

Pre-Budget Submission 2022

Summary of key asks for budget 2022

- An increase of €600,000 in annual investment in the MS Care Centre
- Protection from funding cuts for Section 39 organisations
- Invest in Neurology Services
- Funding for neurorehabilitation teams in each Community Health Organisation in 2022
- Support for Carers through Carers Guarantee and refreshed National Carers Strategy

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 impact of the COVID-19 pandemic has continued to impact on people living with MS and those supporting them. While many services have resumed, people living with MS are still experiencing delays in accessing some services. The demand on many of these services including neurology services, neuro-rehabilitation and home care, pre-dates the COVID-19 pandemic and the issues have only been exasperated by the current pandemic. It is imperative that that these services be appropriately supported in order to address the needs of people living with MS.

MS Ireland is aware that the impact of the pandemic may continue to have an effect for considerable time to come. 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 developed, supported and 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.

MS Ireland calls on the Government to increase annual statutory investment in the MS Care Centre by €600,000¹

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.

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 a burden on them and their families. During the pandemic, family carers, including those who may not have performed caring duties prior to the pandemic, had to increase their caring responsibilities and duties, sometimes in addition to other familial and employment related obligations. As Ireland begins to emerge from the pandemic, it is essential that family carers are supported and that respite services such as the MS Care Centre are enabled to operate at their full potential. This will 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.

The Irish State is estimated €20 billion on an annual basis due to the 500,000 family carers that provide unpaid care each week to the elderly and those living with disability or illness². They play a vital role in the provision of informal care in Ireland. Despite their significant contribution to society, they are left feeling invisible and forgotten about (Family Carers Ireland, 2020). Caring can have an impact the life of the carers social and work life (O'Sullivan, 2019). 68% of carers feel their health has suffered as a result of caring (Family Carers Ireland, College of Psychiatrists of Ireland & University College Dublin, 2019)

The ability to secure respite care allow carers to take a break for self-care or to have their own medical needs addressed. Carers should be supported to prioritise their own care too and should never have to neglect themselves 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

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

²Family Carers Ireland State of Care 2020 <https://familycarers.ie/media/2022/family-carers-irela20.p nd-state-of-caring-20df>

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.

MS Ireland echo the Neurological Alliance of Ireland in calling on the Government to protect Section 39 organisations from any funding cuts in 2022 and for sustainability supports for the community and voluntary sector introduced during the COVID-19 pandemic to be sustained for as long as restrictions continue to impact on public fundraising³

Prior to the COVID-19 pandemic, MS Ireland along with a number of other Section 39 organisations were vocal on the unsustainable demand on our resources. Growing demand for our services coupled with rising insurance and regulatory costs threatened the sustainability of the services we provide. The COVID-19 pandemic has placed additional burden on Section 39 organisations. Our organization, 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. MS Ireland and fellow Section 39 organisations were calling for help prior to the pandemic. Throughout, we have been adaptable and dynamic in continuing to provide services to our community members despite unprecedented challenges. Our funding must be protected in order to enable us to continue providing vital services to our community members.

MS Ireland support the ask of the Neurological Alliance of Ireland and the National Clinical Programme for Neurology to;

- Tackle high outpatient waiting lists in neurology by funding a series of integrated pathways for neurology conditions
- Address the critical shortage of nurse specialists across neurology services
- Fund the development of a specialist service to respond to emerging need, including the needs of patients presenting with symptoms of long COVID

A recent report published by the Neurological Alliance of Ireland highlighted overstretched and underfunded neurology services in Ireland⁴. Years of

³Neurological Alliance of Ireland Pre-budget Submission https://www.nai.ie/assets/55/D65D5E77-4EBF-4A1A-81D546B0691D2E09_document/Pre_Budget_Submission_2022_FINAL.pdf

⁴Neurological Alliance of Ireland Key Findings from 2020 Survey on Neurology Services <https://www.nai.ie/assets/45/B24F59A3-51B6-452C->

underfunding have resulted in serious capacity issues and with growing numbers of neurology patients and additional people requiring support from neurology services due to long-COVID, it is imperative that support is provided. To comply with recommendations, the number of MS clinical nurse specialists in Ireland should be 30. Additionally we have far fewer consultant neurologists than international recommendations outline. The Association of British Neurologists recommends a ratio of one consultant neurologist per 70,000 population⁵. In Ireland, this ratio is greatly exceeded. MS Ireland's report 'Time to Act: A consensus on early treatment' outlines research-based evidence demonstrating the importance of access to early diagnosis, early treatment and regular monitoring of people living with MS⁶. Investment is required in order to provide the evidence-based internationally recommended standard of care that people living with MS in Ireland deserve.

