

Unheard: Women's journey through gynaecological cancer

Health and Social Care Committee Short Inquiry

September 2025

1. Introduction

Marie Curie are pleased to provide evidence as part of the Health and Social Care Committee's short inquiry to scrutinise the implementation of the Committee's report *Unheard: Women's journey through gynaecological cancer*.

Our response below focuses on progress in implementing the two recommendations specifically related to palliative and end of life care, highlighting some ongoing challenges that prevent an accurate picture of how women with terminal gynaecological cancers are accessing and experiencing palliative and end of life care.

2. Palliative and end of life care in Wales

- 2.1. End of life care in Wales is at breaking point. Gaps in care and a system under severe pressure mean too many people are spending their final days isolated, in pain, and struggling to make ends meet.
- 2.2. Wales has an emerging policy framework for palliative and end of life care. The quality statement sets out a clear destination that government, health boards and providers should be working towards. The forthcoming service specification and commissioning framework for hospice services should support greater consistency in delivery towards these high-level ambitions.
- 2.3. However, we currently have a significant implementation gap.

- 2.3.1. 37% of bereaved people reported that healthcare professionals had not discussed death and dying with the person who died.¹
- 2.3.2. Almost one in five people in Wales had no contact with a GP either in person or over the phone in their final three months of life.²
- 2.3.3. Of every emergency department attendance in Wales, one in 14 is related to someone in the last year of life.³
- 2.3.4. In 2023, on average, over a fifth of hospital beds in Wales were occupied every day by people in the last year of life.⁴
- 2.4. It is in this context that women with terminal gynaecological cancer will be seeking care and support.

3. Recommendation 25: The Welsh Government should work with health boards and relevant stakeholders to ensure the benefits of palliative care are promoted to patients, general practitioners and clinicians in acute hospital settings to address the misconception that palliative care is only for the very end of life

- 3.1. The current data landscape makes it very difficult, if not impossible, for organisations such as ourselves to determine whether women with terminal gynaecological cancer are being referred to palliative care at the appropriate time, whether women are accessing palliative care services and whether those services are meeting women's needs.
- 3.2. Without regular, publicly available data it is very difficult to determine whether the ambitions of the quality statement are being realised, particularly in relation to specific groups of people.
- 3.3. As the service specification for palliative and end of life care has been developed, we have made clear the need for KPIs underpinned by robust monitoring. The specification is due to be published in October 2025 and we hope that this will include the necessary KPIs and routine monitoring that is essential to the successful implementation of the quality statement.

¹ Marie Curie (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'*

² Ibid.

³ Marie Curie (2025) *At breaking point: Time to transform end of life care in Wales*
<https://www.mariecurie.org.uk/get-involved/campaigns/senedd-manifesto>

⁴ Ibid.

4. Recommendation 26: In its response to this report, the Welsh Government should provide an update on the progress it has made in implementing the quality statement for palliative and end of life care, and specifically how it is ensuring access to palliative care is underpinned by equity

4.1. In the formal response to the Committee's report the Welsh Government provided a short update on how the quality statement for palliative and end of life care is being implemented. A more substantive written statement was laid in October 2024 on improving access to palliative and end of life care.⁵ While this was not in direct response to the committee's report, it did provide an important update on progress and ministerial priorities.

4.2. The written statement addressed a number of key issues:

4.2.1. **Funding:** additional funding from Welsh Government to support hospice services is very welcome, including the annual £3m allocated from the 2025-26 budget onwards. The statement referenced an ongoing commitment to find a sustainable funding settlement, including a commissioning framework for Wales. Progress on the commissioning framework has been slow, with it now due for publication by end of March 2026. While commitments have been made to keep hospice providers up to date with the latest iteration of the framework as it's finalised over the autumn, the delay does create challenges as hospices look to set budgets and make operational decisions ahead of the 2026-27 financial year.

The statement also made reference to Further Faster as the vehicle through which out of hours capacity of district nursing and community clinical nurse specialists would be increased. It is not clear what impact Further Faster has had on the delivery of out of hours palliative care. Improving access to primary care, especially out of hours, overnight and at weekends remains a critical issue, which could reduce avoidable hospital admissions for people living with a terminal illness.

4.2.2. **Role of the national palliative and end of life care programme:** the national programme does provide important leadership on

⁵ <https://www.gov.wales/written-statement-improving-access-palliative-and-end-life-care> [Accessed Sept. 2025]

palliative and end of life care and we have enjoyed a constructive working relationship with the board. Recent changes, including the transition from NHS Wales Executive to NHS Wales Performance and Improvement, have impacted on how regularly the programme board has met in 2025-26. Moving into the autumn, it will be important to get back to regular meetings so that stakeholder advisory groups can be fully engaged in the work of the national programme.

4.2.3. **Service specification for palliative and end of life care:** the written statement notes the development of a service specification for palliative and end of life care. This is a critical element of the strategic framework for palliative care, which should support more effective and consistent delivery towards achieving the ambitions of the quality statement for palliative and end of life care. Progress on this service specification has been slow, although we do welcome the ongoing consultation and engagement by the national programme throughout the development process. The service specification is now due for publication in October 2025. Usability will be critically important to ensure that all parts of the health and social care system understand the expectations for palliative and end of life care delivery.

4.2.4. **Workforce:** the written statement notes an ambition to recruit and retain a motivated and skilled palliative and end of life care workforce and the development of a core competency framework. We welcome the development of the competency framework.

If we are to deliver equitable palliative and end of life care we must recognise that people living with a terminal illness get care and support from across the health and social care system, not just specialist palliative care teams. It's therefore imperative that the skills, knowledge and capacity for supporting people with a terminal illness are strengthened throughout the health and social care system. The core competency framework can play a key role in achieving this but must be accessible to all health and social care professionals and be supported with realistic implementation plans and investment, to not only provide newly qualified professionals with the relevant skills but also to upskill the existing workforce.

We still lack a clear picture of the palliative and end of life care workforce in Wales. This is why we have called for a regular palliative and end of life care workforce census to ensure we have an accurate picture to inform workforce planning and development.⁶

4.2.5. **Data:** as outlined above, data remains a critical challenge. It's currently very difficult to get an accurate picture as to whether people are accessing the care they need. This is even more acute when looking to apply an equity lens. We must urgently improve the availability of data so that organisations involved in the delivery of palliative and end of life care can clearly understand the gaps and opportunities at both health board and national level. This is also a critical challenge to overcome if the service specification is to be underpinned by reliable, measurable KPIs.

4.2.6. **Equity:** in terms of equity there is still much to be done. It is near impossible to assess whether current services are reaching people equitably with the available data. This is why we have called for a review to determine whether services are meeting the needs of minoritised and disadvantaged groups.⁷

It's imperative that the forthcoming service specification addresses equity, however the draft that was consulted upon earlier this year needed further work to do this effectively. While high level aspirations were set out this did not translate into tangible actions for health boards, commissioning bodies and providers. We hope this will be addressed in the final version due for publication in October 2025.

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⁶ Marie Curie (2025) *At breaking point: Time to transform end of life care in Wales*

⁷ Ibid.