

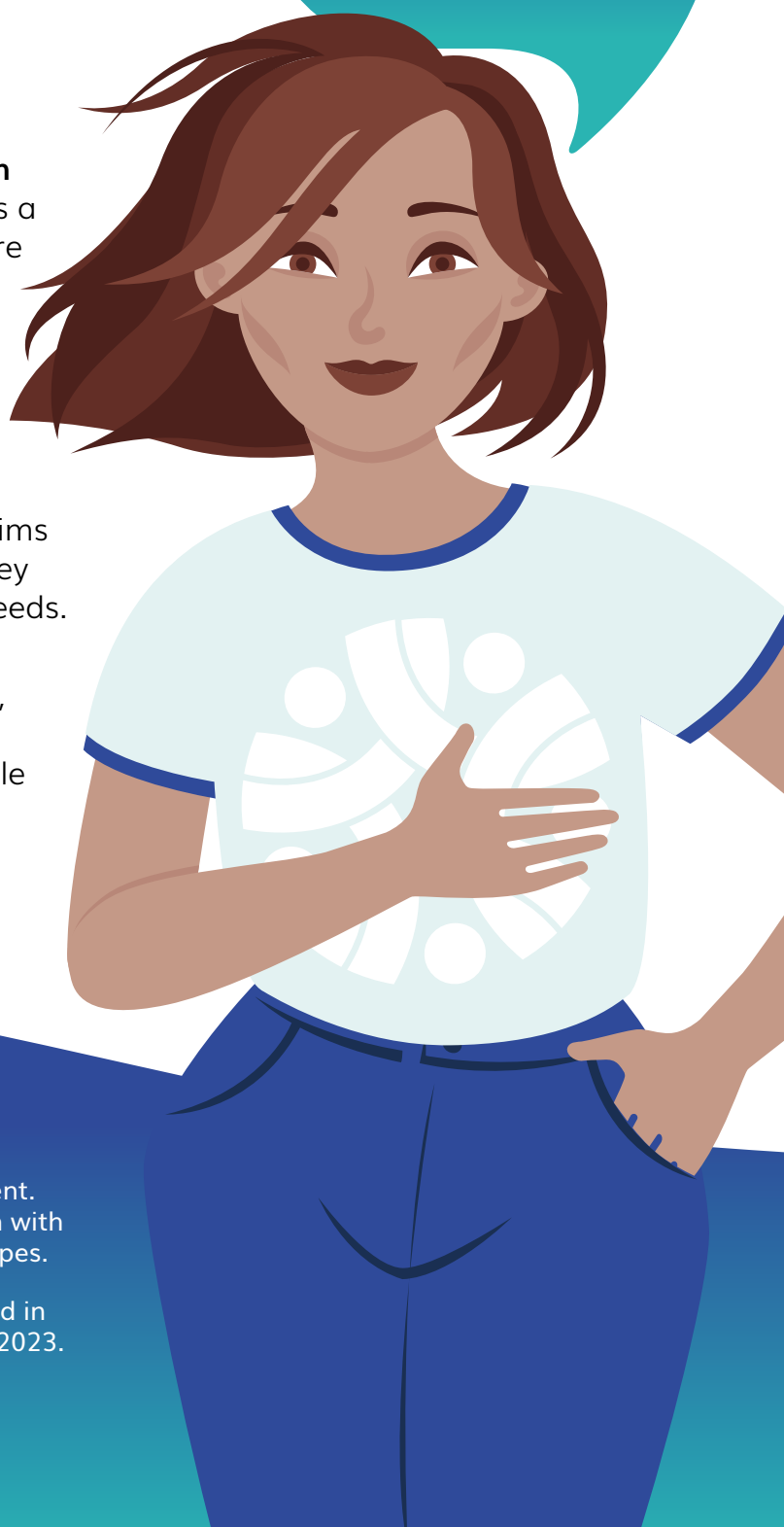
Impact of Multiple Sclerosis Symptoms (IMSS) in Iceland

Despite progress in multiple sclerosis (MS) care, healthcare systems across Europe still lack a **coordinated and prioritised approach** to managing MS symptoms effectively. MS is a lifelong neurological condition affecting more than 1.2 million people in Europe, yet many continue to face gaps in care and support.

