

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [dyfodol ymarfer cyffredinol yng Nghymru](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [the future of general practice in Wales](#)

GP19: Ymateb gan: | Response from: Marie Curie



The future of general practice in Wales

Marie Curie response to the Senedd Health and Social Care Committee

March 2025

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 delivered by a complex mix of generalist and specialist services across the health and social care system. Out-of-hours and community support is vital in enabling people living with a terminal illness to remain at home, if that is their preference, and reducing pressure on other parts of the NHS.

General practice has a critical role to play in supporting people closer to home. This response focuses on how this role can be strengthened as part of broader delivery of palliative and end of life care, addressing issues including workforce planning, training and continuing professional development, the multidisciplinary team and equitable access to care.

2. Key messages

- 2.1. Demand for palliative and end of life care is growing. By the 2040s, 37,000 people in Wales will likely need palliative and end of life care each year.¹ Research shows that too many people are currently unable to access the care they need, when they need it, and that spending on palliative and end of life care is disproportionately distributed towards hospital care.²

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*

² Ibid / Marie Curie (2025) *Public expenditure in the last year of life – Policy briefing February 2025*

- 2.2. To deliver care that better meets people's needs and preferences we need to see greater investment in palliative and end of life care in the community. General practice is integral to this shift.
- 2.3. Swift identification of palliative and end of life care needs, including the addition of patients to the palliative and end of life care register, is essential to getting people the right care and support at the right time.
- 2.4. General practice can also play an important role in care coordination, through effective multi-disciplinary team working and embedding palliative and end of life care skills and expertise within primary care teams.

3. Palliative and end of life care in the community

- 3.1. Palliative and end of life care is a critical part of the health and social care system. When we get it right, it can have a profound impact on people living with a terminal illness and those close to them.
- 3.2. However, research shows that too many people are unable to access the care and support they need, when they need it. A post-bereavement survey carried out in Wales in 2022 found that³:
 - More than one in three people were severely or overwhelmingly affected by pain (36%) and breathlessness (40%) in their final week of life.
 - One in nine people who died in hospital had been there less than 24 hours, suggesting an emergency admission.
 - 48% of people had used an ambulance and 45% had visited an A&E in their final three months.
 - One in four people who died either probably or definitely did not know they might die because of their illness.
- 3.3. These figures highlight fundamental challenges within our current system. Conversations about death and dying are not happening consistently, which will mean care preferences are unlikely to be being discussed either. Gaps in community provision are leading to high emergency care use at end of life.
- 3.4. Demand for palliative and end of life care is growing, with 37,000 people a year likely to need care by the 2040s in Wales.⁴ If the system is unable to cope now, it has little chance of responding to this future need.
- 3.5. A shift towards primary and community care is essential to better meet people's needs and preferences at the end of life. It can also ease pressure on other parts of the NHS. However, recent analysis by the Nuffield Trust estimates that across the UK, five times as much is spent on supporting people in the final year of life as

³ Marie Curie (2024) *Better End of Life 2024: Time to Care in Wales*

⁴ Marie Curie (2024) *Time to care in Wales*

hospital inpatients, compared to supporting them with primary care, community health and hospice care.⁵

- 3.6. If we are to move more palliative and end of life care into the community, where appropriate, general practice will have a critical role to play. "GPs have an important role in identifying those in need of palliative care, providing them individualised medical management, liaising with specialist teams and families and supporting carers before and after death."⁶
- 3.7. If general practice is to fulfil this role, action is needed to bolster both capacity and expertise in relation to palliative and end of life care.

4. Identification of people with a palliative care need

- 4.1. The Welsh Government's quality statement for palliative and end of life care notes that "all efforts will be made to recognise dying in a timely manner and communicate this to those close to the person." Early identification of palliative care needs is recognised as best practice and being integral to supporting advanced care planning and ensure effective care coordination.⁷
- 4.2. NICE quality standard [QS13] includes identification of adults who are likely to be approaching the end of life using a systematic approach. It states that "*Using a systematic approach enables healthcare professionals to identify adults who are likely to be approaching the end of their life in a timely manner. Once recognised as approaching the end of their life, people can have their needs assessed and managed, and their carers and the people important to them can also be offered support. Timely recognition gives people the opportunity to make informed decisions about their care, make plans for their future and establish their preferences for how and where they would like to be cared for and die.*"⁸
- 4.3. **There is an important role for GPs in identifying people with a palliative care need and ensuring that they are added to palliative care registers to support the multidisciplinary team to respond to people's needs.**
- 4.4. The Royal College of General Practitioners (RCGP) notes that around 1% of people on a GP list will be coming towards the end of their life.⁹ As at 1st April 2024, 0.3% of patients in Wales were recorded on palliative care registers; this ranged from 0.2%

⁵ Marie Curie (2025) *Public expenditure at the end of life*

⁶ R. Jones, J. Dale and J. MacArtney (2023) "Challenges experienced by GPs when providing palliative care in the UK: a systematic qualitative literature review" *BJGP Open*, 2023;7 (2)

⁷ NHS England (2023) *Specialist palliative and end of life care services Adult service specification* / I. Leach, C. R. Mayland, N. Turner and S. Mitchell (2023) "Understanding patient views and experiences of the IDENTification of PALLiative care needs (IDENTI-PALL): a qualitative interview study" *British Journal of General Practice* 2024; 74 (739)

⁸ NICE "End of life care for adults" <https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-1-Identification> [Accessed 06.03.25]

⁹ <https://www.rcgp.org.uk/your-career/gp-extended-roles/palliative-care-in-general-practice> [Accessed 24/02/25]

to 0.5% across health board areas.¹⁰ This suggests up to two thirds of people who should be included on palliative care registers may not be.

