Proposed Right to Palliative Care (Scotland) Bill

Independent Age response

June 2024

About Independent Age

Independent Age is the national charity for older people living in poverty.

Our helpline and expert advisers offer free, practical support to older people without enough money to live on. Through our grants programme, we support local organisations working with older people in their communities, across the UK.

We use the knowledge and insight gained from our services and partnerships to highlight the issues experienced by older people in poverty and campaign for change.

We believe no one should face financial hardship in later life.

1. **Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have the right to palliative care?**

Strongly Agree

Independent Age support the introduction of the right to palliative care for people of all ages in Scotland. We believe this could be a vital step to improving the experience for those at the end of life and that it could be a key driver in reducing poverty among people who are terminally ill and their families.

Currently, across Scotland, one in seven pensioners live in poverty – a total of 150,000 people and 15% of Scotland's older people.[1] The diagnosis of a terminal illness can drive people into poverty, with pensioners across the UK who are in the last year of their life 23% more likely to live in poverty than if they had not received a terminal diagnosis.[2] Independent Age recommend that within the Bill, there must be an emphasis on promoting financial entitlements and advice on maximising income for those experiencing end of life care.

There are many barriers that terminally ill people may face when accessing adequate housing, social security benefits and health services. For older people diagnosed with a terminal illness and who access disability related social security, under current rules for Attendance Allowance - and in the proposals for Pension Age Disability Payment - older people are the only age group who do not have access to the additional mobility component (present in Adult Disability Payment and Child Disability Payment). Independent Age recommend that the Scottish Government commit to a reviewing Pension Age Disability Payment within two years of full rollout, specifically focussing on the mobility component and overall adequacy. In doing so the Scottish Government could improve and increase the social security support available to people as they receive palliative care through the rights in this Bill.

[1] Relative poverty, after housing costs. DWP, HBAI

[2] h420-poverty-at-the-end-of-life-in-the-uk-2nd-pp.pdf (mariecurie.org.uk)

Providing care for someone at the end of life can have a financial, physical and mental impact. Many older people with terminal illnesses are being cared for at home by people who also have their own health issues. Independent Age heard from an older person who has reduced mobility and cares for their terminally ill husband at home. They told us:

"I depend on neighbours to help and my daughter and the family don't live near me. I'm waiting to go into sheltered housing so I can be near all my family to help us both out. We're really struggling at the moment. I can't nurse my husband and he can't nurse me, we're just stuck in a rut".

We also heard from older people providing end of life care at home who are experiencing increased household costs. One older person told us:

"My husband has terminal lung cancer, we keep him well with various supplements & vitamins, heating and cost of hospital visits - any benefit of my pension is eaten up by these costs."

The introduction of the right to palliative care is crucial not only for the person at the end of life, but also for their families and people they are close to. Independent Age recommend that consideration should be given to ensuring that the right to palliative care includes support and information on finance, social security and housing for the family and support network of the person who is receiving end of life care. Given the negative impact that bereavement has on the finances of older people and the increased likelihood of entering poverty after bereavement[3], support and advice on maximising incomes is not only vital for the person receiving palliative care but also for their family members.

2. **What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a legal right to palliative care?**

WHO definition: *Palliative care is an approach that improves the quality of life of patients (people and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.*

While Independent Age support the WHO definition of palliative care being the basis for the legal right to palliative care in Scotland, we recommend that consideration should be given to including "financial" in the "other problems" category which currently identifies the physical, psychological and spiritual problems often associated with terminal illness.

The diagnosis of a terminal illness can push people and their families into - or further into - poverty. For example, when a partner dies, pension income is often significantly reduced, despite household costs remaining at a similar level. Three in five (61%) pensioners enter poverty during later life following a reduction in social security income, and bereavement can be a key trigger for this.[4]

Independent Age therefore recommend the definition of palliative care fully reflects the impact that end of life, and death, can have on individual's and a household's financial circumstances.

[3] Independent Age, Poverty in later life report, January 2022
[4] Independent Age, Poverty in later life report, January 2022