"It's a nightmare scenario" – death, dying and financial hardship in Northern Ireland

A briefing: September 2024

More than 2,000 people die in poverty every year in Northern Ireland. But our 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.

What did we find:

Hospice UK spoke to people with lived experience and professionals across the UK. These conversations revealed the mental and physical toll of facing death, dying and bereavement alongside financial hardship.

"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

"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

There are significant and hidden costs for this group. These include transport to appointments, energy bills for medical devices and funerals.

"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

"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

Our society 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.

"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

"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

What needs to be done:

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. Below are the key recommendations for decision makers and other stakeholders in Northern Ireland.

Recommendations for Northern Ireland

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.
- 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 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.
    - Extending the period during which bereaved carers receive Carer's Allowance from 8 weeks to 6 months.
- 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.

The Strategic Planning and Partnership Group and Area Integrated Partnership Boards (as they are established) 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.
- 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.

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.
- 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.
- Consider bidding for funding for social security advisor posts that support hospice patients.
- 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.

Read the full list of recommendations in the report.