MSIreland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

Pre-Budget Submission 2020

Summary of key asks

- €600,000 increase in annual funding to optimize the use of the MS Care Centre.
- Investment in specialist service provision by voluntary neurological organisations.
- €2m investment in neurology services to address growing waiting lists and unacceptable waiting times for neurology services.
- €4.5m investment in neurorehabilitation services.
- Multi-Annual Investment Programme of €211m each year for five years 2020-2024 for community services for people with disabilities.
- €28.38m investment to support Housing Adaptation.
- Automatic entitlement to a GP Visit Card for all on Long Term Illness Scheme.
- Ring-fence saving from the 2016 IPHA agreement for spending on access to new and innovative medications.
- Supporting voluntary organisations to raise awareness of Assisted Decision Making.

Background and context

Multiple Sclerosis (MS) is the most common chronic disabling neurological disease in younger adults. MS affects over 10,000 people in Ireland and is usually diagnosed between the ages of 20 and 40. Symptoms and disease course vary from person to person, with common symptoms including fatigue, mobility problems, visual disturbances, bladder and bowel issues, cognition issues and speech and swallowing problems. Approximately 80-85% of people with MS are initially diagnosed with a relapsing-remitting form, characterized by episodic flare-ups of symptoms which typically appear over a period of several days and then stabilize, with complete or partial recovery. Around 65% of people with relapsing-remitting MS will eventually go on to develop secondary progressive MS, whereby their condition steadily deteriorates without relapses, and generally with increasing levels of disability. A small proportion of people with MS are diagnosed with a progressive form from the outset (MS Ireland, 2015).

Research by the Multiple Sclerosis Society of Ireland (MS Ireland) suggests that MS costs the Irish taxpayer approximately €429 million per year. The cost of the illness increases steeply from €35,000 per person per year for those with mild MS to €100,000 per person per year for those with severe MS. MS relapses cost approximately €16.9 million per year (MS Ireland, 2015). Furthermore, quality of life for people with MS is rated 32% less than for the general population (MS Ireland, 2017a).

People with MS require high levels of care and support. MS Ireland's 'Societal Costs of Multiple Sclerosis in Ireland 2015' study found that in a representative sample of 594 people with MS 63% received an average of 15 hours of care from family members or friends in the previous week. The study attributes an annual societal cost of €77.8 million per year to informal care due to caregivers having to stop work or reduce working hours. Another recent survey of a large, representative sample of Irish people with MS found that 73% of people with MS receive care and support from a family member or friend. People with progressive forms of MS need considerably more care and support than those with the relapsing remitting form, with 16% of people with progressive forms of MS requiring full time assistance. 12% of people surveyed also reported that they needed paid home care but were unable to access it for a variety of reasons, and 60% of those who required full time care felt that their caregivers needed more information and support than they received (MS Ireland, 2017b).

Key asks for Budget 2020

1. **An increase of €600,000 in annual investment in the MS Care Centre.**

MS Ireland calls on the Government to increase annual statutory investment in the MS Care Centre by €600,000. The Multiple Sclerosis (MS) Care Centre is a 12 bedded unit which provides respite care for people with MS (PwMS) and other progressive neurological conditions. This additional funding will see the MS Care Centre open 350 days per year, providing an additional 1,128 bed nights annually. The MS Care Centre currently caters for approximately 400 people per year. Increased investment would provide more people the chance to avail of respite care, support carers and maintain the sustainability of home care.

Further information on this can be found in MS Ireland's Care Centre Business Case - https://www.ms-society.ie/sites/default/files/2019-06/MS%20Care%20Centre%20Report%20-%20FINAL.pdf

2. **Investment in specialist service provision by voluntary neurological organisations.**

MS Ireland supports the request of the Neurological Alliance of Ireland in requesting investment in specialist service provision. The valuable role of the voluntary sector in providing flexible, responsive and innovative responses to health and social care needs was recognised in the recently published report of the Independent Review Group 7. Numerous cutbacks by the HSE have resulted in many voluntary providers are struggling to continue to meet the cost of providing services. This issue was highlighted in a series of presentations to the Joint Oireachtas Committee on Health on June 19th 2019, where the cumulative deficits among voluntary disability providers were estimated to be in excess of €40m. MS Ireland as members of the Neurological Alliance of Ireland supports the calls from this hearing for a review of these deficits and the relationship between the HSE and voluntary providers in the context of the full implementation of the recommendations of the Independent Review Group.

