working-age people, a terminal diagnosis can come with a significant loss of income, as several respondents, including Hospice UK, Marie Curie, and benefits advisers, highlighted. Some people, with some types of condition, can and want to continue to work for as long as possible. But others have no choice but to reduce their hours, or stop work altogether. For couples, the impact can be even greater if the partner also has to reduce their working hours or stop working, as they take on greater caring responsibilities. The Hospice and Palliative Care Welfare Advisers Network – London & South-East England explained that people frequently continue working despite feeling unwell, due to uncertainty about what happens at the end of occupational or statutory sick pay.

While the benefits system provides a basic level of income, depending on other household income and savings, the evidence described the "shock" people felt about how little they might receive from the Department for Work and Pensions (DWP), and the fear that this prospect can cause. As a result, many families fall into financial hardship at a time when stability and care should be the focus. For others, particularly among groups that are already more likely to be in poverty even before a terminal diagnosis (including households with a disabled person, or headed by someone from a minoritised ethnic community), this maintains and exacerbates existing poverty.

This is particularly acute for people of working age. Research from Marie Curie has found a particularly large discrepancy between the guaranteed benefits for someone under Pension Age who relies on Universal Credit, compared to someone over Pension Age who can access the State Pension and Pension Credit. This is shown in Figure 1.

Figure 1: Weekly benefits income after housing costs for households with someone with a terminal condition, under or over State Pension Age (SPA)



Based on childless households in receipt of Universal Credit/Pension Credit and maximum rates of PIP/Attendance Allowance. For couples, one partner is assumed to be providing care. Full calculation details in appendix.

These discrepancies are already large – £46 a week, or £200 a month, for single households, and £112 a week, or more than £400 a month for couples. This inequity is likely to increase in coming years given the Triple Lock is set to continue to outstrip increases to Universal Credit, despite the welcome above-inflation rises in coming years.

This is neither fair nor necessary. Analysis by Dr Juliet Stone from the Centre for Research in Social Policy at Loughborough University has found that most people who die in working age have made National Insurance Contributions, yet will never benefit from this because they die too young.[2] And by dying too young, they will receive far less financial security. While the State Pension and Pension Credit do not guarantee that someone will have financial security, they provide a considerable protection against poverty.

Marie Curie has pointed out, in its Dying in Poverty 2024 report, that current plans to raise the State Pension Age will mean more people dying before they can access the State Pension. If current rates of deaths in poverty among working-age people go unaddressed, this could mean almost 4,500 people dying in poverty every year.

Most pressingly, there is an urgent need to increase the support provided within Universal Credit, to benefit the lowest-income households dealing with terminal illness. There are at least two options for doing this. One is to introduce a new element within Universal Credit, making use of its 'modular' and flexible design. The other is to build on the precedent set by the forthcoming changes to Universal Credit, which creates different Universal Credit Health Element rates for different groups.

The recently-announced Pensions Commission[3] also provides an opportunity to consider the wider inequity of lack of access to the State Pension for terminally ill people of working age. Previous reviews have considered in general terms the challenges around providing variable State Pension payments based on, for example, life expectancy. However, they have not considered specifically extending access to the State Pension to people at the end of life. This is both operationally achievable (as people at the end of life are already an identifiable group within the benefits system) and poses limited financial risk; previous research from Loughborough University, commissioned by Marie Curie, has found that this would cost just 0.1% of current spending on the State Pension.[4] The time is right to fully explore how this specific group could be granted the financial security that comes with access to the State Pension.

Evidence heard by this inquiry has made clear the unjustifiable disparity between incomes for terminally ill people below and above state pension age. Closing this gap is key to ensuring everyone with a terminal illness has sufficient financial support, regardless of age.

Recommendation

The Government should conduct a review of the financial support available to households with a terminal illness.

Recommendation

The Government should ensure that a household receiving Universal Credit in which a claimant has a terminal condition has an equivalent level of income to that provided by Pension Credit.

Recommendation

The Pensions Commission should explicitly consider how access to the State Pension can be provided early for working-age people with terminal conditions as part of its review due to report in 2027.

Carers

Financial insecurity caused by a terminal condition does not only affect the person diagnosed with a terminal illness, but also those caring for them. Carers' finances are jeopardised not just by a limited ability to do paid work and increased bills related to caring, but also by a multitude of barriers to the right financial and practical support spanning: self-identification; access to needs assessment; eligibility criteria, awareness and adequacy of support.

The demands of caregiving impact employment opportunities; Carers UK estimate that 600 people each day give up work to care for someone, with many more reducing their hours or changing jobs to accommodate caring.[5] Restrictions on Carer's Allowance exacerbate carers' predicament, effectively forcing many to choose between employment or financial support. While the recent changes to the earnings limit for Carer's Allowance are welcome, it still only allows for 16 hours a week at minimum wage, and many carers use sick leave or annual leave just to continue to provide care to a loved one without jeopardising their job.

Kim gave evidence to the APPG about her and her partner's experience of caring for elderly parents who want to remain at home. She explained that she had to give up work, as well as cash in her private pension, remortgage the house, and take out loans, while her partner had experienced serious mental health problems as a result of the stress involved. She has been unable to claim Carer's Allowance due to the strict earnings limit (despite its recent increase). Combined with the uncertainty of how long the parents might live for, this has made it extremely difficult to plan financially for the future.

We also heard concerning evidence that households in some communities may be missing out on caring-related benefits, as they do not identify as being a 'carer', a point made by both Rekha Vijayshankar, a former Marie Curie nurse, and Beka Avery, Head of Wellbeing and Community Support for East of England at Sue Ryder. Many continue to view themselves only relationally to the patient (e.g. as a spouse) and feel ambivalent about the legitimacy of their support needs. Language barriers can complicate self-identification as the word 'carer' does not translate into languages such as Urdu or Bengali. Further, end-of-life caring responsibilities can accumulate gradually, lacking a clear start point, and accepting a terminal diagnosis can be a further barrier to identification.

Even for those who access financial support, carers' benefits remain inadequate. Carer's Allowance is one of the lowest benefits of its kind at £83.30/week, failing to recognise the contribution unpaid carers make to society and to the economy, and leaving 62% of recipients living in poverty.[6] For households on the lowest incomes, who rely on Universal Credit, any award of Carer's Allowance is deducted pound-for-pound from Universal Credit, while the Carer Element is little over half the value of Carer's Allowance. Yet without their contribution to the person's care, the financial load of failures to maintain care at home would fall on the NHS.

Evidence provided to this inquiry shows that the current system of support for people providing unpaid care for a terminally ill person is far from sufficient, and causes additional and ongoing financial hardship.

Recommendation

The Government should legislate to introduce a new statutory right to paid Carer's Leave for employees with unpaid caring responsibilities.

