HospiceUK

"It's a nightmare scenario"

– death, dying and financial hardship

About Hospice UK:

Hospice care eases the physical and emotional pain of death and dying. Letting people focus on living, right until the end.

But too many people miss out on this essential care. Hospice UK fights for hospice care for all who need it, for now and forever.

Disclaimer:

How to cite this report:

Hospice UK. "It's a nightmare scenario" death, dying and financial hardship. London: Hospice UK; 2024.

Acknowledgements

This report was co-produced with a Steering Group of experts by lived and professional experience. We owe this group a debt of gratitude for all the time, effort and energy they have contributed to this work. The members of the Steering Group are listed below:

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We would like to thank the five hospices who shared their space, expertise and networks to enable focus groups in their local areas. These were Ardgowan Hospice, Foyle Hospice, Teesside Hospice, East Lancashire Hospice and Hospice of the Valleys. We would also like to thank co-production expert Gemma Allen for facilitating these groups.

A huge thank you to everyone who joined these focus groups. Your powerful, personal stories helped us understand people's experiences of death, dying, bereavement and financial hardship across the UK.

Finally, we would like to thank the many other individuals and organisations (listed in the Appendix) who contributed to this report by sharing their insights and feedback. We hope the result reflects the broad range of experience and expertise heard over the course of this project.

The report was authored by Katie Reade, Head of Policy and Public Affairs at Hospice UK. This was supported by colleagues from across Hospice UK.

Foreword from the Steering Group

The last thing anyone who is sick should have to worry about is money. But, a life-limiting condition, being an unpaid carer, and bereavement devastate finances and mental health.

This report contains our personal experiences and those of others across the UK. We struggle with these issues every day. Not knowing where to start, where to go, how to stay out of poverty, how to survive.

Our society and services ignore people's social and financial needs at this tough time. Current financial support and social security payments are insufficient, hard to access and changeable. It takes time to overcome losing someone, and it is not easy to find help.

We hope this report brings our experiences to life for those with the power to make change.

The report's recommendations would create a vital safety net for people with a life-limiting condition and their families. But this hardship is a symptom of larger structural inequities. We need fundamental social and economic reform to fix this.

Sickness and death come with so many financial hardships for everyone involved. We hope this report helps patients, carers, and families so they can focus on what matters.

Executive Summary

An estimated 90,000 people die in poverty every year in the UK.[1] But this report finds that the significant financial and social needs of this group and their loved ones are not being met.

For people to have a good death, their financial and social needs need to be treated as seriously as their clinical ones. However, the current support available is inadequate, inaccessible and inconsistent.

Conversations with people with lived experience, and professionals, across the UK are telling. They reveal the mental and physical toll of facing death, dying and bereavement alongside financial hardship. They demonstrate the significant and hidden costs for this group. These include transport to appointments, energy bills for medical devices and funerals.

It is clear that our society is at fault. It does little to stop people with a life-limiting illness, and those important to them, from falling into financial hardship. And once they have, the welfare state is not there to catch them. Our welfare and social security system is hard to navigate, understand or access. There are obstacles at every turn. Availability of advice and support is inconsistent and reliant on the voluntary sector. This leads to a postcode lottery in support.

Governments, local health systems and services have a responsibility to prevent financial hardship. They must ensure people facing financial hardship and experiencing death, dying and grief get the support they desperately need.

The UK Government could make a fundamental difference to people's lives. By introducing an Essentials Guarantee within Universal Credit, they would ensure everyone can afford the basics, ahead of any diagnosis. Providing people with a life-limiting condition of working age with a state pension-level income would help them live well to the end.

Health and care systems across the UK could end the postcode lottery in finance and social security advice. This would involve ensuring a minimum standard of welfare and social security advice in all areas for people with a life-limiting condition and their loved ones.

Health and care services could identify and help so many of the people who need support. They could ensure their staff ask about money worries at key trigger points and signpost to local financial support services.

The founder of the modern hospice movement, Dame Cicely Saunders, created the term 'total pain'. It describes how pain at the end of life is not just physical but also psychological, social and spiritual.[2] Hospices with truly holistic referral processes and services can model what successful palliative and end of life care looks like.

Recommendations

To stop people living on the edge, or in, financial hardship prior to a diagnosis:

The Department for Work and Pensions (DWP) should introduce an Essentials Guarantee. This should include a legal minimum of support in Universal Credit. It should also include an independent process to regularly recommend this level of support.

To stop people with a life-limiting condition and their loved ones falling into financial hardship:

The DWP should enable people of working age, with a life-limiting condition, to access their state pension. Where needed, they should be able to access the Pension Credit Element of Universal Credit.

The Department for Energy Security & Net Zero should introduce an energy social tariff. This would reduce the energy bills of vulnerable and low income households.

To enable unpaid carers of people with a life-limiting illness to meet their needs and the needs of their loved ones:

The DWP and Northern Ireland Executive should urgently reform the level of Carer's Allowance paid and its eligibility rules, as well as means-tested social security payments relating to carers. This should include:

- An increase in the amount given to carers which adequately values and supports them to continue to provide care and to look after their own needs.
- An increase in the earnings limit for Carer's Allowance, which is linked to the National Living Wage.
- Extending the period during which bereaved carers receive Carer's Allowance from 8 weeks to 6 months.
- Providing additional financial support to carers of the state pension age, which is not means tested.
- Additional financial support for those caring for more than one person.

The Scottish Government should set out a clear timetable for the introduction of its planned reforms to the Carer Support Payment.[3] This should include:

- Extending the period during which bereaved carers receive Carer's Allowance from 8 weeks to 6 months.
- An increase in the earnings limit threshold. This should be increased annually in line with inflation.
- Additional financial support for those caring for more than one person.

To enable people with a life-limiting condition and their loved ones to access the social security payments they need:

The DWP should:

- Increase the number of staff providing information and advice on social security. This would ensure they can meet the demand for advice and support.
- Provide staff with training on the needs of people with a life-limiting condition, their carers and those experiencing bereavement.
- Fully review the social security system to reduce its complexity and increase accessibility.

Local health systems across the UK[4] 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.

Health and care services should:

- Ensure health and care professionals ask about money worries at key trigger points.
- Ensure health and care professionals have details of local financial support services to which they can signpost patients.
- Hospices should:
- Collaborate with organisations who support people living in financial hardship. They could also train them on the needs of people with a life-limiting condition and their loved ones.
- Consider bidding for funding for social security advisor posts that support hospice patients.

To enable people with a life-limiting illness and their loved ones to afford to travel to essential care and spend final moments together:

Local health systems across the UK should:

- Ensure flexible, easy to access, funded transport is available. People with a life-limiting condition could access this to get to appointments or services.
- Provide funding that family and carers can access. This would pay for fuel, public transport and parking. It would allow them to visit loved ones in inpatient units, or drive them to appointments.
- Account for travel to and from local charitable hospices when examining and planning patient transport needs across their area.

Hospices should:

- Improve physical access to their services. This could include outpatient clinics/services and transport support to reach people who cannot travel to them.

To enable people with a life-limiting condition and their loved ones to access the holistic support they need:

Primary and secondary health and care services should:

- Develop close relationships, and collaborate, with local voluntary sector providers, including hospices. They must have a good understanding of the variety of services they offer.

Hospices should:

- Ensure their first assessments and triaging of patients include questions about social security payment eligibility and money worries.
- Ensure their referral criteria and service provision take a truly holistic approach to palliative and end of life care. This would include social, financial and emotional needs.
- Use population and service data to understand who they are and are not supporting.
- Fund projects and roles within the communities they need to build links with.

To stop people being penalised for losing a loved one:

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.

The Ministry of Housing, Communities & Local Government, Scottish Government and the Northern Ireland Executive should:

- Introduce new regulations to create statutory minimum standards for public health funerals.
- Legislate to require landlords in private and social rented sectors to give at least 6 months' notice for an eviction when an original tenant dies.

Introduction

The conditions we are born, grow, work, live, and age in, and the forces and systems that shape the conditions of our lives, all influence our health.[5] Many of the social determinants of health, such as income and food insecurity, relate to financial hardship. People living in deprived areas have shorter life expectancies and spend more of their lives in poor health.[6]

It is likely that people who have faced financial hardship throughout their lives will need more care and support at its end.[7]

But, research shows that, in high income countries like the UK, markers associated with a poor experience at end of life are more common for people with a lower socioeconomic position. These markers include frequent hospital admissions, dying in hospital and a lack of specialist palliative care.[8]

People facing financial hardship are more likely to need care and support at the end of their lives. But they are also less likely to get it. And having a life-limiting condition can push people into financial hardship.

Marie Curie has found that people of working age and families with children are at high risk of falling into poverty at end of life.[9]

Bereavement and caring responsibilities also impact financial resilience. For example, in the 12 months before referral to Trussell Trust network food banks, 18% of people had experienced a bereavement. In the general population, this figure was 14%.[10] And 28% of carers live in poverty, compared to 20% of people without caring responsibilities.[11]

An estimated 90,000 people die in poverty every year in the UK. But people's experiences of death, dying and financial hardship often go unheard by those with the power to make change.[12]

Groundbreaking studies such as 'Dying in the Margins' in Scotland are leading the way. In this study, people with lived experience of financial hardship took images that told their story of dying at home. There is a clear need for more work, like this, that supports the sharing of people's lived experiences.[13]

Within this context, Hospice UK aimed to share people's experiences of financial hardship and death, dying and bereavement. We want to ensure these voices reach, and are heard by, decision-makers across the UK.

