



My MS My Needs
COMPREHENSIVE SURVEY OF THE NEEDS OF PEOPLE WITH MS



Introduction



Friends

I am delighted to present the results of MS Ireland's My MS My Needs survey, a comprehensive survey of the needs of people with MS in Ireland. This is the first such survey of its kind and our intention is to repeat it in the future. The results of the survey will help us to plan our services and will inform our ongoing advocacy work. It will also help to inform us of where there are gaps currently in service provision and the information gathered will offer us an evidence based platform to campaign on your behalf.

I would therefore like to sincerely thank every person that took the time to complete the survey – it is through research such as this that we are able to gather the information and evidence we need to make a positive and practical difference to the lives of people affected by MS in Ireland.

I hope you enjoy reading this report. If you would like further information about how we intend to use the results of the survey, please get in touch with Harriet Doig, Information, Advocacy and Research Officer, at harrieta@ms-society.ie

Ava Battles CEO



Acknowledgements

Survey design and recruitment:

Aidan Larkin National Services Development Manager, MS Ireland
Harriet Doig Information, Advocacy and Research Officer, MS Ireland
Diana Carthy Communications, MS Ireland

Research analysis and report:

Sophie Crowe, Trinity College Dublin and Harriet Doig, MS Ireland

MS Ireland would also like to thank the members of MS Ireland's Advisory Panel for their assistance in designing this survey.

This research was made possible by contributions to MS Ireland core funding by Biogen (Ireland) Ltd and Merck Serono (Ireland) Ltd. The concept, design, development of the survey and final report are independent of Biogen and Merck Serono. MS Ireland retains editorial control of this research.

Contents

What is multiple sclerosis?	3
About MS Ireland	3
Previous studies	5
Methodology and sample	5
Executive summary	7
Access to medications and services	9
Care and support	13
Emotional wellbeing	15
Financial security	16
Discussion and recommendations	19
Limitations	22
Conclusion	22
References	22

What is multiple sclerosis (MS)?

Approximately 9,000 people in Ireland have multiple sclerosis (MS). 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. 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. 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.

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. 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 varies 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, but huge advances have been made in treatments in recent years with a wide range of medications now available to manage symptoms and reduce relapses in RRMS. Treatment options for progressive forms of MS are currently much more limited, but there have been some very promising discoveries in research into progressive MS in recent years.



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 MS news magazine, 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

Our dedicated research fund annually finances a number of medical and social research projects 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.



MS Ireland 2016 in numbers

1 National Office in Dublin



10 10 professionally staffed Regional Offices

412 412 residents in the MS Care Centre



37 Voluntary Branches

3000+ Volunteers



1,422 People engaged in one-to-one services

1,297 Interactions with the MS Information Line



Previous studies

This is the first comprehensive survey of the needs of people with MS in Ireland, looking at the whole country and covering a wide range of domains including healthcare, social care, impact on family and caregivers, employment, finances and emotional and physical wellbeing. Previous, smaller studies into the unmet needs of people with MS in Ireland have focused on specific areas of need and/or specific geographical regions, such as MS Ireland's Focus on MS study (1999) which looked at the utilisation and perception of health and community services by people with MS in the Western Health Board region. This study found high levels of dissatisfaction with these services. For example, 75% stated that they were not happy with the home help service and 84% were not happy with the community occupational therapy service.

Lonergan et al (2015) surveyed 632 people with MS in three geographical regions – South Dublin, Wexford and Donegal. They found significant levels of unmet need, in particular regarding access to rehabilitative and therapeutic services – physiotherapy was the most frequently reported unmet need. They also found significant levels of unmet financial and social needs, and noted that people with MS in rural areas were more likely to have unmet needs than those in urban areas. They also found that people with progressive forms of MS were more likely not to be able to access the services and supports they required than people with relapsing remitting MS.

MS Ireland's 'Societal Costs of Multiple Sclerosis in Ireland 2015' study looked at the economic costs of MS. The study found that MS costs Irish society approximately €429 million per year and that people with MS require high levels of medical care – healthcare resources used included 54,000 GP visits per year, 21,800 neurology visits per year, 16,450 nights in hospital and 7,600 visits from MS Ireland's community workers. The study also found that people with progressive forms of MS and more severe levels of disability had higher levels of need and resource use in terms of healthcare, and that quality of life for people with MS is rated 32% lower than that of the general population. In terms of financial and emotional wellbeing, the study found that 61% of respondents felt they could not provide financially for their children, and 38.5% of the sample had experienced either depression or anxiety, or both (MS Ireland, 2015).

Previous studies have also noted that MS impacts considerably on employment. In 'Multiple Sclerosis and Employment: Facts and Figures' (2016) MS Ireland found that 34.2% of people with MS had to retire early due to their MS, and 68% felt MS had limited their career potential.

Methodology and sample

The My MS My Needs survey was carried out in the month of May 2016. The survey was hosted on MS Ireland's website and shared extensively via Facebook and Twitter. Paper copies of the survey were also made available to those who requested them. In total, 829 people completed the survey. Of these, 46 reported that they did not have a diagnosis of MS and were excluded from the final analysis, leaving a sample of 773.

Nearly 75% of the sample was female and approximately 25% male. This reflects previous research findings on the gender breakdown of people with MS in Ireland (MS Ireland, 2015; O'Connell, Tubridy, Hutchinson & McGuigan, 2017).