Recommendation

The Government should comprehensively review Carer's Allowance and other carers' benefits to ensure they adequately support carers. This must include a review of the levels and eligibility criteria.

Recommendation

Local authorities should work to increase self-identification of carers and ensure that every carer of someone with a terminal illness is offered a Carers Needs Assessment at least annually (including an assessment of financial need).

People living alone

While some people who live alone are nonetheless cared for by a friend or family member, people who live alone are more likely to need to arrange – and quite possibly pay for – their own care.

This of course adds to the financial pressure that they experience, and in some cases may deter people from accessing care that they need. It is also hard to understand why, for working-age people with care needs living at home, the Minimum Income Guarantee (the income people should be left with before charging is considered) is less than half of the comparable amount for pension-age people.[7]

Expenditure

Such an income shock is difficult enough to manage if regular bills stay the same. Yet in reality, many bills increase hugely after a terminal diagnosis. The Motor Neurone Disease Association (MNDA) has found that on average, families with a motor neurone disease (MND) diagnosis face added annual costs of £14,500 on average – with some families facing even more. Young Lives Vs Cancer has found that the additional costs of a cancer diagnosis is £8,400 a year on average. Academic research has found that the direct costs of Huntington Disease was £14,600 in 2020 – before the recent and persistent increase in household energy bills.[8]

Energy costs are a major cause of these extra costs. People with terminal conditions often need additional medical devices, such as powered wheelchairs, ventilators, oxygen concentrators, or powered beds to reduce the risk of pressure sores. According to MNDA, these electricity costs can reach as high as £10,000 a year on their own.[9]

While the NHS will often provide the devices themselves, there is very limited help available for the running costs of such machines – only for oxygen concentrators and some types of dialysis machines. These costs can be significant. Analysis from Marie Curie has found that a household that includes a person with a terminal illness may see an additional monthly energy cost equivalent to 6.9% over an average household if they have an electric bed, 15.8% if they are receiving at-home dialysis, 20.6% if they are on a ventilator, and as much as an extra 37.8% more than the average household if they are receiving oxygen concentration.[10] People needing multiple devices will, of course, see these extra costs stack up.

Even for the limited types of devices that can attract rebates for running costs, these are paid in arrears, meaning households can still struggle to pay up-front, or nonetheless limit their usage due to 'cashflow' problems. And of course these schemes provide no support with other additional energy costs that households face. There is no coherent policy rationale for this patchwork of support.

The combination of reduced income and higher costs also pushes households into fuel poverty. Research from Loughborough University's Centre for Social Policy Research has found that 128,000 people a year die in fuel poverty – yet there is no consistent or substantial support for energy bills available. A social tariff providing a 50% reduction in bills could move up to 54,000 of these people out of fuel poverty, and reduce the fuel poverty faced by 74,000 more.

The evidence submitted to this inquiry has highlighted the huge increases in energy costs that can accompany a terminal diagnosis. It has also demonstrated the inadequacy of the support, both for 'general' energy costs, and for the running costs of at-home medical devices that many people with a terminal illness rely on for treatment, safety, and dignity.

Recommendation

The Department of Health and Social Care should ensure that there is a single, simple and comprehensive, scheme providing up-front support with the running costs of medical devices provided by the NHS.

Recommendation

The Department of Energy Security and Net Zero should introduce a social tariff for households in which someone has a terminal illness.

Travel costs

Transport is another important consideration. This was particularly highlighted in evidence from respondents in rural areas, as well as Young Lives Vs Cancer, who identified this as the single biggest cost faced, reaching £250 a month on average. While free or subsidised transport schemes do exist, these aren't always convenient or appropriate for someone with a terminal illness. This leaves people reliant on paying parking charges, or paying for public transport or even taxis to attend appointments.[11]

Katie Reade, Head of Policy and Public Affairs at Hospice UK, explained that transport costs can be a "fundamental barrier" to people receiving the treatment they need, or visiting a friend or family member who is dying: "We have heard stories of patients using credit cards to pay for transport or not going to appointments at all because of the cost of getting there. This hits people living in remote, rural or island communities the hardest who face long distances to access treatment, medication or to visit loved ones."

Recommendation

Local health systems across the UK should ensure flexible, easy to access, funded transport is available, and account for travel to and from local charitable hospices when examining and planning patient transport needs across their area.

Figures converted for this report into pounds using the average 2020 exchange rate data from the European Central Bank.

Other costs

Other reasons extra costs can vary widely depending on the nature of the condition and its effects. These can include heating costs to keep warm, additional food costs if a special diet is required, home adaptations, or care services. All of these are vital costs to meet to maintain safety, quality of life, and dignity at the end of life, as well as allowing the person to be cared for at home as much as possible.

People in a precarious financial situation before their diagnosis are of course likely to struggle with these extra costs. However, the scale of these costs and the loss of income mean that even previously high-earning households can struggle. This is clearly shown by a story shared with us by staff in a South Wales Hospice:

> *"Our hospice supported a couple who were previously on £1,000 a week take home pay. Upon the patient receiving a terminal diagnosis and subsequently giving up work, she went immediately to statutory sick pay and her husband had to give up his self-employed job, which meant their income dropped massively.*
>
> *Then due to increased transport costs, high energy costs, and combined with their loss of income, this put them under significant financial and emotional stress. The family lost their home, they couldn't access social housing, and so had to move in with one of their children in a cramped and overcrowded house. The patient died after being taken into hospital, as the family was unable to manage her needs at home."*
>
> *Case study shared by Jill Bowen and Sarah Bennett, Hospice of the Valleys*

All of these additional costs come alongside regular outgoings. One of the larger bills households face – and one that can quickly escalate to serious enforcement action if unpaid – is council tax. While low-income households including someone with a terminal illness might benefit from Council Tax Support, these schemes differ greatly across the country, and many councils have increased the minimum payment that those on the lowest incomes must make. The recent announcement from Manchester City Council that they will charge no council tax to households where someone is likely to be in the last year of life is therefore very welcome.[12] Others are considering similar steps, the most effective approach would be for the Ministry of Housing, Communities, and Local Government (MHCLG) to amend the prescribed requirements for Council Tax Support Schemes in England to ensure a consistent and compassionate approach.

Recommendation

The Ministry of Housing, Communities, and Local Government should amend the prescribed requirements for Council Tax Support Schemes in England to exempt households containing someone nearing the end of life. Until that point, other councils should take similar steps to provide support to residents at a highly difficult time.

