



My MS. My NEEDS.
2023 Summary Report



My MS My Needs

2023 Summary Report

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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 a repeat of a 2016 comprehensive survey of the needs of people with MS. 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 Alison Cotter, Advocacy and Research Officer, at **alisonc@ms-society.ie**

Ava Battles CEO

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What Is MS?

Multiple Sclerosis (MS) is a condition which causes damage to the nerves in the central nervous system (CNS), which consists of the brain and spinal cord. The CNS controls the motor, sensory and cognitive functions of the body by processing and transmitting messages through a network of nerves. The nerves in the CNS are coated in a protective coating called myelin, which helps to conduct these messages.

The role of the immune system is to protect the body from infection. Typically, the body is able to distinguish between the body's own cells and those that have invaded the immune system. However, in some circumstances, the body is unable to recognise one from the other and begins to attack the body's healthy cells. This is what happens in autoimmune diseases such as MS.

In MS, when the immune system attacks the nerves it damages or destroys the myelin sheath, causing inflammation in the area of attack. When myelin is damaged, the messages that are transmitted along the nerves cannot do so as efficiently, so messages can be delayed or sometimes blocked. These areas of damage are called lesions and they cause the symptoms of MS. Symptoms of MS include: altered sensations, fatigue, visual disturbances, cognitive issues, balance and spasms.

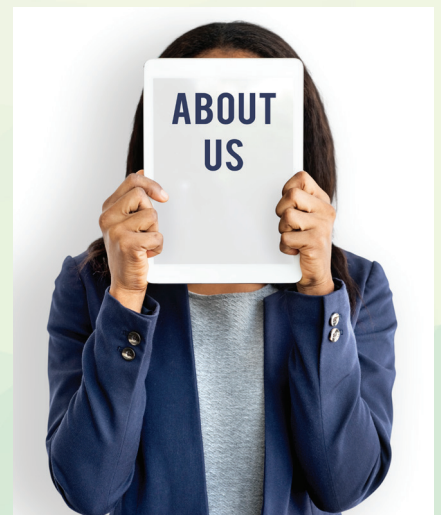
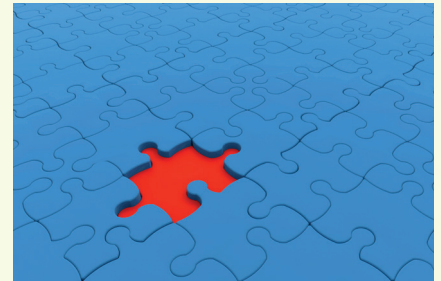
The presence, severity and duration of all MS symptoms vary considerably from person to person.

About MS Ireland

MS Ireland is the only national organisation providing information, vital services and support to the MS community on a national, regional and local level. We have grown and developed our services over the years to meet the needs of the MS community including transforming the availability of many of services into the digital world. Our services include: Case Work, Group peer support, Wellness and symptom management programmes and events, Exercise and Physiotherapy Programmes, Information and Advocacy Services and Respite.

Case Work Service

MS Ireland offers a Case Work service to people with MS and their families, especially individuals with a recent diagnosis. Community Workers provide support on issues such as emotional & psychological support, social welfare, medical cards applications, employment, education, housing, symptom management and relationships. Case work supports the PwMS and family members (where appropriate), early in the disease course and throughout the transitional changes of their MS.



Group Peer Support

People diagnosed with MS share common concerns and experiences in an informal and safe environment. The goal of these groups is to share emotional support and give and receive practical ideas in dealing with issues specific to the group members through their lived MS experience.



Wellness and Symptom Management

MS Ireland offers programmes and events that aim to improve the overall well-being of people with MS. We provide up to date information, in an environment that encourages peer engagement and support and provide optimises symptom management. The FACETS fatigue management programme, mindfulness programmes and our newly diagnosed information days are examples of this service.



Exercise and Physical Activity

MS Ireland is the largest provider of physiotherapist led exercise and physical activity programmes for PwMS. We also provide yoga and fitness instructor led programmes for PwMS. The primary aim of our group and individual programmes is to promote health and prevent further disability and to enable people with MS to live healthily in their communities.



Information Services

We provide up-to-date, relevant and accurate information through a range of resources including our publications, social media platforms, mailings and website (www.ms-society.ie). We also have an information phone line and respond to queries through email and our social media platforms providing trusted, confidential access to information regarding any aspect of living with MS. 0818 233 233, Monday – Friday, 9:30 -17:00

Advocacy Services

PwMS may experience challenges in accessing appropriate services, supports, resources and entitlements and we advocate for the adequate provision of State services, resources and entitlements for people and families living with Multiple Sclerosis. These issues can present themselves on an individual, regional and national level.



National MS Respite Centre

The MS Care Centre is the only dedicated respite centre for people with Multiple Sclerosis in Ireland. It offers short-term respite care to people with MS and other neurological conditions, therapeutic services, neurological assessments and many social activities in a homely environment in the suburbs of Dublin. Our 'home away from home' is a place of rest and relaxation for people from all over Ireland.



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 and fundraising events.



MS Ireland 2023 in numbers

1 National Office in Dublin



10 Regional Offices



368 Residents in the National MS Respite Centre



29 Voluntary Branches



4,418 Members



2,665 People Engaged in One to One Services



Executive Summary

The My MS My Needs survey aimed to explore the background, needs and experiences of people living with Multiple Sclerosis (MS) in Ireland in 2023. Building on a similar study conducted in 2016, this survey collected data from over 900 people with MS (PwMS) in the Republic of Ireland, which represents approximately 10% of the MS population here. Results revealed that PwMS come from a range of different backgrounds, with varying levels of disability (e.g. 34% had progressive MS, which is a higher proportion than in the 2016 survey). There were a number of differences between respondents in terms of access to, and uptake of, various financial, healthcare and social support services, suggesting that, while the needs of many PwMS in Ireland are met, some are clearly more disadvantaged than others.



Some Key Observations are as Follows:

Almost all **(91%)** of respondents noted that MS had at least some impact on their daily life, with **31%** noting that it impacted them very much.



Having MS was reported as having a wide array of challenges. These include dealing with various symptoms of MS as well as the psychological and social impacts that may ensue. In addition, a number of challenges accessing a range of services were reported.



Positively, compared to 2016, slightly more **(79% vs. 75%)** of the sample reported taking some form of Disease Modifying Treatment (DMT), which may reflect the greater range of DMTs available today. Those with progressive MS however were less likely to be taking a DMT compared to those with relapsing remitting MS. Only **63%** reported having received enough information about DMTs from healthcare professionals indicating a clear need for greater provision of support in this area.



About half of PwMS had a friend or family member that provided them with care and support. Of these, **35%** required care for more than 31 hours a week, with **8%** requiring full-time care and assistance. **32%** felt that their family/caregivers needed more information and support. Separately, **9%** of the sample reported needing formal care, but had encountered barriers (most notably cost) in accessing this.



28% of the sample were unemployed, which is far higher than rates of unemployment in the general Irish population. One third reported having to change their employment status due to MS, with fatigue being cited as the most common reason for this. However, concerning, some respondents reported a lack of reasonable accommodations from their employers. Of those PwMS who were employed, **34%** worked remotely for at least part of the week which may help some cope with challenges such as fatigue.



20% reported struggling on their current income, which compares favourably to 2016, when **30%** reported that they were struggling. However, it is clear that challenges accessing financial supports were encountered by many.



43% of the sample held a medical card and just **18%** held a GP visit card. Also, even though all PwMS are entitled to it, **22%** did not hold a long term illness card. Two thirds held private health insurance, which is higher than rates in the general population.



While most PwMS live with others, it is notable that **14%** live alone. The majority of PwMS feel their accommodation is suitable, however **15%** feel it is not, with a number expressing a need for home adaptations.



In terms of access to healthcare, the greatest unmet needs were expressed for psychological support **(31%)**, followed by physiotherapy **(24%)**, however it is notable that uptake of physiotherapy has increased since 2016, which is likely due to the increased provision of online physiotherapy services from MS Ireland.



A number of respondents expressed needs for MS specialist nurses **(19%)**, occupational therapy **(17%)** and neurology services **(8%)**, with some regional differences in need apparent.



While numbers availing of respite were low, many PwMS reported needing this but not having access to it **(6%)**. In addition, **7%** reported a need for speech and language therapy. Only **2%** had availed of neurorehabilitation which is dramatically lower than in 2016 **(25%)**.



The main reasons cited for lack of access to services were cost, not having these services in their locality and a general lack of awareness of what certain services were.



A range of MS Ireland supports were used by respondents including, most frequently, the MS Ireland website **(63%)**. Over a quarter of respondents attended MS Ireland webinars **(29%)** and physical activity services **(26%)**, with the vast majority reporting high levels of satisfaction with these services. A number of improvements, however, were also suggested by respondents.



Taken together, these findings may be helpful in identifying future targets for supports and advocating for the needs of all people with MS.

