



**MS treatment in Scotland:
is access still a lottery?**



Foreword

There are over 11,000 people living with MS in Scotland, one of the highest prevalence rates of anywhere in the world. This fluctuating neurological condition affects not just those diagnosed but also their families and friends. MS can manifest itself in many different ways, from problems with vision, balance and mobility to issues with cognitive function and incontinence. Most people are diagnosed between the ages of 20-40, but it can affect younger and older people too. As yet there is no cure for MS.



However, the MS landscape has changed a great deal over the last 20 years, with research taking huge steps in understanding the condition, and treatments to reduce relapses and slow the progression of MS. There are now 11 disease modifying therapies (DMTs) licensed for relapsing forms of MS, with more on the horizon.

Public policy and guidance about how to treat and manage MS have been substantially revised. Crucially, we know that treatment with a DMT as close to diagnosis as possible improves long term outcomes for people with MS.

In 2013 we published the results from the first ever My Ms My Needs survey. We conducted the survey to find out how accessible treatments, services and support were for people living with MS in the UK. What we discovered was a postcode lottery, with disparities in the services offered both across the UK and within Scotland.

This year, we undertook a second survey to build on this research. The results documented in this report give us cause to celebrate the improvements that have been made. However we also need to understand and find solutions to the challenges that still remain for people with MS when accessing vital services and support to manage their condition.

Morna Simpkins
Director, MS Society Scotland

About MS

Over 100,000 of us in the UK have MS. 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 driving research into more – and better – treatments. For everyone.

Together, we are strong enough to stop MS.

Key findings

- ▶ In Scotland, 57% of those who could potentially benefit from taking a disease modifying therapy (DMT) are doing so (an increase from 36% in 2013).
- ▶ Only 6% of people are on a licensed treatment for the symptoms of MS. This is up from 2% in 2013, but is still incredibly low. One of these treatments, Fampyra, will be assessed by the Scottish Medicines Consortium (SMC) later this year. If it is accepted for use on the NHS, Scotland will be the first country in the UK to approve routine use of this treatment for people with MS.
- ▶ 72% of those who had seen an MS nurse in the last 12 months were taking a DMT, compared to 11% who had not seen an MS nurse within a 12 month period.
- ▶ 85% of respondents had their need for access to a neurologist met (an increase from 75% in 2013).
- ▶ Despite a policy drive from the Scottish Government to move from acute to community care, 80% of respondents saw their MS nurse in a hospital setting.
- ▶ 84% of respondents had not been offered a care plan by their health professionals.
- ▶ 13% of survey respondents answered “not at all” when asked if they felt that the professionals who help plan their care worked well together.
- ▶ More than one in four respondents identified their GP as their key contact for health care and support in relation to their MS.
- ▶ 23% of respondents required support to remain physically active in the last 12 months but had not received any.
- ▶ 21% reported they had not received the emotional support they needed.

Recommendations

The findings from our survey show that while improvements have been made, we still have some way to go to ensure that people with MS are able to access the right treatment at the right time, no matter where they live. To achieve the Scottish Government's ambitious and aspirational policies, including health and social care integration, 2020 Vision and the National Clinical Strategy, MS services will need to evolve and become person-centred, reactive and more community based.

We want to work with decision makers across Scotland to make our recommendations a reality for everyone living with MS.

1. All licensed treatments for MS should be made available on the NHS in Scotland, through local health board formularies.
2. Everyone living with MS should have an annual review with their MS specialist to discuss their treatment options, regardless of how long they have been diagnosed, as recommended by the 2009 Clinical Standards for Neurological Services.
3. In line with guidelines from the Association of British Neurologists (ABN), conversations about treatment options, including DMTs, should begin as close to diagnosis as possible.
4. The Scottish Medicines Consortium should accept Fampyra as a symptom management therapy for people with MS.
5. People with MS should be offered a comprehensive review with an MS specialist at least once a year that draws on expertise across a multidisciplinary team.
6. People with MS should be offered support across the breadth of the multidisciplinary team. This support should be accessible out with a hospital setting.
7. All people with MS should be offered a care plan, which should be regularly reviewed.
8. GPs should be supported to undertake professional development opportunities to support their patients with MS.
9. People with MS should be offered information and support at diagnosis to understand their condition and how it can be best managed. Their information and support needs should be reviewed regularly.
10. In line with the Scottish Government's priorities people with MS should be supported to self-manage, promoting physical and mental wellbeing and reducing medical interventions where possible.

