



## Marie Curie Briefing

### [Dying in the Margins](#) Members Business Debate 16/11/23

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To begin to address end of life poverty the Scottish Government must:

1. **Include terminally ill people in the eligibility criteria for any increased support for energy bills this winter.**
2. **Provide comprehensive social security support for terminally people and their carers.**
3. **Ensure terminally ill people are offered timely and affordable adaptations to their property.**

We are grateful to Paul O'Kane MSP for leading this debate.

*"[Dying in the Margins](#)" is a joint study undertaken by the University of Glasgow and Marie Curie and funded by the Economic and Social Research Council, part of UKRI. It examines barriers to, and experiences of, dying at home for people living in poverty. The study is the first of its kind, using photovoice and digital storytelling to enable people directly affected by different aspects of poverty at the end of life, including housing, energy and transport costs, to tell their own story, in their own words and images. The "[Cost of Dying](#)" exhibition is part of the "Dying in the Margins" study and we are grateful to Evelyn Tweed MSP for sponsoring the exhibition in parliament, which MSPs can view from 14<sup>th</sup>-16<sup>th</sup> November.*

#### **Inequity at the end of life**

- Terminal illness exacerbates existing inequity and poverty, it does not act as an equaliser.
- Poverty at the end of the life impacts a terminally ill person's ability to die at home if that is their wish.
- Marie Curie hospice and hospice care at home teams frequently witness people living and dying in poverty.
- Our Glasgow hospice often provide care packages with essentials such as soap, a washing basin and fresh cloths, on home visits, as they know many are unable to afford these basic items.
- Community palliative care services such as Marie Curie's Hospice Care at Home service reduces pressure on unscheduled care services, which currently cost the NHS £190million each year (for people in their last year of life).<sup>1</sup>

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<sup>1</sup> Mason B, Kerssens JJ, Stoddart A, et al. Unscheduled and out-of-hours care for people in their last year of life: a retrospective cohort analysis of national datasets. *BMJ Open* 2020.

- Use of unscheduled care services through ambulance calls, accident and emergency visits and unplanned hospital admissions by those in the last year of life who live in more deprived areas of Scotland is almost double that of those living in the least deprived areas.<sup>2</sup>

### **Poverty at the end of life:**

**Linda's story** – as told by her daughter **Nicola from Dying in the Margins**

- There is a 24 year gap in healthy life expectancy between the most and least deprived communities in Scotland.<sup>3</sup>
- One in four working age people die in poverty at the end of life every year in Scotland, one in three in areas of acute deprivation, and one in eight pensioners.<sup>4</sup>
- Two in three people living with a terminal illness are reliant on benefits as a main or sole source of income.<sup>5</sup>
- Reliance on benefits is driven by the diagnosis of a terminal illness, which can mean the affected person and their carer have to reduce their working hours or give up work entirely.
- This reduced capacity to earn income is compounded by the additional costs associated with terminal illness, such as increased heating bills and paying for home adaptations, which are estimated to cost on average £12-16,000 per year per household.<sup>6</sup>
- This creates a "**double burden**" and can leave people struggling to make ends meet.
- At the end of life people are particularly vulnerable to certain types of poverty including transport poverty.
- For Marie, who took part in the Dying in the Margins study, taxis to get to medical appointments were her biggest expense. They cost her up to £100 per week, this was money that she was not able to use to make memories with her daughter.<sup>7</sup>
- We support calls from the Poverty Alliance for people on disability benefits, such as Adult Disability Payment, to have free access to public transport.<sup>8</sup>

### **Energy:**

***"It's difficult because all my stuff is electrically powered and that uses a lot of electricity...I was getting offered my own place, but I turned it down...There's no way***

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<sup>2</sup> Mason B, Kerssens JJ, Stoddart A, et al. Unscheduled and out-of-hours care for people in their last year of life: a retrospective cohort analysis of national datasets. *BMJ Open* 2020.

<sup>3</sup> National Records of Scotland, 2022.

<sup>4</sup> Marie Curie and Loughborough University . *Dying in Poverty: Examining poverty at the end of life in the UK.* 2022.

<sup>5</sup> Marie Curie. *Cost of Dying.* 2019.

<sup>6</sup> Marie Curie and Loughborough University. *Dying in Poverty: Examining poverty at the end of life in the UK.* 2022.

<sup>7</sup> University of Glasgow and Marie Curie

<sup>8</sup> The Poverty Alliance. *Challenge Poverty Week 2023: A Scotland where we can all get to where we need to go.* 2023.

