

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

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Marie Curie response to Senedd Health and Social Care Committee inquiry into supporting people with chronic conditions

Response on behalf of Marie Curie Cymru, May 2023

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1. Introduction

We welcome the opportunity to inform stage 1 of the Committee's inquiry into supporting people with chronic conditions. Our evidence focusses on the needs of those who are living with terminal chronic illnesses, meaning illnesses that are likely to lead to that person's death. We recognise that the inquiry has a wider focus and will rightly be considering how people with chronic conditions can be supported to live well. Ensuring that people are supported to live as well as possible until their death is a vital yet still sometimes taboo aspect of this.

We therefore encourage the Committee to include the following key issues in the second stage of its work:

1. The specific needs of people living with terminal chronic conditions, their families and carers
2. Availability of and access to palliative care at an appropriate point in the care pathway
3. Provision of financial support and simplifying access to benefits for people with chronic conditions, with fast-track eligibility for people with terminal illness
4. Improving data and involvement of people with lived experience to understand where the gaps in care and support are so that resources can be effectively targeted

2. Context

Someone with a terminal illness may live for days, weeks, months, or years, depending on their diagnosis and any treatment they are having. Common chronic conditions that might be terminal include cancer, dementia, chronic obstructive pulmonary disorder (COPD), heart failure, end-stage liver disease, motor neurone disease (MND), multiple sclerosis (MS) and Parkinson's disease.

Palliative care is a person-centred approach to improving the quality of life of patients with terminal illness and also supporting their families¹. It is a holistic form of care which aims to make patients feel supported and comfortable, rather than to cure their illness. Though it can include end of life care, palliative care can last much longer – some people have palliative care for years. The Welsh Government's Quality Statement for Palliative and End of Life Care published in 2022 states 'Good palliative care can make a huge difference to the quality of life for people and those who care for them, helping them to live as well as possible and to die with dignity. Anyone requiring palliative and end of life care in Wales should have access to the best possible care'².

Approximately 25,000 people die each year in Wales from conditions that would benefit from palliative care: in 2021, 8,858 died from cancer; 8,837 died from organ failure (including heart, renal and liver failure, and COPD); 4,099 died from dementia, and 2,505 died from causes such as MND, MS and Parkinson's disease. Many others will be living and dying with chronic conditions for which

palliative care is appropriate but may not be the underlying cause of their death (for example, in the first three months of 2023, one in six people who died from Covid-19 had dementia or Alzheimer's disease as a pre-existing condition, though this was not their main cause of death³). From the data currently available, it is difficult to know how many of these individuals received the support they needed towards the end of life, but broader research and anecdotal evidence suggests there are significant gaps in provision and access.

3. NHS and social care services

a. The readiness of local NHS and social care services to treat people with chronic conditions within the community

Many people with a terminal chronic illness will spend most of their time living in the community, being cared for by family and informal carers, supported by general practice, community nurses and voluntary sector services, or in care homes. Currently, nearly half of all deaths in Wales take place in hospitals, roughly a third occur at home, and about a fifth take place in care homes⁴, but it is anticipated that there will be a shift from hospital to home and care homes in the future. Prior to the pandemic, research projected a substantive increase in demand for care in the community by 2040 in Wales and England, with deaths at home increasing by 89%, and deaths in care homes projected to increase by as much as 108%⁵. Though many people express a preference for dying at home, it is vital that the right services are available to ensure that priority outcomes such as pain, symptom control and personal dignity are maintained⁶.

With the shift of care from hospitals into people's homes and care homes because of Covid-19, the pandemic was an early stress test for how ready services are to treat more people in the community. In 2021, Marie Curie commissioned a survey of bereaved people to explore their experiences of having a loved one die at home during the pandemic⁷. Themes of responses from Wales included:

- High levels of need for more care visits, in-person support and respite
- Excessive waits for equipment
- Limited practical support following discharge from hospital
- Poor communication from healthcare professionals about a loved one's condition and prognosis, with no central or familiar point of contact
- Inadequate pain and symptom control
- Over reliance on family carers without adequate support, with one carer saying they felt 'constantly completely out of [their] depth' and others saying they were left feeling guilty for not being able to provide their loved one with the right level of care
- Positive feedback about support from District Nurses

While some of these issues were a direct result of service changes in exceptional times, the disruption caused by the pandemic exacerbated endemic issues within the health and care system. Gaps in community care in Wales are well evidenced, with particular challenges 'out of hours' (i.e., overnight, at weekends and on Bank holidays)⁸. Common issues with out of hours care include problems accessing medicines and having the right staff to administer them, limited access to equipment, unavailable care packages, and a heavy reliance on already stretched community nursing services. There is often no single point of access to palliative and end of life care services out of hours, meaning distressed patients and their families can experience delays and difficulties in being connected to local services and the support they need. When the right community care is not available or accessible, this can lead to distressing experiences for patients and their families and

potentially avoidable admissions to hospital. In 2020, people in their final year of life had more than 56,000 emergency department attendances, meaning one in every 14 emergency department attendances in Wales was by someone in the last year of life⁹.

