



Ein cyf/Our ref: MA-P-VG-2928-17

Assembly Members

5 September 2017

Dear colleague,

During the Business Statement on 27 June the Leader of the House agreed that I would update Assembly Members on Welsh Government policy in respect of motor neurone disease since Nick Ramsay's short debate in July 2014.

Health Boards are responsible for planning, securing and delivering high quality care for patients with neurological and/or rare conditions, such as motor neurone disease.

Motor Neurone Disease is a relatively rare neurodegenerative condition, which affects around 250 people living in Wales. Two people in every 100,000 are likely to develop the disease over their lifetime.

People with neurological conditions may have complex physical, psychological and social needs which affect their ability to function. People need wide ranging support to achieve their best possible outcome and quality of life. To improve services for people living with a neurological condition is challenging and multifaceted.

People with motor neurone disease will be covered by more than one health delivery plan - those on neurological conditions, end of life care and rare diseases. The updated Neurological Conditions Delivery Plan was published on 27 July 2017. The first plan, published in 2014, focused on raising awareness of neurological conditions, ensuring quick diagnosis of patients, providing fast and effective care, and helping people live with their condition. The plan also aimed to improve the information available on neurological conditions and treatment; as well as help target research into causes, treatments and cures.

The new plan informs the work of the Neurological Conditions Implementation Group, chaired by Alison Shakeshaft, Executive Director of Therapies and Health Science, Aneurin Bevan University Health Board.

It builds on the previous plan to drive forward the vision for improving neurological services across Wales more effectively and at a greater pace, in conjunction with health boards' local vision for their resident population described in their Integrated Medium Term Plans. Collaborative working between the Implementation Group, NHS organisations, social

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

services and third sector partners is essential to ensure services are effective to meet population need and reduce variability of services.

We are committed to transparent reporting of progress against the plan and the last annual statement of progress was published in March. Both the plan and annual statement of progress can be accessed here:

<http://gov.wales/topics/health/nhswales/plans/neurological/?lang=en>

In 2016, the Neurological Conditions Implementation Group started to work with the Stroke Implementation Group to develop appropriate Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs) for stroke and neurological conditions. The Groups have also provided £1.2m joint funding for the expansion of neurorehabilitation services across Wales to build capacity across the neurological rehabilitation workforce. Due to the synergy between the groups, they have appointed a joint co-ordinator to ensure they are working collaboratively to develop local interventions and services based around the common impairments of both stroke and neurological disorders.

The neurological conditions implementation group has identified a number of priorities for 2017-18:

- Developing a co-productive approach to increasing awareness of neurological conditions
- Delivering clear consistent patient information
- Delivering access to neurology services, for patients of all ages, consistently throughout Wales
- Developing consistent and coherent neuro-rehabilitation services, for patients of all ages
- Developing and responding to patient experience and outcome measures

The updated Rare Diseases Implementation Plan for Wales was published on 26 July 2017. It reaffirms the commitments to empower those with a rare disease and ensure those with rare diseases have timely access to high quality pathways of care. The plan is led by the Rare Diseases Implementation Group, chaired by Dr Graham Shortland, Medical Director at Cardiff and Vale University Health Board.

The Rare Diseases Implementation plan can found at:

<http://gov.wales/topics/health/nhswales/plans/rare/?lang=en>.

Its priorities for 2017-18 are:

- Identifying the support pathway for patients with unknown diagnosis;
- Creating and ensuring better use of best practice and evidence in primary and secondary care and improve pathways for accessing specialist services;
- Undertaking significant event analysis including delayed diagnosis of a rare disease and shared evidence learning;
- Ensuring feedback from patients is utilised to enhance rare disease pathways within health boards.

Both the neurological conditions and rare disease implementation plans reflect national guidelines for effective care of people with a neurological or rare condition. These include the National Institute for Health and Clinical Excellence (NICE) guidelines, care pathways and other documents such as professional standards. Services should be developed and delivered in line with the relevant guidance for those conditions, where they apply, but the wide range of neurological conditions means many will not have disease specific guidance.

NICE guidance (NG42) for the assessment and management of motor neurone disease were published in February 2016.

People in the later stages of motor neurone disease should be supported in having early discussions about their end of life care, if appropriate. Individuals, and those important to them, need to be able to have open and transparent discussions about personalised plans that enable a holistic approach to promoting their choices of treatment, care and support; in line with the *Delivering End of Life Care Plan*.

Yours sincerely,

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive style with a large initial 'V'.

Vaughan Gething AC/AM

Ysgrifennydd y Cabinet dros Iechyd, Llesiant a Chwaraeon
Cabinet Secretary for Health, Well-being and Sport