



## Advocacy Strategy

2024

**Advocacy is one of five Strategic Priorities in MS Ireland's Strategic Plan 2024. This document outlines MS Ireland's advocacy priorities for the lifetime of the current Strategic Plan. In addition, this document outlines the activities that will be undertaken to achieve these priorities.**

### Contents

1. Introduction
2. Advocacy priorities
3. Key partnerships and collaborations
4. Advocacy actions for 2024/25
5. Reporting
6. Contacts
7. Further reading

### 1. Introduction

Multiple Sclerosis Ireland (MS Ireland) is the only national organisation informing, supporting, and representing the MS community. Our concern is the adequate provision of services, resources, and entitlements for people and families living with Multiple Sclerosis (MS). Where services, resources, and entitlements are unavailable or inaccessible, MS Ireland aims to highlight the deficiency and take action to solve the issue.

The Board, Chief Executive, and MS Ireland staff team represent the MS community on collective issues at a national and international level. These are the issues that affect the entire MS community irrespective of individual circumstance or geography.

MS Ireland believes it is crucial that a collective voice for people affected by MS is heard in response to national policy decisions to ensure the interests of the MS community remain represented. MS Ireland's Strategic Plan for 2022 sets out the following aims and objectives regarding advocacy:

#### Specific aims:

- To optimise relationships and understandings between relevant umbrella groups
- MSI will be established as 'the' voice of MS in Ireland
- To increase awareness and understanding of the circumstances and needs of people with MS across civil society and government
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#### Objectives:

- To liaise and work with umbrella organisations (nationally and internationally) to create a more cohesive and united voice
- Strengthen current advocacy alliances and develop new links to harness the strength of shared visions
- Utilise data sets and service delivery experiences available to MS Ireland to inform our advocacy agenda
- People with MS will have access to effective treatments for their condition, including treatments which can slow, stop or reverse the accumulation of disability

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- To raise MS Ireland's profile as a leading voice and resource for people with MS

## 2. Advocacy priorities

The following advocacy priority areas have been established using a variety of methods including:

- Informal discussions with people with MS and their families/carers
- Informal discussions with service providers and healthcare professionals, including MS Ireland's Regional Community Workers
- Results of 2023 'My MS My Needs' survey

MS Ireland will commit to regularly reviewing the organisation's advocacy priorities. Methods by which this will be done include:

- Completing the 'My MS My Needs' survey periodically, subject to funding
- Effective utilisation of data from MS Ireland's Salesforce database, to identify the key issues with which people affected by MS present to MS Ireland for support, and assess where gaps and deficiencies exist in service provision nationally

It should also be noted that these priorities will remain flexible, and that MS Ireland will remain responsive and reactive to other issues of importance to the MS community, as they arise. The numbering of the priorities does not indicate their order of importance.

### Priority 1 - Implementation of the 2019-2021 National Neurorehabilitation Strategy

Neurorehabilitation services are essential for helping people with MS recover from relapses and slow disease progression. The 2019-2021 National Neurorehabilitation Strategy laid out the need for neurorehabilitation services in Ireland, with minimal progress since its publication. Irish neurorehabilitation services are under-developed and under-resourced. Data from the Neurological Alliance of Ireland (NAI) indicates that since the publication of the framework in 2019:

- Only two neurorehabilitation teams of the nine promised have been funded, none outside the East of the country.
- Fewer than thirty new neurorehabilitation beds have been introduced despite the redevelopment of the National Rehabilitation Hospital, with Ireland having a minimum of 288 inpatient beds for our population.
- At a minimum, nine community neurorehabilitation teams nationwide are needed, one in each Community Health Organisation (CHO) as a starting point. Currently, there are only three such teams in the entire country, and they are only partially staffed.
- There has been no funding to develop critically needed new community neurorehabilitation services such as day services, vocational services, transitional and long-term care.
- Ireland has the lowest number of consultants in rehabilitation medicine anywhere in Europe. Data from the My MS My Needs study (2023) showed that only 2% of respondents had ever availed of neurorehabilitation, and a percentage of respondents did not know what neurorehabilitation is.

