

# Evolving approaches to measuring and managing disability in people with multiple sclerosis in the United States



**Multiple sclerosis (MS)** is a chronic neurological condition that significantly impacts the lives of **nearly 1 million adults** in the United States, typically emerging between ages 20 and 40.<sup>1,2</sup> MS may involve periods of sudden relapses or a gradual increase in disability and symptoms over time without relapses.

As the **leading cause of progressive neurological disability among working-age adults**, MS presents a substantial health and financial challenge—about 30% of patients rely on Social Security Disability Insurance for support.<sup>3</sup>

The costs of MS are significant, driven largely by medications and inpatient care as well as indirect losses in productivity.<sup>3</sup> Despite its rising prevalence and profound effects on daily life, **critical gaps persist in how disability related to MS is recognized and managed.**

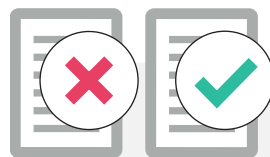
Supported by **sanofi**

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To better understand views and experiences with measuring and managing disability in real-world clinical environments, we conducted a survey with 250 MS specialists and neurologists in the United States. To further capture the economic impact of MS-associated disability (including both direct and indirect impacts), we also conducted a quantitative analysis. This infographic summarizes the results for the United States.

## Critical gaps in national MS policies and registries 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, and public health; however, many countries still lack these essential frameworks.<sup>4</sup>

Due to its fragmented healthcare system, the United States lacks a comprehensive government-owned or supported registry for MS, making it difficult to know the exact number of people living with MS. However, subnational efforts are currently underway to address this gap.

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

Source for table data: MS Barometer 2020

## There is a large spectrum of MS symptoms, but many, such as sexual function and bowel dysfunction, are not regularly assessed

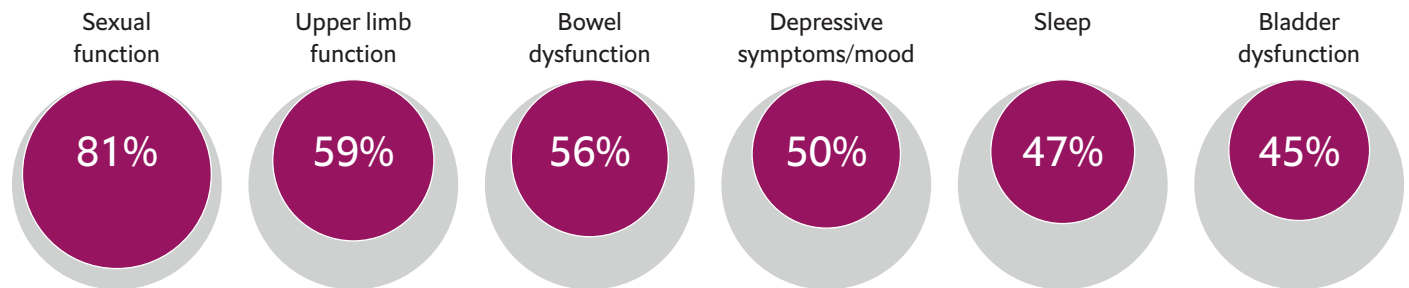
MS is a condition that can lead to a broad range of symptoms, which vary widely from person to person. Our survey found that neurologists most often assess symptoms affecting mobility, safety, and cognitive health, such as walking ability, balance, and cognition. Meanwhile, sexual function and swallowing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



**“When you meet one person with MS, you meet one person with MS. Everyone’s progression, everyone’s symptoms are different, and so that is one thing that makes it difficult to treat.”**

Anita Williams, Person Living with MS

### Percentage of neurologists that **don't** routinely assess the following symptoms of MS:



Despite 80% of people with MS in the United States experiencing fatigue, a significant gap remains in assessing this. Only 68% of MS care teams are actively inquiring about this debilitating symptom, highlighting a critical disconnect between patient experience and clinical attention.