We also wanted to learn more about the relationship between financial hardship and hospice care. It is vital to amplify hospices' work in this area and explore how the sector can better prioritise, design and deliver its services to support people facing financial hardship.

Our approach

Research and policy work relevant to this project use a variety of terms and definitions such as poverty (deep, relative and absolute), low socioeconomic status and deprivation. We chose to frame our work around financial hardship to capture the broadest range of experiences possible.

We started by informing our understanding of the experiences of people facing financial hardship at the end of their lives and the barriers they face. To do this, we held five focus groups with people with lived experience in areas of high deprivation across the UK. We also interviewed professionals, including academic researchers, policymakers and frontline health and care staff. Using an online form, we collected people's views and experiences. Frontline service interviews had a particular focus on hospice care, which provided insight into sector-specific challenges and opportunities.

We purposefully selected focus group locations in areas outside of major cities and they all took place within a hospice. The focus groups' purpose was twofold. First, to provide a safer environment for people with lived experience of financial hardship to share their stories and experiences. Second, to explore the themes and challenges that people encounter when caregiving, living with a life-limiting condition or bereaved.

All participants were aged 18 and over, lived within the demographic area of the hospice and, with the exception of two people, accessed hospice care. Many focus group attendees had been primary carers with experience of multiple caregiving responsibilities for a spouse, elderly parents and children. There were also experiences of a variety of life limiting conditions, including cancers, organ failure, neurological illness and dementia.

To guide and shape this report's production, we convened a Project Steering Group. This consisted of experts by professional or lived experience, and included participants from the focus groups. The group met online four times to analyse the data collected from the focus groups and interviews and to support the final report and recommendations.

Our findings

We have themed our findings from the focus groups and professional interviews and included quotes and anonymous case studies.

Varying experiences of financial hardship and deprivation

In all our conversations, the financial toll of living with a life-limiting condition or caregiving was clear. As was the emotional and mental trauma of trying to understand and navigate finances and money concerns when bereaved.

People we spoke to described how individuals and carers often fall into financial hardship as a result of a terminal diagnosis, caring responsibilities or bereavement. For example, they might have had to resign from work or fund care. Professionals described the hidden costs of living with a life-limiting condition. These could include not having the energy, time or money to shop around for the best prices, relying on more expensive local shops and having to pay for transport to attend clinical appointments.

> *"You may have never claimed benefits because you've always had a job but then suddenly you're unable to work and you have no income or savings to fall back on."*
>
> *focus group participant*

> *"I've had to cash in all my pensions. They are gone because we needed the money now we are full time carers."*
>
> *focus group participant*

> *"We had to have adaptions like a shower room and different flooring and had to pay for all that. It came from our savings and left nearly nothing."*
>
> *focus group participant*

People described the compounding impacts of financial hardship and of living with a life-limiting condition, caring responsibilities or bereavement. This might include having to pay for a funeral when you are already financially struggling or navigating the social security system when you are unwell.

It is clear that there needs to be stronger safeguards to prevent people from falling into financial hardship in the first place. A positive step towards this would be to introduce an Essentials Guarantee, as called for by the Joseph Rowntree Foundation and the Trussell Trust. This would consist of a legal minimum level of financial support provided via Universal Credit. There would be an independent process that regularly recommends what this legal minimum should be based on the cost of essentials, such as food, travel and electricity.[14]

> “*We've managed to claim what we can but I haven't been able to work since November as I'm looking after them and my partner is self-employed. There is nothing that I can claim because we've got some savings. I can't claim carer's allowance. The welfare officer helped us but our mental health is awful. We are down over £2,500 a month. We are paying for carers, the hospice is great, but we are financially worse off and we cannot do it all. Financially we are going to be broke. We've got a broken boiler and can't afford to replace it because we must pay our mortgage. We can't claim universal credit because we've got just over the threshold in savings which we are trying to hold onto to pay for the boiler, or the car when it breaks. But we are financially ruined and we weren't before this.*”
>
> *focus group participant*

> “*It has a profound effect to have no money and be terminally ill. You'd think I might as well end my life and it's a nightmare scenario.*”
>
> *focus group participant*

> “*I'm going back to work in a month, but my life has fallen apart. I'm only going back because I have no choice financially.*”
>
> *focus group participant*

Many hospice workers described the increasing number of younger adult patients they are supporting and their specific needs. For example, having dependent children can impact on where a patient can receive care, or their finances. Given that working age people are at higher risk of dying in poverty, it is essential that their needs are considered by services. People of working age with a life-limiting condition must be able to get their state pension. And where needed, the Pension Credit Element of Universal Credit, as proposed by Marie Curie in their Dying in Poverty report.[15]

> *"I spent the majority of my savings to care for my wife before she passed that left me worrying when I would have to go to work. I now have to work for myself to give me the time to take my daughter to school. Every school holiday I have to have the time off now so I don't bring any income in. It's a big hit financially."*
>
> *anonymous contribution via online form*

Recommendations

The Department for Work and Pensions (DWP) should introduce an Essentials Guarantee. This should include a legal minimum of support in Universal Credit. It should also include an independent process to regularly recommend this level of support.

DWP should enable people of working age, with a life-limiting condition, to access their state pension. Where needed, they should be able to access the Pension Credit Element of Universal Credit.

Stigma of financial hardship

Focus group participants found it difficult to open up about money worries. The stigma of financial hardship was felt across all of the groups. Some people referred to their experiences as exceptional and others initially masked their financial concerns and experiences.

> ***"I'm still working but other than my personal debt, we've been ok… It's just the struggle of coping with it all with a progressive disease. I lose a bit more of her every day."***
>
> *focus group participant*

> ***"We might work with someone for a while and then months later they admit their [financial] situation."***
>
> *professional contribution*

Many frontline professionals told us that the stigma surrounding financial hardship leads to patients and carers not disclosing money worries or accessing services. For example, one hospice shared a story of an individual who was not willing to access a food bank because they lived in a small community where everyone knows everyone. Frontline professionals also shared that older patients and men are least likely to talk about money or admit to struggling financially.

Palliative care professionals shared that they are often the first to learn the full extent of a patient's financial situation when other health and care workers have only met with a patient in a clinical setting. One hospice worker described a patient who had been well known to oncology and in hospital for a significant period of time but was not known to the community nursing team. Hospice staff were the first to visit the patient at home and immediately referred the patient to a benefits advisor as an emergency due to their living conditions. Professionals spoke about the value of normalising financial support by referring everyone for a social security assessment. They also explained how accessing financial support at health and care centres enables people to access advice without being 'seen' to need it.

Patients and families are unlikely to volunteer information about their financial situation. So, it is vital that frontline workers ask the right questions with sensitivity and at key trigger points, such as diagnosis, referral, triaging, admission and discharge, and at health assessments. They need to create a safe environment where patients feel comfortable sharing this information and have details of services to which they can signpost patients.

Professionals we spoke to shared that health and care workers are often not comfortable asking people about money. For health and care workers outside of specialist palliative and end of life care, this discomfort is increased by a lack of confidence around talking about death and dying. To support early open and non-stigmatising conversations about finances between health and care workers and patients and the people important to them, the University of Glasgow End of Life Studies Group and Marie Curie have produced a 'Money Matters at the end of life' guide.[16] This guide supports health and care professionals with conversations about financial hardship and deprivation with people approaching the end of their lives.

Recommendations

Health and care services should:

- Ensure health and care professionals ask about money worries at key trigger points.
- Ensure health and care professionals have details of local financial support services to which they can signpost patients.

Hospices should ensure that their first assessments and triaging of patients include questions about social security payment eligibility and money worries.

Good practice example

Saint Francis Hospice in Romford's family support team pulled together a 'Financial wellbeing support guide' and distributed this to different teams across the hospice to ensure they were equipped for conversations about money. This guide includes a list of what people could be eligible for in different areas, what different local authorities are doing, local charities and food banks.

Conflicting priorities

A strong theme in the focus groups was the conflict in priorities that people experienced when caregiving and when a person's condition deteriorated, and their care needs increased. Many participants described the emotional turmoil caused by having to prioritise financial tasks or seek welfare advice at a difficult time. In some cases, these conflicting priorities were exacerbated by a lack of access to care, or confidence in its quality.

> *"If you're trying to work to keep your head above water you have two problems. You should be at work but you're needed at home. Your loved one needs you and you can't be there."*
>
> *focus group participant*

> *"When you've got the emotional turmoil of all this, how can you work? I'm dealing with all this and working harder than I've ever worked before to keep them out of going into a home. I promised no care home."*
>
> *focus group participant*

> *"I often have to go back when I finish work and do the things that they [the carers] are supposed to do but don't do it. It's hard but I need to work."*
>
> *focus group participant*

Carers said they struggled to consider the impact of their circumstances on their financial situation as it was impossible to think past what their loved one needed, or their grief. For many bereaved people, it was impossible to think about returning to work or have the capacity to seek and navigate different systems for financial support.