### Priority 2 - Increased investment in neurology services

MS Ireland is aware of serious deficiencies in the current provision of neurological services. NAI and the Dublin Neurological Institute published findings of a survey of neurology centers in 2016; however, data from the NAI has shown that access to these services has deteriorated further. The recommended ratio is for one consultant neurologist per 70,000 populations, but this is exceeded within every hospital group. Less than half of the minimum recommended number (100 beds) of dedicated inpatient beds are available to support the neurology service nationwide. Figures from the 2015 report noted that four of the 11 hospitals reported no dedicated occupational therapy services for neurology patients. As of 2020, these services have stayed the same or declined across most centers despite increased demand and activity within neurology centers. Data from the My MS My Needs study (2023) showed that 7% waited more than 12 months for their last neurologist appointment, 68% of respondents had an MRI scan in the past 12 months, 6% of respondents waited more than a year for an MRI, and 19% of respondents noted the need to see an MS Nurse but were unable to access the service.

**Priority 3 – Mechanisms to ensure that access to physiotherapy/neurorehabilitation/multidisciplinary care is not a ‘postcode lottery’**

Community neuro-rehabilitation is a vital support for people living with neurological conditions, helping to support recovery and prevent disability. However, only 15% of people have access to community neuro-rehabilitation teams. The vital importance of community rehabilitation teams is recognised by the health system. A team was promised for every CHO area, but only two of the nine have been delivered. For people living with progressive conditions such as Multiple Sclerosis, access to these teams can help prevent unnecessary disability and hospital readmissions. Physical activity is essential in enabling people living with neurological conditions, including MS, to remain well in their communities and in preventing the development of secondary health issues. However, access to a sustainable physiotherapy service is not available in every region. Data from the My MS My Needs study (2023) showed that over a quarter (28%) of respondents had availed of physiotherapy, which is an increase from 2016, when just 15% attended a physiotherapist. 24% of respondents noted a need for physiotherapy, suggesting that, in spite of increased uptake of services since 2016, physiotherapy needs are still not being fully met for all people with MS.

**Priority 4 - Promote employment retention and return to work for people with MS**

Most people with MS will be diagnosed between the ages of 20-40. Therefore, MS has a serious impact on employment and financial independence. The ‘Multiple Sclerosis and Employment: Facts and Figures’ report, published in June 2016, found that 28% of respondents were unemployed, which is far higher than rates of unemployment in the general Irish population. 33% of respondents reported having to change their employment status due to MS, with fatigue being cited as the most common reason for this.

**Priority 5 – Increased investment in services that support people to continue to live in their communities, such as home care, Housing Adaptation Grants and community therapy services such as physiotherapy and occupational therapy**

MS Ireland is aware from people affected by MS who contact our Regional Community Workers and Information Line that there are various issues with community support services including:

- Lengthy waiting times to access physiotherapy, occupational therapy, and speech & language therapy, and insufficient access to these services with a lack of follow-up.
- Geographical inconsistencies regarding access to services.
- Long waiting lists for home care services, and when a service is provided, it is often inadequate.
- Housing adaptations – grants are available but the means testing threshold is very low, and the full cost of adaptations is usually not covered. Data from the My MS My Needs study found that 31% of respondents would have benefited from a housing adaptation.
- People as young as 40 are availing of nursing home care due to a lack of alternatives – there is a statutory entitlement to nursing home care but not home care and supports, and most of the state funding is channeled into nursing home care via the Fair Deal scheme, whereas no such equivalent fund exists for community services.

**Priority 6 – Increasing of availability of access to medical cards and GP visit cards, with application processes that account for the additional financial costs of living with MS**

People with MS have a high level of use of medical services. Data from the ‘Societal Costs of MS in Ireland 2022’ report found that in the last year, people with MS visited their GP an average of seven times and the frequency of visits were similar across the disability severity categories. Some 30.8% had spent at least one night in the hospital. When travel to appointments, time off work, childcare costs, and other costs associated with accessing medical treatment are taken into account, MS can carry a substantial financial burden to the individual and their family. Data from the My MS My Needs study (2023) showed that 57% of respondents did not have a medical card, 24% did not apply as they were not eligible for a card, or applied and were ultimately refused, and 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 ranked the most highly.