Chapter 2

What this means for people living with terminal illness and their families

Dealing with rising costs and lower income alongside a terminal illness inevitable has an impact on the mental health of people with a terminal illness. As Simon Smith, Head of Wellbeing and Community Support at Sue Ryder for the region of Berkshire West and South Oxfordshire, told the inquiry:

“In all these things, there is not only a practical impact upon the patient and those close to them – but also an existential and emotional impact. The patient feels, because of the subsequent financial hardship, that they are becoming a burden, that they are to blame for the hardship, the stress and the uncertainty.”

Peter, a man in his 70s living with a terminal illness, explained how this affected him in winter:

“I’m here with lots of clothing on and a cover around me, I’ve got a heated blanket as well. I’m mainly cold most of the time. Once I get like that, it puts me off of eating. It puts you off of doing a lot of things.

“Especially now, when temperatures have been minuses lately. Sometimes, I can put £50-£60 on my electric a week. I’ve only got little heaters because I can’t afford to run the electric ones on the wall. I’ve got a nice one-bedroom flat, but I’ve been living in one room for months and months now to try and keep warm, and I really do need to move.”

These impacts on quality of life for people living with terminal illness are worrying enough, but there is also evidence that financial concerns are directly affecting people’s treatment. MNDA cited a survey showing that more than a quarter – 28% – of people with the condition have had to reduce their use of at-home medical equipment as a result of rising energy costs, placing risks on their health and wellbeing.[13]

The charity Sue Ryder similarly cited their survey finding that a 81% of respondents had been unable to run essential medical equipment as a result of high energy costs since the cost-of-living crisis began, with 40% reporting that this happened frequently.[14] This not only jeopardises the person relying on that equipment, but also increases visits to healthcare services, and visits from healthcare professionals, which in turn means higher costs to the NHS.

Several respondents also said that patients would miss appointments, or even refuse treatment or support, due to the travel costs of attending appointments. This is particularly acute in rural areas, where public transport can be inconsistent or sporadic. Frontline workers have also reported patients suffering from cold or not eating properly as a result of financial difficulty, and several hospices give out food vouchers or make foodbank referrals to support people.

In some cases, these financial impacts can lead to people dying early, as the shocking case study below shows.

> *“A patient was skipping meals to be able to feed her children because she couldn’t afford to, and missed appointments at the hospital for vital treatment because she couldn’t afford the petrol costs and had no one to support her with taking care of the children, or to take her to and from hospital. She stopped her treatment and died within months of her diagnosis. She was 34 years old. Her two young children were left without a mother due to the financial impacts of her diagnosis.”*
>
> *Case study provided by St Barnabas Hospice*

Impacts on families

Seeing someone you love dealing with a terminal illness is of course an extremely difficult experience. But this is only heightened by financial insecurity.

In part, this is because it leads directly to financial difficulties for carers. In a survey by MNDA, nearly half of unpaid carers of people with the condition experiencing money worries, and 68% had to make significant cuts to their essential spending to meet the additional costs the disease.[15] This financial strain leads to stress, debt, and depleting savings or even retirement funds, which carries serious long-term consequences after the cared-for person has died.

> *“Rasheed’s sister, Farah, was unwell with cancer for 1-2 years before her death. Rasheed explained that during this time Farah managed to save £1,500 from her benefits to contribute to her funeral. However, this had meant that, at times, she had chosen to go without proper food or sometimes heating, to put the money aside.”*
>
> *Case study provided by Quaker Social Action*

But the emotional impact of financial security must not be overlooked either. The last period of life should be a time for making memories, perhaps by visiting a place that has been important to someone during their life, or seeing friends and family for the last time. Being unable to do that as a result of worrying about the cost can cause great distress, as well as (unjustified) guilt for the family of the person for not being able to support them in this way. Hospice UK’s evidence also highlighted the guilt and upset experienced by carers feeling they needed to choose being caring responsibilities and paid work.[16]

For families with children, meanwhile, the prohibitive cost of childcare, combined with the restriction of much childcare support to working families, means that it may be impossible to arrange such care. This can deny terminally ill people (and their partners) much-needed respite from caring responsibilities, but can also add additional stress to children themselves.

Recommendation

The Department for Work and Pensions should ensure that free childcare provision that is available to working families is also available to terminally ill parents.

Financial impacts after death

Struggling with finances at the end of life makes someone’s final days more difficult, and can also be extremely distressing for those around them. But in many cases, these challenges continue or indeed worsen after the death of the person being cared for.

After someone you love has died, you need time to grieve, as well as to undertake the administrative tasks that come with death. Yet evidence suggests that for too many people, what should be a time of reflection and remembrance is a time of acute financial hardship.

Research by academics at Leeds, Sheffield, and Loughborough universities has found that poverty among end-of-life carers increased by 10 percentage points after the cared-for person dies, and that this was driven by the end of caring-related benefits. They also found that this effect continued for at least three years after death, demonstrating an ongoing impact.[17]

Bereavement is the second-highest reason people report needing to use Trussell's foodbanks[18], behind only having a new disability or serious health condition. Young Lives Vs Cancer also reported that bereaved people continue to face higher costs.

Part of the reason for this ongoing impact is what the Hospice and Palliative Care Welfare Advisers Network – London & South-East England called the "financial cliff edge" of moving from being a carer to being a bereaved carer: "There is no transitional support between income stopping and then having to reclaim or make new claims to benefits. They can also face long waiting periods for claims to be paid. Often savings have already depleted to maintain a satisfactory level of living. What is left of any savings (if anything) are used to pay funeral costs. Those who are bereaved and without sufficient income are unable to replace these savings and therefore, their own care and support needs in illness, or old age, are at risk of being funded by the state."

A similar point was raised by Quaker Social Action and Young Lives Vs Cancer, who also highlighted the risk of parents feeling pressured to return to work too soon following their bereavement, due to the lack of financial support available to them.

The cost of funerals was repeatedly raised in evidence as having a negative impact on both the finances and the stress and mental health of bereaved people, on top of the grief. As one focus group participant cited in a recent Hospice UK report[19] said:

"My brother died a year ago and he hadn't prepared for his funeral and suddenly I had to find £6,000 to bury him. I still owe £2,000. That was the big thing, thinking how do I get him buried? It's horrendous."

