

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Cyllid](#) ar [Cyllideb Ddrafft Llywodraeth Cymru 2025-26](#).

This response was submitted to the [Finance Committee](#) consultation on the [Welsh Government Draft Budget 2025-26](#).

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Welsh Government Draft Budget 2025-26

Marie Curie response to the Senedd Finance Committee Inquiry

November 2024

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.

2. Key messages

- 2.1. Research shows that there is currently a significant implementation gap between the ambitions set out in the *Quality Statement for Palliative and End of Life Care* and the experiences of many people across Wales.¹ The Quality Statement should inform priorities and the allocation of resources if it is to drive meaningful change and ensure that people can access the care and support they need, when and where they need it.
- 2.2. The changes to employer National Insurance Contributions (NICs) announced as part of the UK Government's Autumn Budget risk making a challenging financial situation even worse. The changes announced are likely to cost Marie Curie around £3m across the UK, and almost £260,000 in Wales alone. If mitigating action is not taken, and funding levels for commissioned services remain flat, this will place even greater financial pressure on the charity and could result in a reduction in services. If an exemption is not applied by the UK Treasury for third sector providers, the Welsh Government will need to take action to protect vital services.
- 2.3. Investment in palliative care, including the resourcing of palliative and end of life care in the community, should be considered essential preventative spending. Early provision of palliative care is linked with improved quality of life, reduction in

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*

interventions of low benefit, and significant reductions in hospital admissions². Learnings from the implementation of 'Further Faster' and other initiatives should be shared and recurrent, ring-fenced funding put in place to support community palliative and end of life care capacity.

- 2.4. Terminally ill people are at a higher risk of experiencing poverty and fuel poverty. Too many people are left unable to make the most of the time they have left because of spiralling bills and constant worries about how to make ends meet. Terminally ill people should be able to access existing tackling poverty schemes such as the Warm Homes Programme and additional targeted support should be introduced. Schemes to maximise people's incomes, such as 'Claim What's Yours' should be evaluated, and if proven successful should be made permanent alongside pro-active steps to ensure terminally ill people claim all benefits they are entitled to.

3. Is the support provided by the Welsh Government for third sector organisations, which face increased demand for services as a consequence of the cost-of-living crisis and the pandemic, sufficient?

- 3.1. The Welsh Government has set out in its *Quality Statement for Palliative and End of Life Care* the ambitions for palliative care in Wales and made a commitment in the Programme for Government to review hospice funding. The third sector is an essential partner in making these ambitions a reality, delivering care to terminally ill people in hospices and in the community, often in people's own homes.
- 3.2. Demand for palliative and end of life care is likely to grow. If current trends continue approximately 37,000 people will die with palliative care needs in Wales each year by the 2040s.³
- 3.3. Third sector providers of palliative and end of life care continue to face substantial financial pressures against this backdrop of growing demand for services. The 16 charitable hospices operating in Wales are forecasting a combined deficit in 2024-25 totalling £9.5m.⁴ These financial pressures are likely to result in fewer inpatient beds or reduced hospice services.
- 3.4. In addition, the changes to employer National Insurance Contributions (NICs) announced as part of the UK Government's Autumn Budget risk making a challenging financial situation even worse. The changes announced are likely to cost Marie Curie around £3m across the UK, and almost £260,000 in Wales alone. If mitigating action is not taken, and funding levels for commissioned services remain flat, this will place even greater financial pressure on the charity and could result in a reduction in services.

² Murray SE et al. (2017) Palliative care from diagnosis to death. *BMJ* 2017;356:j878 doi: 10.1136/bmj.j878.