> *"I feel at that moment in time nothing mattered other than time spent with my wife, and that my children had that too. I detached from bills and day to day problems and just concentrated on what mattered."*
>
> *anonymous contribution via online form*

> *"I had money problems. I was so busy thinking about my partner that I didn't give a thought to money at all. Then when he actually died it was that realisation and I thought 'oh my goodness, what am I going to do?' I had to attend financial fitness and they helped me along with a social worker who came and talked to me at length and explained everything to me. I don't know what I would have done without that because I really struggle. In the end I managed to get pension credit which was enough to keep me going as I wasn't getting enough money to live on. I struggled to get by for around seven months, but you just don't think about your finances when your partner is lying there dying."*
>
> *focus group participant*

Financial hardship and mental ill health

The mental toll of financial hardship while caring for someone, living with a life-limiting condition or experiencing bereavement were strong themes in the focus groups and interviews.

People spoke about the anxiety and mental ill health caused by money worries. Those with caring responsibilities spoke about the guilt and stress associated with honouring commitments to the people they care for. People who live in areas of high deprivation are also much more likely to have unmanaged mental ill health. As a result, they are less likely to access support and resources, which creates an additional stressor.[17]

> ***"Money worries during grief is one more weight on my shoulders that I really can't carry. I am using so much energy surviving and money struggles just add to that."***
>
> *anonymous contribution via online form*

> ***"It's the guilt that gets you. I just have no idea where we are going from here."***
>
> *focus group participant*

> ***"They will be coming to our funerals, before we go to theirs. We're knackered. We're done. The money is going down. I'm trying to keep working but all I'm thinking about is how can I earn another £50 this week."***
>
> *focus group participant*

Focus group participants spoke about the relationship between mental health and work. Some described how going to work helped them cope with being a carer and daily responsibilities. Others shared the struggles of trying to balance working to bring in much needed income alongside caring responsibilities or too soon after a bereavement.

> ***"I worry about going back to work as I won't get as much help. If I go to work it has got to cover everything as I won't earn enough to pay rent, bills or to survive. It's been such a tough time and I'm not ready. It is causing so much anxiety."***
>
> *focus group participant*

> *I may be the odd one out but I need to go to work for my mental health. I need that time away."*
>
> *focus group participant*

People discussed the mental health impact of being unable to work and the distress of not being able to provide for their family. Professionals shared how people with a life-limiting condition experience angst over how outstanding debt may impact the people they care about when they die, and how that impacts their mental health in their final days of life. Where people in the focus groups had been able to access bereavement support, carer support and counselling from their local hospice, they spoke about the positive difference this had made to their mental health.

> *I don't know this system, this has never happened to me before but if it wasn't for the support from the hospice, I wouldn't be here. I just thought there was nothing or no one and I thought what do you do?"*
>
> *focus group participant*

The cost of living

Professionals emphasised how much more difficult the cost-of-living crisis has made living, or caring for someone, with a life-limiting illness or experiencing bereavement.

Years of rising costs, including energy costs, mean that many people no longer have savings. Many have been struggling for a long time. This is reflected in the demand for financial support. One hospice's referrals for welfare support increased by 48.7% between 2020 and 2023-4.

> ***"People don't have money anymore. The cost-of-living crisis has caused even more problems for everybody."***
> *professional contribution*

> ***"I think people's quality of life has gone down and it's just about surviving."***
> *professional contribution*

Professionals described the impact of the cost-of-living crisis on services. Many charities are no longer accepting new referrals, or have closed or restricted the eligibility criteria for grants. Hospice workers said it has become harder to collaborate with local community organisations because they are so visibly stretched. They commented on the value of flexible funding provided by local authorities or donors, which has enabled hospices to provide funding independently to support patients and meet their end of life needs.

> ***"Everyone is concerned about their bills and it varies from person to person what bill they are worried about."***
> *professional contribution*

Likewise, our findings demonstrate the impact of the cost of energy bills and the significant rise in tariffs in recent years. Professionals shared that patients are often having to choose between "through the roof" utility bills or not turning the heating on. Frontline workers described coming out of people's homes in the winter months "unable to feel their thumbs" and patients scared to put the heating on because they cannot afford it. One hospice worker said older people in particular will often do everything they can to pay their bills and avoid debt. Ironically, they then often cannot access financial support because they are not in energy arrears.

This is concerning because decreased mobility and treatment often mean people near the end of their lives feel the cold more. By not turning the heating on, people's conditions may worsen. Marie Curie has found that a terminally ill person's energy bill can rise by 75% after diagnosis. This is due to additional costs such as the use of at-home medical equipment, increased use of utilities and the need to keep homes warmer than average.[18]

One hospice worker described patients not receiving the compensation they were entitled to for running an oxygen condenser 24 hours a day. Marie Curie found that rebate schemes only exist for oxygen concentrators and occasionally for dialysis machines. Rebate schemes are also inconsistently administered. Some schemes refund patients only three months in arrears, some do not refund the full cost that patients incur and some common devices have no rebate scheme at all.[19]

Hospice workers described using grant funding to pay people's energy bills for them. They explained how they have worked with gas and electric companies willing to put people with a life-limiting condition on a lower tariff. Age UK and many other non-profit organisations have called for an energy social tariff for those in greatest need. This would provide targeted support via a reduction in energy bills.[20]

Recommendation

The Department for Energy Security & Net Zero should introduce an energy social tariff. This would reduce the energy bills of vulnerable and low income households.

The cost of care

Focus group participants and professionals shared the impact of the high cost of care.

Frontline workers outlined cases where people are choosing not to accept care and 'making do' or getting into debt from extortionate social service bills. For example, one hospice worker discharged a patient home with a care package of five visits a day. They claimed a higher rate of Attendance Allowance but only had £3.80 left from it after paying for care costs. As a result, the patient reduced essential care visits to twice a day to afford essential items. This came at a fundamental cost to their care needs.

> **"*I was caring for my Mum and couldn't get any help. She wanted to die at home, but she wasn't safe to be left alone. Dad was also in and out of hospital and it was hard to get time off. The care package provided by social care wasn't enough as it was only twenty minutes (not even long enough for me to drive home) and we looked into private carers to come in so I could do the shopping or pop home from time to time. But it was £24 an hour and the savings that we did have were for my Mum's funeral which cost nearly £5,000. It was a horrendous situation. My friends helped but it was really just down to me. You wonder how you get through some things. Even trying to get the services started, my phone records show about forty phones calls a day, I was supposed to be going back to work but I couldn't. Luckily, I was paid for six months but now I'm forced to go back and I'm not ready to go back but I need to because I can't afford to not get paid."***
>
> *focus group participant*

Other professionals described a disparity between the support available to those at the very of end of their lives and those at an earlier stage in their condition. For example, people are waiting to receive free social care via continuing healthcare funding, which is available to those with long-term complex health needs. This is because they are not eligible for the 'fast track' assessment available for people rapidly deteriorating and nearing the end of their lives. Those with social care needs who are not eligible for a 'fast track' assessment will often become eligible or have died by the time a regular social care assessment is done. They also cannot afford to self-fund care while they wait for their assessment.

> **"*Some people are getting a lot of choice and control, some people are getting no choice and no control."***
>
> *professional contribution*

Many professionals spoke about how financial hardship prevents people from having choice and control at the end of their lives. They highlighted the contrast between this and the experience of people with financial resources. For example, people able to self-fund a package of social care have choices around when they receive home visits, but people receiving state-funded care do not. This aligns with research arguing that the palliative care movement assumes individuals can make choices around death and dying and ignores the personal, social and economic context limiting their choices.[21]

Good practice example

Birmingham Hospice runs a Personal Health Budget (PHB) team. This team manages the personal health budget for people at the end of life for people within Birmingham and Solihull Integrated Care System. Professionals refer patients in their last 12 weeks of life to a team of clinical nurse specialists who use personal health budget funding to provide extra social support for people who need it. This could include providing extra towels, bedsheets and bedding for a hospital bed. As well as house cleaning, washing, and ironing services. This enables people facing financial hardship or crisis situations to have a better end of life experience. It also prevents avoidable hospital admissions.

In over four years of operation, the team's remit has expanded. It has become part of the overall social team. This includes social workers and a Befriending Service who support care coordination for people in their last few months of life. The team liaises with Continuing Healthcare to put packages of care in place and refers to the hospice's wellbeing team for counselling or the Macmillan Benefits Advisor who visits the hospice once a week. The reach of the PHB and social end-of-life team means that they often come into contact with people who would never have been referred to the hospice previously but could benefit from its services.

The team is established within the community and has become a focal point for positive community action. For example, individuals, such as cleaners or hairdressers, have volunteered to provide their services for free or at a reduced price for patients. The team was originally funded through the Better Care Fund but is now commissioned solely by the Birmingham and Solihull Integrated Care Board (ICB). Funding restrictions mean this team cannot intervene any earlier in people's journeys, and it only receives referrals when the individual is in their final 12 weeks of life.