> *"90% of my headspace was just around the funeral. … I wasn't thinking of grieving, I was just thinking of giving him the dignity of laying him to rest.*
>
> *…because financially we weren't strong I work until the furthest I knew I could go to. … where people are not financially able to bury their loved one and they have to work I think they missed out on vital time that they can't get back because the person is gone forever.*
>
> *I couldn't take much bereavement [time] off. And then while I'm at work, I'm grieving, so I'm at work and I'm breaking down … if I don't work, I don't get paid."*
>
> *Quote from Brianna, shared by Quaker Social Action*

Hospice benefits advisers also cited the tight restrictions on eligibility, and the inadequacy for those who are eligible, of the DWP Funeral Expenses Payment (in contrast, the Funeral Support Payment in Scotland has less strict criteria).[20] This drives people to either use credit options they can't realistically manage, or to rely on funerals funded by the local authority or NHS, which still carry stigma and limit choice and dignity. With no statutory minimum standards for these funerals, research into council funerals has shown they can be difficult to obtain, that Government guidance is not consistently followed and that it can be a postcode lottery whether mourners are able to attend or receive ashes back.[21, 22]

In the context of the profound upheaval of a bereavement, grieving people are also at heightened risk of losing their home, largely due to the financial impact of a bereavement. A representative survey by Opinium for Marie Curie in 2023 found that 11% of grieving adults are forced to move home because of their bereavement, with more than half of these (52%) citing affordability reasons. This issue has worsened over time with twice as many people affected in 2023 compared to the period between 2018 and 2021.[23] The Under Occupancy charge (also known as the Bedroom Tax) is a cruel burden to place on people at this already difficult time, and extending exemption to a year could enable many to stay in their home in the first year after a bereavement.

Evidence received by this inquiry has shown that current support for bereaved families exacerbates the challenges that come after the death of a loved one. Improving this support would greatly reduce the stress faced by people at this difficult time.

Recommendation

The Department for Work and Pensions should review support for funeral costs and ensure that these cover reasonable expected costs of a funeral.

Recommendation

The Ministry of Housing, Communities and Local Government should bring in statutory minimum standards for council funerals.

Recommendation

The Department for Work and Pensions should update eligibility criteria of Funeral Expenses Payment to match those of the Funeral Support Payment in Scotland.

Recommendation

Carer benefits should be payable for at least six months after the death of the care recipient, rather than the current two months.

Recommendation

Claimants should be given 6 months to make a claim for Bereavement Support Payment without any loss in award, and payments should be excluded from capital for at least 3 years.

Recommendation

The Department for Work and Pensions should extend exemption from the Under Occupancy Charge (bedroom tax) to a year (up from 3 months) after a bereavement.

Chapter 3

Gaps in support for people living with terminal illness and their families

The Special Rules for End of Life (SREL) provide valuable guaranteed and fast-track access to disability and ill-health benefits if an application is accompanied by an SR1 form, which certifies that a clinician would not be surprised if the person died in the next 12 months.[24] This relates to non-means-tested extra-cost disability benefits,[25] as well as the Health Element[26] in Universal Credit.

Currently, the SREL guarantees access to the Enhanced Daily Living component of Personal Independence Payment (PIP). However, Jamie Thunder, Senior Policy Manager for Financial Security at Marie Curie, explained that there is no such guaranteed access to the Mobility component. While the vast majority of SREL PIP claims do include this component, others will have not received it at first, and will need to report a change of circumstances to DWP in order to receive it – yet another administrative task that may not take precedence over the array of demands a terminally ill person faces.

The policy rationale for providing access to the Enhanced Rate of the Daily Living Component is presumably that, regardless of function on the day of application, the applicant will at some point in the next 12 months qualify for the Daily Living component, so it is humane and appropriate to guarantee access to it. Yet this is also true for the Mobility component. The fact that the majority of SREL recipients do receive this further raises the question of why it should not also be provided as standard in a SREL claim, as is the case for people in Scotland meeting their definition of 'terminal illness'.

Recommendation

The Department for Work and Pensions should ensure that the Special Rules provide automatic entitlement to the Mobility Component of PIP, in the same way and for the same reason as they do for the Daily Living Component.

We also heard repeated concerns about a lack of awareness, or of misunderstandings, about the Special Rules amongst clinicians. Crucially, the 'test' for the Special Rules is whether the clinician would be surprised if their patient died within the next 12 months – not whether the patient is certain or almost certain to.

Given that a clinician's judgement is essential for a claim under the Special Rules to be made, this is highly concerning, as it suggests people are missing out on the benefits Parliament has legislated for them to receive at the end of life.

Recommendation

The Department for Work and Pensions should undertake an awareness campaign about the Special Rules for End of Life among clinicians likely to interact with terminally ill people and track uptake.

Citizens Advice Gateshead have also provided evidence of delays in the processing of some SREL claims.[27] This is concerning, as it means terminally ill people may not be receiving the fast-track that both government policy, and a common-sense compassionate approach, says that they should. In some cases, this leads to that person having to unnecessarily struggle financially for weeks or months while they wait for what should have been provided extremely quickly. In others, inevitably, the person will sadly die before the claim is fully processed and never receive what was rightfully theirs.

Recommendation

The Department for Work and Pensions should urgently investigate whether reported slow timelines for processing SREL claims are localised or wider issues, and take immediate steps to ensure such claims are not delayed.

Terminal illness not under the SREL

Hospice benefits advisers told us that there remain complex forms, long waits, stressful assessments, and uncertain outcomes for people with a terminal condition who do not meet the Special Rules criteria. In particular, dementia, neurological disorders, and end-stage heart or respiratory disease were cited.

There is an ongoing review into PIP, led by Sir Stephen Timms MP, which may lead to improvements. However, it is implausible that this will provide all claimants of PIP with the degree of certainty and speed that claims made under the Special Rules receive. There is therefore a strong case for action. This inquiry has not looked in detail at the relatively new definition of 'terminal illness' used in Scotland[28], which replaces the time-based prognosis requirement with a broader clinical judgement.[29] However, there are potential benefits in moving from a definition using a time-based prognosis, which can be difficult to determine, to a definition that relies more heavily on clinical judgement of the stage of illness someone is at.

These benefits were also brought up by advisers and MNDA, who said: "Currently, fast-tracking for Personal Independence Payment (PIP) is only available to those with a prognosis of less than 12 months. For people with MND, who may live two years or more after diagnosis but face rapidly escalating costs, this is unsuitable."

The Department for Work and Pensions evaluated the Special Rules in 2021, which led to the extension of the prognosis period for eligibility from six to 12 months.[30] This welcome step has expanded access to vital and guaranteed financial support to a wider group of people living with terminal illness. However, since then, with the ongoing devolution of disability benefits to Scotland, there is an opportunity to take the evidence from Scotland's experience and the remaining concerns about a time-based definition of terminal illness and consider whether the criteria used in Scotland should be adopted more broadly.

Recommendation

The Department for Work and Pensions should review the Special Rules and consider whether a revised definition more in line with the one used by Social Security Scotland would improve certainty and widen access among terminally ill people.

Whatever definition is used, the Special Rules do not currently apply across the entire benefits system, meaning terminally ill people and their families still face waits and uncertainty for many elements of their entitlement. There is currently no Special Rules route for carer benefits, or Pension Credit, nor is there an exemption to the five-week wait for Universal Credit.

