Impact of Multiple Sclerosis Symptoms (IMSS) in Romania

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 Romania, **417**[1] people with MS participated in the IMSS survey from May 5 to August 31, 2023.

A Life Changed by MS

Mariana had always been full of energy — a mother, a graphic designer, and a passionate swimmer in her free time. But at 31, 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 three long years, Mariana lived with uncertainty, her daily life becoming a patchwork of pain, confusion, and questions without answers.

Participant demographics

44.2
THE MEAN AGE OF PEOPLE WITH MS

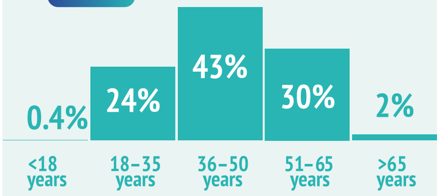
43%
ARE 36–50 YEARS OLD

DUE TO MS
1 in 3
ARE NOT WORKING

65%
HAVE HIGH-LEVEL EDUCATION

83%
LIVE WITH THEIR FAMILY

AGE



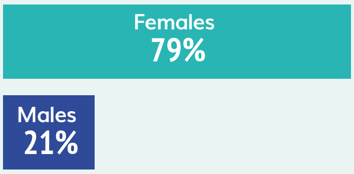
People between **18–35** reported the most anxiety among all other age groups but reported the least of all other symptoms.

Individuals aged **36–50** experienced the highest sensory problems, depression or mood changes and dizziness.

Between **51-65**, the highest of all symptoms were reported.

Above 65, the sample size was small to draw conclusions.

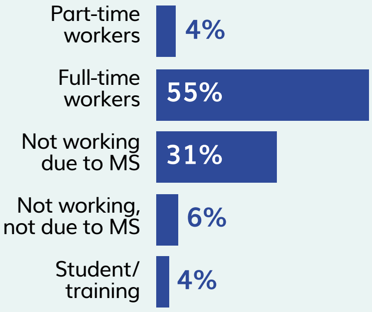
GENDER[‡]



Females reported significantly *fewer* tremors, but *more* **heat or cold intolerance, pain** and **anxiety** compared to males.

Males reported significantly *fewer* heat or cold intolerance, pain and anxiety, but *more* **mobility impairment** and **tremors** than females.

WORKING STATUS



Full-time workers reported significantly less presence of all symptoms, with the exception of anxiety which was the highest.

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

For other groups, the sample size 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 Mariana, these questions resonate deeply. Her diagnosis eventually came at age 34, but the journey didn't end there. Her symptoms — fatigue, pain, tingling fingers, and bladder control problems — 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.

Mariana'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 Mariana across the continent.

Clinical situation

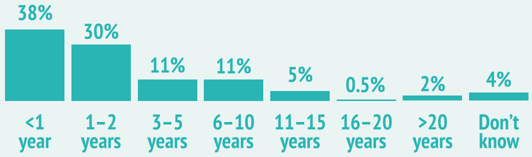
DIAGNOSIS AND SYMPTOM ONSET

57% diagnosed between 18–35 yrs

10.2 YEARS average disease duration

2 in 5 have at least 1 additional illnesses

Delay from symptom onset to diagnosis



31.2 symptom onset age

AVERAGE DELAY OF 2.8 YEARS

34 average diagnosis age

TYPES OF MS

68% **RRMS,** Relapsing Remitting MS

10% **PPMS,** Primary Progressive MS

11% **SPMS,** Secondary Progressive MS

11% **Unsure of their MS type**

DISABILITY LEVELS

15% of the respondents had mild disability while 38% had moderate disability and 14% had severe disability. People living with PPMS reported more moderate (72%) and severe disability (21%) compared to RRMS. People with SPMS reported the most severe disability (52%)[2].

QUALITY OF LIFE

The majority of respondents had no or slight problems, while 9% 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 (15%)[3].

USE OF DMDs

82% of respondents have used **Disease Modifying Drugs** (DMDs), with 70% currently using them. 61% reported *less* than a 1-year delay to start DMDs, while 9% experienced delays of 6 years or more. Among non-users, the main reasons were:

- 39% concerns about use
- 29% never being offered
- 8% physicians advising against them.

