

Marie Curie Briefing

Scottish Labour Debate – Supporting Carers during the Cost of Living Crisis

Overview

The role of family carers in a person's palliative and end of life care is crucial in helping terminally ill people get the day-to-day support they need for a good quality of life

But **support for family carers of terminally ill people has historically been overlooked¹** with many issues exacerbated during the pandemic. This requires urgent action to reduce the impact of the cost of living crisis

Recent Marie Curie and Loughborough University research into poverty at the end of life found:

1. **Over 8,200 people in Scotland die in poverty every year; equating to 1 in 4 people**
2. **Being terminally ill and reaching the end of life can substantially increase the risk of poverty, not just for the person who is terminally ill but also for carers and families who look after them**
3. **The 'double burden' of income loss and increased cost of living expenditure brought on by a terminal illness, such as higher energy bills and home adaptations, can leave people struggling to make ends meet, and force those who were already on the threshold below the poverty line**
4. **Women are more likely to experience poverty than men due to long-standing, structural inequality in the labour market, lower individual retirement income, and disproportionate unpaid care responsibilities.** These inequalities are significantly magnified at the end of life.

Scottish Government must:

1. **Extend the upcoming Scottish Carer's Assistance for up to six months after a person's caring role ends**
2. **Implement a Carers Strategy in Scotland which sets out how the cost of living can be tackled, and recognises the physical, emotional and financial needs of carers of terminally ill people**
3. **Reflect the physical, emotional, spiritual and financial needs of carers in its upcoming Palliative and End of Life Care Strategy**

Caring for someone who is terminally ill

The role of family carers in a person's palliative and end of life care is crucial in helping terminally ill people get the day-to-day support they need for a good quality of life. **But support for family carers themselves has historically been overlooked and exacerbated during the pandemic².**

Identifying family carers to ensure they receive the support they are entitled to can often be difficult, as many do not self-identify as carers or get picked up by formal services and therefore miss out on support and benefits they may be eligible for. **Work to identify carers must be improved including supporting carers to recognise themselves as carers.**

¹ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/marie-curieand-macmillan-getting-it-right-forcarers-final-report-november-2018.pdf>

² <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/marie-curieand-macmillan-getting-it-right-forcarers-final-report-november-2018.pdf>

Family carer breakdown is the most likely factor in a person with a terminal illness being admitted to a hospital, hospice or a care home. Having a live-in carer is also the single most important factor in whether someone is able to die at home or not.

Carers should be able to access respite care when needed, as well as information and peer support through carers' centres, and others, to enable them to continue to provide care to the person they are looking after and maintain their own wellbeing.

This is especially important given the recent shift from hospital to community deaths through the COVID pandemic, as well as the projected increase to two-thirds of people dying in community-based settings by 2040.

During the pandemic, there has been a 40% increase in deaths at home, and **almost 80% of family carers have said the needs of the person they were caring for increased**³. But it is unclear if carers of terminally ill people received all the support they needed during a time when health and social care services were so stretched.

It is **estimated that an additional 400,000 people took on unpaid caring roles during the first Covid-19 lockdown**, taking the total number of unpaid carers in Scotland to 1.1 million⁴. Many are completely exhausted and are at breaking point; **66% have reported a worsening in their own mental health**⁵.

Evidence from Marie Curie services during the pandemic found that many terminally ill people with family carers were slow to engage with services and often much later at crisis point which caused further challenges.

Demographic changes predict more people will be dying in the next 20 years – 10,000 more than currently – with more complex palliative care needs⁶, which is likely to see a mirrored increase in the number of family carers.

Identifying gaps now is crucial for development of future support available to family carers of terminally ill people and health and social care staff, to ensure they have full access to everything they need. Otherwise, the gap will grow considerably during this time, potentially creating a bigger crisis of care.

Poverty at the end of life; women and unpaid care

Marie Curie and Loughborough University's research has found that (on a UK scale) women have a higher risk of poverty at the end of life than men, reflecting higher levels of poverty than men in the general population and persistent employment and income inequalities. But these are not new findings.

