

Legislative Consent Memorandum for the Terminally Ill Adults (End of Life) Bill

Health and Social Care Committee Scrutiny

June 2025

1. Introduction

Marie Curie retains a neutral position on assisted dying. We neither campaign for nor against a change in the law. As the Terminally Ill Adults (End of Life) Bill has progressed through the UK parliament, there has been increased discussion of death, dying and palliative and end of life care. This increased focus is much needed and has highlighted that the palliative and end of life care system in Wales, and across the UK, is at breaking point.

To date, action to strengthen and improve the availability, accessibility and quality of palliative and end of life care has been far too slow. The increased discussion of death and dying must create a renewed sense of urgency in transforming end of life care. This action is required whether the law on assisted dying changes or not, so that everyone in Wales can access the right care, in the right place, at the right time.

Legislating for assisted dying poses some complex questions in respect of devolution. While justice is reserved, health is devolved. As drafted the Terminally Ill Adults (End of Life) Bill straddles both of these areas.

Palliative and end of life care in Wales is a matter for the Welsh Government and the Senedd, and it's imperative that accountability remains with the appropriate bodies. Should amendments be made to the Terminally Ill Adults (End of Life) Bill that relate directly to the assessment, delivery and availability of palliative and end of life care, these must be cognisant of devolved responsibilities.

In our detailed response below we have addressed a number of the questions posed by the Health and Social Committee to support their scrutiny of the legislative consent memorandum (LCM).

2. Detailed response

Clause 39

2.1. Question Five: How do you anticipate the forthcoming regulations by Welsh Ministers on voluntary assisted dying services will (if approved) impact current palliative care practices in Wales, considering the details of these regulations are still to be determined?

- 2.1.1. Marie Curie retains a neutral position on the issue of assisted dying. We neither campaign for, nor against a change in the law. While the issue of palliative and end of life care has featured heavily in discussion around the Bill, assisted dying and palliative and end of life care are not fundamentally linked. As drafted, the Bill will not directly impact on the delivery of palliative and end of life care in Wales. Therefore, there is no reason to presume that regulations produced by Welsh Ministers will directly impact the delivery of palliative and end of life care in Wales. Although this ultimately will depend on the detail of these regulations.
- 2.1.2. Recent discussions of death, dying and end of life care must result in a renewed sense of urgency in addressing the systemic issues that prevent people living with a terminal illness from receiving the care they need and deserve.
- 2.1.3. Whether the law on assisted dying changes or not, urgent action is needed to transform end of life care and ensure that everyone can access the right care, in the right place, at the right time, in their last phase of their life.
- 2.1.4. The need for palliative and end of life care is going to increase in the coming decades, with an additional 5,000 people a year requiring care in Wales by the 2040s.¹
- 2.1.5. Wales has an emerging policy framework for palliative and end of life care. The quality statement for palliative and end of life care sets out a clear destination that government, health boards and providers should be working towards. The forthcoming service specification has the potential to act as an implementation plan

¹ Marie Curie (2024) *Better end of life 2024 Time to Care in Wales Implications for Wales of 'Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales*

for this quality statement, and the development of a commissioning framework should help to achieve greater consistency in service delivery across Wales. (This framework is set out in more detail in [Annex One](#)).

- 2.1.6. However, there is currently a gap between these high-level ambitions and delivery. Almost one in five people in Wales had no contact with a GP either in person or over the phone in their last 3 months of life; of every emergency department attendance in Wales, one in 14 is related to someone in their last year of life; and in 2023 over a fifth of hospital beds were occupied every day by people in their last 12 months of life.²
- 2.1.7. We must urgently close this implementation gap if we are to meet the needs of people in Wales. Our manifesto '[At Breaking Point: Time to transform end of life care in Wales](#)' sets out the action needed to do this.
- 2.1.8. As the Bill progresses in Westminster, any amendments that directly relate to palliative and end of life care will need to be cognisant of devolved responsibilities and will need to interact with the existing policy framework in Wales. It's imperative that accountability for palliative and end of life care in Wales remains clear. It would not be appropriate for a UK Bill to significantly change or direct the delivery of palliative care in Wales.

Clause 45

2.2. Question 6 What are your views on proposals to enable the Welsh Ministers to (a) refer any matter connected to the operation of the Act to the Voluntary Assisted Dying Commissioner for investigation; (b) require the Commissioner to consult with the Chief Medical Officer for Wales when preparing an annual report on the operation of the Act; (c) require the Welsh Ministers to publish the annual report submitted by the Voluntary Assisted Dying Commissioner, and prepare and publish a response to that report which must both be laid before the Senedd?

- 2.2.1. Where the Commissioner may need to consider palliative and end of life care, or may report on palliative and end of life care, it's important that this is situated within the Welsh context, that

² Figures cited in Marie Curie (2025) *At breaking point: Time to transform end of life care in Wales*; analysis of hospital bed days in 2023 based on data from the Last Year of Life Dashboard and Stats Wales "NHS beds by organisation and year 2009-10 onwards"

relevant bodies in Wales are consulted and that accountability for palliative and end of life care is recognised as sitting with Welsh Ministers.

2.2.2. These provisions within the Bill should enable this to be the case.

2.2.3. A similar approach should be followed with any further amendments to the UK Bill that specifically relate to palliative and end of life care. It is for appropriate national bodies to undertake any activity related to palliative care, in line with devolved responsibilities. The UK Bill must acknowledge the role of Welsh Ministers in the delivery of palliative and end of life care in Wales and the role of the Senedd in scrutinising delivery of palliative and end of life care in Wales.