3. Investment of €2 million in neurology services.

MS Ireland calls on the Government to invest €2 million in neurology services in 2020, to address critical staffing shortages in neurology services nationwide.

A survey of neurology clinics by the Neurological Alliance of Ireland (NAI) and the National Clinical Programme for Neurology found critical deficits in staffing across all neurology centres and unacceptable waiting times for MRI scanning. Key findings include:

- No centre has MRI access for routine referrals in under two months and seven of the eleven neurology centres cannot get access within one year of referral
- The ratio recommended by the British Association of Neurologists is for one consultant neurologist per 70,000 population. This ratio is exceeded within every hospital group in Ireland and in one hospital group (Mid West) the ratio is 1:200,000 (NAI, 2016).
- Ireland has less than half the number of MS specialist nurses that we should have

MS Ireland's report 'Time to Act: A consensus on early treatment', launched in March 2017, clearly lays out research evidence that shows the importance of access to early diagnosis, early treatment and regular monitoring for people with MS. It is not possible to achieve a standard of care for people with MS that is in line with the research evidence and international recommendations for best practice without investing further in neurology services.

The National Clinical Programme for Neurology Model of Care, released in September 2016, details exactly what is required in terms of staffing and resources to achieve a model of care for people with MS that is in line with international recommendations. MS Ireland is calling on the Government and the HSE to formally commit to supporting the implementation of the Model of Care, including publishing a plan with specific timescales and budgets that outline how implementation will be achieved.

MS Ireland is one of 11 organisations who have joined the Neurological Alliance of Ireland's 'Invest in Neurology' campaign, which is calling for:

1. Immediate investment to address critical deficits in neurology staffing, including neurologists, specialist nurses and health and social care professionals to recommended levels

2. Targeted long term investment in neurology services to support implementation of the Neurology and Epilepsy Models of Care

3. Dedicated resources to support the development of clinical pathways for headache, multiple sclerosis, Parkinson's disease and rare and genetic neurological conditions

More information about the Invest in Neurology campaign and their asks is available here: www.nai.ie/assets/2/2602D555-2BAD-409A-A7327EEBB4A50F30_document/Manifesto_final.pdf

4. **Investment of €4.5 million in neurorehabilitation services.**

The function of neurorehabilitation is to both prevent unnecessary deterioration in a person's condition and functioning, and to help compensate for any function that has been lost as a result of a neurological condition. MS Ireland calls on the government to make necessary funds available to give effect to the National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland Implementation Framework 2019-2021, which outlines the fundamental principles of design and service delivery required to implement the National Neurorehabilitation Strategy 2019-2021.

In September 2018, a neurorehabilitation demonstrator project was establish in CHOs 6 & 7 to provide critically needed access to specialist rehabilitation services and address growing waiting lists in the National Rehabilitation Hospital. MS Ireland supports the Neurological Alliance of Ireland's call for investment of €4.5m in 2020 to enable the implementation of the demonstrator project in CHO's 6 & 7 as the first step in the delivery of the three year implementation framework for the National Neurorehabilitation Strategy 2019-2021.

5. **Multi-Annual Investment Programme of €211m each year for five years 2020-2024 for community services for people with disabilities.**

People living with Disabilities who, with some support, could continue living in their own homes are being forced into residential care. Adequate provision of appropriate community services would allow people to remain living in their homes and communities. In 2018, the Disability Federation of Ireland published '*The situation of younger people with disabilities living in nursing homes in Ireland - phase 1'* which outlines the impact of younger people being inappropriately placed in nursing homes. The majority of people reflected in this report live with a condition of the nervous system, including multiple sclerosis. Providing adequate funding of community based services and allowing people to remain in their own homes would be a step towards the implementation of the United Nations Convention of the rights of people with Disabilities, which the Government passed a motion to ratify on the 7th of March, 2018.

MS Ireland supports the Disability Federation of Ireland's call for investment of €11 million in community support packages that allow a person with a disability or long term illness to remain living in their own home as part of a multi-annual investment programme of €11 million a year over five years. This will fund community supports and services including:

- Personal Assistants (PAs)
- Home care
- Home help/support
- Therapy services such as physiotherapy, occupational therapy and speech and language therapy

As members of the Homecare Coalition, MS Ireland support their call for €110 million to cover home supports for people living with disabilities and the elderly.