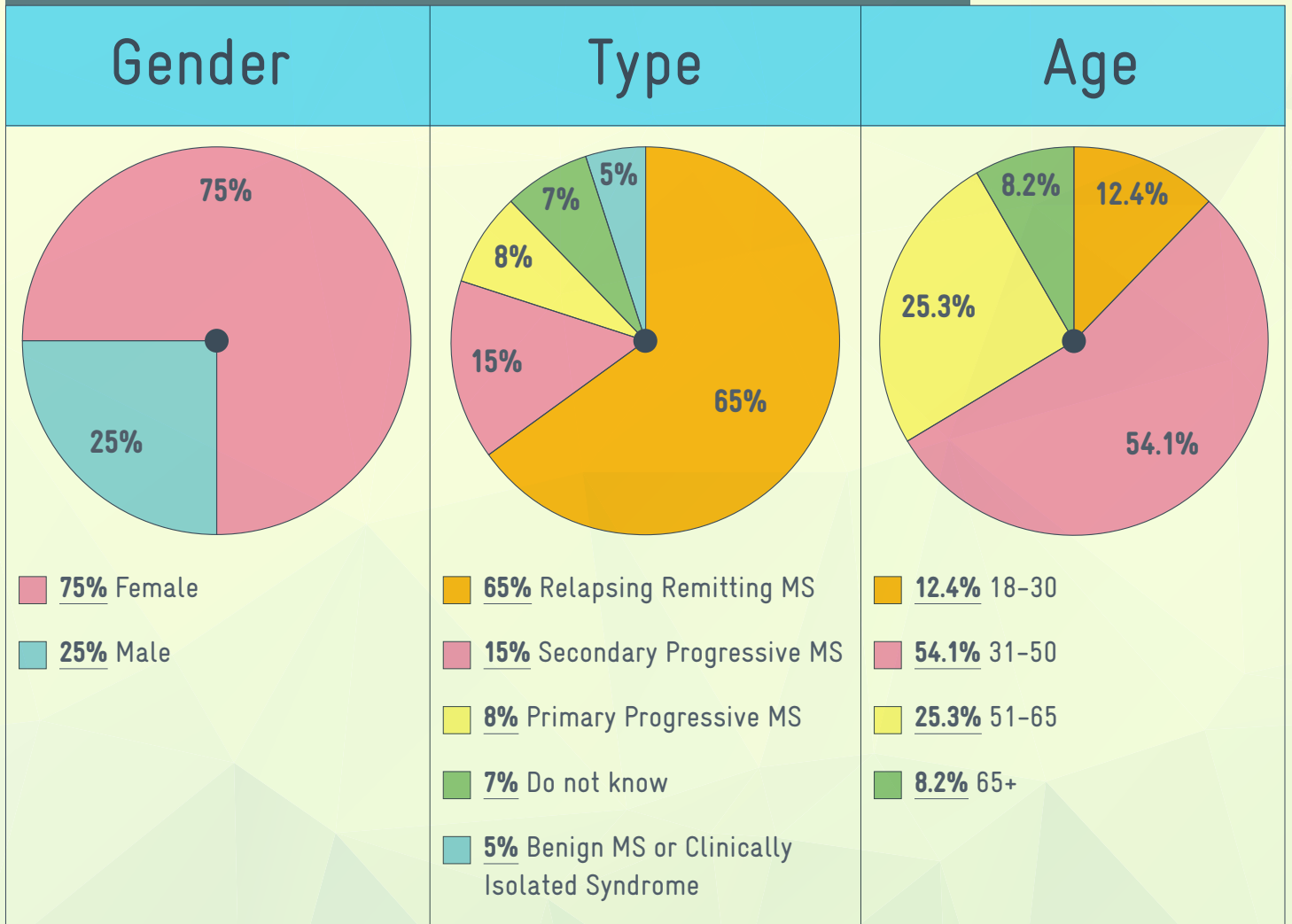
65% of the sample were diagnosed with relapsing remitting MS and nearly 15% with secondary progressive MS. 8% had primary progressive MS. Nearly 7% did not know what type of MS they had. The remainder of the sample either had benign MS or clinically isolated syndrome (a first attack of symptoms suggestive of MS, before a confirmed diagnosis is made). Again, this is broadly similar to other recent Irish research. MS Ireland's 'Societal Costs of Multiple Sclerosis in Ireland 2015' report, for example, found that 63% of their sample had RRMS, 16.3% had SPMS, 11% had PPMS and 6.2% did not know what type of MS they had. O'Connell et al (2017), in a sample of 113 people newly diagnosed with MS between March 2014 and February 2015, found that 10% were diagnosed with PPMS initially.



Reports available to download from www.ms-society.ie/pages/living-with-ms/information-centre/our-publications

61% of participants said they lived in an urban area and 39% in a rural area. 31.5% of the total sample lived in the Dublin area, 10.2% in Galway and 9.1% in Cork.

In terms of age, 12.4% were in the 18-30 age range, 54.1% were in the 31-50 range, 25.3% were in the 51-65 range and 8.2% were 65+. It should be noted that as the vast majority of the surveys were completed online via social media and the MS Ireland website, it is possible that the older age group were somewhat under-represented (see Limitations).



Key

- **RRMS**
Relapsing Remitting MS
- **PPMS**
Primary Progressive MS
- **SPMS**
Secondary Progressive MS
- **PFMS**
Progressive forms of MS
(primary progressive and secondary progressive)

Key Findings

Access to medications and services

25% Over 25% are not taking a Disease Modifying Therapy (DMT) for their MS

20% Almost 20% had not received enough information from healthcare professionals about available drugs

25% Less than 25% have been offered neurorehabilitation. More people with PFMS have accessed neurorehabilitation than people with RRMS

10% Only 10% had not had an MRI scan but believed they needed one.
Nearly 50% waited two months or less for a scan

50%

44% 44% waited six months or more for their last neurologist appointment
Munster residents appear to have the best access to treatments and Connacht the worst



Care and support

73% 73% receive care and support from a family member or friend

16% 16% of people with PFMS require full time care and assistance

12% Only 12% of care givers are in receipt of Carer's Allowance

60% 60% of those requiring full time assistance felt their care givers had needed more information and support

12% 12% had not received formal (paid) care but had needed it

18% 18% needed home adaptations but could not get them

77% 77% of recipients of Housing Adaptation Grants had not had the full cost of adaptations covered

No regional differences were found in accessing formal (paid) care



Emotional wellbeing

32% **Almost 32%** had not received enough support for mood and emotional issues

35% **35%** said MS impacts on family life a lot of the time

25% **Almost 25%** said their MS impacted their participation in daily life “very much”



Financial security

30% **Nearly 30%** were either struggling or really struggling on their current income

65% **65%** have private health insurance

57% **57%** did not have life insurance

48% **48%** have a Medical Card

80% **Almost 80%** have a Long Term Illness book

Fatigue, cognition issues, mobility problems, balance and eyesight problems were common reasons given for having to stop working or reducing working hours



Key recommendations

- Improve access to healthcare services – Neurologists, MS Nurses, therapeutic services and neurorehabilitation
- More information about entitlements, supports and services that are available for people with MS, and how to access them, (including the services provided by MS Ireland) should be made available at the point of diagnosis
- Applications processes for Medical Cards and other means tested benefits and entitlements should account for the additional financial burden of living with MS
- More flexible options for accessing life insurance and health insurance should be made available to people with MS
- Further research is required around how people with MS consider medication options and what information would be required to help them make informed decisions



- More specific and targeted information and supports should be made available to people with progressive forms of MS
- More information, services and supports are required for care givers of people with MS
- Low cost options for accessing support with the emotional issues that MS can cause should be made available
- Increase funding to and improve access to formal paid care and respite care, so as to relieve pressure on care givers
- Review of the Housing Adaptation Grant system, to enable more people who would benefit from housing adaptations to be able to access them
- Continued advocacy is required to improve services, supports and policies around employment, to enable more people with MS to carry on working for as long as they wish to



