

Don't let the plan run out for dying people in Wales

Marie Curie & Motor Neurone Disease Association: Briefing for Petitions Committee

Background and policy context

Dying, death, and bereavement have been at the forefront of the nation's attention over the last two years. Since March 2020, over 75,000 people have died in Wales throughout the pandemicⁱ, and it is estimated almost 700,000 people have been left bereavedⁱⁱ.

Covid-19 has meant that thinking about end of life – whether a loved one's or our own – has become inescapable for many of us. Albeit in unfortunate circumstances, more of us are coming to realise the importance of planning for end of life and Welsh Government have since assumed a new focus and policy prioritisation around palliative and end of life care (PEOLC). This includes a commitment to an End of Life Care Programme¹.

A dedicated End of Life Care Programme is welcome news, but for the benefit of dying people and their loved ones we urgently need this commitment to be translated into practice.

In her letter of response to the Petitions Committee, the Minister for Health and Social Care highlights a 'Quality Statement'. This is a short policy intention document for PEOLC in Wales and when published, it will become one pillar of the End of Life Care Programme. The high-level Quality Statement will sit alongside a more detailed implementation/action plan, and together, these documents were due to replace the last [End of Life Delivery Plan](#) which came to an end on March 31.

We are yet to see a published Quality Statement or implementation/action plan. This means it is the first time in a decade that no strategic plan is in place for PEOLC in Wales².

The problem

Wales has an ageing population and the number of people dying with more than one condition is growing. By 2040, the number of people needing palliative care is expected to rise by 42%ⁱⁱⁱ, with deaths at home expected to increase by over 88% in Wales and England alone^{iv}.

Usually, around 34,000 people die in Wales each year and at least 75% would benefit from some form of palliative and end of life care^v. However, for many reasons 25% of these people will not have access to the care that they need to die well^{vi}. This leads to people dying in pain, without sufficient support, and their preferences and wishes at end of life going unfulfilled. This not only impacts the person who is dying, but the loved ones left behind.

The pandemic has created serious barriers over the last two years and resources and capacity have rightly had to be redirected to respond to the Covid-19 crisis. However, considering the projected increase in demand for EOLC, and in the context of a global pandemic, it is more important now than ever that PEOLC is prioritised.

The Minister for Health & Social Care Services states in her letter of response, "the Quality Statement for End of Life Care is progressing well and is being co-produced with statutory

¹ Published in March 2021, the [National Clinical Framework](#) sets out ambitions for design and delivery of NHS clinical services in Wales. It included a commitment to a dedicated End of Life Care Programme.

² Please note that this does not mean that commissioning and delivery of PEOLC services will cease in Wales, but that the strategic direction is unclear going forward and we risk losing the focus and progress we've achieved over the last decade.

and voluntary stakeholders". Marie Curie sit on the EOLC Board and is one of the many stakeholders who have been consulted during the development of the Quality Statement.

We agree that the Quality Statement is a good first step, however we understand from government officials that work on Quality Statements for all health and disease areas has been paused for review. We are also aware that this review sits within a complex overhaul of governance arrangements for various disease and service areas within NHS Wales.

Despite assurances from the Minister and her officials, we are not confident that an EOLC Quality Statement alone will be robust enough to drive forward the necessary changes we need to meet the increasing demand for palliative care in the next 20 years.

Lived experience: Why is an End of Life Care Programme so important?

At any one time there are around 200 people in Wales living with motor neurone disease (MND), with a third of people dying within one year of diagnosis, and more than half within two years^{vi}.

MND is a fatal, rapidly progressing disease that affects the brain and spinal cord. It attacks the nerves that control movement so muscles no longer work. It can leave people locked in a failing body, unable to move, talk and eventually unable to breathe.

Due to the rapid progression of the disease, palliative and end of life care is vital for people with MND in Wales. Access to a health and social care system which is supported by an End of Life Care Programme provides the opportunity for more people diagnosed with MND to have a better quality of life towards the end. As no two cases of MND are the same, there is no typical trajectory to end of life, making ease of access to services and person-centred care essential. Those living with MND should be able to spend their final days how and where they choose, and the End of Life Care Programme can enable this.

Jon Griffiths, supports his father caring for his mother who has motor neurone disease. He said:

"When Mum had her diagnosis, we were all in shock. We were introduced really early on to our Palliative Care Consultant alongside our MND consultant. Being able to have honest and open conversations about how the disease is progressing and planning ahead for each of the different stages has been a huge help to both Mum and to us as a family. It makes it easier each time something has to be introduced to help her cope with her symptoms.



For people like us who are living with the daily reality of supporting someone we love to have the best quality of life, it's important to me to know that the NHS is planning to constantly learn and improve the services that she and others receive to ensure the best possible care."

The need for an End-of-Life Care Programme in practice is emphasised by Caroline Bidder, Lead Care Coordinator at the South Wales MND Care Network. She said:

"Establishing a new End of Life Care Programme is vital to ensure support, control and choice for those living with MND, their families and carers. Patients need to be given the opportunity to live & die with dignity and access the best palliative care possible, all the while creating a healthy grieving process for those left behind."

