

Impact of Multiple Sclerosis Symptoms (IMSS) in Czech Republic

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

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.



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.



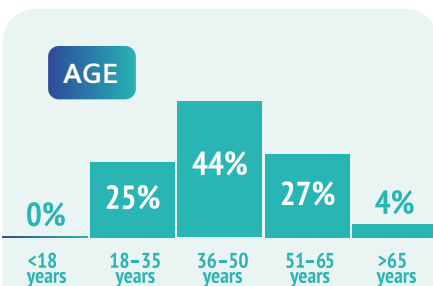
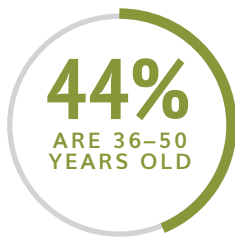
In Czech Republic, 282¹ people with MS participated in the IMSS survey from May 5 to August 31, 2023.

A Life Changed by MS

Tereza had always been full of energy — a teacher and a passionate painter in her free time. But at 30, her life took an unexpected turn. She started noticing strange sensations in her legs, 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 three long years, Tereza lived with uncertainty, her daily life becoming a patchwork of pain, confusion, and questions without answers.



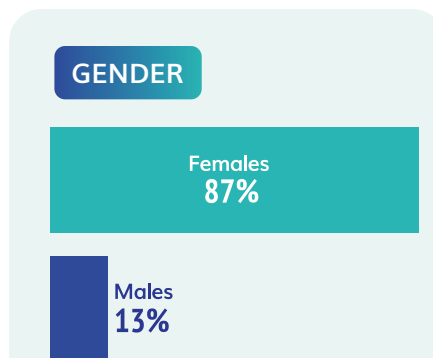
Participant demographics



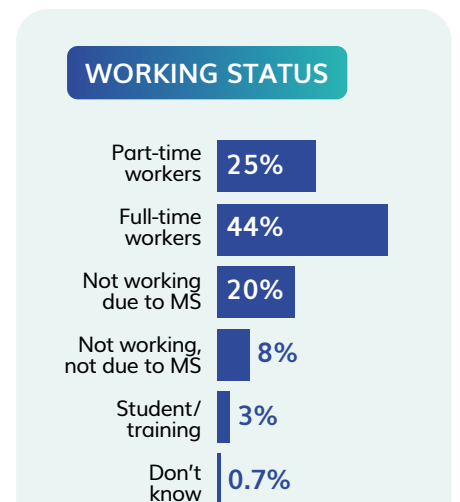
People between **18-35** reported the most anxiety, but reported the least pain, balance problems, spasticity, bowel and bladder control problems, mobility impairment, arm and hand problems and trouble swallowing.

Individuals aged **36-50** experienced higher presence of symptoms compared to 18-35 but not significantly different than other groups.

Between **51-65**, the highest spasticity problems, vision problems, bladder control problems and mobility impairment.



Females reported significantly *more* **fatigue, sensory problems, sleep disturbances, pain, cognitive impairment, vision problems, muscle weakness, dizziness** and **hearing problems** compared to males.



Part-time workers experienced more sleep disturbances.

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

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

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 Tereza, these questions resonate deeply. Her diagnosis eventually came at age 33, but the journey didn't end there. Her symptoms — fatigue, sensory problems, sleep disturbances, 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.

Tereza'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 Tereza across the continent.

Clinical situation

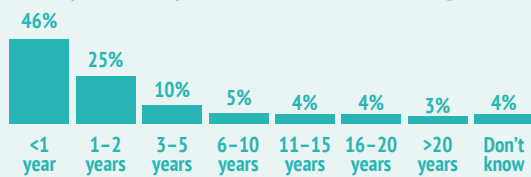
DIAGNOSIS AND SYMPTOM ONSET

59% diagnosed between 18–35 yrs

10.8 YEARS average disease duration

2 in 5 have at least 1 additional illnesses

Delay from symptom onset to diagnosis



30.5 symptom onset age

AVERAGE DELAY OF 3 YEARS

33.6 average diagnosis age

TYPES OF MS

66% RRMS, Relapsing Remitting MS

10% PPMS, Primary Progressive MS

14% SPMS, Secondary Progressive MS

10% Unsure of their MS type

DISABILITY LEVELS

21% of the respondents had mild disability while 42% had moderate and 16% had severe. People living with PPMS reported more moderate (50%) and severe disability (38%) compared to RRMS while people with SPMS reported the most severe disability (55%)².

