

Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)

HSC PSS 47

Ymateb gan: | Response from: Marie Curie



Q1. Which of the issues listed above do you think should be a priority, and why?

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

Everyone deserves the best possible end-of-life experience, but the reality is that far too many do not receive the palliative and end-of-life care they need to help them die well. Longstanding estimates suggest that up to 75% of people who are dying need palliative care¹ whilst more up to date insight tells us that this figure could be as high as 90%.².

In the next section, we have set out our argument as to why we believe the Health and Social Care Committee should dedicate time examining the specifics of the end-of-life care agenda. Research around projections and trends at end-of-life care mean we need to act now to prepare for the future, as demand for palliative and end of life care is set to grow as the numbers of those dying increase.

In addition to the specific focus we believe the Committee should give to end-of-life care, Marie Curie also supports the intention to review the priority areas outlined above. In particular we welcome the focus on the health and social care workforce and mental health as focus on these areas would help to address the wider issues in relation to the delivery of palliative and end of life care provision in community settings.

The health and social care workforce

Wales, along with other UK nations, has an ageing population, and whilst this is cause for celebration, we must also acknowledge that this group will have additional needs due to the ever-increasing rise in people living with co-morbidities. This increase in demand means we need to think differently about how we use our existing workforce, both those who are working within the specialist palliative care field and those who work more generally to support this group.

At our recent [event](#) focussing on how we support people to die well in Wales by 2040, participants identified challenges that need addressing if we are to successfully meet the demand of providing community palliative care in the future.

¹ Murtagh, F E et al (2014). How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine*,

² 3 Von Petersdorff C, Patrignani P, Landzaat W. Modelling demand and costs for palliative care services in England: A final report for Sue Ryder. London Economics 2021.

People who are dying receive care and support from a wide range of professionals. Concern was raised around the pressure facing the acute workforce, with clinical nurse specialists (CNS) within hospital and in supporting community teams under more and more pressure. The CNS nursing crisis that existed pre-pandemic, due to retirement and work fatigue, will only continue to add pressure to workforce shortages in the future.

Whilst it was acknowledged that specialist palliative care providers are vital in delivering the best possible care, emphasis was also placed on workforce shortages in community settings. There was consensus that a lack of community nursing and social care support will only increase in the future. Inevitably, this will also place immense pressure on unpaid carers, families and loved ones.

Participants at our event also discussed the importance of ongoing palliative and end of life care education and training for these non-specialist teams, with a particular focus on those working in social care and care home settings. Whilst it was recognised that many professionals working in these settings already receive high quality training, it is not universal, and gaps exist in training, education, and experience.

We need to do better if people in Wales are to receive the compassionate support they deserve to enable them to die well. A targeted focus by the Committee on the health and social care workforce in the context of palliative and end-of-life care would be welcome.

Mental Health and bereavement

The focus on mental health services is also positive. In particular we would encourage the committee to consider bereavement within this topic. This is particularly important now as the nation faces mass bereavement because of loss during the pandemic. Those who lost loved ones, from Covid-19 and/or other conditions, are experiencing complex grief as a result of being separated from loved ones as they were dying or being left to care for their loved ones without the usual support. Many are experiencing complex grief due to the traumatic and sudden loss that the pandemic caused.

Cardiff University has recently received funding to explore the delivery of end-of-life care and bereavement support during and beyond the coronavirus pandemic. The first report of interim data identified high levels of emotional support needs, as well as difficulties getting support from friends and family³. The research highlights limited access to professional bereavement services, including for those identified as most vulnerable in their grief. Marie Curie believes that when considering mental health as a priority, that focus is also given to those who are grieving and in particular the impact on Covid in creating more complex emotional needs.

³ Harrop, E et al Support needs and barriers to accessing support: Baseline results of a mixed-methods national survey of people bereaved during the **COVID-19 pandemic**

Question 2: Key priorities for the Sixth Senedd

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

- a) health services.**
- b) social care and carers.**
- c) COVID recovery?**

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

a) Health services b) social care and carers c) Covid recovery

Marie Curie wishes the Committee to consider taking a closer look at the provision of palliative and end of life care services. More specifically, we believe that more focus is needed to explore the challenges of how the NHS, social care and third sector partners will adapt during this Senedd term to meet the needs of the increasing number of people who will die in community settings, which includes private homes, care homes and hospices.

