



Advocacy Strategy

2015-2019

Advocacy is one of five Strategic Priorities in MS Ireland's Strategic Plan 2015-2019. 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.

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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 which 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 in order to ensure the interests of the MS community remain represented.

MS Ireland's Strategic Plan for 2015-2019 sets out the following aims and objectives regarding advocacy:

Specific aims:

- To optimise relationships and understandings between relevant umbrella group
- 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

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 the disability
- 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 2016 'My MS My Needs' survey, completed by 826 people with MS
- Consultation exercise conducted in December 2015 – draft Advocacy Statement circulated to MS Ireland's members via email and displayed on MS Ireland website, with request for feedback

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 every two years
- 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 2011-2015 National Neurorehabilitation Strategy

Neurorehabilitation services are essential for helping people with MS recover from relapses and to slow disease progression. The 2011-2015 National Neurorehabilitation Strategy clearly laid out the need for neurorehabilitation services in Ireland and a plan for delivering them. However, since the publication of the strategy, no tangible progress has been made to deliver on this. Irish neurorehabilitation services are under-developed and under-resourced. Data from the Neurological Alliance of Ireland (NAI) indicates that:

- Ireland should have 270 inpatient beds for our population, there are less than half that and none outside Dublin
- There should be four regional inpatient specialist rehabilitation services nationwide, we have none
- There should be at a minimum nine community neurorehabilitation teams nationwide, one in each Community Health Organisation as a starting point. There are only three such teams in the entire country and they are only partially staffed
- We have the lowest number of consultants in rehabilitation medicine anywhere in Europe¹

Data from the 'My MS My Needs' study showed that:

- Less than 25% of respondents had ever been offered neurorehabilitation
- 23% of respondents did not know what neurorehabilitation is

¹ http://www.nai.ie/assets/66/066FC20D-F533-4231-8B474ADEC2C696F4_document/NAI_Leaflet_Web2.pdf

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 centres in 2016²:

- The recommended ratio is for one consultant neurologist per 70,000 population. This is exceeded within every hospital group and in one hospital group (Mid West) the ratio is 1:200,000
- Less than two thirds of the minimum recommended number (90 beds) of dedicated inpatient beds are available to support the neurology service nationwide
- The number of specialist nurses is significantly below what is recommended for our population with less than half the recommended number of MS nurses
- Four of the 11 hospitals reported no dedicated occupational therapy services for neurology patients
- Five centres reported no dedicated speech and language therapist for neurology patients
- Five neurology centres reported no dedicated medical social worker for neurology patients
- Only Beaumont and Tallaght Hospital have dedicated neuropsychology services available to patients. Within these centres, waiting lists can be up to one year
- Three hospitals report no or very limited dedicated posts for any of the core supporting therapies of occupational therapy, speech and language therapy, physiotherapy and neuropsychology
- Every hospital group exceeds the ratio for consultant neurologists for our population

Data from the My MS My Needs study showed that:

- 44% waited more than 6 months for their last neurologist appointment
- 71% of people with RRMS had an MRI scan in the past 12 months. 28% of these waited 6 months or more
- 16% needed to see an MS Nurse in the last 6 months but were unable to access the service

² http://www.nai.ie/assets/22/E622B527-41E1-4471-9EFDAE484E1745B2_document/NAI_Report_on_National_Services_2015_C.pdf

Priority 3 - Mechanisms to ensure that all licensed medications for MS are made available to those who would benefit from them

Disease Modifying Treatments (DMTs) are drugs that can modify or change the course of MS. They can reduce relapse rates, reduce hospitalisations and slow the progression of disability. Data from the 'Societal Costs of Multiple Sclerosis in Ireland 2015' report shows that avoiding relapses in people with MS could save €10 million per year and delaying disability progression up to €19 million per year³.

Currently some DMTs (i.e. DMTs requiring an IV infusion) are only available through individual hospital budgets because there is no national funding for hospital-only medications – as a result, some people with MS are frequently denied access to medication that is most appropriate to their needs. This means there is a 'postcode lottery' with unequal access to medications across the regions.

There are also currently unacceptable delays in the time it takes for licensed treatments to be made available. For example, a license for one symptomatic treatment for MS was granted in July 2014, yet the product still remains unavailable as approval has not been granted for reimbursing the cost of the drug.

