

**Right Treatment, Right Time
– Understanding MS Prescribing
in Scotland**

Exploring prescribing
perspectives of the MS
community in Scotland

World MS Day
May 2018

Let's stop MS together

1. Foreword

Across Scotland more than 11,000 of us live with multiple sclerosis (MS). It can affect the way we think, feel, see and move. It is a lifelong condition with no cure at present, however, over the past 25 years we have seen great strides made in treatments for people living with the relapsing form of the condition.



Access to disease modifying therapies (DMTs) can play an important role in an individual's MS journey, helping to reduce relapses and slow down the progression of the condition.

The decision to take a DMT and which one to take can be a difficult one. The range and complexity of treatments can often be confusing, some are more effective than others, and they have different methods of administration such as injection, tablets and infusion, and sometimes come with side effects and potential risks.

We wanted to find out more about the reasons people have for their treatment decisions and whether they felt there were any barriers in place to them

accessing treatments. This report outlines our findings and indicates an improved treatment environment for many people living with MS in Scotland.

What was abundantly clear throughout was the important role of neurologists and MS nurses in supporting people with MS. The hard work and dedication of MS health professionals cannot be underestimated and it's important for us all to recognise their invaluable contribution.

The growing range of treatments means that for people with MS the treatment landscape is becoming increasingly complex. And the way we access information and support is changing every day. Thanks to the internet and social media, accessing this has never been easier, or more complex. There is a role to play for all of us in the MS community to make sure people are being supported and that advice and information is easy to access and understandable. We will now work with stakeholders to push for our recommendations to be adopted in Scotland.

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.

2. Introduction and Recommendations

This report explores the reasons people have for taking particular treatments, what influenced their decision and what levels of choice they had. It takes perspectives from across the MS community and seeks to understand any potential influences and barriers to treatment in Scotland.

In undertaking the research for this report we gathered 438 survey responses from people living with MS in Scotland, we spoke to MS nurses and carried out focus groups. We also utilised findings from our 2016 report "MS treatment in Scotland: Is access still a lottery?".

Recommendations

Our report comes to five key recommendations. These are all discussed in greater detail at the end of the report.

1. There is a need for the Scottish Government and the NHS to continue to invest in specialist MS nurse and neurology services across the country.
2. People with MS need to be treated as individuals with their preferences and needs being respected and factored in to decision making processes and care planning.
3. Increased availability of information regarding DMTs that includes details regarding efficacy, side effects and associated risks.
4. Improved definitions of what constitutes a relapse, a significant relapse and a disabling relapse are required.
5. Increased access to support to enable assessment of relapses.

3. The DMT landscape

Disease modifying therapies (DMTs) can treat people who have relapsing MS. These treatments can mean people get fewer, and less serious, relapses. They can also slow down the progression of the condition. The Association of British Neurologists (ABN) recommend that treatment with a DMT should start as early as possible for people who are eligible to take one¹.

People with relapsing MS now have more treatment options than ever. In 2009, there were only five DMTs available, now there are 12. There aren't currently any treatments available for people living with progressive forms of MS on the NHS. However the very first treatment for primary progressive MS (ocrelizumab) was approved for licence in January 2018, and is expected to be assessed by the Scottish Medicines Consortium by the end of the year.

Alongside the increase in the number of treatments available we have seen an increase in the effectiveness of treatments. The different treatments carry their own side effects and risks, and so have their own treatment protocols and monitoring processes, all of which have different implications for an MS service. There are also a variety of administration methods with DMTs now available as injections, tablets and infusions. Finally, your treatment options are affected by how 'active' your MS is (as defined via MRI) - people have the option to escalate the treatment they are taking, dependent on how they respond to treatment, or opt for a more efficacious, higher risk treatment first, if their MS is highly active.

Access to DMTs

DMTs can reduce relapses and slow progression of MS, and the right treatment can support people with MS to take control of their condition. As an organisation guided by the priorities of people living with MS, our number one goal is that people with MS will have access to effective treatments, including treatments which can slow, stop or reverse the accumulation of disability. However, despite the increased number of treatments available for relapsing MS, evidence suggests that prescribing rates in the UK are lower than other countries in Europe², and that rates vary across the UK.