Case study

Leah* is a 40-year-old woman. Her mother recently died, shortly after being diagnosed with cancer.

"My mum died 9 weeks ago and it was nerve wracking to come and talk about this today, but I wanted to share our experience. Mum was initially an inpatient in a city a couple of hours away from our hometown and my siblings and I were travelling to see her every day. If someone is an outpatient and receiving benefits, they get some financial support to travel to appointments, but you are not eligible for this as an inpatient.

There were so many costs that we didn't consider such as fuel and car parking for hours every day. Because my mum had cancer, her body was changing all the time and we were constantly having to buy new clothes and underwear for her. She wasn't eating and her tastebuds were changing, so we were buying food, ice and drinks every day to try and find something she could have.

Because of the distance from our hometown we couldn't just nip back to the house and get food or anything else needed, so we ended up buying it. If she needed something, we would just get it for her because she was ill and she needed it. My mum had six children, so we were doing it together, all tapping our credit cards and saying we would work it out later. My children were at home and I didn't want to leave my mum, so they were also calling to ask me to order food. It started to feel like playing monopoly. I was just thinking about my mum and what she needed.

Mum spent time in two hospitals and nobody offered us any support with finances. We just did it. Some people said to us that we could have claimed things, but it's really difficult if you don't know who to speak to. I tried to call a helpline, but I couldn't get through, so we just carried on buying the things she needed. We knew things would take ages and we just wanted to get her what she needed because she would have done the same for us.

When my mum was diagnosed with cancer, we applied for Personal Independence Payment for her. However, because she deteriorated so quickly, it came through the day after she died. Once she had died, there were suddenly loads more costs: the funeral directors, the wake, flowers, the headstone, new funeral clothes for everyone. I looked back at my banking app and there were just so many payments. Nobody puts away money in case someone in their family gets cancer."

Transport costs

A key finding raised in professional interviews and focus groups was how the cost of transport is a fundamental barrier to accessing crucial services or visiting loved ones at end of life.

Frontline workers spoke of the anxiety that patients experience about affording fuel or transport to attend appointments. They also spoke about patients using credit cards or experiencing conflicting priorities around choosing to pay for transport or food.

> *"This is people's lives. This is their finances. We are seeing people not going to treatment because it is in a different county and they can't afford the transport."*
>
> *professional contribution*

Professionals commented on the limitations of existing non-emergency patient transport services to hospital or other services. If patients are eligible for such a service, they are often required to be picked up first thing in the morning, dropped-off late at night and stay at the service-site all day, which is inappropriate for many patients with a life-limiting illness. Focus group participants and professionals also raised the impact of transport costs on people visiting loved ones in inpatient units.

> *"If you don't have the money and you can't get in, you know your husband is in the IPU but you don't get to see him and you can't afford to see him."*
>
> *professional contribution*

People shared the detrimental impact of transport costs in rural and remote areas. In these areas, there are long distances to treatment, healthcare appointments, visiting a loved one or accessing a pharmacy for vital medication. One frontline worker described how a patient received a social care placement 50 miles away from home. The patient's husband of 62 years could not drive or travel on several trains to visit her because of his own health. His only option was to pay £168 each way per day for a taxi and as a result was unable to afford the costs to visit his wife in her final weeks of life.

> *"People, when they become palliative, they are less likely to drive so then they are isolated in rural villages and rural towns where there is no access or bus service or even a taxi service"*
>
> *professional contribution*

Focus group participants and professionals raised the impact of where services are located on transport costs and time. For example, hospice buildings are often not centrally located or accessible. One hospice said they found people were declining essential referrals to their services because of the cost implications of attending.

> *"If you live in that area and haven't got a car, it is quite a trek to get here. It would take about an hour coming and going. The financial impact with the cost of fuel, taxis or even if you need to clock in and out for work and drop a loved one off at the hospice it makes it all so difficult for people to access the hospice or attend the groups."*
>
> *focus group participant*

The impact of services not being considered by health systems and local authorities can exacerbate the poor accessibility of hospices. For one hospice, being outside of the city centre's catchment area meant local free transport accessible to people living in social housing, could not be used beyond the local authority boundaries. This prevented people from accessing its day services and social space. Several hospice workers shared approaches they are taking to improve physical access to their services. They included delivering more outpatient services in local communities, opening new facilities and offering a free volunteer-run transport service.

> *"He meets people at the hospice every week, it helps to talk to people who are going through the same as him, but we have to rely on the hospice providing free transport. We can't do it because we are at work and financially unable to take time off every week."*
>
> *focus group participant*

Recommendation

Local health systems across the UK should:

- Ensure flexible, easy to access, funded transport is available. People with a life-limiting condition could access this to get to appointments or services.
- Provide funding that family and carers can access. This would pay for fuel, public transport and parking. It would allow them to visit loved ones in inpatient units, or drive them to appointments.
- Account for travel to and from local charitable hospices when examining and planning patient transport needs across their area.

Hospices should improve physical access to their services. This could include outpatient clinics/services and transport support to reach people who cannot travel to them.

Good practice example

Many people living with a life-limiting illness in Inverclyde, which includes parts of Greenock, cannot afford to pay for taxis to attend numerous appointments outside of the local area. They struggle to use the Patient Transport Service operated by the Scottish Ambulance Service because it can be difficult to arrange and picks up over six patients in each vehicle, requiring passengers to wait for the vehicle and/or travel for long periods of time despite being unwell.

In response to this, Ardgowan Hospice in Inverclyde offer a free and personalised transport service. Volunteer drivers pick up and drop off the patient at a time convenient to them. This service is available to:

- Anyone receiving treatment for a life-limiting illness at a hospital out of Inverclyde who does not have access to transport from family and friends.
- People who are able to travel unaided and do not use oxygen or require an escort and can sit, stand from a low seat, walk and take the stairs unaided.

Between October 2023 and March 2024, the service enabled 792 appointments. This service is co-funded by the hospice and Strathclyde Partnership for Transport, which provides an annual grant of £30,000. The service costs £75,000 a year to run, with the remaining £45,000 provided by the hospice. Without this service, many patients would not be able to attend hospital appointments such as at the Beatson Oncology Centre in Glasgow, which is a 45 minute drive from Ardgowan Hospice.

Case study:

**Paula* is 54-years-old and lives in an area of multiple deprivation.
When her husband died suddenly it caused immediate financial hardship.**

"I worked for the NHS but stopped working to care for a family member. My husband's wage supported us and he had received his pension early to pay for our daughter's wedding. He suddenly became very unwell and was admitted to hospital. I don't drive so I had to get a train and taxi every day to visit him, costing me £400 for two weeks. I asked the hospital about support for travel costs, but all I could get was a car park pass.

When he died, I received a bereavement payment and money was coming in and out of the bank, but I didn't know what it was and after seven months everything stopped. You don't worry about money at first. It just doesn't click. I received his monthly pension but it was taken off my allowances. I went to the job centre for advice, but I was still in shock and numb. I didn't feel supported at all, it was as though nobody wanted to help. They explained about the bereavement payment but when it stopped suddenly it was a huge chunk out of my money. I walked out of the jobcentre feeling dumbstruck, I thought where's all the help? I've worked all my life and there was nothing.

Trying to sort out rent and bills was difficult, I struggled to pull myself together and didn't have enough money to pay the bills. My husband may as well left me nothing. It's taken years to get together financially but it's been a huge worry. I'm stuck because of my small pension and the government penalise me because of it. Someone dies and there's no support.

I had no financial help with the funeral which blew me away. I was going into the funeral directors each month paying it off a bit at a time from my benefits. The job centre said afterwards I may have received half towards it if I hadn't got the bereavement payment or if I'd have asked when he died. My head was all over the place I didn't know what I was doing from one day to the next. My children had to step in and help pay the bills. A year after his death I still hadn't paid the funeral off and it was another worry when I received a letter from the funeral directors asking for the outstanding balance. Luckily, they were very understanding when I explained the situation, but I was just crying everyday wondering how I would pay it off."

The cost of dying

The impact of bereavement and the costs associated with organising a funeral on personal finances were raised frequently.

Professionals spoke about bereaved people struggling on zero-hour contracts. They described individuals no longer able to work after caring for a loved one who has died and having to rely on the social security system.

> *People find it hard enough to live without funding the cost to die."*
> *professional contribution*

> *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."*
> *focus group participant*

People in the focus group spoke about the unexpected and high costs of a funeral. Professionals said they have seen an increase in public health funerals and people requesting direct cremations because of the cost-of-living crisis. They shared stories of families not being allowed to attend public health funerals and not being informed of when they will take place. One palliative care social worker shared a story of someone who died and wanted their ashes scattered where their dad was buried. Her friend, who was arranging the funeral, could not pay to fulfil her wishes or attend the funeral. The social worker encouraged her to plant a rose bush on the day she knew the funeral was happening and say a few words instead.