The European Multiple Sclerosis Platform (EMSP) is spearheading research to understand how people with MS experience and manage their symptoms across the continent. By **identifying disparities** EMSP aims to promote stronger collaboration among key stakeholders to effectively address unmet needs.

The Impact of Multiple Sclerosis Symptoms (IMSS) initiative seeks to drive policy change, improve care pathways, and enhance rehabilitation outcomes, ensuring that people with MS receive the **comprehensive support** they deserve.

Kristín's story is just one example of how MS reshapes lives — and why understanding these experiences is crucial for improving care.



EMSP and 24 national MS societies across 22 European countries collected real-life evidence on MS symptoms and management. Behind these findings are real people, each with their own challenges, uncertainties, and hopes.



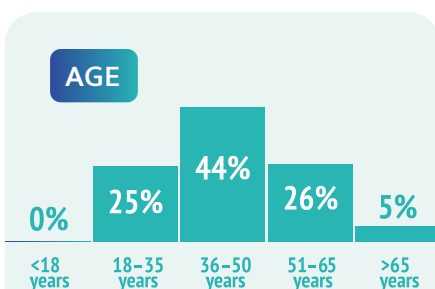
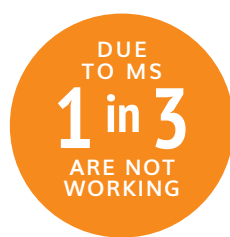
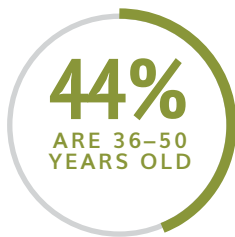
In Iceland, 269¹ people with MS participated in the IMSS survey from May 5 to August 31, 2023.

A Life Changed by MS

Kristín had always been full of energy — a teacher and a passionate painter in her free time. But at 29, her life took an unexpected turn. She started noticing strange sensations in her hands, followed by bouts of overwhelming fatigue. Over time, these symptoms grew harder to ignore. Tasks she once did effortlessly became a struggle. Her doctor ran tests, but the results were inconclusive. For five long years, Kristín lived with uncertainty, her daily life becoming a patchwork of pain, confusion, and questions without answers.



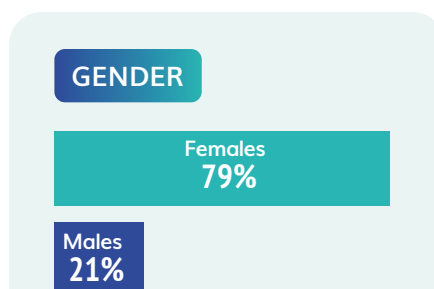
Participant demographics



People between **18-35** reported low symptom levels overall.

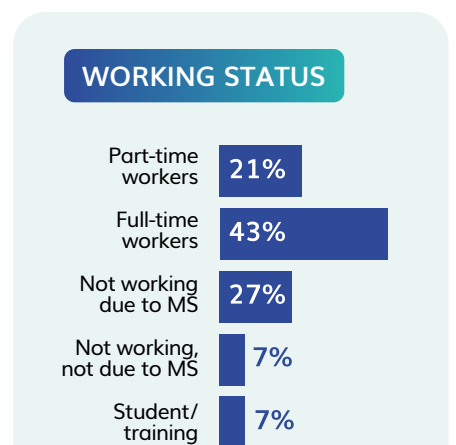
Individuals aged **36-50** experienced the highest anxiety, depression or mood changes, and arm and hand problems.

Between **51-65**, people reported the lowest cognitive impairment, anxiety, and depression or mood changes but showed high levels of sensory problems, balance issues, bladder control problems, spasticity, muscle weakness, and mobility impairment.



Females reported significantly fewer spasticity problems and arm and hand problems but **more temperature intolerance** compared to males.

Males reported significantly fewer sensory problems, temperature intolerance and vision problems, but **more spasticity problems, and arm and hand problems** than females.



