Health, Care and Sport Committee
30 September 2026
6th Meeting, 2026 (Session 7)

Palliative care: how can this be better supported in Scotland?

Introduction

1. At today's meeting, the Committee will hold a **roundtable discussion** with various stakeholders on the topic of palliative care and how it can be better supported in Scotland.

2. This is the first meeting in session 7 of the Committee with a specific focus on palliative care. Palliative care is commonly defined with reference to the World Health Organisation's description:

> "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."

3. Issues around palliative care services were a key consideration during session 6 debates on the then Assisted Dying for Terminally Ill Adults (Scotland) Bill, with a cross-chamber consensus on the need to improve services regardless of the outcome of the Bill.

4. A separate SPICe briefing paper (**Paper 2**) is available in order to inform this session.

5. Written submissions from witnesses ahead of this meeting have been included in **Annexe A** of this paper.

6. Once the session has concluded, the Committee will be able to assess whether more focused work is needed on the topic of palliative care and evidence taken will help inform discussions regarding its future work programme.

Today's meeting

7. The Committee will hear from the following stakeholders at today's meeting:

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

8. Members will have up to 90 minutes for discussion in a roundtable format.

9. The normal format in which a committee takes evidence from witnesses is via a question-and-answer session. However, in a roundtable format, Committee Members and witnesses sit together around the committee table.

10. The idea of a roundtable format is to promote a more collaborative and informal discussion in which an issue is explored collectively. This means that a witness could respond directly to a point made by another witness, for example.

11. Roundtable formats are often used for topics that more naturally lend themselves to free-flowing discussion, such as those which are complex or multi-faceted in nature which would benefit from the collaborative sharing of ideas.

Action

12. Members are invited to discuss the topic of palliative care with the stakeholders in a roundtable format and consider what future work or output the Committee may wish to conduct on the back of said discussion.

Clerks to the Committee
September 2026

CHAS' Fingerprint in Scotland in 2025/26

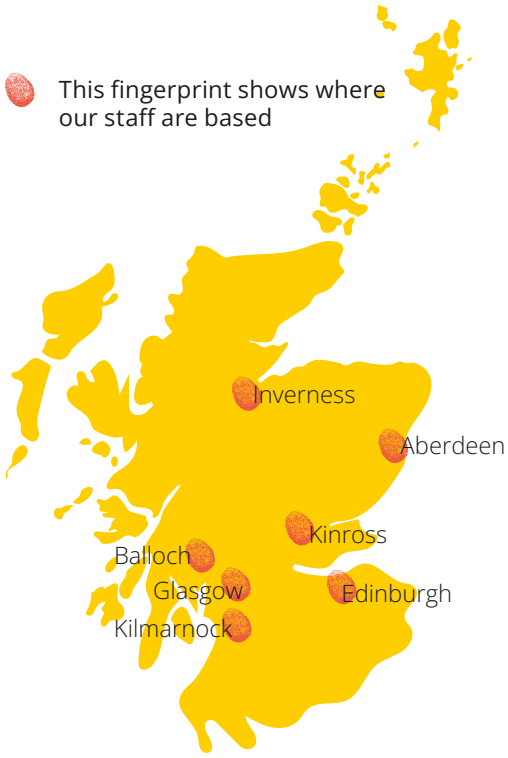
Children's Hospices Across Scotland

About CHAS

Children's Hospices Across Scotland (CHAS) is Scotland's only specialist provider of palliative and hospice care for babies, children and young people (0–21) with life shortening conditions, and their families. Through strategic partnerships across Scotland and joint CHAS/NHS teams in every children's hospital, CHAS provides coordinated specialist care and greater choice for families.

Children's palliative care is whole-family support for children living with life shortening conditions from diagnosis to bereavement, enabling choice and helping children and families to live as well as possible. Three children die with a life shortening condition every week in Scotland, yet many families still cannot access the palliative support they need.

This is a snapshot of the support CHAS provides in Scotland in 2025/26. We want to work with all MSPs to ensure every family can access high-quality palliative care wherever they are.



Right care from the start – providing earlier access and 24/7 support

1. **Over 540 children and families were supported by CHAS at home, in the community, and in hospital as well as almost 1,350 additional family members,** demonstrating local reliance on CHAS as a core service provider.
2. **8500 out-of-hours contacts[2] provided 24/7 support to CHAS families** enabling them to stay at home, preventing crises and supporting shifts to community-based care.
3. **1705 professionals across Scotland, the UK and Europe accessed paediatric palliative care training from CHAS**, strengthening skills, resilience and prevention across specialist children's palliative care and generalist workforces.

Helping families through every stage of their illness closer to home

1. **1475 CHAS at Home visits and 4870 hours of care** demonstrate the scale and complexity of need, while supporting families at home and helping prevent hospital admissions.
2. **Over 10,000 specialist CHAS hospice bed nights (3285 bed nights for children, including Rainbow Rooms[3], and over 7,170 for family members)**, gives families planned respite and end-of-life care while reducing reliance on acute beds.

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[1] Please note the figures in this document are provisional, and are subject to change.

[2] Out-of-hours contact include advice provided between 17:00–09:00 on weekdays and all-day weekends and bank holidays, via phone, text or email.

[3] CHAS has a Rainbow Room in both of its hospices at Rachel House in Kinross and Robin House in Balloch. These offer families a safe, private space to have meaningful time with their child after death. The Rainbow Rooms are available to any child who dies in Scotland, and is the only service of its kind in the country.

3. With children's hospital care costing £5,000-£6,800 per case **CHAS helps prevent avoidable or prolonged hospital stays, while saving families over £225,000.** CHAS also helps the NHS reduce its healthcare spend by 180%, equating to savings of £15.6m per year.

4. **CHAS' Financial Wellbeing and Energy Advice (FWEA) service secured over £1.6 million for families,** while helping manage up to £240,000 of debt and write off over £28,000, reducing financial hardship and enabling parents to focus on their child's care.

5. **Over 1,000 CHAS volunteers gave 46,125 hours of their time to support children and families,** generating over £1 million of social value in communities across Scotland.

