IMSS

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Asociación Española de Esclerosis Múltiple
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emsp EUROPEAN MULTIPLE SCLEROSIS PLATFORM

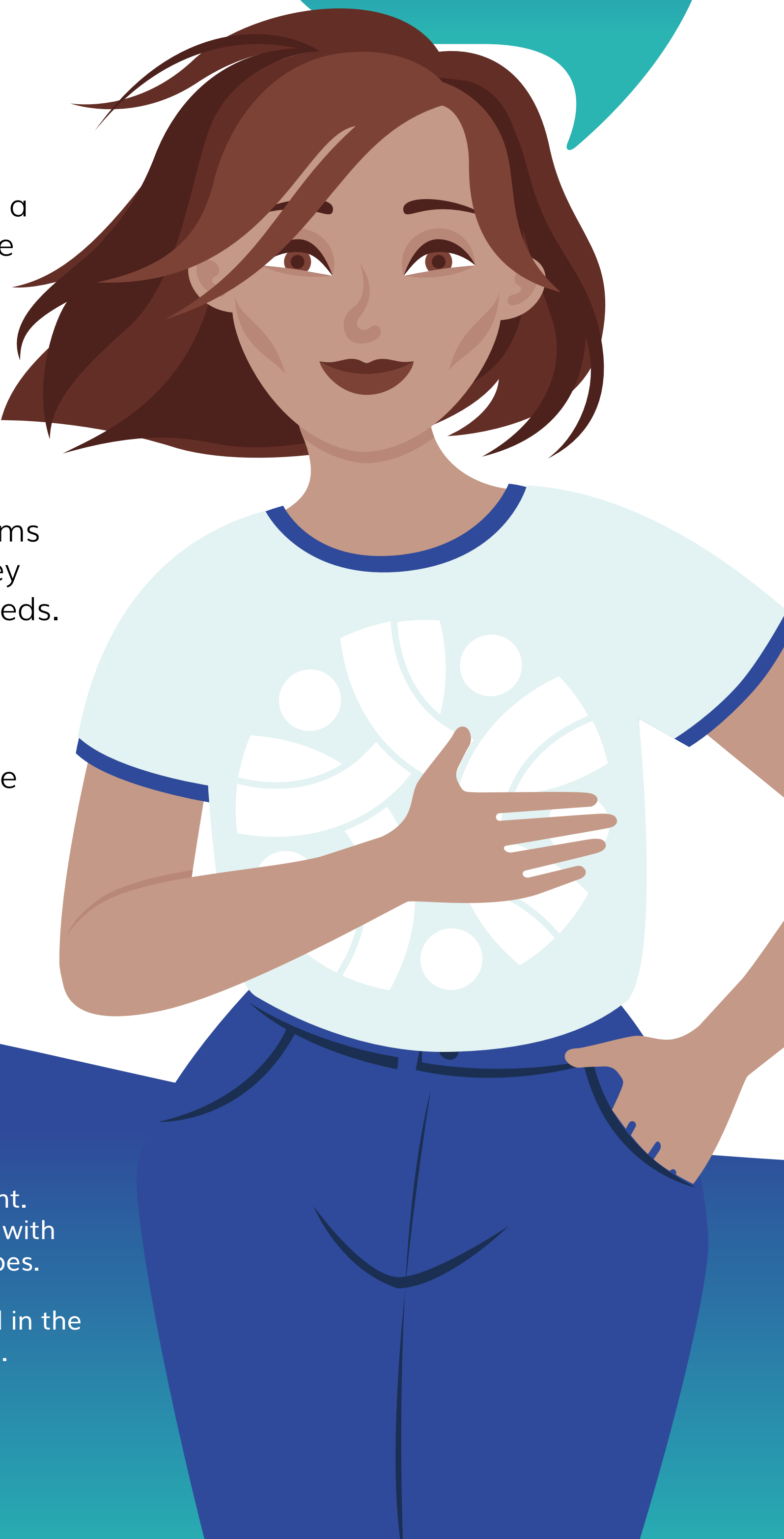
Impact of Multiple Sclerosis Symptoms (IMSS) in Spain

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.

