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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: Multiple Sclerosis Society Cymru

Response from: Multiple Sclerosis Society Wales

Response to Priorities for Health, Social Care and Sport Committee

Over 100,000 of us in the UK have MS, with approximately 4,900 of us living in Wales. It's unpredictable and different for everyone. It's often painful, exhausting and can cause problems with how we walk, move, see, think and feel. But it doesn't have to be this way.

We're the MS Society. Whether you have MS, or care about someone who does, our community is here for you through the highs, lows and everything in between.

We understand what life's like with MS. And together we are stronger. We're researching, writing, campaigning and fighting. Running, walking, caring and talking.

Together, we are strong enough to stop MS.

1. Introduction

1.1 We welcome the opportunity to respond to your request for our views on what the priorities for the Committee should be for the first 12 to 18 months, we are using the findings of our recent My MS My Needs Survey to inform our view.

1.2 We first undertook the survey in 2013 and we discovered a postcode lottery of treatment, care and support, with apparent shortcomings and disparities in the services offered both across the UK and within Wales.

1.3 This year, we undertook a second survey to build on this research. This data provides an unparalleled insight into the challenges that still remain for people living with MS when accessing vital services and support to manage their condition.

1.4 Our research has shown us that while some improvements have been made, we still have some way to go to ensure that people living with MS are able to access the right treatment at the right time, no matter where they live in Wales.

1.5 Results from the survey in Wales show that; 49% of respondents who could potentially benefit from taking a disease modifying therapy (DMT) are doing so (an increase from 30% in 2013). Whilst this increase is positive we still lag behind the rest of the UK (56%), Scotland (57%) and Northern Ireland (77%).

2. My MS My Needs Survey 2016

2.1 The MS Society conducted a survey of 11,024 people across the UK with MS between February and April 2016, 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.

2.2 Access to effective treatments is the top priority for people living with MS in Wales. It is also the MS Society's number one goal to ensure that people living with the condition have access to effective treatments to reduce relapses and slow disease progression until the day we can stop MS. All figures related to DMTs are calculated among those who could benefit from these treatments (i.e. those with relapsing remitting MS or secondary progressive with relapses).

2.3 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. ⁱ

2.4 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.

2.5 By preventing relapses and disability progression, people living with MS should be able to take greater control of their condition and their lives, directly and indirectly improving physical, economic, emotional and social outcomes. Access to treatment and services helps people living with MS manage their condition, and to identify early signs of complications and put in place prevention and treatment strategies to avoid unscheduled hospital admissions. ⁱⁱ

2.6 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.ⁱⁱⁱ 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.

2.7 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.

2.8 There are also several symptom management therapies (SMTs) specifically licensed to treat MS, which can make a significant difference to the day-to-day lives of those living with the condition. These treatments can help with problems such as spasticity and walking or an overactive bladder. Licensed SMTs for MS include Sativex, Fampyra and Botox. Wales was the first UK nation to approve Sativex for routine use on the NHS in 2014. Yet, two years following its approval by the AWMSG, our survey revealed that only 1% of respondents are currently taking it.

2.9 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.^{iv} 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. Respondents to our survey were asked to indicate their need for and access to support from various professionals over the past 12 months.

2.10 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.

2.11 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.

2.12 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. Given that Public Health Wales identify that there is an overall shortage in Wales of between 7 and 9 Specialist MS nurses it is no surprise that 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 shortfall is addressed urgently.

2.13 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.

2.14 In 2013, 72% of respondents reported that they had their need to see their neurologist met. Our survey this year showed a 3% increase, with 75% of respondents saying that they had this need met. (17%) had not seen a neurologist in the past twelve months but felt that they needed to. Our survey shows that the more recently a person with MS was diagnosed the more likely they are to have seen a neurologist in the twelve months.

2.15 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.

2.16 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.

2.17 Other services that support people living with MS to remain physically active are important in helping them to remain healthy and independent in their day-to-day lives. In addition, research suggests that support to remain physically active has resulted in a decrease in GP and hospital consultant visits and reduced hospital bed days for people living with MS.^v More than a quarter (29%) of respondents said that they needed support to remain physically active but had not received any.

2.18 Half the number of people living with MS experience anxiety and half experience depression, with many experiencing both.^{vi} 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.^{vii} 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.

2.19 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.^{viii} 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”.

3. Conclusions

3.1 Our research has shown us that while some improvement has been made, we still have some way to go to ensure that people living with MS are able to access the right treatment at the right time, no matter where they live in Wales. It is encouraging to see that the number of people receiving DMTs in Wales has risen since 2013. However, access to DMTs among those who could benefit in Wales remains the lowest in the UK.

3.2 People living with MS require access to treatments to manage their condition to improve their outcomes. There are now 11 DMTs licensed for relapsing forms of MS approved for use but as we know only too well, they are not all equally available across Wales. With an increasing number of treatments options, it’s more important than ever that people living with MS can access the best treatment for them, regardless of where in Wales they live. The unacceptable delays in accessing new treatments are caused by a variety of issues including the under resourcing and lack of infrastructure in place to monitor a new treatment or drug and the process that Local Health Boards go through to add a new drug onto their formulary.

3.3 In 2014 Welsh Government published its Neurological Conditions Delivery Plan to ensure that those affected by a neurological condition have timely access to high-quality care, integrated with social services where appropriate, irrespective of where they live and how these services are delivered. The then Minister for Health Mark Drakeford stated that “in particular it is essential that NHS Wales and its partners focus on meeting our population needs, reducing inequalities in health and variation in access to services across Wales.”

3.4 As our survey illustrates there are still some areas where improvements still need to be made and we would therefore ask the Health, Social Care and Sport Committee to carry out a short Inquiry into the implementation of the Neurological Conditions Plan prior to the proposed refresh of the Plan in 2017.

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- ⁱ MS Society (2015) *Time to Act – a consensus on early treatment*
- ⁱⁱ Nhs. Measuring the burden of hospitalisation in multiple sclerosis: A cross-sectional analysis of the English Hospital Episode Statistics database 2009-2014 <http://www.nhs.com/uploads/reports/NHIS-MS-Report-2015.pdf>
- ⁱⁱⁱ MS Society (2013) *A lottery of treatment and care – MS Services across Wales and the UK*
- ^{iv} NICE (2016) *Quality Standard: Multiple Sclerosis*. <https://www.nice.org.uk/guidance/qs108>(Accessed July 2016)
- ^v Physiotherapy works. Multiple Sclerosis CSP January 2012
- ^{vi} Jones, Ford *et al.* (2012) A large-scale study of anxiety and depression in people with Multiple Sclerosis: a survey via the web portal of the UK MS Register. *PLoS One*, 7(7)
- ^{vii} The King's Fund (2012) Long-term and mental health: the cost of co-morbidities. http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf (accessed July 2016)
- ^{viii} <https://www.nice.org.uk/guidance/cg186?unlid=2967616602016128161311>