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Health, Social Care and Sport Committee
Wednesday 30 September 2026
6th Meeting, 2026 (Session 6)

Palliative Care

At today's meeting, the Committee will take evidence from the following stakeholders on the topic of Palliative Care:

- Mark Hazlewood, Chief Executive, Scottish Partnership for Palliative Care
- Amy Dalrymple, Associate Director for Policy & Public Affairs, Marie Curie
- Rami Okasha, Chief Executive, CHAS
- Helen Malo, Senior Policy and Public Affairs Manager (Scotland), Hospice UK

The meeting will be conducted in roundtable format.

Introduction

The Assisted Dying for Terminally Ill Adults (Scotland) Bill was considered by the Scottish Parliament in session 6. This was the third attempt to legislate for assisted dying in Scotland and the Bill proceeded to stage 3 where it was subsequently defeated with 69 votes against, 57 votes for and 1 abstention.

For many, the shortcomings in palliative care were a key consideration when deciding how to vote on the Bill. However, despite the polarised positions and highly charged debate, there was cross chamber consensus on the need to improve palliative care services, regardless of the outcome of the Bill.

It is likely that the issue of palliative care will continue to be topical over session 7.

The following paper is intended to inform today's discussions with key stakeholders. Much of it is drawn from the SPICe briefing on Palliative Care and Assisted Dying which contains more detailed information on some aspects.

Definition of Palliative Care

Palliative care is commonly defined with reference to the World Health Organisation's description which is:

> "Palliative care is an approach that improves the quality of life of patients (adults 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."

Palliative care services are often described as being either specialist or generalist:

- Specialist palliative care is provided through multidisciplinary teams which have undergone recognised specialist palliative care training and is provided in a variety of acute, hospice and community settings.

- General palliative care is also delivered in a variety of settings but is delivered by generalist professionals such as GPs, community nurses, allied health professionals, social workers, social carers and unpaid carers.

Dying in Scotland

61,726 deaths were registered in Scotland in 2025. The latest National Records of Scotland quarterly publication indicates that cancer remains the leading cause of death (28% of deaths), followed by dementia/Alzheimer's disease (10%), coronary heart disease (10%), respiratory disease (9%) and cerebrovascular disease (6%).

People spend the majority of the final 6 months of their life at home or in a community setting and this trend has stayed largely unchanged over recent years.

Table 1: Percentage of last 6 months of life spent at home or in a community setting Scotland 2015/16 to 2024/25 (Public Health Scotland, 2025)

Financial Year	Home/Community	Hospital
2015/16	87.0%	13.0%
2016/17	87.4%	12.6%
2017/18	88.0%	12.0%
2018/19	88.0%	12.0%
2019/20	88.2%	11.8%
2020/21	90.2%	9.8%
2021/22	89.7%	10.3%
2022/23	88.9%	11.1%
2023/24	88.9%	11.1%
2024/25	89.2%	10.8%

Of all the deaths registered in Scotland (in 2022-23)[1] 45.8% took place in hospital (27,926), 30.7% at home (18,797), and 18.8% in care homes (11,529). Approximately 4.7% of deaths (2,882) were in a hospice or specialist palliative care unit.

[1] Excluding sudden or accidental deaths.

However, there is some variation in place of death depending on age and the underlying health condition.[2]

For example, in 2022-23, 43% of deaths occurred at home in people aged under 69. This compares to 27% of deaths in people aged 70+. Similarly, 3.3% of deaths occurred in a care home for people aged under 69 compared to 23.4% for people aged 70+.