These issues were recently highlighted in the Phase 2 Funding Review by the NHS National Palliative and End of Life Care Programme. The review's recommendations to increase district nursing capacity for out of hours provision and improve the palliative care clinical nurse specialist numbers have been accepted by the Minister for Health and Social Services. While this is encouraging, it will not go far enough to future proof services in advance of a significant rise in demand for palliative and end of life care. The charitable sector plays a significant role in provision of care - Marie Curie alone provides care to more than 3,000 people across Wales each year - but relies heavily on fundraising income. A sustainable model of funding which does not rely on supermarket collections and bake sales is vital to ensure access to good end of life care for everyone who needs it, now and in the future.

Further, better data and methods for gathering feedback and involving people who have experience of living with a terminal diagnosis are required so we can better understand the gaps and inequalities in care provision at a more local level. Data from the Quality Assurance and Improvement Framework disease registers show that for 2019-2020, only 10,340 people were recorded on GP palliative care registers in Wales – barely a third of the number of people who need palliative care¹⁰. Though there are limitations to this data, we know from speaking to families and from research evidence that there is significant unmet need for palliative care and appropriate support at the end of life for people with a range of terminal conditions.

b. Access to essential services and ongoing treatment and barriers faced by certain groups

Marie Curie has recently published the findings from research into gender inequalities at the end of life¹¹, which evidences that women often face disproportionate challenges in accessing, engaging with, and experiencing palliative and end of life care. Key findings include that women are slightly less likely than men to note a preferred place of death at home, which international evidence highlights is likely due to worries about being a burden on loved ones who have to care for them¹². Furthermore, although in small numbers, it appears that more women than men are dying in places other than their preferences – namely, care homes, nursing homes and hospitals. More research is needed to explore this substantively and ensure that holistic and person-centred packages of support are available in the community to enable more women to die at home if this is their true preference. Key findings and recommendations in the report can be found [here](#).

Evidence shows that barriers to palliative care and support towards the end of life also exist for people aged 85 years or over, racialised or minority ethnic communities, people living in rural or more deprived communities, people with learning disabilities, people experiencing homelessness, and LGBTQ+ communities¹³.

4. Multiple conditions

a. The ability of NHS and social care providers to respond to individuals with multimorbidity

Multimorbidity is becoming increasingly common towards the end of life. A Scottish study estimated that in 2017, people with multimorbidity accounted for more than 27% of all deaths and by 2040, people with multimorbidity would account for at least 43% of all deaths¹⁴. A similar trend is likely to

be seen in Wales, with significant implications for health and care services and providers, and individuals themselves.

Compared to people with a single condition, people who are managing multiple conditions frequently face additional challenges related to coordinating care from multiple services which are often not joined-up. There is evidence that people with advanced multimorbidity (ie. those who may be approaching the end of life) seek and obtain less support than merited by the symptom burden and impact of their conditions, and that their understanding of their illnesses and the services available to support them is generally poorer than for those with a single condition¹⁵. This limited understanding affects the likelihood that someone will have made advance plans for their future treatment, and the acceptability of a palliative approach as part of their care. There is some evidence that patient navigation interventions, including care navigator roles, can reduce barriers to accessing care and lower readmission rates¹⁶.

From a provider perspective, professionals may be unsure or lack confidence about when and how to initiate conversations about prognosis, future care plans, introducing palliative care or scaling back active treatment for people with multiple and complex conditions¹⁷. More work is needed to ensure that people who would benefit from palliative care – particularly those with multiple conditions and conditions other than cancer – are identified by services and that palliative care is integrated into their care alongside condition management in a sensitive and timely way.

