IMSS

Ελληνική Εταιρία για τη Σκλήρυνση Κατά Πλάκας

MS HELLAS hellenic federation of persons with multiple sclerosis

emsp EUROPEAN MULTIPLE SCLEROSIS PLATFORM

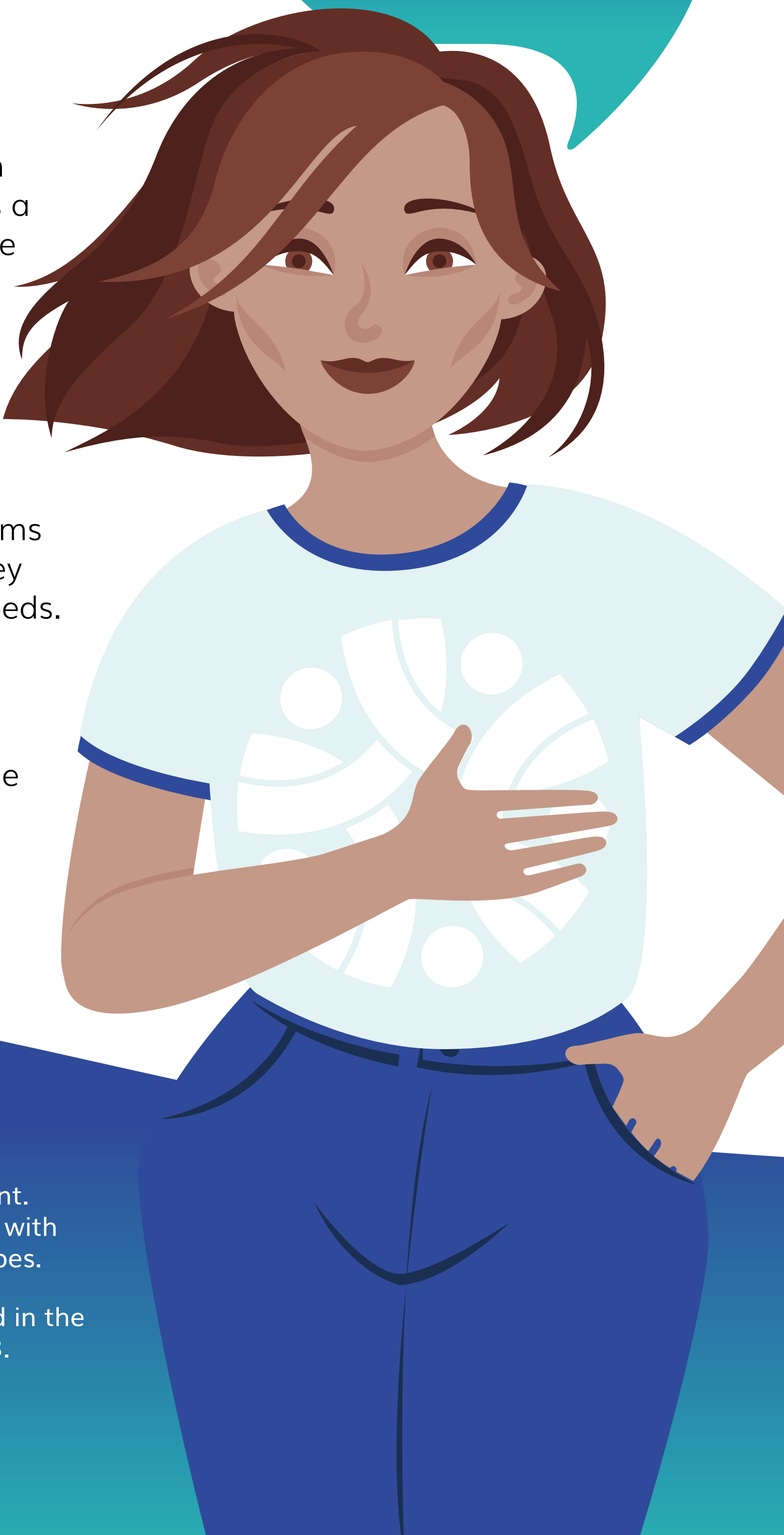
Impact of Multiple Sclerosis Symptoms (IMSS) in Greece

Eleni'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.