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

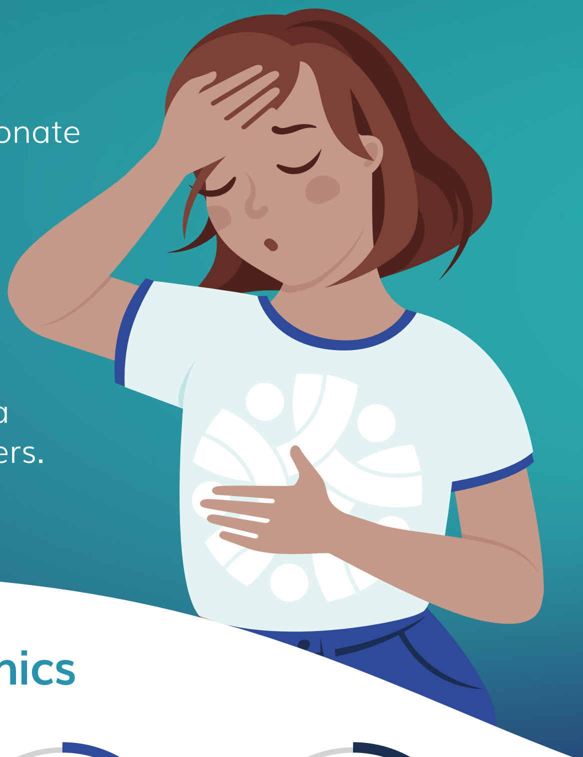


EMSP and **24** national MS societies across **22** European countries collected real-life evidence on MS symptoms and management. Behind these findings are real people, each with their own challenges, uncertainties, and hopes.

In Spain, **1322**[1] people with MS participated in the IMSS survey from May 5 to August 31, 2023.

A Life Changed by MS

Lucía had always been full of energy — a chef and a passionate painter in her free time. But at 31, 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, Lucía lived with uncertainty, her daily life becoming a patchwork of pain, confusion, and questions without answers.



Participant demographics

44.3 THE MEAN AGE OF PEOPLE WITH MS

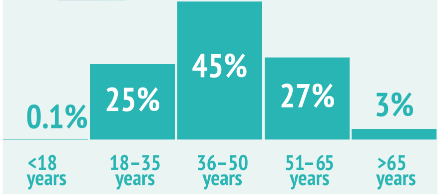
45% ARE 36–50 YEARS OLD

DUE TO MS **1 in 3** ARE NOT WORKING

65% HAVE HIGH-LEVEL EDUCATION

86% LIVE WITH THEIR FAMILY

AGE

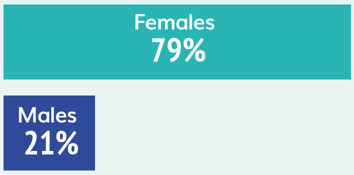


People between **18–35** reported the most anxiety among all other age groups but reported the least of all other symptoms.

Individuals aged **36–50** experienced low bowel problems but high sensory problems, sleep disturbances, pain, cognitive impairment, and arm/hand problems.

From age **51**, the highest incidence of symptoms was observed, although the responses **over 65** were significantly lower.

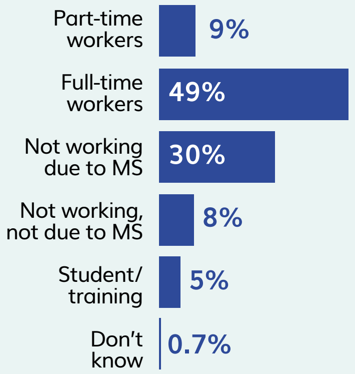
GENDER



Females reported *fewer* spasticity problems, mobility impairment, and tremors, but *more* **depression or mood problems, pain, cognitive impairment, heat or cold intolerance, anxiety,** and **dizziness.**

Males reported significantly *fewer* depression or mood problems, pain, heat or cold intolerance, anxiety and dizziness, but *more* **spasticity problems, mobility impairment,** and **tremors.**

WORKING STATUS



Part-time workers experienced the least bladder problems and trouble swallowing.

Full-time workers reported less presence of all symptoms, similar to students and people in training.