As well as the issues of adequacy of benefits, submissions and witnesses raised more minor yet consequential issues within the benefits system. Sandra Cayzer from Heart of Kent Hospice highlighted, for example, that the threshold amount for pension income for contributory Employment and Support Allowance has not changed since 2008, meaning that some people able to access their private or workplace pension early due to their diagnosis would be denied this benefit. Jamie Thunder from Marie Curie also pointed that a life insurance payout on the basis of a terminal illness would be counted as 'capital' under Universal Credit rules, and so could easily put someone over the threshold for receiving means-tested benefits – a threshold that was last updated in 2006.[31] This also is a serious disincentive to those responsibly planning for their family's future.

Recommendation

The Department for Work and Pensions should undertake a comprehensive review of the design and operation of benefits applicable to people living with terminally ill people to ensure their ongoing adequacy, and ensure that fast-track access is available for all such benefits.

Academics from York University and the University of Bath also highlighted the lack of further support for housing costs for people living with terminal conditions: "It is likely that a household facing a shortfall in their housing support [prior to diagnosis] will continue to face that shortfall but with reduced capacity to increase earnings to make good the shortfall. Benefit shortfalls are intended to operate as a nudge, encouraging tenants to move to cheaper accommodation or to increase their earned income. In cases where a terminal diagnosis has been given, neither strategy is tenable."

This was echoed by Peter, the Marie Curie storyteller, who said: "I've been renting private. It's a lot of money. It's just been going up since I've been here. It's gone up three times since I've been here, the rent. Out of my pension every 28 days, I give my landlord £250 top up rent and then I pay roughly £250 a month."

Data from DWP shows that 48% of households in receipt of Universal Credit face a shortfall in their Local Housing Allowance.[32] Comparable data for Housing Benefit is not available. While we do not know how many affected households include someone with a terminal illness, as Peter's story shows, this will clearly affect some terminally ill people, who have no reasonable way to reduce their housing costs.

More widely in relation to housing, Beka Avery from Sue Ryder highlighted that while there is fast-track access to parts of the benefits system, there is no such support for people in need for housing support from their local authority. Hostels or Temporary Accommodation are unlikely to be suitable for someone with a terminal condition[33], yet there is neither a fast-track route to local authority housing support, nor specific provision of accommodation suitable for the needs of people in this situation.

Recommendation

The Department for Work and Pensions should consider ways to increase housing costs support for people with a terminal illness, given that increasing income or undergoing the additional disruption of moving home are unviable for someone living with a terminal illness.

Recommendation

The Ministry for Housing, Communities and Local Government and local authorities should ensure that the unique needs of people living with a terminal condition are properly reflected in processes around and commissioning of homelessness services.

We also heard of people struggling to access the benefits they are already entitled to – and the precarious nature of both the services that support them to access those, and charitable funds that can fill some of the gaps in the current system.

> *"There's nothing written down or a leaflet that you can get from the library or the doctors or wherever about what you may be entitled to. It would be so helpful to know what you are entitled to and what you can apply for. There's nothing. A lot of it is just through word of mouth"*
>
> *Hospice UK focus group participant, cited in "It's a nightmare scenario" – death, dying and financial hardship*

> *"I get PIP being on the sick, but other than my pension, I don't get other benefits. I don't know what other benefits I'm allowed. I tried to get a mobility scooter because I don't walk too far. I've got a bus pass, but apparently I'm not in the right criteria for a scooter. I don't know how that worked out, because I'm terminally ill."*
>
> *Peter, Marie Curie storyteller*

> *"As my disease progresses, there isn't much information I was given around coping with terminal illness. This was before I was with Marie Curie, and I was kind of told that there was nothing they could do and then that was the end of it. I didn't know where to go or who to ask for help."*
>
> *Anonymous respondent to inquiry*

Awareness of the support available, and the ease of accessing that support, is not evenly distributed across the population. Rekha Vijayshankar, a former Marie Curie nurse, highlighted that in her experience, people living in deprived communities often lacked the agency and confidence to access the support they might be eligible for. For example, they might not realise that they are classified as 'carers' by the state – a point echoed by Beka Avery from Sue Ryder.

Rekha also pointed out the often-lower levels of health and death literacy among minoritised ethnic communities, in part due to language barriers, and in part due to mistrust of institutions and government services. She explained how racialised minority ethnic communities can be additionally penalised by language differences, and that whilst undertaking the challenge of navigating health and related support infrastructure, they frequently face additional language barriers and don't get the support they need to fully understand the breadth of support available to them. She gave an example of a patient she knew who was completing a Carer's Allowance form whilst using a public library computer, not only struggling to understand the complications of the form, but also battling their ability to find the time and energy to fill it in.

Clearly, if people are unaware of or unable to claim what they are entitled to, they are at greater risk of struggling with the additional costs a terminal diagnosis brings. Expert advisers in hospices can and do play a crucial role in supporting people to access benefits, as Katie Reade from Hospice UK pointed out: "What we have found is that people living with a life-limiting condition, their families and even their health and care professionals are often unaware of the financial support available or how to access it. Many people have told us that they had no idea they were entitled to social security payments until they were referred to their local hospice." She also pointed out that unfamiliarity with the benefits system, as well as stigma associated with claiming benefits, can prevent people understanding their entitlement, and that it is therefore "crucial that health and care workers ask about money worries and refer patients and families to welfare advice so they can get the support they need".

Yet existing specialist welfare rights services in hospices are at near-constant risk of closure due to the lack of statutory funding. They are fully reliant on donations and fundraising, which can fluctuate and is not guaranteed. While advisers in other locations such as Citizens Advice Bureaux can also provide support, they are rarely expert in the specific challenges people with a terminal diagnosis face, and there are clear benefits to holistic support being provided by a single location such as a hospice.

The value of this specialist, in-depth casework is well demonstrated by the following example:

> *"Our benefits advisers recently undertook a visit to a patient and his wife with dementia and other conditions, who had been without Attendance Allowance since 2021 due to them not able to provide hospital dates/care home dates correctly and failing security checks. The patient had a social worker, yet this still had not been resolved.*
>
> *We visited and sorted all the dates out by calling and researching the medical records. The DWP have now been updated and the Attendance Allowance will now be paid back to 2021 and ongoing. The patient/wife could not have done this without our support. Other agencies have left them without these vital funds as no one has been prepared to do what we have done."*
>
> *St Barnabas Hospice*

Recommendation

Local health systems across the UK should ensure provision of a minimum standard of welfare and social security advice for people with a long-term condition, including people with a life-limiting condition, and their carers in their area.