Data from the My MS My Needs study showed that:

- 18.3% of people with relapsing remitting MS waited over a year from diagnosis to starting treatment

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:

- 43% of people with MS in Ireland are working, compared to the EU average of 60%
- 34.2% of people with MS are retired due to their MS or unable to work at present
- 68% of people with MS feel that MS has limited their career potential
- Nine out of ten people with MS are of working age

³ <http://ms-society.ie/uploads/File/Living%20with%20MS/Our%20publications/MS%20Ireland%20-%20Societal%20Cost%20of%20MS%20in%20Ireland%202015cc.pdf>

- Productivity losses due to MS are €135.5 million per year⁴

Priority 5 – Increased investment in services that support people to continue to live in their own 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 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 18% of respondents would have benefitted from a housing adaptation but could not get it
- People as young as 40 are availing of nursing home care due to 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 2015’ report found that In the last year, people with MS visited their GP an average of seven times. Some 21% had spent at least one night in hospital⁵. 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.

MS Ireland conducted a survey in 2014 which found:

⁴ <http://www.ms-society.ie/uploads/File/What%20We%20Do/Corporate%20Publications/2016/Multiple%20Sclerosis%20and%20Employment%20-%20Facts%20and%20Figures.pdf>

⁵ <http://ms-society.ie/uploads/File/Living%20with%20MS/Our%20publications/MS%20Ireland%20-%20Societal%20Cost%20of%20MS%20in%20Ireland%202015cc.pdf>

- 71% of our respondents deemed access to GP services as essential to enable them to remain well
- 63% thought access to medicines under the medical card were essential
- 64% thought that the medical card was critical in access in therapy services in the community
- 68% of respondents thought the medical card was critical in accessing specialist equipment e.g. walking aids, wheelchairs, continence equipment etc.
- 70% of respondents said that the medical card was critical in sourcing affordable respite⁶

Data from the My MS My Needs survey found that:

- 58% of respondents did not have a medical card
- Of these, 71% applied and were refused and 23% had never applied

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 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 who 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.

⁶ <http://www.ms-society.ie/blog-articles/1616-survey-results-medical-cards>

- 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 organization of charities active in medical research. The MRCG promotes a 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 2017

The following actions will be undertaken in 2017 to try and progress each of the advocacy priorities outlined above.

Priority 1 - Implementation of the 2011-2015 National Neurorehabilitation Strategy - Key Activities:

- i. Continued participation in the NAI working group for the 'We Need Our Heads Examined' campaign
- ii. Attendance at meeting with Minister for Health as part of campaign group, scheduled for January 2017
- iii. Pre-budget submission to be made requesting direct investment in neurorehabilitation services in 2018, based on costings produced by NAI
- iv. Identification of two spokespeople (people with MS and/or family carers) willing to speak publically about how the lack of availability of neurorehabilitation services has impacted on them
- v. Use of World MS Day theme Quality of Life to highlight the importance of neurorehabilitation on maintaining independence and preventing unnecessary accumulation of disability, using mainstream media and social media

Priority 2 - Increased investment neurology services – Key Activities:

- i. Through NAI, monitor and seek opportunities to influence the implementation of the National Clinical Programme for Neurology
- ii. Launch of Time to Act paper on early identification and treatment, to include specific policy recommendations on the need to invest in neurology services to bring staffing and waiting times for diagnosis and treatment in line with international guidelines for best practice
- iii. Dissemination of Time to Act paper – to be sent to Minister for Health and contacts in Minister's office, health spokespeople for all political parties, key officials in Department of Health and HSE, requesting meetings to discuss the recommendations in the report. Support to be sought from clinicians in the dissemination of the report
- iv. Pre-budget submission to be made requesting direct investment in neurology services in 2018, based on costings produced by NAI and information in the Time to Act report

Priority 3 - Mechanisms to ensure that all licensed medications for MS are made available to those who would benefit from them – Key Activities:

- i. Submission to be made to the HSE Corporate Pharmaceutical Unit on Sativex, using personal testimonies from people with MS affected by the lack of availability of Sativex
- ii. Continue to seek opportunities to highlight Sativex in the media
- iii. Work with the HSE to develop a communications protocol for proposed new centralised funding system for medications delivered via hospital-only infusions
- iv. Make Patient Group Submission to National Council for Pharmacoeconomics (NCPE) regarding potential new medications which receive licenses in 2017, in consultation with the relevant pharmaceutical companies

