



Disease Modifying Therapies for Multiple Sclerosis:

A Review of the Perspectives of Irish People with MS



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Survey designed and conducted and report written by Harriet Doig, Information, Advocacy and Research Officer, MS Ireland.

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Forward



Friends,

Welcome to MS Ireland's new report "**Disease Modifying Therapies for Multiple Sclerosis: A Review of the Perspectives of Irish People with MS**".

Access to treatments and medications is a key part of MS Ireland's advocacy agenda. In 2015, we launched our Access to Medicines Campaign Handbook, to help people with MS to advocate on their own behalf to get access to the treatments they needed. In 2017, we released our report "Time to Act – A Consensus on Early Treatment" which made the case for starting

treatment with disease modifying therapies (DMTs) as soon as possible after a diagnosis of MS. This report also made a number of key recommendations for policy makers on the need to properly resource Ireland's critically overstretched neurology services so people with MS can have access to a level of treatment and care that is in line with international standards of best practice. MS Ireland has also been engaging in collaborative advocacy and lobbying with a number of other organisations to try and improve the systems by which new medications are made available in Ireland – currently we lag far behind the rest of Europe in this regard.

This is an exciting time for MS treatments. Two new DMTs for relapsing remitting MS have received licenses from the European Medicines Agency in the last two years, and in 2017 we also received the news that the first ever DMT for progressive MS has received a license. It is amazing to think how far we have come in terms of treatment options for people with MS in a relatively short space of time, given that the first ever DMTs were only launched 22 years ago. This also gives us cause to be excited and optimistic that even more effective treatments will become available in the near future.

With this in mind, this new report is very timely. As well as providing further evidence to support our ongoing advocacy work to improve access to medications and call for investment in neurology services, the results will also guide us as to what information and supports people with MS need to help them choose and manage DMTs from an increasing range of options.

I hope you enjoy reading this report. I'd also like to take this opportunity to thank the 236 people with MS who took the time to complete this survey – it is through research such as this that we are able to build an evidence-based platform to campaign on behalf of the MS community and deliver resources and services that meet the needs of Irish people affected by MS.

Kind regards,

Ava Battles
CEO

Dear All,

I am one of the statistics you are reading about in this report. I take a DMT. It means that I can play an active part in raising my children. It means that I can still walk and use my hands. It means that I can live a semi-active life. It means that I can still work and pay my taxes. Simple things you take for granted like washing, feeding and dressing myself continue to be possible because I take a DMT.



The Irish Government pays for my DMT. I know that this is not the case in a lot of other countries. This removes one of the many stresses of living life with multiple sclerosis. I am grateful for this.

Had I been diagnosed 22 years ago, there would have been no DMTs available to me. Medicine research and design has come a long way since then. I am grateful for this.

I know that my DMT is working as my last MRI scan showed no evidence of disease activity. I am grateful for this.

I feel great sorrow for people living with primary progressive MS as they currently do not have access to a DMT. I feel that it is unfair that I have such a choice of treatments and they have none.

I feel that there needs to be more two-way communication between Irish people living with multiple sclerosis, healthcare providers and policy makers. This survey is a way for us to say that "We Are Here" and express our needs and opinions in one clear voice. We want to participate. We don't want to stand at the sidelines. We want to play a part!

I feel hope that the multiple sclerosis community in Ireland is empowered by expressing itself through the results of this survey. Together we are stronger. Please consider the findings and recommendations.

Taking a DMT means that I can type this letter.

Thanks for listening!

Joan Jordan

**EUPATI Content Co-ordinator,
MS&Me Blogger & MS Advocate**

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Executive Summary

MS Ireland conducted a survey in September 2017, distributed via the MS Ireland website and social media channels. The sample consisted of **236 people** with MS. Of these, over **80%** had relapsing remitting MS. **14.8%** were aged 18-30, **57.2%** were aged 31-50, **26.3%** were aged 51-65 and **1.7%** were aged 65+.

Key findings:

- Nearly 84% of the sample was currently taking a DMT. 16% were not currently taking a DMT
- The most commonly reported reason why a person with MS had chosen not to take a DMT was that they felt their MS symptoms were mild and they therefore did not need to
- Experiencing relapses while on treatment and side effects were the most commonly reported reasons for changing from one DMT to another
- Gilenya® was the most widely taken DMT, followed by Copaxone®, then Rebif®. Among those who had only ever taken one DMT and never changed, Tecfidera® was the most widely used
- Nearly 75% started taking a DMT within a year of diagnosis
- Among those who were diagnosed 10 years ago or less, 82.4% had started treatment within a year of diagnosis, compared to 57.5% of those diagnosed more than 10 years ago
- 67% felt that they had been given enough information by their healthcare professional team about the range of treatment options available. Nearly 25% felt they had not been given sufficient information
- 76.8% said that the information given to them about different medications was clear and easy to understand. 16% said that it was not and 7.3% were unsure
- 69% said they had received enough information about the benefits and risks of different DMTs to make informed decisions. 21.8% said they had not
- 74% had experienced a side effect from taking a DMT
- Of those who had experienced side effects, 88.7% had reported the side effect, 6.6% hadn't and 4.6% were unsure what it meant to report a side effect
- The MS Nurse was the most popular choice to report a side effect to (70.7%) followed shortly by the neurologist (69%)
- The majority reported that they found the experience of managing and administering their DMTs either easy (44%) or fairly easy (43%). 10.4% found it hard and 2.5% found it very hard
- 36% said managing administering their DMT had not impacted on their daily life at all, 48.5% said it had impacted somewhat, 11% quite a lot and 4.5% a great deal
- 37% were very satisfied with their current DMT, 34% were satisfied, 14.2% were neither satisfied or dissatisfied, 4% were dissatisfied and 2.5% were very dissatisfied
- The most used source of information and support for managing administering DMTs was the MS Nurse, followed by the neurologist and then specialist nurse services for a particular DMT (i.e. from a pharmaceutical company)
- 60.3% felt that their healthcare professional team communicate(d) effectively to them about how well their medication is/was working. 22% felt this was not communicated effectively and 17.5% were unsure

Recommendations for healthcare professionals:

- Clear, detailed and impartial information on different medications should be made available to people with MS on diagnosis. Existing materials are provided predominately by the pharmaceutical manufacturers for individual products while more general and comparative information on treatment options would assist the patient to understand the choice between DMTs. These materials should clearly detail any potential side effects and the likelihood of these occurring, as well as administration methods and frequency. As well as information leaflets, people with MS should be provided with concise information in the form of a table, so that key information about each DMT can be viewed 'at a glance' to aid with decision-making
- Neurologists and MS Nurses should 'signpost' people with MS to reliable sources of further information about DMTs, for those who wish to conduct their own research, including peer support services
- Neurologists, MS Nurses and GPs should provide further information and guidance around managing common medication side effects – for example, what other medications or treatments can be safely taken to mitigate the effects of common side effects such as flu-like symptoms, injection site reactions and nausea
- Neurologists and MS Nurses should clearly communicate as part of conversations about when or if to initiate DMT treatment that even if a person's MS symptoms are mild disease activity may be ongoing. The relative benefits and risks of starting treatment in terms of reducing and preventing relapses, controlling symptoms, delaying or preventing disease progression and delaying or preventing the accumulation of disability versus the risk of side effects should be clearly explained so as to support informed decision-making

- Neurologists and MS Nurses should provide information to people with MS about whether or not their treatment is working and how the effectiveness of the treatment is assessed. Reasons for discontinuing or changing medications should be clearly articulated

Recommendations for MS Ireland:

- MS Ireland should conduct a review of the information currently provided by the organisation on different DMTs and ensure that all information is clear, concise and consistent. This information should be available in a variety of different formats including printed information sheets and online. Consideration should also be given to incorporating more information on different medications into information seminars and events
- MS Ireland should investigate the possibility of establishing peer support networks for people with MS to facilitate sharing of information about choosing and managing DMTs
- MS Ireland should raise awareness among people with MS of the importance of reporting side effects to the Health Products Regulatory Authority, and how this can be done
- MS Ireland must continue to advocate for increasing resources for neurology services so that people with MS can receive appropriate levels of support, advice and guidance around choosing and managing medications from their healthcare professional teams. In particular, there is a need to advocate for more MS Specialist Nurse posts

Recommendations for policy makers:

- The current systems for making new medications available in Ireland should be reviewed, so that new therapies for progressive forms of MS can be made available as soon as possible after licensing

What is multiple sclerosis (MS)?

Approximately 9,000 people in Ireland have multiple sclerosis (MS) (Carney et al, 2018). MS is the most common disease of the central nervous system in younger adults, with most people being diagnosed between the ages of 20 and 40 (Compston & Coles, 2002; Milo & Kahana, 2010). This is the time of life when most people are developing their careers and starting families, and as such the impact of a diagnosis can be devastating for the person and their loved ones.

No two people will experience MS in exactly the same way. There are several different types of MS and the symptoms vary widely. Common symptoms include fatigue, vision problems, mobility difficulties, tremors, memory problems and depression (Carney et al, 2018). The most common form is relapsing remitting MS (RRMS) which affects approximately 80-85% of all people with MS. With RRMS, new symptoms appear or existing symptoms suddenly worsen. A relapse may last for a matter of hours or for months, and they vary in severity. Sometimes people require hospital treatment as a result of a relapse. Recovery from a relapse may be complete or only partial (Balk et al, 2014).

Around 65% of those initially diagnosed with RRMS go on to develop secondary progressive MS (SPMS), when the person's condition starts to steadily worsen and disability starts to build up over time. A small percentage of people with MS are diagnosed with primary progressive MS (PPMS) in which the condition gradually worsens from the point of diagnosis, without relapses (Balk et al, 2014). Even with progressive forms of the condition, MS is unpredictable as the speed at which the condition progresses and the order in which symptoms appear and disability accumulates vary from person to person.

The exact causes of MS are unknown although a number of factors appear to play a role in the risk of someone developing MS including gender (more women are affected than men), vitamin D deficiency, viruses, genetic factors and lifestyle

factors such as smoking. There is currently no cure for MS (Milo & Kahana, 2010; Hedstrom, Hillert, Olsson, & Alfredsson, 2013). However, earlier treatment with appropriate medications can delay disease progression (Giovannoni et al, 2015).

About MS Ireland

Multiple Sclerosis Ireland is the only national organisation providing information, support and advocacy services to the MS community. We work with people with MS, their families and carers and a range of key stakeholders including health professionals, students and others interested in or concerned about MS to ensure that we meet our goals.