Access to medications and services



Access to drugs

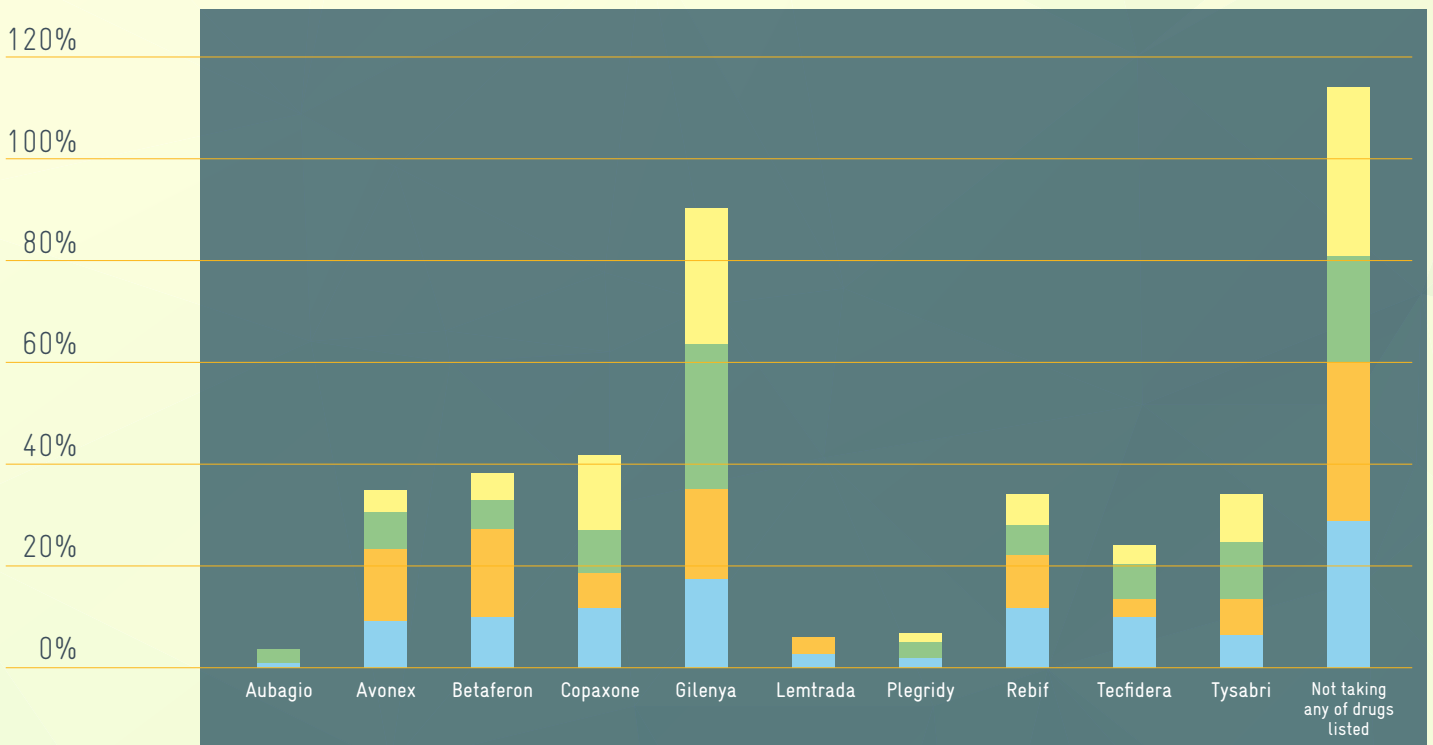
Just over 40% of the total sample started treatment within three months of diagnosis and those with RRMS had the greatest proportion to report this, at 45.5%. About a fifth started treatment twelve months or more following diagnosis.

Over a quarter (n=166) of the total sample were not taking any listed drugs for their MS. There were greater proportions of respondents with progressive forms of MS (PFMS) (62.4%, n=83) and the unsure group (31.4%, n=11) not being prescribed any drugs compared to those with RRMS, as would be expected.

A quarter of respondents with RRMS (n=109) were taking Gilenya; 8% (n=34) of the RRMS group were taking Tysabri, as were 8% of the PFMS group and 6% of the unsure group. None of the unsure group, nor respondents with PFMS, were taking Lemtrada and only 2% (n=8) of those with RRMS were prescribed this drug.

Higher proportions of respondents across the country were prescribed Gilenya compared to Tysabri and Lemtrada. Almost 29% (n=34) of Munster residents took Gilenya, as did over a quarter of Connacht residents, 17% (n=60) of Leinster residents and 17% (n=5) of Ulster residents. 11% (n=13) of Munster residents took Tysabri, as did nearly 10% (n=10) of residents of Connacht and only 6.5% (n=22) of those living in Leinster. A relatively high proportion of respondents across the country were not taking any drugs for their MS: a third (n=34) of Connacht residents, 31% (n=9) of Ulster residents, 21.2% (n=25) of Munster and 28.7% (n=98) of Leinster residents were not prescribed any medication listed. Residents of Munster, however, had higher levels of people being prescribed a drug to treat their MS, compared to other provinces.





- Leinster ■
- Ulster ■
- Munster ■
- Connacht ■

Information on drugs

Personal finances did not appear to play a role in whether respondents were taking a drug. Of respondents struggling on income, 27% (n=46) were not taking any listed drugs. This was also true for almost 30% (n=72) of the group who were just managing on their income, and 26.5% (n=48) of those financially comfortable.

Nor was there a strong connection between taking drugs and having accessed adequate information on available drugs. Just over a quarter (n=30) of respondents who had not been provided with enough information on drugs by their healthcare professionals were not taking drugs. The same proportion of respondents who did access this information were also not prescribed anything (n=97).

Almost a fifth of respondents overall had not received enough information from healthcare professionals on available drugs for MS. Most RRMS respondents (70%) received enough information on drugs from healthcare workers, compared to only a third of the unsure group. This might suggest the unsure group were at an earlier stage of treatment, had less advanced types of MS, or had poorer access to MS specialists.

Access to healthcare

63.4% (n=402) of the total sample had had an MRI scan in the last 12 months. Just under half (48%, n=190) waited less than two months for a scan, although over a quarter (n=109) waited more than six months. Over half of those who had had an MRI scan had either paid for it themselves (5%, n=20) or had it paid for through private health insurance (45.5%, n=183).



Of the total, 12.3% (n=75) had not seen an occupational therapist but had needed to, with a quarter (n=9) of the unsure group reporting this, the highest proportion of the three groups.

Nearly 86% (n=548) of the total sample had seen a neurologist in the last 12 months. Of those who hadn't, 8.6% (n=55) said they had not needed to and 5.5% (n=35) said they had needed to but couldn't. Just over 44% (n=238) of the sample waited six months or more for their appointment. When attending the appointment, the majority (60.4%, n=329) waited for less than an hour to be seen.