METHODOLOGY

The My MS My Needs Survey was conducted in April-May 2023. This survey employed a similar methodology to that conducted in 2016, with some additional questions. Throughout this report, where possible, comparisons have been made between the two surveys so that emerging trends may be identified.

In order to be eligible to participate in the survey, respondents had to have a diagnosis of MS and be living in the Republic of Ireland. People with MS were recruited in a number of different ways, including through MS Ireland's social media channels and mailing list. While this survey was primarily conducted online, paper copies were made available for those who requested it which were then provided and returned via post or to one of our regional offices and then inputted. All responses were anonymous.

It should be noted that, while most respondents completed most questions on the survey, this was not the case for every question. In these instances, the percentages provided relate to those who answered specific questions (rather than percentage of all the survey respondents).

PARTICIPANT DEMOGRAPHICS

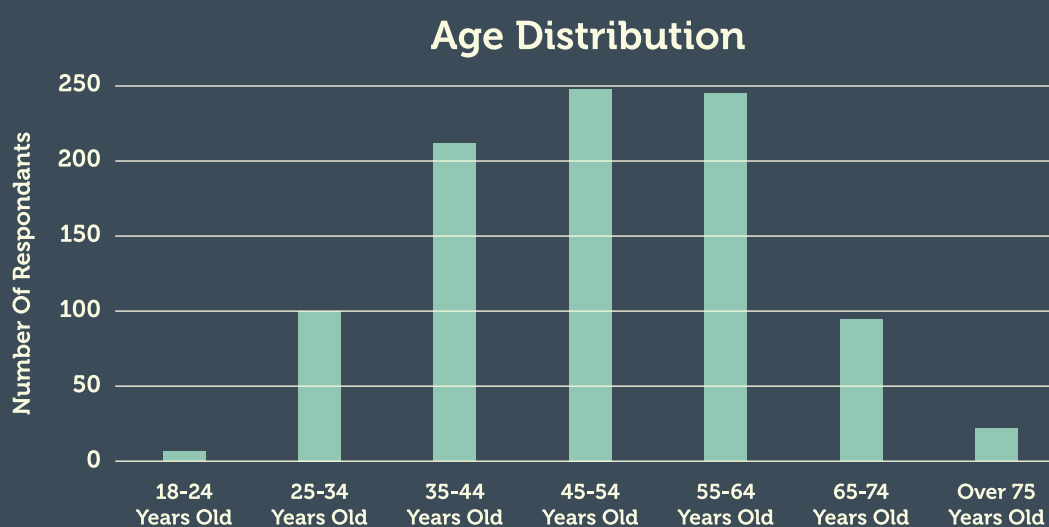
While a total of 982 people accessed the survey, some were excluded due to not having an MS diagnosis, being under 18 years of age, not living in the Republic of Ireland or having a large amount of missing data. Following these exclusions, a total of 935 people with MS were included in the final analysis. This is a considerable increase from the number of people who participated in the 2016 survey (n=773 respondents).

Gender

In terms of gender breakdown, most (78%) of the respondents were female, which is a slight increase from the percentage of females who participated in 2016 survey (75% female), but still broadly representative of the MS population, in which there are three times as many women as men diagnosed (Walton et al., 2020). Of the remaining participants, most (22%) were male, while 4 identified as non-binary. A further 4 preferred not to disclose their gender.

Age

Respondents came from a range of age groups, with 60% aged between 25-54 years old.



Location

Most respondents reported living in an urban area (61%), with the remainder (39%) living in a rural area. In terms of province, most (57%) resided in Leinster, followed by Munster (24%), Connacht (15%), and Ulster (5%). A detailed breakdown of county in which respondents came from can be seen below.

County	N	%	County	N	%
Carlow	10	1.07%	Longford	4	0.43%
Cavan	7	0.75%	Louth	22	2.35%
Clare	15	1.60%	Mayo	40	4.28%
Cork	83	8.88%	Meath	32	3.42%
Donegal	30	3.21%	Monaghan	6	0.64%
Dublin	289	30.91%	Offaly	10	1.07%
Galway	64	6.84%	Roscommon	17	1.82%
Kerry	20	2.14%	Sligo	8	0.86%
Kildare	66	7.06%	Tipperary	38	4.06%
Kilkenny	14	1.50%	Waterford	21	2.25%
Laois	11	1.18%	Westmeath	10	1.07%
Leitrim	2	0.21%	Wexford	40	4.28%
Limerick	32	3.42%	Wicklow	44	4.71%

Living Situation

While most respondents reported living with others, 14% lived alone. The majority (71%) lived with a spouse/partner. Of these, about half (32% of overall sample) reported also living with children under the age of 18, while a further 12% lived with other family (e.g., parents or other relatives). Smaller numbers lived with friends or housemates (3%), while just 6 of respondents (<1%) lived in supported accommodation such as a nursing home.

Living situation	N	%
I live with a spouse or significant other	359	38.73%
I live with a spouse or significant other and a child/children under 18 years of age	292	31.50%
I live alone	132	14.24%
I live with my parents or other relatives	111	11.97%
I live with friends/housemates	27	2.91%
I live in supported accommodation e.g. nursing home /assisted living	6	0.65%

In terms of home ownership, most (72%) indicated they owned their place of residence, while another 12% indicated their residence was owned by a family member. Just 15% indicated they were renting their residence which is lower than overall norms in the population (CSO, 2023). Of PwMS renting, most (76%) reported that their tenancy was secure, however the remaining 24% of renters indicated that their tenancy was not secure.

While the majority (85%) of respondents indicated that their current living circumstances were suitable, it is concerning that 15% felt that it was not. This may in part be due to adaptations needed (discussed in the Home Adaptations section on page 23).

MS CHARACTERISTICS

Type of MS

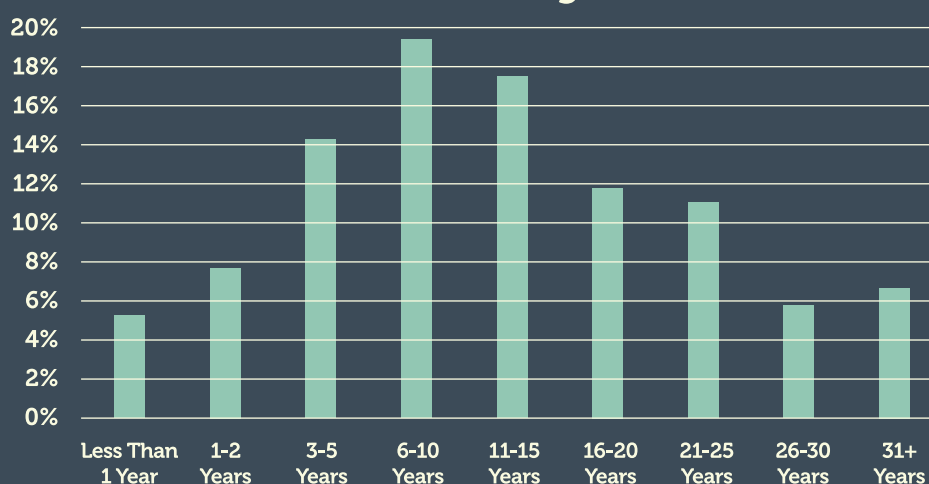
The majority (60%) of respondents had relapsing remitting MS, while 34% had progressive MS (18% with secondary progressive MS and 13% with primary progressive MS). 7% did not know what type of MS they had, while the remaining 2% either had benign MS or clinically isolated syndrome (a first attack of symptoms suggestive of MS, before a confirmed diagnosis is made). When compared to the 2016 survey, a higher proportion of this sample reported a diagnosis of progressive MS and a slightly lower proportion had RRMS though again, this is broadly in line with what would be expected for the MS population.

Type of MS	N	%
Relapsing remitting	540	59.80%
Secondary progressive	158	17.50%
Primary progressive	114	12.62%
Benign	16	1.7%
Clinically isolated syndrome	9	1.00%
Don't know	66	7.31%

Time Since Diagnosis

There were wide variations in the number of years people had been diagnosed with MS. Just under half (49%) of the sample were diagnosed between 6-20 years ago. 5% had been diagnosed less than one year ago, with 7% being diagnosed over 30 years ago.

Time Since Diagnosis



Level of Mobility

Most of the sample (61%) reported being able to walk unaided, however there were others who had a higher level of disability, as can be seen below.