Part-time workers experienced the highest muscle weakness and speech difficulties.

Full-time workers reported significantly less presence of all symptoms.

People not working due to MS reported the most presence of all symptoms.

The sample size of other groups was small to draw conclusions.

Understanding MS Across Europe

IMSS aims at uncovering the truths behind the symptoms, struggles, and stories of MS. How do people across Europe experience the condition? How do healthcare systems respond to their needs? And most importantly, where are they falling short?

For Kristín, these questions resonate deeply. Her diagnosis eventually came at age 34, but the journey didn't end there. Her symptoms — fatigue, numbness, memory problems, and pain — continued to affect her daily life. Navigating the healthcare system felt like an uphill battle, and she often wondered if there was more that could be done.

Kristín's experience reflects a broader reality revealed through the IMSS survey. Thousands of respondents shared their stories, offering insight into the challenges of living with MS: delays in diagnosis, inconsistent care pathways, and limited support for symptom management. Despite these challenges, EMSP saw an opportunity to drive change. By amplifying these voices, EMSP could push for policies that prioritise comprehensive, equitable care for people like Kristín across the continent.

Clinical situation

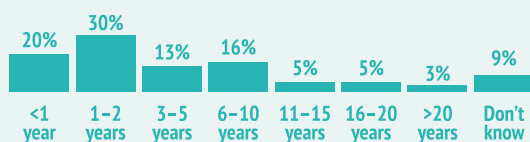
DIAGNOSIS AND SYMPTOM ONSET

58% diagnosed between 18–35 yrs

10.9 YEARS average disease duration

2 in 5 have at least 1 additional illnesses

Delay from symptom onset to diagnosis



28.9 symptom onset age

AVERAGE DELAY OF 4.9 YEARS

33.7 average diagnosis age

TYPES OF MS

72% RRMS, Relapsing Remitting MS

11% PPMS, Primary Progressive MS

10% SPMS, Secondary Progressive MS

8% Unsure of their MS type

DISABILITY LEVELS

10% of the respondents had mild disability while 34% had moderate disability and 11% had severe disability. People living with PPMS reported more moderate (53%) and severe disability (29%) compared to RRMS. People with SPMS reported the most severe disability (35%)².

QUALITY OF LIFE

The majority of respondents had no or slight problems, while 8% were experiencing moderate or severe problems affecting their quality of life. The quality of life deteriorated more among people with PPMS (28%) and people with SPMS (11%)³.

USE OF DMDs

84% of respondents have used **Disease Modifying Drugs** (DMDs), with 71% currently using them. 62% reported *less* than a 1-year delay to start DMDs, while 8% experienced delays of 6 years or more. Among non-users, the main reasons were:

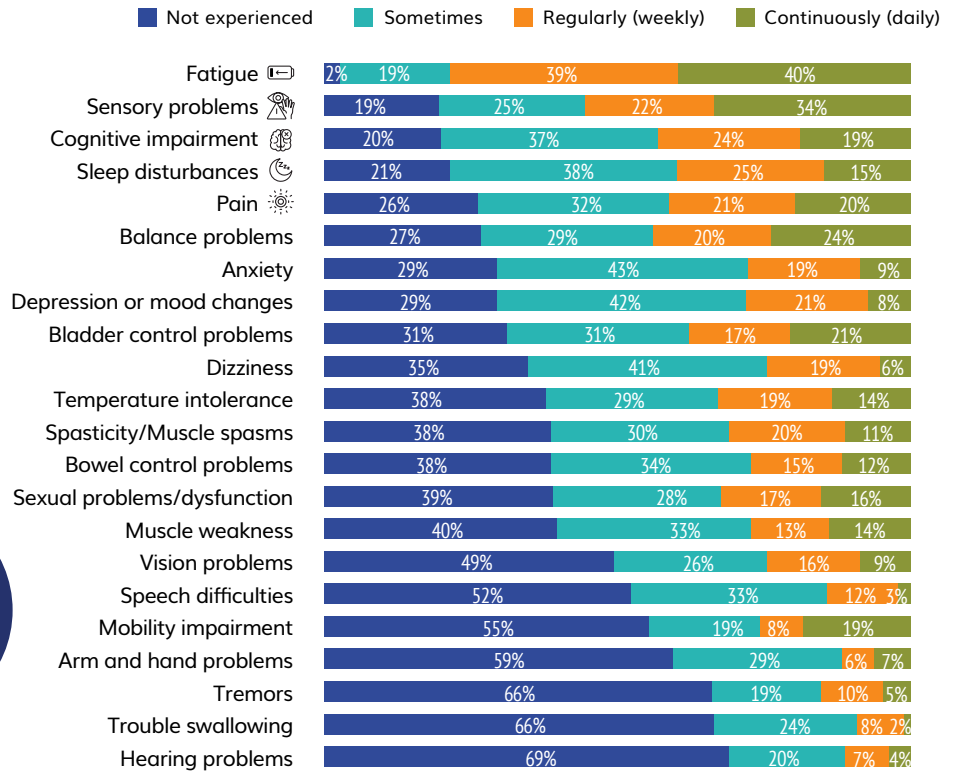
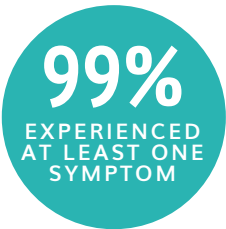
- 29% concerns about use
- 33% never being offered
- 27% physicians advising against them.