Treat Me Right

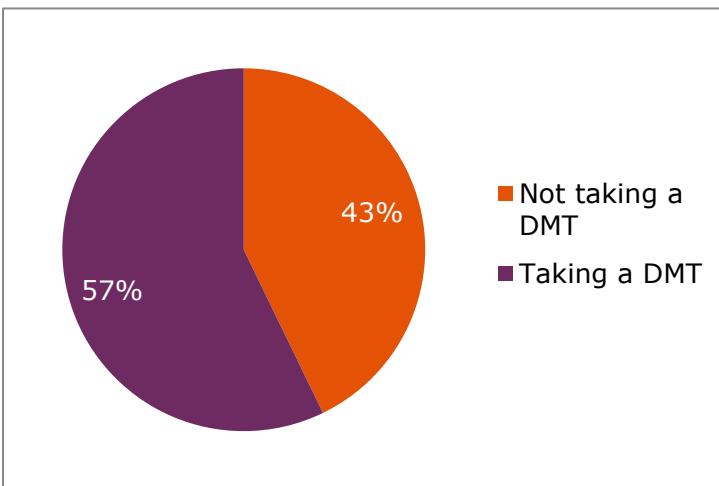
Our number one goal is to ensure people with MS have access to effective treatments to reduce relapses and slow disease progression until the day we can stop MS.

Access to disease modifying therapies

In recent years, several new disease modifying therapies (DMTs) for MS have become available. There are now 11 licensed DMTs for people with relapsing forms of MS. 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.¹

All figures related to DMTs are calculated among those who could benefit from these treatments (that is, those with relapsing remitting MS or secondary progressive with relapses).

Figure 1: Access to DMTs in Scotland



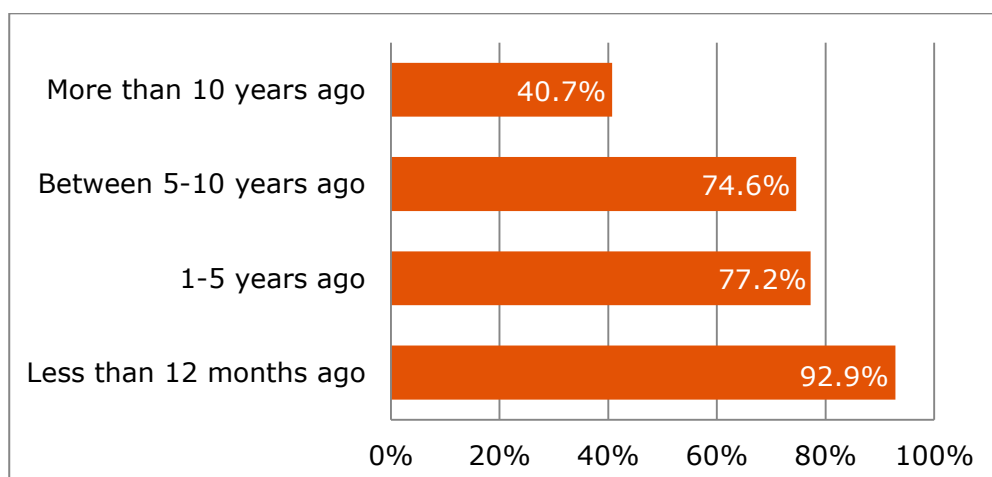
With an increasing number of treatments available, it's more important than ever that people with MS can access the best treatment for them, regardless of where in Scotland and the UK they live. It's encouraging to see the number of people receiving a DMT in Scotland increase to 57% of those who could potentially benefit, up from 36% in 2013. This shows real progress in the availability and accessibility of DMTs. Coupled with what we now understand about the importance of early treatment, this

increase in the use of DMTs demonstrates a significant improvement in MS health care.

However, this still puts us behind our counterparts in Northern Ireland, where 77% of respondents who could potentially benefit are taking a DMT.

There is also huge inequality between those who have been recently diagnosed with MS and those who were diagnosed some years ago. 93% of people diagnosed within the last 12 months are receiving a DMT, compared to just 41% who were diagnosed more than 10 years ago.

Figure 2: Access to DMTs by time since diagnosis



There are a number of factors that make it more likely that a person will be taking a DMT. Most important is access to professionals. 96% of people who had seen an MS specialist nurse in the last 12 months are taking a DMT, compared to only 3% who had needed to see their nurse but were unable to do so. Similarly, those people who had seen a neurologist in the last 12 months were more likely to be on a DMT (82%), compared to 4% who had needed to see their neurologist and been unable to do so.