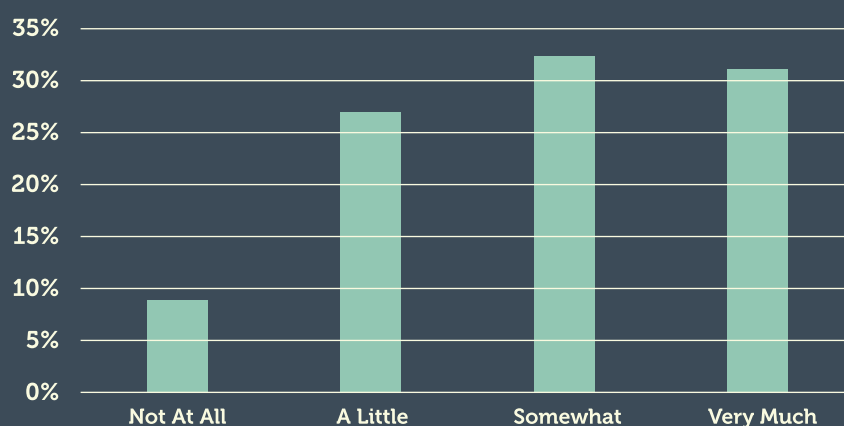
Level of mobility	N	%
I walk unaided	548	61.43%
I use a stick/crutch to mobilise	134	15.02%
I use two sticks/crutches to mobilise	24	2.69%
I use a rollator	75	8.41%
I use a manual wheelchair	37	4.15%
I use a mobility scooter	22	2.47%
I use a motorised wheelchair	47	5.27%
I am unable to mobilise even with assistance	5	0.56%

Impact of MS on Daily Life

Almost a third (31%) reported that MS affected their participation in daily life 'Very much', while most others (60%) said it affected them to some degree. Only 9% stated their MS did not affect their participation in daily life at all.

MS was more likely to have a greater impact on people's lives if they were living with progressive forms of the disease.

How has MS impacted you in relation to participation in daily life over the past 12 months?



Challenges of MS

Respondents were asked to list their biggest challenges in managing their MS. While a small number of respondents (n=43) noted that they had no challenges, the vast majority did, with many mentioning numerous challenges. A range of symptoms and practical needs were highlighted here, in addition to concerns regarding the psychological and social impacts of MS.

As can be seen in the table below, the most frequent challenges mentioned related to specific symptoms of MS (n=855). Those which were the most commonly reported included fatigue, mobility and cognitive difficulties, though the diversity of responses illustrates the numerous ways in which MS can impact an affected individual. It is also notable that quite a number of respondents cited the psychological and social impact of living with MS (n=170), including issues accepting MS and fears for the future. Some also reported experiencing stigma and social isolation.

A number of practical impacts, including difficulties accessing practical supports, were also mentioned (n=159). These included problems carrying out daily tasks, and issues accessing transport and equipment. In addition, socioeconomic difficulties were mentioned by some (n=69), including issues relating to employment and financial problems. Finally, some respondents noted difficulties accessing services, including healthcare and treatment (n=65).

Theme	Challenge	N
Symptom Impacts		
	Fatigue	271
	Mobility	164
	Cognition	82
	Balance	78
	Pain	74
	Bladder	44
	Muscle issues	40
	Bowel	29
	Sensory symptoms	16
	Treatment effects	12
	Changing symptoms	10
	Vision	8
	Sleep	8
	Dizziness	5
	Temperature regulation	4
	Trigeminal neuralgia	3
	Sexual problems	3
	Tinnitus	2
	Stomach	2
Psychological and Social Impacts		
	Mental health	65
	Fear of future	39
	Stigma	32
	Acceptance of MS	18
	Social isolation	16

Theme	Challenge	N
Practical Impacts		
	Carrying out daily tasks	43
	Transport difficulties	32
	Accessibility issues	27
	Lack of independence	22
	Equipment needs	18
	Exercise	9
	Impact of falls	8
Socioeconomic Factors		
	Work difficulties	36
	Financial problems	20
	Family issues	13
Access to Services and Healthcare		
	Access to health care professionals	15
	Access to treatment	15
	Access to physiotherapy	5
	Access to respite	2

MS TREATMENT

Disease Modifying Treatments

The majority (79%) of respondents were taking a Disease Modifying Treatment (DMT) at the time of survey completion, which is a slight increase from 2016, in which 75% reported using a DMT.

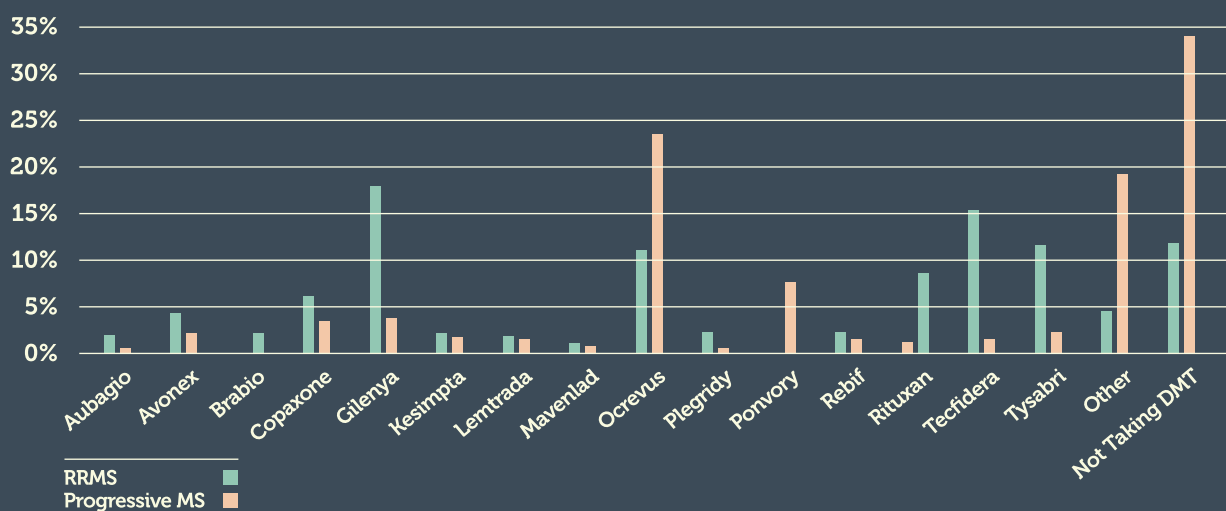
Among those who reported they were currently taking DMT, the most common medications were Ocrevus (Ocrelizumab) at 14% and Gilenya (Fingolimod) at 12%. However, a range of treatments were reported and (as can be seen in the figure below) this varied according to MS type. Respondents also had the option to list other treatments not included here, and a further range of treatments were mentioned here, including Fampyra and AHSCT. Many respondents noted that they had changed treatments for various reasons.



DMT	N	%
Ocrevus (Ocrelizumab)	125	14.09%
Gilenya (Fingolimod)	107	12.06%
Tecfidera (Dimethyl Fumarate)	95	10.71%
Tysabri (Natalizumab)	71	8.00%
Copaxone (Glatiramer Acetate)	47	5.30%
Mavenlad (Cladribine)	32	3.61%
Avonex (Beta Interferon-1a)	30	3.38%
Rituxan (Rituximab)	30	3.38%
Rebif (Beta Interferon-1a)	17	1.92%
Kesimpta (Ofatumumab)	14	1.58%
Plegridy (Peginterferon beta-1a)	14	1.58%
Brabio (Glatiramer acetate)	12	1.35%
Aubagio (Terflunomide)	11	1.24%
Lemtrada (Alemtuzumab)	6	0.68%
Ponvory (Ponesimod)	1	0.11%
Other	88	9.92%
NOT currently taking any of the drugs listed	187	21.08%

The range of treatments availed of is one key point of departure from the 2016 survey. In particular, Ocrevus, which can be prescribed for both RRMS and progressive MS, was not widely available in 2016, but now represents the most common DMT for those with progressive MS, with almost a quarter (23%) of those with progressive disease taking this. However, it is also clear that those with progressive MS were more likely to not be on any of the DMTs listed, with 33% of this group (as opposed to 12% of those with RRMS) not taking a DMT. While this is a dramatic improvement from 2016, when 62% of those with progressive disease did not take a DMT, it is clear that this group remains relatively disadvantaged.

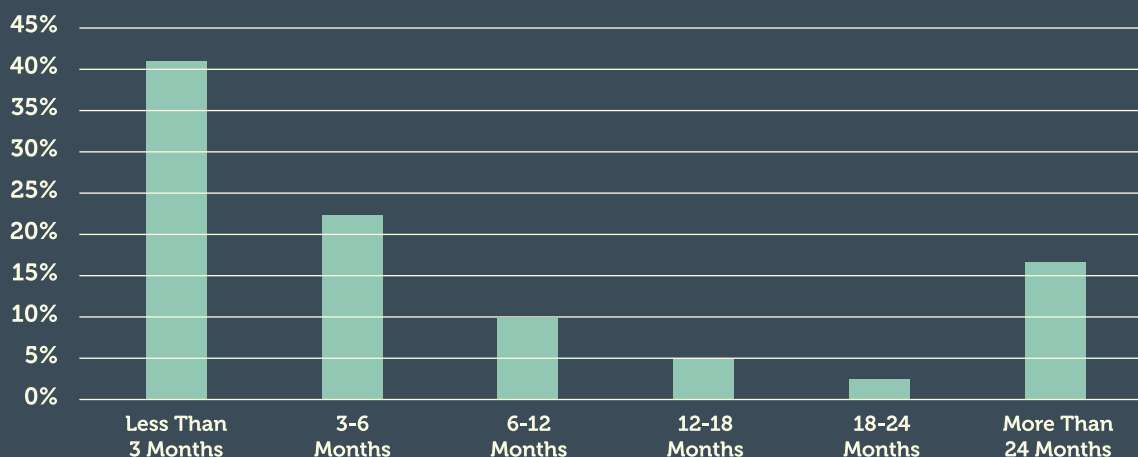
Comparison of DMT usage between RRMS and PPMS/SPMS



Time From Diagnosis To Treatment

42% of those on a DMT had started it three months after diagnosis (just slightly higher than the 40% receiving DMT within 3 months in 2016). However, it is concerning that 17% started DMT more than 24 months after diagnosis.