### Multidisciplinary care teams often lack essential specialties, resulting in the diverse and complex needs of patients with MS remaining unaddressed

Our survey found that:

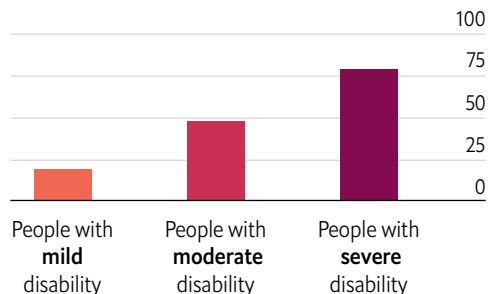


**“I feel like there needs to be a holistic approach to MS care, and that doesn't seem to exist at all. I think when you are initially diagnosed, you should be connected with a dietician and a therapist and that lifestyle medicine and mental health should be integrated into your entire healthcare journey with MS.”**

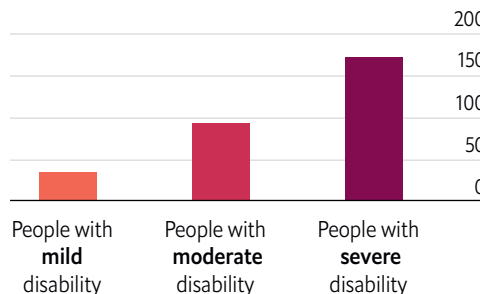
Kate Durack, Person Living with MS & MSIN Director of Communication and Patient Focus, Multiple Sclerosis Association of America

**Over three-quarters of people with MS with severe disabilities are unable to work. Those who do work, take on average of 172 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



## There is no universally adopted standard for assessing disability in MS

Our survey found that even the most common clinician-led assessments, such as the Expanded Disability Status Scale (EDSS) and the Multiple Sclerosis Performance Test (MSPT), are only used by  $\approx 40\%$  of clinicians. They are also time-consuming to administer, making them impractical for regular clinical practice.

For patient-reported outcome measures (PROMs), the most used are the Multiple Sclerosis Impact Scale (MSIS-29) and the MS Quality of Life-54 item instrument (MSQoL-54), used by just 55-60% of neurologists.



**“I think our system in the United States is still based on treating sick people rather than keeping people as well or healthy as possible. So that’s a huge barrier.”**

Bari Talente, Executive Vice President, Advocacy & Healthcare Access, National MS Society

## Most neurologists in the United States (74%) report that a more comprehensive approach is needed to measure MS-associated disability

### Neurologists in the United States want better and simpler tools.

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



**64%** report **insufficient time during appointments** to administer standardized measures of disability



**55%** report a **lack of staff/resources** to support comprehensive assessments



**49%** report concerns about existing measures’ **ability to detect disability progression**

When asked what would most improve assessment of disability in people with MS, respondents thought the following were the most promising:

- 1 Augmenting the EDSS scale with supplementary assessments** (eg, related to cognitive function and upper limb function) to provide a more holistic assessment
- 2 Simplifying disability assessment tools** so that they can be completed easily by a clinician in a short period of time
- 3 Developing automated templates** to input data that estimate disability scores, which can then be linked to electronic medical records

