Marie Curie Scotland Briefing for Chief HSCP Officers

Sustainable funding for hospice care: what should the future hold?

Roundtable purpose

To agree a sustainable funding framework for independent hospice care provision in Scotland, including hospice care at home, between HSCPs, Scottish Government and Hospice Care leaders.

What should the framework reflect?

1. **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:
    a. Recognition that these services are integral to the successful delivery of hospice care and hospice care at home in communities across Scotland.
    b. Reflecting varying local population health needs and multi-morbidities.
    c. A whole-system, public health approach which works with all hospice care and hospice care at home providers to ensure successful service delivery.

2. **Financial security and viability of hospice care and hospice at home providers across Scotland** to enable them to deliver person-centred care through:
    a. Ensuring a minimum of 50% statutory funding for independent hospice care providers, including hospice care at home.
    b. Ensuring independent hospice care and hospice care at home providers are funded fairly, relative to NHS funded services, and to each other.
    c. 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.

Why?

1. **Scotland has an ageing population, meaning people are living longer with more complex conditions.** By 2040, up to 10,000 more people will be dying with hospice care needs, and the greatest increase in demand for support will be in over 85s.

2. **Hospice care delivered in community settings, including hospice care at home, reduces pressure on unscheduled care services**, which currently cost the NHS at least £190 million per year (for people in the last year of life)[1].

3. **Two thirds of people will be dying in community settings by 2040**, in people's own homes, care homes and hospices.

---

[1] 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

Marie Curie is a registered charity in England and Wales (207994) and Scotland (SC038731).
Registered as a company limited by guarantee in England & Wales (507597).
Registered Office: One Embassy Gardens, 8 Viaduct Gardens, London, SW11 7BW.

1. End of life in Scotland; now and in the future

In Scotland in 2022-23, almost 63,000 people died; 90% of people (56,700) died with palliative care needs. **Marie Curie research has found that by 2040[2]:**

- Up to 10,000 more people will be dying with palliative care needs
- Multi-morbidities are becoming the norm in Scotland, starting earlier in life and rising steeply with age, and will increase by 80%
- The greatest increase in demand for hospice care, including hospice care at home, will be in over 85s
- Deaths from dementia as the main cause of death will rise by 185%
- Two thirds of people will be dying in community settings; at home, in care homes and in hospices

A rising demand for unscheduled care results in major clinical resource and financial pressures on the Scottish health and social care system, both in and out-of-hours. 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].

Hospice care delivered in community settings, including hospice care at home, reduces pressure on unscheduled care services, which currently cost the NHS at least £190 million per year (for people in the last year of life)[4].

The total cost of unscheduled care used by deprived communities in Scotland is almost double that of the least deprived communities due to large numbers of people dying in these groups, and their higher use of secondary care services[5]. Poverty at the end of life affects one in four working age people in Scotland, one in three in areas of high deprivation, and one in eight pensioners[6].

Equity-informed hospice care and hospice care at home are often not prioritised for those with the greatest needs at the end of life due to insufficient resources e.g. for social care and primary care, in areas of high deprivation, those experiencing, or at risk of, financial hardship and those in rural, remote and island communities.

Eliminating inequality and inequity must be integral to the funding framework's purpose, to enable hospice care and hospice care at home services to deliver support which reflects each terminally ill person's needs. This will include multiple approaches to physical, emotional and spiritual hospice care, including trauma-informed care, which the framework must be resourced to appropriately support.

---

[2] How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery. Authors: Anne M. Finucane, Anna E. Bone, Simon Etkind, David Carr, Richard Meade, Rosalia MunozArroyo, Sébastien Moine, Aghimien Iyayi-Igbinovia, Catherine J Evans, Irene J Higginson and Scott A Murray

[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] 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

[5] 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

[6] Marie Curie and Loughborough University: Dying in Poverty at the End of Life in Scotland

2. Marie Curie Scotland services

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.**

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 can be delivered in a number of models, some planned in advance, matched to need, and some responsive to patents' unscheduled care needs. Most of the people we support are in the advanced stage of a terminal illness, in our hospice care at home service this reflects 45% non malignant disease and 55% cancer, and in our two hospices, 8% non malignant disease and 92% cancer.

Over the past number of 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 disproprotionate 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).

Marie Curie is commited to co-funding the services we deliver, and to work in partnership with our health and care colleagues.

Marie Curie also has two Hospices in Scotland, in Glasgow and Edinburgh. As well our inpatient services, the hospices offer outpatient services and specialist care at home for terminally ill people, their families and carers delivered by clinical staff, allied health professionals and counsellors. Clinicians from both hospices also offer expert palliative support to generalist and community health and social care staff, including care homes.

Marie Curie's **Information and Support** services can be used by anyone affected by dying, death and bereavement for practical and clinical information, and emotional support. In Scotland 2022-23, our Information and Support services were used over 100,000 times.

Marie Curie's **Companion at Home** tackles social isolation and loneliness, and can continue for up to three months after a patient has died to ensure families and carers still receive the support they need.

More information: **Scotland constituency profiles (mariecurie.org.uk)**

3. What should be included in the hospice care funding framework?

Marie Curie Scotland recognises the pressures of the current financial landscape for both hospice care providers, including hospice care at home, and service commissioners.

But without urgent action, terminally ill people in Scotland will continue to die without some or all of the support they need. A national hospice care funding framework should ensure:

1. **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:
    a. Recognition that these services are integral to the successful delivery of hospice care and hospice care at home in communities across Scotland.
    b. Reflecting varying local population health needs and multi-morbidities.
    c. A whole-system, public health approach which works with all hospice care and hospice care at home providers to ensure successful service delivery.

2. **Financial security and viability of hospice care and hospice at home providers across Scotland** to enable them to deliver person-centred care through:
    a. Ensuring a minimum of 50% statutory funding for independent hospice care providers, including hospice care at home.
    b. Ensuring independent hospice care and hospice care at home providers are funded fairly, relative to NHS funded services, and to each other.
    c. 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.

Further information:

Amy Dalrymple
Associate Director for Policy and Public Affairs
Marie Curie Scotland
E: Amy.Dalrymple@mariecurie.org.uk

Libby Milton
Associate Director for Strategic Partnerships and Services
Marie Curie Scotland
E: Libby.Milton@mariecurie.org.uk

Marie Curie is a registered charity in England and Wales (207994) and Scotland (SC038731).
Registered as a company limited by guarantee in England & Wales (507597).
Registered Office: One Embassy Gardens, 8 Viaduct Gardens, London, SW11 7BW.