

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Cyllid](#) ar [Cyllideb Ddrafft Llywodraeth Cymru 2024-25](#).

This response was submitted to the [Finance Committee](#) consultation on the [Welsh Government Draft Budget 2024-25](#).

WGDB_24-25 35: Ymateb gan: Marie Curie | Response from: Marie Curie



Marie Curie submission to the Finance Committee

Welsh Government Draft Budget proposals 2024-25

November 2023

Introduction

Marie Curie is the UK's palliative and end of life care charity. We work hard to enable people who are dying, 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, in their own homes, and in our Cardiff and the Vale Hospice. Our free information and support service, based in Pencoed, also gives expert care, guidance and support to families with any matters relating to dying, death and bereavement. We are the largest charitable funder of palliative and end of life care research in the UK and our Wales Policy and Research team work inside and outside of the Senedd for the changes that are needed to ensure more people in Wales have the best possible end of life experience.

Key messages

1. To ensure that third sector providers can continue to provide essential day-to-day care to thousands of people living with terminal illnesses and their families across Wales, the Welsh Government should provide funding and direct commissioners to apply annual inflationary uplifts to year on year contracts and provide pay awards which align with NHS salaries (e.g. Agenda for Change). Hospices UK alongside Hospices Cymru has calculated that financial support of £4m is required to meet the significant increases that hospices are facing for increased salaries of core and support staff delivering palliative care.
2. To address the impact of cost of living pressures and poverty, the Welsh Government should seek to use the levers at its disposal to ensure that the most vulnerable in society have access to basic facilities, such as a sufficiently warm home and the ability to power essential medical devices. For example, extending the health eligibility criteria for the new Warm Homes Programme to include terminal illness (i.e., people who have less than 12 months to live) would bring the scheme in line with UK legislation that makes it easier for people with a terminal illness to access benefits, and would provide a clearer offer of support to individuals

who are some of the most vulnerable to the health and wellbeing effects of living in cold and damp housing.

3. Investment in palliative care, including the resourcing of palliative and end of life care within the community, should be considered essential preventative spending. Early provision of palliative care is linked with improved quality of life, reduction in interventions of low benefit, and significant reductions in hospital admissions¹. Providing clearer ringfenced budget allocations to increase capacity within community palliative and end of life care would ensure that investments made available to health boards for this purpose would be implemented as intended, and would reflect the Welsh Government's commitment to focus on end of life care set out in the Programme for Government.

Detailed response

1. What, in your opinion, has been the impact of the Welsh Government's 2023-2024 Budget, including funding related to the recovery of the pandemic? Have Welsh Government business support policies been effective, given the economic outlook for 2024-25?

- 1.1. Palliative and end of life care (PEoLC) continues to face challenges as part of the recovery from the pandemic. The pandemic brought about major shifts in place of care and place of death, with more people dying at home and in the community². This presented challenges for both the public and third sectors in the delivery of PEoLC and provided a stress test for future care provision, with deaths in the community projected to increase significantly in the coming years³.
- 1.2. Marie Curie, along with other third sector providers, are facing increasingly difficult financial constraints, due to rising staff and energy costs, workforce pressures, and increasing demand for complex care. According to Hospices Cymru data, charitable hospices provide essential care to more than 20,000 people affected by terminal illness across Wales each year, yet nearly all (90%) of Welsh hospices are budgeting for a deficit in 2023/24. Many providers are already making or considering cuts to services and drawing extensively on limited reserves to meet the shortfall.
- 1.3. While the Welsh Government has committed to moving more care into the community, which is highlighted in the 2023-24 budget, there continues to be challenges in delivering this as it applies to PEoLC. The third sector is a vital delivery partner in this, supporting people who are dying to stay in their own homes or in community-based hospices, reducing hospital admissions, and having a far-reaching impact on people's lives and the wider healthcare system.
- 1.4. Considering government's ambitions to shift care into the community, the Further Faster review and the Programme for Government commitments to review end of life care and hospice funding, it is disappointing that neither PEoLC nor hospices are mentioned in the overall narrative of the 2023-24 budget or Ministers' written evidence to Senedd scrutiny committees.

¹ Murray SE et al. (2017) Palliative care from diagnosis to death. *BMJ* 2017;356:j878 doi: 10.1136/bmj.j878.

² Marie Curie (2022) Fairer Care at Home - The covid-19 pandemic: a stress test for palliative and end of life care in Wales

³ Bone AE, Gomes B, et al. (2017) What is the impact of population on the future provision of end of life care? Population-based projections of place of death. *Palliative Medicine*. 2018;32(2):329-336.