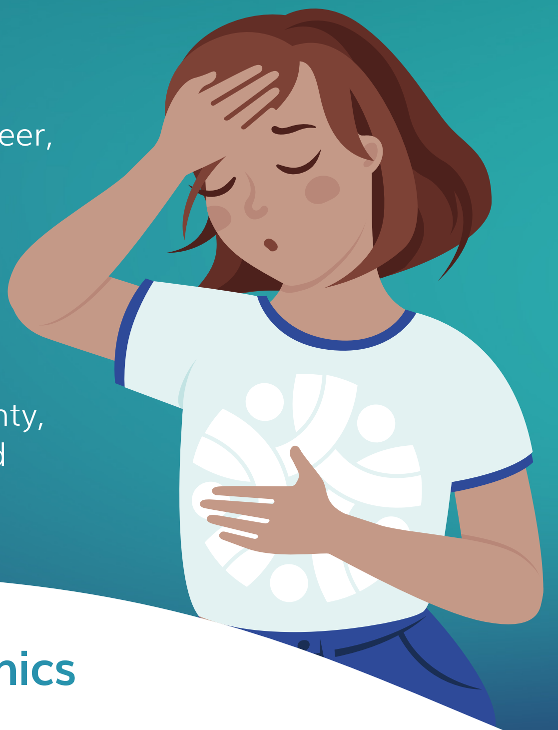


EMSP and **24** national MS societies across **22** European countries collected real-life evidence on MS symptoms and management. Behind these findings are real people, each with their own challenges, uncertainties, and hopes.

In Greece, **696**[1] people with MS participated in the IMSS survey from May 5 to August 31, 2023.

A Life Changed by MS

Eleni had always been full of energy — a mother, an engineer, 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, Eleni lived with uncertainty, her daily life becoming a patchwork of pain, confusion, and questions without answers.



Participant demographics

44.1
THE MEAN AGE OF PEOPLE WITH MS

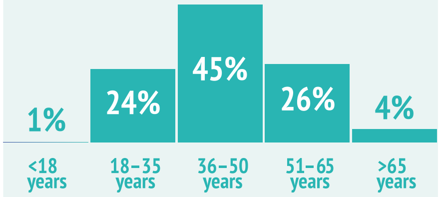
45%
ARE 36–50 YEARS OLD

DUE TO MS
1 in 4
ARE NOT WORKING

65%
HAVE HIGH-LEVEL EDUCATION

69%
LIVE WITH THEIR FAMILY

AGE



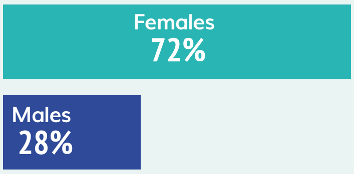
People between **18–35** reported the highest anxiety but the fewest physical symptoms, including balance, mobility, and sensory issues.

Individuals aged **36–50** experienced the most dizziness.

Between **51-65**, the widest range of symptoms.

Over 65, most symptoms persisted but were not the highest compared to other age groups as the sample was small to draw conclusions.

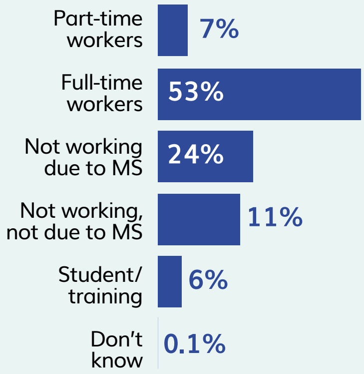
GENDER



Females reported significantly *fewer* balance problems, less muscle weakness, less mobility impairment, less arm and hand problems, but *more* **anxiety, cognitive impairment, dizziness and hearing problems** compared to males.

Males reported significantly *fewer* anxiety, cognitive impairment and hearing problems, but *more* **balance problems, muscle weakness, mobility impairment** and **arm/hand problems** than females.

WORKING STATUS



Full-time workers significantly less presence of all symptoms.

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

People not working not due to MS reported the most fatigue among all.

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 Eleni, these questions resonate deeply. Her diagnosis eventually came at age 34, but the journey didn't end there. Her symptoms — fatigue, numbness, heat sensitivity, and balance 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.

Eleni'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 Eleni across the continent.