Individual and Family Support

Through our case work service our teams of professional Regional Community Workers support the person with MS through the transitional changes that MS, as a disease, presents. Support is also available to the family members in dealing with the challenges they may face as a family unit.

Living with MS programmes

A range of living with MS programmes, workshops and activities are organised throughout the country that are targeted at various groups such as those newly diagnosed, carers, children of parents with MS and health professionals. Programmes include physical therapies, symptom management and information/education seminars.

MS Information Line 1850 233 233

Our confidential information line provides professional information and support to those affected by MS. The Information Line is open from Monday to Friday 10am – 2pm.

Information

Our information tools include a variety of booklets and information sheets, our website www.ms-society.ie, our MSnews magazine, our bi-annual research eZine, conferences, seminars and the valuable knowledge and experience of our staff.

The MS Care Centre

The MS Care Centre is Ireland's only respite and therapy centre for people with MS. It offers short-term respite care, therapeutic services, neurological assessments and many social activities in a homely environment in the suburbs of Dublin.

Voluntary Branches

Our voluntary branches are a support network for people and families living with MS in local communities. They provide a limited financial assistance service, access to various therapies and organise various social gatherings.

Research

We finance medical and social research projects when financial resources allow and we regularly update worldwide research information on our website and publications.

Representation

MS Ireland advocates on an individual and collective platform for the improvement in services, resources and policies affecting people with MS.

What are disease modifying therapies?

Until the 1990s, medical treatments for MS were entirely supportive in nature, as no medications existed that could impact on the underlying mechanisms of the disease and positively influence the course. Since then, a number of disease-modifying therapies (DMTs) have been developed which can reduce the numbers of relapses people with MS experience and slow down the progression of the disease and associated accumulation of disability (Yamamoto & Campbell, 2012; Chevalier, Chamoux, Hammès & Chicoye, 2016). Current research suggests that the sooner after diagnosis an individual is started on a DMT the better their long-term outcome will be in terms of minimising the increase of disability levels (Giovannoni et al, 2015; Cocco et al, 2015; Goodin et al 2011; Goodin et al 2012). However, there is some evidence that questions this viewpoint (Conway, Miller, O'Brien & Cohen, 2012) and decisions around if and when to start treatment with a DMT must also take into account the risk of possible harmful side effects from the medications (Johnson et al, 2006; Glanz et al, 2014).

DMTs vary in their mechanisms of action, administration methods and frequency, and side effect profiles. The first DMTs to be developed were all delivered by injection, with the first oral treatments publically available in Ireland from 2012. Some DMTs also require an infusion to be administered in a hospital setting. Side effects of DMTs vary from mild and common, such as injection-site reactions, to serious and rare such as the brain infection progressive multifocal leukoencephalopathy (PML) (Utz et al, 2014; Lugaresi et al, 2013). Generally, the more effective a treatment is, the greater the risk it carries in terms of serious side effects (Reen, Silber & Langdon, 2017a).

The vast majority of licensed DMT treatments currently on the market are indicated for relapsing remitting MS only. Treatment options for progressive forms of MS are much more

limited at present, although at the time of writing, the first ever treatment indicated for primary progressive MS (ocrelizumab) had received a license from the European Medicines Agency and there are several other promising potential therapies for progressive MS in various stages of development.

DMT usage in Ireland

A recent survey by MS Ireland found that over 75% of a representative sample of 773 people with MS reported being on a DMT (MS Ireland, 2017). This is much higher than previous research had suggested. Fogarty et al (2014) estimated 44.4% of the MS population in Ireland to be taking a DMT. Based on Fogarty et al's findings, the European Multiple Sclerosis Platform's (EMSP) MS Barometer 2015 placed Ireland 20th out of 29 European countries in terms of the percentage of the MS population taking a DMT. In terms of costs associated with DMT usage in Ireland, MS Ireland's 2015 study on the societal costs of MS estimated that yearly medication costs are approximately €60.83 million, representing 45% of total direct societal costs associated with MS (Carney et al, 2018). It should be noted that these figures will also include symptomatic treatments and steroids which are used to support recovery from relapses; however it is clear from this data that costs associated with DMTs are significant.

The DMTs that were licensed in Ireland and reimbursed by the Health Service Executive (HSE) at the time of writing, and were therefore included in this survey, are as follows:

- **Aubagio® (Terflunomide)**
- **Avonex® (Beta Interferon 1a)**
- **Betaferon® (Beta Interferon 1b)**
- **Copaxone® (Glatiramer Acetate)**
- **Gilenya® (Fingolimod)**
- **Lemtrada® (Alemtuzumab)**
- **Plegridy® (Peginterferon beta 1a)**
- **Rebif® (Beta Interferon 1a)**
- **Tecfidera® (Dimethyl Fumarate)**
- **Tysabri® (Natalizumab)**
- **Zinbryta® (Daclizumab)**

At the time of writing, two further DMTs were being assessed by the National Centre for Pharmaco-economics (NCPE) to determine if a recommendation will be made to the HSE that they should be reimbursed. They are Mavenclad® (cladribine) for relapsing remitting MS and Ocrevus® (ocrelizumab) for relapsing remitting MS and primary progressive MS. Furthermore, in March 2018, the European Medicines Agency announced that they were withdrawing the licence for Zinbryta due to safety concerns.

Previous research on DMT treatment preferences, decision-making and adherence

There is some evidence that people with MS should be actively involved in making decisions with their clinicians about if and when to start treatment and which medication to take and that if this shared decision-making takes place, people with MS are more likely to express satisfaction with their treatment and adhere to their medication (Colhoun et al, 2015; Gauthier, de Seze & Brudon, 2012; Remington, Rodriguez, Logan, Williamson & Treadaway 2013). Research into the treatment preferences of people with MS also indicates that oral medications are strongly favoured over injectable medications and that the frequency a treatment needs to be taken is also an important factor for consideration (Utz et al, 2014). Evidence also suggests that people with MS are generally willing to accept more risky DMT treatments if they believe that there will be long-term benefits; however often people with MS are not provided with enough information about relative risks and benefits of different treatments to make fully informed decisions on this (Reen, Silber & Langdon, 2017b).

The purpose of this present study was to ascertain:

- What information and support is provided to people with MS in Ireland to help them make decisions about DMT treatment options
- What additional information and supports people with MS would like to support them in this process and to help them to make fully informed decisions
- What factors are important to people with MS in considering treatment options
- How people with MS find the process of managing and administering DMTs and what information and/or supports would help make this process easier

Methodology and sample

The survey was conducted in the month of September 2017. The survey was designed in the Survey Monkey platform and shared on MS Ireland's website and social media channels as well as being emailed to approximately 5,000 contacts.

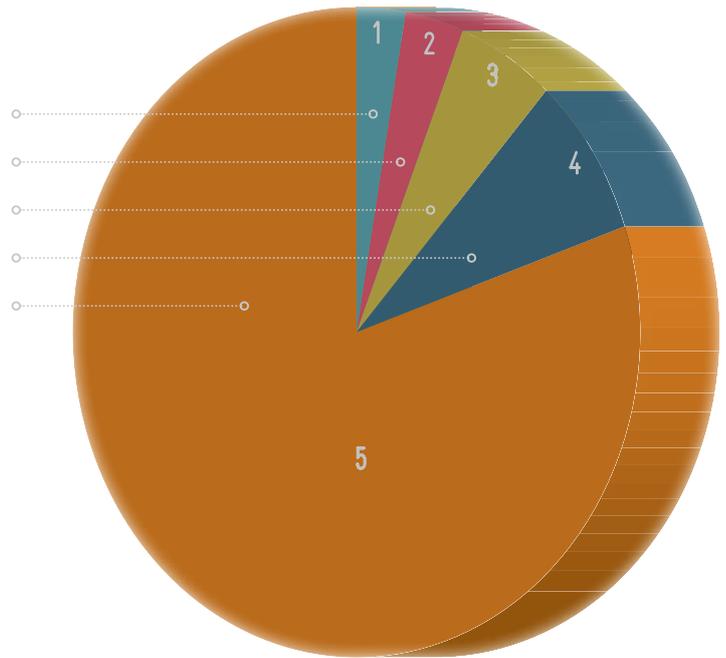
Questions comprised of both quantitative and qualitative responses. A list of the survey questions is available in Appendix 1.

A total of 236 people completed the survey. The breakdown of the sample was as follows:

Type of MS:

- 1. Relapsing remitting **80% (189)**
- 2. Secondary progressive **8% (19)**
- 3. Primary progressive **5.5% (13)**
- 4. Unsure **3.4% (8)**
- 5. Clinically Isolated Syndrome **3% (7)**

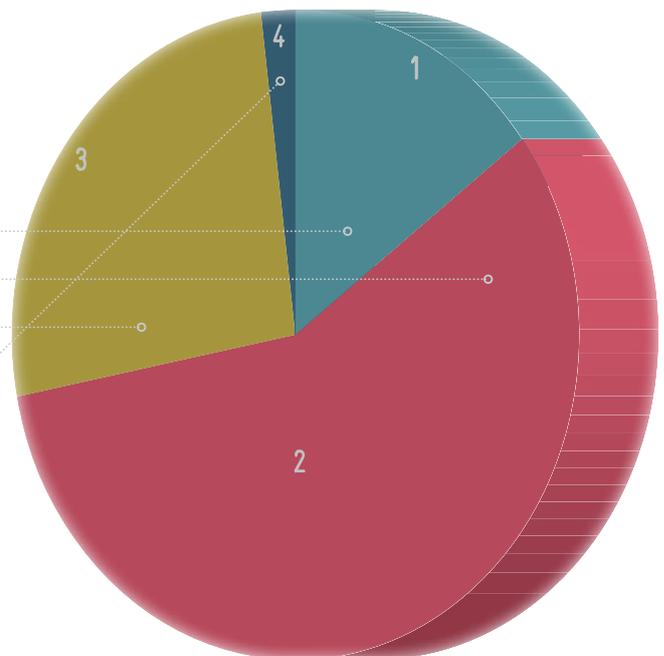
The survey is more heavily weighted in favour of people with relapsing remitting MS than other recent studies such as MS Ireland (2017) and Fogarty et al (2014). This could be because the survey was advertised as being about DMTs and people with progressive forms of MS may not have thought it had relevance to them.