- 1.5. To ensure that third sector providers can continue to provide essential day-to-day care to thousands of people living with terminal illness and their families across Wales, commissioners should apply annual inflationary uplifts to year-on-year contracts and provide pay awards which align with salaries for statutory partners (e.g. Agenda for Change). The pandemic placed huge pressures on frontline staff delivering PEOLC in all settings, including hospices and in the community. Fair remuneration is vital to future staff recruitment and retention.
- 1.6. Welsh Government should make a financial contribution to ensure a fair salary offer for the hospice workforce, equivalent to Agenda for Change increases, so there is parity with NHS colleagues. This must include a commitment to ongoing equivalent funding uplifts resulting from current and future NHS pay negotiations. Hospices Cymru has calculated that financial support of £4m is required to meet the significant increases that hospices are facing for increased salaries of core and support staff delivering palliative care⁴.
- 1.7. Demand for palliative care and the complexity of need is increasing as our population ages, with significant implications for health and social care services. In 2019, prior to the pandemic, the number of people dying with palliative care needs in Wales was approximately 29,000 per year; by 2048, this is projected to reach 37,000^{5 6}. However, a substantial shift towards deaths in the community is projected in the coming decades. Pre-pandemic research forecast that care homes would be the most common place of death by 2040⁷.
- 1.8. Responding to these changes requires both Welsh Government and third sector providers to work together to ensure the sustainability and provision of services. Over the coming year, Welsh Government should work in collaboration with the PEOLC National Programme Board and sector partners to ensure that its Programme for Government commitment to review hospice funding delivers a sustainable national funding formula, a workforce plan, and a palliative and end of life care service specification.
- 1.9. While the lack of specific reference to PEOLC in the budget is disappointing, we do welcome action that the Welsh Government has taken to fund health and social care in the context of challenging times to set an annual budget.

2. How should/could the Welsh Government support the economy and business following the pandemic, Brexit and inflationary and other economic pressures?

How financially prepared is your organisation for the 2024-25 financial year, how will inflation impact on your ability to deliver planned objectives, and how robust is your ability to plan for future years

- 2.1. A survey of members undertaken by Hospices Cymru and Hospices UK in July 2023 revealed a number of financial challenges facing hospices in Wales.

⁴ Hospices Cymru & Hospice UK, July 2023, Impact of NHS pay awards on hospices in Wales. Calculation based on all Welsh hospices relevant staffing costs. These figures don't take into account 2024-25 Agenda for Change negotiations and appropriate support will be required until a sustainable funding formula is developed.

⁵ Marie Curie (2023) [How many people need palliative care?](#)

⁶ ONS. Death registrations and occurrences by health board and place of death, 2022.

⁷ Bone AE et al. (2018) [What is the impact of population ageing on the future provision of end of life care? Population-based projections of place of death](#). Palliat Med. 32(2):329-336.

- 2.1.1. Nearly all hospices (90%) were budgeting for a deficit in 2023/4 and are drawing on reserves to meet the shortfall with 8 in 10 agreeing that cost of living pressures were highly likely to result in them having to reduce the volume of certain services delivered.
- 2.1.2. Furthermore, 7 in 10 Welsh hospices agreed that cost of living pressures were highly likely to result in reduced support being available to the wider system, such as hospitals and care homes.

3. What action should the Welsh Government take to help households cope with inflation and cost of living issues?

- 3.1. Recent inflationary pressures and the cost of living have had a significant impact on people living with a terminal illness. While many of the levers to tackle inflation and the cost of living sit with the UK Government and Westminster, there is more that the Welsh Government could be doing to support those living with a terminal illness.
 - 3.1.1. The Welsh Government should ensure that people who have a terminal illness can access support from the new Warm Homes programme. There is good evidence that people living with terminal illness are particularly vulnerable to the ill effects of living in cold and poor-quality housing⁸.
 - 3.1.2. Currently eligibility for the new Warm Homes programme only cites⁹ chronic respiratory, circulatory and mental health conditions as conditions which would qualify for the less stringent health condition eligibility criteria. The risk of this approach is that individuals who have a terminal illness such as cancer or motor neurone disease will be unable to qualify for the support they need.
 - 3.1.2.1. Of the more than 36,000 people who died in Wales in 2021, ONS data shows that the number of people dying from diseases that are currently not included in the health condition eligibility criteria was: i) cancer with almost 9,000 deaths, ii) dementia with more than 4,000 deaths, iii) liver disease with nearly 700 deaths, and iv) Parkinson disease, multiple sclerosis and motor neuron disease seeing almost 600 deaths combined.
 - 3.1.2.2. It should be noted that not all these individuals would be eligible for support under the new Warm Homes programme as they may not live in a property with EPC D rating or below or some may live in care homes. Others would not meet the low income criteria. Given the high levels of multimorbidity amongst the end of life population, it is also likely that others would already qualify for support from the scheme because they have another eligible health condition.
 - 3.1.2.3. Therefore, it is unlikely that significant additional numbers of people would access support from the scheme.
 - 3.1.2.4. It is not currently possible to produce a definitive figure for how many additional individuals and properties would be eligible if terminal illness was added to the health eligibility criteria as there is no available data on EPC ratings and those living with terminal illnesses.
 - 3.1.2.5. However, adding terminal illness to the health eligibility criteria would provide clarity and support for people who are approaching the end of life who are struggling with the psychological, health, and financial impacts of living in cold and energy inefficient homes.
 - 3.1.3. Building on initiatives such as the Claim What's Yours campaign, the Welsh Government should work with its NHS partners to ensure that people who have been diagnosed with a terminal illness and their carers are effectively signposted to