Time to receive DMT after diagnosis



Information From Healthcare Professionals

Concerningly, just 63% of the sample reported having received enough information from healthcare professionals about drugs available to support the treatment of their MS. While 15% had not sought this information, 21% stated they had not been provided with enough information. This is a slight increase from 20% reported in 2016.

Participation In Clinical Trials

Only 6% of the sample had participated in a clinical trial in the last 12 months, however 55% of respondents would like to be given the opportunity to take part in a trial.

CARE AND SUPPORT

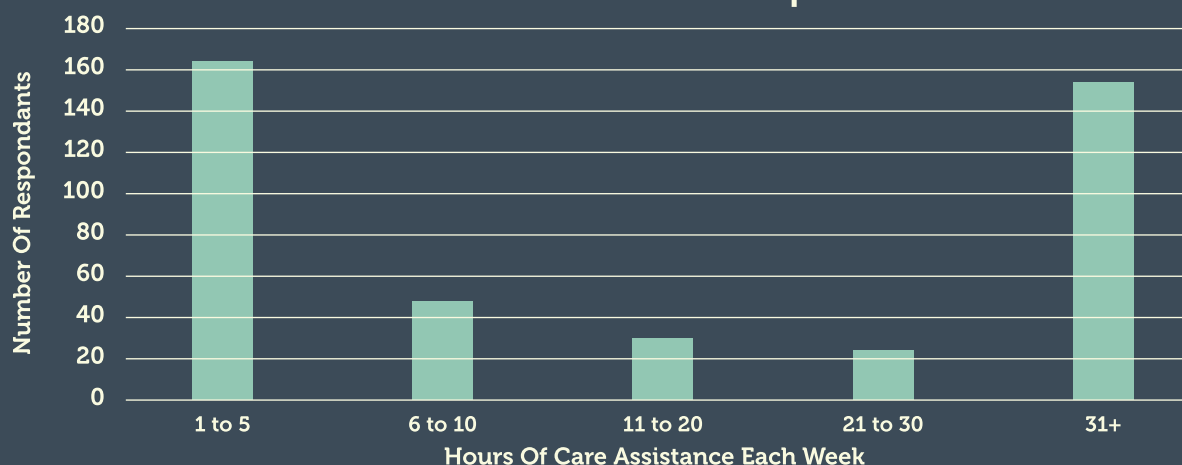
Family Support

About half (52%) of the sample indicated they had a friend or family member who provided them with care and support, which is in line with what we would expect for the MS population, where roughly half receive assistance from an informal caregiver (Maguire & Maguire, 2020).

The amount of care varied in the sample however. When family assistance was provided, 38% only received assistance of just 1-5 hours a week, however, a similar proportion (35%) received care for more than 31 hours a week, suggesting that a cohort of PwMS have high care needs. Those with progressive MS were more likely to require care.



Hours of care recieved from family members each week for PwMS in receipt of care



Care Requirements

Another question asked about the extent of assistance required from others. Of those responding to this question, 8% required full time care and assistance.

Assistance Required From Others	N	%
No assistance	84	19.00%
Occasional assistance	213	48.19%
Frequent assistance	108	24.43%
Full time assistance	37	8.37%

While over half of those responding reported that requirements for care had stayed the same over the past 12 months, most of the remaining respondents (45%) noted that their requirements for care had increased. Just 3% reported that requirements for care had decreased.

As might be expected, the presence of progressive MS diagnosis was associated with requiring significantly more assistance. Among those with a progressive form of MS, frequent or full-time assistance requirements were reported by 53% of respondents, while the same level of assistance was required by just 15% of those without a progressive diagnosis.

Information and Support for Family Members

While most of the sample reported that family members or caregivers did not require information or support to mitigate/manage the effects of respondents' MS, 32% felt that their family/caregivers needed more information and support. Lower numbers (18%) reported that they had received sufficient information, suggesting that this is an area which could be improved upon.

Financial Support for Caregivers

Just 22% of family members providing assistance were reported as receiving a carer's allowance. While positively, this is a significant increase over the 12% reported receiving carer's allowance in the 2016 survey, the high number of care hours provided by some family members suggests that more support is needed for some MS caregivers.

Formal Paid Care

In addition to family support, respondents were asked if they had received any formal (paid) care including personal assistance (e.g. HSE Home Help, Home Instead, Blue Bird) in the last 12 months. While only a small proportion (9%) had received formal care, it is notable that a further 9% reported needing this. When asked what prevented them from accessing such care, cost was a reason cited by 84 respondents, while a further 12 noted that there was no care available in their area. Some other reasons were also cited.

Of the small numbers who had received formal care, most (72%) reported that their requirements had stayed the same in the past 12 months, however more reported that their care needs had increased (19%) than decreased (9%).

In terms of payment for care, most cited that the HSE pays for their formal care (93% of respondents to this question), with most of the remainder having care that was either self-funded or a combination of funding from the HSE and themselves or their family.

EMPLOYMENT AND INCOME

Employment Status

Just under half of the sample (48%) indicated that they were in some form of employment. Of these, most (29% of sample) were employed full-time, with 15% employed part-time. A further 3% were self-employed. Just over a quarter of the sample (28%) were unemployed, which is far higher than rates of unemployment in the general population. Most of the remaining respondents were either retired (18%) or homemakers (6%). A small number of the sample (1%) also reported being students, either in addition to working or (presumably) in full-time study.



Employment Change Due to MS

It is notable that one third of the sample reported some change in employment status due to their MS. For example, 25% reported being unemployed due to their MS, while 8% were working part-time due to their MS. A small number (1%) were self-employed due to MS.

Employment Status	N	%
Full-time employed	270	29%
Part-time employed (Part-time employed due to MS)	139 69	15% (8%)
Self-employed (Self-employed due to MS)	26 10	3% (1%)
Unemployed (Unemployed due to MS)	252 (225)	29% (24)
Retired	164	18%
Other (e.g., homemaker)	65	7%

Respondents were given the option to indicate why their MS had caused them to change their work situation. Fatigue was the most commonly cited reason for this, followed by balance and mobility issues, although a wide range of reasons were provided. 60 people gave additional information on why they had to stop working, including citing problems with bladder/bowel and visual problems, among others. It is concerning that 44 people indicated having to change their employment status due to a lack of reasonable accommodations from their employer.

Reasons for Changing Employment Status	N
Fatigue	423
Balance	224
Mobility issues	214
Cognition	174
Mental health	111
Transport issues	72
Covid-19	50
Lack of reasonable accommodations from employer	44
Other	60

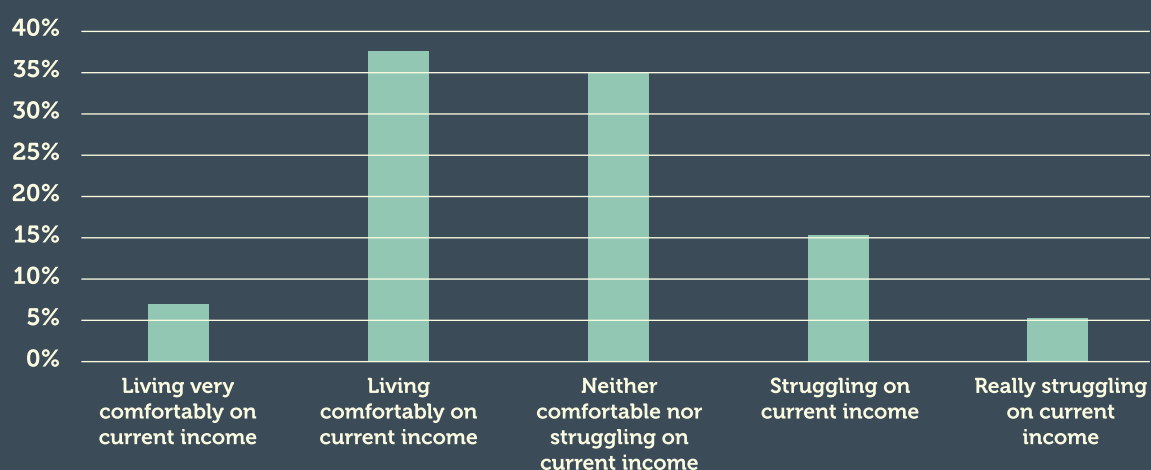
Engagement in Remote Working

Remote working may offer one way in which people with MS may be enabled to more fully participate in employment. Of those who were employed, most (66%) were not engaged in remote working, although 23% worked remotely for part of the week and a further 11% were engaged in fully remote working. It is notable that 4% of the sample would like to work remotely but could not.