***I'm going to afford them on my own, because everything, all my stuff runs on electricity, and you know the electricity prices, they sky rocketed.” – Amandeep<sup>9</sup>***

- Many terminal illnesses limit mobility. This means people are likely to be colder and require the heating on almost permanently. They often rely on electronically powered medical devices and their household utilities such as washing machines are used more frequently to care for them.
- One of the participants from Dying in the Margins, Amandeep, estimates these extra energy costs, cost him £400 extra per month.<sup>10</sup>
- Energy bills on average remain well above the price they were when the energy crisis took hold in 2021 and the energy market remains volatile.<sup>11</sup>
- In 2023 it was estimated by the University of York that 72% of Scottish households could be living in fuel poverty this winter.<sup>12</sup>
- 84% of Marie Curie Hospice Care at Home staff in Scotland tell us that they have cared for patients struggling with energy costs.
- In a poll Marie Curie previously commissioned of the Scottish public, 94% of respondents said they were concerned about family or friends who are terminally ill being able to keep their home warm over autumn and winter.

Call to action:

**Include terminally ill people in the eligibility criteria for any increased support for energy bills this winter.**

**Carers:**

***“What if I lived in Milngavie and was surrounded by loving sons and daughters that have done really well and had a house...I suspect my care would be different.”. Liz.<sup>13</sup>***

- If someone with a terminal illness does not have a live in carer then it is unlikely they will be able to die at home.
- Many terminally ill people also have caring responsibilities of their own while living with their illness. **Donna**, one of the participants in the dying in the margins study has to manage her own terminal diagnosis while being a single parent, and has also experienced multiple bereavements over the last decade, including the sudden death of her son.<sup>14</sup>
- More than a quarter of carers (28%) and 41% of carers on Carer's Allowance are struggling to make ends meet and one in six carers are visiting foodbanks.<sup>15</sup>
- Unpaid carers frequently do not think of themselves as carers, they are partners, parents, children and friends.
- This social role that they play is just as vital as the caring role and they should not have to forgo one role in order to carry out the other.
- Marie Curie note the Scottish Government increased eligibility for carers benefits to those who have been bereaved for up to 12 weeks. While this change was welcome, we support an increase of this period to six months, to

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<sup>9</sup> University of Glasgow and Marie Curie: Dying in the Margins. 2023.

<sup>10</sup> University of Glasgow and Marie Curie: Dying in the Margins. 2023.

<sup>11</sup> Ofgem 2023

<sup>12</sup> University of York. 'Sticking Plasters and Systemic Solutions: Cost of living responses in the UK'. 2023

<sup>13</sup> University of Glasgow and Marie Curie. Dying in the Margins. 2023.

<sup>14</sup> University of Glasgow and Marie Curie. Dying in the Margins. 2023.

<sup>15</sup> Carers Scotland. "State of Caring in Scotland – The financial impact of caring in 2023". 2023

reflect the considerable impact bereavement has on the lives of carers and loved ones.

Call to action:

**Provide comprehensive social security support for terminally people and their carers.**

### **Housing Adaptations and Maintenance:**

***"I prefer being at home. No one wants to be in a hospital. I want to do my own thing."***

**Max<sup>16</sup>**

- We know that people spend most of their last six months of life in community settings. From 2021 to 2022, people who were dying spent around 90% of the last six months of their lives at home.<sup>17</sup> Yet these settings often do not meet their needs.
- Max lived at home with his dog and what was important to him at the end of his life was being able to spend time with his pet. However, Max's home was unfit for his needs; a fourth floor flat with a bath he could not climb into.
- Max was not supported to have his home adapted to meet his needs at the end of life and because of that, he was not able to die at home, with his pet as per his wishes.<sup>18</sup>
- Accessing adaptations can be a postcode lottery, with some people not told they are eligible for financial support to pay for them.<sup>19</sup>
- Being placed on long waiting periods for adaptations are all too common for people living with terminal illness.<sup>20</sup>
- There is also a shortage of accessible homes, as demonstrated by the decision taken to evict Joost ten Woold, the widower of study participant [Stacey O'Brien](#) who was evicted from their home just 12 days after Stacey died.

Call to action:

**Ensure terminally ill people are offered timely and affordable adaptations to their property.**

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Further information:

Ellie Wagstaff

Senior Policy Manger

[Ellie.Wagstaff@mariecurie.org.uk](mailto:Ellie.Wagstaff@mariecurie.org.uk)

Thomas Mulvey

Policy and Public Affairs Manager

[Thomas.Mulvey@mariecurie.org.uk](mailto:Thomas.Mulvey@mariecurie.org.uk)

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<sup>16</sup> University of Glasgow and Marie Curie. Dying in the Margins. 2023.

<sup>17</sup> Public Health Scotland. Percentage of End of Life Spent at Home or in a Community Setting. 2022.

<sup>18</sup> University of Glasgow and Marie Curie. Dying in the Margins, 2023.

<sup>19</sup> MND Scotland. No Time to Lose: Addressing the Housing Needs of People with MND. 2021.

<sup>20</sup> MND Scotland. No Time to Lose: Addressing the Housing Needs of People with MND. 2021.