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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal
Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Cymdeithas Clefyd Niwronau Motor

Response from: Motor Neurone Disease Association

Response to the Health, Social Care and Sport Committee's consultation on future priorities

Introduction

- i. Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.
- ii. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Up to half of people with MND will also experience changes in cognition, some of whom will develop front-temporal dementia.
- iii. There are up to 5,000 people living with MND in the UK at any one time, of whom approximately 210 live in Wales. It can affect any adult, but is most commonly diagnosed between the ages of 55 and 79. MND kills a third of people within a year of diagnosis and more than half within two years, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.
- iv. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and groups, and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.
- v. We wish to make two recommendations to the Committee: one for a possible inquiry within the next 18 months, focusing on diagnosis; and another in response to one of its suggestions for possible inquiry topics, where we recommend the committee investigate what may be a serious misunderstanding by the Welsh Government in its attempts at service redesign.

1. Right diagnosis, right time

- i. We recommend that the Forward Work Programme of the Health, Social Care and Sport Committee include a detailed look at waiting times, including processes of referral and diagnosis for MND.

- ii. People with MND – a rapidly progressive condition - need the right care in the right place at the right time. A timely and accurate diagnosis is a fundamental part of not just identifying but anticipating these needs and ensuring the best possible quality of life. The Association has given detailed consideration to this issue in Wales as part of its 2016 report *MND Won't Wait* (enclosed) from which the following analysis has been adapted.
- iii. Wales has made some progress: the *Neurological Conditions Delivery Plan* of 2014 made diagnosis one of its key priorities.¹ In 2014, the Government also asked the Health Boards to distribute our *Red Flag* tool. Created with the Royal College of General Practitioners, this tool helps GPs identify possible signs of MND and refer to neurology.² However, in our last two surveys of people with MND in 2013 and 2016, one in five people with MND surveyed in Wales waited longer than a year after first having visited their GP to see a neurologist for diagnosis.
- iv. Despite the creation of fast-track processes for people with rapid progression, once a referral is made delays still occur. The Welsh Government's *Neurological Conditions Delivery Plan Annual Report* from 2015 suggests that more than one in ten people with a neurological condition in Wales wait more than half a year for their first neurology outpatient appointments.³
- v. In our report *MND Won't Wait*, we have asked the Welsh Government (and where appropriate Assembly members) to champion the prompt and accurate diagnosis of MND, including:
 - Requesting future neurological reporting includes data on diagnosis, so performance in this area can be monitored
 - Working with and incentivising care professionals and Health Boards to improve existing processes of referral and diagnosis
 - Supporting and evaluating the ongoing dissemination of the *Red Flag* tool to GPs and other health professionals by the Health Boards
 - Promoting the new Welsh-language version of the *Red Flag* tool.
- vi. In our view, a sustained focus by the Health, Social Care and Sport Committee on waiting times, including for referral and diagnosis, would improve scrutiny in this area as well as generating ideas for optimising service delivery. This in turn would support a timely and accurate diagnosis of MND in more cases, enabling a better management of care and quality of life for people with this rapidly progressive disease.

2. Service redesign and 'primary care'

- i. Our second recommendation is that the Committee should proceed with its proposed scrutiny of the Welsh Government's work on primary care.

¹ Welsh Government, [Together For Health – A Neurological Conditions Delivery Plan](#), 2014

² MND Association, [Red Flag diagnosis tool](#), 2013.

³ Welsh Government, [Together for Health Neurological Conditions Delivery Plan, Annual Report](#), 2015

- ii. The Welsh Government is seeking to address the common challenges associated with an ageing population, including by shifting care out of hospitals and into the community. There is a clear case for making such changes, both to secure the financial sustainability of services and to improve experiences of care.
- iii. However, the Welsh Government Strategy for Primary Care Services construes 'community services' as meaning 'primary care'. This is a major error: community services used by people with MND are mostly secondary or tertiary care. More specifically, the strategy defines primary care accurately, but goes on to assert that it also involves co-ordinating access to wider (ie secondary and tertiary) community services. This is not true for MND: care co-ordination is vital, but typically does not happen in primary care. We have previously warned of this error, for instance in our response to the green paper 'Our Health, Our Health Service'.
- iv. The strategy aims to create 'primary care clusters' for planning services at population levels of 25,000 to 100,000. This is clearly too small for less common diseases such as MND, which has a prevalence of at most 7 per 100,000: these clusters will typically contain numbers of people with MND far too small to plan any viable services around. It may be correct to note that there is a consensus in favour of planning primary care at this population level, but this underlines the error of confusing community services overall with primary care.
- v. We have conducted research into how care services for people with MND can best be arranged. Our Models of Care report identifies four key characteristics of MND care:
 - It must be co-ordinated
 - It must be multidisciplinary
 - It must involve MND specialism
 - It must involve community services.⁴
- vi. The points about co-ordination and specialism go hand-in-hand: effective MND care is co-ordinated by a professional with expertise in MND, either in the community or in a hospital clinic. The multidisciplinary teams that deliver MND care are not co-ordinated from primary care, and we are concerned that this initiative from the Welsh Government may undercut existing arrangements, and lead to effective MND provision being deliberately designed out of the system.
- vii. These concerns will be true not just of MND but of many rarer conditions, and no doubt some common ones. We recommend that the Committee investigate the impact of this strategy so far, and interrogate whether the apparent error contained within it is having, or will have, negative consequences for services. It might also ask: if the strategy is not having consequences for service redesign, good or bad, is it achieving anything?

⁴ MND Association, [Models of Care in MND](#), 2016

For further information contact:

Tim Atkinson
Campaigns Manager (West)
MND Association
David Niven House
10-15 Notre Dame Mews
Northampton
NN1 2BG

Tel: [REDACTED]
[REDACTED]

September 2016