



Pre-Budget Submission 2021

Summary of key asks:

- An increase of €600,000 in annual investment in the MS Care Centre
- Establishment of a special fund to meet COVID-19 costs and investment to address deficits among Section 39 providers
- Investment of €3.3m in Neurology Services
- Investment of €4.5m into neurorehabilitation services as a first step in meeting the commitment in the Programme for Government to implement the National Neurorehabilitation Strategy
- Investment to support Housing Adaptation

Background and context

Multiple Sclerosis (MS) is the most common chronic disabling neurological disease in younger adults. MS affects over 9,000 people in Ireland and is usually diagnosed between the ages of 20 and 40. Symptoms and disease can vary from person to person, with 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, characterised by episodic flare-ups of symptoms which typically appear over a period of several days and then stabilise, 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).

Impact of COVID-19

The COVID-19 pandemic has impacted all areas of society, not least of all people living with MS and those supporting them. Vital services which people living with MS rely on, which were under pressure before the pandemic, have now had additional strain and pressure placed on them. COVID-19 is something we may have to live alongside for some time, so it is essential that services are appropriately supported to provide care and support to people living with MS. In addition to this, neurological symptoms have been reported in a significant percentage of those with COVID-19 and so, further investment is essential in order to support the services which may be dealing with this additional pressure moving forward. These services urgently need support and investment.

MS Ireland is aware that the impact of the pandemic may continue to have an effect for a considerable amount of time. People living with MS and those supporting them must not be further disadvantaged as a result of this. The services available to them must be protected. Moving forward, funding issues must be addressed to ensure people living with MS receive the appropriate support and services required to help maintain their condition and independence.

Key asks for Budget 2021;

An increase of €600,000 in annual investment in the MS Care Centre¹

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 to people living with MS and other progressive neurological conditions. The additional funding has the potential to see the MS Care Centre open 350 days per year, providing an additional 1,128 bed nights annually. Increased investment would provide more people with the opportunity to avail of respite care, support carers and maintain the sustainability of home care. Due to the COVID-19 pandemic, MS Ireland had to temporarily close the MS Care Centre until sufficient advice for respite services could be provided. We now find ourselves in a position where we are looking at moving forward with reopening and it is essential that we are supported by Government to provide optimal care and support to our community members.

During the COVID-19 pandemic, some people living with MS who are in need of support witnessed a withdrawal of services such as homecare, personal assistance hours and respite care. This placed an additional pressure on them and their families. Family carers and family members who may not have been Carers prior to the pandemic were in many situations forced to take over or increase their caring duties for their loved one. This simply is not sustainable. It is imperative that respite services such as the MS Care Centre are supported to operate at their full potential in order to relieve stress on Carers and provide people living with MS and other progressive neurological conditions with the opportunity to avail of appropriate respite care. Supporting Carers in this way will help to ensure the sustainability of family Carers to provide support. Providing care with no opportunity for a break is very challenging. Opportunities to avail of respite care allow Carers to take a break for self-care. It is also necessary as carers themselves may have medical conditions or other circumstances which they should not have to neglect in order to care for another person. Carers need support. Respite care, provides Carers with the opportunity to focus on their own needs for a time. The MS Care Centre is fully equipped to meet the needs of people living with MS and offers a homely environment in which people living with MS can interact with each other, engage in activities and be cared for in a comfortable and safe environment. MS Ireland believes that all people who require respite care in the MS Care Centre should have access to it and in order to deliver this to our community members, additional annual statutory funding is essential.

¹ MS Ireland Care Centre Business Case <https://www.ms-society.ie/sites/default/files/2019-06/MS%20Care%20Centre%20Report%20-%20FINAL.pdf>

Establishment of a special fund to meet COVID-19 costs and investment to address deficits among Section 39 providers

MS Ireland, as members of the Disability Action Coalition (TDAC) call on the Government to establish a special fund for Section 39 service providers and investment to eliminate deficits faced by these organisations². MS Ireland and other member organisations of the above groups were vocal on the underfunding of our services prior to the COVID-19 pandemic. Prior to the pandemic, MS Ireland as members of TDAC were asking Government to urgently address a funding crisis. COVID-19 has only further exacerbated the funding issues we face. The voluntary sector provides flexible, responsive and innovative responses to health and social care needs.