5. Impact of additional factors

a. The impact of the pandemic on quality of care across chronic conditions

Please see our response to 3a above. Further, the Cross Party Group on Hospices and Palliative Care's recently published report into end of life care during the pandemic, highlighting how the pandemic revealed the fault lines in community palliative care, as well as access issues for care at home and in care homes¹⁸.

b. The impact of the rising cost of living in terms of their health and wellbeing

Cost of living pressures are having a devastating impact on many people living with terminal illness and their families. In 2019, more than 6,600 people in Wales died in poverty, with one in three terminally ill people of working age being below the poverty line at the end of life¹⁹. We expect this figure to be even higher now. The financial impact of terminal illness on a household can be as much as £12,000 to £16,000 per year because of lost income and additional costs²⁰. As energy prices soar, many terminally ill people are struggling to pay their heating bills, risking worsening symptoms, new infections, and even hastening death.

In a recent survey of Marie Curie nursing service staff in Wales, 95% had cared for patients who were struggling financially in the last year, and 83% said that the number of patients struggling financially had increased or significantly increased since 2021²¹. The most common financial difficulty observed among patients by Welsh respondents was affording their energy bills, including heating. This was followed by affording running at-home medical devices and affording suitable food. Respondents said that financial struggles are having a negative impact on mental health and wellbeing, as well as increasing social isolation and making physical health worse. Worryingly, nearly two thirds (64%) of respondents said they were very concerned that patients would not be able to keep their homes warm over winter. To avoid potential serious harm in the colder months, there is therefore an urgent need to introduce targeted cost of living support for those whose energy costs are driven up

by medical needs, to integrate financial advice into care pathways for everyone with terminal illness, and to test interventions which would improve benefit uptake in the coming months.

- c. The extent to which services will have the capacity to meet future demand with an ageing population

The most recent provisional figures from the ONS project that by 2040 there will be 41,000 deaths each year in Wales²². Research is needed to assess how palliative care needs and service implications will change over time, particularly given the long-lasting impact of the pandemic and associated backlogs in care. If current levels of palliative care need are merely sustained, this would mean approximately 35,000 people requiring some form of palliative and end of life care every year by 2040, compared with approximately 31,000 today²³.

Different models of more complex care may also be needed due to the ageing population, with increasing numbers of deaths from dementia and cancer in older people with co-morbid conditions. As previously noted, research has also forecasted a large increase in need for care at home and in care homes by 2040²⁴.

In her response to the Phase 2 Palliative and End of Life Care Funding Review, the Health Minister has recently asked the National Programme Board for Palliative and End of Life Care to provide a projection of what end of life care costs will be in 2033 and in 2048. With need set to grow significantly in coming years, high quality data and research on this issue will be critical. We hope to see Welsh Government work with the palliative and end of life care service, research and wider third sector community in Wales to bring forward robust plans for delivering sustainable funding and a stable workforce as a result.

References

¹ WHO (2020) [Palliative care](#) (fact sheet)

² Welsh Government (2022) [Quality statement for palliative and end of life care for Wales](#)

³ ONS (2023) [Monthly mortality analysis, England and Wales](#)

⁴ ONS weekly figures on death registrations in Wales by place of occurrence. For the three months period 24 October 2022 to 20 January 2023, the average place of death statistics for Wales were: Home (29%), Hospital (48%), Hospice (2%), Care home (18%), other and elsewhere (3%).

⁵ Bone, A., Gomes, B., Etkind, S. 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. *Palliative Medicine*, 32(2)

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⁷ These findings are unpublished.

⁸ Hospice UK (2022) [Future Vision Cymru: Seamless and sustainable – Report on engagement discussions and ways forward](#).

⁹ Pask S, et al. (2022) [Better End of Life 2022. Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers](#). Research report. London (UK): Marie Curie.

¹⁰ There are numerous ways to estimate the number of people who need palliative care but estimates that best reflect multimorbidity suggest that approximately 90% of people who die have palliative care needs. In 2019, this would have been almost 30,000 people.

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- ¹⁴ Finucane AM, et al. (2021) How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery. *BMJ Open* 2021;11:e041317. doi:10.1136/bmjopen-2020-041317
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- ¹⁸ [The Cross Party Group on Hospices and Palliative Care | Hospice UK](#)
- ¹⁹ Marie Curie (2022) [Dying in poverty: Examining poverty at the end of life in the UK – Implications for Wales](#)
- ²⁰ Marie Curie (2019) [The cost of dying: The financial impact of terminal illness](#)
- ²¹ Marie Curie (2023) [Data briefing – the cost of living: A survey of Marie Curie Caring Services staff](#). Wales specific figures available on request.
- ²² ONS (2022) [National population projections table of contents - Office for National Statistics](#)
- ²³ This is based on an established method for estimating palliative care need using underlying and contributory causes of death in Murtagh et al. (2014) How many people need palliative care? A study developing and comparing methods for population-based estimates; *Palliative Medicine* 2014, Vol 28(1) 49–58
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