Supporting a meaningful goodbye so no family faces loss alone

1. Preferred place of death across Scotland was achieved for **91% of families** demonstrating choice and dignity.

2. **Over 1000 hours of Spiritual Care and Bereavement support were delivered by CHAS** to help 171 families living with bereavement navigate their grief and feel less alone.

Ayla's story

"Since Ayla was diagnosed with Edwards' Syndrome 14 years ago, CHAS has supported our family at Rachel House first with monthly respite, now every few months. They've helped Ayla thrive and are always just a phone call away.

"I've called at midnight and during the day, they are always there. When I lie awake worrying, I know I can phone CHAS. That truly is a lifeline.

"Ayla loves the sensory room and exploring the beautiful grounds. She's sassy, affectionate and full of fun and the staff understand her so well.

"CHAS doesn't just care for Ayla, they support our whole family when we need it most."

Caroline Johnstone, Ayla's mum

Making it happen

CHAS is a core partner in Scotland's health and care system, improving quality of life for children and families while reducing pressure on NHS and local services through community-based, preventative care. We want all MSPs to help CHAS rewrite the future of how Scotland cares for dying children so that no one faces the death of their child alone.

For further information

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Children's Hospices Across Scotland (CHAS) Briefing for the Health, Social Care and Sport Committee 30.09.2026

"I've called at midnight and during the day…CHAS is always there…When I lie awake worrying, I know I can phone CHAS. That truly is a lifeline." - Caroline Johnstone, Ayla's mum.

What is children's palliative care?

Children's palliative care supports babies, children and young people with life-shortening conditions, and their families, from diagnosis through to bereavement. It aims to:

- Improve quality of life throughout a child's illness, not just at the end of life
- Support the whole family, including parents, siblings and wider family members
- Provide clinical, emotional, practical, spiritual and financial support to enable genuine choice and dignity
- Children's palliative care is often provided alongside active treatment and many children receive support for years rather than months

The children's palliative care landscape

- Three children with a life-shortening condition die every week in Scotland, while increasing numbers are living longer with more complex needs
- Almost 50% of families caring for a child with a life-shortening condition live in Scotland's most deprived communities
- Serious illness is never experienced by one person alone. It affects parents, siblings, grandparents, relationships, education, employment, income and wellbeing
- Who is able to live well, die well and grieve well is often shaped by factors such as poverty, housing, transport, family support, digital access and financial security

About CHAS

- CHAS is the specialist provider of hospice services for babies, children and young people (aged 0-21) and their families across Scotland, giving children and families choice about the care and services they receive, wherever they are
- CHAS works in strategic partnership with NHS Boards, Health and Social Care Partnerships (HSCPs), Local Authorities and voluntary sector organisations to deliver specialist children's palliative care across home, hospice, and has joint CHAS/NHS teams in every children's hospital

In 2025/26 CHAS:

- Supported more than 540 children and families and almost 2,000 additional family members
- Delivered 8,500 out-of-hours contacts and 1,475 CHAS at Home visits, helping families stay supported at home
- Secured over £1.6 million for families primarily through social security maximisation**,** while helping manage up to £240,000 of debt and writing off over £28,000, reducing financial hardship and enabling parents to focus on their child's care
- For every £1 of public funding CHAS receives, it generates £6.24 in return saving the NHS approximately £15.6million per year

Key issues affecting children with life shortening conditions and families

1. **Support often comes too late**

- Too many children and families access palliative care only after reaching crisis point
- Families often live with uncertainty for many years, yet palliative care is still too often viewed as support that begins at the very end of life rather than something that can improve quality of life much earlier, and reduce demand on other services
- More open conversations about dying, death and bereavement are needed to support earlier planning, improve understanding of palliative care and help families access support sooner

2. **Families experience fragmented support**

- Families experience one journey, but support is often delivered through multiple organisations with different responsibilities, systems and priorities
- The result can be duplication, gaps in support and families carrying the burden of coordinating services themselves
- Better outcomes require clearer, shared accountability across the system

3. **Inequalities and fragmented systems shape the experience of serious illness**

- Almost 50% of families caring for a child with a life-shortening condition live in Scotland's most deprived communities
- Children and families do not experience serious illness equally. Poverty, rurality, housing, transport, employment and family circumstances can all influence quality of life, access to support and experiences of dying, death and bereavement
- Reform should focus on reducing the inequalities that shape experiences and outcomes

4. **Growing demand requires a different response**

- The number of children with life shortening conditions has risen by 40% in the last 15 years, and continues to grow while health and care services face workforce, financial and capacity pressures
- Palliative care should be viewed as part of the solution by supporting care closer to home, strengthening community capacity and reducing pressure on hospital

What CHAS is doing differently

- Intervening earlier; CHAS at Home, joint CHAS/NHS children's hospital teams and 24/7 specialist children's palliative care advice help families access support, plan ahead and navigate uncertainty before crisis develops
- Joining up support; CHAS coordinates clinical, practical, financial and bereavement support across home, hospice, hospital and community settings
- Sharing power and expertise; CHAS builds local capability through NHS partnerships, education and national access to specialist children's palliative care advice, rather than concentrating expertise in one organisation

Palliative care is public service reform in action

Children's (and adult) palliative care is a lead case of public service reform in action through:

- Earlier support that prevents crisis and reduces avoidable hospital use
- Services organised around children and families rather than organisational boundaries
- Shared responsibility and accountability between NHS, local authorities and voluntary sector partners

Public service reform (PSR):

- Is not the same as public sector reform: **Public service reform is not public sector reform - Enlighten** (Blog author: Rami Okasha, CHAS CEO)
- PSR is about reshaping the relationship between the state and citizens, requiring the public and voluntary sectors to work as strategic partners on agreed outcomes to improve people's lives. This requires sustained focus on culture, behaviours and relationships
- PSR requires organisations to share power, expertise and accountability, while becoming more comfortable supporting people and families through uncertainty rather than simply responding to crisis

Case Study: Public service reform in action; Specialist Paediatric Palliative Care Clinical Advisory Service (CAS)

CAS is hosted by CHAS in partnership with NHS boards to provide a national 24/7 specialist paediatric palliative care advice, and demonstrates how specialist expertise can strengthen the wider system by:

- Supporting local professionals to care for children closer to home
- Making specialist advice available nationally rather than concentrating expertise in one location
- Improving outcomes while building workforce capability and confidence across Scotland
- This delivers improved outcomes for children on a more efficient basis than individual NHS boards and CHAS working separately. The service costs are resourced by CHAS realigning its hospice medical team, achieving Best Value.