Age:

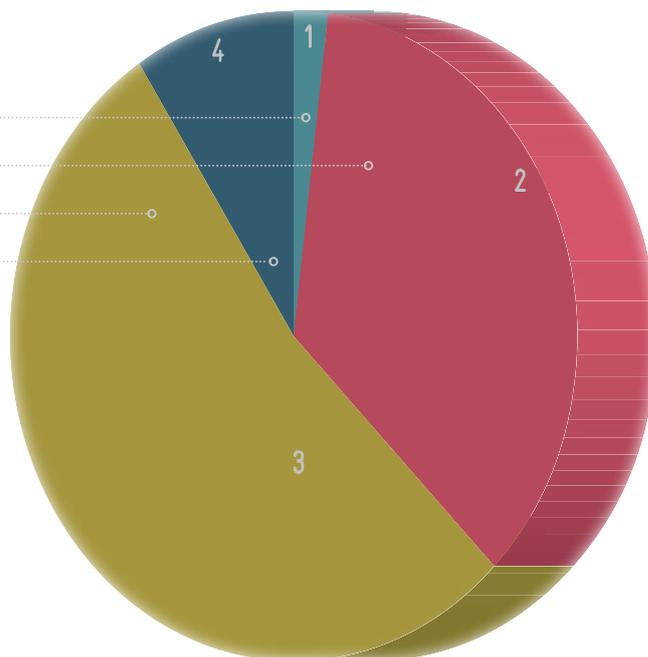
- 1. 18 - 30 **14.8% (35)**
- 2. 31 - 50 **57.2% (135)**
- 3. 51 - 65 **26.3% (62)**
- 4. 65+ **1.7% (4)**

This age breakdown is very similar to that found in MS Ireland's My MS My Needs report (2017).



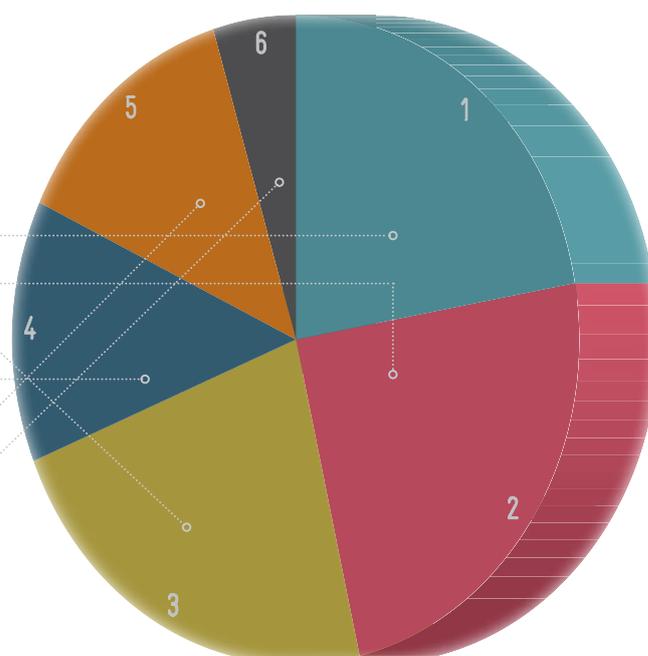
Age at diagnosis:

1. <u>Under 18</u>	2% (5)
2. <u>18-30</u>	35.6% (84)
3. <u>31-50</u>	53.4% (126)
4. <u>51-65</u>	8.9% (29)
5. <u>65+</u>	0%



Time since MS diagnosis:

1. <u>1-2 years</u>	22.5% (53)
2. <u>2-5 years</u>	24% (57)
3. <u>5-10 years</u>	22.5% (53)
4. <u>10-15 years</u>	13% (31)
5. <u>15-25 years</u>	13% (31)
6. <u>25 years+</u>	4.7% (11)



Patterns of DMT usage

Overall, 84% of the sample (198) reported that they were currently taking a DMT. 16% (38) reported that they were not currently taking a DMT.

Characteristics of those who are not currently taking a DMT

Of those who reported that they were not currently taking a DMT, 42% (16) had relapsing remitting MS, 15.8% (6) had primary progressive MS, 21% (8) had secondary progressive MS, 10.5% (4) had Clinically Isolated Syndrome and 10.5% (4) were unsure what type of MS they had. Of these, over half (55.2%) had previously taken a DMT whereas 44.7% had never taken one.

Those who had never taken a DMT were asked why this was, and could select one or more of a number of possible reasons. The most commonly reported reason for choosing not to take a DMT was that the person felt their MS symptoms were mild and they therefore did not need to (43.7%). Worry about side effects was also a commonly cited reason (37.5%). 31.2% reported that they felt they could manage their MS in other ways, i.e. through diet, exercise and other lifestyle changes without the need for a DMT. 25% said they had never been offered the option to take a DMT and 25% said they had been told there were no treatment options suitable for them. Another 25% felt they had not been given enough information about DMTs to make a fully informed decision. Of those who had never been offered the opportunity to take a DMT or had been told that there were no suitable treatment options for them, half had primary progressive MS.

Those who said they had previously taken a DMT but no longer were, were asked to state their reason for stopping taking a DMT. Side effects, being advised by their neurologist to stop taking treatment, entering the secondary progressive stage of MS and not noticing any improvement in

symptoms were the main reasons given. Some were also advised to stop taking a particular treatment due to another medical condition.

Some of the quotes given by respondents are as follows:

"No improvement of MS symptoms while on treatment and poor quality of life".

"I was diagnosed with cancer and I had to check with my neurologist before I had surgery as I was on [medication] if I should stop it and she advised me to stop taking it".

"Told I was no longer relapse remitting but secondary progressive".

"The treatment seemed to make my symptoms worse which impacted on my family and working life".

"The first one after some months made me feel lethargic, the second I reacted badly after second injection".

"No noticeable improvement and neurologist could not define the potential of the drug one way or the other".

Changing DMTs

58.5% of respondents reported having changed DMTs either once (38%) or more than once (20.5%). Experiencing relapses while on treatment and side effects were the most commonly reported reasons for changing from one DMT to another. Others just generally stated that their original treatment was not working. Some reported that they had been advised by their neurologist to change but without specific reasons being given for this.

Some of the quotes given by respondents are as follows:

“Relapsed on [medication A], tried [medication B], adverse reaction, progression on MRI so changed to [medication C] (second line therapy)”.

“First line of treatment was not effective. I had two relapses in short space of time therefore had to change to [second line treatment]”.

“I was just told that it would be better for me to change. No real reason was given”.

“Side effects from [medication] were bad, fatigue, flu like symptoms, headache”.

“I changed to one that is taken less frequently”.

“Issues with DMT altering lymphocyte count, also progress of MS continued based on MRI and neurological symptoms”.

“I was on an injectable DMT that was a waste of time it done nothing for me I hated it but I knew no better, I then got to hear about [medication, second line treatment] and really wanted to try it and I’m lucky and thankful to be on it, I went from relapsing every four or five weeks even with the injectable DMT, I’ve started my 10th year on [medication] and I haven’t relapsed since I started it. So the more expensive DMT works out cheaper long term because my relapses meant hospital stays because every relapse was pretty bad”.

Of those who reported never having changed their DMT, the majority (68%) had been diagnosed with MS within the last five years and a larger majority (79%) had started taking their DMT within a year of diagnosis.

Types of DMTs taken

Below is a breakdown of the different DMTs that the respondents reported taking, in order from most common to least common. Respondents could select more than one answer if they had experience of taking more than one DMT:

Gilenya® (Fingolimod)	33.5% (73)
Copaxone® (Glatiramer Acetate)	28% (61)
Rebif® (Beta Interferon 1a)	24.3% (53)
Tecfidera® (Dimethyl Fumarate)	24.3% (53)
Tysabri® (Natalizumab)	20.6% (45)
Avonex® (Beta Interferon 1a)	19.3% (42)
Betaferon® (Beta Interferon 1b)	16% (35)
Lemtrada® (Alemtuzumab)	7.3% (16)
Plegridy® (Peginterferon beta 1a)	7.3% (16)
Other	3.7% (8)
Aubagio® (Terflunomide)	1.8% (4)
Zinbryta® (Daclizumab)	0.5% (1)
I am unsure of the name of the medication I take/have previously taken	0.5% (1)

Those who reported taking a DMT other than those listed (eight people) also reported having experience of a variety of the listed DMTs including Copaxone, Betaferon and Tysabri. One person specifically mentioned taking Low Dose Naltrexone, a medication licensed for treating alcohol and opioid addiction which has been shown in some small-scale clinical trials to show promise as a symptomatic treatment for MS. It is possible other respondents in this category were referring to symptomatic medications as opposed to DMTs, such as Fampyra (fampridine) which is licensed to treat mobility problems in MS. It is also possible that some of these respondents may have been on clinical trials for other DMTs which are not yet widely available in Ireland.

Of those who had never changed DMTs and therefore only had experience of taking one, the order was as follows:

Tecfidera® (Dimethyl Fumarate)	19.8% (18)
Rebif® (Beta Interferon 1a)	16.5% (15)
Gilenya® (Fingolimod)	13.2% (12)
Avonex® (Beta Interferon 1a)	11% (10)
Copaxone® (Glatiramer Acetate)	11% (10)
Lemtrada® (Alemtuzumab)	7.7% (7)
Tysabri® (Natalizumab)	7.7% (7)
Betaferon® (Beta Interferon 1b)	6.6% (6)
Plegridy® (Peginterferon beta 1a)	4.4% (4)
Aubagio® (Terflunomide)	2.2% (2)
Zinbryta® (Daclizumab)	1.1% (1)
I am unsure of the name of the medication I take/have previously taken	1.1% (1)

Time from diagnosis to commencing DMT treatment

The majority (nearly 75%) who had experience of taking a DMT started doing so within a year of diagnosis. There were noticeable differences in the time from diagnosis to commencing DMT treatment between those who were diagnosed with MS 10 years ago or less and those who were diagnosed more than 10 years ago. Among those who were diagnosed 10 years ago or less, 82.4% had started treatment within a year of diagnosis, compared to 57.6% of those diagnosed more than 10 years ago.

Information about DMTs

A majority (67%) of respondents felt that they had been given enough information by their healthcare professional team about the range of treatment options available. However, a significant proportion at nearly 25% felt they had not been given sufficient information. 8.8% were unsure. There were no noticeable differences in this between people with MS diagnosed more than 10 years ago and those diagnosed less than 10 years ago, nor were there any significant differences between the age groups of the respondents.

When asked to explain their answer, several mentioned the importance of the MS Nurse in providing them with information and helping them to understand it:

“Excellent MS Nurse at [hospital] at the time was very helpful”.

“MS Support nurses excellent. Explained possible side effects etc”.

“I was given lots of brochures and info to read to decide which I liked the look of and then had a meeting with the MS Nurse to go through any questions I had”.

