

Mark Drakeford AC / AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



Llywodraeth Cymru  
Welsh Government

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Nick Ramsay AM  
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Dear Nick,

During the short debate on the motor neurone disease which took place on 9 July, I undertook to write to you on the points raised in your opening statement.

You specifically asked what the Welsh Government was doing to raise awareness of motor neurone disease as a condition. As I said the implementation group has now been set up to take forward the neurological conditions delivery plan led by Prof Matt Makin, the medical director of Betsi Cadwaladr University Health Board. It has its first meeting planned to take place on 14 August during which the implementation priorities will be discussed and awareness raising of neurological conditions will be part of that discussion.

As I mentioned, early diagnosis is also key and tools such as the RCGP red flag are valuable aids to assist in the delivery of this action. I have asked my officials to write to Directors of Primary Care within the Health Boards to draw this tool to their attention and as promised I will raise this issue with Health Boards next time I meet them.

In relation to communication aids, I am due to receive a submission shortly concerning the review of communication equipment. This should address both the proposed service model in terms of assessing the needs of the individual through to the provision of equipment together with the proposed funding arrangements. I will write to you again when decisions are taken.

I understand the North Wales Neuroscience Network had a very interesting discussion about the use of advanced nurse practitioners and the model in use at the Walton centre at its board meeting earlier this month. Following this further discussion will take place about what the role may offer in North Wales.

Nice guideline CG105, *Motor neurone disease: The use of non-invasive ventilation in the management of motor neurone disease*, set outs best practice for non-invasive ventilation management and, if required, referral for cough assist-therapy as part of the patients comprehensive care plan, prepared by their multidisciplinary team in discussion with the patient and their family and carers. I expect Local Health Boards to deliver equitable and timely access to both non-invasive ventilation and cough-assist therapy, in line with NICE guidelines. If there are issues, these should be raised directly with the relevant Local Health Board, which has responsibility for the delivery of care to their local population.

The All Party Parliamentary Group Inquiry into Motor Neurone Disease is of course a matter for the Houses of Parliament. We will however, consider the relevance of any recommendations to the implementation of the Delivery Plan.

I set out the Welsh Government position in relation to research for neurological conditions in the delivery plan. We have a strong neuroscience research base in Wales and would encourage interested researchers to bid for available funding to further strengthen work in this area.

We have a good story to tell in Wales in relation to palliative care in Wales. Thanks to the work of the Palliative Care Implementation Board patients now have access to 24/7 palliative care services in Wales whatever their condition and the Delivering End of Life Care Plan builds on this success.

The recent Dying to Talk conferences started a national conversation encouraging people to talk openly and honestly about end of life issues. How a person is treated at the end of life stays with those left behind forever. It is vital that all those involved in end of life care, families, clinicians and carers are aware of the wishes of the individual and discuss them openly. The establishment of the Dying Well collation in Wales chaired by Hywel Francis MP will continue this conversation.

As I mentioned in the debate, I believe that we have in place some of the necessary building blocks such as a number of relevant Delivery Plans to help us respond positively in the present to the needs of those who suffer from this awful condition and some important developments that will allow us to help improve the position in the future. I am very grateful to you for having raised awareness by putting motor neurone disease forward for debate,

Best wishes,

Mark

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