The role of the Committee: using palliative care as a lens for wider health and care reform scrutiny

- CHAS encourages the Committee to use children's palliative care as a lens through which wider challenges facing Scotland's health and care system can be understood, scrutinised and improved
- The issues and approaches highlighted through children's palliative care are also relevant to wider parliamentary discussions on public service reform, social justice, and education among others, meaning the 'palliative care lens' can be used for collaboration across relevant parliamentary committees.

Three key questions for the committee to consider:

1. How can Scotland ensure people and families access palliative care earlier, before reaching crisis?
2. How can Scotland create a system where children and families experience one coordinated journey, supported by shared responsibility and accountability across health, social care and voluntary sector partners?
3. How can Scotland make better use of palliative care as part of a sustainable, person-centred health and care system, and shift perceptions of palliative care from a response to dying to an approach that helps people live as well as possible throughout serious illness?

For further information

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Hospice UK written evidence to the Health, Care and Sport Committee, 30 September 2026

1. Why palliative care matters to people in Scotland

Death, dying and bereavement are universal – but people's experiences of them are not. The care you receive at the end of life depends on who you are, where you live and why you are ill.

- More than 60,000 people die in Scotland each year, and up to 90% will need palliative care.
- **Nearly one in three people are dying without the care they need.**
- People from minoritised ethnic communities, people living in rural and island communities, people with diagnoses other than cancer and people experiencing financial hardship are all less likely to access palliative care.

This inequity has a profound human impact. For people and families, a "good death" means dignity, compassion and control: being able to make decisions about what matters most to them, having honest conversations and planning ahead, symptoms well managed, and support that wraps around the person and those they love.

> ***"My husband wanted to pass away at home**, so we **made extensive plans** for that. We were incredibly fortunate with the care and attention we received, **allowing us time** to prepare. **We participated fully** in the MDT [multi-disciplinary team] community discussions with the GP practice and district nurses, and the palliative care team. It felt like we were the sole focus of these professionals, which was **a very powerful feeling."***
>
> ***Family member supported by a hospice and wider team***

Poor care feels very different. Families describe distress, fear and exhaustion: not knowing where to turn, repeating their story, trying to join up fragmented services themselves, dealing with unmanaged symptoms, and receiving care too late or not at all. It can leave people stripped of control and dignity, and families carrying guilt and regret.

> ***"**I found it extremely **distressing and frightening**. I was frightened because I didn't think the district nurses during the night were able to get to him in time.**"***
>
> ***Bereaved carer living in a rural community***

2. Why palliative care matters to the wider system

Palliative care should not be viewed as a marginal or peripheral issue. It is central to some of the biggest challenges facing health and social care in Scotland: rising demand, pressures on hospitals, delayed discharges and the need to shift to earlier more preventative, community care.

- **1 in 3 people in Scottish hospitals are in their last year of life**
- **£1.3 billion** of public money is spent on healthcare in the last year of life
- **£1.1 billion of that is spent in hospitals**, 5x more than on community health care

> Too many people end up in hospital in their final months, not because they need – or want – to be there but because earlier, preventative, community-based support is not available. **This is not good for people and it is not a wise use of public money.**

3. We cannot meet growing demand by doing more of the same

Scotland's population is ageing and demand for palliative care is rising rapidly. By 2048, around 10,000 more people in Scotland are expected to need palliative care each year and the care they need will be more complex.

> **Without urgent action, rising demand will mean more people missing out on care,** more overcrowded hospital wards, a greater risk of corridor care and more people spending longer in hospital when they could be better supported at home or in the community.

4. The contribution of hospice care in Scotland

Charitable hospices are an integral part of Scotland's health and care system. They provides expert physical, practical and emotional support to people with a life-limiting illness, helping them to live well until the end. In 2024-25, charitable hospices in Scotland provided:

- palliative and end of life care to 19,000 patients
- direct support to over 5,000 family members, friends and unpaid carers
- 76,000 visits to hospice patients at home and 29,000 outpatient appointments
- 64,000 days and nights of inpatient care to address the most complex needs

Through their community teams, virtual wards, rapid response services and inpatient care, hospices help **prevent unnecessary admissions to hospital, improve patient flow and support timely discharge**. They work alongside GPs, community nursing, social care, ambulance and hospital teams to provide **joined-up support** for people and families and provide specialist expertise, clinical leadership and training across the health and care system. Deeply **trusted and embedded in their local communities**, hospices help bring people's voices and local insight into service planning and delivery, in ways statutory services cannot do alone.

> **The majority of hospice care is delivered in people's own homes and in the community.** Hospices are already delivering the kind of preventative, community-based support Scotland needs more of but that contribution is not yet fully recognised, sustainably funded or consistently available to everyone who needs it.

5. Hospice care as a lead case for public service reform

Improving palliative care is a clear public priority and has strong cross-party support. **Hospices are already delivering reform in practice** - providing joined-up care in people's homes and local communities, built around what matters most to them; supporting families and carers before they reach crisis point; reducing pressure on hospital services; and delivering an excellent return on public investment that is saving the NHS money [see Highland Hospice case study in Annex 1].

> **With the right funding and partnership in place, hospice care offers a practical lead case for public service reform:** demonstrating how the state can work differently with trusted, voluntary sector partners to deliver better outcomes for people and make better use of public resources.

6. What hospices need to contribute fully to reform

Hospices cannot play their full role in strengthening community support and delivering the aims of public service reform while operating with year-to-year financial uncertainty. As independent

charities, they bring significant charitable investment into Scotland's health and care system, but also carry substantial financial risk.