“The nurse gave me info on 5-6 different meds to read through to decide which one I liked the look of and then I had a consultation to decide on the meds”.

“Clinical nurse specialist went through the options with me”.

Others cited their neurologist as being an important source of information and guidance:

“Very well informed by my neurologist”.

“My neurologist discussed each option and up and coming therapies in detail during each visit”.

"I have had the same MS Nurse the whole time I have had MS, she is awesome and has helped me out so much I am also under [neurologist] as my neuro and he is also amazing".

"My neurologist spent a lot of time going through my treatment options. My MS Nurse was also very informative and helpful".

"My neuro, [name] is very, very thorough and helpful".

Of those who had less positive experiences, some spoke about being presented with a large amount of information but little guidance on how to navigate and interpret it:

"Doctors just handed me a range of leaflets. No MS Nurse available at my time of diagnosis. Luckily I'm a nurse and my best friend in the UK is MS Nurse Specialist".

"I was given booklets on the meds that I didn't and still don't understand. When I rang up and asked questions about the meds, I was told to read the booklets again. One year on and none the wiser"

"Sent home with about five booklets regarding different options of medication. The main problem was that I was left to decide on which DMT to start on".

"I feel like I was just handed leaflets to read in my own time, without any treatments being explained to me in person".

"Mostly just leaflets supplied after diagnosis, leaflets were made by manufacturers, so no impartiality and of questionable trustworthiness. Information available has been improved since new MS Nurse started".

"Was just sent bundles of information and left to make my own decision with no help from anyone".

For some, there was a sense of not being properly consulted about treatment options and not being given a clear explanation as to why one treatment was chosen over another. However, for others, too much choice and information was seen as daunting:

"Very little explanation given. I didn't feel I could ask, and that the prescribed medication was effectively the only realistic option".

"I asked my consultant about options and he only offered one of two that I knew were available. He said that the other one was too aggressive, but I think the expense may have been part of the reason".

"I was given the option of two medications by a professional. Too many options would have been daunting at the initial stages. Going forward I would appreciate more information on different treatments. But being offered a smorgasbord of drugs after my diagnosis would have been too much".

"First time I was sent all the different options available through the post. It was all so new to me, I didn't know. When they decided to change me to [medication], it was just said to me. I was given a book and that was it".

Important factors in a positive experience seem to be being offered choice, consideration of lifestyle factors, not feeling pressured and having the opportunity to discuss options with a supportive healthcare professional team:

"I was given a rundown of all of my options and given time to think about it. I was also given their opinion on what they felt was the best option but still not pressured into taking this option".

"I felt confident in my choices due to my chats with the team and the leaflets they gave me".

"I had done a lot of research into DMDs prior to [doctors] and when two choices were proffered by my neuro as being ones she felt I would do well on, both were familiar to me. The neuro nurse took me to her office and answered any outstanding questions I had and gave me info on the two choices. I then did my own online research comparing both from independent sources and seeing which would also fit best with my work and leisure styles".

"I was given comprehensive information on five different drugs. And my lifestyle/habits were taken into consideration. The choice was mine".

"I was given a range of medications to choose from and told about each and provided with information booklets. Also, as I am female and explained the desire to have children in the future, I know one particular drug was excluded from my plan so as not to create any problems with pregnancy which was greatly appreciated".

"At first they did but when I relapsed they didn't. They told me to go on this one drug and I felt very pushed into it and like I'd have a massive fight on my hands if I didn't agree".

Respondents were also asked if the information given to them about different medications was clear and easy to understand. Again, the majority (76.8%) said that it was. 16% said that it was not and 7.3% were unsure. There were no noticeable differences in this between people with MS diagnosed more than 10 years ago and those diagnosed less than 10 years ago, nor were there any significant differences between the age groups of the respondents. Many respondents commented that the leaflets they had been provided on different medications were clear and easy to understand, and helped them in their decision-making process:

"The brochures were very clear and helpful".

"I was given literature about the various treatments; their benefits, side effects etc. I was given plenty of time to read and ask questions".

"I had the information packs for each of the drugs I was choosing from. I was able to make a chart of pros and cons with side effects to compare".

"Leaflets were easy to read and understand".

Others felt the information in the leaflets/ brochures they were given was either not adequate or they could not fully trust it as it was provided by a pharmaceutical company. Some mentioned feeling the need to do further research of their own:

"The information on the leaflets was adequate and a five minute Google could find more data".

"I did my own research. The pharmaceutical companies do not give all the information to the doctor or patient".

"Basic info including clinical trial results, I did further research as felt the pharmaceutical company info re their own product would naturally be biased".

"In the booklets it was explained to a certain extent, had to do more research for myself".

Respondents were then asked "Do you feel that enough information was given to you about the benefits and risks of taking DMTs, so you could make a properly informed decision about your treatment options?" Again, the majority (69%) said they had. 21.8% said they had not and 9.2% were unsure. There were no significant differences based on how long it was since the respondents were diagnosed with MS or between the age groups. Some comments from respondents were:

"I asked which was the most effective treatment at reducing relapses which the DMT were but I was told about the associated risks such as PML".

"The pros and cons were clearly identified to me. I had followed [medication] for years and the consultant provided me with the results of the trials".

"Definitely not, the risks are never explained".

"I was made to feel, that this was by and large the only option, and there no real or substantive discussion pertaining to any possible side effects".

"The consultants left it up to the nurses to advise of risks etc and as they were not present at the consultation this meant me having to ring them to get the information. It's hard to know what questions to ask when starting a new one".

"Some of the information was on the product documentation. A [drug company] nurse called and discussed the DMD before administration. I was made aware that there were risks involved in the drugs use, so regular blood tests were a necessity".

"No, I think now that I was rushed into it and had a choice of DMT or disability. Wasn't really happy with things afterward and went away from treatment completely for a period as a result when the initial DMT had side effects".

"As much information as possible in regards to risks and benefits was given to me".

"I feel the ultimate responsibility lies with the patient to seek clarification from health care professionals in a format that suits their personal learning style so I viewed the info given to me as a signpost to seek more info, this I felt aided me to feel empowered".

"Again the booklets are informative and help is available online. Drs and MS team don't really tell you anything though - you have to search elsewhere".

Being able to speak to someone else who had taken a treatment was seen by many as a potentially valuable source of information and support in making decisions about medication options:

"Definitely would have loved to speak to someone who takes the medication".

"Speaking to existing MS patients would have helped. My decision was based on booklets".

"Statistics and personal reports of patients who have used the medicine and how it made them feel, good or bad".

"A way to get in touch with people taking the same medication in Ireland. There's a lot of international groups, but it would be useful to get in touch with people locally".

“Talking to others who were on the treatment- at the start – side effects can be severe, so getting tips on ways to reduce them, learn how long they would last etc”.

However, several respondents mentioned the need to be cautious in talking to others, as everyone’s experiences are different:

“Nothing other than talking to somebody else using the same medication. But at the end of the day everyone is different and can react differently to medication”.

“I suppose contact with someone on that medication would be helpful but a lot of us MSers seem quite different”.

“Personally, I don’t like to read/speak to people when I am choosing my treatment options. MS is so case specific that I feel I need to come to a decision and put my trust in my neurologist’s hands”.

“Other peoples’ experiences are just anecdote and would not have influenced my decision”.

Others mentioned that information seminars and leaflets/booklets in plainer English would have been helpful. Some mentioned wanting to have access to more scientific data on the drugs and reports from trials.

Side effects

A large majority (74%) of the sample had experienced a side effect from taking a DMT. The level was lower among those who stated that they had never changed DMTs and only ever taken one, at 63%. 19% had never experienced a side effect and 6.9% were unsure.

Reporting side effects

Of those who had experienced side effects, 88.7% had reported the side effect, 6.6% had not and 4.6% were unsure what it meant to report a side effect.

The MS Nurse was the most popular choice to report a side effect to (70.7%) followed shortly by the neurologist (69%). 42% had reported a side effect to their GP and 27.8% to the pharmaceutical company that made the drug. Only 1.5% (two respondents) had made a report to the Health Products Regulatory Authority. Some others also reported to their pharmacist.

Administering and managing DMTs

Experience of managing and administering DMTs

The majority reported that they found the experience of managing and administering their DMTs either easy (44%) or fairly easy (43%). 10.4% found it hard and 2.5% found it very hard.

For those who had only ever taken one DMT and had never changed, there were noticeable differences between the different types of administration methods. For those who had only ever taken injectable DMTs, 40% said they found the experience easy, 44.7% said they found it fairly easy, 13% said they found it hard and 2.6% said they found it very hard. For those who had only ever taken oral DMTs, a much higher number said they found the experience of managing and administering them easy, at 74%. 22.6% said they found it fairly easy, 3.2% said they found it hard and 0% said they found it very hard. Only a small number of respondents (14) had only ever experienced DMTs that are delivered via hospital infusion and of these, 71.4% said they found the experience easy, 21.4% said they found it fairly easy, 7% said they found it hard and 0% said they found it very hard.

Some of the comments from respondents were:

"Pills are blister packed and divided into day and night as well as name of day sections to organise the doses".

"Initially the injections were challenging. Now I am used to it, manage side effects well".

"Oral so easy to take - just have to have discipline to do so at right times".

"Now that I'm taking [oral medication] it's a lot easier, it's a tablet so no more nasty needles".

"Did find doing the [injectable medication] injection daily hard going and emotionally after a few months difficult. However [medication] changed to three days - made it much easier. Also just got used to it".

"Injections, and care of medications that need to be refrigerated can be very awkward, particularly if you are away from home i.e. on holiday. Injection site reactions can be painful and itchy and disposal of needles was made more difficult for me because I live in a rural area and needed to take them to the hospital - a 60 mile round trip".

"Injecting myself was okay when given guidance and the IV infusion I receive is administered by a team, not me".

"It takes one minute of my day to take my injection so I do not think about it too much. Needle is fine too and hold it for 10 seconds is manageable".

"It's one daily tablet and much easier to take than injections".

Impact of managing DMTs on daily life

Respondents were then asked to what extent managing their DMTs has impacted on their daily lives. 36% said it had not impacted on their daily life at all, 48.5% said it had impacted somewhat, 11% quite a lot and 4.5% a great deal. Again, there were very marked differences between the different types of administration methods among the group who had never changed DMTs. Of those who had only ever taken injectable DMTs, 23.7% said it did not impact on their daily life at all, 55.3% said it impacted somewhat, 15.8% said it impacted a lot and 5.3% said a great deal. Of those who only had experience of taking oral DMTs, 54.8% said it did not impact on their daily life at all, 38.7% said it impacted somewhat, 6.5% said it impacted quite a lot and 0% said it impacted a great deal. For those who had only ever experienced DMTs that are delivered via hospital infusion, 46% said it did not impact on their daily life at all, 38.5% said it impacted somewhat, 15.4% said it impacted quite a lot and 0% said a great deal.

