Marie Curie
CYMRU

Unmet palliative care need in Wales

Policy briefing

February 2026

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The briefing draws on research conducted as part of the *DUECare Project: Defining and Estimating Unmet Palliative Care Needs in the UK, funded by Marie Curie. The research was co-led by Dr Anna Bone and Professor Fliss Murtagh and carried out in partnership by the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, and the Wolfson Palliative Care Research Centre, Hull York Medical School, with contributions from the Clinical Psychology, School of Health in Social Science, University of Edinburgh.**

1. Introduction

PALLIATIVE and end of life care is a critical part of our 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.

But end of life care is at breaking point. Gaps in provision and a system under severe pressure means too many people are left without the care and support they need.

This briefing draws on new research which has sought to measure this unmet need for palliative and end of life care. It sets out how many people in Wales are likely to be without the palliative care they need now, and estimates how this situation is likely to change in the future.

In the face of growing demand for palliative care we cannot afford to waste time getting this right. People living with a terminal illness and those close to them deserve better.

2. What is unmet palliative care need?

THE figures presented in this briefing are based on the following definition of unmet need for palliative care:

> **Unmet palliative care needs are present when a person with life-limiting illness has symptoms, psychosocial concerns, or care requirements that are not adequately addressed through available services, with inability to access or receive person-centred care.**

This definition was developed through a review of the literature and workshop discussions with people affected by terminal illness and the health and social care professionals who work with them.[1] Further detail on the methods used to develop this definition are outlined in Appendix A. Methods.

3. Measuring unmet palliative care need

IN order to assess the number and proportion of people with unmet need for palliative care, we have applied the above definition of unmet need to analyse the results of a nationally representative survey of 1,194 bereaved family carers, commissioned by Marie Curie and conducted by the ONS across England and Wales in November 2023.[2]

In analysing this survey, we considered someone to have unmet need for palliative care if they have **both** unaddressed symptoms and concerns, **and** do not receive enough help from GPs.

A more detailed explanation of the methods used are outlined in Appendix A. Methods.

Using the method above it was possible to calculate the number of respondents reporting that their loved ones had unmet palliative care needs in the survey sample, and based on this, to estimate the proportion and number of people with unmet need for palliative care in the wider population.

This has established the most robust available estimate of the number of adults who experience unmet need for palliative care in Wales at population level.

4. Levels of unmet palliative care need in Wales

IN total the findings indicate that **29% of adults in Wales have unmet palliative care needs**. That is equal to 10,246 people who have both unaddressed symptoms and concerns, and who do not receive enough help from GPs at the end of life.

The table opposite breaks this down across the two measures that form our definition of unmet palliative care need.

Table 1: Unmet palliative care need in Wales

Estimation method	Wales (N=35,511)
1. Symptoms and concerns	17,209 (49%)
2. Insufficient primary care provision	15,280 (43%)
3. Unmet need estimate (1 and 2)	10,246 (29%)

Wales has an ageing population and as a result it is likely that palliative care need will also increase in coming years. We estimate that by the 2040s, 37,000 people in Wales will likely need palliative and end of life care each year, an increase of 5,000.[3]

Based on the analysis of unmet need, it is estimated that without additional intervention around 1,500 more people are likely to face unmet palliative care need in 2050, compared to 2025. An increase of 14%.

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5. How are different groups affected by unmet palliative care need?

INEQUALITIES are known to exist in access to, and experiences of, health and social care services, including palliative care.

Drawing on data for both England and Wales our analysis of unmet palliative care need shows variation in levels of unmet need on the basis of diagnosis, age and financial insecurity. People who were 85 or older were less likely to have unmet needs than those in the 65–84 age range. A quarter (25%) of people living comfortably experience unmet need compared to 36% among those ‘just about getting by or finding things difficult’. This means those ‘just about getting by or finding things difficult’ financially faced an increased risk of unmet palliative care need of 45%.[4]

There are many potential factors for these variations that require further research to ensure service providers identify how to improve care.

6. Conclusion

THE figures presented in this briefing bring into stark focus the extent to which our palliative and end of life care system is at breaking point.

Almost 1 in 3 people in Wales are without the care and support they need in their final months of life. This means thousands of people are being left isolated and in pain.

With the demand for palliative care likely to increase and levels of unmet need predicted to grow, urgent action is needed to transform end of life care in Wales.

Marie Curie Cymru has set out a comprehensive programme of policy change in our manifesto *At breaking point: Time to transform end of life care in Wales.*[5] It provides a roadmap for the incoming Welsh Government in 2026 to ensure that services are responsive to people's needs, that palliative care is sustainably funded and to strengthen out of hours and community care so people have 24/7 access to care and support at or close to home.

Our challenge to policymakers, health boards and providers, including ourselves, is to take the radical action needed to fix end of life care and ensure that everyone can access the right care, in the right place, at the right time.