### **Priority 7 - Development of MS registries**

There are currently no registries of people with MS in Ireland. This causes problems including:

- Harder to attract clinical trials
- Lack of proper monitoring of medication safety and efficacy
- Lack of monitoring of disease demographics and trends, including the rate of new diagnosis, incidence rates, progression rates

### **3. Key partnerships and collaborations**

MS Ireland recognises that advocacy and campaigning work is strengthened when conducted in conjunction with other organisations that share our interests in progressing particular issues. Therefore, wherever appropriate and possible, MS Ireland will seek to partner with other voluntary sector organisations and industry partners when seeking to progress our advocacy agenda. In particular, MS Ireland recognises the key role of umbrella organisations in advocacy and campaigning. MS Ireland will work closely with the following umbrella organisations on particular issues of common interest:

- The Neurological Alliance of Ireland (NAI) is the national umbrella body representing over thirty organisations working with people with neurological conditions and their families.
- The Disability Federation of Ireland (DFI) is the national support organisation for voluntary disability organisations in Ireland who provide services to people with disabilities and disabling conditions
- The Medical Research Charities Group (MRCG) is the national organisation of charities active in medical research. The MRCG promotes dynamic medical research in Ireland, seeking a greater understanding of how illness can be prevented, how it can be diagnosed earlier and treated more effectively, with the ultimate goal of improving the whole nation's health.
- Care Alliance Ireland (CAI) is the National Network of Voluntary Organisations supporting Family Carers
- The Irish Platform for Patients Organisations, Science and Industry (IPPOSI) is a patient-led organisation that works with patients, government, industry, science, and academia to put patients at the heart of policy and medicines development
- The Irish Brain Council (IBC) was formally established in 2012 with the aim of promoting all aspects of neuroscience in Ireland via advocacy activities including public outreach, strategic partnership, legislative/policy involvement, and individual member engagement
- All Ireland Institute of Hospice & Palliative Care (AIHPC) is a leading organisation with national and international influence driving excellence in palliative care. AIHPC is a collaborative of hospices, health and social care organisations, and universities on the island of Ireland. AIHPC advances education, research, and practice to improve the palliative care experience of people with life-limiting conditions and their families.

MS Ireland will participate in relevant working groups and campaigns with the above organisations and will also attend conferences, events, and training sessions organised by these umbrella groups that are relevant to MS Ireland's advocacy agenda. MS Ireland will also maintain connections with the following international umbrella organisations and use these networks to gather information on examples of international best practice on issues relevant to our advocacy agenda:

- MS International Federation (MSIF)
- European Multiple Sclerosis Platform (EMSP)
- International Progressive MS Alliance (IPMSA)
- The World vs MS (TWvsMS)

### **4. Advocacy actions for 2024/25**

The following actions will be undertaken in 2024/25 to try and progress each of the advocacy priorities outlined above.

**Priority 1 - Implementation of the 2019-2021 National Neurorehabilitation Strategy - Key Activities:**

- Attendance at meetings with political representatives and attending AV room briefings and hearings of the Joint Oireachtas Committee on Health on the issue
- Pre-budget submission to be made requesting direct investment in neurorehabilitation services in 2023, focusing on the development of demonstration sites in CHO 6 and 7, as identified by the HSE
- Ensure representation from MS Ireland services staff at HSE steering group meetings around the development of the demonstration sites in CHO 6 and 7, to ensure that redevelopment and reconfiguration plans account for the services MS Ireland is already delivering in these areas and the current levels of unmet need of people with MS in these areas

**Priority 2 - Increased investment neurology services – Key Activities:**

- Through membership of the NAI Board, continue to advocate that investment in neurology services and the implementation of the National Clinical Programme for Neurology Model of Care should be an advocacy priority for the organisation
- Participate in new NAI joint advocacy initiative on neurology services
- Seek meetings with members of the Joint Oireachtas Committee on Health to request inclusion of the implementation of the National Clinical Programme for Neurology Model of Care in the HSE Service Plan for 2023
- During Brain Awareness Week use social media and mainstream media to highlight deficits in neurology services and the need to resource and implement the Neurology Model of Care
- Pre-budget submission to be made requesting direct investment in neurology services in 2023, based on costings produced by NAI
- Seek opportunities via membership of the HSE National Patients Forum to advocate for and influence the implementation of the Neurology Model of Care

