



**Your Vote Matters: A Guide for People
Affected by MS and Election Candidates
on Issues Facing the MS Community**

Contents:

Disability Payments	6
Household Benefits	7
Medical Cards and GP Visit Cards	7
Carers	7
Employment	7
Transport	8
Housing and Adaptations	9
Neurology Services	9
Neurorehabilitation	9
Primary Care Services	10
MS Registries	10

Your Vote Matters: A Guide for People Affected by MS and Election Candidates on Issues Facing the MS Community

Over 10,000 people in Ireland live with Multiple Sclerosis. It is critical to manage MS with the support and help from our health system, political leaders, and local representatives.

This guide aims to bridge the gap between those affected by MS and the candidates seeking your vote. It fosters informed decision-making, encourages open dialogue, and elevates the voices of the MS community.

We have provided a toolkit of questions based on the contents of this guide to ask potential representatives. These questions ensure that candidates not only comprehend the challenges faced by individuals with MS but also commit to tangible solutions and policy changes.

This guide is not just for the MS community, but for candidates too.

Candidates should be able to answer each of these vital questions reflecting the concerns and aspirations of the MS community. From healthcare accessibility to inclusive education and employment opportunities, these questions guide candidates in understanding and addressing the pressing issues faced by those with MS.



As we embark on this journey together, “Your Vote Matters” strives to empower voters and candidates alike, fostering a relationship built on understanding, empathy, and, above all, progress. Let’s work towards a more inclusive and supportive future for everyone affected by MS.

For any queries regarding elections or the voting process, scan the QR code to view our elections and voting guide.

Dear Candidate,

As a person affected by MS, I am keen to understand your commitment to addressing the critical issues faced by our community.

Disability Payments:

How will you ensure disability payments are increased in line with the cost of living and the specific costs associated with MS?

Household Benefits Package:

What measures will you take to increase the Household Benefits Package to support those with MS?

Medical Cards:

How will you make the application process for medical cards more inclusive of the additional costs of living with MS?

Primary Care Services:

What are your plans to improve access to occupational therapy, speech and language therapy, and mental health support for people with MS?

Carer's Allowance:

Do you support reviewing the Carer's Allowance/Grant, including abolishing the means-test and increasing the payment in line with inflation?

Employment Opportunities:

What policies will you implement to improve employment opportunities for people with MS, including remote work options and vocational rehabilitation?

Transport Support:

Will you support the implementation of a new Transport Support Scheme to replace the Mobility Allowance and Motorised Transport grants?

Tax Relief Scheme:

How will you assess and potentially broaden the eligibility criteria for the Drivers and Passengers with Disabilities - Tax Relief Scheme?

Primary Medical Certificate:

Will you work to expand the eligibility criteria for the Primary Medical Certificate to take account of non-linear conditions such as MS?

Housing Strategy:

How will you ensure the delivery of the National Housing Strategy for Disabled People 2022-2027, including increased funding for home adaptations?

Neurology Services:

What steps will you take to address the shortage of neurologists and ensure timely access to neurology services such as an MS nurse specialist for people with MS?

Neurorehabilitation Strategy:

How will you support the full implementation of the National Neurorehabilitation Strategy?

MS Registry Funding:

Will you advocate for funding to develop a comprehensive MS registry in Ireland to enhance our understanding and care strategies for MS?

My Issues:

Please use this space to highlight any additional issues you may have at a local or national level.

Disability Payments:

ASK:

Increase disability payments in line with the cost of living and the cost of disability, taking into account direct, indirect and intangible costs of living with MS.

The cost of disability can be measured by the day-to-day expenses that people with a disability incur, which others do not (the 'direct costs' approach), or by the additional income needed for a household with a person with a disability to achieve the same standard of living as a comparable household without a person with a disability (the 'equivalence' approach).