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Annex One

Palliative and End of Life Care Policy in Wales: Summary

January 2025

1. Introduction

This paper provides an overview of palliative and end of life care policy in Wales. It covers key elements of the emerging policy framework:

- Quality Statement for Palliative and End of Life Care
- Service Specification for Palliative and End of Life Care
- Commissioning Framework for Palliative and End of Life Care

As well as a summary of the purpose and content of each of these documents, this paper outlines Marie Curie Cymru's assessment of the strengths and weaknesses of this framework.

2. Key actors and responsibilities for the delivery of palliative and end of life care in Wales

2.1. The **Welsh Government** sets the overall policy direction and makes decisions about health and social care funding.

2.2. **NHS Wales Performance and Improvement (previously NHS Wales Executive)** was set up in 2023 to provide leadership and strategic direction, to enable, support and direct NHS Wales to “transform clinical services in line with national priorities and standards.”³

2.3. The **National Palliative and End of Life Care Programme** sits within NHS Wales Performance and Improvement and provides “national leadership and support, and acts as a forum to drive forward change and oversee health boards’ efforts to deliver the Welsh Government’s vision for improving end of life care in Wales.”⁴

2.4. The **seven local health boards** are responsible for planning, commissioning and providing local healthcare services to address local needs. In addition, **three NHS trusts** are responsible for the delivery of all-Wales services covering public health, specialist cancer

³ <https://executive.nhs.wales/about-us/> [Accessed 21/01/25]

⁴ <https://executive.nhs.wales/functions/networks-and-planning/peolc/#:~:text=The%20National%20Palliative%20and%20End.of%20life%20care%20in%20Wales.> [Accessed 21/01/25]

services and ambulance service and **two special health authorities** are responsible for workforce and digital services for the NHS.

2.5. **Local authorities** are responsible for the delivery of social care services. **Regional Partnership Boards** are responsible for improving the well-being of the population including the improvement of the delivery of health and care services.

3. Quality Statement for Palliative and End of Life Care

3.1. First published in 2022, the [Quality Statement](#) sets out “high level Welsh Government policy intention for children, young people and adult palliative and end of life care”.

3.2. The statement describes what good quality palliative and end of life care services should look like, listing six quality attributes:

- Safe
- Timely
- Effective
- Person centred care
- Efficient
- Equitable

3.3. A recent informal review of the impact and implementation of the Quality Statement by the Third Sector Sub-group of the National Programme Board for Palliative and End of Life Care found mixed views on the extent to which the ambitions of the Quality Statement are being realised.

3.4. While the majority of people surveyed agreed that the Quality Statement has had an impact, satisfaction with achieving the quality attributes peaked at around 55%.

4. Service Specification for Palliative and End of Life Care

4.1. A service specification for palliative and end of life care is due to be published in 2025. This specification should outline how health boards, commissioning bodies and providers can make the ambitions set out in the Quality Statement a reality.

4.2. Marie Curie Cymru has long called for an implementation plan to accompany the Quality Statement. The service specification has the potential to fulfil this role, if it contains the appropriate level of detail and includes tangible, measurable actions.

5. Commissioning Framework for Palliative and End of Life Care

- 5.1. Inconsistent approaches to the commissioning of palliative and end of life care, and the lack of a sustainable funding solution has long impacted on the delivery of quality care in all parts of Wales. A post-code lottery persists.
- 5.2. Work has begun on the development of a commissioning framework. It is hoped that this will support consistency in commissioning and put in place much needed standardisation around unit prices, length and nature of contracts and commitments to agenda for change salary levels.
- 5.3. Work on this framework is at an early stage. In addition, the 2025-26 draft Welsh Government budget includes a commitment to recurring annual funding for hospices of £3m.

6. Is this policy framework delivering change?

- 6.1. This emerging policy framework has the potential to drive change and improve the provision of high-quality palliative and end of life care that is accessible to everyone in Wales.
- 6.2. The Quality Statement sets out a clear destination that government, health boards, commissioners and providers should be working towards. However, the challenge remains how to close the implementation gap between ambition and delivery.
- 6.3. Evidence shows that critical issues remain in the delivery of palliative and end of life care in Wales⁵:
 - One in nine people who died in hospital had been there less than 24 hours, suggesting an emergency admission.
 - 48% of people who died used an ambulance in their final three months.
 - 36% of people were severely or overwhelmingly affected by pain in their final week of life.
 - 25% of people who died either probably or definitely did not know they might die because of their illness.

⁵ Marie Curie Cymru (2024) *Time to Care in Wales Implications for Wales of 'Time to Care: Findings from a nationally representative survey of experiences at the end of life in England and Wales / Marie Curie Cymru (2024) Dying in Poverty in Wales 2024*

- Over 6,000 people died in poverty in 2023, and a fifth of terminally ill people experience fuel poverty in their last year of life.

6.4. For this emerging policy framework to be successful in delivering change, steps must be taken to:

- **Ensure that the forthcoming service specification for palliative and end of life care sets out clear and measurable actions** that will improve the availability, quality and accessibility of palliative and end of life care in all parts of Wales and ensure the aspirations of the Quality Statement are realised.
- **Establish a sustainable funding solution and commissioning framework to support the whole palliative and end of life care system**, which ensures that the diverse needs of terminally ill people are met and the right care is delivered in the right place and at the right time.
- **Establish a robust monitoring framework** which underpins the Quality Statement, Service Specification and Commissioning Framework to measure progress and inform further action.