MS Ireland's 'My MS My Needs' report, published in September 2017, found that 73% of people with MS receive care and support from a family member or friend and 12% felt they would have benefited from formal care but were unable to access it, suggesting that people with MS and their families and carers would benefit greatly from increased investment in community support services.

6. €28.38m investment to support Housing Adaptation.

MS Ireland's 'My MS My Needs' report (2017b) revealed that 18% of respondents needed housing adaptations but could not get them, and 77% of those who had received adaptation grants had not had the full cost of works covered by the grant.

MS Ireland therefore supports the Disability Federation of Ireland in calling for a €28.38 million increase in the Housing Adaptation Grant scheme in 2020, to return funding to 2010 levels. MS Ireland further calls for the means testing criteria for these grants to be reviewed and the thresholds to be revised upwards. This will facilitate people with MS to remain living in their own homes rather than having to avail of nursing home care. This would also support the aims of the proposed statutory homecare scheme.

7. Automatic entitlement to a GP Visit Card for those in receipt of the Long Term Illness Scheme.

Living with MS can accrue many additional costs including travel to appointments, time off work, extra household bills, over-the-counter medications, aids and appliances, household adaptations and costs associated with exercise such as gym membership. In a recent submission to the Clinical Advisory Group for Discretionary Medical Cards, MS Ireland estimated the average additional costs of living with MS to be at least €2,005.70 per year. These figures are average costs and 50% of people with MS will experience higher costs than those reported. Also, the unpredictable nature of MS can mean that people with MS will often be faced with sudden and unpredictable financial burdens when they experience relapses. Studies have found that even a mild relapse can have a significant financial impact on the individual, with more severe relapses being associated with steeper costs (O'Connell et al, 2014).

People with MS have high levels of GP usage. The 'Societal Costs of Multiple Sclerosis in Ireland 2015' report found that on average, people with MS visit their GP 7.2 times per year. Another survey carried out by MS Ireland (2017b)revealed that 58% of people with MS do not have a Medical Card. GP visits may well therefore be an additional financial burden to some people living with MS. MS Ireland calls on the Government to make a GP Visit Card an automatic entitlement for those in receipt of the Long Term Illness Scheme, as an initial measure to ensuring that people with MS and other long term illnesses are not financially disadvantaged as a result of their condition and that inability to pay for GP visits is not a concern for people living with MS in self-managing their condition.

8. Ring-fence savings from the 2016 IPHA Agreement for spending on access to new and innovative medications.

In 2016, the Irish Government and the Irish Pharmaceutical Healthcare Association (IPHA) reached an agreement on the pricing and supply of new medicines, which would result in savings of up to €750 million on the cost of medications. However, currently there are serious problems with the systems for assessment and reimbursement of new medications in Ireland, resulting in Ireland falling behind other European countries in terms of how long it takes to make new medications available to patients (IPPOSI & MRCG, 2018). This issue is of particular concern to the MS community currently as Ocrelizumab, the first ever medication for primary progressive MS, was given a license by the European Medicines Agency in January 2018, yet we have no idea when or if this treatment will be made available to Irish MS patients.

MS Ireland therefore calls on the Government to ring-fence savings from the current IPHA agreement for spending on access to new and innovative medications such as Ocrelizumab, so that they can be made available to Irish patients as soon as possible in line with our European counterparts.

Further information is available in the two ‘Drug Iceberg’ reports, produced by the Irish Platform for Patients Organisations, Science and Industry (IPPOSI) and the Medical Research Charities Group (MRCG) – these reports are available at http://www.ipposi.ie/our-work/publications/collaborative-documents/

9. Supporting voluntary organisations to raise awareness of Assisted Decision Making.

MS Ireland supports the Home Care Coalition’s request for a specific budget line of €100,000 to be made available to the HSE Assisted Decision Making Office to resource it to make materials available for voluntary organisations so they can engage with the public to raise awareness of the Act and to help people plan ahead for future and end of life health care. Forthcoming changes to decision making and the concept of functional capacity which the new Act will bring in need to be clearly communicated to the general public and supporting voluntary organisations to effectively communicate these changes is imperative.