ON AVERAGE **1.9** YEARS DELAY BETWEEN DIAGNOSIS AND DMD START

Symptoms

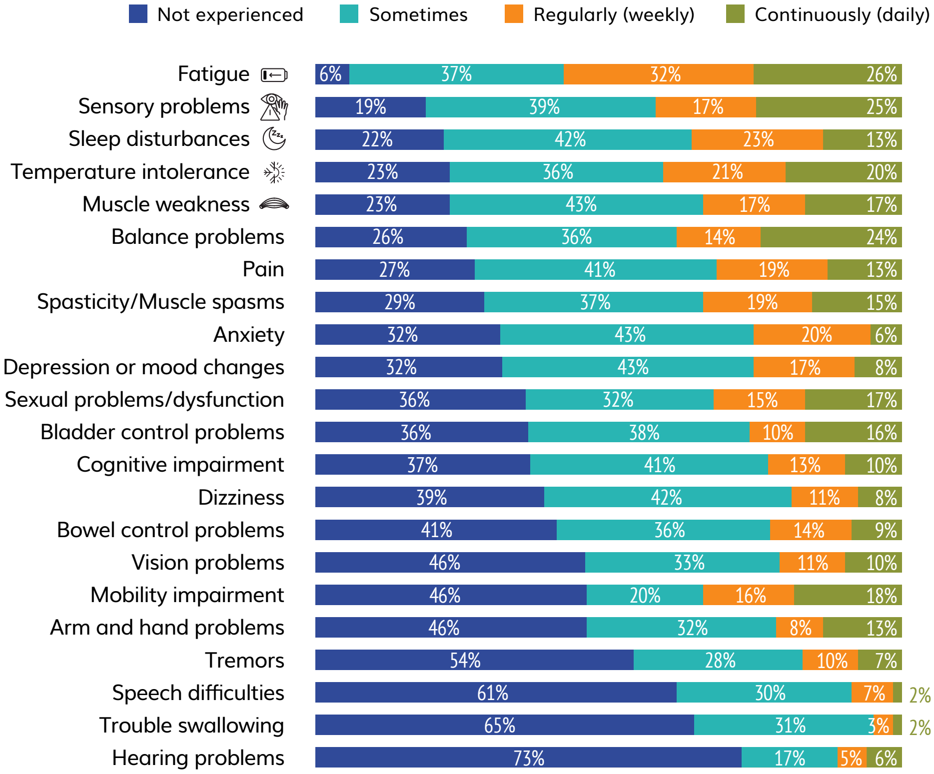
PRESENCE AND PREVALENCE

The symptoms reported the *most* were **fatigue, sensory problems, sleep disturbances, heat or cold intolerance** and **muscle weakness.**

The symptoms *least* reported were **trouble swallowing, hearing problems, speech difficulties, tremors,** and **arms and hand problems.**