Some of the comments from respondents were:

"Have to plan a little, manage timing. Usually inject Mon, Wed, Fri".

"Injectable meds take time to get to grips with and require nurse visits. Oral meds much easier but you have to be your own advocate and keep on top of blood results in your own interests to mitigate risks".

"Can get on with my life - just take at meal times".

"Need to plan and prepare if daily activities change, for example holidays, social events".

"I inject myself once a month. The lack of impact on my daily life was a major reason I chose this modality".

"It's just remembering to take the tablet at a certain time. Very easy to do with a phone alarm to remind me".

"Making sure I'll be home at the right time, staying hydrated before/after, taking anti inflammatories the next day. Often feel tired or grotty next day and have to plan commitments accordingly".

"Injections had to be kept cool and need a quiet space to inject".

"On the day of treatment and the day after I feel extremely tired with bad headaches and low mood. I have to travel 30 km to receive it and I can no longer drive due to my eyesight with the MS".

"I have to plan things around my monthly infusion but it is important so I just factor this in. I also have to travel three hours to receive my treatment each month so have to factor this in".

Several respondents also mentioned side effects again here, and the negative impact these have on their daily lives and routines.

Level of satisfaction with current DMT

Respondents were then asked to do the following: "Rate your level of satisfaction with your current DMT. (When answering, consider all relevant factors including ease of administration, side effects, impact on daily life, costs etc.)".

A comfortable majority were either very satisfied (37%) or satisfied (34%). 14.2% were neither satisfied or dissatisfied, 4% were dissatisfied and 2.5% were very dissatisfied. 8% said the question was not applicable to them as they were not currently taking a DMT.

For those who had only ever taken one type of DMT, there was only a small difference between oral and injectable medications as to how many respondents said they were either very satisfied or satisfied – 64.9% for the injectable group versus 67.7% for the oral group. Those who only had experience of taking medications delivered via infusions had a very large number saying they were very satisfied with their treatment, at 69.2%, with none reporting that they were dissatisfied or very dissatisfied.

Some comments from respondents were as follows:

"I feel it has worked well for me. While I have regular symptoms, disease progression is minimal in my view".

"Does not impact on my quality of life. No side effects experienced. Keeps relapses at bay".

"As of yet I have not found a DMT that has improved or delayed progress of my MS".

"I pick it up at a pharmacy I can walk to. I inject once a month. I don't have side effects. My MRIs are stable. The Long Term Illness Scheme covers the cost. I am a best case scenario and I know to appreciate it".

"I am extremely happy with the meds. Although the side effects at the start were horrific for the first three weeks and even now I get nausea, cramps, etc my last MRI showed no new lesions and a decrease in size of the lesions that were already there".

"I have to take it to make an effort to slow the disease down. I have some unpleasant side effects and I am afraid of more serious side effects. It impacts on my life every day but I don't know what life would be like without a DMT".

“All things measured the negatives are negated by the possible positives”.

“My last MRI showed no new lesions and a decrease in the size of the current lesions. I am being happy with the meds”.

“I am very very happy overall with my experience. The team of nurses are fantastic and a great support to me and the treatment is working great with no side effects. The reason I did not choose Very Satisfied however is because this treatment has its side effects in the long term and it is not certain how long I can stay on it so this can be quite stressful but I try not worry about this and wait until it happens”.

“It’s got me out of a wheelchair and kept me out of it and relapse free for all this time”.

“I can now get on with my life and not worry about injections, tablets, travel etc. I get a monthly blood test so know I am being monitored well”.

Support for managing DMTs

Respondents were then asked if they felt they had been offered enough information and support to help them manage their medication properly. A large majority at 78.4% said they had. Of the remainder, 9.3% said they had not and 12.4% said they were unsure or this question was not applicable to them. As with previous questions, many of the qualitative responses talked about the importance of good support from neurologists and MS Nurses, although a number of respondents did comment on how overstretched these services are and that this can make it difficult to get information and support when needed. Several also mentioned receiving good support from services provided by pharmaceutical companies, including visits by nurses and telephone helplines.

The next question asked respondents to choose from a list of support services and state which they had used to help them manage their medication properly. They could choose more than one answer. The responses, in order from most to least common, are below:

MS Nurse	65.5%
Neurologist	64%
Specialist nurse service for a particular DMT (i.e. from a pharmaceutical company)	48%
Websites	40.2%
Information booklets/leaflets	37.6%
GP	32.5%
Social media	28.9%
Talking to others who have taken the same medication	25.8%
Pharmacist	24.2%
Information/support service for a particular DMT (i.e. information or email helpline provided by a pharmaceutical company)	15%
Apps and other technologies	6%
None	5.7%
Other	5%

Other responses given included MS Ireland and 'Local MS group'. Two people noted in this section that their GP did not have good knowledge of MS.

There were some noticeable differences between the age groups as regards the types of information and support services used. As might be expected, those in the younger age groups (18-30 and 31-50) were more likely to use digital resources such as social media (31.2%), websites (43.3%) and apps (7.8%) than those in the 51-65 and 65+ age groups of whom 20.8% said they used social media, 32% said they used websites and 1.9% said they used apps. Those in the younger age groups were also more likely to seek peer support by talking to someone else who had taken the same medication (28.4%) than those in the older cohorts (18.9%). The younger groups were also noticeably more likely than the older groups to have used information booklets and leaflets (41% versus 28.3%) and nursing support services provided by pharmaceutical companies (51% versus 39.6%).

Effectiveness of DMTs

The next question asked if the respondents felt that their healthcare professional team communicate(d) effectively to them about how well their medication is/was working. A majority (60.3%) said yes, however significant numbers also said either that they felt this was not communicated effectively (22%) or they were unsure (17.5%).

Healthcare professionals taking the time to talk to them and explain scan and test results fully were seen as important factors in communicating the effectiveness of treatments:

"Every infusion consists of an in-depth chat with my nurse about my condition and effects of medication and neurology every six months also does the same".

"I was always shown my most recent MRIs and how they compared over time. I was always told how my bloods were looking and given their impressions of how they feel my treatment is going".

"Neurologist keeps close eye on me. My doctor/nurse monitor my bloods and keep me informed".

"My doctors and nurses have been very clear and they have walked through my MRI scans with me to explain exactly what they were looking for and what they found. I have never felt as though they couldn't answer my questions. They have been quite direct with the results of such scans and blood tests (a quality that I think has really helped me in understanding my MS)".

The issue of limited resources and overstretched staff came up again, with some respondents indicating that they felt this restricted the capacity of their healthcare professional team to communicate effectively with them:

"I felt that they wanted me in and out as fast as possible. Conveyor belt".

"Should have had more than one MRI a year at the start. We would have learned sooner they weren't working".

"Difficult to contact the team when necessary due to restricted hours for receiving phone calls, delays in response to emails and inability to talk directly to medical staff by phone. Was like a blank wall at times".

"Difficult to get time to speak with the team".

For those who felt that the effectiveness or otherwise of their treatment was not being communicated properly, recurring themes included going by MRI scans only and not listening to or accounting for the person's reports of their symptoms, not explaining test or scan results fully, changing or discontinuing medication without a full explanation and general lack of discussion or feedback:

"I have never been told that my medication is working or not working. I'm only assuming it's working because I'm still on it. I would like to hear from my neurologist that the medication is working (or not working)".

"I would like more information re explaining MRI results".

"I felt I was failing my first drug as I ran and I'd noticed very bad weakness creeping in to my legs. I told them but they told me my MRI was stable. I relapsed two months later and have used a stick since. They base everything on MRI rather than asking us how we feel and looking at and grading our disability progression. I have far less lesions than most of my MS peers but yet I'm the only one with chronic pain and using a wheelchair on and off so clearly something is amiss. They just don't listen. It's like they read an MRI quickly and each patient is rushed in and out".

"They have not said anything about the medication but just ask if I am taking it".

"I haven't been advised to switch medication or stay on the one I am on, nothing was said by my neurologist about whether it seemed to be working or not".

"Maybe it's unfair to record a 'No' here. I have only been on this new drug for 6 months and have only had one MRI since starting it. I am not overtly disabled. I am told that there is no change on MRI

so therefore I am fine. But I feel like my symptoms are advancing! So that is where I am dissatisfied. I feel a new weakness in my feet accompanied by cramping, advancing weakness in legs, advancing numbness. But I get the feedback from the team that since I am on the 'best' drug available, that these symptoms must be caused by e.g. old age or other non-MS causes".

"It's often not spoken about in any great detail. My scans are stable so there is the assumption it's working".

The final question of the survey was an open question asking if the participants had any other aspects to being on treatment (positive or negative) that they would like to talk about that they have not already described. Examples of responses given include:

"Occasionally it has been difficult to establish contact with the MS staff at my treating hospital. On one occasion this involved me having to spend a few days as an inpatient in a different hospital while trying to establish a clear line of communication with my treating hospital".

"The HSE is so confusing. I kind of still don't know who I'm supposed to talk to about getting additional medications covered by the LTI scheme if that ever comes up. It's an impenetrable labyrinth".

"I am very annoyed that I was not put on any meds as soon as I was diagnosed. Naively at the time I thought that was good, that it meant the MS wasn't bad. My parents questioned the consultant a lot about why I wasn't on any meds. I started off with CIS which then progressed to R/R. I am sure that if I had been put on meds at the start it would not have progressed".

"When new side effects are linked to a drug patients on that drug should be informed".

"I got all the help I needed at the time. Have no complaints".

"[Medication] has improved my quality of life considerably. It has definitely slowed down disease progression".

"Yes there seems to be little information the long term usage of the medication will have on our systems e.g. liver, kidneys, stomach, etc".

"I am very happy with my treatment. I have a skin rash and can have diarrhoea and bad sinus but I carry on as normal".

"I would love to have all of the medications and side effects on one easy to read piece of paper so I could compare them myself".

"Stress of managing your condition when side effects present takes a lot out of you with all the interaction required with medical team and inability to communicate in a timely manner. Had to resort to collaboration with GP to make a decision to come off a DMT as was unable to get feedback from medical team at the time".