People not working due to MS reported most symptoms.

People not working not due to MS reported almost all 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 Lucía, these questions resonate deeply. Her diagnosis eventually came at age 34, 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.

Lucía'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 Lucía across the continent.

Clinical situation

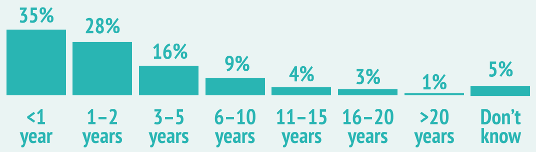
DIAGNOSIS AND SYMPTOM ONSET

58%
diagnosed between 18–35 yrs

10.4 YEARS
average disease duration

2 in 5
have at least 1 additional illnesses

Delay from symptom onset to diagnosis



30.8
symptom onset age

AVERAGE DELAY OF 3 YEARS

33.9
average diagnosis age

TYPES OF MS

75%
RRMS,
Relapsing Remitting MS

9%
PPMS,
Primary Progressive MS

11%
SPMS,
Secondary Progressive MS

5%
Unsure of their MS type

DISABILITY LEVELS

17% of the respondents had mild disability while 40% had moderate disability and 16% had severe disability. People living with SPMS reported the most severe disability (64%) compared to people with PRMS (59%) and people with RRMS (4%). People with RRMS reported the most moderate disability (42%)[2].

QUALITY OF LIFE

The majority of respondents had no or slight problems, while 11% were experiencing moderate or severe problems affecting their quality of life. The quality of life deteriorated more among people with PPMS (29%) and people with SPMS (37%)[3].

USE OF DMDs

87% of respondents have used **Disease Modifying Drugs** (DMDs), with 77% currently using them. 55% reported *less* than a 1-year delay to start DMDs, while 11% experienced delays of 6 years or more. Among non-users, the main reasons were:

- 32% never being offered
- 25% physicians advising against them
- 17% concerns about use.