Just over 15% (n=93) of respondents had not seen a physiotherapist in the previous year though they had needed to. Almost 7% (n=41) of respondents had not accessed a speech and language therapist though they needed to.

Almost a quarter (n=154) of the sample were offered neurorehabilitation in the previous year; the PFMS group had the highest proportion, at almost 40% (n=57). This group also had the highest proportion, at a quarter (n=35), to have needed the service but were not offered it. Almost 23% (n=142) of respondents were not sure what neurorehabilitation was. Of all respondents, 29% (n=175) had not seen an MS Ireland community worker because they were not aware of this service.

Obstacles to accessing healthcare

The reasons that people could not access services when they needed to were broadly similar across the treatments and services discussed above. Many respondents noted that services were not available in their region, or that they lived too far away from certain services. Many had not been offered or made aware of services by their healthcare professionals and so did not know how to access them or whether or not they were eligible.

Some respondents were unaware that certain services existed for MS patients. Several people commented that the MS Nurse service was hard to access – for example, phone messages weren't returned. Several respondents felt the MS specialist nurse in their hospital was unhelpful and unfriendly, which discouraged them from approaching the person for advice or information.

Some had tried to request and arrange appointments with healthcare workers, including the specialist nurse and the speech and language therapist, which were not followed up by hospital staff. A small number of respondents explained that they had not secured an appointment with a healthcare worker because, as the service was overstretched, the person was too busy with other patients. Some respondents were waiting for appointments with various healthcare workers, pointing to long waiting lists for treatments such as physiotherapy.

Several respondents felt that a sense of pride was an obstacle for them in seeking help with certain problems; for example, one respondent decided not to attend group physiotherapy because they did not want to disclose their MS to others, while another did not access a speech and language therapist out of a sense of shame. One respondent had decided against making an appointment with the occupational therapist due to being worried they would waste the person's time. Similarly, one respondent felt embarrassed to contact an MS Ireland community worker because they believed their symptoms were less severe compared to those of others with MS. A key reason for people not accessing treatment they needed, then, was a lack of information about available services for which they were eligible and lack of guidance on accessing them.



Regional differences in access to healthcare

Only 10% (n=63) of the sample had not had an MRI scan but needed one. Ulster residents had the highest proportion to report this (17.2%, n=5). Nearly half of the entire sample (47.9%, n=187) waited two months or less for the scan. The greatest proportion to report this lived in Munster, at 61.5% (n=48). Over a third (n=80) of Leinster residents, on the other hand, waited six months and over for the scan, a greater proportion than other provinces. Almost half (n=197) the sample said the HSE paid for their scan and Ulster residents (77.8%, n=14) had the highest proportion to report this. Over 67% (n=53) of Munster residents, however said their scan was paid for by private health insurance.

Nearly a quarter (n=154) of respondents had been offered neurorehabilitation for their MS in the previous twelve months. Residents of Ulster and Munster had higher proportions than the other two provinces to report this, with one third of Ulster (n=10) and 34.1% (n=43) of Munster residents offered the treatment. Almost 23% (n=142) of respondents had not been offered neurorehabilitation and were unsure what this treatment was. The highest proportion to report this were Leinster residents, at nearly a quarter (n=89).

Nearly 40% (n=247) of the sample had seen an MS specialist nurse. Leinster residents had the highest proportion to report this (44.3%, n=158), compared to a third (n=40) of Munster residents and a fifth (n=6) of Ulster residents. A minority had not seen an MS specialist nurse but had needed to (16.1%, n=100). The highest proportion was among Ulster residents, at a fifth (n=6), followed by Leinster residents, at just over 18% (n=65).

A majority of respondents (64%, n=155) were less than an hour's travel from the MS specialist nurse. Almost 80% (n=31) of Munster residents reported this, as did 65% (n=101) of Leinster residents and over half (51.2%, n=22) of Connacht residents; 16.3% of Connacht residents spent over two hours traveling to the nurse.

One pattern identified here is that Munster residents had better access to certain treatments than those living in other provinces. Residents of Munster fared better on access to some treatments, including access to neurorehabilitation, getting a timely MRI scan as a private patient, and seeing the neurologist in their private rooms, of whom 42% (n=47) reported this. This group also had the greatest proportion to be within close proximity to the MS specialist nurse.

In contrast, residents of Connacht had the lowest proportion of respondents to have seen the neurologist in the past year, at 80.9% (n=89), compared to 93.3% (n=28) of Ulster residents. This group also had the lowest proportion, at just over half (n=57), to have an MRI scan, compared to 67.7% (n=243) of Leinster residents and 63.3% (n=396) of all respondents. Connacht residents also had highest proportion, at a fifth (n=22), to have needed neurorehabilitation but not been offered it, compared to 15.4% of all respondents.





Out of the total, 73% (n=508) had a friend or family member to provide support or assistance in relation to their MS.

There was a link between the level of assistance respondents needed from others and the type of MS they had. Only 4.8% (n=33) of the total needed fulltime assistance but the PFMS group had the highest proportion in this category, with 16.6% (n=26), compared to 2% (n=1) of the unsure group and 1.3% (n=6) of the RRMS group. The PFMS group also had the highest proportion of respondents to need frequent assistance, with 38.2% (n=60) reporting this compared to 23.4% (n=11) of the unsure group and 10% (n=48) of the RRMS group.

There was a link between whether levels of assistance needed from others had changed over the past year and respondents' type of MS. Around three quarters of the RRMS group (75.5%, n=360) and of the unsure group (73.9%, n=34) did not need any more assistance. However, levels of assistance needed from others increased for a majority (53.5%, n=83) of the PFMS group, compared to roughly a fifth (n=97) of the RRMS group and the unsure group (n=10). As these findings indicate, people with PFMS may require more help than others with managing the effects of their MS. Therefore, greater attention to the needs of those people requiring the most support may be called for within healthcare policy.

Support for caregivers

There was a link between whether caregivers had received adequate support to mitigate the effects of MS and how strongly MS impacted on respondents' family life. Respondents who said MS impacted on family life a lot of the time had a greater proportion to report that their caregivers had needed more information to manage their MS, at 46.5% (n=93), compared to those whose MS impacted family life only some of the time (26%, n=75) or not at all (13%, n=13). Respondents whose MS impacted family life only some of the time had the highest proportion, at 23% (n=66), to feel their caregivers received sufficient information or support, compared to a fifth (n=41) of those whose MS impacted family life more severely.