QUALITY OF LIFE

The majority of respondents had no or slight problems, while 6% were experiencing moderate or severe problems affecting their quality of life. The quality of life deteriorated more among people with PPMS (19%) and people with SPMS (18%)³.

USE OF DMDs

75% of respondents have used **Disease Modifying Drugs** (DMDs), with 62% currently using them. 56% 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:

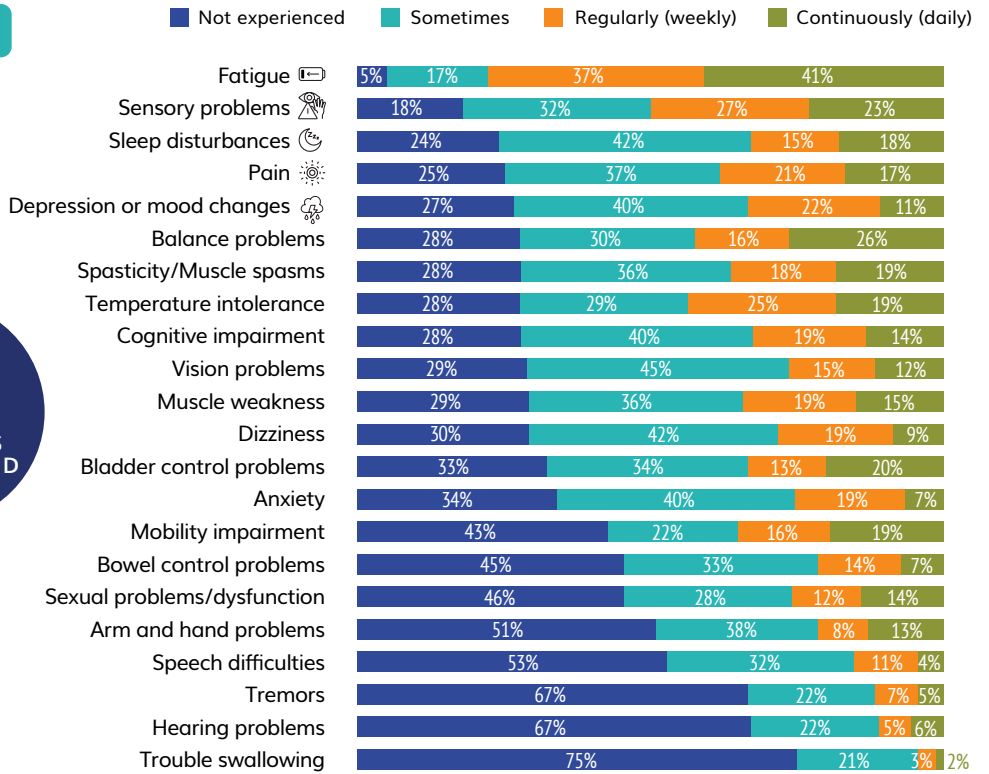
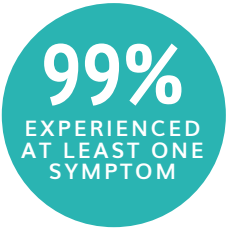
- 16% concerns about use
- 36% never being offered
- 11% physicians advising against them.