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

Symptoms

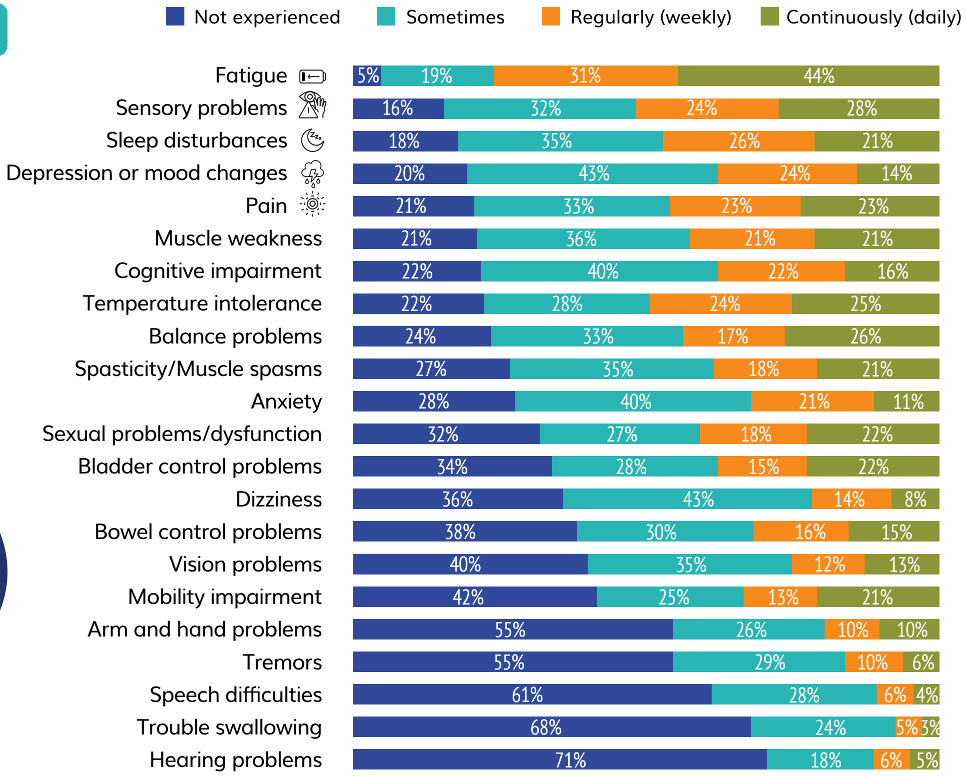
PRESENCE AND PREVALENCE

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

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

99% EXPERIENCED AT LEAST ONE SYMPTOM

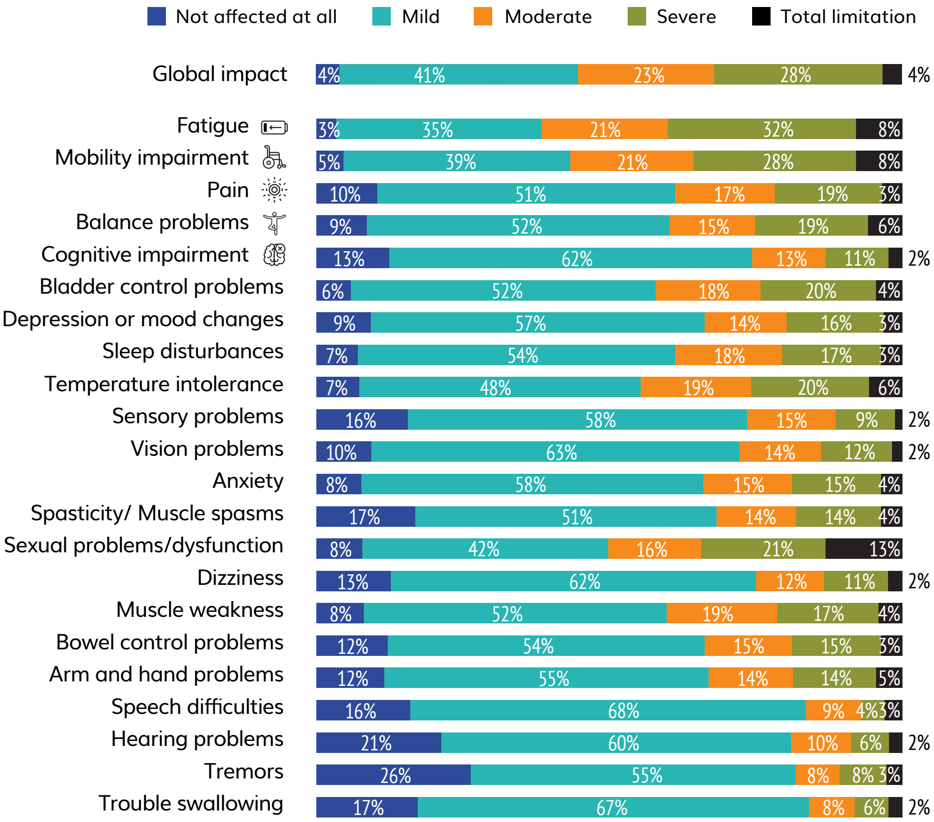
ON AVERAGE **14.4** SYMPTOMS EXPERIENCED TOGETHER



SEVERITY AND IMPACT

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

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



Treatment and care

CARE FOR SYMPTOMS

79%
HAVE ANY CARE/ TREATMENT

21% don't use any care /treatment. The *top reasons* for not using a specific treatment were having no need, they cannot afford the treatment, or treatment was not offered to them.

ON AVERAGE
5.4
TREATMENTS OR CARE

People with MS reported using 5.4 treatments or care on average for their symptoms.

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

Lifestyle changes

Personal life modifications	41%
Physical activity	40%
Dietary changes	28%
Quitting smoking	8%

Medication for symptom management

Prescription medication	62%
Non-prescription medication	11%

Therapy/treatments

Physical therapy	34%
Psychological therapy	19%
Bladder and bowel management	13%
Neuro-cognitive rehabilitation	10%
Occupational therapy	6%
Speech therapy	3%

Social support

Friends and family	35%
Other people with MS	14%
Formal sessions with social worker	3%

Complementary and alternative therapies

Meditation	13%
Dietary supplements	13%
Alternative medicine	8%
Mindfulness	7%
Other alternative therapy	4%

Other

Assistive devices	18%
Home modifications	15%
Diaries and applications	10%
At-home massage device	9%
Other	3%
Service/support animals	3%

Surgery 1%

INVOLVEMENT OF PROFESSIONALS

ON AVERAGE
4.5
HEALTHCARE PROFESSIONALS

People with MS had 4.5 healthcare professionals on average taking care of their MS. 59% reported that their healthcare professionals are coordinating together.