7. Appendix A. Methods

7.1. Defining unmet palliative care need

The research findings presented in this briefing are underpinned by work to develop a shared definition of unmet need, based on a review of the literature and workshop discussions with people affected by terminal illness and the health and care professionals who work with them.

A number of factors that may contribute to unmet need were identified and ranked by workshop participants. The most highly prioritised elements focused on service delivery, quality and access, (for example: lack of timely and holistic assessment of symptoms or suffering, inability to access services needed, and lack of coordination and continuity of care). Other key priorities identified were the lack of recognition of palliative care needs, absence of a single point of contact for support (including out-of-hours care), lack of timely follow up to address symptoms and concerns, insufficient skilled and competent care, and not being treated with respect, dignity, and empathy. Lack of timely and holistic assessment of symptoms or suffering received the highest total score, and inability to access services needed was the item most frequently appearing in the top 10 (74%).

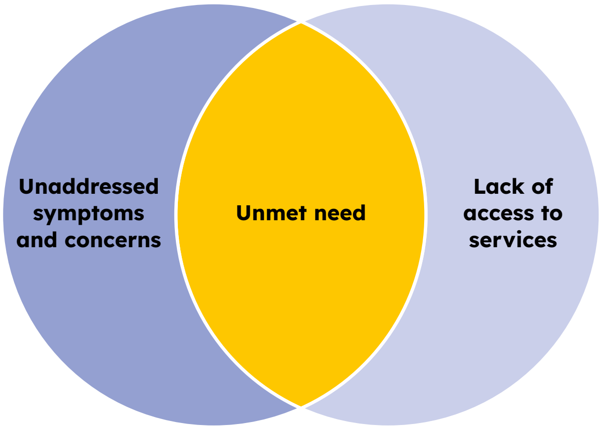
Based on these findings, the research established the following short definition for unmet need for palliative care:

> **Unmet palliative care needs are present when a person with life-limiting illness has symptoms, psychosocial concerns, or care requirements that are not adequately addressed through available services, with inability to access or receive person-centred care.**

7.2. Measuring unmet palliative care need

The figures in this briefing are based on analysis of a nationally representative survey of 1,194 bereaved family carers, commissioned by Marie Curie and conducted by the ONS across England and Wales in November 2023.

In analysing this survey we considered someone to have unmet need for palliative care if they have **both** unaddressed symptoms and concerns, **and** do not receive enough help from GPs at the end of life.



Unaddressed symptoms and concerns

The first element is based on the proportion of people with unaddressed symptoms (physical and psychological) and concerns in the last week of life using the Integrated Palliative Care Outcome Scale (IPOS). IPOS is an internationally used assessment tool that enables patients to self-report their experience of common symptoms and issues. (A proxy version is available when patients are unable to answer questions themselves).

For the purposes of this research someone is considered to have “unaddressed symptoms and concerns” if bereaved former carers reported that they had more than half the maximum possible total score across all 17 IPOS items (≥34 out of 68) in their final week of life.

Lack of access to services

The second element is based on the proportion of people lacking access to services from primary care to resolve symptoms and concerns.

For the purposes of this research inadequate access to basic primary care services was estimated based on bereaved former carers’ responses to the survey question “In the last three months before they died, overall, do you feel they got as much help as needed from GPs?”

Endnotes

1. A. E. Bone, M. Diggle, T. Johansson, A. Finucane, K. E. Sleeman, J. M. Davies, I. J. Higginson, L. K. Fraser and F. E. Murtagh (2025) “Coproducing a conceptual understanding of unmet palliative care needs: stakeholder workshops using modified nominal group technique” BMC Palliative Care https://link.springer.com/article/10.1186/s12904-025-01971-4
2. Survey completed as part of the Better End of Life project (mariecurie.org.uk/research-and-policy/policy/better-end-life-report). NB: There is a small variation in the reported number of respondents between the *Better End of Life* report and this study. The *Better End of Life* report included survey data to September 2023 with a total of 1,179 respondents. The analysis undertaken for the DUECare project, on which this briefing is based, included data from respondents up to November 2023 with a total of 1,194.
3. Marie Curie analysis cited in *At breaking point: Time to transform end of life care in Wales*
4. Marie Curie calculations based on data from the *DUECare Project: Defining and Estimating Unmet Palliative Care Needs in the UK*
5. mariecurie.org.uk/get-involved/campaigns/senedd-manifesto

* This briefing draws on the following: *Defining and measuring unmet palliative care needs* https://pubmed.ncbi.nlm.nih.gov/41652311/, *Coproducing a conceptual understanding of unmet palliative care needs* https://pubmed.ncbi.nlm.nih.gov/41437023/ and *Unmet palliative care needs in England and Wales: population-based estimates and future projections (2025-2050)*