**Priority 3 – Mechanisms to ensure that access to physiotherapy/neurorehabilitation/multidisciplinary care is not a ‘postcode lottery’ - Key Activities:**

- Produce a business case for sustainable funding for a national physiotherapy service
- Work with other organisations to find areas of common interest and participate in discussions to progress these issues
- Actively participate in the 2023 Patients Deserve Better Campaign regarding access to community neurorehabilitation teams
- Include the proposal for sustainable funding for a national physiotherapy service in MS Ireland Pre-Budget Submissions

**Priority 4 - Promote employment retention and return to work for people with MS – Key Activities:**

- Continue to engage with the Disability Federation of Ireland (DFI) and respond to consultation opportunities that arise as a result
- Liaise with the Disability Federation of Ireland (DFI) to seek progress updates on Comprehensive Employment Strategy for People with Disabilities.

**Priority 5 – Increased investment in services that support people to continue to live in their communities, such as home care, Housing Adaptation Grants and community therapy services such as physiotherapy and occupational therapy – Key Activities:**

- Submission to the HSE about the importance of physiotherapy in MS, using up-to-date research evidence, requesting increased investment in community physiotherapy services. Data and costings from this submission to be included in pre-budget submission also.
- Respond to the report from home care consultation when launched, and engage with other campaign groups in follow-up advocacy to push for implementation
- Submission to the Department of Health consultation on deprivation of liberties, to highlight the issue of people with MS being forced to live in nursing homes due to a lack of alternative

options

- Use National Carers Week to highlight issues of concern for carers of people with MS (using mainstream media and social media) such as a lack of home care services and lack of respite options
- Engage with the Department of Environment, Community and Local Government on the issue of bin charges to try and ensure that changes to bin charges systems do not negatively impact on people with MS who are affected by incontinence. Liaise and consult with other voluntary sector organisations on this issue as relevant

**Priority 6 – Increasing of availability of access to medical cards and GP visit cards, with application processes that account for the additional financial costs of living with MS:**

- Production of a self-advocacy guide for people with MS on applying for a medical card where their income is above the means testing threshold. This will be incorporated as part of the second edition of the Access to Medicines Campaign Handbook
- Production of Briefing Document and Position Paper on medical cards and GP visit cards
- Continue to engage with HSE and political contacts regarding the publication of the new framework for assessing applications for discretionary medical cards. Ask PQs to be raised on when the framework will be published
- Seek opportunities via membership of the HSE National Patients Forum to advocate on Medical Cards and ensure publication of the new framework

**Priority 7 - Development of MS registries – Key Activities:**

- Work with MRCG, IPPOSI, IBC, and NAI to seek opportunities to partner with other organisations with an interest in the development of registries
- Develop Terms of Reference for a research project into the feasibility of establishing an MS registry iv. Subject to obtaining funding, identify a suitable researcher to carry out the feasibility study into the development of an MS registry
- Engage with international organisations (EMSP and MSIF) to seek further opportunities to learn from other MS organisations about the process of establishing registries
- Proactively engage with clinicians and industry partners on the issue of registries, to highlight the need and seek opportunities for further collaboration

**5. Reporting**

Reports on the activities in this Strategy will be provided to the Board of MS Ireland, in advance of every Board meeting.

Members of MS Ireland will be updated on the progress of the Strategy via the Annual Report.

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## **2. Further reading**

The 'My MS My Needs' survey, 'Societal Costs of Multiple Sclerosis in Ireland 2022' report and 'Multiple Sclerosis and Employment: Facts and Figures' report are all available here:

[www.ms-society.ie/pages/living-with-ms/information-centre/our-publications](http://www.ms-society.ie/pages/living-with-ms/information-centre/our-publications)

Neurological Alliance of Ireland – 'We Need Our Heads Examined' campaign leaflet:

[www.nai.ie/assets/66/066FC20D-F533-4231-8B474ADEC2C696F4\\_document/NAI\\_Leaflet\\_Web2.pdf](http://www.nai.ie/assets/66/066FC20D-F533-4231-8B474ADEC2C696F4_document/NAI_Leaflet_Web2.pdf)