ON AVERAGE
1.3
YEARS DELAY BETWEEN DIAGNOSIS AND DMD START

Symptoms

PRESENCE AND PREVALENCE

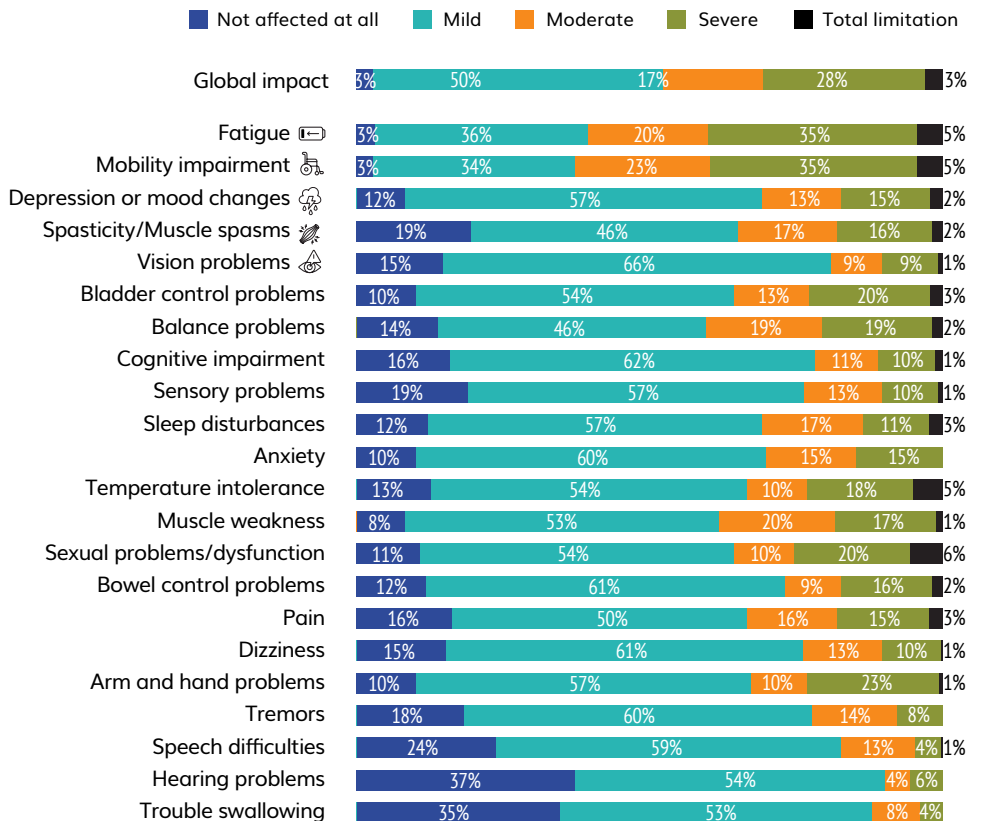
The symptoms reported the most were **fatigue, sensory problems, sleep disturbances, pain** and **depression/mood changes**.



SEVERITY AND IMPACT

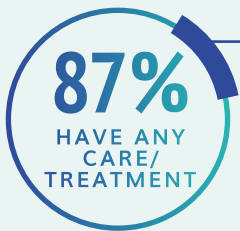
The symptoms that were affecting the daily lives of people with MS were **fatigue, mobility impairment, muscle weakness, bladder control problems, and arm/hand problems**⁴.

The top 3 most debilitating symptoms were **fatigue, mobility impairment, and depression/mood changes**⁵.



Treatment and care

CARE FOR SYMPTOMS



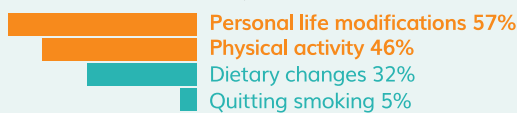
13% don't use any care /treatment. The top reasons were having no need, treatment was not offered to them, treatment was not close to where they live or they cannot afford this treatment.



People with MS reported using 6.5 treatments or care on average for their symptoms.

