



WF 20

Ymchwiliad i gynaliadwyedd y gweithlu iechyd a gofal cymdeithasol
Inquiry into the sustainability of the health and social care workforce

Ymateb gan: Multiple Sclerosis Society Cymru

Response from: Multiple Sclerosis Society Wales

Response to Health, Social Care and Sport Committee Inquiry into the sustainability of the health and social care workforce.

9th September 2016

1. Introduction

- 1.1.1. MS Society Cymru welcomes the opportunity to respond to the Health, Social Care and Sport Committee Inquiry into the sustainability of the health and social care workforce.
- 1.1.2. In particular we would like to respond to the particular question 'How well equipped is the workforce to meet future health and care needs?' The MS Society initially undertook a 'My MS My Needs in 2013 and found a postcode lottery of treatment, care and support, with apparent shortcomings and disparities in the services offered both across the UK and within Wales. This year, the MS Society conducted a survey of 11,024 people across the UK with MS making it the largest collection of patient-reported data from the UK MS community to date. The data presented here is from the 575 respondents who live in Wales. A section of the survey asked respondents to indicate their need for and access to support from various health professionals over the past 12 months, and as such this response only focuses on the health workforce, particularly those working in neurology.

2. Access to Disease Modifying Treatments

- 2.1.1. There are now 11 DMTs licensed for relapsing forms of MS, all with different efficacies, side effects and methods of administration. They can decrease the number and severity of relapses and slow the progression of disability. Added to this, there is now consensus among the MS and clinical community that early treatment with a DMT can improve long-term outcomes.
- 2.1.2. The recently revised Association of British Neurologists guidelines for prescribing DMTs recommends that decisions about treatment should be jointly taken by the person with MS and their neurologist, with treatment starting as early as appropriate after diagnosis. For people living with relapsing forms of MS, treating it early and effectively can suppress the disease and presents the best chance of preserving brain and spinal cord tissue during the course of the condition.
- 2.1.3. With the increasing number of treatments options, it's more important than ever that people living with MS are supported to make choices about their treatment, and can access the best treatment for them, regardless of where in Wales they live. In 2013 our survey found that access to DMTs in the UK was low (40% across the

UK) with Wales having the lowest rate - just 30% of people with relapsing forms of MS taking a DMT. It is encouraging to see that the number of people receiving DMTs in Wales has risen to 49% in 2016. This increase in DMT uptake demonstrates a significant positive improvement in MS healthcare in Wales. This is likely to be linked to the newer treatments that have become available on the NHS, which are judged to be more effective and easier to take. However compared to the rest of the UK; England (56%), Scotland (57%) and Northern Ireland (77%), access to DMTs among those who could benefit in Wales remains the lowest in the UK.

- 2.1.4. There are several drivers that make it more likely that a person will be taking a DMT. Access to health professionals and the right information are key; 81% of people who had access to MS Specialists and the right information in the last twelve months are taking a DMT, whereas only 20% of those who haven't accessed any of these services in the last twelve months are.
- 2.1.5. With an increasing number of treatments available, each with different support and monitoring requirements, it is vital that people with MS are fully supported to make an informed choice about their treatment. Conversations about treatment options, including DMTs, should begin close to diagnosis, with follow-up after diagnosis with a specialist within six weeks and again within six months. However, feedback from the MS community and clinicians in Wales suggest that timely follow up is becoming more and more difficult resulting in less time to assess people effectively, discuss treatment options and manage risks. With this added pressure on MS Neurologist and Specialist Nurse case-loads, people living with progressive MS tell us they feel they are being pushed further down the waiting lists with little or no support.

3. NICE Quality Standard for MS

- 3.1.1. People living with MS require access to professionals from all parts of the health and social care systems to best manage their condition. We believe that people with MS should have timely access to professionals and be at the centre of decision-making about their care. Published earlier in 2016, the NICE Quality Standard for MS recommends that people with MS have access to care from a multidisciplinary team with expertise in MS, and access to a comprehensive review of their treatment and care annually. This team should consist of a range of professionals including neurologists, MS specialist nurses, physiotherapists and occupational therapists, speech and language therapists, psychologists, dietitians, social care, continence specialists and GPs.
- 3.1.2. MS specialist nurses play a crucial role in the care and support of people with MS. Their role and responsibilities can be wide-ranging and varied but typically include providing information and support on how to best manage the condition and on DMTs, initiating and monitoring treatment for people with relapsing forms of MS, providing psychological support and co-ordinating care. 88% of people who needed to see an MS nurse were able to in the past twelve months, which is comparable to

the other nations of the UK. 11% of respondents had not seen an MS nurse but felt they had needed to. Given that people living with MS regularly cite their MS nurse as their key contact for treatment, care and support. (54% of respondents identified their MS Nurse compared to 14% who listed their GP) it is vital that this lack of access for some people with MS is addressed urgently.