Professionals spoke about people taking out unaffordable loans to pay for funerals. They discussed the stigma around not being able to pay for a funeral and the lack of awareness of less expensive options and eligibility for support. For example, people often cannot afford life insurance. Therefore they incorrectly assume that because they receive social security payments their family will receive financial support with funeral costs. There is a clear need for consistent availability of compassionate public health funerals and sufficient public information on this option. We support the UK Commission on Bereavement's call for statutory minimum standards for public health funerals.

Professionals also spoke to us about the variation in approach of funeral directors. For example, some funeral directors would not proceed with a funeral unless the balance had been paid due to the rising amount of money owed to them. This has a disproportionate impact on people who need to hold a funeral as soon as possible for religious and cultural reasons. It also creates increased stress and anxiety for people navigating grief. Others spoke about funeral directors in areas of high deprivation who know people do not have the funds to pay for a funeral upfront. They therefore allow people to pay later after claiming for a Funeral Expenses Payment or Funeral Support Payment.[22]

> *Right, they've passed away. What do we do now? We need to get the house all ready, we need to get the funeral directors, we need to get a headstone, we need to get a plot in the cemetery."*
>
> *focus group participant*

Recommendation

The Ministry of Housing, Communities & Local Government, Scottish Government and the Northern Ireland Executive need to introduce new regulations to create statutory minimum standards for public health funerals.

Case study

Emily* is 38-years-old and her husband accessed end of life care at their local hospice. Emily explains the financial hardship her family experienced following the death of her husband.

"Before we accessed the hospice, I got Carer's Allowance and he got Personal Independence Payment and the hospice supported our family to access grants that paid for our family to have a weekend break, transport, and days out to make memories with our family. After my husband died, I received a bereavement payment, but this just stopped after many months with no notice. It is hard trying to find £350 to make ends meet whilst still grieving and trying to support a young family.

I'm no longer entitled to Carer's Allowance, PIP or my husband's pension. Our car was a disability car and got sent back so I had to get a car, plus find the money to pay for tax and insurance. My family allowance was reduced as my one child is older but is still living at home. Overall, I've lost over £1,000 a month.

There needs to be more financial support out there. I couldn't go back to work after six weeks, you're still trying to sort everything out, you've only just had the funeral and all the practicalities take a long time. There really needs to be more support available."

Housing concerns

> *"How do you get the care you need when you can't offer the nurses a door to come from and you can't have a hospital bed because you have nowhere to put it but you don't qualify for a hospice because you aren't end of life enough."*
>
> *professional contribution*

Professionals described people dying in inappropriate and unregulated rental accommodation with damp and mould or inaccessible facilities as well as the difficulty in getting people rehoused.

Some reflected on the lack of housing available and described people living in homes they would have previously been removed from for safeguarding reasons, simply because there is now nowhere for them to go. One interviewee also said they were aware of local authorities deprioritising people for housing once they know they are dying.

Professionals spoke about local authority placements not accounting for individual needs. For example, someone with bowel cancer who was experiencing homelessness was placed in a budget hotel with no access to laundry to wash their sheets or clothes. Professionals said that, where they have succeeded in rehousing someone, often there is a lack of funding to help with moving costs, basic furniture or living equipment.

Concerns were raised around the barriers experienced by people with no recourse to public funds. One hospice worker shared a case study of a family who had not lived in the country long enough to meet the criteria for rehousing.

Marie Curie has found that each year more than one in ten bereaved people are forced to move home following the death of someone they lived with. Reasons for this include loss of income and not holding the tenancy.[23] Several professionals we spoke to raised issues around family members facing insecure housing because the person they were living with has died or has a life-limiting condition. For example, one patient receiving hospice care had significant anxiety over whether their son with additional support needs would be made homeless when they died. This is because their tenancy could only be passed on once and it had already been transferred by her husband when he died.

Another hospice worker described a single parent living in a council property with two children. They were placed in a care home at 42 because they couldn't be admitted to the hospice inpatient unit. As a result, they had a change in address and were no longer eligible for a council house. Because the children are under 18 they are not eligible for succession of tenancy.

The UK Commission on Bereavement called for legislation that requires landlords in private and social rented sectors to give at least 6 months' notice for an eviction when an original tenant dies, which would give bereaved loved ones more time to find somewhere to live.[24] The Welsh Government has made positive reforms, including enabling succession of tenancy to take place twice, a succession right for unpaid carers and requiring at least 6 months' notice for an eviction. Other nations across the UK should follow in Wales' footsteps.[25]

Palliative care social workers we spoke to in England and Wales raised incidences of a death in the home leaving 'a spare room' resulting in people having their housing support cut under the 'bedroom tax'. In order to support people facing the immediate costs of bereavement, the DWP should extend exemption from the Under-Occupancy Charge (bedroom tax) to a year (up from 3 months) after a bereavement.

Throughout our conversations, professionals spoke about the value of inpatient units to people who cannot stay at home for social reasons. Some hospices we spoke to said they have supported people in inpatient units because of complex social needs but others restrict these spaces to patients with high-clinical need. Some professionals expressed concerns about decision-makers reducing funding for inpatient services because of the policy focus on dying at home. Research has also noted how this policy focus impacts access to care for people who are vulnerably housed.[26]

Another key theme that emerged was respecting where people want to die even if health and social care providers see an environment as inappropriate. However, some hospice workers said they were unable to respect people's wishes to die at home because of limitations around medical equipment and caring. This supports arguments by academics about policy and practice being designed around an *"imagined palliative care patient …[who] lives in secure housing, with family support and is white, middle class and male"*.[27]

For example, one hospice worker spoke about supporting someone with Chronic Obstructive Pulmonary Disorder (COPD) who was sleeping on a mattress on the floor. She said they had to admit him to the hospice because it was not possible to get a hospital bed into his accommodation and this would have resulted in unsafe manual handling for both the patient and care staff.

> ***"People in really small flats have the constraints of healthcare imposed on them."***
> *professional contribution*

Professionals highlighted the cost implications and system pressures of poor care and support for people living in inappropriate and insecure housing or experiencing homelessness. One hospice worker described a patient who was placed in temporary accommodation and had 14 avoidable hospital admissions in just three months. Upon discharge, the patient is sent to an empty and isolated room with no other support or family and is readmitted to hospital as a result.

Awareness and understanding of social security and financial support

Focus group participants shared that they were let down by the lack of information on social security.

Many were unaware of what they were entitled to. Professionals highlighted how patients, families and healthcare staff are often unaware of what individuals can claim. They also spoke about the need for better integration across services and shared systems to prevent both gaps and duplication in social security advice support.

Professionals said that patients and carers who are just about managing to meet costs often assume they have to continue managing without social security support after a diagnosis. They think they cannot access financial support if they have savings, or a partner is working. People in the focus groups described a lack of information on social security and financial support from professionals or official sources, with knowledge often shared via word of mouth.

> “*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.”*
>
> *focus group participant*

> “*I didn't know there was (financial) help out there. Nobody offered it to me.”*
>
> *focus group participant*

> “*It's when you are at your most vulnerable and you need someone to step in and support you. I had no idea about our finances or what benefits I could claim.”*
>
> *focus group participant*

Hospice frontline staff shared several examples of people who were eligible for social security payments or a high level of social security payment but nobody made them aware of this until they came into contact with the hospice. They said people often miss out on what they are entitled to for years partially because services they come into contact with do not ask questions about what they are claiming and what they might be eligible for.

> “*We have seen people die before they are referred to us. We have seen people die before we get the medical report.”*
>
> *professional contribution*

> “*Things could improve hugely for people if they had the right information and advice.”*
>
> *professional contribution*

Staff said that patients and carers who are already in receipt of social security payments experience anxiety about ‘rocking the boat’. They do not want to risk the loss of existing payments by applying for additional support. This is mainly due to news coverage of people being unable to access social security payments or having to pay back payments when they have been wrongly calculated. One hospice worker described a patient with a historic claim for Disability Living Allowance, which provided her with access to a mobility scheme vehicle. She was entitled to a higher rate of support through Personal Independence Payment but was nervous that the new claim would affect her access to a vehicle, which she relies on to get to appointments in her rural area. DWP were unable to confirm over the phone that the vehicle was not at risk so she refused to move forward with the claim.

Navigating social security payments and financial support

Focus group participants shared their personal experiences of the overwhelming nature of having a life-limiting illness, caring for someone or experiencing bereavement and how this makes it difficult to navigate the welfare system or prioritise seeking financial support.

> *“If I’m honest, I just took a step back and thought that the system would know what I was entitled to and sort it out.”*
>
> *focus group participant*

> *“It wasn’t my immediate thought. I didn’t know what I was entitled to and probably still don’t. It’s been such an awful time and I shouldn’t be worrying about having no money on top of everything else.”*
>
> *focus group participant*

Many focus group participants commented on the complexity of navigating the overall welfare system and how difficult and exhausting it is to apply for support. Professionals spoke about the impact of physical symptoms, such as memory loss and fatigue, and how this makes it even more difficult for people to navigate such a complex system. They also said that people are often asked for excessive information for claims that can be difficult to obtain when in hospital or a hospice.

