



MS Ireland Advocacy Statement 2016

Our Key Priorities:

- Implementation of the 2011-2015 National Neurorehabilitation Strategy
- Increased investment in hospital and community-based neurology services
- Mechanisms to ensure that all licensed medications for MS are made available to those who would benefit from them, including centralised funding for Disease Modifying Treatments that are currently only available subject to individual hospital budgets
- Promote employment retention and return to work for people with MS, in line with the actions laid out in the Comprehensive Employment Strategy for People with Disabilities 2015-2024
- Revision of the assessment tools for access to services that support people with MS to continue living in their communities, including the Housing Adaptation Grant and Home Care Packages
- Automatic entitlement to a GP Visit Card for those on the Long Term Illness Scheme, and development of a robust framework for the assessment of eligibility for medical cards that accounts for the additional financial costs of living with MS

Introduction

Over 9,000 people live with Multiple Sclerosis in Ireland. MS Ireland is the only national organisation providing information, support and advocacy for people with MS and their families.

A recent report by MS Ireland revealed that Multiple Sclerosis costs Irish society €429 million per year, in addition to the huge physical, personal, emotional and social impact for those living with the illness.

Research suggests that much of this impact could be reduced by providing timely interventions that reduce relapses and disability progression and support working and independent living. MS Ireland calls on political representatives to make people affected by MS a priority when drawing up programmes for the next government, after the 2016 general election.

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 societal costs of MS increase sharply as the illness progresses, from €34,942 per person per year for those with mild MS to €100,554 per person per year for those with severe MS. Slowing disease progression could amount to substantial savings to society, as well as drastically improving the quality of life for those living with MS.

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.

We ask, along with our partner organisations in the Neurological Alliance of Ireland (NAI), that the new programme for government includes specific guarantees to implement the National Neurorehabilitation Strategy, with a three year programme of investment to develop regional inpatient units and community neurorehabilitation teams.

Increased investment in hospital and community-based neurology services

MS Ireland is aware of serious deficiencies in the current provision of neurological services. Ireland has the lowest number of neurologists per head in Europe, and our recent study showed that nearly one-third of people with MS had not seen a neurologist in the previous 6 months. Regular monitoring is essential to ensure that people with MS are receiving optimal treatments to manage symptoms and slow disease progression.

In addition, many people with MS have to travel huge distances to see their neurologist – for example, a person with MS in Donegal could have to travel to Dublin.

There are also serious deficiencies in community-based therapeutic services such as physiotherapy and occupational therapy. Only 40.4% and 15.7% of people with MS have seen physiotherapists and occupational therapists respectively in the last year.

We ask for adequate funding through the neurology clinical programme to address understaffing and other serious deficits across neurology services. We also ask for a commitment to increasing funding for community-based physiotherapy and occupational therapy services.

Mechanisms to ensure that all licensed medications for MS are made available to those who would benefit from them, including centralised funding for Disease Modifying Treatments that are currently only available subject to individual hospital budgets

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. Avoiding relapses in people with MS could save €10 million per year and delaying disability progression up to €19 million per year.

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.

We ask for an end to the ‘postcode lottery’ of access to appropriate treatments with a centralised funding system for hospital-only DMTs, and that a mechanism is found to make all licensed treatments available immediately to those who would benefit from them.

Promote employment retention and return to work for people with MS, in line with the actions laid out in the Comprehensive Employment Strategy for People with Disabilities 2015-2024

Most people with MS will be diagnosed between the ages of 20-40. Therefore, MS has a serious impact on employment and financial independence. Total productivity losses for people with MS, including early retirement, reduced working weeks, time off for appointments and presenteeism, amount to more than €135 million per year. In addition, a loss of employment and productivity can have hugely negative non-financial consequences for people with MS.

In October 2015, the Taoiseach launched the Comprehensive Employment Strategy for people with Disabilities 2015-2024. This strategy outlines various actions to promote job retention and re-entry to work for those that acquire a disability, including developing guidelines to promote intervention in the early stages of absence from work and a continued programme to train trade union ‘disability champions’ to support colleagues to return to work following the onset of disability.

We ask that the new programme of government commits to delivering on the actions contained in this strategy and that specific consideration is given to the effects of long-term, progressive, and unpredictable disease activity as associated with MS when developing targeted actions on job retention. People with MS should have more options to contribute to society beyond early retirement and long-term dependency on social services. (Figures available)

Revision of the assessment tools for access to services that support people with MS to continue living in their communities, including the Housing Adaptation Grant and Home Care Packages

MS Ireland is aware of many people with MS under the age of 65 resorting to nursing home care due to lack of services that could support them to continue living at home. For example, changes in eligibility and means-testing rules for the Housing Adaptation Grants scheme and Mobility Aids Grants scheme mean it is now harder for people with MS to get adaptations to their homes to make them accessible as their level of disability increases.

There are also serious inequities in the availability of Home Care Packages. Because this scheme is not established in law, there is currently no standardised assessment tool for determining eligibility for the scheme and what supports will be made available. Furthermore, the scheme is designed primarily for older people and the current guidance states that “if a younger person’s assessed needs can be best met by services designed for older people then occasionally such an application may be considered”. This lack of clarity and uncertainty results in many people with



MS being denied access to vital home care services which could prevent the need for admission to a nursing home.

We ask that the means testing rules for Housing Adaptation Grants and Mobility Aids Grants are revised upwards to enable more people to access these vital schemes, and that a standardised assessment tool is developed for assessing eligibility for Home Care Packages which makes specific reference for allocating resources to those under 65 with a disability. An equivalent fund to the 'Fair Deal' scheme should also be set up for those under 65, which is not restricted for use on nursing home care and can be used for services such as home care and housing adaptations.

Automatic entitlement to a GP Visit Card for those on the Long Term Illness Scheme, and development of a robust framework for the assessment of eligibility for discretionary medical cards that accounts for the additional financial costs of living with MS

People with MS have a high level of use of medical services. In the last year, people with MS visited their GP an average of seven times. Some 21% had spent at least one night in hospital. However, nearly 62% of people with MS do not have a medical card. 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.

We ask that those on the Long Term Illness Scheme be automatically eligible for a GP Visit Card. Also, the new framework that is currently being developed for assessing eligibility for medical cards must fully account for the personal expenses involved in living with MS.

Ms Ireland's report "Societal Cost of Multiple Sclerosis in Ireland 2015" can be accessed here:

<http://www.ms-society.ie/pages/living-with-ms/information-centre/our-publications>

MS Ireland also supports the election manifestos of the Neurological Alliance of Ireland, the Medical Research Charities Group and the Disability Federation of Ireland.