

Evolving approaches to measuring and managing disability in people with multiple sclerosis in Spain

Multiple sclerosis (MS) is a chronic neurological condition that causes progressive physical, cognitive and sensory disability, often resulting in decreased longevity (especially with later diagnosis) for individuals and considerable health and economic burden for countries. In Spain, around 61,750 people live with MS—approximately one in every 800 individuals.¹ The disease most often affects adults of working age, with the average age of diagnosis being just 32, magnifying its impact on employment, independence and overall quality of life.²


As the world's leading cause of progressive neurological disability among working-age adults, MS carries extensive social and financial consequences. Disease progression is closely linked to rising costs, driven not only by the increased need for informal care, but also by indirect costs such as job loss and reduced productivity. For many individuals living with MS, the ability to remain in the workforce diminishes over time, further compounding the economic impact on families and society.³



Despite its rising prevalence and profound effects on daily life, critical gaps persist in how disability related to MS is recognised and managed.

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Critical gaps in national MS policies hinder comprehensive disease management

National policies, guidelines, and registries play a vital role in managing chronic and neurological diseases like MS because they significantly influence patient care, research priorities, and public health. However, these are lacking in many European countries. While Spain is ahead of many countries in having a national policy for neurological disease management, it does not yet have a national policy for chronic disease management. Spain also lacks a comprehensive, government-owned or government-supported registry for MS, making it challenging to determine the precise number of people living with the disease. Nevertheless, subnational initiatives are currently underway to address this gap.⁴



	 National policy for neurological disease management	 National policy for chronic disease management	National registry for MS	Treatment guidelines for MS
Spain	✓	✗	✗	✓
France	✓	✗	✓	✓
Germany	✗	✗	✓	✓
Italy	✗	✓	✓	✓
Sweden	✓	✗	✓	✓
United Kingdom	✗	✗	✓	✓
United States	✗	✗	✗	✓

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To better understand views and experiences with measuring and managing MS-related disability in real-world clinical environments, we conducted a survey with 100 MS specialists and neurologists in Spain. To further capture the economic impact of MS-associated disability (including both direct and indirect costs), we also conducted a quantitative analysis. This infographic summarises the results for Spain.

“The list of symptoms is quite wide. It includes so many things that people with MS don’t think about. When you’re newly affected...you don’t necessarily relate one symptom to the condition, and that makes it even more tricky to understand and to make sure we address all the needs of the people.”

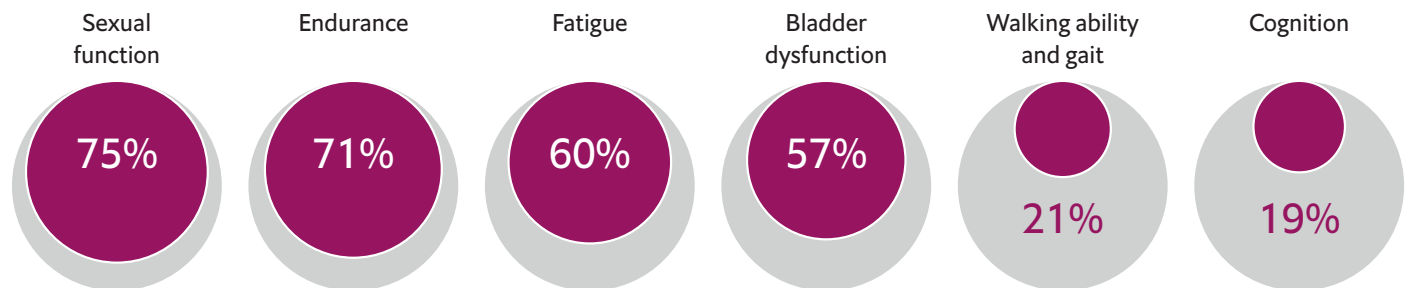
Lydia Makaroff, Chief Executive Officer, Multiple Sclerosis International Federation

Approximately 80% of people with MS experience fatigue, but our survey found that less than 50% of neurologists in Spain routinely assess it

MS is a condition characterised by a broad range of symptoms, which vary widely from person to person. Our survey found that neurologists most often assess symptoms affecting mobility and cognitive health, such as walking ability, balance, and cognition. Meanwhile, bladder dysfunction, fatigue, endurance and sexual function are reviewed less routinely, despite their significant impact on quality of life.