Respondents whose MS impacted on daily life much of time had the highest proportion, at 52.4% (n=75), to say their caregivers had not received adequate information to manage their MS in the past year, compared to 26.5% (n=101) of respondents whose MS impacted daily life "somewhat" and only 10.3% (n=7) of respondents whose MS did not impact daily life "at all".

There was a connection between the type of MS respondents had and whether caregivers received Carer's Allowance. Of the total, 12.7% (n=64) said their caregivers received Carer's Allowance. The PFMS group had the highest proportion here at 21.5% (n=29), compared to only 8.7% (n=29) of the RRMS group. There was also a link between whether caregivers got adequate support and if they received Carer's Allowance. A higher proportion (40%, n=120) of



respondents whose caregivers received Carer's Allowance said their caregivers needed more information and support, compared to the group who did not receive the allowance, at 32.2% (n=121).

However, the group receiving the allowance also had a higher proportion, at 34% (n=17), to say their caregivers had received adequate information. The group not receiving an allowance had the highest proportion to report not needing any information, at over 44% (n=166).

This might indicate that Carer's Allowance is given to people with more severe and debilitating forms of MS. Yet, despite getting this support, some caregivers are not getting sufficient information and support. In terms of policy focus, there seems to be a big gap in the extent to which different types of MS affect the individual's life. Those whose lives are strongly affected, including those caring for them, are not always getting adequate support.

Respondents who required fulltime assistance had the highest proportion, at 60% (n=15), to say their caregivers had needed more information or support in the past year, compared to under 47% (n=45) of respondents who needed frequent assistance and about a quarter (n=122) who did not require much assistance. Those requiring fulltime assistance and those whose caregivers receive Carer's Allowance are also often those people who said their caregivers did not receive adequate information and support to manage the effects of their MS. This suggests that people with more severe and debilitating types of MS, and their caregivers, are struggling to manage the impact of the disease on day to day life.

Formal care

Almost 12% of the total sample said they had not received formal paid care but had needed it and there was no difference found between provinces. A majority of those who had received this type of care said the HSE paid for it (84.1%, n=74). Among this group, just over 90% (n=37) of Leinster residents, all of those residing in Ulster (n=4), almost a quarter (n=20) of those in Munster and 81% (n=13) of Connacht residents, reported this.

Among those who had needed formal care, 23 did not know how to access it or that they may be eligible for such a service. 11 respondents had been refused funding for formal care by the HSE, or the home help they had been receiving was cut off due to cutbacks in the HSE. 10 respondents said they did not access this care due to the cost of the service, while nine spoke of pride or embarrassment preventing them from accessing the service. The findings point to a lack of awareness among people with MS about what they may be eligible for in terms of formal care. However, it is also clear that cut-backs in public healthcare services are adversely affecting people's access to care.

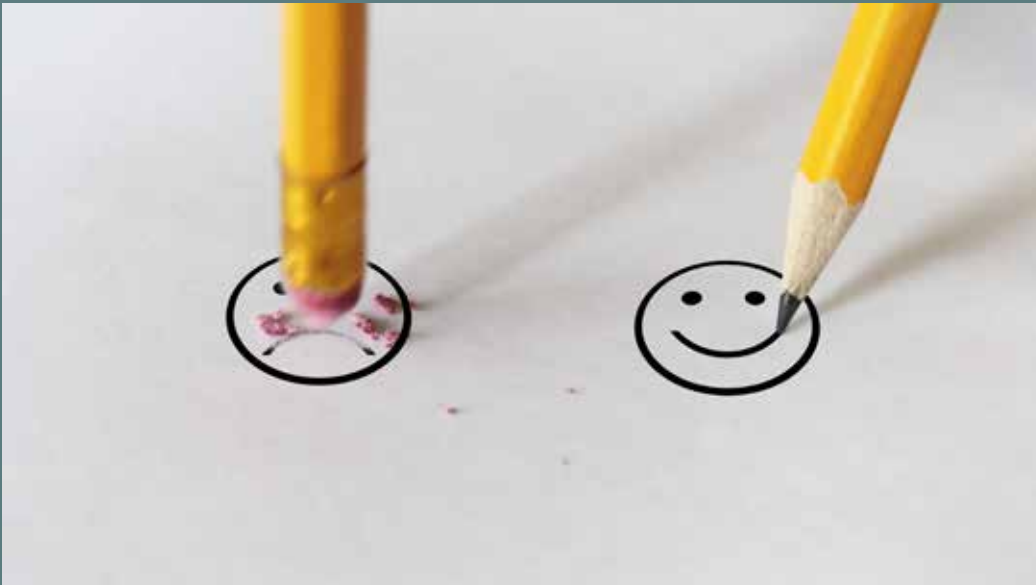
Home adaptations

Almost 18% (n=120) of respondents across the country said they had not made adaptations to their home due to their MS, though they would benefit from this; 8.5% (n=58) had made some adaptations but needed more but most (61.4%, n=423) did not require any.

A majority of respondents (65%, n=92) did not apply for a Housing Adaptation Grant from their local council to help with making necessary adaptations to their home. Just over 56% (n=43) who applied for this grant said their application was successful but over three quarters (77.3%, n=58) of these said it did not meet the overall costs of the adaptations.

Seventy-three respondents pointed to a lack of financial resources as an obstacle to making required adaptations to their homes. Seven lived in rented accommodation so felt they could not easily make adaptations to the property. Several respondents lacked relevant information and guidance on what would be needed and how to go about organising such work. A small number of respondents pointed to the emotional implications and barriers to making home adaptations, two citing fear and one stubbornness, as obstacles. Fatigue was also mentioned by a minority as a reason for not having addressed the issue.





Access to emotional support

Almost 32% (n=196) of the entire sample said they had not received enough support for mood and emotional issues relating to their MS. Many respondents had not accessed support for these issues because they had not been offered or made aware of any such services by their healthcare professionals. Emotional support was not available in some hospitals while others were unsure of how to access it. Several respondents felt reluctant to seek out support due to feelings of pride or a sense of stigma attached to talking about MS.

Practical issues such as distance from relevant services, trying to juggle organising appointments with jobs and family commitments, and the cost of such services presented an obstacle to some. A small number had accessed emotional support, including a psychiatrist and counsellor, as private patients.

A high proportion of the entire sample cited friends and family as a top source of support for mood and emotion issues. A greater proportion of those with RRMS than the unsure group saw a paid counsellor; while a greater proportion of the unsure group used online support groups or forums. The PFMS group had the highest proportion to see a psychologist or other therapist. Higher proportions of the RRMS and PFMS groups used their GP for support, compared to the unsure group.

Respondents who were unsure what type of MS they had seemed to find support for dealing with the impact of MS online more so than the other two groups, who sought support from health and mental health professionals in greater numbers. There may be a connection between the unsure group's use of the internet and less communication with their MS specialists.