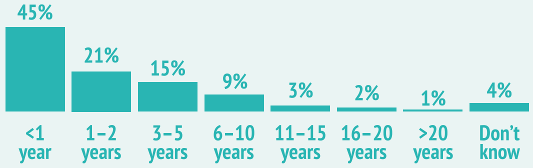
Clinical situation

DIAGNOSIS AND SYMPTOM ONSET

54% diagnosed between 18–35 yrs

10.1 YEARS average disease duration

2 in 5 have at least 1 additional illnesses


Delay from symptom onset to diagnosis

31 symptom onset age

AVERAGE DELAY OF 2.8 YEARS

34 average diagnosis age

TYPES OF MS

50%	17%	15%	19%
RRMS, Relapsing Remitting MS	**PPMS,** Primary Progressive MS	**SPMS,** Secondary Progressive MS	Unsure of their MS type

DISABILITY LEVELS

15% of the respondents had mild disability while 32% had moderate and 16% had disability. People living with PPMS reported more moderate (52%) and severe disability (25%) compared to RRMS while people with SPMS reported the most severe disability (58%)[2].

QUALITY OF LIFE

The majority of respondents had no or slight problems, while 14% were experiencing moderate or severe problems affecting their quality of life. The quality of life deteriorated more among people with PPMS (32%) and people with SPMS (33%) while people living with RRMS reported better quality of life[3].

USE OF DMDs

83% of respondents have used **Disease Modifying Drugs** (DMDs), with 71% currently using them. 61% 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:

- 20% concerns about use
- 49% never being offered
- 18% physicians advising against them.

ON AVERAGE **1.5** YEARS DELAY BETWEEN DIAGNOSIS AND DMD START

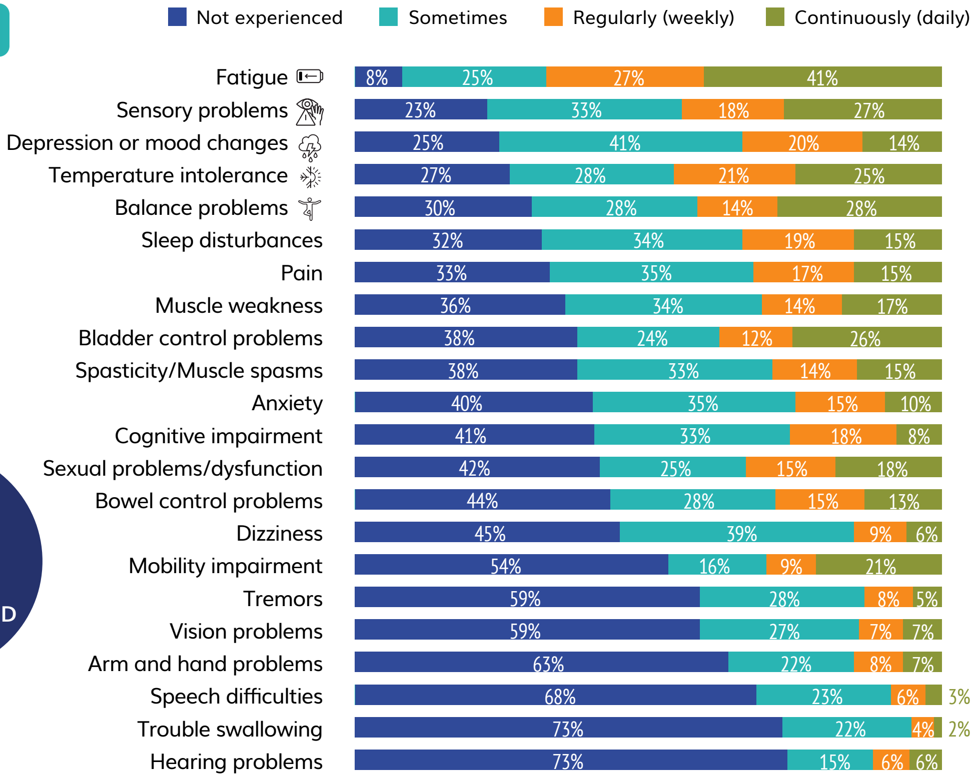
Symptoms

PRESENCE AND PREVALENCE

The symptoms reported the *most* were **fatigue, sensory problems, depression/mood changes, heat/cold sensitivity** and **balance problems.**