MS Ireland supports the Neurological Alliance of Ireland (NAI) in calling for the funding of neurorehabilitation teams in each Community Health Organisation in 2022, including teams in CHO's 1, 2, 4, 5, 8 & 9 as well as addressing the shortfall in the funding of the teams in CHO's 6 & 7

Neurorehabilitation services are essential for helping people with MS recover from relapses and to slow disease progression. Without access to 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 a severe MS⁷. Slowing disease progression could drastically improve the quality of life for those living with MS as well as resulting in substantial savings to society. However, due to inadequate access to neurorehabilitation, this potential increase in quality of life for people living with MS and the potential saving to the state is jeopardised. It places unnecessary additional burden on the health service as it

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<https://www.theabn.org/media/docs/ABN%20publications/Local%20adult%20neurology%20services%20for%20the%20next%20decade.pdf>

⁶ <https://www.ms-society.ie/sites/default/files/2019-06/Time%20to%20Act%20-%20A%20consensus%20on%20early%20treatment.pdf>

⁷ 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>

significantly contributing to delayed discharge and lower quality of life for people living with MS.

A key commitment in the current Programme for Government is the implementation of the Neurorehabilitation Strategy which can "...significantly improve people's quality of life"⁸. This strategy is at risk of coming to an end in December without delivering on its commitments. The quality of lives of people living with MS is being jeopardised while this plan remains unimplemented.

MS Ireland support the pre-budget submission of the Disability Federation of Ireland which calls for a number of supports and considerations for people living with disability, including MS⁹

MS Ireland support pre-budget submission of the Disability Federation of Ireland which asks for;

- Increase core social protection rates as per the Vincentian Partnership for Social Justice Minimum Essential Standard of Living (MESL) recommendations i.e. by €9.80 per year, until 2026 to ensure income adequacy.
- Publish the Indecon Cost of Disability report and make financial provision in Budget 22 to implement its recommendations.
- Introduce a €20 per week cost of disability payment for those on Disability Allowance and Blind Pension as an interim measure (cost €161 million).
- Address issues of digital poverty which COVID has highlighted by reviewing and updating Household Benefits package and Telephone Support Allowance to include support for internet services, broadband and hardware such as laptops and tablets.
- Raise the €350 threshold on earnings disregard for Disability Allowance by €20 (cost €2m).
- Ensure all budget decisions are subject to equality proofing, specifically assessing their impact on disabled people, including taking into account the cost of disability.
- Ensure employment supports for disabled people are not deprioritised, make the Workplace Equipment Adaptation Grant more flexible, consider creating a 'Working from Home' grant, implement recommendations of other disability organisations.
- Work together with other Departments to invest €1.5 million in an Assistive Technology (AT) passport.

People living with disabilities, including MS who are in receipt of Disability Allowance have not had an increase in their weekly payment since 2019 despite an ever-

⁸ <https://www.gov.ie/en/publication/7e05d-programme-for-government-our-shared-future/>

⁹ https://www.disability-federation.ie/assets/files/pdf/dfi_prebudget_submission_to_dsp_for_budget_22_final.pdf

increasing cost of living. Disability is estimated to come at an additional cost of €207 per week on average. This means the current Disability Allowance fails to even meet the additional cost of disability. Social protection rates must be increased in order to allow those living with disabilities in receipt of social protection payments to have a good standard of living. Provision must be made to help people living with disability offset associated costs. Disability related poverty must be addressed as a matter of urgency.

Support for those living with disabilities to engage in employment should be provided. Flexibility with the Workplace Equipment Adaptation Grant is required as well as a 'Working from Home' grant. MS Ireland conducted a survey in relation to employment and MS during the COVID-19 pandemic. The feedback from our community was positive in terms of their ability to self-manage certain debilitating symptoms such as fatigue, by working from home. Supporting people to enter and remain in the work force has benefits for the person, the employer and the State.

MS Ireland support the pre-budget submission of Family Carers Ireland which calls for a number of supports for family carers in Ireland, including those caring for people living with MS

Family carers play a vital role in the provision of informal care in Ireland. It is estimated that they save the State approximately 20 billion annually¹⁰. Despite their significant contribution, carers report lower health outcomes and many are experiencing financial hardship¹¹.

Family carers are essential in care provision but the structures and mechanisms currently in place to support carers are inadequate and unsustainable. Carers need meaningful recognition and support. MS Ireland support the asks of Family Carers Ireland pre-budget submission including;

- €5 million in annual funding to deliver the Carers Guarantee
- Increases in weekly carer payments, the Carers Support Grant and the Carers Allowance income disregards
- Annual funding towards a dedicated Carers pension for long-term family carers
- €5 million to publish an updated version of the National Carers Strategy 2021 – 2025
- The introduction of the Statutory Homecare Scheme including a Carer Needs Assessment for fulltime carers and an annual entitlement to 20 days respite

Further Information

¹⁰ <https://familycarers.ie/media/1967/family-carers-ireland-fci-budget-submission-14pp-a4.pdf>

¹¹ <https://familycarers.ie/media/2022/family-carers-ireland-state-of-caring-2020.pdf>

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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 which currently operates 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.

Advocacy

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