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

Neurologist/ MS neurologist	99%
General practitioner	76%
Nurse/MS nurse	56%
Physiotherapist	46%
Clinical psychologist/ psychiatrist	38%
Urologist	28%
Neuro-ophthalmologist	16%
Rehabilitation physician	15%
Social worker / social care specialist	14%
Occupational therapist	11%
Dietitian	11%
Gastroenterologist	9%
Speech therapist	7%
Pain specialist	5%
Neuro-radiologist	5%
Spasticity specialist	1%
Neuro-otologist	1%
Other professional	15%

CAREGIVER PRESENCE AND ASSISTANCE

77% have no need for assistance

13% do not have caregivers but need assistance

11% have caregivers

Of those caregivers, **89%** were a family, partner, or friend. **22%** were paid professionals*.

89%
ARE A FAMILY, PARTNER OR FRIEND

ON AVERAGE
38.8
HOURS/ WEEK

The caregivers supported people with MS for 38.8 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 (40%) or needing one (27%). People with PPMS reported the most needing a caregiver but not having one (32%) while people with RRMS reported the most not having/needing a caregiver (86%).

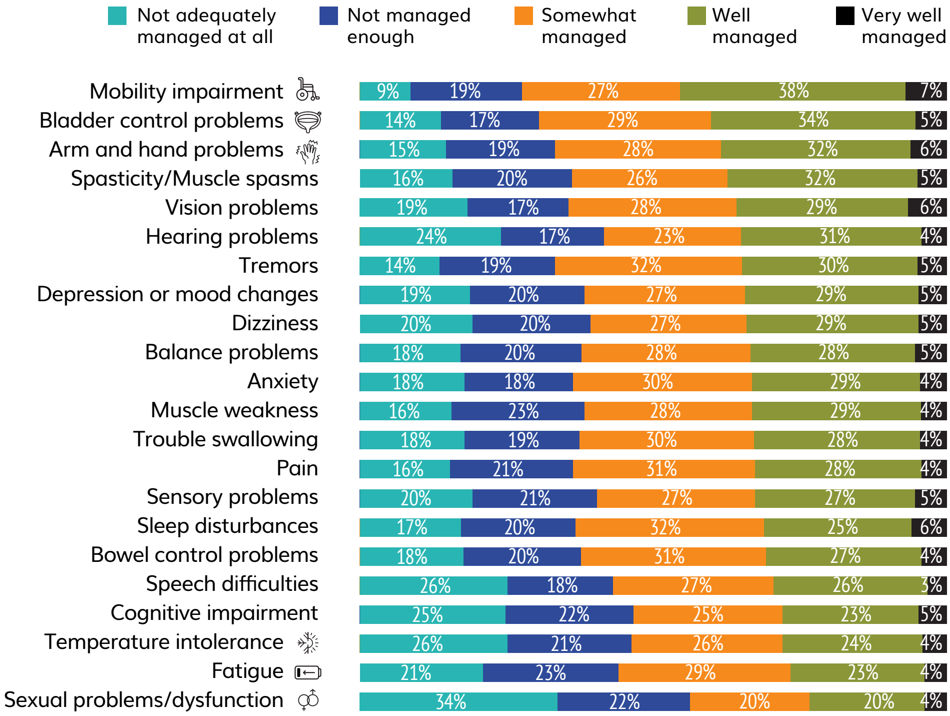
Satisfaction with management of symptoms

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

The *least* well managed symptoms were **sexual problems/dysfunction, fatigue,** and **heat and/or cold intolerance.**

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 Lucía, 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: 0.1

References: [1]Among respondents, 44% were MS society members, 17.6% were linked but not members, and 38.4% 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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