- 3.1.3. NICE recommends that all people living with MS have a comprehensive review of all aspects of their care at least once a year, and that this review is carried out by healthcare professionals with expertise in MS. If a person is on a treatment, a comprehensive review could also be used to assess how that is working, typically including an MRI scan. There are only four neurologists who specialise in MS in Wales and all four are based along the M4 corridor in South Wales. The only other provision is provided by an MS specialist neurologist based at the Walton Centre in Liverpool who covers North Wales. Only 75% of respondents reported that they had their need to see their neurologist met. 17% had not seen a neurologist in the past twelve months but felt that they needed to.
- 3.1.4. Many people living with MS experience bladder and urinary problems, including incontinence and infections. Continence advisers can provide people living with the condition with information, for example about products and treatments for bladder problems, and confidential advice. In Wales 75% of respondents to our survey who had required specialist continence advice had received it. However, more than one in 10 (14%) people had not received this support despite needing to.
- 3.1.5. 48% of respondents had seen a physiotherapist in relation to their MS within the last year, but nearly 1 in 5 people (18%) had not seen a physiotherapist and felt that they needed to. Physiotherapy can have a significant impact on a person's rehabilitation after a relapse, or can improve movement and mobility for someone living with disability as a result of MS. Timely access to evidence based and appropriate physiotherapy should be a basic entitlement, available for everyone living with MS in Wales who could benefit.
- 3.1.6. Half the number of people living with MS experience anxiety and half experience depression, with many experiencing both. Moreover, there is a strong link between mental and physical health – in 2012, £1 in every £8 spent on long-term conditions was linked to poor mental health. Ensuring people living with MS can access emotional support is vital, however 28% of respondents said that they had needed emotional support in the last twelve months but hadn't received any/enough help or support.
- 3.1.7. NICE guidelines state that people living with MS should have access to a single point of contact who acts as a care and treatment coordinator and that care and treatment should be made available through multi-disciplinary teams. Care planning and care co-ordination has a vital role to play in ensuring that people living with MS can access the full suite of support they require to best manage their condition. Our survey found that overwhelmingly people in Wales reported that they had not been offered a care plan or a review of their care plan by their health

professional in the last 12 months (86%) For people to feel fully supported and empowered in their care, the MS multidisciplinary team must consist of health and social care professionals working with the person living with MS to achieve the best outcomes. When asked if they felt that the professionals who help plan their care worked well together, 18% of our survey respondents answered "not at all" meanwhile 15% responded "completely" and 34% "to some extent"

4. Treatment Options for People with progressive forms of MS

4.1.1. All the DMTs we have at the moment only work with types of MS that have relapses. New drugs are being tested to see if they work against progressive (non-relapsing) types of MS. We hope that the first one that works against primary progressive MS, ocrelizumab, will be available in 2017 or 2018.

4.1.2. People with primary progressive forms of MS make up approximately 15% of people diagnosed with MS. Of the 85% of people diagnosed with relapsing forms of MS, 65% will have moved onto secondary progressive MS after 15 years.

4.1.3 As highlighted earlier, as more treatments become available feedback from the MS community and clinicians in Wales suggest that timely follow up is becoming more and more difficult resulting in less time to assess people effectively, discuss treatment options and manage risks. Given that the system is already under pressure and understaffed (Public Health Wales Neurological Conditions Needs Assessment 2015 identified that there is a significant shortage of consultant neurologists in Wales and that this is compounded by a severe shortage of neurology clinical nurse specialists [an overall shortage of between 7.1 and 9.5 multiple sclerosis nurses]when only 49% of those with relapsing forms of MS who could benefit from taking currently available treatment taking them, we are very concerned about the workforce capacity to ensure that all those who are eligible for currently NICE/ AWMSG approved medicines and future NICE/ AWMSG medicines are able to access these treatments equitably across Wales.