³ 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*

⁴ Figures sourced from Hospices Cymru

- 3.5. **If an exemption is not applied to charitable providers of palliative and end of life care by the UK Treasury, Welsh Government will need to take action to protect vital PEOLC services. Additional funding to the sector, either via commissioning bodies or a direct payment will be essential. A direct payment would ensure that this much needed financial support gets to providers as a matter of urgency, and would avoid the potential issue of uplifts not being passed on by commissioning bodies.**
- 3.6. In April 2024, much needed additional funding was provided to Welsh hospices to help maintain services, meet staffing costs and improve the quality of end-of-life care.⁵ However, this does not diminish the need for a long-term, sustainable funding solution. The sector is increasingly reliant upon fundraising and charitable donations to deliver critically important care to terminally ill people.
- 3.7. **There remains an urgent need for a sustainable commissioning arrangement and funding settlement for Welsh hospices that applies consistent and sustainable contracting arrangements with all Health Boards. This should be coupled with a data-driven, holistic process for assessing population need and experiences of palliative and end of life care to enable a more joined-up approach to commissioning.**⁶
- 3.8. In the short-term, action is also required to ensure that third sector providers of palliative and end of life care can recruit and retain specialist staff. While some Health Boards pass on Agenda for Change uplifts to third sector providers, this is not the case in all parts of Wales. **The Welsh Government should make a financial contribution to ensure that a fair salary offer is made to palliative and end of life care staff throughout Wales, equivalent to Agenda for Change increases, and commit to ongoing equivalent funding uplifts resulting from NHS pay negotiations.**

4. Is the Welsh Government's approach to preventative spending represented in resource allocations?

- 4.1. One in 14 of every Emergency Department attendance in Wales is in relation to someone who is in the last year of life, with too many cases of unnecessary admissions.⁷ Our 2024 research found that one in nine people who died in hospital had been there less than 24 hours, and that emergency care use was high among people in their last three months of life with 48% using an ambulance and 45% visiting an A&E.⁸

⁵ <https://www.gov.wales/vital-funding-support-welsh-hospices> [Accessed 16/10/2024]

⁶ Marie Curie (2024) *Time to Care in Wales*

⁷ Analysis based on Marie Curie (2022) *Better End of Life Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers* and figures from StatsWales <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/emergency-department/emergencyattendances-by-age-sex-site>

⁸ Marie Curie (2024) *Time to Care in Wales*

- 4.2. Accessible and effectively resourced care services not only support the wellbeing of patients and their carers, but also prevent avoidable hospital admission at the end of life.⁹
- 4.3. A narrow definition of preventative spending fails to consider how quality palliative and end of life care, delivered in the right place at the right time, can improve quality of life, reduce interventions of low benefit and reduce hospital admissions.¹⁰
- 4.4. In June 2023, the then Minister for Health and Social Services announced that an additional £30m would be put into supporting enhanced care in communities.¹¹ This would support a number of investments including strengthening community specialist palliative care. The Minister also noted the need for making specialist nurses available overnight to better support people to die in the place of their choosing and avoid an unnecessary hospital admission. **An update on this investment and the impact it has had is needed, to enable lessons to be shared. Additionally, a commitment is needed to ongoing, ring-fenced funding to support community palliative and end of life care capacity into the future and meet the objectives of the ‘Further Faster’ Statement of Intent.**¹²
- 4.5. To understand whether investments are delivering the desired change there is an urgent need to put a **monitoring framework in place that underpins the Quality Statement on Palliative and End of Life Care to understand what works, what doesn’t and where change is needed.**

5. Is enough being done to tackle the rising costs of living and support those people living in relative income poverty? What action should the Welsh Government take to help households cope with inflation and cost of living issues?

- 5.1. Recent Marie Curie research has shown that terminally ill people are at a higher risk of experiencing poverty and fuel poverty. In 2023 17% of those who died in Wales, died in poverty.¹³ 17% of pensioners in their last year of life were in poverty, compared to 15% of those not in last year of life; and 30% of working age people in their last year of life were in poverty compared to 24% of those not in last year of life.¹⁴
- 5.2. Working-age people are at particularly high risk of poverty in their last year of life. This difference can be further exacerbated by inequities in our social security system, which currently provides lower levels of financial support for working-age people compared to pensioners; for example pension credit ensures a minimum

⁹ Ibid.