DMTs currently available on the NHS in Scotland:

- Alemtuzumab
- Avonex
- Betaferon
- Cladribine
- Dimethyl fumarate
- Extavia
- Fingolimod
- Glatiramer Acetate
- Natalizumab
- Plegridy
- Rebif
- Teriflunomide

¹ Scolding, Barnes et al (2015) Association of British Neurologists, Revised (2015) guidelines for prescribing disease-modifying treatments in multiple sclerosis. Practical Neurology, 0, 1-7

² Kobelt G, Kasteng F. Access to innovative treatments in multiple sclerosis in Europe. (2009) Brussels: The European Federation of Pharmaceutical Industry Associations; (EFPIA),

Our 'My MS, My Needs 2' survey of 10,888 people with MS in the UK, found that in Scotland in 2016, 57% of people who could benefit from a DMT are taking one³. This is an increase from our survey of 2013, which found just 36% of people with MS who could benefit from a DMT were taking one.

While this increase is welcome, it still leaves room for improvement. Increased access to treatment also has implications for MS services; they may not have the resources available to support access, meaning having to make difficult decisions about how to allocate resources to the benefit of all people with MS, not just those who may benefit from a DMT.

The most recent data on prescribing

The most recent data we have on prescribing shows that across the UK, with the exception of January 2016, there has been a consistent increase in prescribing from May 2015 to September 2017. Overall representing a 19% rise in prescribing. To find out more about prescribing in Scotland, in 2016 and 2017 we submitted Freedom of Information (FOI) requests to all the Health Boards in Scotland asking them to provide details on the number of people with MS who were currently being prescribed DMTs⁴.

All the Health Boards in Scotland provided details, with the exception of NHS Orkney. Due to the small number of people on a DMT within the NHS Orkney Health Board there were concerns that releasing the data would potentially make individual patients identifiable⁵.

This data further demonstrates that the rate of prescribing DMTs for people with MS has continued to increase over recent years.

- In 2016 the total number of people being prescribed a DMT, was **3,842**. When the exercise was repeated a year later in 2017 this had increased to **4,402** people being prescribed a DMT⁶.
- Overall there have been a minimum of **560** new DMT prescriptions during the year. It is useful to note some people will also have had their treatment stopped during this period.

<http://www.comparatorreports.se/Access%20to%20MS%20treatments%20-%20October%202009.pdf> (accessed 29 May 2018).

³ Redfern-Tofts, D., Wallace, L. and McDougal, A. (2016) My MS, My Needs 2: technical report, <https://goo.gl/sdaErz> (accessed 29 May 2018)

⁴ At the time there were eleven treatments available, the twelfth, Cladribine (Mavenclad), became available in 2018.

⁵ Other Health Boards also expressed some concerns regarding patients being identifiable when the number of people on a specific treatment was less than 5. When this was the case the response was less than 5.

⁶ This figure does not take in to account the Health Board responses where the number of people on a treatment was less than 5 as health boards couldn't provide definitive figures below this number; as a result the actual FOI data figure could actually be slightly higher than reported.

4. Prescribing Practices

As the evidence demonstrates there has been an increase in prescribing rates over recent years. We've spoken to MS professionals and people with MS across the country to better understand the factors that have led to this increase, identify any barriers that still exist, and consider the variety of factors that influence treatment decisions.

Scottish MS nurse perspective

In order to find out more about the influencers and barriers around prescribing, we spoke with MS specialist nurses at one of their regular peer support meetings. The views of the nurses varied depending on the individual and the Health Board where they worked. The key themes that emerged from these discussions were:

- The MS nurse role has changed considerably. Much of this change has been brought about due to the emergence of new treatments and the activities related to administering, monitoring and advising on these treatments. Despite this, it was felt that the majority of services hadn't seen an increase in capacity to manage this additional workload and that this has a knock on impact on the capacity of MS nurses to support people with progressive forms of MS.
- Advances in treatment mean that in the near future there may be a treatment available for some people with primary progressive MS available on the NHS, ocrelizumab. Around 15% of people with MS are initially diagnosed with primary progressive, although not all will benefit from ocrelizumab. There was a view that consideration has not been given to how services would cope with any additional demand this may bring. The majority of nurses we spoke to reported that in their experience everyone who is eligible is offered a DMT.
- A key issue the nurses faced during prescribing discussions was how understanding of who was eligible for a DMT can differ between people with MS and clinicians. This was also problematic during discussions around potentially changing or escalating treatments. People with MS aren't always aware of the criteria that underpin prescribing practices, and so there are lots of cases when they do not report enough information about their condition and relapses to clinicians, which can cause problems for making reliable treatment decisions. If you have relapsing MS it is highly likely there is a treatment that is right for you, but accurate reporting of relapsing is critical to access to DMTs.
- The nurses felt that relapses can sometimes be dismissed or minimised by people with MS or their GPs due to the nature of their symptoms. In some cases this lack of awareness or understanding of symptoms and their escalation means they go unreported. The nurses referred to 'hidden' symptoms such as fatigue, cognitive problems and altered sensation.

- Another area that the nurses identified as key to good prescribing practice is information. In particular making sure that people with MS have understood and processed the information they have researched or been given enough time to reflect on this information and consider their options.

The nurses reported barriers that can impact this, including lack of up-to-date information in clinics and people with MS not having enough time to process the information. One of the ways this lack of information can impact is in terms of people understanding the risks associated with not adhering to their DMT and stopping and starting treatment.

The nurses advocated giving each person the right amount of time to explore their decision and make sure they start the right treatment for them. In some cases they feel that the message of starting treatment as early as possible can add pressure to this situation and rush some people with MS to making a decision about treatment which isn't necessarily right for them. They reported that in some instances this has led to non-adherence with treatment regimes.

In summary

The consultation with MS nurses identified four key areas that help to create positive prescribing practise:

1. The provision of high quality information for people with MS and professionals.
2. People with MS having questions answered quickly and receiving guidance.
3. Being given the appropriate time and support to process diagnosis, treatment options and information.
4. MS nurse services having the capacity to provide effective support.

5. People Living with MS

We consulted people living with MS about their experience of the prescription of DMTs, by holding two sets of focus groups and an online survey.

Focus groups

Two focus groups were held, one in Glasgow and one in Dundee, with a total of eighteen people with MS and four family members and carers.

The initial plan for the focus groups was to discuss these issues to see if there was a general agreement among people with MS as to what influenced their decision making in relation to DMTs. What became apparent was that this was a very nuanced, individual process. The only common response was that almost every attendee had discussed their decision with their MS nurse.

Although there were no obvious trends emerging from the focus groups what it did confirm was the need to explore the DMT decision making process with a much broader section of the MS community.

Online questionnaire

Following the focus groups we conducted an online questionnaire to gather more data in relation to the decision making process regarding DMTs. In total, **438** people living with MS in Scotland responded to the survey⁷ which asked a range of questions about peoples experiences of accessing treatments and their preferences.

Each territorial Health Board in Scotland was represented in these responses. The number of responses ranged from two in the Western Isles and Orkney to 77 in Greater Glasgow and Clyde with the largest response coming from NHS Lothian with 82 respondents.

DMT prescribing

- 83% of respondents reported that they had relapsing remitting MS. For the purposes of analysis this figure was used to indicate the people who may benefit from a DMT.

⁷ The survey was shared via direct email to MS Society mail subscribers and via social media.. It was targeted at people who identified as having relapsing MS. The sample is therefore to an extent self-selecting.

- 87% of people who could benefit from a DMT had been offered one
- 51% of people who were taking a DMT had started within six months of being diagnosed with MS
- 14% started within six months to a year of their diagnosis.

Given what we know now about the benefits of early treatment⁸, these figures provide a positive picture of prescribing in Scotland.

Decision making

A key focus of the survey was to find out what level of choice people wanted when deciding on DMTs.

- 54% of people told us that they would prefer to have some degree of choice or control in relation to making a decision about DMTs.
- 27% who are taking a DMT reported that they didn't want any involvement and wanted their neurologist to make the decision for them.
- A further 13% of people wanted to be given a single treatment option and then be given some time to do some research into the treatment.