ON AVERAGE 1.5 YEARS DELAY BETWEEN DIAGNOSIS AND DMD START

Symptoms

PRESENCE AND PREVALENCE

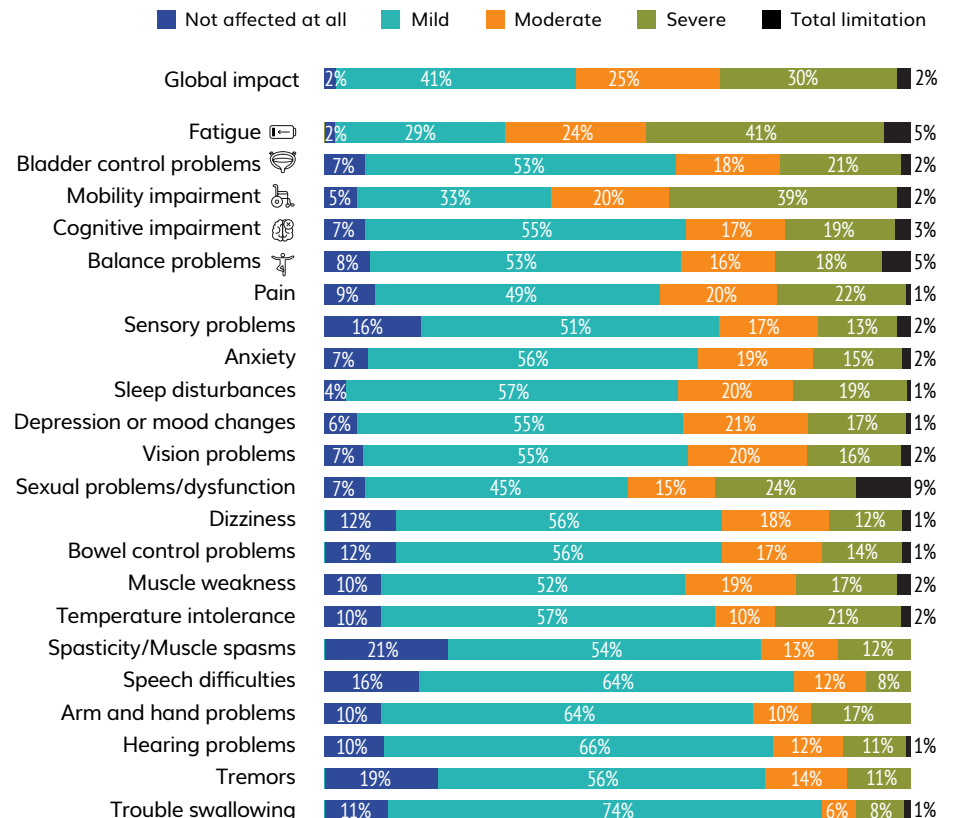
The symptoms reported the most were **fatigue, sensory problems, cognitive impairment, sleep disturbances, and pain.**



SEVERITY AND IMPACT

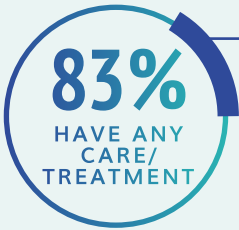
The symptoms that were affecting the daily lives of people with MS were **fatigue, sleep disturbances, mobility impairment, depression and mood changes and bladder control problems**⁴.