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

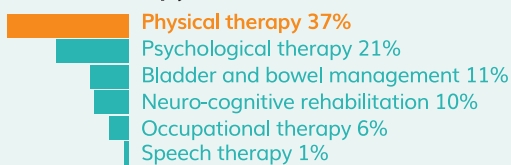
Lifestyle changes



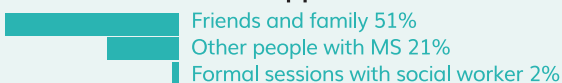
Medication for symptom management



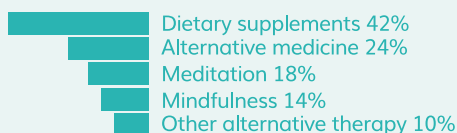
Therapy/treatments



Social support



Complementary and alternative therapies



Other



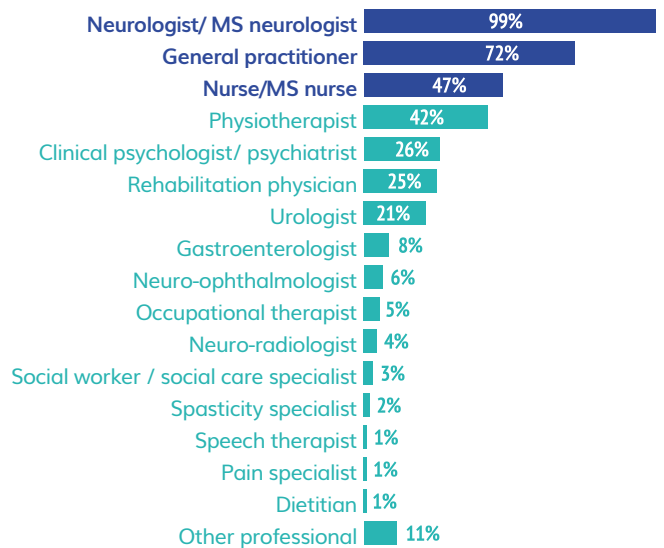
Surgery 1%

INVOLVEMENT OF PROFESSIONALS



People with MS had 3.8 healthcare professionals on average taking care of their MS. 57% reported that their healthcare professionals are coordinating together.

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



CAREGIVER PRESENCE AND ASSISTANCE

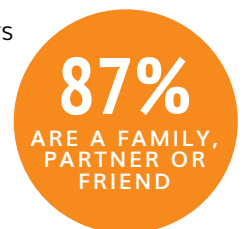


83% have no need for assistance

10% do not have caregivers but need assistance

6% have caregivers

Of those caregivers, **87%** were a family, partner, or friend. **33%** were paid professionals*.



The caregivers supported people with MS for 23.8 hours per week on average. **73%** of respondents mentioned that the carer was of **great or good** help to them.

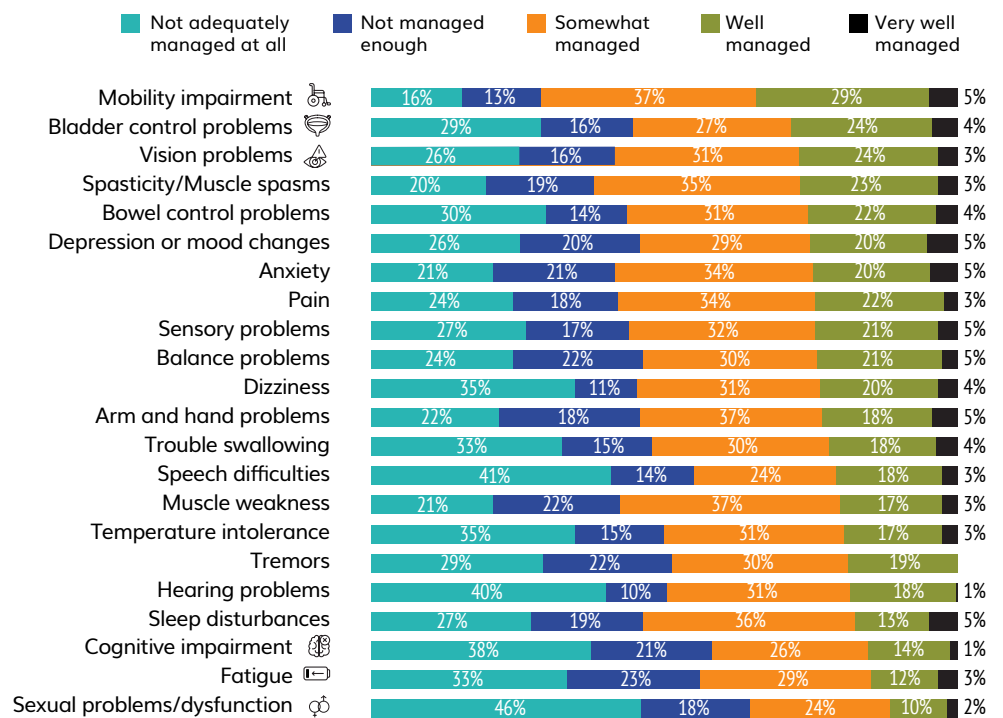
People living with SPMS reported having a caregiver (17%) or needing one (21%) while people with PPMS reported a higher need (29%). People with RRMS reported the most not having and not needing a caregiver (92%).

Satisfaction with management of symptoms

The most well managed symptoms were **mobility impairment, bladder control problems, and vision problems.**

The least well managed symptoms were **sexual problems/dysfunction, fatigue, and cognitive impairment.**

2 in 5
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 Tereza, 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%.

References: ¹Among respondents, 36.5% were MS society members, 23.4% were linked but not members, and 40.1% 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).

Funding: This project has been financially supported by Almiral, Biogen, Bristol Myers Squibb, Coloplast, Merck, Novartis, Roche, and Sanofi.