Financial Situation

Positively, there was a decrease in the proportion of PwMS reporting that they were struggling on their current income (20%) compared to the 2016 survey (30%). However, it is clear that the sample varied greatly in how comfortably they could live on their current income. This did not differ according to MS type (RRMS or progressive MS).

Household Income



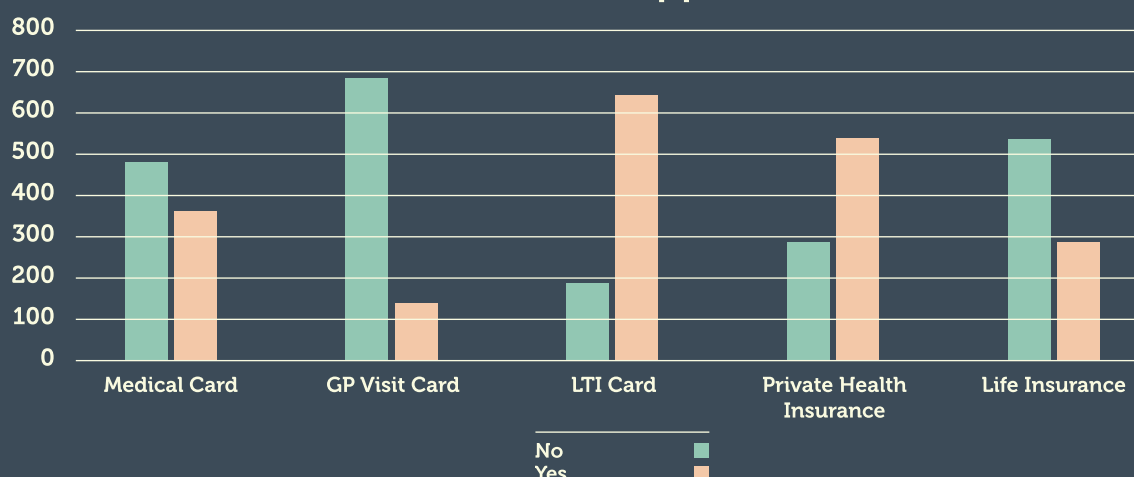
FINANCIAL SUPPORT AND ENTITLEMENTS

Summary of Supports

A summary of the various supports availed of in the sample can be seen below.



Number of respondents in receipt of various financial supports



Department of Social Protection Payments

Just under half of the sample (48%) reported being in receipt of some social protection payment, including an invalidity payment (19%), disability allowance (11%), and disability benefit (4%).

Medical Card

Just over half (57%) of respondents did not hold a medical card which is more than in the 2016 survey, when 48% held a medical card. Most of these did not apply as they were not eligible for a card, or applied and were ultimately refused (n=114, 24% of respondents). However, the vast majority (86%) felt that a medical card is important in meeting the costs associated with MS.

When asked to rank the top five benefits of holding a medical card, access to GP services and prescribed drugs and medicines were highest.

Benefits of Holding a Medical Card	N
Free GP (family service)	747
Prescribed drugs and medicines	690
In-patient, out-patient and medical appointments	515
Physiotherapy and associated equipment	484
Dental, optical and aural services	381
Occupational therapy and associated equipment	283
Psychological services	192
Priority in public health nursing	129
Dieticians	94
Chiropody	93
Respite care	78
Speech and language therapy	54
Maternity and infant care services	36

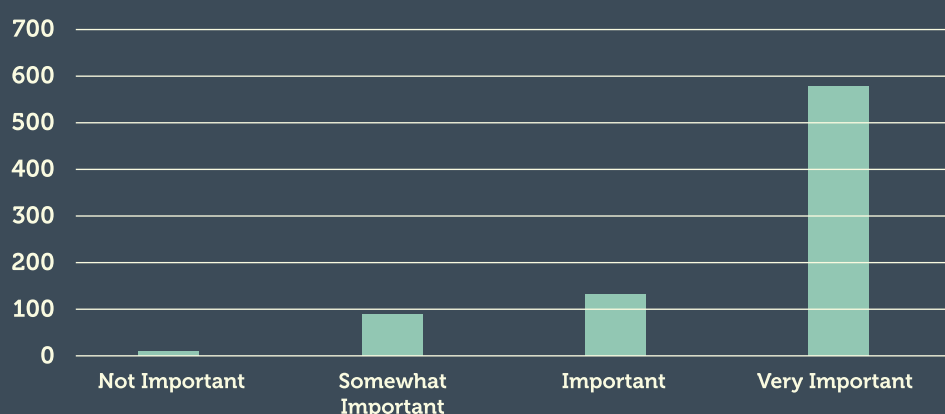
GP Visit Card

Only 18% of respondents held a GP visit card, with most indicating they had not applied. While some noted this was because they already held a medical card, most of the remainder of respondents indicated that they were not eligible, often due to means testing. 10% of those responding (n=67) noted that they had applied and were refused. A number of others noted that they had never heard of a GP visit card.

Importance of GP Access

It is clear that having access to GP services was seen as important to almost all of the sample, with only 2% noting that this was not important.

How important is access to GP services in enabling you to remain well?



Long Term Illness Card

All people with MS entitled to a Long Term Illness (LTI) card as this is not means tested. Despite this, almost a quarter (22%) of respondents did not have one, with a small number (n=10) reporting that they had applied and were refused. Slightly more PwMS held this card in 2016 (80% vs. 78% in 2023). Most others had not applied for an LTI card, but quite a number (n=62) also reported not being aware of the scheme.

Private Health Insurance

Almost two thirds (66%) of the sample indicated that they held private health insurance which is higher than the general population at approximately 48% (RTE, 2023), but similar to proportions of PwMS holding insurance in 2016. For those who did not, unsurprisingly the most commonly-cited reason was cost. In the comments, some respondents noted that their MS diagnosis meant that the cost of insurance had increased significantly.

Life Insurance

Compared to health insurance, less than (35%) of the sample had life insurance. Again, cost was the most commonly-cited reason here, although others noted that they did not require life insurance (e.g. because their mortgage was paid off). This is lower than in the general population, where 46% hold life insurance.

ADAPTATIONS

Home Adaptations

It is notable that only 37% were aware of financial supports to assist with housing adaptations (e.g., installation of wetroom or downstairs bedroom).

While over half of the sample reported not needing home adaptations or additional home adaptations (59%), it is concerning that a combined 31% of the sample felt they would benefit from home adaptations which is an increase from 2016 at 18%.

Home adaptations in the past 12 months	N	%
No, and I have not needed any more home adaptations	495	59.00%
No, but I would benefit from home adaptations	205	24.43%
Yes, and I do not currently need any more home adaptations	86	10.25%
Yes, but I need more home adaptations	53	6.32%

When asked what prevented PwMS from making the adaptations they need, most (55%) cited cost, however, a range of other factors were cited including fatigue. 10% noted that they couldn't make adaptations as the property was rented. Some made a comment that they or their spouse earned too much to be eligible for a grant.

For those respondents who had home adaptations, only a small number (n=44) applied for a Housing Adaptation Grant for People with a Disability from their Local County or City Council. While most responding reported that their grant application was successful (82% of respondents), only half reported the grant met the overall costs.



Transport

A large majority (72%) of respondents used an unadapted private car or van as their regular mode of transport, with another 14% used a private, adapted car.



Most Regular Mode of Transport	N	%
Private car/van	587	71.59%
Private adapted car	112	13.66%
Public transport e.g. LUAS, DART, Train, Bus	81	9.88%
Standard taxi service	17	2.07%
Bicycle	11	1.34%
Adapted taxi service	10	1.22%
Voluntary organisation transport service (e.g. Centres for Independent Living, Irish Wheelchair Association etc)	2	0.24%

Primary Medical Certificate

25% of those responding noted that they were a primary medical certificate holder, with most of these noting that they applied in the capacity of a driver (68%) or passenger (30%). A large proportion of those who were not primary medical certificate holders reported not having been aware of this scheme (57%) suggesting that more needs to be done to raise awareness of this. A small proportion (5%) noted that they had applied but were refused.