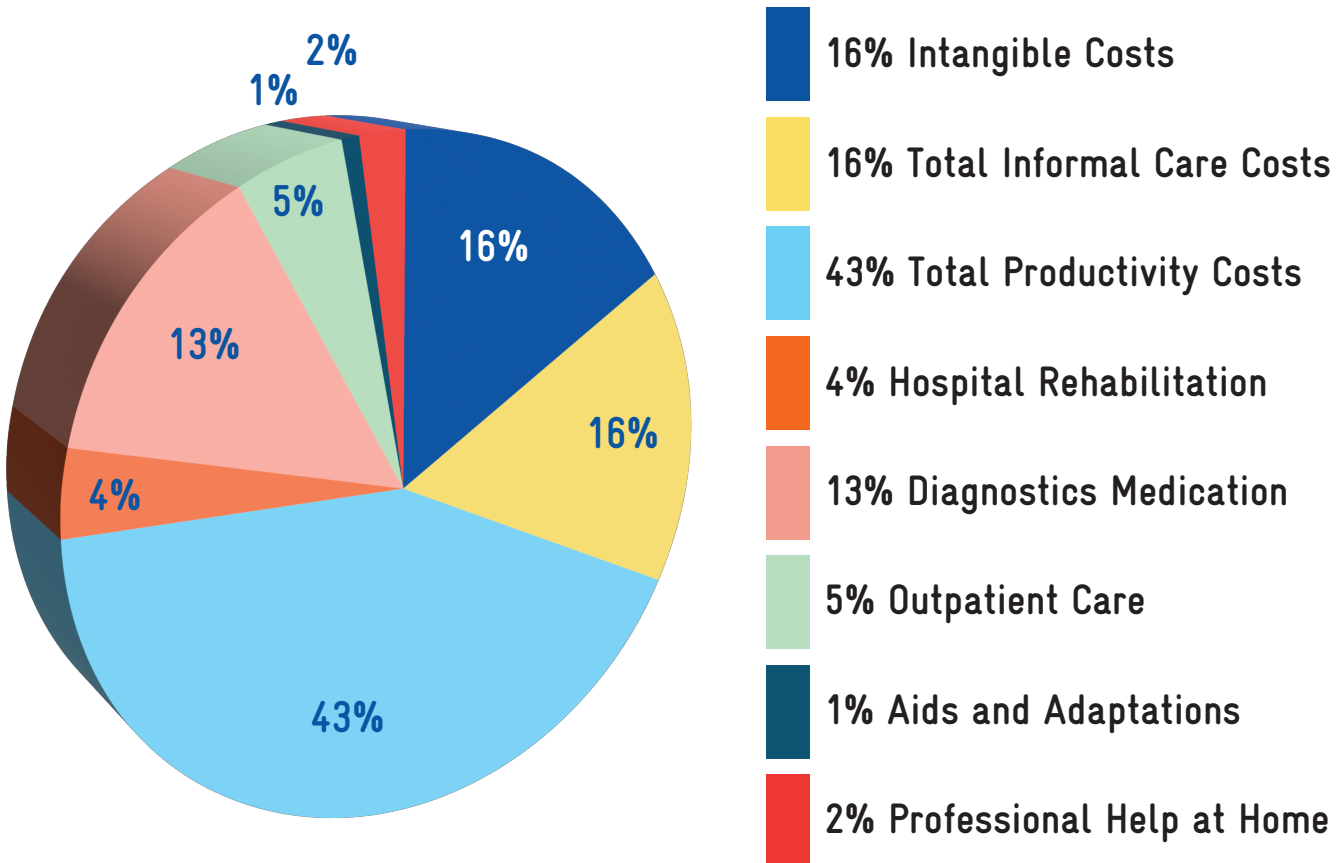
The average cost of living with a disability in Ireland ranges from €9,482 to €11,734 per annum, or €182 to €225 per week (Indecon 2024). While some of these costs are covered by

the State, many are borne directly by the person with the disability or their household. These additional costs cover areas such as:

- Equipment, aids, and appliances
- Mobility, transport, and communications
- Medicines
- Care and assistance services
- Additional living expenses

MS Ireland's 2022 research (Societal Cost of MS 2022) highlighted the total societal costs associated with life with MS. Total societal costs of MS amounted to €483.33 million per annum, equating to €53,704 per person with MS, a 12% increase from the 2015 estimate of €429.15 million. Direct costs constitute 25% of total costs at €13,407 per person per year. Indirect costs represent 59% of total costs at €31,992 per person per year. Intangible costs, calculated from quality adjusted life year losses, represent 16% of the total societal costs at €8,304 per person with MS.

Total Annual Societal Costs: €483.33 million



Household Benefits:

ASK:

Increase the Household Benefits Package in line with the cost of living.

In 2023, 20% of people with MS reported struggling on their current income. Substantial increases are needed in the electricity and gas allowances included in the Household Benefits Package for those with disabilities due to rising energy prices. Many people with disabilities who receive the Household Benefits Package are not eligible for the means-tested Fuel Allowance and bear higher energy expenses directly.

Medical Cards and GP Visit Cards

ASK:

Ensure that means-testing of medical cards takes into account additional costs of living with MS.

Ensure that people both in and out of employment are enabled to avail of this.

Urgent increases are needed in the availability of medical cards and GP visit cards, where the application processes account for the additional financial costs of living with MS. The medical card acts as a gatekeeper to essential community-based services, which many people with MS cannot access without it.

Data from the 'Societal Costs of MS in Ireland 2022' report shows high use of medical services among people with MS, with significant associated costs.

In a 2023 survey:

- 71% deemed access to GP services essential for remaining well.
- 63% thought access to medicines under the medical card was essential.
- 64% believed the medical card was critical for accessing therapy services.
- 68% said the medical card was essential for accessing specialist equipment.
- 70% noted the medical card was crucial for sourcing affordable respite.