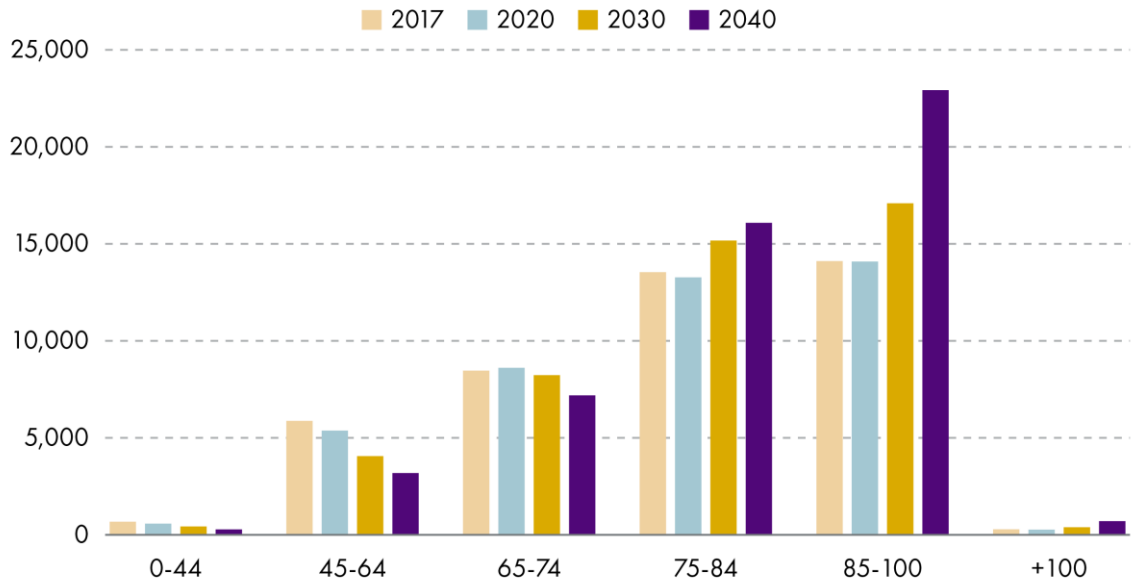
In terms of underlying conditions, cancer deaths are more likely to occur at home or in hospices, while deaths from dementia and neurological conditions are concentrated in care homes. Hospital remains the most common place of death for many non-cancer conditions, particularly circulatory, respiratory and other diseases.

Projected Need

Around 89% of deaths are estimated to be in people with a palliative care need. This would equate to around 55,000 people annually. The number of people dying with palliative care needs is projected to increase as Scotland's population ages, and the number of people dying with multiple health conditions increases.

A 2021 study led by Marie Curie projected that by 2040, the number of people dying with palliative care needs in Scotland will be 14% higher than in 2017, with the largest increase in those aged 75 or over. The number of people dying with multiple health conditions is projected to increase by 82% compared to 2017.

Figure 1: Projected number of people dying with palliative care needs in Scotland by 2040, by age group



Source: Finucane et al, 2021. Reproduced with permission

[2] Scottish Government (2024) Palliative care strategy – population data and research: overview using data supplied by Public Health Scotland.

Unmet Need

Marie Curie estimated that approximately one in three people who die in Scotland have unmet palliative care needs, such as unaddressed symptoms or a lack of timely access to care. This equates to around 18,500 people.

Access to palliative care is affected by inequalities. People experiencing poverty are less likely to receive the palliative care support they need, and may face additional challenges at the end of life due to financial hardship. People living in Scotland's remote, rural, and island communities can experience difficulties in accessing palliative care. People from ethnic minority communities might be offered culturally inappropriate care, or struggle with language barriers. Some LGBTQ+ people may experience discrimination when seeking care.

People with dementia can also face inequalities in access to palliative care. Although the number of people dying with dementia in Scotland has increased in recent years, the availability and quality of palliative care for those affected by the condition is variable.

Service Provision

A mapping exercise conducted by the Scottish Government found significant variation across Scotland in how palliative and end-of-life care services are organised, managed and resourced.

Respondents identified a strong need for greater integration between NHS Boards and Health and Social Care Partnerships (HSCPs) and more equitable funding across care settings.

Other key findings include:

Structures and planning

- Collaborative relationships between Health and Social Care Partnerships (HSCPs) and NHS Boards are diverse and complex, with variation in how general and specialist palliative care services are managed and reported across and within NHS Board areas.
- Respondents highlighted a strong need for better integrated working and fair resourcing across all care settings for palliative and end-of-life care.
- Most HSCPs (86%) and NHS Boards (78%) reported having nominated palliative care leads, usually in clinical rather than executive roles.
- While most HSCPs included palliative care in their 2023-24 strategic plans, detailed commissioning or service delivery plans for general or specialist palliative care were rarely found in published documents.

Adult specialist palliative care

- Specialist services are delivered through a mix of NHS and third-sector providers, but with the majority of care delivered by the third sector.

- Services reported providing specialist care at home, in hospital, in care homes, in outpatients and within hospices/specialist palliative care units. Delivery varied in terms of resourcing, service models and provision.

- Specialist community palliative care is available in every NHS Board area, predominantly led by clinical nurse specialists, although it varied in approach, structure and resourcing.

- Hospital specialist teams exist in most NHS Boards, but staffing levels and access to dedicated inpatient beds vary. Fewer than half of the boards responding had hospital inpatient palliative care beds. There were 245 specialist inpatient beds across 18 units (4.5 per 100,000 population).