Evidence (outlined below) projects the increasing demand that will be placed on the system in the next twenty years; by 2040, the demand for palliative care in England and Wales could increase by 42%⁴

In the coming months the Governance arrangements for NHS Wales service delivery will undergo change. In March 2021, the Welsh Government launched proposals for a new National Clinical Framework, which sits within planned arrangements for a new NHS Wales Executive function. This clinical framework includes plans to develop a dedicated end of life care programme to sit alongside a newly designed end of life care Quality Statement. These new arrangements will replace the oversight arrangements of the End-of-Life Care Delivery Plan.

This period of change and progress presents an opportunity for the palliative and end of life care

⁴ Etkind, S., Bone, A. et al, 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', BMC Medicine, 15 (102), 2017

community to come together and create new and progressive solutions to address the challenges of more complex deaths taking place in community settings and help put plans in place to deal with the projected increase in demand. This in turn will lead to more consistent and improved quality end of life experiences for all those who need it.

Marie Curie believes it would be a good use of Committee time and resource to gather evidence from health, social care, third sector providers, as well as people with lived experience and their carers. This should be used to set out recommendations in relation to the development, resourcing and implementation of the developing End of Life Care Programme in Wales whilst also supporting the prioritisation of focus areas.

Context for proposed inquiry

Impact of population ageing on future demand of end-of-life care.

Research by Bone et al estimates that by 2040, annual deaths in England and Wales will rise by 25.4%, from 501,424 to 628,659⁵. Due to the overall increase in deaths, with more deaths happening at older ages, as well as a projected rise in deaths from chronic diseases, palliative care need is set to increase significantly. If age- and sex-specific proportions with palliative care needs remain the same as in 2014, the number of people requiring palliative care in 2040 will grow by 25.0% (from 375,398 to 469,305 people/year)⁶. However, if recent upward mortality trends continue, then 160,000 more people in England and Wales will need palliative care by 2040⁷. This would represent an increase in need of 42% from 2014 to 2040⁸. Predominant illnesses driving increased palliative care need are projected to be cancer and dementia⁹.

This research tells us that healthcare systems need to start adapting to the age-related growth in deaths from chronic illness and more resource is urgently needed. There needs to be increased specialist palliative care capacity to cope with increasing numbers of patients at end of life with comorbidities and complex conditions. In addition, more primary and secondary care generalists that are aware of advance care planning and symptom management will be key (see response to question 1)

Trends and future projections on place of death

Further research from Bone et al found that if recent trends continue, overall deaths in the community are projected to increase by 2040, with hospital deaths (as a proportion of all deaths)

⁵ Etkind, S., Bone, A. et al, 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', BMC Medicine, 15 (102), 2017

⁶ Ibid.

⁷ Ibid.

⁸ Ibid.

⁹ Etkind, S., Bone, A. et al, 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', BMC Medicine, 15 (102), 2017

expected to decline by more than 50% in the same period¹⁰. Deaths at home will increase by 88.6% by 2040¹¹, while deaths in care homes are projected to increase by as much as 108% by 2040¹²; deaths in the community (care homes, homes and hospices) will nearly double by 2040, and account for 76.0% of all deaths. Care homes are projected to become the most common place of death by 2040.

As such, researchers have concluded that end of life care provision in care homes and the community needs to double by 2040.

Covid pandemic – a stress test for community death

Most people express a preference for home over hospital as the place of care at the end of their life. Furthermore, over the past decade fewer people have been dying in hospital. The Covid-19 pandemic has increased the number of deaths taking place in care homes and private homes and has been a stress test for our health and care system.

Our collective experience through the pandemic provides us with a platform to understand and consider the demands that will be placed on our systems in the coming years. A recent Marie Curie survey of carers of people who died at home during pandemic found that:

- 76% said their loved one did not get all the care and support they needed
- 64% said they did not get the care and support they needed with pain management
- 61% said they did not get the care and support they needed with personal care; and
- 65% said they did not get the care and support they needed out-of-hours.

