

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

Marie Curie & Motor Neurone Disease Association: Briefing for Petitions Committee, June 2023.

RE: Marie Curie Cymru and MND Association are seeking assurance from the Minister for Health and Social Services that the National Palliative and End of Life Care Programme is being supported and sufficiently equipped to begin work on a longer-term End of Life Care workplan, beyond that of the Phase 3 Review.

We are grateful to the Petitions Committee for agreeing to defer discussion on the above petition until now. We had previously asked that actions be paused in light of ongoing changes in the health and social care environment, including developments with regards to the NHS Wales Executive. We can confirm that the NHS Wales Executive has now been formally established and we have seen some recent movement in the National Palliative and End of Life Care Programme.

We would welcome the further support of the Committee to write to the Minister for Health & Social Services to:

- Seek assurances that the National Palliative and End of Life Care Programme will receive the appropriate resources to be able to undertake the ambitious programme of work as set out under the Palliative Care and End of Life Quality Statement.
- Seek clarification on the development of 'enabling plans' to take forward the Palliative and End of Life Quality Statement as set out in the Minister's correspondence to the Committee in August 2022.
- Receive an update on timescales for delivery of the Palliative and End of Life Quality Statement.

As of March 2023, Marie Curie has been a key member of the Programme Board on an interim basis as a representative of third sector organisations. We are pleased that we have maintained our position on the Programme, despite concerns that third sector engagement had been omitted from its future work initially. In addition, we secured a formal third sector sub-group focused on policy development within the Programme infrastructure, to work in collaboration with the Board. Its first meeting is due to take place 9 June.

We hold some concerns around the delayed progress that has been made over the past few months with regards to setting up the various workstreams of the Programme and the publication of a workplan or implementation plan that can allow us to see how the Welsh Government Palliative and End of Life Care Quality Statement will be implemented. We understand that the Programme has been operating in a constantly shifting environment with the creation of the NHS Wales Executive, which has led to a substantial delay on the establishment of the programme in its current form. Nonetheless, demand for palliative and end of life care will be increasing dramatically in the near future and we must start planning for this, with the Programme playing a central role in leading change across the system.

We recognise the Phase 3 Palliative and End of Life Care Funding Review is a significant undertaking as part of Welsh Government's Programme for Government, we are therefore eager to receive assurance from the Minister for Health and Social Services that the Programme is being supported with the necessary resources and capacity to continue establishing workstreams and its workplan alongside this important review.

We wish to highlight to the Petitions Committee and the Minister for Health and Social Services that Marie Curie, MND Association, and the third sector sub-group of the Programme are ready to start tackling the challenges facing palliative and end of life care and to ensure more people in Wales have the best end of life experience possible.

Kind regards,

Marie Curie Cymru & Motor Neurone Disease Association