Access to symptom management therapies

There are also several symptom management therapies (SMTs) specifically licensed to treat MS, which can make a significant difference to some people's day-to-day lives. These treatments can help with problems such as spasticity and walking or an overactive bladder. Licensed SMTs for MS include Sativex, Fampyra and Botox. In 2013 Botox was accepted by the Scottish Medicines Consortium (SMC) as a treatment for use on the NHS. Later this year Fampyra (which can significantly help with walking ability) will be assessed by the SMC. If this treatment is accepted by the SMC, Scotland will be the first country in the UK in a position to make Fampyra routinely available to those who could benefit from it.

At present Fampyra can only be accessed by making an Individual Patient Treatment Request (IPTR), meaning only a handful of respondents currently receive Fampyra (1%). In total, only 6% of respondents said they were on any of the listed symptom management treatments. Through Freedom of Information Requests we have found that there is huge variation in access to Fampyra across Scotland. We hope that if Fampyra is accepted by the SMC as a cost effective treatment we will begin to see parity of access to Fampyra across Scotland, meaning that anyone who could benefit from using it has the opportunity to do so.

Recommendations

1. All licensed treatments for MS should be made available on the NHS in Scotland, through local health board formularies.
2. Everyone living with MS should have an annual review with their MS specialist to discuss their treatment options, regardless of how long they have been

diagnosed, as recommended by the 2009 Clinical Standards for Neurological Services.

3. In line with guidelines from the Association of British Neurologists (ABN), conversations about treatment options, including DMTs, should begin as close to diagnosis as possible.
4. The Scottish Medicines Consortium should accept Fampyra as a symptom management therapy for people with MS.

The right support to manage my MS

Timely access to specialist health professionals is essential so people with MS in Scotland can access potentially life changing treatments. However, the role of health professionals in supporting someone with MS goes well beyond this.

The 2009 Clinical Standards for Neurological Services state that everyone living with MS in Scotland should have access to an “MS multidisciplinary team, consisting of, as a minimum: a consultant who specialises in the diagnosis and management of MS, an MS clinical nurse, the patient and carer. Additional input from other health professionals with experience and training in neurological conditions is offered from the following services: physiotherapy, occupational therapy, speech and language therapy, dietetics, neurorehabilitation services, pharmacy services, mental health services”.

Despite this requirement, the reality for many people living with MS in Scotland is quite different.

MS nurses

MS specialist nurses play a vital role in the care and support of people with MS. Their role and responsibilities can be wide-ranging and varied. Typically, these include providing information and support on how to best manage MS and on DMTs, initiating and monitoring treatment for people with relapsing forms of MS, providing psychological support and co-ordinating care. People with MS regularly cite their MS nurse as their key contact for treatment, care and support.

out of people who had seen an MS nurse



80% had seen MS nurse in a hospital setting.

85% of survey respondents had their need for access to a specialist MS nurse met. This is a welcome increase from our 2013 findings, when 83% of respondents had their need met. In 2015 the Scottish Government committed an extra £2.5million to specialist nursing posts for neurological conditions. This shows the importance of specialist nurses in managing neurological conditions. It is essential that everyone living with MS in Scotland has access to a specialist nurse.

Earlier this year, the Scottish Government published its National Clinical Strategy for Scotland, which sets out its overarching strategy to transform Scotland’s health and social care services. Key to this is a move towards: “more community-based services to replace some that have previously been provided in hospital”.

We would therefore expect to see shift of care from hospital to community settings. Yet our research shows the opposite, with 80% of respondents reporting they had seen their MS nurse in a hospital setting, compared to 74% in 2013. In fact, only 10% of respondents had seen their nurse in a community setting. With the National Clinical Strategy as a key policy driver, health boards will need to redesign their MS service, with more focus on outreach services and community based care.

The current service specification for neurological services is too defined by where care is provided, in particular within specialist centres, rather than who should provide it or what care is being provided.

Neurologists

There has been a significant improvement in people's access to a neurologist. In 2013, 75% of respondents reported that they had their need to see their neurologist met. This year we saw a 10% increase, with 85% of respondents saying that they had this need met.

MS is a fluctuating condition, and no two people will experience the same journey. It is essential that everyone with MS has an annual appointment with a neurologist so that their condition can be monitored and reviewed, and support can be responsive. There are also new treatments emerging, particularly those for progressive forms of MS, and as these treatments come on line i people with MS need to have timely contact with their neurologist in order to access them.

Professionals across the team

As stated in the 2009 Clinical Standards for Neurological Health Services, an MS multidisciplinary team may be made up of several different health professionals. We asked survey respondents about their access to other types of support including physiotherapists and continence professionals. Building capacity across a multidisciplinary team is another way of ensuring that people with MS can access the support they need. This will become increasingly important as the health and social care integration agenda progresses, particularly if these services are moved from an acute to a community setting.

