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



Ein cyf/Our ref MB/MD/2414/14

Nick Ramsay AM

nick.ramsay@wales.gov.uk

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Dear Hick

I am writing to provide you with an update on Motor Neurone Disease following the commitment given in Business Questions on 20 May.

Motor neurone disease (MND) is rapidly progressive in the majority of cases, and life limiting. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK, approximately 250 of them in Wales. Half of people with the disease die within 14 months of diagnosis.

The Motor Neurone Disease Association (MNDA) five point Charter aims to make sure all people with MND receive the right care, in the right place, at the right time.

People with this devastating condition need support and services to help them manage their condition and maximise the quality of life during the progression of the disease. As a Government, we support the MNDA Charter and the principles of the five points are all reflected throughout the Neurological Conditions Delivery Plan, launched last month. This plan together with the delivery plans for respiratory health and end of life set out the standards of care patients with MND should expect to receive from the NHS in Wales.

The NHS in Wales is currently developing local delivery plans for neurological conditions setting out how they will achieve the expectations set out within the Delivery Plan. From 2015, they will be reporting annually on their progress.

Mark Drakeford AC / AM

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Minister for Health and Social Services

Bae Caerdydd • Cardiff Bay Caerdydd • Cardiff CF99 1NA

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English Enquiry Line 0845 010 3300 Llinell Ymholiadau Cymraeg 0845 010 4400 Correspondence.Mark.Drakeford @wales.gsi.gov.uk Printed on 100% recycled paper