The top 3 most debilitating symptoms were **fatigue, bladder control problems, and mobility impairment**⁵.



Treatment and care

CARE FOR SYMPTOMS



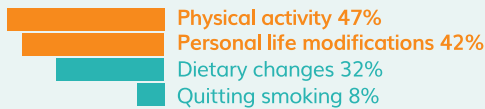
17% don't use any care /treatment. The top reasons for not using a specific treatment were having no need, treatment was not offered to them, or they cannot afford this treatment.



People with MS reported using 5.5 treatments or care on average for their symptoms.

The most used treatments were*: **prescription medication, physical activity, personal life modifications, and social support.**

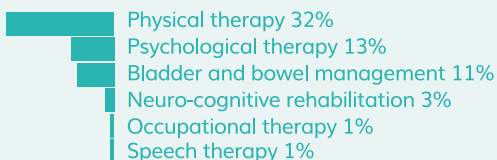
Lifestyle changes



Medication for symptom management



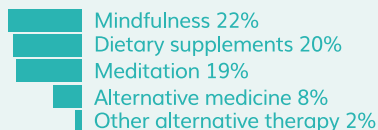
Therapy/treatments



Social support



Complementary and alternative therapies



Other

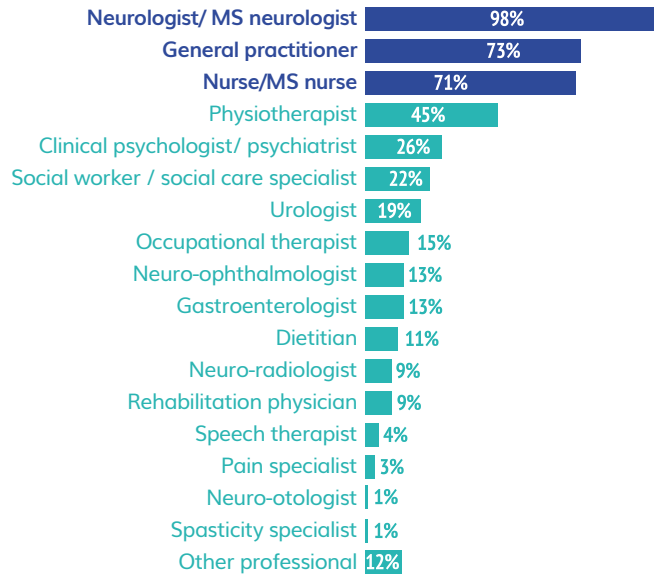


INVOLVEMENT OF PROFESSIONALS



People with MS had 4.4 healthcare professionals on average taking care of their MS. 56% reported that their healthcare professionals are coordinating together.

The most involved professionals were **neurologist, general practitioner, and nurse/ MS nurse**.*



CAREGIVER PRESENCE AND ASSISTANCE



86% have no need for assistance

5% do not have caregivers but need assistance

9% have caregivers



Of those caregivers, **72%** were a family, partner, or friend. **37%** were paid professionals*.



The caregivers supported people with MS for 19.2 hours per week on average. **84%** of respondents mentioned that the carer was of **great or good** help to them.