⁸ Marie Curie (2020) The vicious cycle of fuel poverty and terminal illness

⁹ Welsh Government (2023) New Warm Homes Programme: policy statement

financial advice and supported to access benefits. There is already an established approach to help people with cancer access the right welfare advice; this should be extended to anyone with a terminal illness and built into the care pathway.

- 3.1.4. The Marie Curie Support Line frequently hears from individuals who are living with or caring for someone with a terminal illness who are struggling to navigate the benefits system and to claim what they are entitled to. The Welsh Government should aim to streamline and reduce the complexity of accessing benefit support, for example, by progressing towards the implementation of a Welsh benefits system¹⁰.
- 3.1.5. The Welsh Government should also review and clarify support for childcare costs for those living with a terminal illness since working age people with dependent children are the most vulnerable to experiencing poverty at the end of life¹¹. While we welcome the Welsh Government's commitment to invest in childcare, the system remains overly complex and challenging for parents to navigate¹².

How should the Budget address the needs of people living in urban, post-industrial and rural communities and in supporting economies within those communities?

- 3.2. Census data shows that rural elderly populations are increasing, but with lower demand and accessibility to specialist healthcare, patients living in rural and remote areas who have an illness they are likely to die from are at significant risk of having unmet care needs towards the end of life.
- 3.3. Marie Curie has been working with Same but Different CIC and Hospice UK to better understand people's experiences of living with terminal illness. This has included interviews with people in mid-Wales. Worryingly, one theme to emerge from the interviews is that some individuals are basing their treatment decisions on whether they feel able to travel to distant appointments¹³.
- 3.4. Delivery of PEOC in rural areas can be constrained by distance, with home visits requiring lengthier periods of travel, which may be compounded by adverse weather and road conditions.
- 3.5. Recruitment of healthcare workers in rural areas is particularly challenging, with an ageing local workforce and the impact of domestic migration of younger people towards cities. We reiterate our previous recommendation for the Welsh Government to ensure fair pay for the community hospice workforce by providing pay uplifts which secure alignment between the salaries of those in the third sector with colleagues in the NHS.
- 3.6. Furthermore, investment in the community palliative care workforce will reduce demand on urgent and emergency care, and is particularly important in rural areas where hospital-centric models of care may be inappropriate.

7. The Committee would like to focus on a number of other specific areas in the scrutiny of the Budget. Do you have any specific comments on any of the areas identified below?

¹⁰ Bevan Foundation (2023) A common approach to Welsh benefits: Feasibility study

¹¹ Marie Curie (2021) Dying in poverty – Examining poverty at the end of life in the UK: Implications for Wales

¹² Equality and Social Justice Committee (2022) Minding the future: The childcare barrier facing working parents

¹³ Same but Different CIC, Marie Curie, Hospice UK (2023) What Matters Most – Mo. Available online: [What matters most? - Mo & Graham — Same but Different \(samebutdifferentcic.org.uk\)](https://www.samebutdifferentcic.org.uk).

- 7.1. The existing lack of commitments within the Programme for Government or strategy on poverty as a whole makes determining how to allocate resources to tackle poverty challenging. Especially in the context of the continued increase in the cost of living, it would be helpful to have a comprehensive cross-government strategy to tackle poverty to ensure that resources are being targeted at those both in and most at risk of poverty.
- 7.2. People in Wales had the highest rate of end of life poverty of all the UK nations – with nearly one in three (30.4%) of working age adults in Wales dying in poverty in 2019¹⁴. People living with a terminal illness with dependent children are the most vulnerable of all family types to experiencing poverty in the last five years of life.
- 7.3. Any comprehensive strategy to tackle poverty must take into account the needs of those living with terminal illness.
- 7.4. Alongside partner organisations in the Welsh NHS Confederation Health and Wellbeing Alliance, we have called on the Welsh Government to produce a cross-government plan to reduce poverty and tackle inequalities. Though poverty and inequality have significant implication for the nation's health, and need for health and social care services, the NHS and local authorities do not have the levers to address these.
- 7.5. Survey research has shown that 60% of people in Wales feel their health has been negatively affected by the rising cost of living: 90% said this was due to increased heating costs; over three quarters (76%) said it was a result of the rising cost of food and almost half (45%) said it was down to increased transport costs¹⁵. We therefore again urge the Welsh Government to produce a cross-government plan for reducing poverty and inequalities in adults and children, which outlines action being taken across government departments, and setting out how success will be measured and evaluated through shared performance measures.
- 7.6. As highlighted previously, the Welsh Government should expand the less stringent health eligibility criteria for the new Warm Homes programme to include those living with a terminal illness.