- Workforce and service provision differ significantly between areas, including access to consultants, outpatient clinics and out-of-hours advice. There were 138 whole time equivalent (WTE) community clinical nurse specialists (2.5 per 100,000 population) and 53 WTE hospital nurse specialists (0.98 per 100,000 population). There was an average of 0.9 WTE palliative medicine consultants per 100,000 population but 3 NHS boards had no palliative medicine consultants in their area. These boards linked virtually with other board areas for support.

Babies, children and young people

- There were 359 referrals to Paediatric Palliative Care services in 2022-2023, and 80% of these referrals came from 3 services.

- 28 young adults transitioned from paediatric services in 2022-2023. Numbers are under-reported, increasing and cases are complex.

- Only third sector services have dedicated transition teams. Partnership between third sector partners offers a transitions pathway in 4 NHS Board areas.

- The majority of specialist paediatric palliative care staff were funded by the third sector to deliver many services, particularly in the community, as well as bereavement support and transitions to adult services.

- There was large variation in referral patterns and referral routes in paediatric palliative care. Respondents mentioned the third sector as an important referral partner.

Overall, the mapping exercise highlighted widespread variation in service models, workforce capacity and access to support, alongside a significant dependence on third-sector providers, particularly in children's services.

Funding and Expenditure

Evidence on palliative care spending in Scotland is limited. The most recent official estimate, from Audit Scotland (2008), found that £59 million was spent on specialist

palliative care in 2006-07, with 56% funded by the NHS and 44% by the voluntary sector. Spending on general palliative care could not be separately identified.

More recent research by the Nuffield Trust and Health Economics Unit (2025) estimates that £2.29 billion is spent annually in Scotland on supporting people in their final year of life (2022 prices).

This is comprised of:

- £1.33 billion on healthcare (58%),
- £454 million on social care (20%), and
- £512 million on social security (22%).

Within the healthcare spend, most expenditure is on hospital care (£1.13 billion), particularly emergency admissions (£766 million), while hospice care expenditure is around £39 million.

A 2011 study for the UK Department of Health estimated that extending palliative care services to people who needed them, but were not receiving them, would cost around £2,400 per person. Applying this approach to Scotland, the study estimated that providing specialist and core palliative care to everyone who could benefit would cost approximately £16.8 million (2011 prices).

Research suggests that specialist palliative care accounts for only around 6% of formal healthcare costs in the last year of life. However, the evidence indicates that multidisciplinary palliative care services improve outcomes for patients and families while also reducing avoidable healthcare use and generating savings through fewer emergency admissions and shorter hospital stays.

Legislation

There is no specific legislation relating to the provision of palliative care services in Scotland but there have been attempts over the years to legislate to ensure better provision. To date, these attempts have been unsuccessful.

Most recently, a proposal for a 'Right to Palliative Care Bill', in the name of Miles Briggs MSP, was lodged in 2024 but did not progress. Mr Briggs recently indicated his intention to bring forward proposals for a Member's bill in the current session of Parliament.

Policy

In September 2025, the Session 6 Scottish Government published its first palliative care strategy. The Strategy has two overarching aims:

- **Enabling people and communities** - Scotland is a place where people of all ages and their communities can help and support each other to live as well as possible with life shortening conditions, dying, death and bereavement.

- **Strengthening palliative care** - People of all ages with life shortening conditions and their families and carers receive palliative care, care around dying and bereavement support based on what matters to them.

The strategy is supported by an initial delivery plan, covering the period from 2025-28. The delivery plan lists 23 actions across six groups: enabling communities; delivering palliative care; future care planning; education and learning; data and experiences; and governance and reporting.

Programme for Government

The Programme for Government contained a commitment to improve palliative and end-of-life care while providing greater support for people with terminal illnesses. This included a commitment to explore financial support for electricity costs linked to life-saving equipment used at home and other energy-related costs.

In addition, through 2026-27, the Scottish Government committed to delivering a new paediatric palliative care facility, Molly's Suite, in Glasgow. Other commitments include funding to support NHS pay parity for hospice staff, developing new national palliative care guidelines, and providing free palliative care training resources for the health and social care workforce.

Key Themes

Members may wish to explore the following themes within the roundtable:

- what good palliative care looks like,
- unmet need,
- addressing inequalities in access,
- meeting future demand,
- funding and service model,
- the national palliative care strategy and Programme for Government commitments, and
- the role of legislation.

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Date: 24 September 2026