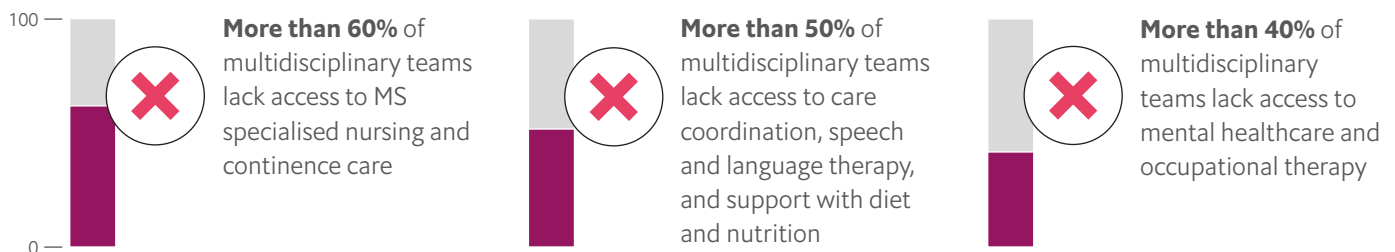


Percentage of neurologists that do not routinely assess the following symptoms of MS:



Significant gaps exist in multidisciplinary support for people with MS

Our survey found that:



There is no universally adopted standard for assessing disability in MS




Our survey found that even the most common clinician-led assessment, the Expanded Disability Status Scale (**EDSS**), is used by only 63% of clinicians, and nine other assessments are in use in the country, used by 15-40% of clinicians. Many clinician-led assessments are also time-consuming to administer, making them impractical for regular clinical practice.

For patient-reported outcome measures (PROMs), the most widely used in Spain is the Multiple Sclerosis Impact Scale (**MSIS-29**), used by 71% of neurologists, though six other PROMs are also regularly used.

Most neurologists in Spain (77%) report that a more comprehensive approach is needed to measure MS-associated disability

Neurologists in Spain want better and simpler tools.

Our survey found that many barriers exist to assessing disability in people with MS:

-  **53%** report a **lack of staff/resources** to support comprehensive assessments
-  **51%** report **difficulty integrating measures into workflows** or electronic health records
-  **48%** report **insufficient time during appointments** to administer standardised measures of disability

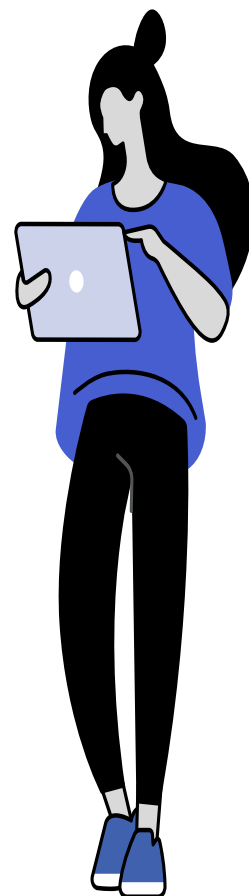
When asked what would most improve assessment of disability in people with MS, respondents identified the following actions as the most promising:

- 1** **Developing better patient self-monitoring** and reporting options for disability
- 2** **Improving options for remote assessment** of disability (eg, telemedicine)
- 3** **Developing automated templates** to input data that estimate disability scores, which can then be linked to electronic health records
- 4** **Augmenting the EDSS scale with supplementary assessments** (eg, related to cognitive function and upper limb function) to provide a more holistic assessment



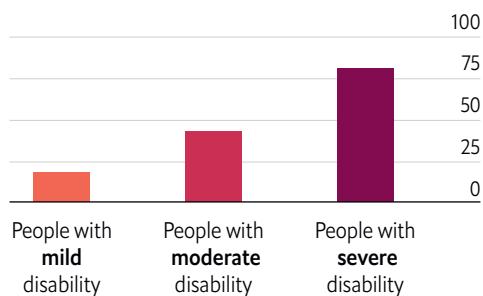
“Disability assessment now is very time-consuming in our clinics, and it is increasingly more difficult to do all the tests in the same visit for a patient.”

José Manuel García-Domínguez,
Neurologist, Hospital General Universitario Gregorio Marañón

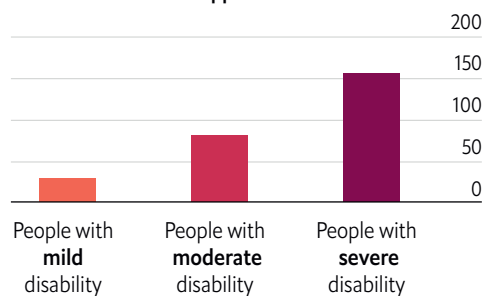


Over 80% of people with MS with severe disabilities are unable to work. Those who do work, take an average of 157 days of leave per year.