40% of respondents had seen a physiotherapist in relation to their MS. 42% of respondents had not seen a physiotherapist in the last 12 months but indicated they did not need to. 17% had not seen a physiotherapist and felt they had needed to. For those who did see a physiotherapist, the sources of this support ranged, with the largest number of people receiving support from the NHS (30% of respondents). 6% received physiotherapy through private health care, another 6% through a charity or voluntary organisation and 1% through another source.

This shows a slight decrease from 2013, when 47% of respondents had seen a physiotherapist in relation to their MS. 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 physiotherapy should

be a basic entitlement, available for everyone living with MS in Scotland who could benefit.

Recommendations

1. People with MS should be offered a comprehensive review with an MS specialist at least once a year that draws on expertise across a multidisciplinary team.
2. People with MS should be offered support across the breadth of the multidisciplinary team.
3. People should have access to their multidisciplinary team out with a hospital setting.

Managing my MS

The 2009 Clinical Standards for Neurological Health Services state that: “patients with MS have access to a review by an MS specialist service at least every 12 months”.

This review can be led by a neurologist or an MS specialist nurse, but should draw on expertise from professionals across a multidisciplinary team. It should be tailored to the needs of the person with MS and cover symptoms, the disease course, general health and provide an opportunity for the person with MS to discuss how they feel they are managing their condition. If a person is on a treatment, a comprehensive review could also be used to assess how that is working and, if relevant, to discuss new treatments.

Care planning and care co-ordination has a vital role to play in ensuring that people with MS can access the full suite of support they require to best manage their condition. However, 84% of respondents had not been offered a care plan by their health

professionals. 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 with MS to achieve the best outcomes. 13% of survey respondents answered “not at all” when asked if they felt that the professionals who help plan their care worked well together.

1/4 identified their GP as their key contact for healthcare and support in relation to their MS.



We also asked respondents who their key contact was for health care or support in relation to their MS. The MS nurse was the most common key contact for 42% of people, highlighting the crucial role that they play in supporting someone to manage their condition. This second most common key contact was a GP (27%). With the new GP contract beginning in 2017, and the implementation of the National Clinical Strategy, the role of the GP will expand so we would expect this number to increase. To ensure that people with MS receive the right information, support and treatment we want GPs with MS patients to be supported to undertake professional training so they have a good knowledge and understanding of MS.

Recommendations

1. All people with MS should be offered a care plan, which should be regularly reviewed.
2. GPs should be supported to undertake professional development opportunities to support their patients with MS.

My MS, my choice

In 2008 the Scottish Government published its strategy for self-management, 'GauN Yersel', which set out its principles for the self-management of long term conditions in Scotland.

The government has further demonstrated its commitment to self-management by setting up the Self-Management Fund. This supports projects promoting and developing self-management for people living with long term conditions in Scotland, to "promote a shift in the current model away from people being passive, dependent recipients of care to a model that engages, empowers and supports people in a partnership approach with their health care professionals, carers and community".ⁱⁱⁱ

However, to achieve such a person-centred health service as detailed in the Scottish Government's 2020 Vision, a pre-cursor to the National Clinical Strategy, people need to feel empowered and informed to make decisions about living with their condition. This includes decisions about which treatments to take. 78% of respondents who felt they had received enough information about available treatments chose to take a DMT.

Staying physically active

Services that support people with MS to remain physically active are important in helping people 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 with MS.^{iv}

Each year a person with MS is absent from work for an average of 16.6 days due to their MS. At a full time living wage (35 hours per week) this equates to £958.65 each year in lost revenue. Additionally, when we consider the cost of medical interventions each acute bed day in NHS Scotland costs £595 and the cost per in-patient intervention for a person with MS is £4,396.^v

Supporting people to remain physically active is a key tenet of self-management and demonstrates the value in investing in preventative approaches. 23% of respondents required support to remain physically active in the last 12 months but had not received any. 27% had received some form of support, but sources of this support varied – only 8% of all respondents received it from the NHS. 5% received support

in the last 12 months
1/4 of respondents



required support to remain
physically active

...but had not received any

from their local council, 7% from a charity or voluntary organisation and 10% from somewhere else. This suggests that statutory services can play an increasing role in supporting people with MS to remain healthy and independent.

Support to stay physically active is crucial to the successful delivery of the Scottish Government's 2020 Vision and the National Clinical Strategy, both of which put self-management and prevention at the heart of Scotland's future health care.