This raises questions about how clinicians can plan discussions about prescribing and how much choice they delegate to people with MS. It is clear however that decisions about treatment are highly personal and vary significantly from person to person:

- 19% of people stated that they would like to be given a curated choice of two or three treatments.
- 18% would have preferred to be told all the treatments for which they were eligible and be given time to research these options.
- 17% wanted to research their options prior to discussing treatment with their neurologist.

We also asked people who they felt was in control of the decision making process:

- Encouragingly 65% of people felt that this was either a joint decision or that they were in control of the decision. It shows that people with MS generally are feeling empowered and are participating in the decisions that are being made about their health care.

⁸ The Association of British Neurologists Revised (2015) Guidelines for Prescribing Disease-Modifying Treatments in Multiple Sclerosis. <https://www.theabn.org/news/abn-ms-guidelines-2015l.html> (Accessed 29 May 2018)

- 19% felt that their neurologist was in complete control of the decision regarding treatment.

Factors that influence decision making

We asked which people had the most influence on their decision on whether or not to take a DMT. The top three were;

1. Neurologist
2. My MS Nurse
3. Spouse/Partner

This is unsurprising as the neurologist is the first person that is likely to discuss the possibility of DMTs with someone, and is the person most likely to prescribe the treatment.

However when we then asked how useful these people were when making a decision 74% said their MS nurse was useful or very useful, and 70% said their neurologist was useful for very useful. This gives weight to the view expressed by the MS nurses that having capacity within the MS nurse service is key to supporting people with MS to make informed decisions about DMTs.

We also explored which sources of information people used while making their decision. One of the key sources of information that the MS nurses said they would signpost people to was the MS Decisions website, they also reported that the vast majority of the neurologists they worked with would signpost to this website. However, 58% of respondents said they had not used this as a source of information at all while making their decision.

Other than the clinical team, the two most popular sources of information were MS charities, the MS Society and the MS Trust. For both charities, 46% of people rated their information as either useful or very useful. Only 25% of people did not access MS Society information at all and 39% did not access MS Trust information.

Effectiveness of information

The table below illustrates how people were feeling when they made their decision about DMTs.

Over two thirds of people felt that they had enough information to make an informed decision; we also found 12% of respondents did not want to have any information at all and wanted their neurology team make the decision for them. Further to this, 6% of respondents felt overwhelmed by the amount of information that they received.

I didn't have enough information to allow me to make an informed decision	10%
I had enough information to allow me to make an informed decision	68%
I had too much information and I felt overwhelmed by it	6%
I did not want/need any information. I wanted the neurology team to make the decision for me	12%
Not sure	4%

Additionally, when asked to agree or disagree with the following statements, 65% of people either agreed or strongly agreed with them:

- I knew which DMTs were available for me
- I knew the benefits of each DMT
- I knew the risk and side effects of each DMT
- I was clear about which benefits mattered most to me

However this means that a significant minority were unable to agree or actively disagreed with these statements. This again highlights the need for appropriate information and resources being made available to support people with MS to make informed decisions about DMTs.

Time to make a decision

At our focus group with MS nurses, the length of time people were given to make a decision was raised as a concern. A number of nurses believed that some people had to rush their decision about starting a DMT and that they had not been given enough time to fully evaluate their options.

NICE Quality Standards for MS recommend that conversations about treatment options, including DMTs, should begin close to diagnosis, with follow-up after diagnosis within six weeks and again within six months.⁹

However, from our survey we found that;

- 6% of respondents stated that they would have liked more time to make their decision.
- 14% of people felt that the decision making process took longer than they would have liked

⁹ NICE (2016) Quality Standard: Multiple Sclerosis. <https://www.nice.org.uk/guidance/qs108> (Accessed 29 May 2018)

- 79% of respondents said that they had been given the right length of time to make their decision.

In light of the importance of early treatment it is encouraging that only a small percentage of respondents felt that the decision making process took too long.

In summary

Overall the survey responses presents a positive outlook on the decision making process for people with MS in Scotland. The majority of respondents felt they had the time and information to make an informed choice. The responses highlighted the range of input and choice people want to have in their treatment – of those that wanted a choice the majority felt they had been offered it. Finally, respondents were clear on the importance of MS nurses and neurologists in their treatment decisions and saw them as key players when coming to a decision.