> *“I needed help from my family and the hospice to try to complete the benefits forms.”*
>
> *focus group participant*

> *“You’re not in the right frame of mind in that moment to be sitting and dealing with all the forms and phone calls. But if you get someone supporting you to do that it is really helpful. It’s just a minefield as they ask you a thousand questions and if you get it wrong it could impact your benefits.”*
>
> *focus group participant*

Even welfare and benefits advisors said they can find it very complex to apply for grants, the warm homes discount or local authority schemes because there are different rules, eligibility criteria and definitions of income. Securing direct payments for patients can be very slow and often, by the time these are processed, people have died.

Professionals and focus group participants described the difficulty of accessing systems to receive advice and support about social security payments and financial support. For example, spending hours on the phone trying to get through to the DWP, time-consuming application forms or having to speak to and share their stories with numerous individuals.

> *I was on the phone for an hour and a half only to be told they don't do this over the phone."*
>
> *focus group participant*

> *It takes easily two hours to get through to them (HMRC) to speak to someone. It adds to the stress and worry at a really upsetting time."*
>
> *focus group participant*

> *The government needs to help people in our situation and just one person. Not having to talk to this person, that person, two hours on the phone here another two hours wait there before speaking to someone else. You can't see anyone or speak to the same person twice. It destroys you. One conversation with one official can wipe you out for a day. Listening to that music for hours on end whilst waiting to speak to someone. It's destroying."*
>
> *focus group participant*

Welfare and benefit advisors commented that often DWP staff on the other end of the phone have insufficient knowledge of the social security system or are unable to advise claimants effectively. For example, one hospice worker described spending two hours on the phone to find that the DWP staff member had no access to the system with the information her patient needed.

People in the focus groups said that the current system did not provide them with the support they needed and that it lacked the necessary compassion and empathy to their circumstances. Professionals said they found that DWP staff have less flexibility and compassion since the beginning of the cost-of-living crisis.

> *Citizens Advice Bureau were helping me with that, but it didn't get anywhere. It's just a failed system."*
>
> *focus group participant*

> *He isn't earning anything, he left his job to be a full time carer but can't claim universal credit because I'm self-employed."*
>
> *focus group participant*

Our findings around awareness of financial support and the complexity of the social security system are supported by evidence of poor take-up of payments that would help people with a life-limiting condition and their families. For example, 800,000 households in Great Britain are entitled to, but not receiving, Pension Credit.[28]

Recommendations

The DWP needs to:

- Increase the number of staff providing information and advice on social security. This would ensure they can meet the demand for advice and support.
- Provide staff with training on the needs of people with a life-limiting condition, their carers and those experiencing bereavement.
- Fully review the social security system to reduce its complexity and increase accessibility.

Eligibility and level of social security and financial support

Many welfare and benefits advisors said people with a life-limiting condition and their families are often turned down for social security payments and that they have to fight to get them the support they need.

For example, one welfare and benefits advisor said that the organisation doing social security assessments in their area will declare someone can wash and dress themselves if they can lift their hand over their head. Another said it took nine months for a decision to be made on whether their patient with dementia could claim Personal Independence Payment. Even then, the patient was not granted the daily living component, which prevented their wife claiming carer's allowance. The hospice fought this decision for a year and were finally successful but throughout this period the couple had no access to payments they were entitled to.

Welfare and benefits advisors also discussed the impact of having to wait to apply for social security payments, leaving individuals reliant on statutory sick pay or employment support allowance following a diagnosis. For example, needing to wait six months to claim attendance allowance.

Professionals and people from the focus groups specifically highlighted problems with Carer's Allowance and Carer Support Payment, including the low level of financial support it offers. Professionals said people with palliative care needs often need to go into a care home because their unpaid carer cannot afford to live on Carer's Allowance.

The Scottish Government provide a carer's allowance supplement and a young carer's grant, which is welcome. However, people we spoke to in Scotland said the level of financial support is still too low to meet people's basic needs. The threshold for the amount of money you need to be earning to receive Carer's Allowance is also much too low and people over the state pension age can only receive means-tested Pension Credit and not Carer's Allowance.

Numerous individuals emphasised the challenges and mental health impacts of rapid changes in social security eligibility and payments, particularly after the death of a loved one. This caused significant distress at an already painful and emotional time. Professionals also commented that the short time period that pre-bereavement social security payments continue for after a death forces people back to work with limited support before they are ready.

> **“*Suicidal. We had help, money came in from the government but then as soon as it went in it went straight out again. She died on the Saturday and her pension was paid on the Monday. Three weeks afterwards we had a letter claiming the money back and I had to pay it back. I thought it was a little below the belt.*”**
>
> *focus group participant*

> *A week after her death I had a letter to say the carer's payment had been overpaid and it needed to be paid back. I just didn't need this or the worry about paying it back."*
>
> *focus group participant*

> *I did the Tell us Once and all my payments stopped. I then had to pay £400 overdue payments to the council tax until the Universal Credit was sorted."*
>
> *focus group participant*

Recommendations

The DWP and Northern Ireland Executive should urgently reform the level of Carer's Allowance paid and its eligibility rules, as well as means-tested social security payments relating to carers. This should include:

- An increase in the amount given to carers which adequately values and supports them to continue to provide care and to look after their own needs.
- An increase in the earnings limit for Carer's Allowance, which is linked to the National Living Wage.
- Extending the period in which bereaved carers receive carers allowance from 8 weeks to 6 months.
- Providing additional financial support to carers of the state pension age, which is not means-tested.
- Additional financial support for those caring for more than one person.

The Scottish Government should set out a clear timetable for the introduction of its planned reforms to the Carer Support Payment. This should include:

- Extending the period in which bereaved carers receive carers allowance from 8 weeks to 6 months.
- An increase in the earnings limit threshold. This should be increased annually in line with inflation.
- Additional financial support for those caring for more than one person.

Inequitable access to social security and financial support

Conversations highlighted the disproportionate impact of challenges around social security and financial support on specific groups. For example, they supported findings around the significant impact of a diagnosis on people of working age.[29]

Professionals said they found those who are employed are often struggling the most because they can't access Universal Credit or means- tested support and have to manage on statutory sick pay. A significant reduction in salary when people have to take time off work means that they very quickly get into debt. Focus group participants stressed the need for increased short-term support to help people in this situation navigate unexpected changes in circumstances.

> ***"For my health and mental wellbeing, just a short-term payment to get us through the next few months as we navigate all this. That would be such a big help and take away some of the stress and anxiety."***
>
> *focus group participant*

> ***"I just need a bit of help now, at this point. Until we can get settled and I know that they are ok so that I can go back to work. I don't want to be a carer. I just want to be a son."***
>
> *focus group participant*

Since April 2023, anyone who health professionals think may die within one year, rather than six months, is eligible for fast-track access to all eligible social security payments, except for in Scotland where no prognosis is needed.[30] Professionals we spoke to welcomed this extension and said it has made a big difference.

However, in England, Wales and Northern Ireland there are many people with a life-limiting condition who are not eligible for fast-track support and are suffering delays or rejections of applications. There are instances of GPs being confused by changes to application processes or not being aware that they can apply for this support for patients. In Scotland, the need to fill out different forms for people above and below the state pension age has contributed to this confusion.[31]

Professionals highlighted the additional obstacles to accessing social security payments experienced by groups who are often excluded from care and support. For example, one person supported someone living in a permanent caravan who was unable to access household support or warmer homes schemes because he rented from the caravan site.

Frontline workers described the challenges of providing support to people who have no recourse to public funds as 'hitting your head against a wall'. Another professional described a patient who came to the UK as a care worker. She could not work because of her cancer diagnosis but her visa status meant she had no access to public funds. The hospice contacted food banks on her behalf. Some provided basic necessities, but others refused to help because of her visa status.

Professionals raised concerns about the impact of the increasing digitisation of financial support on people who are digitally excluded. Public libraries are a good resource for people without internet access at home. However, it is not always appropriate or possible for people who are very unwell to visit the library to apply for financial support, particularly in rural areas.

Professionals also shared that older people can be particularly anxious about filling in forms or providing their details online for fear of being scammed. Further barriers to accessing support for people who cannot speak English or read or write were raised. Language and literacy barriers prevent equitable access to completing application forms, updating journals online or accessing information or advice.

> **“*I don’t have an email address and that makes online forms not accessible.”***
>
> *focus group participant*

> **“*We (hospice) support someone who was too unwell to leave their flat and they did not have a smartphone or internet connection. They were informed by text message about an update to their benefits journal but they couldn’t access it from home and are now too sick to go to the local library. The hospice had to step in to ensure he received what he was entitled to and wasn’t forced to go to work capability interviews at the job centre to receive this.”***
>
> *professional contribution*

> **“*If you’re sick in bed, you are not going to be holding on the phone for hours trying to sort things out... and that is if you have a phone.”***
>
> *focus group participant*

Case study

Elaine* is 54-years-old. Elaine shares her experience of financial hardship as a carer and the angst of accessing benefits and support when her husband was ill and after his death.