99% EXPERIENCED AT LEAST ONE SYMPTOM

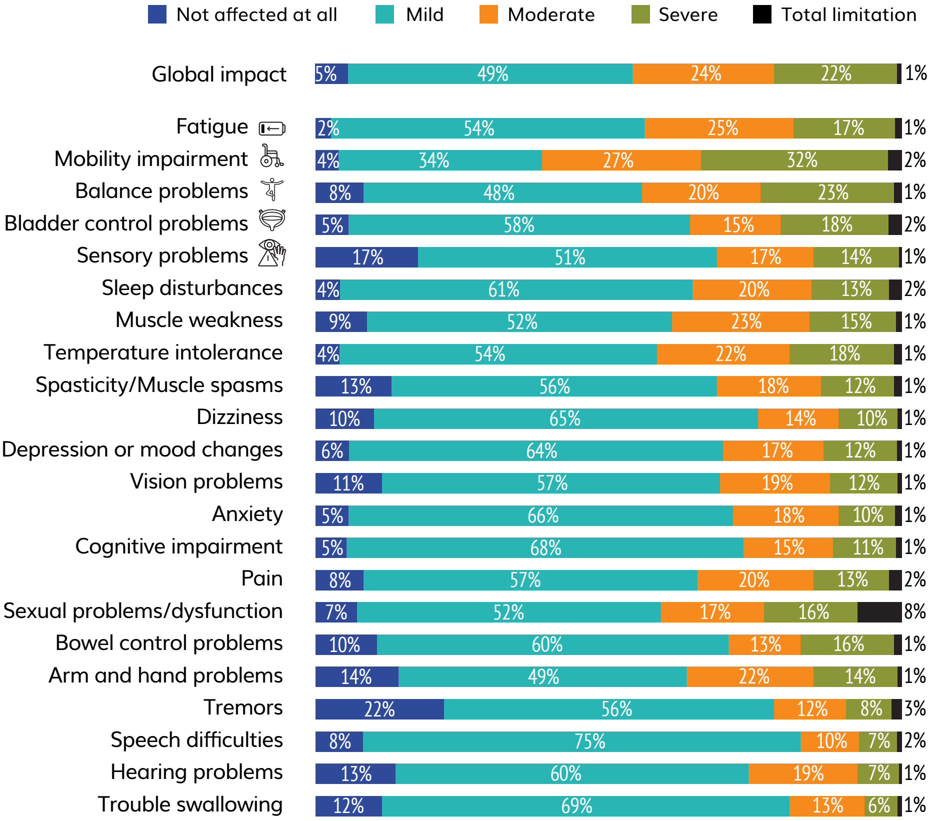
ON AVERAGE **13.8** SYMPTOMS EXPERIENCED TOGETHER



SEVERITY AND IMPACT

The symptoms that were affecting the daily lives of people with MS were **fatigue, mobility impairment, sleep problems, heat and cold intolerance** and **bladder problems**[4].

The top 3 *most* debilitating symptoms were **fatigue, mobility impairment,** and **balance problems**[5]**.**



Treatment and care

CARE FOR SYMPTOMS

80% HAVE ANY CARE/ TREATMENT

20% don't use any care /treatment. The *top reasons* for not using a specific treatment were that they cannot afford this treatment, have no need, or the treatment was not offered to them.

ON AVERAGE **5.1** TREATMENTS OR CARE

People with MS reported using 5.1 treatments or care on average for their symptoms.

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

Lifestyle changes

- Physical activity 35%
- Personal life modifications 33%
- Dietary changes 32%
- Quitting smoking 7%

Medication for symptom management

- Prescription medication 52%
- Non-prescription medication 21%

Therapy/treatments

- Physical therapy 30%
- Psychological therapy 12%
- Bladder and bowel management 6%
- Neuro-cognitive rehabilitation 5%
- Occupational therapy 4%
- Speech therapy 1%

Social support

- Friends and family 29%
- Other people with MS 14%
- Formal sessions with social worker 2%

Complementary and alternative therapies

- Dietary supplements 38%
- Alternative medicine 15%
- Meditation 11%
- Mindfulness 8%
- Other alternative therapy 6%

Other

- Assistive devices 16%
- At-home massage devices 8%
- Diaries and applications 6%
- Home modification 6%
- Service/support animals 4%
- Other 4%

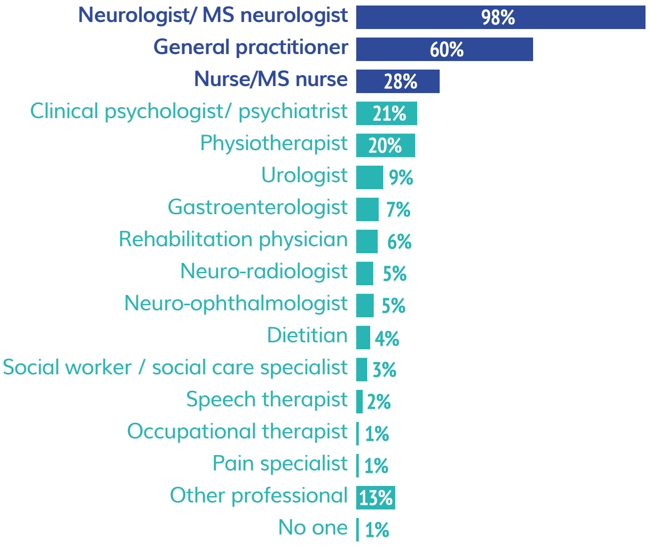
Surgery 2%

INVOLVEMENT OF PROFESSIONALS

ON AVERAGE **5** HEALTHCARE PROFESSIONALS

People with MS had 5 healthcare professionals on average taking care of their MS. 68% reported that their healthcare professionals are coordinating together.