The COVID-19 pandemic has presented us with unprecedented challenges. Prior to COVID-19, MS Ireland had joined with a number of other organisations which provide disability services under Section 39 of the Health Act, to highlight that our services were at breaking point. Additional pressures and challenges we now face as a result of COVID-19 have only further exacerbated these issues. We support the calls of The Disability Action Coalition, the Disability Federation of Ireland and other groups for the establishment of a special fund to help protect voluntary organisations and the services they provide.

Our organisation, like many others in the not-for-profit sector had to abruptly alter our service delivery model in response to the pandemic. In order to continue providing vital support to our community members, we moved our services online, provided tailored information on COVID-19 and MS to our community and our staff were tasked with responding to the needs of people living with MS in a digital format. Fundraising losses have resulted in further financial pressure for our organisation. A large part of MS Ireland's income is brought in by fundraising activities. The restrictions that were put in place since March has impacted many of our planned fundraising activities. We expect that our fundraised income will be reduced by 38% in 2020 at a cost of over €1m. We are not alone in this, other organisations have experienced similar issues in the past number of months and we are under threat.

The Disability Federation of Ireland recently conducted a survey³ of 20 disability service providers. The survey found that;

- 37% are concerned that they won't be viable after 6 months
- 50% have laid off or are preparing to lay off staff
- Essential services are threatened for 55% of organisations due to loss of fundraised income

² *The Disability Action Coalition Submission to the Special Committee on COVID-19 Response* <https://tdac.ie/publications/>

³ *Disability Federation of Ireland Submission on the Impact of COVID-19* https://www.disability-federation.ie/assets/files/pdf/dfi_submission_impact_of_covid-19_on_people_with_disabilities_and_the_disability_sector_290620_1.pdf

- The sample of 20 disability service providers expect a potential fundraising loss of over €7 million in 2020. The sector-wide loss will be substantially higher

In addition to loss of income, we are faced with increased costs due to the purchase of PPE, enhanced cleaning and staff training. Section 39 organisations were calling for help prior to the pandemic, during it we have displayed resilience and versatility during this time but we cannot continue indefinitely without further support. Our organisations play a crucial role in providing people living with disability with essential services and we need the support of Government to continue this.

Investment of 3.3m in Neurology Services

MS Ireland supports the €3.3m investment in acute neurology services called for by the National Clinical Programme for Neurology and the Neurological Alliance of Ireland (NAI).⁴

Additional investment is urgently required in order to address long waiting lists, provide appropriate multi-disciplinary care which will help to reduce hospital admissions and reduce the demand on already overstretched services.

In 2015, NAI conducted research⁵ which showed that all neurology centres across Ireland were understaffed but that patients of regional centres in the North West, Mid-West and South East were further disadvantaged due to understaffing. Since this audit, out-patient waiting lists have almost doubled⁶, yet there has been no investment to address this issue.

Ireland has less than half the number of MS Nurse Specialists than what is recommended. In addition to this, we have a shortage of consultant neurologists. The British Association of Neurologists recommends a ratio of one consultant neurologist per 70,000 population.⁷ In Ireland, this ration is exceeded within every hospital group. MS Ireland's report "Time to Act: A consensus on early treatment"⁸, outlines research-based evidence that demonstrates the importance of access to early diagnosis, early treatment and regular monitoring of people living with MS. It is not possible to achieve a standard of care for people living with MS that is in line with the evidence-based international recommendations for best practice without further investment in neurology services.