Third sector and discretionary local authority support

The uncertainty caused by the current nature of specialist advice provision causes challenges for people in need of advice. But such uncertainty extends beyond advice provision, and to the provisions of grants, which applies both to third-sector grants and local authority grants under the Household Support Fund (soon to become the Crisis and Resilience Fund).

MNDA, for example told us that the reliance of charitable support to help people financially, "highlights the fragility of the current system": "In 2024, the Association issued emergency cost-of-living grants to 1,902 people, a 50% increase from 2023, while the average grant value rose from £340 in 2024 to £499 in 2025. This sharp rise in both demand and the value of grants illustrates the deepening financial insecurity faced by people with MND and their carers."

Similarly, researchers from Cardiff University reported the following comment from a hospice:

"We [the hospice] had like a fund where we could support like a hardship fund, and we could kind of bridge that gap where the government and other organizations maybe couldn't. And now, because of the current situation of the hospice industry and the fact that you know our money is dwindling. It means that like, we can't use that fund either. It's just not there really."

Indeed, shortly before this inquiry began, Macmillan announced the closure of its grants scheme, demonstrating the uncertain nature of these sources of support.[34]

Even where support from charities or local authorities is available, it is often time-consuming to find details and apply, and applying to multiple funds means re-stating often upsetting details of someone's condition and circumstances – with no guarantee of the application being accepted. Other factors include the location-specific nature of many funds that can lead to a postcode lottery, and that many periodically close for applications. While this is understandable for a fund trying to responsibly manage its resources, it is of little comfort to someone needing support, and underlines the inadequacy of relying so heavily on charitable sources to meet essential needs.

We also heard frustrations from hospice-based advisers at the lack of awareness of their role by DWP, which can cause delays and difficulties in communication (in contrast to other advisers who may have partnership arrangements with local authorities or Citizens Advice).

A particular separate concern is around people with No Recourse to Public Funds (NRPF) as part of their immigration status – a group whose number is set to increase if proposals in the Government's White Paper on Immigration are brought forward.[35] Professor Liz Forbat from Stirling University summarised her recent research on the experience of people with NRPF and terminal illness: "Migrants in the UK affected by terminal illness are experiencing extreme financial hardship and destitution. They may experience food and fuel poverty, reliance on food banks, eviction and homelessness, or have stress and anxiety about how they will pay rent. They may experience debt, be reliant on friends or family for financial assistance, or resort to borrowing money from unregulated money lenders. Interviewees indicated that support for terminally ill migrants is disproportionately coming from non-statutory/community-based services such as charities, schools, and faith-based organisations."

Someone with NRPF who has a terminal illness needs the same support as anyone else. While there is scope to grant access in this situation as an 'exceptional circumstance', the Professor Forbat's research suggests that in practice this is not happening, leaving people in exceptionally precarious situations.

Recommendation

The Government should review its guidance on granting access to public funds to ensure it clearly covers people diagnosed with a terminal illness. It should also work with healthcare and administrative professionals to ensure rights to medical and palliative care for people with NRPF are understood and upheld.

Another source of inconsistency highlighted in evidence relates to local authority financial assessments for care costs. Eligibility criteria for Continuing Health Care, also varies depending on the Integrated Care Board, and can be difficult to access.

> *"My mom's financial contribution to her care at her end of life meant that living any longer than she did would have drastically impacted on her ability to support herself financially in her own home. We applied for CHC funding and were repeatedly told she did not meet the criteria. I mean how ill do you have to be? Mum was bed bound, her quality of life was deteriorating."*
>
> *Claire, respondent to inquiry*

We also heard that not all areas have fast-track schemes for Blue Badges for people with a terminal illness, meaning they have to pay parking fees until the badge is processed, and some charge people for an application, even if they have a terminal illness. This adds more bureaucratic and financial hurdles to people accessing support that they need, and local authorities should remove such barriers.

Recommendation

The Government should ensure that guidance to local authorities and ICBs on issues like Blue Badge applications and Continuing Healthcare makes clear the acceptable minimum of level and nature of support for people living with terminal illness.

Chapter 4

The future of the disability benefits system

While this inquiry was ongoing, the Department for Work and Pensions (DWP) published the Pathways to Work Green Paper, and subsequently the Universal Credit and Personal Independence Bill which was to enact some of the changes set out in that Green Paper.

In the course of the inquiry, we heard significant concerns about the impact of proposed changes to PIP eligibility for people who do not fall under the Special Rules. MNDA highlighted in relation to PIP that “proposed changes requiring claimants to score four points in one activity could wrongly disqualify people in the early stages of MND, even as their needs increase. For example, someone may need supervision to wash or bathe safely, but still not reach the new scoring threshold”.

These proposed changes to PIP were ultimately removed altogether from the Bill during the Committee Stage in the House of Commons, and there are protections relating to the remaining Universal Credit provisions. People under the Special Rules will be eligible for the higher Universal Credit Health Element, not the significantly reduced amount that will be paid to most new claimants from April 2026. People who are not under the Special Rules, but who meet the Severe Conditions Criteria, will be similarly protected.[36]

These protections are welcome, yet they do not go far enough. They do little more than maintain current levels of income for those protected groups – they will not reduce the prevalence of deaths in poverty among working-age people, which according to Marie Curie stands at 28%, far higher than the equivalent rate among people over pension age.[37]

We are also concerned about the impact of these changes on people who do not qualify for either protected group, particularly people in the earlier stages of progressive, terminal conditions such as MND, multiple sclerosis (MS), or corticobasal degeneration (CBD), or with terminal cancer but a relatively long prognosis. Such claimants may not yet have an SR1 form, so would not qualify for this under the Special Rules. Their function may also not yet have deteriorated enough to mean that they are assessed as having Limited Capability for Work and Work-Related Activity, which is a requirement to meet the Severe Conditions Criteria.

This means that this group will continue to be ineligible for any additional Universal Credit (UC) until such time as their function or prognosis worsens. This is a major missed opportunity to reduce the gap between poverty at the end of life between working-age and pension-age people.

This is also a missed opportunity in relation to conditionality for people with these conditions. The Limited Capability for Work category is intended to apply to people who are not currently well enough to work, but may be in the future, and so are expected to take steps to move nearer the labour market. This makes no sense for someone with a progressive, life-limiting condition – while at the moment of assessment their function might place them in this category, their trajectory is sadly only going to take them further away from work.

At some point, they will qualify for the Health Element, and at the higher rate DWP proposes after April 2026, under either the Special Rules or the Severe Conditions Criteria, provided they complete a Change of Circumstances form. Yet until that point, they are denied the extra income and protection from conditionality requirements.

Recommendation

The Department for Work and Pensions should not expect someone with a progressive, life-limiting illness to take steps to move back towards work when that is exceptionally unlikely to happen. It should expand the Severe Conditions Criteria to include people with life-limiting progressive conditions with Limited Capability for Work, and exempt this group from any conditionality requirements.