"I was the sole carer for my husband for twenty-five years and the only support I received was once I accessed the hospice. My husband had been made redundant several years ago and we were living on ESA, then DLA and other benefits. He had several conditions and life limiting illnesses but when the government changed to PIP the benefits reduced from the highest rate as they said he didn't need it. He was referred to palliative care and the Macmillan nurse couldn't believe that they had reduced his payment and that we weren't entitled to other benefits. We lost £200 a month. The Macmillan nurse supported us to reapply for the higher rate. When my husband reached state pension age, I only received carer's allowance to cover everything and a form for my prescriptions and dental care.

When my husband died, I rang the 'Tell us Once' service and everything stopped abruptly, apart from the carer's allowance which continued for a few weeks. Because I'm not pension age and don't have a mortgage, I applied for Universal Credit but that was a nightmare. Everything must be done online so if you're not used to doing that or filling in forms it is awful. I phoned the helpline that the government gives you for support filling in the form and they advised that I go to the library or ask a family member. As a carer for a long period of time the form is just yes or no answers and I didn't fit into any of their boxes. Because I couldn't get help and the hospice hadn't had training in Universal Credit to help me, I answered the questions alone but it was hard. It left me with such anxiety that I'd done something wrong. I was extremely lucky that when someone did contact me she had similar experiences to me, so she was kind and understanding.

I now receive basic money of £85 a week and £100 bereavement payment. I get in total £468 a month and even without food I'm £300 a month short, it is extremely difficult, and I have anxiety and extreme panic attacks which has come about through all this, and the Universal Credit form was the final straw. It just all adds to your grief and makes everything twice as hard.

Conversations also highlighted inequity in care and support due to diagnosis and the financial implication of this. This included the impact of organisations offering 'condition specific' support or funding, which is only available to people with a specific diagnosis. This was most commonly raised in relation to cancer, where for example, benefit advisors can only apply for certain grants for people with a cancer diagnosis. One hospice commissioned a benefits advisor role for one day a week but had the partner organisation withdraw from this arrangement because all their services had to fit their criteria of a cancer diagnosis. Services, funders and decision makers need to be flexible with their criteria to prevent the need for duplication of services and maximise the impact of existing resources for everyone in need."

The value of financial advice from the third sector

The impact and value of access to a welfare or benefits advisor to people with a life-limiting illness and their families was clear throughout our conversations.

Where people were able to access advisors who could provide financial advice and signpost to other services, it was evident how highly they thought of the individual or team and valued the support they received.

> “*They helped to take the worry and some of the stress away. Just that one piece of support to address financial concerns is a lifeline.*”
> *focus group participant*

> “*If you're on your own the paperwork is overwhelming but if you're got someone like them (hospice welfare advisor) they will help you to process everything and apply for what you need.*”
> *focus group participant*

It was also clear from our conversations how financial and welfare support for people with a life-limiting illness and their families is dependent on third sector provision available locally. These services are not universally available across the UK. The welfare and social security support available also varies across the hospice sector. Some hospices have dedicated welfare and benefit advisors and/or palliative care social workers, often within broader carer support teams. Other hospices refer or signpost to support provided by Macmillan Cancer Support, Citizens Advice and the council where available.

> “*I think it's good that the hospice provides financial support. My husband died in hospital and there was nothing like that available.*”
> *focus group participant*

> “*The support just wasn't available at the other hospice.*”
> *focus group participant*

Throughout our conversations we came across numerous good practice examples from the hospice sector, including many productive partnership arrangements with other services. However, there is a fundamental need for consistent provision of welfare and social security advice for people with a life-limiting condition and their families across health and care systems. It should be the responsibility of the local health system to ensure that people with a life-limiting illness, unpaid carers and people experiencing bereavement have access to this kind of support, regardless of which service provides it.

Recommendations

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.

Hospices should consider bidding for funding for social security advisor posts that support hospice patients.

The Myton Hospices

Have a Citizens Advice Financial and Benefit Advisor based in the hospice 4-5 days a week. This advisor attends all of the hospice multi-disciplinary meetings and is able to make and receive referrals. This post is funded by Macmillan Cancer Support but Macmillan have agreed for the service to support patients with both cancer and non-cancerous conditions. Coventry Citizens Advice only covers a small part of the hospice's geographical footprint so the Citizens Advice services in Rugby and Warwick have given permission for the post to work across the area of the hospice.

Hospice of the Valley

Family Support Service includes social workers, family support practitioners, a complementary therapist and a benefits advisor. By pooling all these services together, the hospice can provide holistic support for families of people with a life-limiting condition. This support includes listening, practical and financial support, complementary therapy and bereavement care.

Ardgowan Hospice in Inverclyde

Work very closely with their local Macmillan Financial and Benefits Advice Worker who comes to the hospice regularly and holds a drop-in at the hospice one day a week. This worker is funded by the Inverclyde Health and Social Care Partnership and Council. Their team supports people with a life-limiting condition or a cancer diagnosis in the area.

The impact of advocacy

The value of advocacy when dealing with the health and care or social security system was another key theme that emerged from the focus groups and interviews.

Professionals commented on how people with more resources are often more likely to advocate for themselves. They are also more likely to push for more support or understand how to participate in assessment processes to ensure their needs are seen as a priority. People who have experienced significant barriers throughout their lives are less likely to push for more support and less likely to be heard or believed.

> *People living in financial hardship 'don't feel entitled, don't feel well enough, [are] so sick of arguing with people about benefits and housing and they know nothing ever happens and they're getting old and they feel their voice is tiny."*
>
> *professional contribution*

Professionals who worked in hospices with palliative care social workers or welfare advisors spoke about the significant impact of these roles in advocating for patients and carers in financial hardship. Palliative care social workers also see financial hardship in its broadest context. They can respond to how it is impacting a person's relationships and their spiritual, psychological and emotional wellbeing.

These professionals have the time and energy to fight for their clients and a good knowledge of the system and what people are entitled to. They also have good local links and knowledge of local services and opportunities. For example, one hospice was able to write to a credit card company on a patient's behalf and get their debts dealt with. Another hospice social worker was able to help people hire stair lifts at a reduced rate using a local company. Many hospices also refer to food banks and other local services for people struggling financially.

Some hospice welfare and benefits advisors said that they found people are more likely to be believed and secure support with hospice involvement. However, others said that DWP, councils and energy providers often refuse to speak to hospice staff as a proxy for the patient or carer and that these organisations need to be mindful of why a hospice is involved.

A key recommendation that emerged from the focus groups was for better coordination of care and support, including social and financial support. Participants spoke about the need for a first point of contact. This would help with giving practical advice, applying for social security and signposting to other services rather than having to constantly phone individual services and explain their situation repeatedly. Different areas will have different approaches to this, such as a single-point of access phone line for palliative care patients or working through GP link workers. It is vital that systems ensure these roles are in place and work towards better sharing of health and care records.

> *“We need counselling, we need help with financial concerns and our money worries and we need help with hands on care. That’s not one person but wouldn’t it be great to have just one phone call to get this wraparound support. We don’t have the time or energy to make all the phone calls and find who can help us to cover everything. Some days we have a list of everyone to call and it’s overwhelming. It would just make it easier if everyone knew and treated us like one ‘case’ without having to explain our story time and time again.”*
>
> *focus group participant*

Lack of knowledge about, or access to, hospice provision

Hospice workers told us how people who have experienced financial hardship throughout their lives are often less likely to access support from their local hospice.

However, the positive impact that holistic hospice services can have on the lives of people facing financial hardship came through strongly in the focus groups. People were passionate about the need for hospices to ensure people facing financial hardship are aware of their services and feel comfortable accessing them.

> *"I dread to think what would have happened if the hospice hadn't stepped in when they did."*
> *focus group participant*

> *"They support the community and the hospice put us in touch with other agencies and have supported us with the financial side. We need you. We can't function without you. You are our crutches all the way at the moment."*
> *focus group participant*

> *"There should be something out there that says that this is somewhere that you can access."*
> *focus group participant*

But focus group participants said that there are numerous hurdles to accessing hospice care for people facing financial hardship. These include a lack of awareness and understanding of hospice services, misconceptions around paying for hospice services or thinking of a hospice only as a place people go to die. Hospice workers we spoke to said that these barriers and misconceptions often apply to professionals who don't refer to the hospice as they are not aware of its breadth of support.

> *"Do you have to pay for this service?"*
> *focus group participant*

> *"I didn't know where the hospice was until today, I've never visited. As someone from the South Asian community we try to care for our family members at home. I don't know what support the hospice provides."*
> *focus group participant*

Many hospices we spoke to discussed work they were doing to break down the barriers to access for people living in financial hardship and improve their quality of support for this group. Some hospices are taking a data-led approach, for example, by analysing the postcodes of their patients or their GPs to identify whether they are supporting people living in areas of high deprivation. Several Integrated Care Systems are also using data to find people who are facing financial hardship and in need of health and care support. Hospices would benefit from being linked into this work.

Hospice workers also emphasised how partnership with local services - such as food banks and hostels - and being able to refer, and take referrals, from them can help more people access hospice care. However, a key risk that emerged in our interviews was under- resourced community engagement capacity in hospices. Often one individual is expected to broker links and build trust with a broad spectrum of communities and services, including people living in financial hardship and organisations that support them. Some of the best examples of successful community engagement have been when hospices take a targeted approach. This approach is led by the appropriate individual or partner for that project, rather than taking a 'one size fits all' approach and recognises that having an impact will take time and expertise.