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

- i. Work with the Disability Federation of Ireland (DFI) to form working group of organisations representing people with chronic illnesses and acquired disabilities, with the aim of seeking to influence policy and services regarding employment retention
- ii. Production of resource for occupational therapists on MS and employment. Dissemination of this resource via the Association of Occupational Therapists of Ireland
- iii. Political engagement regarding release of Department of Social Protection report on Making Work Pay – ask TDs to raise PQs if release of report is delayed. Release analysis and response to report when it is released

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

- i. 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
- ii. Further engagement with other voluntary sector organisations involved in the 'Invest in Home Care' campaign, to progress this campaign, highlight the issues in the media and seek political engagement
- iii. Formation of sub-group of organisations within this campaign group representing people under the age of 65, to formulate policy responses specific to this age cohort

- iv. Continue to attend Community Living Task Group meetings (subgroup of implementation working group for the National Housing Strategy for People with Disabilities) to seek opportunities to influence housing policy for people with disabilities
- v. Pre-budget submission to include costings for increasing the threshold for means testing for the Housing Adaptation Grants and increasing the budget for this. Work with DFI to obtain accurate costings if necessary
- vi. Use of World MS Day theme Quality of Life to highlight the importance of services that support people to carry on living in their own homes and communities
- vii. Production of Briefing Document and Position Paper on treatment decisions in advanced MS, covering palliative care and assisted suicide
- viii. Partner with CAI for National Carers Week and use this week to highlight issues of concern for carers of people with MS (using mainstream media and social media) such as lack of home care services and lack of respite options

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

- i. Production of self-advocacy guide for people with MS on applying for a medical card where their income is above the means testing threshold
- ii. Production of Briefing Document and Position Paper on medical cards and GP visit cards
- iii. Continue to engage with HSE and political contacts regarding the publication of the new framework for assessing applications for discretionary medical cards. Submit feedback to the HSE on the framework when it is published

Priority 7 - Development of MS registries – Key Activities:

- i. Work with MRCG, IPPOSI, IBC and NAI to seek opportunities to partner with other organisations with an interest in development of registries
- ii. Through membership of MRCG Communications and Advocacy Working Group, request that MRCG organise an information sharing or training event, whereby organisations who have experience of the process of establishing registries can share their learnings with others
- iii. Development of Briefing Document and Position Paper on registries
- iv. Inclusion of the need for development of an MS registry as a policy recommendation in Time to Act paper

- v. Proactively engage with clinicians and industry partners on the issue of registries, to highlight the need and seek opportunities for further collaboration

5. Reporting

- i. Reports on the activities in this Strategy will be provided to the Board of MS Ireland, in advance of every Board meeting
- ii. Members of MS Ireland will be updated on the progress of the Strategy via the Annual Report

6. Contacts

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7. Further reading

MS Ireland's 2016 Advocacy Statement:

www.ms-society.ie/uploads/File/Community/MS%20Ireland%20Advocacy%20Statement%2021012016.pdf

'My MS My Needs' survey – preliminary results:

www.ms-society.ie/uploads/File/Research/2016/MS%20Ireland%20-%20My%20MS%20My%20Needs%20Infographic.pdf

MS Ireland Neurorehabilitation Strategy Briefing Document and Position Paper:

www.ms-society.ie/uploads/File/What%20We%20Do/Corporate%20Publications/MS%20Ireland%20Neurorehabilitation%20Briefing%20Document%20and%20Position%20Paper.pdf

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

'Multiple Sclerosis and Employment: Facts and Figures' report:

www.ms-society.ie/uploads/File/What%20We%20Do/Corporate%20Publications/2016/Multiple%20Sclerosis%20and%20Employment%20-%20Facts%20and%20Figures.pdf

'Societal Costs of MS in Ireland 2015' report:

www.ms-society.ie/uploads/File/Living%20with%20MS/Our%20publications/MS%20Ireland%20-%20Societal%20Cost%20of%20MS%20in%20Ireland%202015cc.pdf