¹⁰ Murray, SE et. Al “Palliative care from diagnosis to death”

¹¹ <https://record.senedd.wales/Plenary/13377#C508563> [Accessed 16/10/2024]

¹² <https://www.gov.wales/sites/default/files/publications/2023-06/building-capacity-through-community-care-further-faster.pdf> [Accessed 16/10/2024]

¹³ Marie Curie (2024) *Dying in Poverty in Wales 2024*

¹⁴ Ibid.

weekly income of £218.15 for single person households, while Universal Credit provides £393.34 **per month** for a single person over 25.¹⁵

- 5.3. In 2022, one fifth of people in their last year of life in Wales were in fuel poverty.¹⁶ A terminally ill person's energy bill can rise by 75% after their diagnosis.¹⁷ This can be in relation to needing to run medical devices, needing to maintain a particular body temperature or simply spending more time at home. The cost of running an oxygen concentrator can be £65 per month, a dialysis machine £27 per month and a ventilator £35 per month.¹⁸
- 5.4. While not all levers for tackling poverty are available to the Welsh Government, there are steps that can be taken to better support terminally ill people and reduce the number of people dying in poverty. Welsh administered benefits can and should be used to prevent terminally ill people from reaching financial crisis point as well as ensuring that crisis support meets their needs.
- 5.5. The Welsh Government has focused on maximising people's incomes as a means of tackling poverty, making sure that people claim all of the financial support they are entitled to. **Schemes to maximise people's incomes, such as 'Claim What's Yours' should be evaluated, and if proven successful should be made permanent alongside pro-active steps to ensure terminally ill people claim all benefits they are entitled to.**
- 5.6. The Warm Homes Programme remains the main vehicle through which the Welsh Government are seeking to reduce fuel poverty. **Marie Curie has long called for terminal illness to be included in the primary eligibility criteria for the Warm Homes Programme.** While it may not be the right intervention for all terminally ill people, it would open up an additional avenue of support for a group that are at a higher risk of fuel poverty.
- 5.7. This change alone however, would not reach all terminally people who are at risk of fuel poverty. The Welsh Government should therefore also focus on how the Welsh benefits system can plug evidenced gaps and better support vulnerable groups, including terminally ill people. **Marie Curie is calling on the Welsh Government to increase financial support for terminally ill people to help with energy costs.** This could be done in a number of different ways, one of which would be plugging the gaps in the Winter Fuel Payment, extending support to working-age people with a terminal illness and to pension-age people with a terminal illness who are on a low income but are not eligible for pension credit.

¹⁵ <https://www.gov.uk/government/news/pension-credit-what-you-need-to-know--2> / <https://www.gov.uk/universal-credit/what-youll-get> [Accessed 07/10/24]

¹⁶ Ibid.

¹⁷ Marie Curie (2023) *One charge too many: The impact of rising energy costs on people at the end of life* <https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/k406-povertyenergyreport-finalversion.pdf> [Accessed 25/09/24]

¹⁸ Ibid.

5.8. **Marie Curie is also calling on the Welsh Government to include terminally ill people in the new Council Tax Reduction Scheme.** Council Tax is the biggest fixed cost that most households have after housing.¹⁹ Work should begin on designing the new national regulations for the CTRS as soon as possible, with reductions applied for terminally ill people. Based on average Band D council tax in 2024-25 this could save households up to £168 per month.

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¹⁹ Citizen's Advice (2022) *Indebted: Experiences of council tax arrears in Wales*
<https://www.citizensadvice.org.uk/Global/CitizensAdvice/Wales/Wales%20Policy%20and%20Campaigns/Indebted%20Experiences%20of%20council%20tax%20arrears%20in%20Wales.pdf> [Accessed 26.09.24]