⁴ Neurological Alliance of Ireland Pre-budget Submission https://www.nai.ie/assets/32/F4E32311-7BCF-4397-93CDABE24748058A_document/NAI_Prebudget_Submission_2021.pdf

⁵ NAI Report on National Services https://www.nai.ie/assets/22/E622B527-41E1-4471-9EFDAE484E1745B2_document/NAI_Report_on_National_Services_2015_C.pdf

⁶ Outpatient waiting list by speciality <https://www.ntpf.ie/home/outpatient.htm>

⁷ Local Adult Neurology Services for the Next Decade (June 2011) Report of a working party Royal College of Physicians and Association of British Neurologists

⁸ MS Ireland Time to Act: A Consensus on Early Treatment <https://www.ms-society.ie/sites/default/files/2019-06/Time%20to%20Act%20-%20A%20consensus%20on%20early%20treatment.pdf>

COVID-19 has created additional issues in relation to neurology services⁹. The public health measures which were introduced earlier this year resulted in a backlog of people trying to access neurology services. Smaller numbers in clinics, temporary suspension of medication administration and monitoring have all resulted in additional delays and wait times for people living with MS and other neurological conditions.

Investment of €4.5m into neurorehabilitation services as a first step in meeting the commitment in the Programme for Government to implement the National Neurorehabilitation Strategy

MS Ireland supports the Neurological Alliance of Ireland (NAI) in calling for investment into neurorehabilitation services. Neurorehabilitation services are essential for helping people with MS recover from relapses and to slow disease progression. Without access to vital neurorehabilitation services, people with MS face deterioration of their condition and loss of independence which, with the right supports, could be prevented or delayed. 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 (MS Ireland, 2015)¹⁰ Slowing disease progression could drastically improve the quality of life for those living with MS as well as resulting in substantial savings to society.

Inadequate access to neurorehabilitation can place an unnecessary additional burden on the health service as it significantly contributes to delayed discharge. Currently, there are less than half the numberS of neurorehabilitation inpatient beds in the country. Two thirds of our Community Health Organisations do not have a community neurorehabilitation team. This issue existed prior to the COVID-19 pandemic. Now, there is a backlog of these existing patients as well as new patients in need of these services.

In February 2019, the National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland was published.¹¹ This long-awaited three-year implementation plan, has so far received no investment. In 2018, the Neurorehabilitation Demonstrator Project in CHOs 6 & 7 was established. Disappointingly, progress on this project has been halted due to lack of funding to see its implementation.

MS Ireland supports the call of NAI for immediate additional funding to be made available to enable the implementation of the Neurorehabilitation Demonstrator

⁹ *Consensus Statement on Neurological Care Post Covid19 Lockdown (June 2020) Clinical Advisory Group of the National Clinical Programme in Neurology*

¹⁰ *MS Ireland Societal Cost of MS* <https://www.ms-society.ie/sites/default/files/2019-06/MS%20Ireland%20-%20Societal%20Cost%20of%20MS%20in%20Ireland%202015cc.pdf>

¹¹ <https://www.hse.ie/eng/services/list/4/disability/neurorehabilitation/national-strategy-policy-for-the-provision-of-neuro-rehabilitation-services-in-ireland.pdf>

Project in CHOs 6 & 7. This project was established in 2018 and progress halted due to funding issues. This project needs urgent investment in order to;

- provide urgently needed neurorehabilitation services in counties Dublin, Kildare and Wicklow
- support the discharge of patients from the major neuroscience centres in Dublin which are experiencing lengthy hospital stays and delayed discharges due to the lack of neurorehabilitation services in the region
- reduce demand on the National Rehabilitation Hospital which has seen waiting lists and times steadily increase to unacceptable levels

Investment to support Housing Adaptation

MS Ireland supports Care Alliance Ireland in calling for an increase in funding to the Housing Adaptation Grant. People living with MS can experience an abrupt change in levels of ability. Timely availability of funding to support them to make essential adaptations to their homes is vital. This will facilitate people with MS to remain living in their own homes rather than having to avail of nursing home care. This funding being made available in a timely manner has a positive economic impact as the funding required is often significantly smaller than the amount that would be required if an individual were forced to avail of residential care due to their housing being inadequate.

MS Ireland's 'My MS My Needs'¹² report (2017) 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 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.

Further Information

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:

¹² MS Ireland My MS My Needs Report https://www.ms-society.ie/sites/default/files/2019-06/My%20MS%20My%20Needs%202016_0.pdf

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 which currently operates from Monday to Friday 10am – 5pm.

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.

Advocacy

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