"For someone trying to decide on a treatment it is important to realise each treatment works differently for everyone so it is important to do a lot of research but you will still need to take the risk and choose what you feel is right for you. If this option doesn't work it is important to not get stressed but instead to focus on finding the right treatment. Stress will only speed up the progression of the disease which you are trying to avoid by taking the DMT's. Things will work out as long as you remain positive".

"Overall, I am very happy with the treatment and support that I have received because I understand why it is necessary to be on such treatment. I can see why some people opt to go without treatment because I was briefly off it for a couple of weeks and I actually felt better, I had more energy and a better clarity of thought. But, I am under no illusions and I know that a lack of treatment will not be helpful long-term. I have been well informed of the different treatment options and I have chosen the one that is best for me right now".

The numbers of people taking DMTs was much higher in this survey than in previous research. This could be largely due to the fact that people who had never taken a DMT felt that the survey would not be applicable to them, although when advertised via MS Ireland's social media and eNews channels it was stated that it was not necessary to have experience of taking a DMT to participate. Another possibility could have been that the age of the participants was heavily weighted in favour of the 18-50 age group and younger people who have been diagnosed more recently may be more likely to be taking DMTs due to changes in treatment practices. A strong indication of changes in treatment practices can be seen in the differences between those who were diagnosed 10 years ago or less and those who were diagnosed more than 10 years ago as to when they started taking a DMT, with many more of those who were diagnosed 10 years ago or less starting treatment within a year of diagnosis than those who were diagnosed more than 10 years ago. Changes in treatment practice are being largely driven by the emerging consensus that the earlier a person with MS is started on a DMT, the better their long-term outcomes will be (Giovannoni et al, 2015).

As might be expected, given that all the currently available DMTs are licensed for relapsing remitting MS only, the vast majority of the respondents in this survey had relapsing remitting MS with higher numbers of people with primary progressive MS and secondary progressive MS in the group who reported they were not currently taking a DMT. These findings again highlight the urgent need to make new treatment options for progressive forms of MS (such as ocrelizumab) available in Ireland as soon as possible after they receive a licence from the European Medicines Agency, and for more research to be done into treatments for progressive forms of MS.

The impact of side effects was a common theme throughout these findings. Worry about side effects was a commonly reported reason why people with MS had chosen never to take a DMT. Experiencing side effects was also frequently cited as a reason for either changing from one DMT to another or for stopping taking a DMT altogether. Of particular interest are the noticeably lower levels of side effects reported by the group who had only ever taken one DMT compared to those who had changed DMTs, again reinforcing that minimal side effects are an important driver of treatment adherence and continuation. Many respondents also stated that side effects are the main reason why taking a DMT impacts on their daily life and routine. Therefore it is important that people with MS are provided with clear, detailed information about the various potential side effects of medications and how likely these are to

occur when they are making decisions about treatment options. People with MS should also be provided with advice and support about how to manage side effects and mitigate their impact. There is also a definite need to raise awareness of the importance of reporting side effects to the Health Products Regulatory Authority and how to do this.

The findings regarding the provision of information about DMTs were broadly very positive, with the majority saying that they felt that they had been given enough information by their healthcare professional team about the range of treatment options available, that the information they had been given was clear and easy to understand and that they felt they had been given enough information about the benefits and risks of various DMTs to make informed decisions. Many made very positive comments about the support they receive from the healthcare professionals, in particular neurologists and MS Nurses. The importance of the role of the MS Nurse was highlighted strongly in these findings with many citing their nurse as playing a vital role in their decision-making process about which treatment to go on. The MS Nurse was also the most commonly used source of information and support in managing administering DMTs. However, there is also a strong sense from these findings, as with previous research (MS Ireland, 2017), that healthcare services are extremely overstretched and under-resourced and this can make it hard to access information and support when needed, despite the best efforts of staff. This provides further support for MS Ireland's ongoing advocacy work on the need to invest in and develop Ireland's neurology services and in particular provides evidence for the need to advocate for more MS Nurse posts.

Although the findings were generally very positive, nearly 25% of respondents said they did not feel they had been provided with enough information about treatment options, and 21% felt that they had not been given enough information about the benefits and risks of different treatments in order to make a fully informed decision. It is clear that healthcare professionals taking the time to fully discuss different treatments, consider individual lifestyle factors and answer questions and concerns is of great importance, although it is recognised that resource constraints make this very difficult in some settings, as outlined above. There is also an identified need for people with MS to be given information materials or signposted in the direction of materials (in a variety of formats) that are not produced by pharmaceutical companies as many respondents commented that they did not feel they could fully trust information from this source. Some mentioned that the volume of information materials they were

provided with was daunting and hard to navigate and understand – one recommendation following from this would be to produce a summary table that lists all the currently available DMTs with their administration methods, administration frequency and possible side effects. MS Ireland could also consider incorporating more information on medications into Newly Diagnosed seminars and similar events.

People with MS should also be provided with clear information about the potential risks of not taking a treatment or delaying treatment and what the current research is saying about this. It is important that the person with MS knows that even if their symptoms are mild disease activity may be ongoing, as mild MS symptoms were the most commonly reported reason why respondents decided not to take a DMT.

Highlighting the existence of services through which people with MS can access peer support and talk to others who have experience of taking different medications, such as Shift.MS or local MS Ireland branch groups, could be valuable and reassuring and there may be a need to develop further peer support networks and services. Peer support services may also have a role in sharing of tips and advice for managing side effects.

Clear indications emerged in both the quantitative and qualitative data that people with MS generally prefer oral DMTs to injectable DMTs and that oral medications are easier to manage and have less impact on daily life and routines. This is in line with previous research findings (Utz et al, 2014). However, there was a strong sense from the comments that regardless of the administration method, most people were able to manage their DMTs well and that with time and support most respondents got used to the practice of administering their medication. The vast majority felt that they had received enough information and support to enable them to manage their DMT usage. There were, as might be expected, noticeable differences between age groups as to the types of information and support services used to help with managing DMTs, with the younger age groups being more likely to use online resources than the older groups. Also interesting to note is the fact that younger people were more likely to speak to others who had taken the same medication and to consult information leaflets and booklets than the older cohort, suggesting that younger age groups may feel more empowered to do their own research and seek out their own sources of information and advice than the older groups who may be more inclined to rely on traditional sources of authority, i.e. the healthcare professionals. This provides more evidence for the need for information and support services to be provided in a variety of different formats and for healthcare professionals to signpost to sources of reliable information where people who are confident to do so can do their own further research.

Overall, levels of satisfaction with DMT treatments was high, with over 70% being either very satisfied or satisfied with their current treatment. The most common theme in the comments that indicated high levels of satisfaction with the treatment was that it was perceived to be working – the person was not experiencing relapses, symptoms were minimal or manageable and they were being told that their MRI scans were stable. A number of people commented that even though they were experiencing side effects and/or found their DMT inconvenient to administer, the advantages in terms of controlling their MS were perceived to be well worth it. This reinforces the need for healthcare professionals to be clear in communicating the potential advantages of DMT treatments in terms of reducing and preventing relapses, controlling symptoms, delaying or preventing disease progression and delaying or preventing the accumulation of disability, so that these can be fully weighed against the disadvantages of potential side effects. These findings are also in line with previous research that suggested people with MS are generally willing to accept more risky DMT treatments if they believe that there will be long-term benefits (Reen, Silber & Langdon, 2017b). This is further supported by the fact that, among those who had only ever taken one DMT, there were very noticeable differences between oral and injectable medications when respondents were asked how easy they found their DMT to manage and how much impact it had on their daily life, but the difference was very small between oral and injectable medications for overall satisfaction. This suggests, again, that people with MS are willing to accept the inconveniences associated with taking a medication if the benefits are clear in terms of controlling disease activity.

Nearly 40% of respondents either felt that they had not received clear communication about whether or not their treatment was working, or were unsure if they had, suggesting that this is an area in which communication from healthcare professionals could be improved. Those who felt that they had had good communication in this regard stated that the results of scans were clearly explained to them and that thorough explanations were always given as to why treatments were either changed or discontinued. Another important factor to emerge here was the need for healthcare professionals to fully account for the symptoms a person with MS is reporting to them in considering whether or not a treatment is working, rather than going on MRI scan results alone.

Limitations

As this survey was conducted entirely online, it is possible that the older cohort and people whose MS is more progressed may be under-represented in the sample as these groups tend to be less likely to be regular internet users. For this reason and also because of the description of the survey as being about DMTs, the very high level of DMT usage reported here should not be taken as representative of overall levels of DMT usage in Ireland. It should also be noted that this was a relatively small sample size and larger-scale research on this topic is needed. Further research is also needed among people who have never taken a DMT to look at the reasons behind this, as this group had low representation in this survey.

Conclusion and recommendations

Despite some limitations, this survey has provided useful insights into the views and needs of people with MS when it comes to practices around prescribing and managing disease modifying therapies. Based on these findings, the following recommendations can be made:

Recommendations for healthcare professionals:

- Clear, detailed and impartial information on different medications should be made available to people with MS on diagnosis. Existing materials are provided predominately by the pharmaceutical manufacturers for individual products while more general and comparative information on treatment options would assist the patient to understand the choice between DMTs. These materials should clearly detail any potential side effects and the likelihood of these occurring, as well as administration methods and frequency. As well as information leaflets, people with MS should be provided with concise information in the form of a table, so that key information about each DMT can be viewed 'at a glance' to aid with decision-making
- Neurologists and MS Nurses should 'signpost' people with MS to reliable sources of further information about DMTs, for those who wish to conduct their own research, including peer support services
- Neurologists, MS Nurses and GPs should provide further information and guidance around managing common medication side effects – for example, what other medications or treatments can be safely

taken to mitigate the effects of common side effects such as flu-like symptoms, injection site reactions and nausea

- Neurologists and MS Nurses should clearly communicate as part of conversations about when or if to initiate DMT treatment that even if a person's MS symptoms are mild disease activity may be ongoing. The relative benefits and risks of starting treatment in terms of reducing and preventing relapses, controlling symptoms, delaying or preventing disease progression and delaying or preventing the accumulation of disability versus the risk of side effects should be clearly explained so as to support informed decision-making
- Neurologists and MS Nurses should provide information to people with MS about whether or not their treatment is working and how the effectiveness of the treatment is assessed. Reasons for discontinuing or changing medications should be clearly articulated

Recommendations for MS Ireland:

- MS Ireland should conduct a review of the information currently provided by the organisation on different DMTs and ensure that all information is clear, concise and consistent. This information should be available in a variety of different formats including printed information sheets and online. Consideration should also be given to incorporating more information on different medications into information seminars and events
- MS Ireland should investigate the possibility of establishing peer support networks for people with MS to facilitate sharing of information about choosing and managing DMTs
- MS Ireland should raise awareness among people with MS of the importance of reporting side effects to the Health Products Regulatory Authority, and how this can be done
- MS Ireland must continue to advocate for increasing resources for neurology services so that people with MS can receive appropriate levels of support, advice and guidance around choosing and managing medications from their healthcare professional teams. In particular, there is a need to advocate for more MS Specialist Nurse posts

Recommendations for policy makers:

- The current systems for making new medications available in Ireland should be reviewed, so that new therapies for progressive forms of MS can be made available as soon as possible after licensing

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List of survey questions

Introduction

MS Ireland is conducting a short, anonymous survey about disease modifying therapies (DMTs). The DMTs that are currently available in Ireland are:

- **Aubagio (Terflunomide)**
- **Avonex (Beta Interferon 1a)**
- **Betaferon (Beta Interferon 1b)**
- **Copaxone (Glatiramer Acetate)**
- **Gilenya (Fingolimod)**
- **Lemtrada (Alemtuzumab)**
- **Plegridy (Peginterferon beta 1a)**
- **Rebif (Beta Interferon 1a)**
- **Tecfidera (Dimethyl Fumarate)**
- **Tysabri (Natalizumab)**

This survey will take approximately 10-15 minutes to complete. The purpose of the survey is to help us to understand what is important to people with MS regarding their treatment options. Our recent My MS My Needs survey found that almost 20% of people with MS felt they had not received enough information from healthcare professionals about available drugs.

