

Priorities for the Seventh Senedd – Health and Social Care Committee

Marie Curie response

1. Introduction

Marie Curie is the UK's largest palliative and end of life care charity. We work hard to enable people who are living with a terminal illness, and their loved ones and carers, to have the best possible experience at the end of life. We offer expert care across Wales, in people's communities and in our Cardiff and the Vale Hospice and deliver specialist care, guidance and support to families with matters related to dying, death and bereavement through our free information and support services. We are also the largest funder of palliative and end of life care research, and we work with Members of the Senedd and policymakers to ensure that more people in Wales have the best possible end of life experience.

Palliative and end of life care is a critically important part of our health and social care system that is facing increasing demand. It is also under immense pressure.

During the Seventh Senedd it is essential that steps are taken to fix palliative and end of life care to ensure that people living with a terminal illness can access timely, equitable and well-coordinated care and, wherever possible, are able to receive care in their preferred place.

2. Do the Welsh Government's health and care priorities reflect the most significant challenges facing communities across Wales?

- 2.1. The listed priorities cover many of the main areas of our health and social care system that require action but it's important that the wider context is understood and informs how these priorities are pursued.
- 2.2. Demand for palliative and end of life care is projected to increase over the coming years. By the 2040s, 37,000 people in Wales will likely need palliative and end of life care each year (Marie Curie, 2025). In 25 years, demand will have increased by 21% (Marie Curie analysis 1).
- 2.3. As well as increasing demand, the complexity of care and support needed by people living with a terminal illness is also likely to increase. With an ageing population we will likely see increasing comorbidities, with people living for longer with multiple, complex, life limiting conditions.
- 2.4. Our health system is already struggling to meet the needs of people at the end of life. Almost one in three adults were found to have unmet palliative care needs in Wales, meaning more than 10,000 people whose symptoms were not managed

effectively and who did not have the support they needed from primary care services in the last three months of life (Marie Curie, 2026).

- 2.5. Pressure is also being placed on our health system. Of every emergency department attendance, one in 14 is in relation to someone in the last 12 months of life (Marie Curie, 2025). On average, in 2023 a fifth of hospital beds in Wales were occupied every day by people in the last 12 months of life (Marie Curie analysis 2).
- 2.6. While for some hospital will be the most appropriate place for them to receive care, others could be supported in the community if services were better equipped to respond to their needs.
- 2.7. This Senedd term it is essential that steps are taken to fix palliative and end of life care to ensure that people living with a terminal illness can access timely, equitable and well-coordinated care and, wherever possible, are able to receive care in their preferred place.

3. Are there any important priorities missing?

- 3.1. There is a risk that palliative and end of life care could be overlooked. There remains a societal discomfort around discussing death and dying and only a small number of organisations are focused on palliative and end of life care in Wales.
- 3.2. An additional risk is that only one element of palliative and end of life care is considered.
- 3.3. While some people living with a terminal illness will receive some of their care from specialist palliative care services, most if not all will be receiving support from across the health and social care system. It's therefore imperative that we consider how the whole system can be set up to respond to people's needs, alongside action to put in place a sustainable funding solution for hospice services.
- 3.4. A number of commitments were set out in the Plaid Cymru manifesto on palliative and end of life care, which we anticipate being reflected in the programme for government following recent correspondence from the Cabinet Minister for Health and Social Care. These include action on sustainable funding, population level needs assessments to inform service planning, including palliative care leads on Regional Partnership Boards and improving support for unpaid end of life carers.
- 3.5. There was also significant progress during the last Senedd term on the strategic policy framework for palliative and end of life care.
 - 3.5.1. A refreshed **quality statement** is due to be published in the Autumn of 2026. This sets out what good quality palliative and end of life care services should look like.
 - 3.5.2. The **National Service Specification for Wales: Palliative and End of Life Care Services** sets out in more detail the standards expected from health boards, commissioners and providers to ensure that the ambitions in the quality statement are realised.
 - 3.5.3. The **All-Wales Competency Framework for Adult Palliative and End of Life Care** seeks to ensure that all healthcare professionals are "equipped with the

knowledge, skills and behaviours required to provide compassionate and effective care for individuals at the end of life."

3.6. Work is ongoing on the development of a **national approach to hospice commissioning** and on a **quality and assurance framework**.

3.7. Given these developments, and the commitments from the new Welsh Government, we think it would be timely this Senedd term to carry out an inquiry looking specifically at palliative and end of life care. This could consider the extent to which delivery is currently meeting the ambitions and expectations set out in the strategic policy framework, how services need to respond to growing demand and complexity of care and how palliative and end of life care features in the drive to shift more care from acute settings into the community.

4. What are the main barriers to delivering these priorities and measuring progress?

4.1. The Welsh Government must ensure that support for people living with a terminal illness is considered across their health and social care priorities.

4.2. Priorities of particular importance are:

4.2.1. **Urgent and emergency care**: Hospitalisation rates remain high for people in the last 12 months of life. People nearing the end of life and their carers need rapid access to advice through a simpler, more coordinated system, supported by better integration between community, palliative, ambulance and urgent care services. Action could include further roll out of the advance practice paramedic model in operation in Swansea Bay University Health Board.

4.2.2. **Shift to community-based care**: Many people would prefer to receive care and to die in their community as opposed to hospital. Well-coordinated, well-resourced and person-centred community care is essential to achieving this. The shift to community-based care must consider the needs of those living with a terminal illness and include steps to support 24/7 access to care and support. This could include actions such as the introduction of advance practice palliative care nurses in all primary care clusters and improvements in access to end of life medications.

4.2.3. **Development of national social care service**: Adult social care plays a vital role in supporting people to live and die well, often in their own homes or care settings. It provides personal and practical assistance that enables independence and dignity throughout life's stages, including at the end of life. However, disparities in quality and access can drive avoidable deterioration, crisis presentations and emergency hospital admissions. Any move to a national social care service must consider the role of social care in supporting people nearing the end of life.

4.2.4. **Support for unpaid carers**: End of life carers are a distinct group, with distinct needs. Many are providing complex, intensive care without the support that they need. Improvements in support for carers must include action to improve recognition and support for end of life carers, including better training and information for professionals and carers, access to key healthcare contacts

and 24/7 support, improved respite provision, more consistent signposting to carers' needs assessments, and regular review of support as needs change.

4.3. The changes that we want to see for people living with a terminal illness also depend on improvements to fundamental issues across health and social care:

4.3.1. Workforce development.

4.3.2. Digital infrastructure, including shared patient records.

4.3.3. Sustainability of services delivered with third sector partners.

4.3.4. Tackling health inequities.

4.3.5. Improvements to the collection and publication of data.

5. What should the committee focus on to make the biggest difference?

5.1. To meet current and future demand, urgent action is needed to fix palliative and end of life care. The committee can help to ensure this happens by:

5.1.1. Carrying out an inquiry focused on palliative and end of life care.

5.1.2. Ensuring that palliative and end of life care and the needs of those living with a terminal illness are considered across the breadth of the committee's work.

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References

Marie Curie (2025) *At breaking point: Time to transform end of life care in Wales*

Marie Curie (2026) *Unmet palliative care need in Wales*

Marie Curie analysis 1 – based on analysis of ONS principal projections of deaths in the UK population

Marie Curie analysis 2 – based on analysis of data accessed via the Last Year of Life Dashboard and StatsWales on hospital bed use and total capacity