Access to support and income

There was a link between whether respondents felt they had received sufficient support for emotional and/or mood issues in the past year and household income. Almost half of the overall sample had not needed support for these issues, at 48.7% (n=300). The struggling group had the highest proportion to report feeling that they had not received adequate support for emotional or mood issues though they had needed this, at 42% (n=76); while the financially comfortable group had the lowest proportion to report this, at 23% (n=43). This might indicate that the stress related to financial burden may increase the stress that comes from dealing with the emotional and physical effects of MS.



Impact of MS on personal life

There was a link between the types of MS respondents had and how much impact the disease had on family life. Out of the entire sample, 35.3% (n=245) felt their MS impacted on family life a lot of the time. The PFMS group had the highest proportion to report this, at 64.6% (n=102), while the RRMS group had the lowest, at just over a quarter (n=124).

Almost 55% (n=269) of the RRMS group said their MS impacted family life some of the time, as did 42.6% (n=20) of the unsure group, while only 31.6% (n=50) of the PFMS group said this. Almost a fifth (n=97) of the RRMS group said their MS did not impact on family life at all, compared to only 3.8% (n=6) of the PFMS group.

There was also a link between the types of MS respondents had and how much impact the disease had on their participation in daily life. Almost a quarter (n=171) of the sample said their MS impacted their participation in daily life "very much"; the PFMS group had the highest proportion to answer this, with 48% (n=78), compared to 29% (n=14) of the unsure group and 16% (n=79) of the RRMS group. A majority (70%, n=341) of the RRMS group and of the unsure group (60%, n=29) said their MS impacted on daily life "somewhat", compared to half (n=82) of the PFMS group.

The PFMS group, then, had the greatest proportion to feel that both their family life and day to day life was very much impacted by their MS. This group also had the highest proportion to seek support from a psychologist, suggesting they may need more support for emotional issues based on the impact of MS on their lives.



Financial security



Personal Finances

40% of the sample described themselves as neither comfortable nor uncomfortable on their current income. Just over 30% were either living comfortably or very comfortably on their current income, leaving just under 23% who stated they were struggling and 6.6% who were really struggling.



Private health insurance & life insurance

A majority (65%, n=415) of respondents had private health insurance, though a greater proportion in their 30s (69.5%) had it than those in their 40s (61.9%) and 50s (66.4%). Many respondents had either stopped their private insurance or had never paid for it due to cost and the financial burden it represented. For some, the cost of private health insurance would now be unmanageable since they could no longer work. Other respondents had a full Medical Card and felt they did not need private insurance, or were satisfied with the care provided through the public health system. Several decided not to take private insurance because they disagreed with the privatisation of healthcare and a two-tiered system.

Of the total sample, 57% (n=358) did not have life insurance and there was a link between age group of respondents and whether they had life insurance. The highest proportion who did not have this insurance were the 18-29 age group (86%, n=55) while respondents in their 40s had the greatest proportion to report having it, at 57.5% (n= 96).

For many respondents, cost was a main reason for not having life insurance. Getting a life insurance policy, according to some, was more difficult due to having MS. For example, some had been refused due to being "high risk" while others received quotes that were unaffordable because of having a long-term illness. Some respondents who had no dependents or assets felt life insurance was unnecessary for them. Several noted that as they never anticipated getting sick before old age, life insurance had never been a consideration. Some respondents had life insurance cover as part of their work contract or pension.

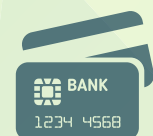
Access to public care

Out of the entire sample, 48% (n=323) had a Medical Card. The highest proportion came from the struggling group, at just under 70% (n=130), followed by the neither comfortable nor uncomfortable group at 45% (n=115). The majority (70.7%, n=237) of those respondents who did not have a Medical Card explained this was the case because they had not applied for one. The financially comfortable group had the highest proportion to report this, at 80% (n=111), compared to 73% (N=41) of the struggling group and only 60.7% (n=85) of the neither comfortable nor uncomfortable group.

The neither comfortable nor uncomfortable group had the highest proportion to report that their application was refused, at 30.7% (n=43), compared to a fifth (n=11) of those struggling and 17% (n=24) of the financially comfortable. A minority had their Medical Card withdrawn following a review, but the highest proportion was from the neither comfortable nor uncomfortable group, at 8.6% (n=12). These findings suggest the group that are just managing financially (neither comfortable nor uncomfortable) may be impacted the most by cuts to public health services such as access to Medical Cards, as preference is given to people with greater financial burdens.

Most respondents (80.7%, n=496) did not have a GP Visit Card, as a majority had not applied (89.3%, n=435). Of the entire sample, almost 80% (n=502) had a Long Term Illness (LTI) Book. The highest proportion of respondents to report this came from the financially comfortable group, at 84.8% (n=162); 80.4% (n=205) of the neither comfortable nor uncomfortable group reported this, while the lowest proportion to have the LTI Book was the struggling group, at 73.4% (n=135).

A main reason that respondents did not have Medical Cards, LTI Books or GP Visit Cards was an assumption that they would not be eligible to apply. This was especially true for respondents explaining why they did not have a Medical Card. Some believed or had been advised by HSE employees that they were not eligible based on their overall household income being above the threshold. Several respondents had access to pensions and had not considered applying for a Medical Card. For example, one respondent received an Invalidity Pension as well as Income Protection payments from their former employer.



Respondents that had Medical Cards did not think they were eligible for GP Visit Cards and LTI Books and vice versa. One respondent had been advised not to apply for a Medical Card as they would lose their LTI Book. Some explained that, as their LTI Book covered the expense of medication prescriptions, they had no need for a Medical Card.

While some respondents were not aware of the GP Visit Card scheme, others said their private health insurance covered a substantial amount of GP visits and so the card was not necessary. Previous negative experiences had deterred some people from applying. For example, one respondent had not applied for the GP Visit Card because, when applying for a Medical Card, the welfare authorities “made [their] life hell when applying or renewing”. For another, applying for the Medical Card was “such a horrible proces” due to the HSE refusing supporting documents and holding up the application for months, after which they “didn’t bother applying again”. A small number felt they could currently afford to finance their trips to the GP independently. Many respondents had never heard of a LTI Book and knew nothing about it. Some were not taking any medication for MS and so had no need for the Book.

Access to healthcare and income

The highest proportion to report that they had not seen the neurologist but needed to was among the struggling group, at 7.5% (n=14), followed by the neither comfortable nor uncomfortable group, at 7.1% (n=18). The struggling group had the greatest proportion (81%, n=129) to report seeing the neurologist in public hospital clinics. This group also had the greatest proportion to have been offered neurorehabilitation in the previous year, at 36% (n=66). However, they also had the highest proportion to report not being offered the service though they needed it, at 17.4% (n=32), followed by the neither comfortable nor uncomfortable group (17%, n=45), compared to those living comfortably (10.5%, n=20). A similar pattern was seen for respondents who did not know what neurorehabilitation was: the neither comfortable nor uncomfortable group had the highest proportion here, at 27.7% (n=70), followed by 22.8% (n=42) of the struggling group.