- Hospice care in Scotland cost £143.5 million to deliver in 2024-25.
- **Statutory funding through Health and Social Care Partnerships covered only 40%.**
- Hospices had to raise the remaining £85 million through local fundraising and charitable income – a major charitable investment in Scotland's health and care system.

Statutory funding has not kept pace with rising costs and the level of funding varies between hospices, creating inequity for patients and families. Hospice services should be growing to meet rising demand, yet they are under increasing pressure and some are facing difficult decisions about reducing services at the very moment that Scotland needs more palliative care.

> **Hospices need the Scottish Government to turn commitments into stability.** Progress on funding for pay parity is welcome: this must now be embedded in a routine process so hospices can match NHS pay for their staff year on year. The promised national funding framework for hospice care has not progressed since it was committed to in 2023. Delivering the framework at pace would give hospices the certainty they need to maintain vital services and act as full partners in wider reform.

7. Turning palliative care ambitions into delivery

Scotland's current palliative care strategy reflects the broad consensus on what good palliative care looks like: early identification of need, future care planning happening routinely, co-ordinated support across services, and care that is available when and where people and families need it.

But successive strategies have not translated into the scale of change required. The key test for Scottish Government's current strategy is whether it can move beyond ambition and set out a credible plan to meet rising demand, shift more care into homes and communities, and tackle the deep-seated inequities people experience at the end of life.

> **Scotland needs a credible delivery plan for palliative care – not another statement of ambition.** That means having clear minimum standards for the palliative care that people and families can expect, stronger accountability and delivery structures, and the resources needed to ensure everyone can access the palliative care they need.

8. Opportunities for the Committee to help drive progress

The Committee's early interest in palliative care is welcome and timely. There is a clear opportunity to improve people's experiences of serious illness, dying and bereavement, while supporting the shift towards earlier, more preventative, community-based care.

To help drive progress, the Committee could explore:

- whether Scotland has a **credible delivery plan** to meet rising palliative care need, shift more support into homes and communities, and reduce avoidable pressure on hospitals.

- what **barriers are preventing implementation** of the palliative care strategy from delivering real change, and what action is needed to reduce inequity, unmet need and variation in access for people and families.

- **how hospices can be better recognised and supported as strategic partners** in planning, delivery and wider public service reform, including the financial stability they need to contribute fully.

About Hospice UK

As the national champion for hospices, Hospice UK represents all 14 charitable hospice providers in Scotland and more than 200 hospices across the UK. Hospice UK would be happy to provide further information, briefings or evidence to support the Committee's work.

Contact: policyscotland@hospiceuk.org

Annex 1: Case study - Highland Hospice community services reduce avoidable hospital use and support more people at home

Highland Hospice's rapid response care at home service helps people with escalating needs in the last 3 months of life receive timely support and remain at home.

- Each person supported through the service used 20 fewer hospital bed days, on average.
- If scaled across North Highland, at a cost of approximately £1m, it would reduce hospital bed usage and create equivalent **value to NHS Highland of £3.5 million a year.**
- NHS Highland asked the Hospice to develop a business case to expand the service two years ago. However **plans to expand the service have stalled** because NHS Highland has no recurrent budget to fund it and is reluctant to use £1.2m committed in principle from Highland Council from the Social Care Transformation Fund because this funding is time-limited.
- Highland Hospice is therefore continuing to fully fund the Inverness service itself, with a limited rural pilot only made possible through legacy donations, creating serious long-term sustainability concerns and preventing a proven community-based service from being expanded.

Highland Hospice's 24/7 Palliative Care Helpline provides support for individuals in the last year of life, their families and carers, as well as professionals from primary care, the ambulance service and care homes.

- In a detailed six month evaluation, people accessing the helpline used 4,105 fewer hospital bed days in total.
- This created an estimated equivalent **value to NHS Highland of £2.2 million a year**.

When Ian's pain and agitation increased through the night his partner and carer, Sarah, called the 24/7 Palliative Care Helpline (PCH) for advice. Sarah had been unable to contact their GP or district nurse and was worried that she couldn't cope with Ian's escalating needs through the night.

Angela, a senior nurse on the helpline, provided guidance on pain management and discussed Sarah's concerns. Sarah made clear Ian's wish to remain at home and that she didn't want him to be admitted to hospital if his symptoms could be managed at home. The PCH team co-ordinated with the local social work team to arrange a package of care to help support Ian at home.

Sarah and Angela also discussed the Marie Curie nursing service and agreed to make a referral. Angela co-ordinated a follow-up from Highland Hospice's Rehabilitation and Wellbeing team to asses Ian's mobility and therapy needs.

Angela referred to the hospice co-ordinator Lynne who created a care plan, arranged the necessary referrals, applied for end of life funding and sourced private home care. She also compiled a report to share with Ian's GP and district nursing team. Once the plan was in place, Angela called Sarah to confirm the arrangements and offer further resources.

Thanks to the helpline's support, Ian received the care he needed to remain at home and Sarah felt reassured knowing help was always available. *Names have been changed*

Helen McDade MSP
Convener
Health, Care and Sport Committee
The Scottish Parliament
Edinburgh
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11 August 2026

Dear Helen

Health, Care and Sport Committee scrutiny on palliative care

I am writing on behalf of Marie Curie Scotland regarding the Committee's upcoming evidence session on palliative care.

We welcome the Committee's decision to undertake scrutiny in this area. As Scotland's population ages and more people live longer with multiple and complex conditions, ensuring equitable access to high-quality palliative care will only become increasingly important.

Palliative care should not be viewed as a niche specialist service, but as an essential component of a sustainable health and care system. It contributes directly to many of the Scottish Government's wider ambitions around prevention, person-centred care, reducing avoidable hospital use, supporting care closer to home, tackling inequalities and improving the sustainability of health and social care services.

From Marie Curie's perspective, the key challenge to be explored by the Committee in relation to palliative care isn't 'what good looks like' or what should be achieved.