Recommendation

Any changes to the PIP assessment and criteria following the Timms Review must protect people living with terminal illness and their carers, including those who do not currently qualify under the Special Rules.

Wider issues with treatment of people living with terminal illness in the benefits system

In principle, the Special Rules provide protection from inappropriate requirements from a JobCentre. Yet we heard repeated evidence that JobCentre staff do not always respect this. As one adviser put it: "It is clear that UC staff have a different approach to terminally ill patients than that of the PIP staff handling SREL… UC's preferred option is to call people into the JobCentre and most attend in fear of doing something wrong and not being paid benefit rather than actually being well enough to attend."

The impact of this can be hugely disruptive and distressing to claimants, as the following case studies demonstrate.

"The hospice helped Jose & his family claim UC. The UC claim was accepted and included information of his terminal illness, that he was unable to attend the JobCentre, and that there would not be a requirement for him to look for work. However, the local office handling the claim asked him to visit the JobCentre to meet with a work coach. Not wanting to delay payment, Jose attended even though he was extremely unwell.

Jose was then told he needs to complete a work capability assessment and was asked to visit the JobCentre again. Jose was hospitalised for a few days and was unable to attend the JobCentre. His UC payments stopped. The hospice supported Jose and his family through food bank vouchers until we could get his UC back into payment."

Case study provided by Heart of Kent Hospice

"A terminally ill client, currently under hospice care and largely bedbound, is facing the devastating prospect of losing access to Universal Credit (UC) due to a rigid identity verification requirement by the Department for Work and Pensions (DWP).

Despite the DWP being in possession of the client's SR1 form—submitted to both the Personal Independence Payment (PIP) team and the local Jobcentre, which clearly outlines the severity of his condition, the client has been instructed to attend a face-to-face appointment at the Jobcentre to verify his identity. This demand is not only medically unfeasible but also deeply distressing for the client and his support network.

The client is currently being supported by a local hospice community team, who are in the process of installing a hospital bed in his home. He is housebound and in no condition to travel.

The UC Helpline has refused to engage with the client's representative, despite a journal entry explicitly authorising the representative to speak on his behalf. Without urgent intervention or a compassionate workaround from the DWP, this man's UC claim is at risk of failing, denying him vital financial support at the end of his life."

Case study provided by Citizens Advice Gateshead

These examples, and others we have not had space to include in this report, come from different parts of the country, which suggests there is a systemic problem, not isolated to a specific area.

Whatever changes are made to Universal Credit and conditionality in the future, including the planned abolition of the Work Capability Assessment, DWP must urgently address these issues to provide meaningful dignity and security to dying people.

We also heard of widespread frustration from advisers specialising in support for people with palliative care or end-of-life needs at DWP's demands, and inconsistencies between approaches taken by Work Coaches. While this is often in relation to individual JobCentres rather than central policy, it is not acceptable, and it is clear that the central Department can and should do more to ensure that where someone needs support from DWP (whether nationally or at a local JobCentre) that they receive it in an appropriate and compassionate way.

Recommendation

The Department for Work and Pensions should issue clear guidance to Universal Credit staff about how people with terminal illness should be treated, and ensure that training on the topic is provided. This should include how complex situations such as an inability to attend an in-person identity check can be resolved.

Recommendation

The Department for Work and Pensions should provide people qualifying for the Universal Credit Health Element under the Special Rules for Terminal Illness with a dedicated Work Coach to improve consistency of their experience during their illness.

Recommendation

The Department for Work and Pensions should ensure it has regular, structured engagement with benefits advisers specialising in working with terminally ill claimants (such as those based in hospices) to identify localised or wider issues in how JobCentres and Universal Credit respond to the urgent and unique needs of their clients.

Conclusion

This inquiry has highlighted deeply concerning evidence of the scale and impact of the additional costs faced by someone after a terminal diagnosis. Many of the drivers of these costs, like the heightened need for energy, are unavoidable. But the real damage is done by the inadequacy of the support provided to help people to meet them, causing worry and financial hardship at the worst possible time, and affecting not only the person with the terminal illness but those around them, both during the illness and after the death.

The better news is that there are practical policy changes that are available to government to begin to address this situation. Key among these is to take steps to close the gap in support between working-age and pension-age people. The forthcoming Pension Commission is a real opportunity to end this injustice by extending access to the State Pension to people who will otherwise die too soon to receive the entitlement their hard work and National Insurance Contributions would have given them.

There is also an urgent need to address the crisis of energy affordability. A social tariff would provide genuine and much-needed support to people facing the often-astronomical increases in energy costs following a terminal diagnosis, while the lack of a comprehensive scheme to provide up-front support with the specific costs of vital medical devices is a major gap in the support provided by the NHS to terminally ill patients.

At times, the evidence in this inquiry has been difficult to hear and read – all the more so because the hardship and distress caused by the additional costs of a terminal illness can be alleviated through policy choices. But those policy choices remain available, and now is the time to introduce them.

Summary of recommendations & timelines

Chapter 1: How terminal illness affects finances

Work should start within the next 6 months

The Government should conduct a review of the financial support available to households with a terminal illness.

The Government should ensure that a household receiving Universal Credit in which a claimant has a terminal condition has an equivalent level of income to that provided by Pension Credit.

Local authorities should work to increase self-identification of carers and ensure that every carer of someone with a terminal illness is offered a Carers Needs Assessment at least annually (including an assessment of financial need).

The Ministry for Housing, Communities and Local Government should amend the prescribed requirements for Council Tax Support Schemes in England to exempt households containing someone nearing the end of life. Until that point, other councils should take similar steps to provide support to residents at a highly difficult time.

Work should start within the next 12 months

The UK Government should legislate to introduce a new statutory right to paid Carer's Leave for employees with unpaid caring responsibilities.

The Government should comprehensively review Carer's Allowance and other carers' benefits to ensure they adequately support carers. This must include a review of the levels and eligibility criteria.

The Department of Energy Security and Net Zero should introduce a social tariff for households in which someone has a terminal illness.

Longer-term

The Pensions Commission should explicitly consider how access to the State Pension can be provided early for working-age people with terminal conditions as part of its review due to report in 2027.

The Department of Health should ensure that there is a single, simple and comprehensive, scheme providing up-front support with the running costs of medical devices provided by the NHS.

Chapter 2: What this means for terminally ill people and their families

Work should start within the next 6 months

The Ministry of Housing, Communities and Local Government should bring in statutory minimum standards for council funerals.

The Department for Work and Pensions should update eligibility criteria of Funeral Expenses Payment to match the Funeral Support Payment in Scotland.