Among respondents who had not seen the MS specialist nurse but needed to (16.1%, n=101), the highest proportion came from the struggling group, at almost a quarter (n=43) and the lowest from the financially comfortable group, at just 11% (n=21). The struggling group also had the highest proportion of respondents to have accessed this service, at just under 46% (n=84), compared to 36% (n=90) of the neither comfortable nor uncomfortable group.

The struggling group had the highest proportion to have not seen a physiotherapist but needed to, at nearly a fifth (n=34); while the lowest was from the financially comfortable group, at 8% (n=15). The struggling group, however, also had the highest proportion of respondents who did access this service, at 48% (n=87).

There was a difference between income groups in access to an MS Ireland community worker. Just over half (n=93) of the financially comfortable group had not needed to access this service in the past year, compared to only 24% (n=43) of the struggling group. The struggling group also had the highest proportion to report not having spoken with an MS Ireland worker though they needed to, at 9.6% (n=17), compared to only 2.5% (n=6) of the neither comfortable nor uncomfortable group and 4.3% (n=8) of the comfortable group. The struggling group, however, also had the highest proportion to have accessed this service, at 35.4% (n=63), compared to a fifth (n=37) of the financially comfortable group.

The struggling group had the greatest proportion, at 22.3% (n=40), to report that they had not accessed an occupational therapist (OT) in relation to their MS though they had needed to. However, the same group also had the highest proportion to report that they had seen an OT, at nearly a quarter (n=43), compared to only 12.5% (n=23) of the comfortable group.

There is a clear pattern here which indicates that people who are struggling financially are finding it more difficult to access services which they need to manage their MS, compared to people who are more financially secure. This could be explained by the fact that the latter group have access to private health insurance and face far shorter waiting lists for treatments. Respondents who were struggling on their income had the greatest percentage to report seeing the neurologist in public hospitals. However, for many services – including the MS specialist nurse, neurorehabilitation, the OT, physiotherapist and the MS Ireland community worker – the struggling group had the greatest proportion to report accessing or being offered these.



Employment and MS

Respondents who were unemployed - as well as those that had to change their work status - due to their MS had greater proportions to require an aid for physical disability. For example, among those that changed their work status (including retiring or going from fulltime to part-time work), 12.8% (n=32) used a rollator for mobility, compared to only 2.5% (n=6) of the group that did not change work status. A fifth (n=31) of the unemployed group used a crutch, compared to only 10% (n=24) of the group that did not change work status. This suggests that mobility issues associated with MS may pose significant obstacles to a person's ability to work full time, and for some, mean their exit from the labour market entirely.

Respondents who were unable to continue working in the same way due to MS emphasised the physical demands of work as part of the problem. For example, problems with balance, hand tremors, sight, walking and driving impaired the ability of some respondents to work safely. Many pointed to fatigue as a key reason for changing work status, as frequent rest became necessary. Cognitive impairments, such as difficulty concentrating, were also cited by several.

Trying to deal with unsupportive employers and management was another problem experienced by many. Respondents cited a lack of understanding for their conditions among employers, including a refusal to accommodate reduced working hours. As one respondent explained, they gave up work due to "no support or consideration". The difficulty in finding suitable hours that were flexible and part-time was a problem for some.

Coping with stress was also expressed as an obstacle for some respondents, usually related to the need to avoid a stressful work environment. One respondent, for example, said they stopped working entirely as their symptoms worsened when they were under stress.

These narratives indicate that many employers may lack an understanding of disability and its impact on employees, as well as its impact on ability to work. This lack of awareness may lead to unsupportive working environments and conditions for employees with MS, which may push them prematurely out of the labour market.



Discussion and recommendations



This is the first survey of the needs of people with MS in Ireland, based on a sample that is broadly representative of what is known about the demographics of the MS population in the country from previous research (MS Ireland, 2015; O'Connell, Tubridy, Hutchinson & McGuigan, 2017).



MS Ireland has extensive experience of delivering services to the MS community, via our regional community work service, our Information Line and our Care Centre. People with MS and their families and carers who use MS Ireland's services report serious difficulties accessing the health and social care services that they need, and this experience is supported by previous research (MS Ireland, 1999; Lonergan et al, 2015). This survey provides further evidence for this, with many noting that services were not available in their area. Several respondents reported needing to access services such as formal (paid) care, neurorehabilitation, occupational therapy, speech and language therapy and physiotherapy but being unable to. Considerable regional variations were also noted, with Munster residents appearing to experience shorter waiting times to access services such as neurology appointments, MRI scans and MS specialist nurse services than other regions. The Connacht region reported the lowest level of service access and longest waiting times. Interestingly no regional differences were noted in access to formal (paid) care, although again MS Ireland's service delivery experience suggests otherwise.

Some findings in terms of access to healthcare services were more positive than might have been expected. Waiting times for MRI scans, for example, were mainly low with just under half waiting less than two months for a scan. On the other hand it should also be noted that considerable numbers either paid for the scan themselves or had it funded through private health insurance, which could be indicative of the 'two tier' healthcare system in practice. However, for many services – including the MS specialist nurse, neurorehabilitation, the OT, physiotherapist and the MS Ireland community worker – those who reported that they were struggling on their current income had the greatest proportion to report accessing or being offered these. This complicates the picture as it suggests that people who are financially disadvantaged might be in greater need of such treatments and therefore may be in worse health than their wealthier counterparts. These findings suggest that greater equity in access to healthcare is needed, so that timely treatment for MS is determined by need and not by patients' access to wealth and resources. This provides further support for MS Ireland's ongoing advocacy work calling for greater investment in public healthcare systems, in particular neurology services, neurorehabilitation services and community health and social care. With less than half of the respondents having Medical Cards, there is also a need to continue to advocate for improvements to the application process for Medical Cards so that the additional financial burdens MS can cause are fully accounted for in the assessment process – as noted in previous studies (MS Ireland, 2015; Lonergan et al 2015) people with MS report unmet financial needs due to their condition and worry about being able to provide financially for themselves and their families as a result. Additionally, many reported problems in accessing and affording both health insurance and life insurance, which shows a need for more flexible insurance options to be made available to people with MS.