The results of this survey will help guide us as to what information materials people would like access to, to help them make decisions about treatments and help them manage their medications. Data and information from the survey may also be used in future Patient Group Submissions to the National Centre for Pharmaco-economics (NCPE), to help with the process of trying to make new medications for MS available in Ireland.

If you have any questions about the survey, please contact Harriet Doig – harrieta@ms-society.ie

1. What type of MS do you have?

- **Relapsing remitting**
- **Primary progressive**
- **Secondary progressive**
- **Clinically Isolated Syndrome**
- **Unsure**

2. What age are you?

- **18-30**
- **31-50**
- **51-65**
- **65+**

3. What age were you at diagnosis?

- **18-30**
- **31-50**
- **51-65**
- **65+**

4. How long is it since you were diagnosed with MS?

- **1-2 years**
- **2-5 years**
- **5-10 years**
- **10-15 years**
- **15-25 years**
- **25+ years**

5. Are you currently taking a disease modifying therapy for MS?

6. Have you previously taken a DMT for MS?

7. What best describes the reason why you have never taken a DMT? You may choose more than one answer:

- **I have never been offered the option**
- **I have been told there are no treatment options suitable for me**
- **I am worried about side effects**
- **I feel that I haven't been given enough information about DMTs to make a decision**
- **I feel my MS symptoms are mild and I therefore do not need to take a DMT**
- **I feel I can manage my MS in other ways i.e. through diet, exercise and other lifestyle changes and therefore do not need to take a DMT**
- **I feel that taking a DMT would be difficult to manage**
- **Other (please specify)**

8. Is there anything further you would like to add regarding your reasons for not taking a DMT?

9. When did you stop taking a DMT?

10. Why did you stop?

11. How soon after diagnosis did you start taking a DMT?

- **Straight away**
- **1-3 months**
- **3-6 months**
- **6-12 months**
- **12-18 months**
- **18-24 months**
- **2-5 years**
- **5+ years**
- **Can't remember/unsure**

12. Have you ever changed from one DMT to another?

- Yes, I have changed once
- Yes, I have changed more than once
- No, I have never changed DMTs

13. Can you explain the reason why you changed DMTs?

14. Which of the following DMTs do you have experience of taking?

- Aubagio (Terflunomide)
- Avonex (Beta Interferon 1a)
- Betaferon (Beta Interferon 1b)
- Copaxone (Glatiramer Acetate)
- Gilenya (Fingolimod)
- Lemtrada (Alemtuzumab)
- Plegridy (Peginterferon beta1a)
- Rebif (Beta Interferon1a)
- Tecfidera (Dimethyl Fumarate)
- Tysabri (Natalizumab)
- Zinbryta (Daclizumab)
- Other
- I am unsure of the name of the medication I take/ have previously taken

15. Do you feel your healthcare professional team offered you enough information about the range of treatment options available?

- Yes
- No
- Unsure

16. Can you explain your answer

17. Was the information provided to you about medications and treatment options clear and easy to understand?

- Yes
- No
- Unsure

18. Can you explain your answer

19. Do you feel that enough information was given to you about the benefits and risks of taking DMTs, so you could make a properly informed decision about your treatment options?

- Yes
- No
- Unsure

20. Can you explain your answer

21. What additional information or support, if any, would have been useful to you to help you make a decision about treatment options? E.g. information sheets/ booklets; talking to someone else who has taken the medication

22. Have you ever experienced side effects from taking a DMT?

- Yes
- No
- Unsure

23. Did you report your side effects to anyone?

- Yes
- No
- I am unsure what it means to 'report' a side effect

24. Who did you report your side effects to? You may choose more than one.

- Neurologist
- MS Nurse
- GP
- Other healthcare professional
- Pharmaceutical company
- Health Products Regulatory Authority (HPRA)
- Other

25. Generally, how have you found the experience of managing administering your DMT(s)?

- Easy
- Fairly easy
- Fairly hard
- Hard

26. Can you explain your answer

27. To what extent has managing your DMTs impacted on your daily life?

- Not at all
- Somewhat
- Quite a lot
- A great deal

28. Can you explain your answer

29. Rate your level of satisfaction with your current DMT. (When answering, consider all relevant factors including ease of administration, side effects, impact on daily life, costs etc)

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied

30. Can you explain your answer

31. Do you feel you have been offered enough information and support to help you manage your medication properly?

- Yes
- No
- Unsure

32. Can you explain your answer

33. Which (if any) of the following support services have you used to help you manage your medication properly?

You may choose more than one answer.

- Neurologist
- MS Nurse
- GP
- Pharmacist
- Specialist nurse service for a particular DMT (i.e. from a pharmaceutical company)
- Information/support service for a particular DMT (i.e. information or email helpline provided by a pharmaceutical company)
- Talking to others who have taken the same medication
- Websites
- Social media
- Information booklets/leaflets
- Apps and other technologies
- None
- Other (Please specify)

34. Do you feel your healthcare professional team communicate(d) effectively to you about how well your medication is/was working?

- Yes
- No
- Unsure

35. Can you explain your answer

36. Are there any other aspects to being on treatment (positive or negative) that you would like to talk about that you haven't already described?

Thank you for taking the time to complete this survey. If you have any questions or comments, please email Harriet Doig - harrietd@ms-society.ie

To keep up to date with how we use the findings of this and other surveys, please sign up for our monthly eNews by emailing communications@ms-society.ie

DMT information list – licensed DMTs as of March 2018

First – line therapies

Drug Aubagio®

Who takes it?

Aubagio is indicated for the treatment of adults with RRMS

What are the benefits?

It reduces the number of relapses by up to 36%

How often do I take it?

Once daily

How is it taken?

Oral tablet

Possible side effects

Very common side effects (may affect more than 1 in 10 people): Diarrhoea and sickness; increase in blood levels of certain hepatic enzymes; hair thinning.

Common side effects (may affect up to 1 in 10 people): Influenza; upper respiratory tract infection, urinary tract infection; bronchitis; sinusitis; sore throat; cystitis; viral gastroenteritis; oral herpes; tooth infection; laryngitis; fungal infection of the foot; low level of white blood cells; anaemia; mild allergic reactions; feeling anxious; pins and needles; feeling weak, numb, tingling or pain in the lower back or leg; feeling numb, burning, tingling or pain in the hands and fingers; increase in blood pressure; vomiting; toothache; upper abdominal pain; rash, acne; musculoskeletal pain; needing to urinate more often than usual; heavy periods; changes in liver and white blood cell test results; weight loss

How is it reimbursed?

High-Tech Scheme

Drug Avonex®

Who takes it?

Adults and adolescents aged 12 years or over diagnosed with relapsing MS or with a single demyelinating event and at high risk of developing MS

What are the benefits?

Slows the progression of disability and reduces the frequency of relapses by 30%

How often do I take it?

Once a week

How is it taken?

Injection into a muscle e.g. the upper thigh

Possible side effects

Common side effects (affecting more than 1 person in 100): flu-like symptoms; headache; injection site reactions; blood cell abnormalities; feeling weak or tired; difficulty sleeping; diarrhoea, nausea and vomiting; muscular or joint pain; infections; depression

Less common side effects (affecting less than 1 person in 100): changes in menstruation (periods); liver abnormalities; allergic reactions; heart problems and hypertension; hair thinning or loss; damage to small blood vessels leading to kidney problems

How is it reimbursed?

High-Tech Scheme

Drug

Betaferon®

Who takes it?

People with a single demyelinating event with an active inflammatory process; people with RRMS; people with SPMS who still mobilise

What are the benefits?

Delay in the progression from first clinical event (CIS) to clinically definite MS. 30% reduction in relapses and reduction in severity of relapses

How often do I take it?

Every second day

How is it taken?

Subcutaneous injection (under the skin)

Possible side effects

Common side effects (affecting more than 1 person in 100): flu-like symptoms; headache; injection site reactions; blood cell abnormalities; feeling weak or tired; difficulty sleeping; diarrhoea, nausea and vomiting; muscular or joint pain; infections

Less common side effects (affecting less than 1 person in 100): changes in menstruation (periods); neurological symptoms, mood changes, depression; liver abnormalities; allergic reactions; heart problems and hypertension; hair thinning or loss; damage to small blood vessels leading to kidney problems

How is it reimbursed?

High-Tech Scheme

Drug

Copaxone® 20mg/ml

Who takes it?

People with RRMS and people who have experienced a well-defined first clinical episode and are determined to be at high risk of developing clinically definite MS

What are the benefits?

Reduces the number of relapses by up to 30%

How often do I take it?

Daily

How is it taken?

Subcutaneous injection (under the skin)

Possible side effects

Possible allergic reactions (hypersensitivity): signs include rash, swelling of the eyelids, face or lips, sudden shortness of breath, convulsions, fainting

Other reactions following injection (immediate post-injection reaction): flushing or reddening of the chest or face; shortness of breath; chest pain; pounding and rapid heartbeat. These symptoms normally do not cause problems and disappear within half an hour

Common side effects (may affect more than 1 in 10 people): infection, flu; anxiety, depression; headache; feeling sick; skin rash; pain in the joints or back; feeling weak; skin reactions at the injection site including reddening of skin, pain, formation of wheals, itching, tissue swelling, inflammation and hypersensitivity; non specific pain

How is it reimbursed?