Despite this, only 43% held a medical card, and 18% had a GP visit card. Many did not apply due to ineligibility or previous unsuccessful applications. Most respondents felt the medical card was vital for meeting MS-related costs, but the application process only considers a narrow range of expenses.

At present, if you have a medical card and you take up employment or go onto a back-to-work scheme you may retain the medical card (for yourself and your dependents) for three years after your change of circumstances. The person does not cease to need the medical card after a certain period as MS is a lifelong condition.

Carers:

ASK:

Urgent review of Carer's Allowance/Grant, including the abolition of the means-test and an increase in Carer's Allowance payment in line with inflation.

A recent survey found that 52% of PwMS had a friend or family member providing care and support, with 35% requiring care for more than 31 hours a week, and 8% requiring full-time care.

Many family members of those living with MS may incur a huge personal and financial cost of caring for a loved one.

Employment:

ASK:

Implement policies to improve employment opportunities, both from a recruitment and retention perspective for the MS community.

MS is most often diagnosed between the ages 20 and 40, a critical phase for career development. A 2022 survey found that 28% of PwMS were unemployed, with many reporting a lack of reasonable accommodations from employers. Remote work can help some cope with challenges such as fatigue.

A significant association was also established in a 2021 MS Ireland study between disability severity and employment status; those with mild MS are more than three times as likely as those with moderate disability to be in paid employment.

People with moderate MS are more likely to withdraw from the workforce due to MS compared to the mild MS subgroup (41% versus 9%).

Reduced benefits when moving from Invalidity Pension to Partial Capacity Benefit are also a factor which often means people do not benefit financially from taking up part-time employment. In addition, there is no automatic pathway back to Invalidity Pension if an employment opportunity is found to be unsuitable.

Lack of timely and appropriate access to vocational rehabilitation is also a barrier to people living with MS gaining and retaining employment.



Transport:

ASK:

- **Implement the proposed 'Transport Support Scheme' to replace the Mobility Allowance and Motorised Transport grants.**
- **Assess the eligibility criteria for The Drivers and Passengers with Disabilities - Tax Relief Scheme.**
- **Expand the eligibility criteria for the Primary Medical Certificate to take account of non-linear conditions such as MS.**

Many people with disabilities depend on cars for medical appointments, work, and social outlets, with limited support for maintaining and running a car. In a recent MS Ireland survey, the majority (72%) of respondents used an unadapted private car or van as their regular mode of transport, with

another 14% using a private, adapted car. At present, The Drivers and Passengers with Disabilities - Tax Relief Scheme is the only support scheme available to disabled drivers but its eligibility is restrictive. As a result, many people with debilitating neurological conditions which severely affect their mobility are excluded from the scheme. For those who do qualify, the cost of purchasing a new or almost new car, even with VAT and VRT rebates, makes it largely unaffordable.

To qualify for tax relief under the scheme, you must have a valid Primary Medical Certificate. Currently, the PMC is issued to individuals who are severely and permanently disabled, meeting strict criteria such as being almost completely without the use of both legs, both hands, or having restricted growth syndrome with serious difficulties in leg movement. However, this restrictive framework excludes many people with conditions like Multiple Sclerosis (MS), where symptoms can vary in duration and severity. By broadening the eligibility requirements, we can ensure that those with fluctuating conditions such as MS receive the necessary support to manage their health and maintain their quality of life.

The Motorised Transport Grant was a means-tested HSE payment for people with disabilities who needed to buy a car in order to retain employment. Consideration was also given to people who were unemployed but could take up available work if that person had a car.

In exceptional circumstances a person with severe disabilities living in isolated locations and who could not use public transport would also have been considered for this grant. This was discontinued in 2011 and 2012 and no further applications were accepted, including from applicants who may have received a grant in the past. It was intended that an alternative scheme would be devised to replace it.

Considering the need of some persons with disabilities to use private transport, the closure of both the Mobility Allowance and the Motorised Transport Grant can significantly impact the ability of persons with disabilities to participate in daily life. Particularly for those who are unable to undertake the first mile/last mile or other elements of their journeys using public transport and active travel. This may preclude them from accessing education and employment as well as from participating in their communities, socialising, and accessing healthcare.

Housing and Adaptations:

ASK:

Deliver on the National Housing Strategy for Disabled People 2022-2027.

Some people with MS need home adaptations or must find accessible housing suitable for their needs. Those unable to afford their own home face long waits for accessible social or affordable housing and struggle to find suitable rental accommodations.

Urgent funding is needed to overhaul the Housing Adaptation Grant for People with a Disability. The current low household income means-test should be increased to reflect building costs and to assist people where the household income exceeds the criteria.



Neurology Services:

ASK:

Address the lengthy waiting times for neurology appointments, regional inequity and lack of access to an MS nurse specialist for people with MS.