6. Conclusion

The report shows that good progress has been made in recent years with an increase in prescribing rates and broadly positive experience of decision making.

Further opportunities exist however to ensure a positive experience for someone living with MS at the start of their treatment journey; not everybody with relapsing forms of MS has been offered a DMT, whilst others felt that it is still taking too long for them to be starting on a treatment, and 10% of respondents didn't feel they were in a position to make an informed decision about treatment.

Coming to a decision about treatments for MS is complex and multi-faceted, with a number of factors impacting on the decision making process. These factors range from how people perceive risk, preference of tablet over injection or vice versa, the availability of information that enables someone to make an informed decision and potentially having timely access to an MS nurse. This is not an exhaustive list, but it does demonstrate that this is a decision that is nuanced and very dependent on the individual, their outlook and personality.

When treatment options are offered or discussed, people have very different views on how this process should unfold. Some people with MS want to be fully involved in researching their treatment options and to lead the decision making process, while others want their neurologist to make the decision for them. The report has highlighted a number of barriers and influences that impact this decision.

Further to this the report highlighted a need to increase the awareness and understanding of the criteria that neurologists use to decide if someone is eligible for a DMT or not, and improved awareness among people with MS about what constitutes a relapse.

Finally, throughout the report there are two factors that have an impact on almost all stages of the decision making process. These are access to an MS nurse and the provision of quality and accurate information.

7. Recommendations

1. There is a need for the Scottish Government and the NHS to continue to invest in specialist MS nurse and neurology services across the country.

Further investment is required in specialist MS nursing across Scotland. Through increasing the capacity of MS nurse teams they will be able to dedicate time to effectively support people who are making decisions about DMTs, whilst still providing support to people with progressive forms of the condition.

The specialist knowledge of the MS nurse role helps ensure people are offered appropriate treatments – reducing relapses and improving long term outcomes for people with MS. In recent years we have seen rising concerns about workforce planning and its potential impact on MS services in Scotland. The NHS and Scottish Government needs to consider its approach to workforce planning to guarantee the resilience of MS services.

2. People with MS need to be treated as individuals with their preferences and needs being respected and factored in to decision making processes and care planning.

It is clear from our research that making a decision about DMTs is a very individual process. The nuances of this include being allowed enough time to accept the diagnosis and research treatment options, explore personal attitudes towards risk versus benefit, analyse potential side effects and review the potential impact of treatments on lifestyle. Decisions about treatment are as individual as every person with MS – healthcare professionals need to be flexible to the wishes, goals and needs of each person with MS. This also relates to the need for broader individualised care planning, something that was highlighted in our 2016 report “MS treatment in Scotland: Is access still a lottery?”.

3. Increased availability of information regarding DMTs that includes details regarding efficacy, side effects and associated risks.

While the survey results are positive in that the majority of people feel they are making an informed decision about treatment there are others that don't have access to the information that they want and need. Many sources of information currently exist but they are not always being accessed. There is a need to explore different models of information provision to identify the most effective way of supporting people to access the information that they want and need to inform their decision making. The MS Society has an important role and responsibility to play in ensuring information is available and accessible at the point of need.

4. Improved definitions of what constitutes a relapse, a significant relapse and a disabling relapse are required.

Providing clarity in terms of these definitions and how they impact on prescribing decisions will empower people to be more proactive in terms of reporting relapses. Accurate reporting of relapses would result in improved decision making as clinicians

will have a better understanding of a person's condition. This would also provide more consistency across the country in relation to treatments being offered and provided.

5. Increased access to support to enable assessment of relapses.

In most cases people with MS will contact their MS nurse to inform them of a change to their symptoms or report a relapse. Alongside an improved understanding among people living with MS of what constitutes a relapse, quick access to an MS nurse for face to face assessment, where appropriate, or other form of support would be beneficial. Such a system that ensured the extent and impact of a relapse quickly and accurately would provide more detail to clinicians and help improve long term outcomes for patients. This relates to the earlier recommendation for continued and targeted investment in MS services.

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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