- 4.5. The Welsh Government has previously required GPs to have regular (at least 2 monthly) multi-disciplinary case review meetings where all patients on the palliative care register are discussed."¹¹ The current Unified Contract Assurance Framework does not include a similar requirement to identify, register and discuss patients with a palliative and end of life care need.¹²
- 4.6. In a statement in January 2025, the Cabinet Secretary for Health and Social Care stated that going forward there would be a contractual requirement for GPs to proactively identify and record people who are living with severe or moderate frailty using an evidence-based tool.¹³ **Welsh Ministers should make it a contractual requirement for GPs to identify people with palliative care needs and add them to the palliative care register.**
- 4.7. Studies have found that some GPs feel they lack sufficient training in palliative care, which can result in challenges defining palliative and end of life care and the initial identification of a patient as having palliative care needs, especially in non-malignant conditions.¹⁴ Staff shortages were also identified as affecting decisions about when to include people on palliative care registers, as it was thought to be of little purpose if resources were not available to provide the necessary care.¹⁵
- 4.8. Identification of palliative care needs is a necessary foundation for discussions about care preferences and advance care planning. Advance care planning enables people living with a terminal illness to have conversations with their healthcare team to make decisions about the care they would like in the future.
- 4.9. As outlined above, with a significant minority of people potentially dying without knowledge that their illness could lead to their death, it is likely that advance care planning discussions are not taking place. Even when advance care plans are in place, they are not always accessible to all medical professionals involved in a person's care. **As the all-patient digital care record rolls out across Wales, it's**

¹⁰ <https://www.gov.wales/general-practice-disease-registers-interactive-dashboard> [Accessed 24/02/25]

¹¹ Welsh Government (2021) *Quality assurance and improvement framework 2021/22*

<https://www.gov.wales/sites/default/files/publications/2022-02/quality-assurance-and-improvement-framework-2021-2022.pdf>

¹² Welsh Government (2023) *Unified Contract Assurance Framework: Guidance for Health Boards and Practices* https://www.gov.wales/sites/default/files/publications/2023-10/unified-contract-assurance-framework_0.pdf

¹³ "Written Statement: General Medical Services Contract Reform for 2024-25"

<https://www.gov.wales/written-statement-general-medical-services-contract-reform-2024-25> [Accessed 06.03.25]

¹⁴ R. Jones et. al (2023) "Challenges experienced by GPs when providing palliative care in the UK: a systematic qualitative literature review"

¹⁵ Ibid.

imperative that this includes the recording of advance care plans and preferences and that this record is accessible to all health professionals.

5. Effective coordination of palliative and end of life care

- 5.1. Primary care services are increasingly shifting to multidisciplinary working to draw upon the skills and experience of a wide range of health professionals and “to connect people to the specialists they need faster.”¹⁶
- 5.2. As outlined above, people will access palliative and end of life care from a range of health and social care services. The proper management of physical, emotional and spiritual needs “requires effective and collaborative multidisciplinary working within and between core and specialist teams, whether the person is at home, in hospital or elsewhere.”¹⁷ Research has found that multidisciplinary team working can be of particular importance when supporting vulnerable groups at end of life, such as those with a severe mental illness or those experiencing homelessness.¹⁸
- 5.3. Studies have found that disjointed multidisciplinary teams and communication issues between services can result in inconsistent care for people living with a terminal illness.¹⁹ “A lack of clarity about the GP’s role in palliative care, difficulty accessing or integration with specialist palliative care and a lack of support from those teams were contributory factors.”²⁰ Poor communication between services and inadequate handover from secondary services at patient discharge further exacerbate issues in care coordination.²¹
- 5.4. Conversely, studies found that regular in-house multidisciplinary team discussion of palliative care cases and exploration of community resources can generate a supportive environment for GPs.²²

5.5. To support better coordination of palliative and end of life care in the community we need to embed palliative and end of life care expertise within general practice and the primary care multidisciplinary team by:

5.5.1. Placing a palliative and end of life care nurse within each primary care cluster to provide expert advice and guidance, and support coordination across services.

¹⁶ National Voices (2023) *A shift to multidisciplinary teams in general practice: What this means for people experiencing health inequalities and frequent users of primary care services*

¹⁷ NHS England (2023) *Specialist palliative and end of life care services Adult service specification*

¹⁸ D. Edwards, S. Antsey, B. Hannigan (2021) “End of life care for people with severe mental illness: Mixed methods systematic reviews and thematic synthesis (the MENLOC study)” *Palliative Medicine* Vol. 35 (10) / M. R. Coverdale and F. Murtagh (2024) “Destitute and dying: interventions and models of palliative and end of life care for homeless adults – a systematic review” *British Medical Journal* Vol. 14 Issues e3

¹⁹ R. Jones et. al (2023) “Challenges experienced by GPs when providing palliative care in the UK: a systematic qualitative literature review”

²⁰ Ibid.

²¹ Ibid.

²² Ibid.

5.5.2. Ensuring that the forthcoming core competency framework for palliative and end of life care includes a plan for upskilling and training the existing workforce.

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