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



CAREGIVER PRESENCE AND ASSISTANCE

77% have no need for assistance

14% do not have caregivers but need assistance

9% have caregivers

Of those caregivers, **89%** were a family, partner, or friend. **15%** were paid professionals*.

89% ARE A FAMILY, PARTNER OR FRIEND

ON AVERAGE **21.4** HOURS/ WEEK

The caregivers supported people with MS for 21.4 hours per week on average. **81%** of respondents mentioned that the carer was of **great or good** help to them.

People living with SPMS reported having a caregiver (29%) or needing one (22%) while people with RRMS reported the most not having and not needing a caregiver (81%).

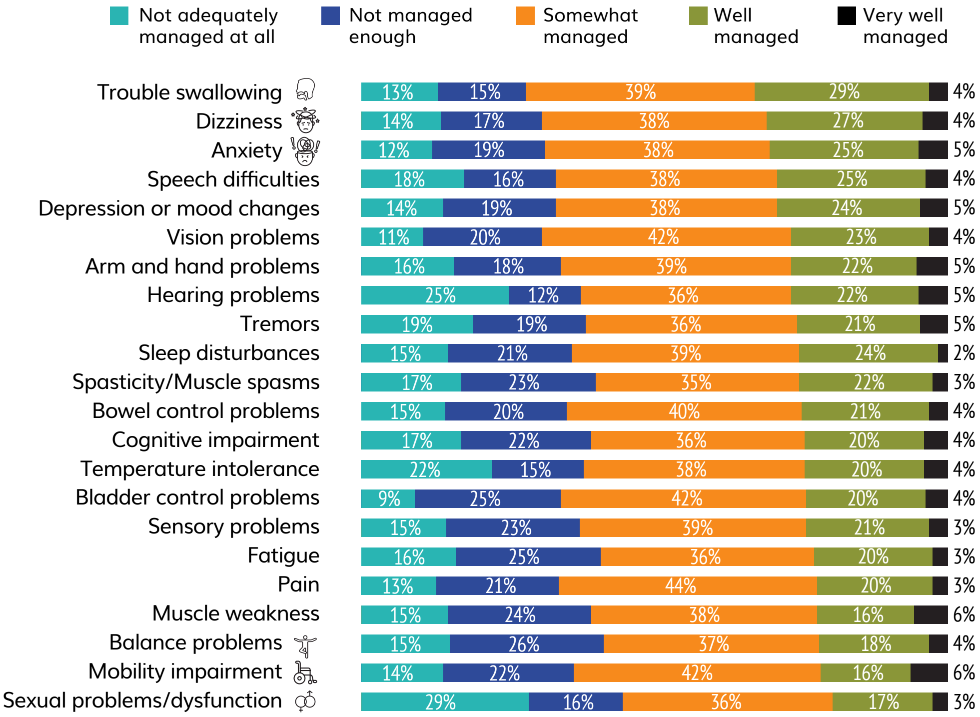
Satisfaction with management of symptoms

The *most* well managed symptoms were **trouble swallowing, dizziness,** and **anxiety.**

The *least* well managed symptoms were **sexual problems/dysfunction, mobility impairment,** and **balance 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 Mariana, 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: Prefer not to say: 0.2%

References: [1]Among respondents, 43% were MS society members, 16% were linked but not members, and 41% had no society affiliation. [2]Measured 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. [3]Measured by EuroQOL Research Foundation: EQ-5D-5L. [4]The 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). [5]The 'Severity and Impact' chart is organized from the most to the least debilitating symptoms.

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