# The economic burden on patients, health systems, carers and society increases as disability worsens

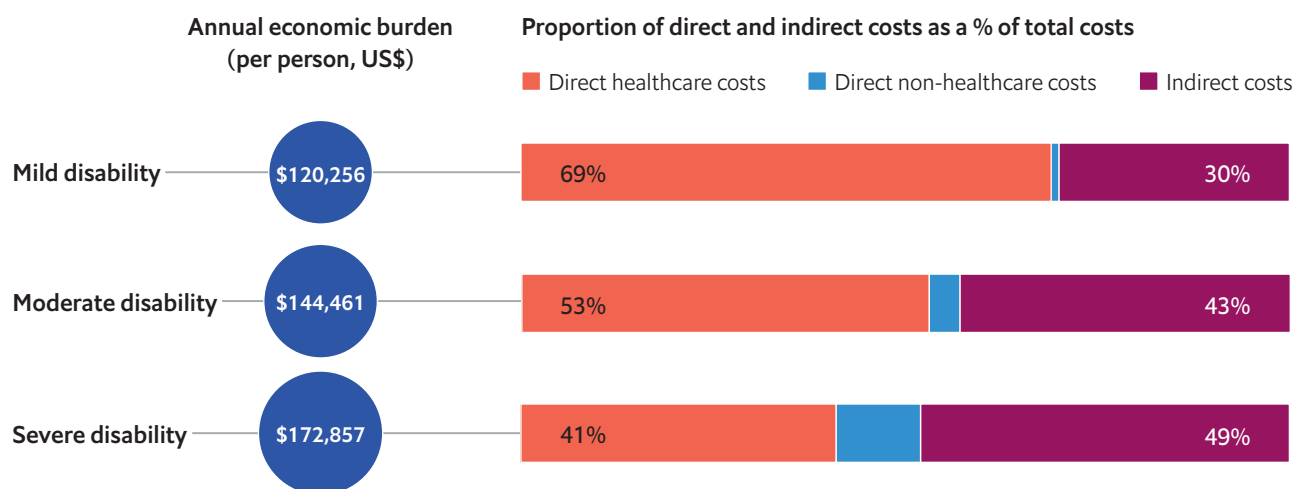


Our economic model found that all costs go up as MS advances and people face more disabilities.






Direct healthcare costs include medicines, consultations, and inpatient admission expenses, while the smaller cost category of direct non-healthcare costs includes home and vehicle adaptations, transportation costs, as well as out-of-pocket expenses for paid assistance.

As disability increases, the most significant costs to people with MS are indirect costs, such as absenteeism, loss of employment, and early retirement, as well as the indirect costs of informal caregiving. For people with severe disability, the cost per year is over US\$172,000, almost 50% higher the annual costs for people with mild disability.

## Our model estimates the annual economic burden of MS in the US is over US\$57 billion.



## Where to from here?

-  **Build a national MS disability registry:** the United States lacks a comprehensive national registry for disability data. Creating a federal MS registry that links existing datasets would help provide stronger data for research, lead to greater accountability in care quality, and enable the tracking of disability trends and informed policy responses.
-  **Address gaps in multidisciplinary care:** access to many key services is uneven, despite the proven effectiveness of multidisciplinary care in managing MS symptoms. To better manage disability and simplify care coordination for patients, team-based care should be expanded, with services such as mental health and continence care co-located or virtually integrated into MS clinics to reduce fragmentation.
-  **Modernize disability assessment:** neurologists in the United States reported that disability assessment tools need to be simplified, and that a more comprehensive approach is needed to measure disability. More holistic approaches to, and assessments of, disability would support better policymaking and optimize resource allocation within the health system.
-  **Expand PROMs and symptom tracking:** fatigue, pain, and mood disorders are often rated among the most debilitating by people with MS but are not routinely assessed. Standardizing a national set of PROMs for MS (fatigue, cognition, mood, bladder etc.) would help neurologists ensure that they are not missing the more 'invisible' symptoms when assessing their patients.
-  **Improve monitoring and personalize care:** advanced tools like multimodal imaging, digital assessments, and biomarkers detect progression without relapses, enabling early risk identification. Stratifying patients by clinical, radiological, and biological data tailors treatments to disability risk, not just relapses. Personalizing care may help prevent irreversible progression and improve outcomes.

**MS places a substantial economic, health, and social burden on individuals in the prime of their life, with costs and disabilities escalating dramatically as disease severity increases.** The progression of MS amplifies the challenges of daily living, as well as the indirect costs from informal caregiving and lost productivity in prime working years, underscoring the critical importance of comprehensive, patient-centered care. Early intervention and improved multidisciplinary approaches could help slow disease progression, lower disability, and ultimately enhance outcomes for people living with MS. Investing in holistic care, symptom tracking, and modernized assessment tools is essential to reduce overall impact and support patient well-being.

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