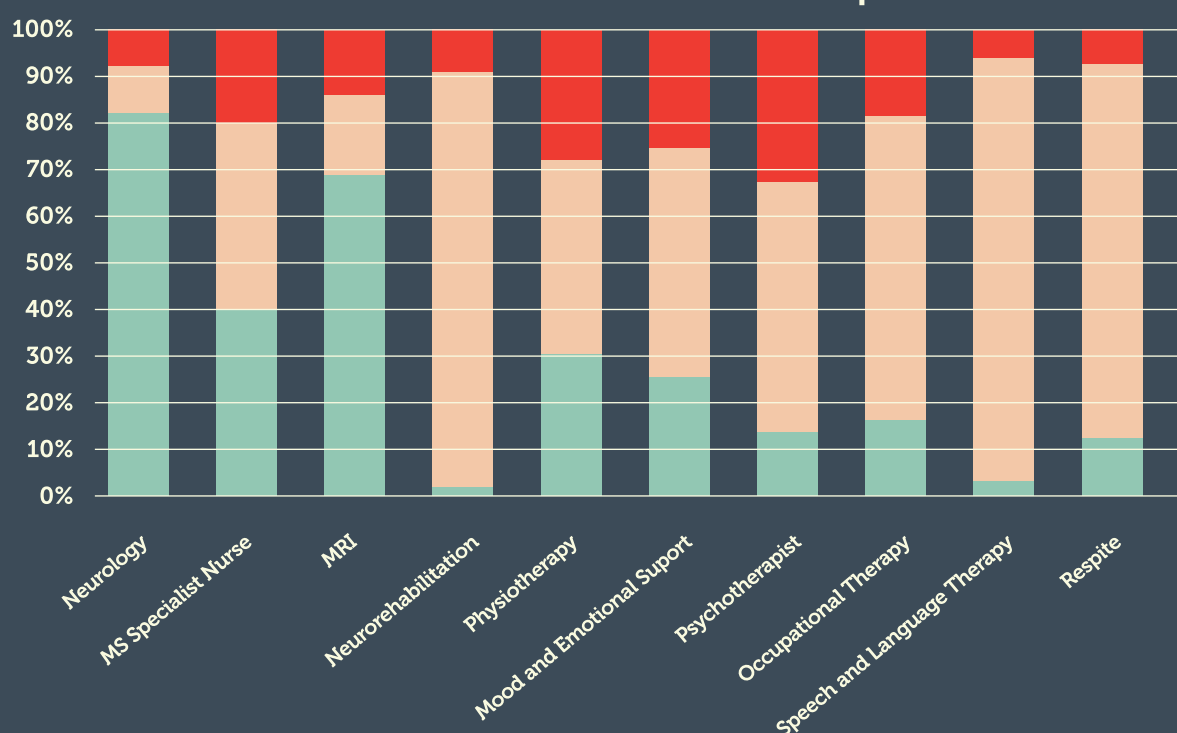
ENGAGEMENT WITH HEALTHCARE SERVICES

Summary of Engagement with Healthcare Services

The figure on the next page highlights the engagement with the various healthcare services and supports, as well as the proportion of those expressing a need that was unmet.



Services availed of and needed in the past 12 months



Attended or availed of service ■ Did not need service/was unaware ■ Needed to attend/avail of service but did not ■

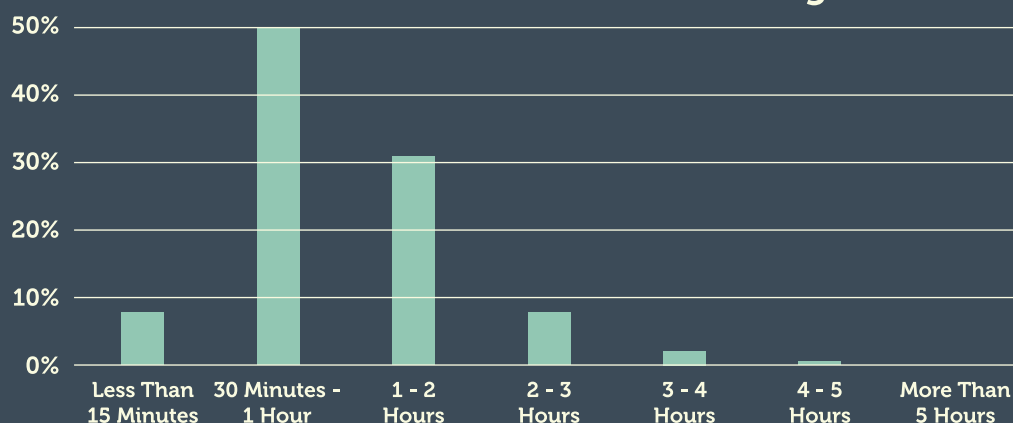
Neurology

Most of the sample (83%) had attended a neurology clinic or had an appointment over the phone in relation to their MS in the past 12 months, although this is a slight decrease from 2016 (in which 86% had seen a neurologist). It is notable that 8% had not attended but needed to, with those living outside of the Leinster region more likely to have an unmet need for this service.

For those who had attended neurology services, most reported that this was a routine annual appointment, however, 7% noted that they had had to wait more than 12 months to get this appointment. Thankfully, the number waiting for more than 6 months for this appointment had decreased (19%) compared to 2016 (44%).

The majority attended their neurologist in public hospital clinics (72%) with the remainder attending privately (28%). Positively, most (79%) reported being able to see their neurologist in an hour or less. However, 41% had to travel more than one hour (one-way) to see their neurologist, with some spending significantly longer.

Time To Travel To See Neurologist



MS Specialist Nurse

Compared to attendance at neurology services, less of the sample reported attending an MS specialist nurse (38%). While the same proportion (39%) reported not needing this, it is notable that 19% of the sample did, suggesting that access to specialist nurse services should be increased. It is also notable that, in some of the comments, respondents noted difficulty accessing services or failing to get called back from nurses in their hospitals.

MRI Imaging

Most (68%) of respondents had availed of an MRI in the past twelve months, which is a slight increase from 2016 (in which 63% had a scan in the 12 months prior), however, those with progressive MS were less likely to have had an MRI when compared to those with RRMS (56% vs. 74% respectively). 13% of respondents reported needing an MRI, which is also an increase since 2016 (in which 10% of the sample reported needing a scan). Those living in Munster (20%) were more likely to report needing a scan than those in other regions (ranging from 8% in Connaught to 15% in Ulster).

Those that had an MRI mostly reported having this as a routine scan (34%) or had to wait less than 6 months for this (47%). A smaller proportion (6%) had to wait for more than a year for an MRI.

In terms of funding, just over half (53%) reported that their scan was funded through the HSE as an in or out-patient, while 44% availed of this through private health insurance. A smaller proportion (3%) self-funded their MRI.

11% of those responding noted that they were advised to change treatment after their MRI.

It is worth noting that people with progressive MS were less likely to have had an MRI than those with RRMS (56% vs. 74% respectively), which may in part be due to the more limited range of treatment options for this cohort. In addition, those living in Leinster (71%) were more likely to have had a scan compared to those in Munster (63%) or Connacht (65%).

Neurorehabilitation

Only 2% of the sample had availed of neurorehabilitation, which is dramatically fewer than those who had availed of it in 2016 (25%). The vast majority who had not availed of this (60%) were not sure what this was, suggesting that greater awareness needs to be raised. 8% reported needing this service.

Physiotherapy

Over a quarter (28%) of respondents had availed of physiotherapy which is an increase from 2016, when just 15% attended a physiotherapist. Uptake was greatest in the Munster and Ulster regions (35%) compared to in Leinster (26%) and Connaught (28%). Those with progressive MS were also more likely to have availed of physiotherapy (68% vs. 24% of RRMS).

While most of the sample (40%) reported not needing physiotherapy, a relatively high proportion (24%) did, suggesting that, in spite of increased uptake of services since 2016, physiotherapy needs are still not being fully met for all people with MS. The most commonly cited reasons for not availing of services were cost and not knowing where to access physiotherapy. A number of other reasons were cited though, including difficulty traveling and time.

For those who had received physiotherapy, this was mainly provided by the HSE (57%), however, almost a third (31%) received physiotherapy services from MS Ireland, while the remaining 11% did this privately. Uptake and need for physiotherapy was more likely among those with progressive MS (68% vs. RRMS at 24%).

While physiotherapy was availed of in a range of settings, it was interesting that the most commonly received place was at home online, which likely reflects the provision of the Getting the Balance Right and Move Smart Programmes delivered via MS Ireland.

Where Physiotherapy was Received	N	%
At home online	61	26.41%
Hospital	49	21.21%
Primary Care Centre	38	16.45%
Health Centre	34	14.72%
Private Clinic	22	9.52%
At Home in person	15	6.49%
Rehabilitation Centre	12	5.19%

Mood or Emotional Support

Just over a quarter of the sample (26%) availed of mood or emotional support. While half (51%) indicated that they did not need such support, the remainder (23%) indicated that they did, with the highest needs for support expressed in respondents from Ulster at 38%. The need for mood or emotional support was greater for those with RRMS (30%) compared to those with progressive MS (20%).