98%
EXPERIENCED AT LEAST ONE SYMPTOM

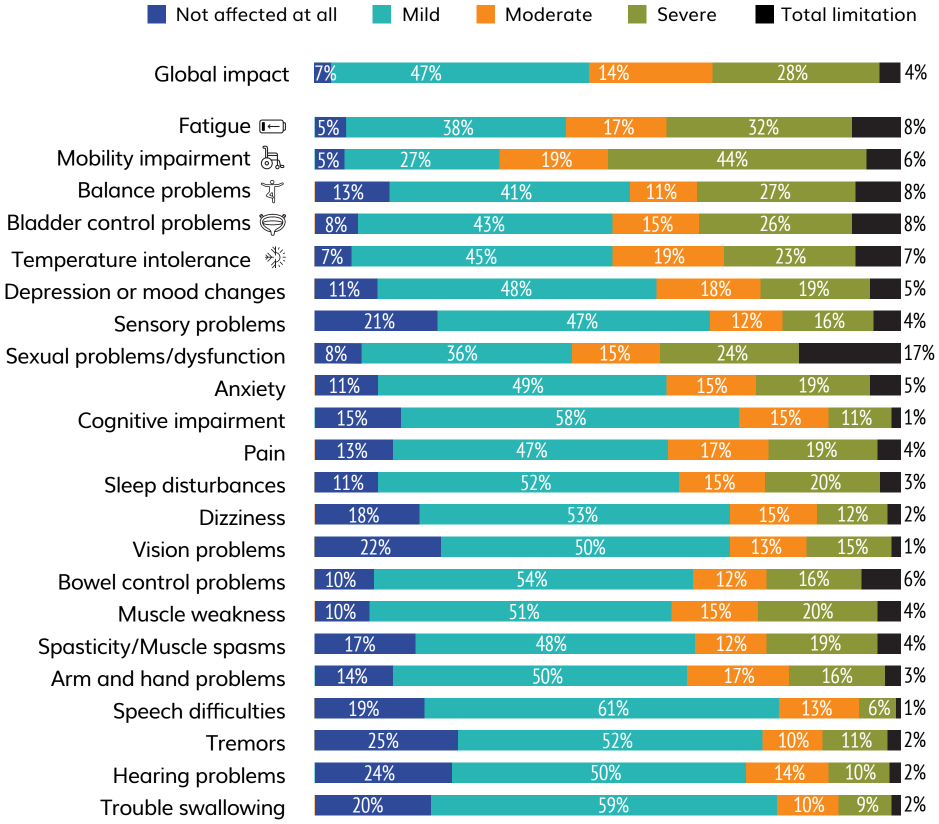
ON AVERAGE
12.5
SYMPTOMS EXPERIENCED TOGETHER



SEVERITY AND IMPACT

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

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



Treatment and care

CARE FOR SYMPTOMS

78%
HAVE ANY CARE/ TREATMENT

22% don't use any care /treatment. The *top reasons* for not using a specific treatment were having no need, they cannot afford it, or 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, personal life modifications, physical activity,** and **social support.**

Lifestyle changes

- Personal life modifications 38%
- Physical activity 36%
- Dietary changes 29%
- Quitting smoking 9%

Medication for symptom management

- Prescription medication 61%
- Non-prescription medication 11%

Therapy/treatments

- Physical therapy 28%
- Psychological therapy 17%
- Bladder and bowel management 9%
- Neuro-cognitive rehabilitation 4%
- Occupational therapy 2%
- Speech therapy 1%

Social support

- Friends and family 34%
- Other people with MS 15%
- Formal sessions with social worker 2%

Complementary and alternative therapies

- Dietary supplements 31%
- Alternative medicine 8%
- Mindfulness 7%
- Meditation 5%
- Other alternative therapy 4%