Over many years, governments, clinicians, charities and people with lived experience have helped build a broad consensus around the importance of early identification, person-centred care, future care planning, support closer to home where appropriate, and coordinated services across health, social care and the third sector.

The more pressing question is whether and how Scotland's current health and social care systems can deliver these ambitions consistently. Access to palliative care continues to vary depending on factors such as geography, diagnosis, age and local service availability. Too many people still receive support too late, experience fragmented care, or struggle to access the services they need.

There is also an opportunity to build on previous scrutiny. Audit Scotland's 2008 review concluded that access to palliative care needed to improve and become more consistent across Scotland. While there has been substantial policy development since then, many of the underlying challenges around variation, access and delivery remain familiar.

For that reason, we would encourage the Committee to focus not only on the challenges facing palliative care services, but also on the systems, governance arrangements, accountability structures and resourcing and funding mechanisms needed to deliver improvement. In particular, we believe the Committee should use the opportunity to examine why progress has been uneven, what is driving variation, and what mechanisms are required to ensure more consistent delivery across Scotland. We

would also encourage an examination of whether there is adequate oversight and information available nationally to understand variation in access and outcomes.

We believe the Committee could usefully explore four key areas:

Earlier access
The Committee could consider exploring:

- barriers to earlier identification of palliative care needs, and who is responsible for addressing these
- inequalities linked to diagnosis, age, geography and protected characteristics
- future care planning and anticipatory care planning
- awareness and understanding among professionals and the public

Coordination and accountability
The Committee could consider exploring:

- whether current arrangements support effective planning and delivery of palliative care
- whether current arrangements support or hinder joined-up care
- information-sharing and coordination between services
- whether accountability for outcomes is sufficiently clear at national and local level

Planning for rising demand
The Committee could consider exploring:

- whether national and local planning adequately reflects future demand
- workforce capacity and training
- the contribution of specialist palliative care, primary care, social care and community services
- the role of hospices and third sector providers as strategic partners
- whether current funding arrangements are sustainable

Transparency, measurement and delivery
The Committee could consider exploring:

- what outcomes are currently measured
- whether there is sufficient national oversight of access and quality
- transparency of investment in palliative care services
- how progress against national ambitions is monitored

In our view, one of the most valuable outcomes of the inquiry would be greater clarity about the services and support that every person in Scotland should be able to expect, regardless of age, diagnosis or postcode. Committee scrutiny presents an opportunity to move beyond broad ambitions and towards a clearer understanding of the minimum components of palliative care that should be

available consistently across Scotland, together with the accountability, governance, workforce and resource arrangements required to deliver them.

We would be very pleased to discuss these issues further with Committee members or clerks as your workplan develops, and we look forward to contributing evidence in due course.

Yours sincerely

Amy Dalrymple
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Health, Care & Sport Committee – Palliative care evidence session

Marie Curie Scotland written evidence

1. Priority areas for scrutiny

Delivering high-quality palliative care equitably across Scotland to everyone who needs it would contribute directly to many of the Scottish Government's wider ambitions around person-centred care, reducing avoidable hospital use, supporting care closer to home, tackling inequalities and ultimately improving the sustainability of health and social care services.

As the Committee considers its work programme, and potential further scrutiny in this area, we strongly encourage it to **identify how an equitable minimum standard of palliative and end of life care can be jointly defined, what delivery structures, accountability mechanisms and resources are needed to achieve improvement, and how change can be prioritised and expedited.**

This should involve exploring the following questions:

- What minimum standards of palliative and end of life care support should people and families be able to expect, regardless of diagnosis, age or postcode, and how could clearer national expectations, standards and accountability help reduce unwarranted variation?
- What barriers prevent timely identification of need and earlier access to palliative care, particularly for groups who currently experience poorer outcomes, and are services sufficiently focused on prevention, early intervention and care closer to home?
- How can governance, planning and delivery arrangements better support joined-up, person-centred care, including effective coordination, information sharing and continuity across settings?
- Do current funding, workforce and resource allocation arrangements reflect current and future need, and how can they more effectively support the shift towards more community-based models of care?
- Does Scotland have the data, oversight and accountability needed to understand unmet need, inequalities, variation in access and outcomes, and to drive improvement at national and local level?

2. Demographic and policy context

Why urgent action is needed: Key stats

> Almost one in three people die with unmet palliative care needs - around 18,500 people in Scotland each year. Without action, this number is projected to rise by 14% in the next 25 years – to 21,400 people by 2050.[1]

> This unmet need is unevenly distributed. The people who most need palliative care are least likely to receive it, including those experiencing socio-economic deprivation, older people,

[1] Microsoft Word - Marie Curie Unmet Need Research - Scotland Briefing FINAL

women, minoritised ethnicities, LGBTQ+ people, people with learning disabilities and rural and island communities.

> Population need is rising: by 2050, the need for palliative and end of life care will increase by almost 20% compared to 2025.[2]

> £1.3 billion is spent on healthcare for people in the last year of life, with £1.1 billion of this spent on hospital care – five times more than on primary care, community health and hospice care combined.

There is a broad consensus shared by the palliative care sector and the Scottish Government around what high-quality, equitable palliative care and end of life care should deliver; this has been built over many years of engagement with clinicians, professional bodies, regulators, the third sector and people with lived experience.

We know what makes a difference: early identification of needs, person-centred care, future care planning, support closer to home where appropriate, 24/7 support, and better coordinated services across health, social care and the third sector.

Much of this is acknowledged in the Scottish Government's strategy '*Palliative Care Matters for All*'.[3] However, while the strategy sets out a vision and direction of travel, it does not in itself guarantee consistent delivery. The continued variation in access and experience suggests that a gap remains between national ambition and what people can reliably expect in practice.

Scotland currently lacks a nationally agreed set of minimum service standards or expectations for palliative care that can provide a clear, shared understanding of what support should be available and delivered, regardless of diagnosis, age or postcode. We also lack the accountability mechanisms and resources needed to monitor delivery and drive improvement consistently and equitably across Scotland.