Personal finances did not appear to play a role in whether or not someone was accessing medications for their MS, and this suggests that the current systems in place to ensure equity in medications access – namely the Medical Card and the non means-tested Long Term Illness Scheme – are valuable and work well. In total, over 75% of the sample reported being on a disease modifying therapy (DMT). This is much higher than previous research suggests – for example, Fogarty et al (2014) estimate 44.4% of the MS population to be taking a DMT. This could be because of the way the research was conducted and the weighting of the sample towards younger people (see Limitations), and may therefore be indicative of changes in prescribing practices and the emergence of a greater range of treatment options in recent years.

It is interesting to note that whether or not a respondent felt they had received adequate information about treatment options did not appear to affect whether or not they were on medication. In total nearly 20% of the sample felt they had not received adequate information from their healthcare providers, with a further 13.8% stating they had not sought any information. This suggests that further research is needed into how treatment options are discussed with people with MS at the point of diagnosis, and what impact this has on uptake of DMT treatment.

As might be expected, and as found in previous research (Lonergan et al, 2015; MS Ireland, 2015) people with progressive forms of MS clearly need higher levels of support and care than those with relapsing remitting MS. This group were much more likely to report that MS has a substantial impact on their personal and family life, were more likely to need high levels of assistance from others and were also more likely to need services but not be able to access them. This indicates a clear need for more information materials, resources and supports for people with progressive forms of MS to help them mitigate the effects of their condition.



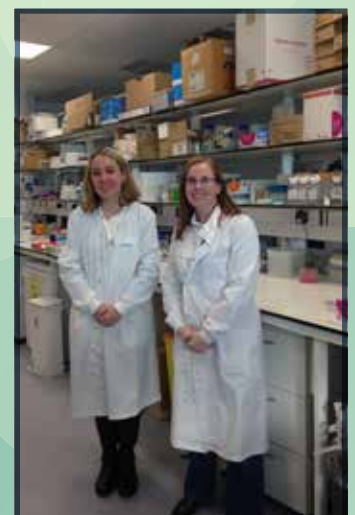
It also provides further support for the pressing need to invest more in research to discover new treatment options for progressive forms of MS. Another interesting finding was that 18% of respondents felt they would benefit from a housing adaptation but could not get one, and that several people cited financial barriers to being able to access the home adaptations they needed, again indicating that as the disease progresses and disability levels increase people with MS find it hard to access supports that enable them to carry on living in comfort in their own homes. This suggests that the support systems designed to help people access housing adaptations, such as the Housing Adaptation Grant, should be reviewed by policy makers.

The findings indicate a lack of awareness of services and entitlements and how they should be accessed. For example, several respondents who reported needing formal care said they did not know how to access it, and although the majority of the sample were in receipt of a Long Term Illness book, a number of respondents indicated that they did not know what this was or did not know how to apply, despite this being a non-means tested and automatic entitlement for someone with a diagnosis of MS. This suggests that there is need for more comprehensive information to be made available to people with MS as soon as possible after diagnosis – one option would be the development of a pack with a range of information materials about services, entitlements and treatments which could be made available in all neurology centres and via MS Ireland's regional offices. An important implication from this survey for MS Ireland's service delivery in particular is the need to raise further awareness of the various services MS Ireland provides (such as the regional community work service), with considerable numbers of respondents not being aware that these services exist, or not knowing how to access them.

Another striking feature of these research findings was the need for more support to be provided to care givers of people with MS. It is clear that many care givers are not receiving enough information and support to help them manage their loved one's condition and to limit the impact of MS on daily and family life. This was particularly seen to be the case for people with more severe and progressive forms of MS. These findings suggest that people with more severe or debilitating types of MS need greater intervention from healthcare professionals and MS specialists to allow their family and caregivers to better manage the effects of their MS. Therefore there is a definite need for MS Ireland to advocate for better supports for carers including access to paid home care, access to respite care and more financial support. More information materials also need to be produced for care givers so that they are made aware of the types of supports and services available.

A significant number of respondents felt they had not received enough support to help them deal with emotional issues. This is concerning, particularly given that levels of depression and anxiety are known to be high among people with MS (MS Ireland, 2015). Again, there was a connection between household income and whether or not someone had received adequate supports to help them with their emotional wellbeing, suggesting that there is a need for a better range of low-cost counselling supports for people with MS. As with other services, it also seems that often people with MS are not being offered services to support them with emotional issues and do not know how to go about accessing them.

Findings on employment in this study broadly agree with previous research conducted by MS Ireland on employment, namely that the more severely the person is impacted by their MS the less likely they are to be in work (MS Ireland, 2016). The results of this survey provide further support for MS Ireland's ongoing advocacy work to try and secure greater state supports for people to retain a job after a diagnosis of MS, and also the need to raise awareness and improve understanding among employers.



Limitations

There are some limitations of this study which must be noted. Firstly, it is important to stress that as the vast majority of responses were received online, the sample may be weighted in favour of younger people and those whose MS is less progressed and therefore are more easily able to access the Internet. Secondly, due to flaws in the survey design, some questions were not answered by all respondents.

Conclusion

In conclusion, the My MS My Needs survey results provide useful insight into the needs of people with MS in Ireland and their experiences of accessing the services and supports they need to manage their condition. The survey indicates that there is a clear need for MS Ireland to continue to advocate for better health and social care services and improved financial supports for people with MS and their families.

References

Fogarty, E., Walsh, C., McGuigan, C., Tubridy, N. & Barry, M. (2014). Direct and indirect consequences of multiple sclerosis in Ireland. *Applied Health Economics and Health Policy*, 12.6, pp.635-45.

Lonergan, R., Kinsella, K., Fitzpatrick, P., Duggan, M., Jordan, S., Bradley, D., Hutchinson, M. & Tubridy, N. (2015). Unmet needs of multiple sclerosis patients in the community. *Multiple Sclerosis and Related Disorders*, 4(2), 144-150.

Multiple Sclerosis Society of Ireland (1999). *Focus for MS*. Galway: MS Ireland.

Multiple Sclerosis Society of Ireland (2015). *Societal costs of multiple sclerosis in Ireland 2015*. Dublin: UCD and Novartis.

Multiple Sclerosis Society of Ireland (2016). *Multiple sclerosis and employment: facts and figures*. Dublin: Novartis.

O'Connell, K., Tubridy, N., Hutchinson, M. and McGuigan, C. (2017). Incidence of multiple sclerosis in the Republic of Ireland: A prospective population-based study. *Multiple Sclerosis and Related Disorders*, [online] 13, pp.75-80. Available at: <http://dx.doi.org/10.1016/j.msard.2017.02.010> [Accessed 7 Jun. 2017].



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 | W: www.ms-society.ie | Charity Number: 05365



An Roinn Tithíochta, Pleanála,
Pobail agus Rialtais Áitiúil
Department of Housing, Planning,
Community and Local Government