Other

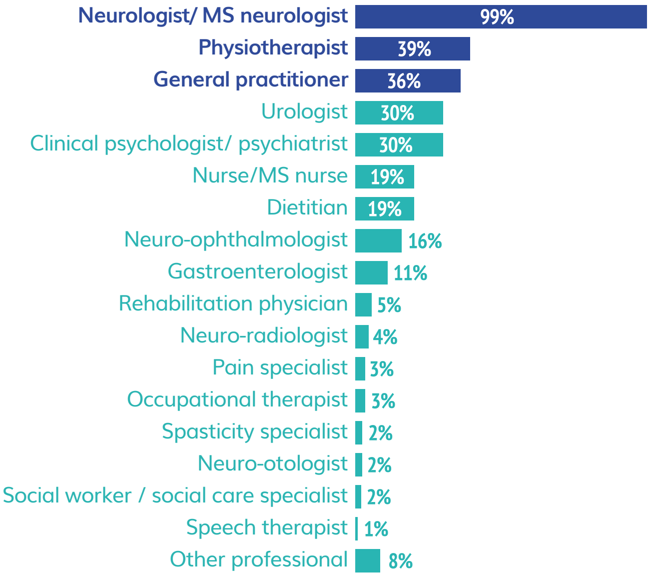
- Assistive devices 20%
- Diaries and applications 8%
- At-home massage devices 7%
- Home modification 6%
- Service/support animals 3%
- Other 2%

INVOLVEMENT OF PROFESSIONALS

ON AVERAGE
3.3
HEALTHCARE PROFESSIONALS

People with MS had 3.3 healthcare professionals on average taking care of their MS. 62% reported that their healthcare professionals are coordinating together.

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



CAREGIVER PRESENCE AND ASSISTANCE

72% have no need for assistance

17% do not have caregivers but need assistance

11% have caregivers

Of those caregivers, **90%** were a family, partner, or friend. **10%** were paid professionals*.

90%
ARE A FAMILY, PARTNER OR FRIEND

ON AVERAGE
43.6
HOURS/ WEEK

The caregivers supported people with MS for 43.6 hours per week on average. **78%** of respondents mentioned that the carer was of **great or good** help to them.

People living with SPMS reported having a caregiver (32%) or needing one (29%) while people with RRMS reported the most not having and not needing a caregiver (84%).

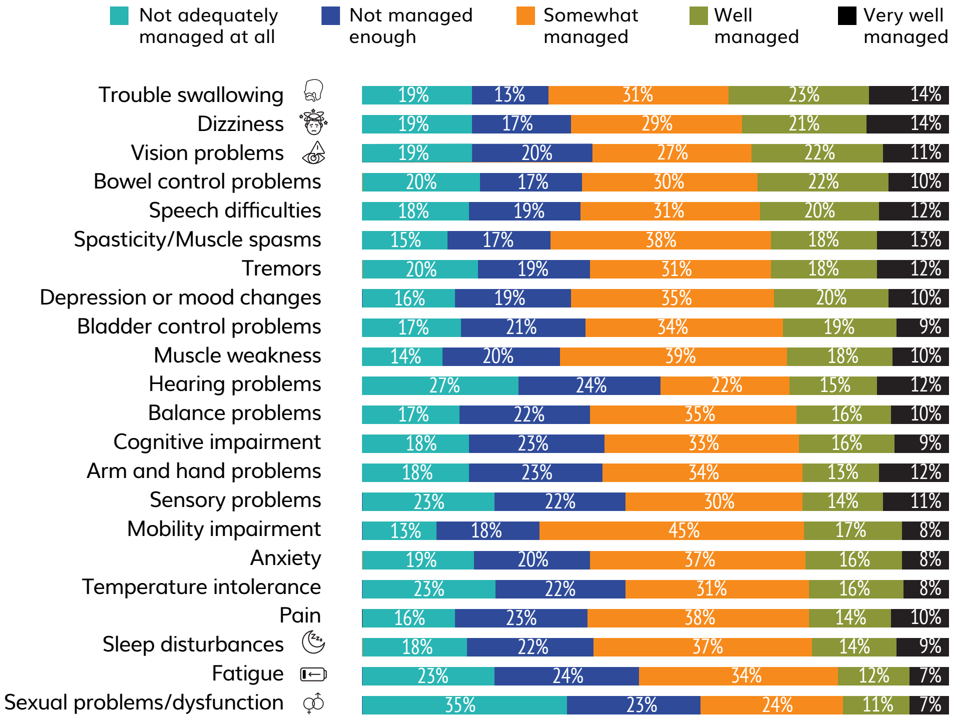
Satisfaction with management of symptoms

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

The *least* well managed symptoms were **sexual problems/dysfunction, fatigue,** and **sleep disturbances.**

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 Eleni, 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: [1]Among respondents, 34% were MS society members, 19% were linked but not members, and 47% 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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