While many high-quality services exist, supported by a skilled and committed, albeit stretched, workforce, provision remains uneven. As a result, significant unmet need and inequities in access to palliative care persist.

For that reason, we encourage the Committee to explore why variation in access and experience continues despite longstanding policy commitments and broad agreement about what good palliative care looks like. This means going beyond identifying the pressures facing palliative care services and examining the systems, governance arrangements, accountability structures and funding mechanisms needed to translate national ambition into consistent delivery.

This is particularly timely in the context of wider Scottish Government reforms to health system governance and planning, which provide an opportunity to explore how greater consistency, accountability and equity in palliative care can be achieved

We hope that the Committee's work programme will contribute to establishing a shared understanding of the minimum standard of palliative and end of life care that people should be able to expect wherever they live. It could also help identify the delivery structures, accountability mechanisms and resources required to achieve that standard and drive improvement at pace.

3. Key opportunities for change

3.1 Prioritising earlier support

[2] Marie Curie, Method for Marie Curie estimation of deaths and future need for palliative care in 10 and 25 years, 2025. Briefing.

[3] Palliative Care - Publications

"My husband passed away in hospital in 2023. He was in hospital for a month before passing away, and nobody ever talked to us about palliative care or end of life wishes." - Carole, Edinburgh

Access to early or timely palliative care has been shown to improve symptom burden[4] and also help to reduce hospital attendance and or admissions later on.[5]

Yet too many people still receive palliative care too late, at multiple junctures of their care trajectory – whether that be late identification of need, late referral to specialist palliative care, delays in access to the right care provision, or delayed discharge from hospital into a community setting, where that is appropriate and preferred.

A proportion will not receive palliative care support at all.[6] For some, that will be because they are never identified for a palliative approach, and don't get the opportunity to discuss what their future care preferences might be.

Earlier identification of palliative care needs remains particularly challenging for some groups, including people with non-cancer conditions, those experiencing socio-economic disadvantage, and some rural and island communities.

Addressing this will require greater focus on systematic identification of palliative care need across all settings, supported by clear pathways into timely support, and earlier conversations about future care.

3.2 Developing a shared understanding of what individuals and their families can expect

Variation in access also raises questions about how to reach a clear and shared understanding of what people should be able to expect from palliative and end of life care services.

There is currently no defined minimum standard of palliative and end of life care that terminally ill people should be able to expect across both specialist and generalist care, and that workforces have the resource and capacity to deliver. As a result, it can be difficult for patients, families, professionals and policymakers alike to understand whether services are meeting expectations or where gaps in provision exist.

A nationally agreed minimum standard of care will help establish clearer expectations, reduce unwarranted variation and provide a stronger basis for planning, delivery and accountability.

See Annex 1 for Case Study on Wales' structured framework for PEOLC.

3.3 Shifting the balance of care from acute to community settings

Hospital care can be an important and necessary part of the care people need toward the end of their lives. But it should be prioritised for those who need it – not as a substitute because the right care isn't available in the communities where people live.

Marie Curie research shows that Scotland spends £1.3 billion on healthcare for people in the last year of life, with £1.1 billion of this spent on hospital care and £787 million on emergency hospital care. Scotland spends five times more on hospital inpatient care for people in the last year of life

[4] https://www.ncbi.nlm.nih.gov/books/NBK561537/pdf/Bookshelf_NBK561537.pdf
[5] https://pmc.ncbi.nlm.nih.gov/articles/PMC4404422/
[6] Microsoft Word - Marie Curie Unmet Need Research - Scotland Briefing FINAL

than on primary care, community health and hospice care combined, despite these services being essential to earlier support and prevention.[7]

There are both ethical and preventative spend reasons to proactively shift the balance of care and spend into the community. People and families often experience acute care as crisis, delay and distress, while lower-cost, higher-value community-based approaches can improve outcomes, reduce avoidable hospital use, and support wider health and social care renewal and public service reform objectives.

Achieving this shift will require sustained investment in community-based palliative care services and the resources and workforce needed to support care closer to home. The availability of responsive 24/7 support also plays an important role in preventing avoidable hospital attendances or admissions.

See Annex 2 for Case Studies on Lothian Advanced Hospice Care at Home, and Marie Curie and University Hospitals Plymouth.

3.4 Coordination across settings

"The system is difficult to navigate - especially for people with little understanding of how the health and social care system works. It can work but takes huge determination." - Family member who shared their experience with Marie Curie

People approaching the end of life often receive support from across multiple services and settings, including primary care, hospitals, social care, community nursing, hospices and other third-sector providers. To be effective, palliative care therefore needs not just for individual services to be of high-quality, but for those services to work in a co-ordinated way, across organisational boundaries.

However, too often people experience fragmented care, repeated assessments and difficulty navigating services, particularly when moving between hospital and community settings. Poor coordination can contribute to late referrals, delayed discharge and avoidable crises.

Stronger mechanisms for shared planning, information-sharing and joint accountability would help create a more seamless experience for patients and families. This should extend between both health and social care and between acute, primary, community and third-sector services. Central to achieving this will be ensuring that hospices and other third-sector providers are involved as strategic partners in planning and decision-making, rather than engaged only once services have been designed and are being commissioned.

3.5 Transparency and accountability

Responsibility for palliative care is fragmented across organisational boundaries. While Integration Authorities are responsible for planning and resourcing adult palliative care, palliative care is provided across the NHS, by local authorities, independent hospices and other third-sector organisations, and in care homes.[8]

The makes clarity about responsibility, oversight and shared outcomes particularly important.

Yet ongoing and unwarranted variation in access raises questions about how effectively it's possible to gather consistent information about population need, identify and monitor gaps in

[7] Marie Curie. Public expenditure in the last year of life, 2025.
[8] Palliative Care - Publications

provision, assess whether national ambitions are translating into effective change locally, and ultimately hold systems accountable for improvement.

Clearer national expectations, better data and more robust accountability arrangements are needed to understand variation and drive improvement.