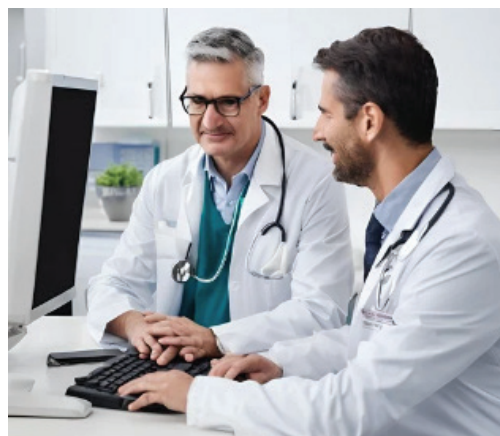
MS Ireland is aware of serious deficiencies in the current provision of neurological services. Waiting lists for a first time appointment to see a Consultant Neurologist now stand at over 21,000. Data from the My MS My Needs study (2023) showed that 7% of respondents waited more than 12 months for their last appointment.

Regional inequity in access to a Consultant Neurologist is also a very significant issue with MS patients travelling long distances because of the lack of neurology services across many regional hospitals. One in ten respondents to the 2023 survey reported having to spend 2-3

hours travelling one way to see their Consultant Neurologist with some spending considerably longer.

Access to MRI scans is also a significant issue for MS patients: while 68% had an MRI scan in the last 12 months, 6% had waited more than a year for an MRI.

The same survey showed that almost one fifth of MS patients (19%) were unable to access an MS nurse specialist, despite needing to. This reflects the overall critical shortage of clinical nurse specialists across neurology services consistently highlighted by the Neurological Alliance of Ireland.



Neurorehabilitation:

ASK:

Implementation of the National Neurorehabilitation Strategy as a key commitment of both the current Programme for Government and the Slaintecare Action Plan.

A three year implementation framework for the National Neurorehabilitation Strategy (2019-2021) was published in 2019 which committed to:

- the establishment of nine community neurorehabilitation teams, one in each CHO (community health organisation) area to provide specialist rehabilitation up to a maximum of 12 weeks.
- a range of specialist community-based services to meet ongoing and long-term neurorehabilitative needs.
- provision of post acute specialist inpatient rehabilitation beds to meet the requirements of the Irish population. The Model of Care for Rehabilitation Medicine outlines a model for the delivery of Consultant Led specialist rehabilitation services through six managed clinical networks across Ireland.

Providing long term specialist neurorehabilitation services in the community represents a key part of the National Neurorehabilitation Strategy and we need to see the proper investment year on year in developing community neurorehabilitation services in line with the Strategy.

This includes services such as MS Ireland's campaign for sustainable funding for a national physiotherapy service for people with Multiple Sclerosis, and other neurological conditions. Services such as this are shown to be incredibly effective in reducing symptom severity, disability, falls and healthcare utilisation with clinical evidence showing a 43% reduction in the latter due to this service (Active Neuro Final Report 2021).

Full implementation of the National Neurorehabilitation Strategy and Model of Care for Specialist Rehabilitation services is required in order for Ireland to meet its commitments under Article 26 of the UNCRPD to provide "comprehensive rehabilitation services" for people with a neurodisability including MS.

Primary Care Services:

ASK:

Improve access to primary care services such as,

1. **Mood and emotional support**
2. **Physiotherapy**
3. **Occupational therapy**
4. **Speech and language therapy**



1. This survey also found that 31% of people with MS surveyed reported a need for psychological support, with higher needs in certain regions. Support is often received from a range of sources, with many citing cost, travel time, and waiting lists as barriers to accessing support.
2. 24% of people with MS expressed an unmet need for physiotherapy. There is limited access to this service through primary care or the disability sector and people with MS are often low priority on waitlists. Even when treatment is available, the typical 6-week duration falls short of the 10-12 weeks recommended for meaningful improvement.
3. 17% of the MS community indicated a need for occupational therapy in a recent MS Ireland survey, with many noting that they had not been offered this.
4. About twice as many people living with MS in a recent survey reported needing speech and language therapy than those who had received it.

MS Registries:

ASK:

Make funding available for the development of a registry for MS.

The absence of comprehensive MS registries in Ireland hinders our understanding of the disease and the formulation of effective care strategies.

This lack of a strategic framework for patient registries affects our ability to attract clinical trials, obtain accurate data on disease prevalence and trends, and ensure effective long-term monitoring of medication safety and efficacy.

Addressing these challenges requires proactive measures, including funding for feasibility studies and promoting nationwide Electronic Health Records and Individual Health Identifiers.

MS Ireland echoes the General Election asks of the Neurological Alliance of Ireland, the Disability Federation of Ireland, and the Home Care Coalition, particularly with regards to Ireland fulfilling its obligations under the UNCRPD



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