Those who did receive support indicated that they received this from a range of sources, including counsellors, psychotherapists and formal hospital or GP services. However, quite a number cited that this support came from family members.

Some others referenced MS Ireland as a source of support.

Just one third of those receiving support accessed this through the HSE, with 66% availing of this privately.



Respondents were also asked explicitly if they had seen a psychotherapist, counsellor or psychologist in relation to their MS. Only a small proportion had (14%), although almost a third (31%) indicated that they needed this support.

Of those that had availed of support, this was mainly delivered privately or through other sources (66%), with the remainder delivered via the HSE (29%) or through MS Ireland (6%).

Reasons for not availing of supports included cost, time to travel, and waiting lists. Others cited the burden of other symptoms (e.g. pain) and a lack of time.

Occupational Therapy

Only a small proportion (15%) had availed of occupational therapy in the past 12 months, which was funded through the HSE in almost all cases (91%). A similar proportion (17%) indicated that they had a need for occupational therapy, with many noting that they had not been offered this. Some noted not wanting to share their information with their employer, while some others noted that they weren't aware as to what occupational therapy was. Uptake of OT was much more common for those with progressive MS (32% vs. 7% for those without progressive MS). Across regions, uptake of OT services was greatest amongst those living in Munster (20%).

Speech and Language Therapy

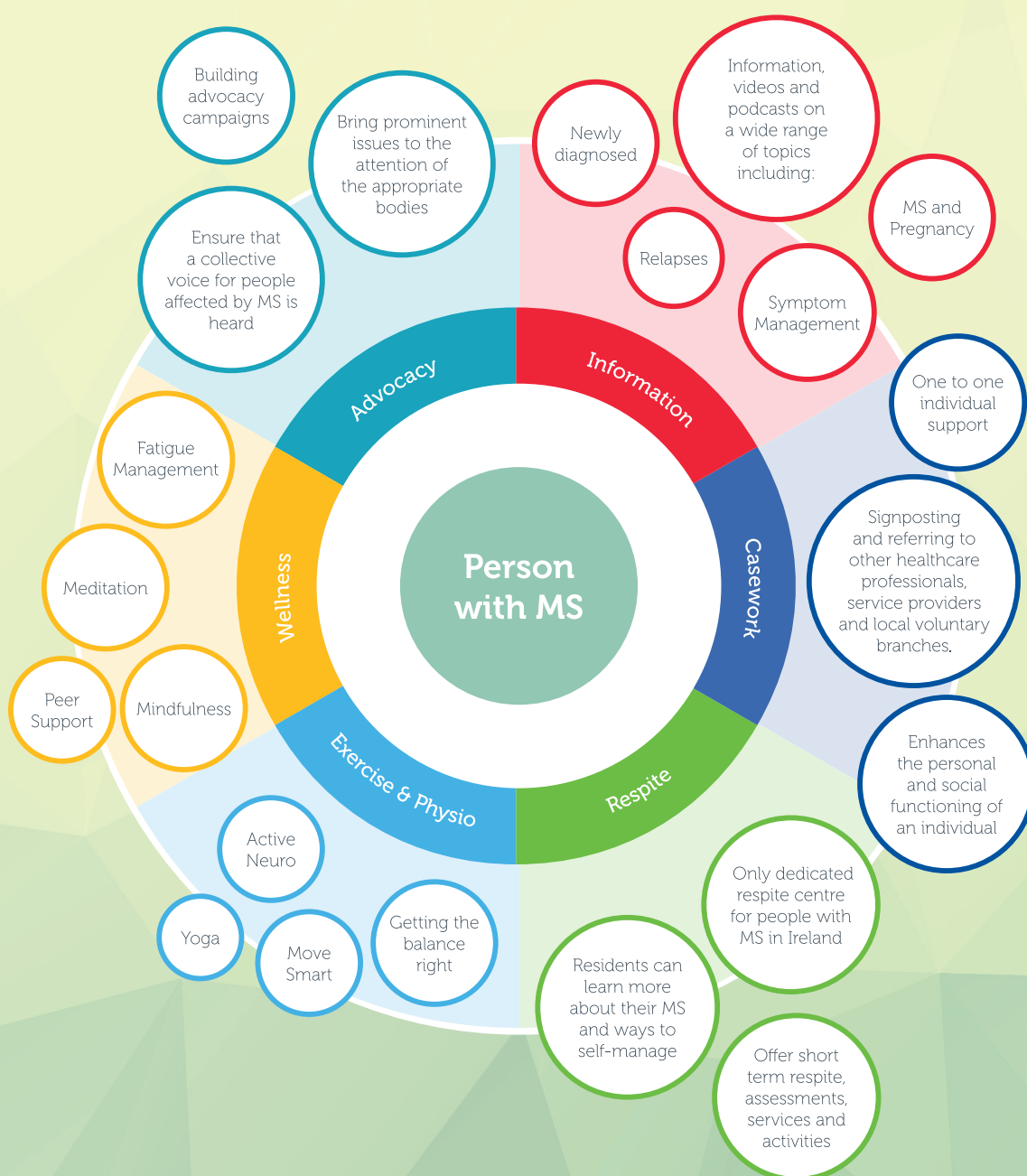
The vast majority of respondents did not have a need for speech and language therapy (90%), however about twice as many reported needing this (7%) than those who had received it (3%). Those who did almost always reported this through the HSE and were more likely to have progressive MS.

Respite

12% of respondents had received respite in the last 12 months, which was mainly delivered through MS Ireland. A further 6% indicated needing this. Some respondents noted not knowing how to get this, while some others noted barriers with cost or not having access to respite services in their area.

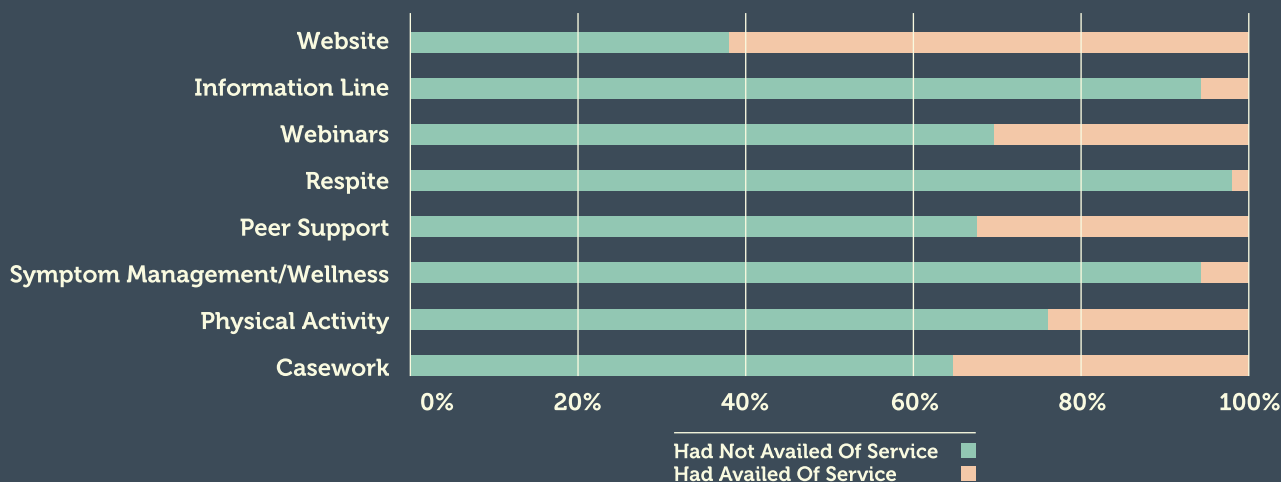
ENGAGEMENT WITH MS IRELAND SERVICES

MS Ireland's Model of Care



The below figure illustrates the proportion of respondents who engaged with the various MS Ireland services. With the exception of the MS Ireland website, uptake of many services was quite low overall.

Ms Ireland Services Aailed of



Casework Services

Just 14% of respondents had availed of casework services over the last 12 months, with the vast majority of those (88%) noting that these services met their needs. Uptake of casework varied by region, with more (20%) of respondents living in Munster availing of casework compared to other regions where engagement in casework ranged from 11-13%.

Physiotherapy Services

A greater proportion of respondents (26%) had engaged with physiotherapy services, including the “Getting The Balance Right” and “Move Smart” physio groups, as well as yoga and exercise classes. A higher proportion of respondents living in Connaught (35%) reported engaging in these groups compared to other regions. The majority noted that they had attended these classes online (88%), with 11% attending in person and the remaining 1% attending a mixture of both. Most reported being very satisfied with these services and the majority (89%) noted that physical activity services met their needs.

Symptom Management and Wellness Service

Few respondents (6%) had attended a symptom management or wellness service, with a small number having participated in programmes such as FACETS and mindfulness/meditation. Slightly higher proportions of those living in Connaught and Ulster (9%) had engaged in these services compared to those living in Leinster or Munster (5%).

