Marie Curie Briefing

Charitable Hospice Care to Meet Future Need 06/12/23

To ensure the financial viability of Hospices and Third Sector delivery of palliative care, the Scottish Government must:

1. **Provide a new national funding framework for hospice care.**
2. **Recognise the cross cutting inequities that impact end of life experience and address them accordingly through emotional, financial and practical support.**

Marie Curie is the largest third sector provider of hospice care services in Scotland for adults, in people's homes and our two hospices. In 2022-23, Marie Curie supported almost 8,000 terminally ill people in Scotland. Marie Curie Scotland's current funding arrangements see commissioned income cover less than 40% of our costs.

Demand for our services is projected to increase[1] as resources from commissioned income decline.

Marie Curie's Hospice Care at Home service is active in 31 of Scotland's 32 local authority areas. Our Hospice Care at Home services vary by Local Authority area, and the service level we deliver is determined by the contract value. Our Hospice Care at Home is delivered through several models, some planned in advance, matched to need, and some responsive to patents' unscheduled care needs.

Over recent years, as costs have increased, there has been a significant decrease in the activity we can deliver. There is no standard approach across the country to determine price or service level and a disproportionate amount of time is spent debating this, rather than agreeing how Marie Curie Scotland can best support the care of people who are dying.

An agreed approach to sustainable funding, with an agreed proportion of costs being carried by both parties, and with equity across the country, will release capacity in the system to remodel our services to better align with the needs of the people. In addition, the added value of Marie Curie Scotland will be appreciated more fully including online and telephone information and support services, bereavement services, research, service development, policy development and education.

What do we mean by a sustainable funding settlement for the palliative care and hospice sector?

Provide financial security and viability of hospice care and hospice at home across Scotland to ensure everyone has access to deliver person-centred care by:

- Ensuring a minimum of 50% statutory funding for independent hospice care providers, including hospice care at home.

[1] Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019).

- Ensuring independent hospice care and hospice care at home providers are funded fairly, relative to NHS funded services, and to each other.
- Ensuring parity of esteem and fair pay for all staff who are employed by hospice care and hospice care at home providers in the NHS, social care and third sector.

Deliver equitable access and delivery of hospice care and hospice care at home in Scotland wherever you are, and whatever your care needs and wishes through:

- Recognition that these services are integral to the successful delivery of hospice care and hospice care at home in communities across Scotland.
- Reflecting varying local population health needs and multi-morbidities.
- A whole-system, public health approach which works with all hospice care and hospice care at home providers to ensure successful service delivery.

Dying, death and bereavement in Scotland

Scotland's ageing population means more people will be dying in the years to come. Marie Curie research has found by 2040[2]:

- 60,000 people will die with palliative care needs, this represents a 20% increase in demand.
- People dying with multi-morbidities (more than one terminal condition) will have increased by over 80%.
- Two thirds of all deaths in Scotland will be in community settings such as people's own homes, care homes and hospices.
- People in the last year of life are significant users of unscheduled care with nearly 500,000 service contacts across Scotland, meaning services must be available 24/7.[3]
- Community palliative care services such as Marie Curie's Hospice Care at Home service reduces pressure on unscheduled care services, which has been estimated to cost the NHS £190million each year for people in their last year of life.[4]
- 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.[5]
- 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.[6]
- Two in three people living with a terminal illness are reliant on benefits as a main or sole source of income.[7] Reliance on benefits is driven by the diagnosis of a

[2] Ibid.
[3] 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).
[4] Ibid
[5] Ibid
[6] Marie Curie and Loughborough University . Dying in Poverty: Examining poverty at the end of life in the UK. (2022).
[7] Marie Curie. Cost of Dying. (2019).

terminal illness, which can mean the affected person and their carer have to reduce their working hours or give up work entirely.

Impact of inequity at the end of life in accessing palliative and end of life care

- Poverty at the end of the life impacts a terminally ill person's ability to die at home if that is their wish.[8]
- There is a 24-year gap in healthy life expectancy between the most and least deprived communities in Scotland.[9]
- Terminal illness exacerbates this existing inequity, it does not act as an equaliser.
- 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.
- 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.[10]
- Liz a study participant from our Dying in the Margins study eloquently surmised her belief that the inequities she faced impacted on her access to palliative and end of life care:

"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.".[11]

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Further Information

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[8] University of Glasgow and Marie Curie: Dying in the Margins. (2023).
[9] National Records of Scotland. (2022).
[10] Mason B, et al .
[11] University of Glasgow and Marie Curie: Dying in the Margins. (2023).