This submission has been prepared by Aoife Kirwan, Information, Advocacy & Research Officer, MS Ireland. Questions and comments can be directed to aoifek@ms-society.ie

About MS Ireland

Multiple Sclerosis Ireland is the only national organisation providing information, support and advocacy services to the MS community. We work with people with MS, their families and carers and a range of key stakeholders including health professionals, students and others interested in or concerned about MS to ensure that we meet our goals. MS Ireland is chiefly a services driven organisation, focused on providing timely, person-centred services that create independence and choice for person with MS and their family.

MS Ireland's Services and Work:

- **Individual and Family Support**

  Through our case work service our teams of professional Regional Community Workers support the person with MS through the transitional changes that MS, as a disease, presents. Support is also available to the family members in dealing with the challenges they may face as a family unit.

- **Living with MS programmes**

A range of living with MS programmes, workshops and activities are organised throughout the country that are targeted at various groups such as those newly diagnosed, carers, children of parents with MS and health professionals. Programmes include physical therapies, symptom management and information/education seminars.

- **MS Information Line 1850 233 233**

Our confidential information line provides professional information and support to those affected by MS. The Information Line is open from Monday to Friday 10am – 2pm.

- **Information**

Our information tools include a variety of booklets and information sheets, our website www.ms-society.ie, our MSnews magazine, conferences, seminars and the valuable knowledge and experience of our staff.

- **The MS Care Centre**

The MS Care Centre is Ireland's only respite and therapy centre for people with MS. It offers short-time respite care, therapeutic services, neurological assessments and many social activities in a homely environment in the suburbs of Dublin.

- **Voluntary Branches**

Our voluntary branches are a support network for people and families living with MS in local communities. They provide a welfare service, access to various therapies and organise various social gatherings.

- **Research**

Our dedicated research fund annually finances a number of medical and social research projects and we regularly update worldwide research information on our website and publications.

- **Representation**

MS Ireland advocates on an individual and collective platform for the improvement in services, resources and policies affecting people with MS.

Further reading

MS Ireland reports and submissions:

- 'Societal Costs of Multiple Sclerosis in Ireland 2015': http://bit.ly/2p91YjT
- 'Time to Act: A Consensus on Early Treatment': http://bit.ly/2t7TdYD
- 'Quality of Life of People Living with MS in Ireland': http://bit.ly/2rsqZYh
- MS Ireland's submission to the Clinical Advisory Group for discretionary Medical Cards: http://bit.ly/2vtDO5w
- 'My MS My Needs' report: https://bit.ly/2LLHEQr

- ‘Multiple Sclerosis and Employment: Facts & Figures’ report: https://bit.ly/2dBUtMC
- ‘Care Centre Business Case’ - https://tinyurl.com/y58ed6ad

HSE documents:

- National Clinical Programme for Neurology Model of Care: http://bit.ly/2v9rJ65
- National Neurorehabilitation Strategy: http://bit.ly/2u0EH7C
- National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland - https://tinyurl.com/y38kdxaf

Other:

- IPPOSI & MRCG ‘Drug Iceberg’ reports: https://bit.ly/2KsXYse
- ‘Make Work Pay’ report: https://bit.ly/2q7gMB5
- United Nations Convention on the Rights of People with Disabilities: https://tinyurl.com/hqq9r4q
- The situation of younger people with disabilities living in nursing homes in Ireland - phase 1 https://tinyurl.com/y2s32eso

References

IPPOSI & MRCG (2018). *Steering a course to avoid the ‘drug iceberg’ – the challenges of accessing new and innovative medicines in Ireland and the call for a new national strategy.* Dublin: IPPOSI & MRCG.

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

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

Multiple Sclerosis Society of Ireland (2017a). *Quality of life of people living with MS in Ireland.* Dublin: MS Ireland and Novartis.

Multiple Sclerosis Society of Ireland (2017b). *My MS My Needs*. Dublin: MS Ireland.

O'Connell K et al. (2014). Economic costs associated with an MS relapse. *Multiple Sclerosis Rel Disord* [published online 16 September 2014]

Pozzilli et al. (2002). Home-based management in multiple sclerosis: Results of a randomized controlled trial. *Journal of Neurology, Neurosurgery and Psychiatry,* Vol. 73, No 3, pp. 250-55.

Ward, A., Barnes, M., Stark, S. and Ryan, S. (2009). *Oxford Handbook of Clinical Rehabilitation* (2nd edition). Oxford: Oxford Medical Publications.