3.6 Planning for future demand

As outlined above, the current system is failing to meet the needs of almost one in three people who die with palliative care needs in Scotland – raising serious questions about how it will cope with meeting the rising and increasingly complex demand projected in decades ahead.

Workforce planning must take a wider lens than just specialist staff, and consider how palliative care knowledge, confidence and capability can be strengthened across all settings.

Sustainable planning also requires hospices and third-sector providers to be recognised as core health and care infrastructure. Short-term or uncertain funding limits their ability to retain staff, plan services, innovate and respond to rising demand.

Meeting future demand will require long-term workforce, service and funding planning that reflects both the scale of projected need and the contribution of hospices and the third sector.

4. About Marie Curie

Marie Curie is the UK's leading end of life charity, and a campaigning and social justice organisation with a mission to close the gap in end of life care. We're here for anyone with an illness they're likely to die from, and those close to them.

We are the largest provider of adult palliative care outside of the NHS in Scotland, and provide expert care and support through our inpatient and outpatient services at our two hospices in Edinburgh and Glasgow, as well as our community palliative care services in most local authorities.

In 2025 we supported approximately 6,241 patients and provided 75,440 hours of care across Scotland to people at their end of life. In 2024/25, our Information and Support services – which provide practical and clinical information, and emotional support to anyone affected by dying, death and bereavement – were used more than 91,000 times.

Marie Curie is also the UK's largest charitable funder of palliative and end of life care research.

Annex 1: Case Study - Wales' structured framework for PEOLC

The Welsh Government, in partnership with key organisations across the sector including Marie Curie, has developed a structured national framework for palliative and end of life care. A Quality Statement[9] sets out the Welsh Government's overall ambitions, while a National Service Specification[10] translates those ambitions into detailed expectations for how services should be organised and delivered. The specification establishes a nationally agreed baseline for what high-quality palliative and end of life care should look like across Wales, regardless of diagnosis, age or

[9] Quality statement for palliative and end of life care for Wales [HTML] | GOV.WALES
[10] performanceandimprovement.nhs.wales/our-work/peolc/documents/national-service-specification-for-wales-peolc/

where someone lives. A national competency framework[11] sits alongside it, and work has begun on a hospice commissioning framework.[12]

While implementation and accountability challenges remain, the Welsh approach demonstrates how high-level policy commitments can be supported by clearer service specifications, workforce expectations and accountability mechanisms designed to reduce unwarranted variation and improve consistency across a health system.

Annex 2:

Case study - Enhanced Hospice Care at Home, Lothian

In 2024, Marie Curie launched its Enhanced Hospice Care at Home service in Lothian, building on its existing home-based palliative care offer.

The service provides 24-7 support from specialist nurses and doctors for people with complex symptoms and challenging circumstances who might otherwise require admission to hospital or hospice care. Working alongside GPs and district nursing teams, the service delivers expert assessment, symptom management and responsive care in patients' own homes.

Without this enhanced level of care, patients supported by this service would often require admission to an in-patient unit at an acute hospital or hospice. By providing support at home, the service not only prevents these admissions but also facilitates earlier discharges, enabling patients to return home sooner with the right care in place. This improves patient experience while easing demand on acute and hospice services.

An evaluation of the first year found that 179 patients were admitted to the service, with 154 avoiding admission to hospital or hospice as a result.

Case study - Marie Curie and University Hospitals Plymouth

Marie Curie's partnership with University Hospitals Plymouth, Devon combines proactive identification of people nearing the end of life, conversations about care preferences, and support to transfer patients to home, hospices, care homes or community hospitals where appropriate.

A dedicated hospital-based team helps identify patients earlier and coordinate timely discharge, supported by referrals from professionals, patients and families. Marie Curie also supports 12 dedicated end of life beds in a community hospital, providing an alternative to acute wards for people whose needs can be better met outside hospital. Additional support is available in the Emergency Department and through trained volunteers.

The programme demonstrates that, with the right community capacity and coordination, more people can be cared for in settings that better reflect their needs and preferences, while reducing pressure on acute hospitals.

[11] heiw.nhs.wales/files/final-all-wales-end-of-life-care-framework-oct-2025/
[12] An Approach to Commissioning Hospice Care in Wales

Key Challenges and Steps for Improvement in Palliative Care

ABOUT SCOTTISH PARTNERSHIP FOR PALLIATIVE CARE

SPPC is a collaboration of over 100 organisations involved in providing care towards the end of life. SPPC's membership includes all the territorial NHS Boards, IJBs, local authorities, Scottish Ambulance Service, Scottish Care, the hospices, other Third Sector organisations and a range of professional associations. SPPC works closely with SG to facilitate engagement with the sector and to inform and support implementation of SG policy.

SPPC brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement. SPPC provides a voice for organisations and individuals working in this area, a means of staying informed and connected, and a vehicle for collaboration. SPPC also engages with the public and communities through our Good Life, Good Death, Good Grief alliance.

KEY CHALLENGES

Palliative care is poorly understood

Palliative care is poorly understood by policy-makers, professionals and the public. Ambiguous language usage is part of the problem - "palliative care" is often heard as meaning something done by (and accessible via) specialist services. The huge scale and importance of generalist provision of palliative care in communities, care homes and hospitals can be neglected as a result. There is also a widespread misunderstanding that palliative care deals only with people who are at the very end of life and dying. However, palliative care has value throughout the course of a life shortening condition, and earlier identification of people who have palliative care needs is important.

The health and social care system in Scotland is in a fragile state.

General practice is time-scarce with continuity of care and relationship often lacking; the community nursing workforce is spread too thin with a significant percentage approaching retirement; chronically under-funded social care is often crisis-focussed, unresponsive and inflexible; voluntary hospices are struggling to achieve sustainable funding; less visibly NHS specialist units are under great service pressures; overwhelm

of hospital capacity regularly leads to "corridor care"; and the specialist palliative care presence is inadequate in many Scottish hospitals. Provision of services in rural areas face unique challenges. Other Third Sector providers of information, care and support are struggling financially whilst demand for their services is rising.