How could the budget further address gender inequality in areas such as healthcare, skills and employment?

- 7.7. In respect of gender inequality in healthcare, it would be helpful if the government could provide more detail on its timescales for producing a Women and Girl's Health Plan following the publishing of the Quality Statement for women and girls' health¹⁶.
- 7.8. As highlighted in previous research by Marie Curie, it is essential that palliative and end of life care are included in the Plan due to the different experiences and outcomes women have¹⁷.
- 7.9. The government should provide more clarity, in the budget, on how the Plan is to be resourced.

Is the Welsh Government's approach to preventative spending represented in resource allocations (Preventative spending = spending which focuses on preventing problems and eases future demand on services by intervening early).

- 7.10. As has been mentioned previously in this response, charitable and third sector palliative care providers are key partners in relieving pressure on NHS services. It would be helpful

¹⁴ Marie Curie (2022) [Dying in poverty: Examining poverty at the end of life in the UK – Implications for Wales](#).

¹⁵ Royal College of Physicians (2022) [Mind the gap: The cost of living crisis and the rise in inequalities in Wales](#).

¹⁶ Welsh Government (2022) [The Quality Statement for women and girls' health](#)

¹⁷ Marie Curie (2023) [Gender and end of life care: A Marie Curie policy paper exploring gender differences in end of life experience in Wales](#)

if the government could undertake further work with the sector to determine how pressures could be relieved on the NHS more effectively.

- 7.11. Furthermore, in order for the sector to successfully support the government in relieving pressures on the NHS, there is a need for a sustainable funding formula to support the delivery of serviced and ensure that the workforce within the third sector are treated the same as staff within the NHS.
- 7.12. We believe there is a strong case to view investment in palliative care, including the resourcing of palliative and end of life care within the community, as preventative spending. Early provision of palliative care is linked with improved quality of life, reduction in interventions of low benefits, and significant reductions in hospital admissions¹⁸. Providing ringfenced budget allocations to increase capacity within community PEOLC would ensure that investments made available to health boards for this purpose would be implemented as intended, and would reflect the Welsh Government's commitment to focus on end of life care set out in the Programme for Government.
- 7.13. While we welcome the Welsh Government's proposals through the Rebalancing Care and Support Programme to clarify the duty on local authorities to promote the delivery of the third sector and social value organisations, and the bolstered guidance for local authorities on co-production¹⁹, we would like to see guidance replicated as it applies to health boards and other decision making bodies within health and social care.
- 7.14. Currently, funding from the Welsh Government, which is directed through local authorities, health boards or RPBs, is often distributed between statutory organisations first before considering the role the third sector could play. The third sector therefore needs to be treated as a genuine partner at the outset and there needs to be transparency regarding the resources available for care and support and how these have been allocated.

How should the Welsh Government prioritise its resources to tackle NHS waiting lists for planned and non-urgent NHS treatments. Do you think the Welsh Government has a robust plan to address this issue?

- 7.15. As has been highlighted previously in this response, the third sector is a vital partner to deliver on the Welsh Government's goals to move more care into the community and relieve pressures on hospitals and other NHS services. In order to move more care into the community, it is vital that the Welsh Government continues to work closely with third sector providers of care.
- 7.16. Furthermore, it would be helpful to have further clarity on how these ambitions of the Welsh Government are going to be resourced.

Is the Welsh Government providing adequate support to the public sector to enable it to be innovative and forward looking through things like workforce planning.

- 7.17. As has been mentioned earlier, considering the role that third sector providers play in providing essential day-to-day care to thousands of people living with terminal illness, commissioners should apply annual inflationary uplifts to year on year contracts and provide pay awards which align with salaries for statutory partners (e.g. Agenda for Change).
- 7.18. This is essential to ensure that there is not a two-tier system which rewards some of the workforce better than others and enables third sector providers to recruit.

¹⁸ Murray SE et al. (2017) Palliative care from diagnosis to death. *BMJ* 2017;356:j878 doi: 10.1136/bmj.j878.

¹⁹ Welsh Government (2023) [Rebalancing care and support programme](#)

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?

- 7.19. As has been highlighted previously, the cost of living and inflation have put a number of pressures on the ability to deliver services as a third sector provider.
- 7.20. In this response we have presented a number of actions we would like to see from the Welsh Government to guarantee that third sector providers are better supported to continue delivering essential services and relieve pressure on the NHS.

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