The Department for Work and Pensions should extend exemption from the Under Occupancy Charge (bedroom tax) to a year (up from 3 months) after a bereavement.

Work should start within the next 12 months

Carer benefits should be payable for at least six months after the death of the care recipient, rather than the current two months.

Claimants should be given 6 months to make a claim for Bereavement Support Payment without any loss in award, and payments should be excluded from capital for a least 3 years.

The Department for Work and Pensions should ensure that free childcare provision that is available to working families is also available to terminally ill parents.

The Department for Work and Pensions should review support for funeral costs and ensure that these cover reasonable expected costs of a funeral.

Chapter 3: Gaps in support for people living with terminal illness and their families

Work should start within the next 6 months

The Department for Work and Pensions should ensure that the Special Rules provide automatic entitlement to the Mobility Component of PIP, in the same way and for the same reason as they do for the Daily Living Component.

The Department for Work and Pensions should undertake an awareness campaign about the Special Rules for End of Life among clinicians likely to interact with terminally ill people and track uptake.

The Department for Work and Pensions should urgently investigate whether reported slow timelines for processing SREL claims are localised or wider issues, and take immediate steps to ensure such claims are not delayed.

The Ministry for Housing, Communities and Local Government and local authorities should ensure that the unique needs of people living with a terminal condition are properly reflecting in processes around and commissioning of homelessness services.

Local health systems across the UK should ensure flexible, easy to access, funded transport is available, and account for travel to and from local charitable hospices when examining and planning patient transport needs across their area.

Local health systems across the UK should ensure provision of a minimum standard of welfare and social security advice for people with a long-term condition, including people with a life-limiting condition, and their carers in their area.

The Government should ensure that guidance to local authorities and ICBs on issues like Blue Badge applications and Continuing Healthcare makes clear the acceptable minimum of level and nature of support for people living with terminal illness.

Work should start within the next 12 months

The Department for Work and Pensions should review the Special Rules and consider whether a revised definition more in line with the one used by Social Security Scotland would improve certainty and widen access among terminally ill people.

The Department for Work and Pensions should undertake a comprehensive review of the design and operation of benefits applicable to people living with terminally ill people to ensure their ongoing adequacy, and ensure that fast-track access is available for all such benefits.

The Department for Work and Pensions should consider ways to increase housing costs support for people with a terminal illness, given that increasing income or undergoing the additional disruption of moving home are unviable for someone living with a terminal illness.

The Government should review its guidance on granting access to public funds to ensure it clearly covers people diagnosed with a terminal illness. It should also work with healthcare and administrative professionals to ensure rights to medical and palliative care for people with NRPF are understood and upheld.

Chapter 4: The future of the disability benefits system

Work should start within the next 6 months

The Department for Work and Pensions should not expect someone with a progressive, life-limiting illness to take steps to move back towards work when that is exceptionally unlikely to happen. It should expand the Severe Conditions Criteria to include people with life-limiting progressive conditions with Limited Capability for Work, and exempt this group from any conditionality requirements.

The Department for Work and Pensions should issue clear guidance to Universal Credit staff about how people with terminal illness should be treated, and how complex situations such as an inability to attend an in-person identity check can be resolved.

The Department for Work and Pensions should provide people qualifying for the Universal Credit Health Element under the Special Rules for Terminal Illness with a dedicated Work Coach to improve consistency of their experience during their illness.

The Department for Work and Pensions should ensure it has regular, structured engagement with benefits advisers specialising in working with terminally ill claimants (such as those based in hospices) to identify localised or wider issues in how JobCentres and Universal Credit respond to the urgent and unique needs of their clients.

Any changes to the PIP assessment and criteria following the Timms Review must protect people living with terminal illness and their carers, including those who do not currently qualify under the Special Rules.

Appendix 1 – Inquiry terms of reference and witnesses

Oral evidence sessions

March 26th 2025

Sandra Cayzer, Welfare Adviser, Heart of Kent Hospice and Welfare Lead, Association of Palliative Care Social Workers

Jamie Thunder, Senior Policy Manager – Financial Security, Marie Curie

Katie Reade, Head of Policy and Public Affairs, Hospice UK

May 14th 2025

Simon Smith, Head of Wellbeing and Community Engagement, Berkshire West and South Oxfordshire, Sue Ryder

Peter, expert by experience

Jill Bowen, Palliative Care Social Worker, and Sarah Bennett, Welfare Rights Advisor, Hospice of the Valleys

July 2nd 2025

Kim, expert by experience

Rekha Vijayshankar, Former Palliative Care Nurse, Marie Curie

Beka Avery, Head of Wellbeing and Community Support for East of England at Sue Ryder

Expert written evidence was received from:

Cardiff University; Cardiff University and University of Bath; Hospice UK; Less Survivable Cancers Taskforce; Motor Neurone Disease Association; Pancreatic Cancer UK; Quaker Social Action; St Barnabas Hospice, Lincolnshire; Sue Ryder; Universities of Leeds, Sheffield, and Loughborough; University of Stirling; Young Lives Vs Cancer

In addition, we received written evidence through our survey from 13 people with lived experience of having or caring for someone with a terminal condition, and 37 people with professional experience of these issues, ranging from academics to staff working directly with palliative care patients, including clinical staff and non-clinical staff such as social workers or benefits advisers.

Unless otherwise stated, all quotes and statistics featured in this report are from evidence submitted to the APPG's inquiry, or from experiences shared with the organisations providing the Secretariat.

Appendix 1 – Detail of comparison of working-age and pension-age benefits

All values taken from: https://www.gov.uk/government/publications/benefit-and-pension-rates-2025-to-2026/benefit-and-pension-rates-2025-to-2026

Values presented weekly and to the nearest pound. Universal Credit monthly values converted to weekly by multiplying by 12 then dividing by 52. We assume that only one member of the couple has any disability or long-term health condition.

Working-age households

		Single	Couple
Universal Credit	Standard Allowance	£92	£145
	LCWRA	£98	£98
	Carer Element		£47
PIP	Daily Living	£110	£110
	Mobility*	£74	£74
Total		**£374**	**£474**

*the Mobility component of PIP is not guaranteed to be paid to someone qualifying under the Special Rules, but in practice is paid to the vast majority of such claims.

Couple households

		Single	Couple
Pension Credit	Guarantee Credit	£227	£347
	Additional severe disability amount	£83	£83
	Carer amount		£46
Attendance Allowance		£110	£110
Total		**£420**	**£586**

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Report of the All-Party
Parliamentary Group for
Hospice and End of Life Care

Inquiry into the financial impact of a terminal diagnosis

HospiceUK

Marie Curie

Sue Ryder
Because no one
should face death
or grief alone