There are no national standards, agreed service specifications and governance is sometimes opaque

There are no national standards or meaningful quality indicators for palliative care to inform the planning and commissioning of services or to help the public understand what care they might reasonably expect to receive. There are no common specifications of what general and specialist palliative care are expected to deliver. Service levels vary geographically and sometimes reflect history rather than population need. Receiving adequate palliative care is part of the human right to health but the reality in Scotland is enormous unwarranted variation and opaque accountability for outcomes. Although the legal responsibility for palliative care has been delegated to IJBs at a practical local level is sometimes unclear where managerial leadership lies[1].

Health and wellbeing inequalities[2] - death is not the great leveller

People who are already disadvantaged by socio economic factors, geography, individual circumstance and/or personal characteristics often have worse experiences and outcomes at the end of life. For example, living with a life shortening condition exacerbates financial disadvantage. People living in deprived areas have different patterns of service use/ access. They are less likely to access specialist palliative care, they are more likely to spend time in hospital during the last 3 months of life, more likely to die in hospital and less likely to die at home or in a hospice. People from the most deprived areas are less likely to report that they received sufficient support from health and social services to care for someone at home.

HOW TO IMPROVE THE SITUATION

Resources and the national palliative care strategy *Palliative Care Maters for All*

SPPC contributed to the development of *Palliative Care Matters for All* the current national strategy. The strategy describes broad and ambitious outcomes which we

[1] Background paper SG Palliative Care Strategy 2025 https://www.gov.scot/publications/palliative-care-strategy-service-mapping-survey-additional-paper/pages/3/

[2] By health and wellbeing inequalities we mean avoidable, unfair and systematic differences in health and wellbeing between groups of people. These inequalities of outcome can be driven by inequalities or inequities in such things as: access to services; experience of care; discrimination; and wider determinants of health and wellbeing such as financial hardship, poor housing, education, geography and employment.

welcome. However, whilst we support the outcomes in the national strategy it is not clear how service providers can possibly achieve many of these outcomes given that the strategy also states *"The strategy delivery plan is not based on substantial additional funding…"*. Of course change and improvement is not all about money. However, there is a need for a *realistic assessment* of the resourcing required to deliver the changes identified in the strategy.

Aside from the need for "new money" there is an opportunity for existing resources to be moved around the health and social care system and deployed more effectively to deliver better outcomes for people. There is good evidence that palliative care interventions can reduce expenditure on time in hospital when it is likely to be ineffective, whilst also shifting care closer to home[3] and improving people's outcomes and quality of life. However, the mechanisms do not seem to exist to make such shifts in investment possible See below). New models such as revolving funds and Investment Standards need to be considered. There is a need for imagination, innovation and risk-taking.

Governance, leadership, strategic policy making and system-wide change

Recent research by Marie Curie and the Nuffield Trust estimates that Scotland spends £2.3 billion on health and care in the final year of life. We know from listening to people and their families and by analysing service use that care is often fragmented and overly reactive (as opposed to preventative). As a result expenditure is not sufficiently focussed on delivering what people value.

Whilst time in hospital towards the end of life can be important and valuable a proportion of bed use in the final year of life is currently due to inadequate provision of community supports (particularly supports which respond rapidly and effectively to crisis). Paradoxically the most expensive care (emergency admission to hospital) is the most reliably and readily accessible support available, whilst social care support (relatively inexpensive and capable of avoiding unwanted and ineffective time spent in hospital) is tightly rationed and slow to access.

At any time 1 in 3 acute hospital beds in Scotland is occupied by someone in their final year of life. This is not therefore a marginal issue but a substantial challenge (but with real potential to contribute to the aims of the *Health and Social Care Renewal Framework*). A final year of life lens is extremely valuable in understanding what is happening and also in generating appropriate and effective policy responses.
There is good evidence that investment in a variety of palliative care interventions can reduce time spent ineffectively and expensively in hospital and improve outcomes for people and their families.

Thus the situation is crying out for system reform but we observe the need for these changes to enable reform:

[3] Clarke, May et al Costs and cost-effectiveness of adult palliative and end-of-life care Evidence briefing (2025) NIHR Policy Research Unit in Palliative and End of Life Care

1. **Bring a final year of life lens to strategic policy making**. There is sometimes a perception that end of life is a marginal issue whereas in fact headline concerns like acute capacity and flow, unscheduled care, delayed discharge and shifting the balance of care can all be valuably analysed, understood and addressed as final year of life issues. There is an absence of a "final year of life" lens in central policy analyses and frameworks (e.g. not mentioned in the Health and Social Care Renewal Framework or Scotland Population Health Framework). This leads to a lack political and senior leadership engagement (which is essential if reform is to be truly across the system).
2. **Strengthen Governance** in the ways envisaged in the palliative care strategy. Also consider the role of national standards and service specifications can play.
3. **Enable system redesign** across organisational barriers. This requires senior sponsorship and political leadership (see above). It also requires effective mechanisms for properly integrated financial planning (see above)

Societal change: improving end of life literacy

Much of the care and support which people need when living and dying with a life shortening condition, or when bereaved, comes from friends, neighbours, colleagues and other community members. The capacity for such informal support can be nurtured and grown. End of literacy[4] is about the capacity to deal with and support others with the difficult times that can come with serious illness, dying, death, loss and care.

For **individuals**, this means having knowledge and skills to cope when these issues impact on their life. For **communities**, end of life literacy is about creating environments and opportunities for people to learn about and support each other with these issues. For **health and social care professionals**, end of life literacy means understanding their professional role in supporting people with these issues, and being able to put this into practice. For **policy makers and decision makers**, end of life literacy means understanding the impact of life shortening illness, ageing, caregiving and bereavement across all areas of society, and how they can use their influence to make improvements.

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[4] More formally end of life literacy can be defined as "*as an umbrella term to refer broadly to the collection of knowledge, skills, experiences, attitudes, opportunities, and behaviours that enable an individual to plan for, deal with, and support others through the difficult times that can come with dying, death, loss, and care*." Patterson & Hazelwood, Chapter 13, Oxford Textbook of Public Health Palliative Care 2022