Lynwen Griffith, a Community Nurse and volunteer Association Visitor at the MND Association, reiterated the need for an End-of-Life Care Programme, and said:

"Ensuring a good death needs advanced planning encompassing patient centred care, allowing the patient to be treated as an individual, without pain, in familiar surroundings and in the company of loved ones. Community care and health support must also be readily available for this to be achieved."

What next?

We hold serious concerns around the lack of robust timeline, the amount of resource, and the number of personnel allocated to the development of the End of Life Care Programme and a new approach to end of life care service delivery across Wales.

The Minister for Health & Social Care Services announces in her letter of response that the Quality Statement will be published this summer. This is welcome news, but we believe the more pressing issue and unanswered question is when we can expect work to commence to organise, develop and deliver on the ambitions of the End of Life Care Programme in a wider sense.

For the Quality Statement to reach its potential and to enable the development and the delivery of a successful End of Life Care Programme in Wales, we urgently need to see

- (1) a clear, bold and detailed implementation/action plan
- (2) a commitment to sustainable and ringfenced funding, and
- (3) sufficient capacity/end of life care personnel within government and supporting NHS organisations e.g. The NHS Collaborative and when put in place, the new NHS Executive

Newly published findings from research led by the Marie Curie Research Centre at Cardiff University, reveals 80% of people in Wales think that end of life care should be given equal priority in the NHS as care for people in any other stage of life^{viii}.

A successful and ambitious End of Life Care Programme gives us the opportunity to ensure that end of life care is given the same priority as care and support at any other phase of one's life. It is a positive stepping block towards ensuring that everyone in Wales has access to the care and support they need to achieve the end of life experience they want.

Suggested recommendations for the Petitions Committee

We would urge the Petitions Committee to seek Ministerial Commitment with regards to progressing work on the End of Life Care Programme at pace.

We would suggest the below outcomes to be achieved by April 2023, two years on from initial commitment to an End of Life Care Programme.

1. Increase in EOLC programme personnel within government and supporting NHS organisations, in line with other condition and disease areas.

We would encourage the appointment of a full time Senior Programme Lead for the EOLC Programme in order to:

- Work closely with the Clinical Lead for End of Life Care and the new End of Life Care Programme Board
- Guide programme development. This must include (a) the infrastructure around the programme and (b) the various workstreams of the programme
- Develop and embed a robust monitoring framework for EOLC in Wales, aligned with agreed outcome domains for specialist palliative care in Wales for both adult and paediatric care

2. Ringfenced funding for the development and delivery of the End of Life Care Programme for the next three years

- A three year funding timeline has been selected to align with a rolling, three-year implementation/action plan (see below).
- Ringfenced funding for the development and delivery of the EOLC Programme has been specified to avoid resources being redirected to fund direct service provision within health boards, as has been the case during the pandemic.
- The results of the Phase 2 funding review into end of life care services, due in January 2023, should be taken into consideration.

3. Publication of a rolling, three-year implementation/action plan for PEOLC in Wales. This will follow on from the publication of the Quality Statement due in Summer 2022.

- When determining areas of focus within the implementation/action plan, meaningful consultation must place with patients, service users and the public, and relevant NHS, social care, academic and third-sector stakeholders.
- The [Review of Specialist Palliative Care Services in Wales from 2020-2021](#) and the [Seamless and Sustainable](#) report by Hospices UK must be considered.
- The areas of focus within the implementation/action plan should inform the workstreams of the overall programme, with each workstream

We hope to see the Petitions Committee monitor the progress of the End of Life Care Programme and to follow up with the health minister and her commitments in Summer 2023.

References

ⁱ As of 6 April 2022, 75,237 people have died in Wales since 13 March 2020. [Deaths registered weekly in England and Wales, provisional - Office for National Statistics \(ons.gov.uk\)](#).

ⁱⁱ It is estimated that each death leaves approximately 9 people bereaved. Verdery, A.M. et al., 2020. [Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States. PNAS, 117\(30\)](#). Based on ONS stats above, we can therefore estimate that 677,000 people have been left bereaved in Wales in the same timeframe.

ⁱⁱⁱ Bone 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 – Feb; 32(2): 329-336

^{iv} 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)

^v Marie Curie, 2015. *Triggers for palliative care Improving access to care for people with diseases other than cancer*

^{vi} MND: *What are the facts?* <https://www.mndassociation.org/about-mnd/what-is-mnd/>

^{vii} Dixon, J., King, D., Matosevic, T., Clark, M., and Knapp, M., 2015. 'Equity in the Provision of Palliative Care in the UK: Review of Evidence', *Personal Social Services Research Unit London School of Economics and Political Science*

^{viii} Marie Curie, 2022. [Public Attitudes to Death and Dying in Wales](#).