Peer Support

Slightly more (12%) had attended peer support programmes, although it is notable that this is still a minority of the sample, given that needs for peer support have been frequently reported by PwMS. The most frequently attended peer support reported was coffee mornings, in addition to informal forms of peer support (e.g. the “Time to Chat” programme). While slightly more (58%) reported engaging in peer supports in an in-person format, just under a third (32%) engaged with these supports online, with the remainder (11%) engaging in both. Most (88%) reported that these supports met their needs. It is worth noting that all MS Ireland group programme programmes involve elements of peer engagement and support.

Respite Care

Only 2% of respondents (n=18) had stayed at the MS Care Centre in Bushy Park, with most of these (89%) reporting that it met their needs, however, a few suggestions for improvements were suggested.

Webinars

29% of respondents had attended webinars or information sessions offered by MS Ireland, and almost all (98%) of these were found useful. A number of other suggestions for future information sessions were provided.

Information Line

A small proportion (7%) had phoned the information line in the past 12 months. While most (77%) of these noted that this met their needs, those who felt it did not, mainly cited issues regarding access (e.g. that they could not get through).

MS Ireland Website

The MS Ireland website was the most frequently used service, with 63% of respondents having visited this in the past 12 months. Most reported that it was easy to navigate (91%) and that it met their information needs (86%), however, a number of suggestions regarding the content of this was provided.

Sources of Information

Respondents were asked to indicate their top 5 sources of information regarding MS. As can be seen below, the most commonly reported sources of information were neurologists or other healthcare professionals, as well as MS websites.

Sources of Information	N	Sources of Information	N
Neurologist	443	Webinars	96
MS nurse	344	Peer group	74
MS Ireland Website	230	MS Regional Office	66
Healthcare professionals	225	Ms Ireland Community Worker	65
MS News	140	Enews	33
Ms Ireland social media	137	Seminars/conferences	30
Other social media	133	MS information helpline	19
Research journals/publications	129	Case worker	17
Online support groups/forums	105	Personal assistance	13
MS Regional Newsletters	100	Wellbeing/symptom management group	10

Importance Of Services

When asked to rank how important services were in order of importance, physiotherapy was ranked as most important, followed by information sessions, mindfulness/meditation and peer support.

CONCLUSIONS AND RECOMMENDATIONS

It is clear from these findings that, while many people with MS have access to the services they need, there is a need for improvement in a number of areas. It is also apparent that people with MS have different needs depending on their health status and place of residence. While it is positive that access to treatments has improved since the previous 2016 My MS My Needs survey, there are clearly a number of barriers that need to be overcome.

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 those outside of the Leinster region more likely to have an unmet need for neurology services and those living in Leinster (71%) being more likely to have had an MRI scan compared to those in Munster (63%) or Connacht (65%).

Some findings in terms of access to healthcare services were more positive than might have been expected. Positively, compared to 2016, slightly more (79% vs. 75%) of the sample reported taking some form of Disease Modifying Treatment (DMT), which may reflect the greater range of DMTs available today. It is interesting to note however, that like in 2016, 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 only 63% reported having received enough information about DMTs from healthcare professionals indicating a clear need for greater provision of support in this area.

Most (68%) of respondents had availed of an MRI in the past twelve months, which is a slight increase from 2016 (in which 63% had a scan in the 12 months prior), however, those with progressive MS were less likely to have had an MRI when compared to those with RRMS (56% vs. 74% respectively). 13% of respondents reported needing an MRI, which is also an increase since 2016 (in which 10% of the sample reported needing a scan). Those living in Munster (20%) were more likely to report needing a scan than those in other regions (ranging from 8% in Connaught to 15% in Ulster).

Those that had an MRI mostly reported having this as a routine scan (34%) or had to wait less than 6 months for this (47%). A smaller proportion (6%) had to wait for more than a year for an MRI.

In terms of funding, just over half (53%) reported that their scan was funded through the HSE as an in or out-patient, while 44% availed of this through private health insurance. A smaller proportion (3%) self-funded their MRI.

With regards to neurology appointments, 7% noted that they had had to wait more than 12 months to get this however thankfully, the number waiting for more than 6 months for this appointment had decreased (19%) compared to 2016 (44%).

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.

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, 22% 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.

In 2016, 18% of respondents felt they would benefit from a housing adaptation but could not get one, this alarmingly has increased to 24% with several people citing 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.

As might be expected, and as supported by our 2016 results, 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.

The need for more support to be provided to care givers of people with MS was striking throughout this survey. It is clear that many care givers felt they are not receiving enough information and support to help them manage their loved one's condition (32%) 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.

About half of PwMS had a friend or family member that provided them with care and support. Of these, 35% required care for more than 31 hours a week, with 8% requiring full-time care and assistance. To add context to this, these hours of unpaid care provided are similar to those found in full time contracts for paid employment. Separately, 9% of the sample reported needing formal care, but had encountered barriers (most notably cost) in accessing this.

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. 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.

In terms of access to healthcare, the greatest unmet needs were expressed for psychological support (31%), followed by physiotherapy (24%), however it is notable that uptake of physiotherapy has increased since 2016, which is likely due to the increased provision of online physiotherapy services from MS Ireland. In addition, 7% reported a need for speech and language therapy. Only 2% had availed of neurorehabilitation which is dramatically lower than in 2016 (25%).

The main reasons cited for lack of access to services were cost, not having these services in their locality and a general lack of awareness of what certain services were.

20% reported struggling on their current income, which compares favourably to 2016 when 30% reported that they were struggling. However, it is clear that challenges accessing financial supports were encountered by many.

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.

28% of the sample were unemployed, which is far higher than rates of unemployment in the general Irish population. One third reported having to change their employment status due to MS, with fatigue being cited as the most common reason for this. However, concerningly, some respondents reported a lack of reasonable accommodations from their employers. Of those PwMS who were employed, 34% worked remotely for at least part of the week which may help some cope with challenges such as fatigue.

A range of MS Ireland supports were used by respondents including, most frequently, the MS Ireland website (63%). Over a quarter of respondents attended MS Ireland webinars (29%) and physical activity services (26%), with the vast majority reporting high levels of satisfaction with these services. A number of improvements however were also suggested by respondents which are being considered in the development and improvement of MS Ireland services.

In conclusion, the 2022 My MS, My Needs survey has provided us with a profound glimpse into the intricate tapestry of the lives of those affected by Multiple Sclerosis (MS). The voices echoed in the survey reflect resilience, challenges, and, most importantly, the collective strength of a community navigating the complexities of MS. This endeavor has not only illuminated the diverse needs and experiences but has also underscored the urgency for tailored solutions to enhance the quality of life for individuals living with MS. As we reflect on the findings, it becomes clear that there is no one-size-fits-all solution. The multifaceted nature of MS demands a nuanced and comprehensive approach to address the varied needs voiced by the community. It is crucial that we leverage these insights to inform policies, healthcare practices, and support systems that are not only inclusive but also adaptable to the dynamic nature of MS.

MS Ireland has created a set of 10 recommendations on the basis of this report:

Enhance Accessibility of Services:

Address regional variations in access to neurology services, ensuring equitable availability across different regions.

Explore ways to reduce waiting times for neurology appointments further.

Improve Information Dissemination:

Develop a comprehensive information pack about services, entitlements, and treatments, making it available in neurology centres and MS Ireland's regional offices.

Increase awareness of existing services provided by MS Ireland, ensuring that individuals are informed about available support.

Support Medical Card Application Process:

Advocate for improvements to the Medical Card application process, considering the additional financial burdens imposed by MS.

Review Housing Adaptation Support Systems:

Review existing support systems for housing adaptations, such as the Housing Adaptation Grant, to ensure they adequately meet the needs of individuals with MS.

Enhance Support for Caregivers:

Advocate for better support for caregivers, including access to paid home care, respite care, and increased financial assistance.

Raise awareness among healthcare professionals about the specific needs of caregivers, particularly for those supporting individuals with severe and progressive forms of MS.

Address Emotional Support Needs:

Advocate for increased access to psychological support services, recognizing the high prevalence of depression and anxiety among people with MS.

Promote awareness and availability of emotional support services for individuals with MS.

Expand Access to Physiotherapy and Rehabilitation Services:

Continue efforts to increase access to physiotherapy, building on the success of online services provided by MS Ireland.

Continue to support the rollout of community neurorehabilitation teams.

Enhance Financial Support Accessibility:

Work towards addressing challenges in accessing financial supports, ensuring that individuals with MS can meet their financial needs effectively.

Advocate for Employment Support:

Advocate for greater state support for individuals with MS in the workforce, taking into account the impact of MS on employment status.

Promote reasonable accommodations in the workplace for employees with MS.

Continue Improving MS Ireland Services:

Consider the suggestions provided by respondents for improvement in MS Ireland services. Explore new avenues for support, considering the high satisfaction reported with existing services.

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.

Best efforts were made by MS Ireland to ensure equity through distribution of hard copies upon request.



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