

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

Marie Curie & Motor Neurone Disease Association: Briefing for Petitions Committee, September 2022

### **RE: Marie Curie Cymru and MND Association have decided to request that the Petitions Committee defer discussion on this petition until later in the term.**

We are grateful to the Petitions Committee for their ongoing support of Marie Curie Cymru and MND Association's petition on End of Life Care. This has opened a direct communication channel with the Minister for Health and Social Services, and positive steps forward have been made since the launch of the petition in March 2022. We welcome the Minister's response and are delighted with the progress she has outlined, particularly around increased personnel within the NHS Collaborative and more clarity around the potential role of an implementation/action plan.

However, although we welcome the positive developments over recent months, we are still concerned about the implementation of the End of Life Care Programme.

As the Petitions Committee may know, there are currently delays around the development of the new NHS Executive and a lack of clarity on its objectives. The proposed NHS Executive and the End of Life Care Programme are inextricably linked, and we believe that the stalled End of Life Care Programme is not due to a lack of urgency to act, but the ongoing delays around the NHS Executive. We understand that this issue is much wider than just palliative and end of life care, and many other condition-specific implementation groups and networks are working in similar challenging contexts.

Marie Curie continue to work as part of the End of Life Care Board and we have confidence that all efforts are being made to ensure progress on the End of Life Care Programme, despite delays around the NHS Executive. However, we are unsure how the uncertain external environment and new NHS governance arrangements will impact this eagerness to act over the next few months. We would therefore like to ask the Petitions Committee to revisit this petition, along with the Minister's recent response, later on in the term.

The primary objective of this petition was to see tangible progress on implementing the End of Life Care Programme, including the development of an implementation/action plan. Our hope is that in a few months' time, the function of the NHS Executive will be clearer, and the environment will have allowed progress to be made on the End of Life Care Programme and on our petition's key objectives.

### Clarifying the role of Welsh Government staff working on end of life care

In the meantime, we would appreciate if the Petitions Committee could seek to clarify some information with regards to the "three Welsh Government staff with part of their roles dedicated to supporting the end of life care agenda", as mentioned in the Minister's response.

- Given the commitment in the Programme for Government 2021-2026 to prioritise end of life care, we would like to understand how much time each Welsh Government staff member gives to the end of life care agenda.
- In addition, considering the recent increased capacity for end of life care in the NHS Collaborative, are we likely to see a corresponding increase in capacity within Welsh Government to allow for quicker implementation of the End of Life Care Programme?