% of people with MS who are currently unemployed due to MS



Number of days per year that people with MS take as leave of absence from work due to MS-associated sick leave or medical appointments



Mild disability: EDSS 0-3.5; moderate disability: EDSS 4-6.5; severe disability: EDSS 7-9.5

As MS progresses, the financial burden faced by patients and their caregivers increases substantially

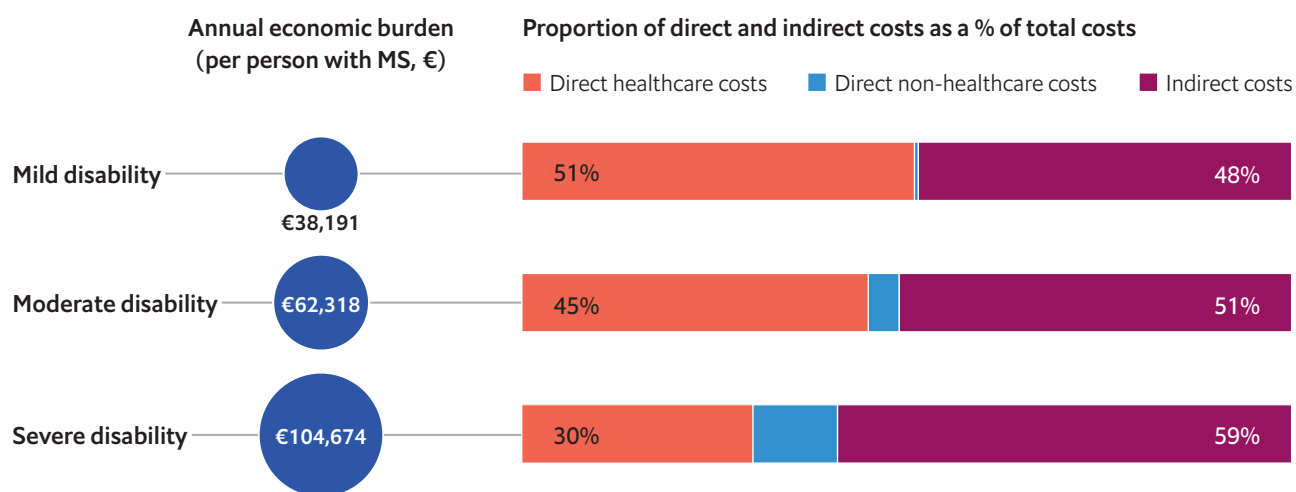


Our economic model found that as MS advances, costs incurred by people with MS, particularly direct non-healthcare and indirect costs, dramatically go up.

Direct healthcare costs come from medicines, consultations and inpatient care, while direct non-healthcare costs include home and vehicle adaptations, transportation costs, and out-of-pocket expenses for paid assistance.

As disability increases, the largest cost to people with MS comes from indirect costs, such as absenteeism, loss of employment and early retirement, as well as the costs of informal caregiving. For people with severe disability, the total cost per year is over **€104,673**, more than double the annual cost of someone with mild disability.

Our model estimates the annual economic burden of MS in Spain to be over **€2.5 billion**.



Where to go from here?

Address gaps in symptom assessment: symptoms such as fatigue, bladder dysfunction and changes in sexual function are common in MS but are often not assessed by neurologists in Spain. A more comprehensive assessment of all symptoms affecting quality of life should be routinely done, and neurologists should ask about these symptoms and their impacts more regularly to ensure that patients receive timely support or treatment adjustments.

Modernise disability assessment: neurologists in Spain reported that disability assessment tools need to be simplified, and that a more comprehensive approach is needed to measure disability. More holistic approaches and assessments of disability would not only improve care for individual patients, but also support better policymaking and optimise resource allocation within the health system.

Leverage digital and remote monitoring tools: barriers to measuring disability in Spain include lack of staff and limited time and resources available to clinicians. Wider use of digital solutions—such as tele-assessments, wearables and smartphone apps—would enable more consistent and holistic patient follow-up, while reducing travel demands for patients and easing workloads for healthcare professionals. Self-monitoring between clinic visits could also support earlier identification of symptom progression, timely adjustments to therapy, and greater patient empowerment.

Support patients' ability to work: MS disproportionately affects people of working age, and many patients in Spain face loss of income, financial insecurity and reduced independence, while society absorbs the cost of lost productivity and increased reliance on social support systems. To mitigate this, there is a need for more inclusive workplace policies, rehabilitation services, and flexible employment options to protect the productivity and independence of people living with MS.

MS imposes a substantial health, economic and social burden on individuals during their most productive years, with costs and disability levels escalating dramatically as disease severity progresses.

The progression of MS amplifies the challenges of daily living, and generates significant indirect costs from informal caregiving demands and lost productivity during prime working years. This burden underscores the critical importance of comprehensive, patient-centred care strategies.

Early intervention and enhanced multidisciplinary care approaches represent strategic investments that can slow disease progression, reduce disability accumulation, and ultimately improve clinical and economic outcomes for people living with MS. Investing in holistic care models, symptom monitoring, and modernised assessment tools is essential to reduce the overall impact of MS and support patient well-being.



A description of the methodology and sources for all insights in this infographic can be found in the white paper available via <https://impact.economist.com/health/measuring-what-matters>.

References:

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