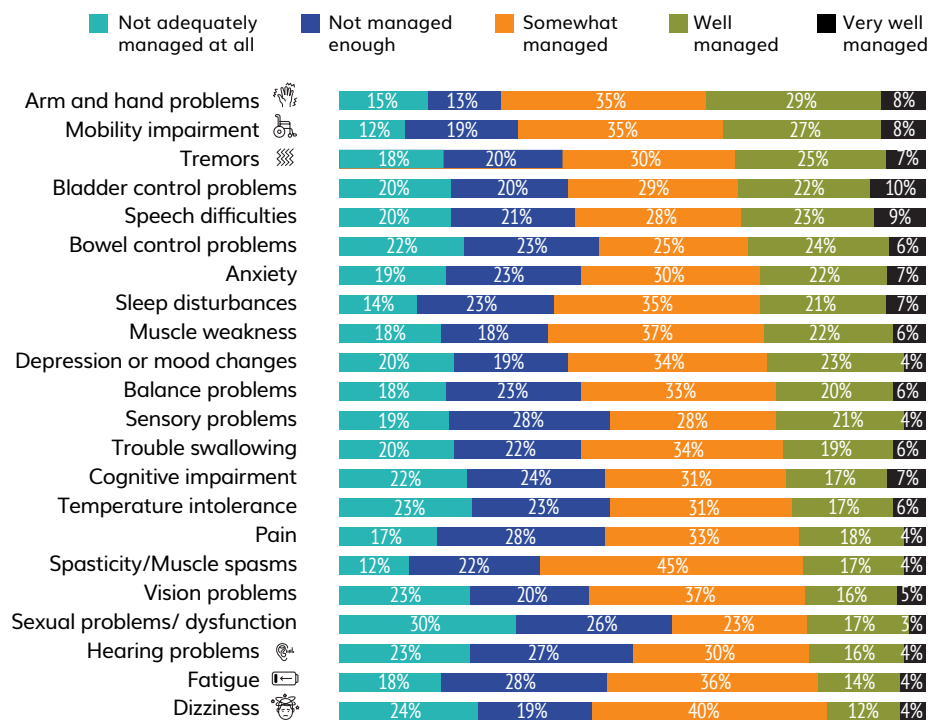
People living with SPMS reported having a caregiver (23%) or needing one (11%), slightly less than people with PPMS, 29% with caregiver and 18% needing one. People with RRMS reported the most not having and not needing a caregiver (93%).

Satisfaction with management of symptoms

The most well managed symptoms were **arm and hand problems, mobility impairment, and tremors.**

The least well managed symptoms were **dizziness, fatigue, and hearing problems.**

1 in 2
NOT SATISFIED
WITH THEIR
CARE



The promise of change

As the IMSS initiative brings together people with MS, researchers, policymakers, and healthcare providers, we hope to have a future where no one has to face their symptoms alone. A future where MS care isn't just about managing symptoms but **empowering people to lead fulfilling lives.**

The story of MS isn't just about the condition; it's about the people living with it. And for Kristín, it's a story that continues, now with **the promise of a brighter tomorrow.**



Note: Percentages are rounded for simplicity and may not sum to 100% or match exactly.

*Participants were allowed to give more than one answer (multiple choice), hence the total can be more than 100%.

‡Gender: Non-binary: 0.5%.

References: ¹Among respondents, 80.3% were MS society members, 9% were linked but not members, and 10.7% had no society affiliation. ²Measured by the PDDS: Patient-Determined Disease Steps, provided for use by the NARCOMS Registry: www.narcoms.org/pdds. NARCOMS is supported in part by the Consortium of Multiple Sclerosis Centres (CMSC) and the CMSC Foundation. ³Measured by EuroQOL Research Foundation: EQ-5D-5L. ⁴The tool used to measure the severity of symptoms is SymptoMScreen: <https://www.symptomscreen.org>, categorised into 5 groups: Not affected at all (0); Mild (1 and 2), Moderate (3), Severe (4 and 5), Total limitation (6). ⁵The 'Severity and Impact' chart is organized from the most to the least debilitating symptoms.

Acknowledgement: EMSP thanks people with MS and their caregivers across Europe for participating in this IMSS survey experience. EMSP thanks the Scientific Working Group which included MS experts and the national MS societies for their support. EMSP thanks the young people with MS who supported the development of the survey part of the Young People's Network, the MS International Federation, and GfK Spain (expert in Healthcare Market Research).

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