Hospices also spoke about working together on joint community initiatives. For example, Darlington Connect is a physical community support centre, funded by NHS England, which provides information and guidance and refers people to different services across Darlington.[32] A strong theme that emerged in the focus groups was that people do not care about where support comes from, only that it is coordinated and available. Hospices should think about where they can add the most value within their own local system. They should work in partnership to ensure people with a life-limiting condition and their families have the support they need.

Recommendations

Primary and secondary health and care services should develop close relationships, and collaborate, with local voluntary sector providers, including hospices. They must have a good understanding of the variety of services they offer.

Hospices should:

- Collaborate with organisations who support people living in financial hardship. They could also train them on the needs of people with a life limiting condition and their loved ones.
- Use population and service data to understand who they are and are not supporting.
- Fund projects and roles within the communities they need to build links with.

Case study

Robert* is a 65-year-old man who explains how his hospice supported him to access Carer's Allowance.

"My wife was diagnosed with cancer seven years ago but it wasn't diagnosed as terminal at that stage, "so life went on and I continued to work. We'd go back and forth to the hospital, and she'd come out and smile but then one day she didn't come out and smile. We got the results back that the cancer had spread, and it was end stage, that was the day that I stopped working.

That was three years before she was admitted to the hospice. When she was admitted I was talking with one of the doctors and he advised a meeting with the hospice welfare officer who asked if I was managing financially. I explained we were living off our savings and they asked if I had carer's allowance and I said what's that? They said I could've been getting it for the past three years. It was only through a chance meeting with the doctor that I received ten weeks carer's allowance. It was £90 a week and it helped. After she died, I did get a few other payments, but this stopped as it coincided with receiving state pension."

Good practice example

A number of healthcare services, such as palliative care services across Warwickshire North, have undergone Children North East's Poverty Proofing© programme. The ethos of Poverty Proofing© is that no activity or planned activity would identify, exclude, treat differently or make assumptions about those whose household income or resources are lower than others. Its three core principles are to ensure the centrality of the voices of people affected by poverty, understand the context of the community and place and identify what structural changes can be made at an organisational level to eliminate the barriers that people in poverty face. The programme includes:

- A training course for all staff working within a service and consultation with them on barriers faced by people living in poverty that staff identify within their role.
- A scoping exercise where Children North East develop an understanding of the service's work.
- Discussions, interviews, surveys and focus groups with patients receiving support from the healthcare team.
- A comprehensive report with recommendations and discussion points presented back to the service's senior team.
- A review of the progress the service has made and early analysis of the impact of any interventions six months later.

Mary Ann Evans Hospice undertook the programme alongside other services in Warwickshire North. This was funded by Warwickshire County Council as part of its Tackling Social Inequalities strategy. At the hospice, Children North East identified areas of good practice and improvement around travel and appointments, financial support, technology and connectivity and support and communication.

Good practice example

St Oswald's Hospice in the North East wanted to improve access to its Focus on Living Service for people currently missing out on the hospice's services. The Focus on Living Service provides personalised support for people with a life-limiting condition including emotional/spiritual support as well as financial support, physiotherapy and symptom management. St Oswald's analysed the postcodes of the GP surgeries that had referred to Focus on Living Service between 2020 and 2023 and found that:

- 20% of its referrals were from an area with a population of 10,543, which is in the 10% least deprived areas of the country.
- 9% of them were from an area with a population of 16,126, which is in the 10% most deprived areas of the country.
- 4.5% of them were from an area with a population of 12,032, which is in the 10% most deprived areas of the country.

As a result of this mapping, the hospice was able to apply for grant funding from Hospice UK for a programme of work to increase referrals to the hospice from these postcodes. This work included conversations with GPs in these areas to understand their perception of the hospice and what is offers and raise awareness of the Focus on Living Service.

Valuing holistic needs in the hospice sector and the relationship with hospice funding models

> *The whole point of hospice is that it is holistic, that is what makes it different, we care about their spiritual and emotional wellbeing, we care about their financial wellbeing, we care about their family, that is the whole point."*
>
> *professional contribution*

> *Sometimes the specialist palliative care need is they have nothing and there is nothing there to support this person."*
>
> *professional contribution*

The high level of financial and social need experienced by people living with a life-limiting condition and their families was clear in the focus groups.

However, professionals we spoke to raised concerns that hospices can default to responding to clinical needs first, even if they are not the needs that are most important to the person. A key barrier to this is referral criteria, which varies significantly from hospice to hospice. For example, some hospices have a 'clinical need first' culture where people either have to reach a certain level of clinical need to access support or referrals without clinical needs are rare. In comparison, other hospices support many people with counselling or financial support who have never needed their clinical support.

Hospice workers we spoke to emphasised the importance of holistic care. But they also acknowledged that a sector reliant on charitable funding does not have infinite resources and some level of 'gatekeeping' will always be needed. It is important to ask 'what is the need', even if that isn't simply clinical need, and to understand their service's role in the system and how it can have the most impact.

> *If we don't have those donations and the organisation decides that the clinical team is all the organisation can afford, where are these 400 a month [welfare advice] patients going to go?"*
>
> *professional contribution*

> *The people who need us are not the people who are going to leave their £300,000 house to us when they die, because they don't have it."*
>
> *professional contribution*

> *If we come up with fantastic feedback about what is needed within communities, with a small resource team, how can we deliver that effectively?"*
>
> *professional contribution*

There is a clear relationship between some of the challenges in providing and improving hospice support to people facing financial hardship and the hospice funding model. This report is being written at a time when hospices and the broader charity sector are struggling with rising costs. Services are being cut back when people facing financial hardship need them more than ever. Professionals expressed concerns that palliative care social workers and benefit advice roles in hospices are being cut due to a lack of funding. They also commented on how better-funded hospices can provide more financial support, leading to a 'postcode lottery'.

The hospice sector's reliance on charitable giving acts as a disincentive to increasing their proportion of patients experiencing financial hardship. Wealthier patients and their loved ones have more money to donate to the hospice and staff expressed concerns about how they would fund services.

In the interviews, a tension emerged between maximising the reach of a service and improving equity of access. For example, many hospices told us about how resource intensive it is to advocate for patients and their loved ones to secure financial support or access to social security. This can make it difficult to justify such work to funders or internal stakeholders on the basis of reach. They also raised concerns about what message events for wealthy donors send to the community about who the hospice is and the importance of providing opportunities for people facing financial hardship to feel connected to the hospice.

Hospice staff expressed the need for more sustainable funding for core services to support them to expand access. We support this call. However, hospices also have freedom and flexibility in how they spend their charitable income which enables them to prioritise this work and target support where it is really needed. Hospices we spoke to also raised thinking beyond their services when identifying how they can better support people facing financial hardship. This could be, for example, by promoting financial support at their charity shops, getting involved in local campaigning or offering their hospice as a warm space.

Recommendation

Hospices should ensure that their referral criteria and service provision take a truly holistic approach to palliative and end of life care. This would include social, financial and emotional needs.

Good practice example

St Barnabas Hospice in Lincolnshire has a welfare and benefits service as part of their wellbeing team. This service supports anyone with cancer or a life-limiting diagnosis across Lincolnshire and their families. Consisting of eight advisors, it receives 400-500 referrals a month and supports patients, carers and family members, as well as helping people understand their entitlements after bereavements. Because the service supports anyone with a life-limiting diagnosis or cancer regardless of stage of disease or clinical complexity, it often identifies people who need (or will need) further support from the hospice's clinical services. This service is currently fully-funded by charitable donations.

Conclusion

It is clear from this report that the needs of people facing financial hardship in addition to caring responsibilities, living with a life-limiting illness or bereavement are not being met. It is the duty of governments and local health systems and services to ensure that this group gets the support they need.

The hospice movement, and palliative care more broadly, is known for providing holistic care and support that places the person at its centre. Hospices and other providers must ensure services are truly holistic and prioritise helping people with social and financial pain alongside other forms.

However, this goes much further than health and care services. National and local decision makers across the UK need to stop people with a life-limiting illness and those important to them from experiencing financial hardship.

The right financial support must be put in place. Everyone who needs support must eligible to receive it and systems for getting support must be easy to navigate and understand.

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Appendix

With thanks to:

Alice House Hospice

Association of Palliative Care Social Workers

Ashgate Hospice

Birmingham Hospice

Carers UK

Children North East

Citizens Advice

Compton Care

Dougie Mac

Glasgow University End of Life Studies Group

Heart of Kent Hospice

Inverclyde Health and Care Partnership

Joseph Rowntree Foundation

Keech Hospice Care

Marie Curie

Mary Ann Evans Hospice

Mountbatten Group

Princess Alice Hospice

Phyllis Tuckwell Hospice

Rowcroft Hospice

Saint Francis Hospice in Romford

Saint Michael's Hospice, Harrogate

St Catherine's Hospice, Sussex and Surrey

St Teresa's Hospice

St Oswald's Hospice

St Barnabas Hospice, Lincolnshire

Sue Ryder

The Myton Hospices

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