Several additional research initiatives have taken place recently which provide context to the changing demands of palliative and end of life care. Evidence gathered is showing that our current system isn't sufficiently equipped or resourced to support the increased number of deaths in the community, which has unfortunately resulted in people not receiving the care they need or deserve.

Better End of Life Programme

The Marie Curie Better End of Life Programme reinforces the increasing shift towards more deaths happening at home and within community settings. The programme seeks to understand the outcomes and experiences of people affected by death, dying and bereavement in the UK and to propose a policy agenda aimed at ensuring that everyone has the best possible end of life experience. The programme is a multi-year collaboration between Marie Curie, King's College

¹⁰ Ibid.

¹¹ Bone, A., Gomes, B., Etkind, S. et al, '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*, 2018, 32(2)

¹² Ibid.

London Cicely Saunders Institute, Hull York Medical School, University of Hull, and the University of Cambridge.

The first research [report](#) from the programme, published in March 2021, explored the ongoing impact of the Covid-19 pandemic on dying, death and bereavement in the UK¹³. It looks back at 2020 and brings to light lessons learned for the future of palliative and end of life care and bereavement support.

As well as outlining key Covid-19 specific challenges around lack of PPE, medicines and equipment, the report highlights key learning around the impact that sustained increase in deaths at home can have on people's experience of dying. Even outside of pandemic peaks in 2020, there was an increase of 40% of people dying at home in the UK compared to the five-year average.

Conclusion

We hope that this short insight provides evidence as to why Marie Curie believes a closer look at the development of a new End of Life Care programme would be a valuable exercise, after all – dying, death and bereavement is universal to us all and this is an issue that will affect every citizen of Wales. We would suggest that this Inquiry takes place relatively soon to provide insight and support to the End-of-Life Care Steering Board as they work with partners to establish and set the direction of the new End of Life Care programme.

Question 3: Any other issues

Q3. Are there any other issues you wish to draw to the Committee's attention?

¹³ Sleeman, K., Murtagh, F., Kumar, R., O'Donnell, S., Cripps, R., Bone, A., McAleese, J., Lovick, R., Barclay, S. & Higginson, I., *Better End of Life 2021: Dying, death and bereavement during Covid-19, Research report*, Marie Curie, April 2021

One of Marie Curie's priorities in Wales going forward is a focus on health inequalities. The first part of this project is looking at the inequalities faced by women when it comes to accessing end of life care and support; this includes both receiving and providing care. International evidence shows that there are gender differences in reported symptom burden, pain management and women being less likely to achieve a home-based death¹⁴. We are currently working with a group of third sector organisations who are developing a women's health quality statement, and any support the Committee can give to encourage the adoption of a women's health plan would be welcomed.

More broadly, and aligned to our strategic priorities about tackling inequalities, Marie Curie is part of a wider coalition of organisations which is calling for an inquiry across all Senedd Committees on tackling wider health inequalities in Wales. Health inequality is the result of many and varied factors.

While COVID-19 has revealed and exacerbated pre-existing health inequalities, there have been many detailed and well-evidenced reports on health inequalities in recent years. In just the past year, many reports have called for system-wide action on health inequalities including the Welsh Health Equity Status Report initiative, *Placing health equity at the heart of the COVID-19 sustainable response and recovery* (Public Health Wales and Welsh Government), *Mitigating the impact of COVID-19 on health inequalities* (British Medical Association), *The Marmot Review 10 Years On* (Institute of Health Equity and the Health Foundation) and the most recent *Unequal pandemic, fairer recovery* (the Health Foundation). Every one of these reaffirms the need for coherent, coordinated activity across all delivery partners and in COVID-19 recovery, there is an opportunity to create a healthier, more resilient society, by addressing the root causes of poor health and invest in people and their communities – their jobs, housing, education and communities.

Through having a cross-Committee Senedd inquiry it will enable all Committees to consider what action each Welsh Government department is doing to tackle the root causes of health inequalities.

¹⁴ Gott, M, Morgan, T, Williams, L Gender and Palliative Care: A Call to Arms. SAGE Publications 2020