High-Tech Scheme

Drug

Copaxone® 40mg/ml

Who takes it?

People with RRMS

What are the benefits?

Reduces the number of relapses by up to 30%

How often do I take it?

Three times per week, with a minimum of 48 hours between injections

How is it taken?

Subcutaneous injection (under the skin)

Possible side effects

Possible allergic reactions (hypersensitivity): signs include rash, swelling of the eyelids, face or lips, sudden shortness of breath, convulsions, fainting

Other reactions following injection (immediate post-injection reaction): flushing or reddening of the chest or face; shortness of breath; chest pain; pounding and rapid heartbeat. These symptoms normally do not cause problems and disappear within half an hour

Common side effects (may affect more than 1 in 10 people): infection, flu; anxiety, depression; headache; feeling sick; skin rash; pain in the joints or back; feeling weak; skin reactions at the injection site including reddening of skin, pain, formation of wheals, itching, tissue swelling, inflammation and hypersensitivity; non specific pain

How is it reimbursed?

High-Tech Scheme

Drug

Gilenya®

Who takes it?

People whose neurologists consider their disease is rapidly evolving

What are the benefits?

54% relapse rate reduction but also benefits on disability, MRI and brain atrophy

How often do I take it?

Once daily

How is it taken?

Oral

Possible side effects

Common side effects (affecting more than 1 person in 100): headache; back pain; diarrhoea; cough; raised liver enzyme levels; infections: herpes virus, fungal, flu; changes in heartbeat; dizziness, weakness; lowering of white blood cells; skin rash, itching; depression; eye pain, blurred vision; mild increase in blood pressure; basal cell carcinoma

Less common side effects (affecting less than 1 person in 100): pneumonia; swelling in the back of the eye (macular oedema); low mood; lowering of neutrophils (type of white blood cell)

How is it reimbursed?

High-Tech Scheme

Drug

Lemtrada®

Who takes it?

People with RRMS with active disease defined by clinical or imaging features

What are the benefits?

Reduces the number of MS relapses by about 70% and helps to slow down or reverse some of the signs and symptoms of MS

How often do I take it?

Administered in two treatment courses. For the first treatment course people receive one infusion per day for five days. One year later people receive one infusion per day for three days.

How is it taken?

Infusion

Possible side effects

Common side effects (affecting more than 1 person in 100): overactive or underactive thyroid; infusion associated reactions including headaches, rashes, fever and nausea; infections - respiratory and urinary; decrease in white blood cells (lymphopenia); changes in blood pressure, heart rate; rash; musculoskeletal pain

Less common side effects (affecting less than 1 person in 100): idiopathic thrombocytopenic purpura (ITP) a blood clotting disorder; kidney problems; thyroid disorders; increased levels of liver enzymes

How is it reimbursed?

National Drugs Management Scheme

Drug

Mavenclad®

Who takes it?

Adults with RRMS whose disease remains active whilst on any one other DMT or those with very active MS (two or more disabling relapses within a year and MRI evidence of new areas of MS activity)

What are the benefits?

Mavenclad can reduce the number of relapses experienced by about 50% and also reduces number and size of lesions

How often do I take it?

Mavenclad is taken as a pill in two treatment courses, twelve months apart

How is it taken?

Oral

Possible side effects

Common side effects (more than 1 in 100): decrease in white blood cells (lymphopenia), herpes virus infection (shingles or cold sores), rash, cold sores, hair loss

How is it reimbursed?

Awaiting decision on reimbursement from the NCPE

Drug

Ocrevus®

Who takes it?

Adults with active relapsing MS and early active primary progressive MS

What are the benefits?

Reduces number of relapses and number of active lesions in RRMS. Slows or reduces disability progression in PPMS

How often do I take it?

Ocrelizumab is taken as an intravenous infusion (drip). The first dose is given as two separate infusions, two weeks apart. Further doses are given as one infusion every six months.

How is it taken?

Infusion

Possible side effects

Across all the clinical trials, infusion-related reactions, chest infections and herpes (oral herpes and shingles) were more frequent in those taking ocrelizumab.

Neoplasms (abnormal growth of tissues which can be benign or malignant), including several cases of breast cancer, were reported more frequently in those taking ocrelizumab. This will need to be monitored closely.

How is it reimbursed?

Awaiting decision on reimbursement from the NCPE

Drug

Plegridy®

Who takes it?

Adults with RRMS

What are the benefits?

Slows the progression of disability and decreases the frequency of relapses by up to 30%

How often do I take it?

Once every two weeks

How is it taken?

Injection under the skin of the thigh, abdomen or upper arm

Possible side effects

Common side effects (affecting more than 1 person in 100): flu-like symptoms; headache; injection site reactions; blood cell abnormalities; feeling weak or tired; difficulty sleeping; diarrhoea, nausea and vomiting; muscular or joint pain; infections

Less common side effects (affecting less than 1 person in 100): changes in menstruation (periods); neurological symptoms, mood changes, depression; liver abnormalities; allergic reactions; heart problems and hypertension; damage to small blood vessels leading to kidney problems

How is it reimbursed?

High-Tech Scheme

Drug Rebif®

Who takes it?

People with RRMS

What are the benefits?

Reduces the number of relapses by up to 30% and reduces the severity of relapses. Slows the progression of disability

How often do I take it?

Three times per week

How is it taken?

Subcutaneous injection (under the skin)

Possible side effects

Common side effects (more than 1 in 100 people affected) include: flu-like symptoms; injection site reactions; liver enzyme abnormalities; headache; depression; nausea or vomiting; difficulty sleeping; hair loss.

Less common side effects (less than 1 in 100 people affected): thyroid dysfunction; allergic reactions; liver inflammation; increased sweating; blood clots

How is it reimbursed?

High-Tech Scheme

Drug Tecfidera®

Who takes it?

Adults with RRMS

What are the benefits?

Slows the progression of disability and reduces the frequency of relapses by up to 50%

How often do I take it?

Twice a day

How is it taken?

Oral capsule

Possible side effects

Common side effects (affecting more than 1 person in 100): flushing and feeling hot; gastrointestinal upset (feeling sick, diarrhoea, abdominal pain, vomiting, indigestion); decrease in white blood cells; rash; increased levels of liver enzymes; ketones and protein in urine

Cases of progressive multifocal leukoencephalopathy (PML) have

been reported for people taking Tecfidera. The risk of developing PML on Tecfidera is considered very low.

How is it reimbursed?

High-Tech Scheme

Drug Tysabri®

Who takes it?

Adults with highly active rapidly evolving severe relapsing remitting MS

What are the benefits?

Disabling effects of MS approximately halved and the number of MS attacks decreased by two-thirds in clinical trials

How often do I take it?

Once a month

How is it taken?

Infusion into a vein

Possible side effects

Common side effects (affecting more than 1 person in 100): urinary tract infections; inflammation of the nose; shivering; itchy rash (urticaria); headache; dizziness; nausea, vomiting; joint pain; fever

Less common side effects (affecting less than 1 person in 100): severe allergic reaction during infusion (rash, swelling of face, lips or tongue, difficulty breathing); discomfort during the infusion including feeling sick, headache, dizziness; progressive multifocal leukoencephalopathy (PML); serious infections; liver problems

How is it reimbursed?

National Drugs Management Scheme

Second – line therapies

Drug Gilenya®

Who takes it?

People who have failed on a first-line treatment

What are the benefits?

Relapse reduction of 54%, reduction in the number and size of MRI lesions, reduction in brain volume loss, less likely to experience worsening of disability

How often do I take it?

Once daily

How is it taken?

Oral

Possible side effects

Common side effects (affecting more than 1 person in 100): headache; back pain; diarrhoea; cough; raised liver enzyme levels; infections: herpes virus, fungal, flu; changes in heartbeat; dizziness, weakness; lowering of white blood cells; skin rash, itching; depression; eye pain, blurred vision; mild increase in blood pressure; basal cell carcinoma

Less common side effects (affecting less than 1 person in 100): pneumonia; swelling in the back of the eye (macular oedema); low mood; lowering of neutrophils (type of white blood cell)

How is it reimbursed?

High-Tech Scheme

Drug

Mavenclad®

Who takes it?

Adults with RRMS whose disease remains active whilst on any one other DMT or those with very active MS (two or more disabling relapses within a year and MRI evidence of new areas of MS activity)

What are the benefits?

Mavenclad can reduce the number of relapses experienced by about 50% and also reduces number and size of lesions

How often do I take it?

Mavenclad is taken as a pill in two treatment courses, twelve months apart

How is it taken?

Oral

Possible side effects

Common side effects (more than 1 in 100): decrease in white blood cells (lymphopenia), herpes virus infection (shingles or cold sores), rash, cold sores, hair loss

How is it reimbursed?

Awaiting decision on reimbursement from the NCPE

Drug

Tysabri®

Who takes it?

Adults with relapsing remitting MS who have high disease activity despite treatment with other DMTs

What are the benefits?

Disabling effects of MS approximately halved and the number of MS attacks decreased by two-thirds in clinical trials

How often do I take it?

Once a month

How is it taken?

Infusion into a vein

Possible side effects

Common side effects (affecting more than 1 person in 100): urinary tract infections; inflammation of the nose; shivering; itchy rash (urticaria); headache; dizziness; nausea, vomiting; joint pain; fever

Less common side effects

 (affecting less than 1 person in 100):

severe allergic reaction during infusion (rash, swelling of face, lips or tongue, difficulty breathing); discomfort during the infusion including feeling sick, headache, dizziness; progressive multifocal leukoencephalopathy (PML); serious infections; liver problems

How is it reimbursed?

National Drugs Management Scheme

Symptomatic treatments

Drug

Fampyra®

Who takes it?

Adults with MS related walking disability

What are the benefits?

Walking speed improvement

How often do I take it?

Twice daily

How is it taken?

Oral tablet

Possible side effects

Very common side effects include urinary tract infection

How is it reimbursed?

Reimbursed by the HSE on a responder basis

Multiple Sclerosis Ireland,
80 Northumberland Road, Dublin 4

T (01) 678 1600

F (01) 678 1601

MS Info Line 1850 233 233

E info@ms-society.ie

www.ms-society.ie

Charity Number 05365

Connect with us



An Roinn Tithíochta, Pleanála,
Pobail agus Rialtais Áitiúil
Department of Housing, Planning,
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