Emotional support

As with access to support to remain physically active, people with MS received emotional support from various sources. 22% respondents indicated they had received emotional support in the last 12 months. 15% of respondents received it from the NHS, 4% from a charity or voluntary sector organisation, 2% through a private organisation and 3% from somewhere else. While 54% indicated that they had not accessed emotional support and felt they did not need to, 21% had not accessed support and felt they needed to. Given the strong links between mental and physical health, it is important that people with MS are able to access such services when they need them.

Recommendations

1. People with MS should be offered information and support at diagnosis to understand their condition and how it can be best managed. Their information and support needs should be reviewed regularly.
2. In line with the Scottish Government's priorities people with MS should be supported to self-manage, promoting physical and mental wellbeing and reducing medical interventions where possible.

Our commitment

We will use evidence and insight and work with others to support implementation of these recommendations by:

- ▶ Providing reliable information and support to enable people with MS to take control of their lives.
- ▶ Supporting people with MS to connect with other people with the condition.
- ▶ Funding the best, most relevant research to enable new treatments to reach people with MS as quickly as possible.
- ▶ Campaigning for fair and appropriate access to treatment, care and support for every person with MS.



Strength in numbers

We conducted a survey of 11,024 people across the UK with MS between February and April 2016, making this the largest collection of patient-reported data from the UK MS community to date.

75% of the sample completed a paper-based survey, sent out to MS Society members, and 25% responded through an email link via the MS Register and Shift MS. Due to age and gender bias in our sample, the data has been weighted to be representative of the UK MS population.

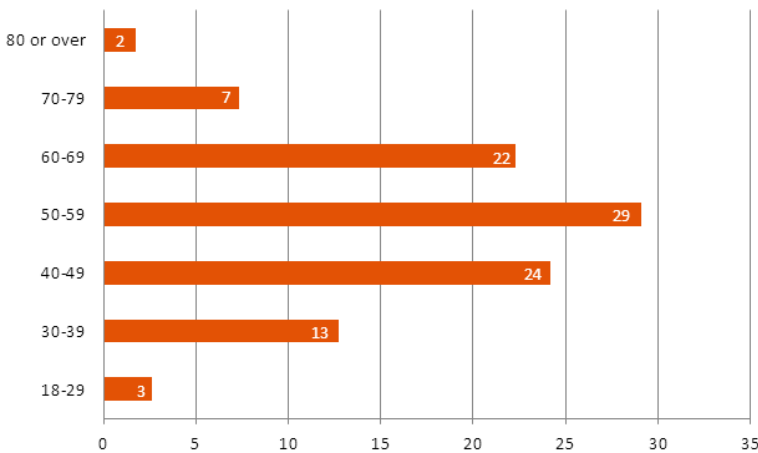
There are an estimated 11,000 people living with MS in Scotland.^{vi} The data presented in this report is from the 939 respondents who live in Scotland.

75% of respondents were women, 25% men. The majority were aged 50 to 59 years, and 64% were diagnosed more than 10 years ago. 74% of respondents had relapsing remitting MS.



3/4 of respondents were women

Figure 3: Age of respondents



This report focuses on the treatment, health and care aspects of the survey. Many of the figures cited are the proportion of people with a given need who said that this need was met, that is the number of people who answered 'Yes' to a specific question, divided by the number of people who answered either 'Yes' or 'No, but I needed to'.

References

- ⁱ MS Society (2015) *Time to Act - a consensus on early treatment*, London, MS Society
- ⁱⁱ The Scottish Government (2016) *A National Clinical Strategy for Scotland*, p9, Edinburgh, the Scottish Government
- ⁱⁱⁱ Scottish Government's principles of self-management <http://www.gov.scot/Topics/Health/Support-Social-Care/Self-Management> (Accessed August 2016)
- ^{iv} Chartered Society of Physiotherapy (2012) *Physiotherapy works: Multiple Sclerosis*. <http://www.csp.org.uk/professional-union/practice/evidence-base/physiotherapy-works/multiple-sclerosis> (Accessed July 2016)
- ^v Scottish Health Service, *2013/14 Scottish Tariffs for Cross Boundary Flow Costing* <http://www.isdscotland.org/Health-Topics/Finance/Publications/2013-10-29/1314ScotTariffs.xls> (Accessed August 2016)
- ^{vi} MS Society estimate based on 2010 incidence and prevalence rates (Mackenzie et al. 2013) adjusted for accuracy based on the assumption that 82% of cases from this study can be validated (estimate based on Alonso et al. 2007). These adjusted rates have been applied to 2014 population estimates (Office of National Statistics).

We're the MS Society.

Our community is here for you through the highs, lows and everything in between.
We understand what life's like with MS.

Together, we are strong enough to stop MS.



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▶ Let's stop MS together