In Scotland existing research has shown that^{7, 8}:

- Less than 12% of women receive the full basic state pension based on their own contributions
- A woman's average retirement income is 53% of men's because they take time out to care
- The average woman working full-time is paid 15% less than a man. The pay gap is 35% less per hour for part-time workers

This evidence plainly highlights long-standing, structural inequality in the labour market, lower individual retirement income, and unpaid care responsibilities which have a

³ Carers Scotland

⁴ https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf

⁵ Carers UK: [Caring behind closed doors six months on; the continued impact of the Coronavirus pandemic on unpaid carers](#) (October 2020)

⁶ Finucane et al <https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefings-consultations/scotland-briefings/marie-curie-palliative-care-need-by-2040.pdf>

⁷ Engender: [Taking forward the Government Economic Strategy; a discussion paper on tackling poverty, inequality and deprivation in Scotland](#)

⁸ Public Health Scotland: [Child Poverty in Scotland; priority groups; lone parent families](#)

significantly disproportionate impact on women. These inequalities don't lessen at the end of life, they magnify.

Marie Curie and Loughborough University's research has highlighted that (on a UK level):

- If women were to lose their job or give up work, nearly two-thirds of working age women have savings that would last a month or less while a third have savings that would last less than a week⁹
- Exiting the labour market is the single biggest risk factor for falling below the poverty line in the last years of life

Existing research has also shown that^{10,11,12}:

- Around 70% of unpaid carers in Scotland are female
- Women take on caring responsibilities 12 years earlier than men
- The average person in Scotland has a 50:50 chance of caring by 49, long before they reach retirement age
- 69% of people claiming Carers Allowance (to May 2021) were women

The role of being a carer for someone who is terminally ill has a huge impact on the life of the person they are caring for.

Costs for unpaid care are usually categorised into three main areas¹³, and **have risen sharply during the pandemic, exacerbating the cost of living crisis for carers of terminally ill people:**

1. **Work related** (e.g. changes in employment such as going part-time or giving up work entirely)
2. **Carer time costs** (related to time investment required by carers)
3. **'Out of pocket costs'** (direct outgoings including transport, food, medicines)

The financial burden of caring is currently recognised through the Carer's Allowance, and Carer's Allowance Supplement in Scotland, which some carers are eligible for.

But once a caring role comes to an end it can have a significant impact on the carer's wellbeing, financial position, relationships and virtually every aspect of their life.

Much of the support provided to them while they were a carer is withdrawn following the death of the person they were caring for, putting them at risk of poverty and continuing in a cost of living crisis. It is imperative that urgent action is taken to address this, and as such:

Scottish Government must commit to extending eligibility for the upcoming Scottish Carers Assistance for up to six months after the person's caring role ends

Marie Curie asks of Scottish Government to support carers of terminally ill people and reduce the impact of the cost of living crisis:

1. **Extend the upcoming Scottish Carer's Assistance for up to six months after a person's caring role ends**
2. **Implement a strategy for unpaid carers which sets out how the cost of living can be tackled and recognises the physical, emotional and financial needs of carers of terminally ill people**
3. **Reflect the physical, emotional, spiritual and financial needs of carers in its upcoming Palliative and End of Life Care Strategy**

⁹ Ibid

¹⁰ [Carers Scotland; Facts and Figures](#)

¹¹ Scottish Government; [Carers Census Scotland 2019-20 and 2020-21](#)

¹² Disability, Carer Benefits to May 2021; Social Security Scotland

¹³ Gardiner, C et al *Equity and the financial costs of informal care giving in palliative care: a critical debate* BMC Palliative Care 2020

About Marie Curie

Marie Curie is here for people living with any terminal illness, their families and carers. We offer expert care and guidance through our two [Hospices](#) in Edinburgh and Glasgow, and [Marie Curie Nursing Service](#) in 31 out of 32 Local Authorities.

Our [volunteer-led Helper service](#) provides companionship and support to those affected by terminal illness and has a presence across all 32 Local Authorities, as well as our [Information and Support lines](#), including dedicated bereavement line, which provide emotional support and practical and clinical information about terminal illness. Marie Curie is also the biggest charitable funder of [palliative care research](#) across the UK.

In 2020-21, Marie Curie Scotland cared for over 9,000 people at the end of life, our highest number of patients on record since the charity was established 70 years ago. With more and more people dying in the community throughout the pandemic, we saw a 14.5% rise in use of our community nursing services.

Further information:

Ellie Wagstaff

Policy & Public Affairs Manager

ellie.wagstaff@mariecurie.org.uk

@wagstaff_ellie @MarieCurieSCO

