IMSS

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'SOCIEDADE PORTUGUESA DE ESCLEROSE MÚLTIPLA.

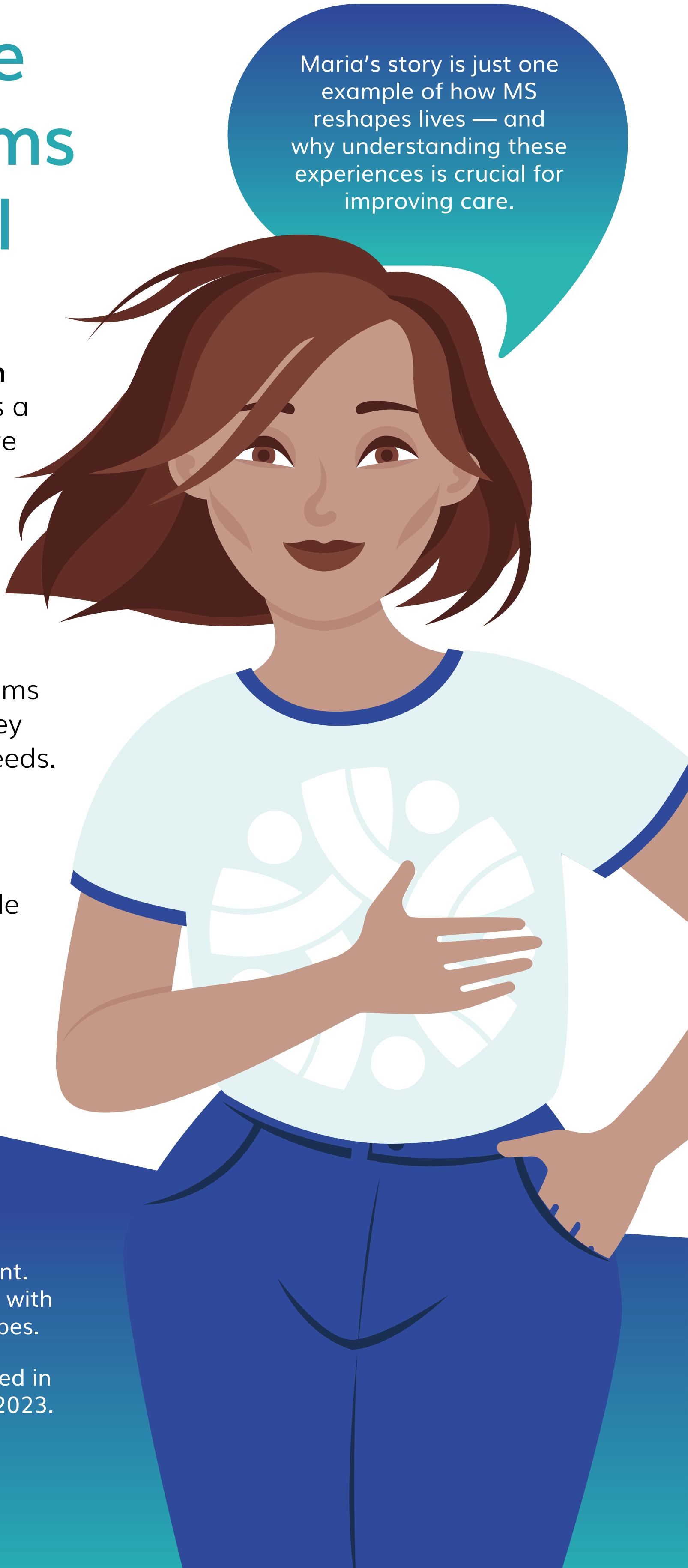
emsp
EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Impact of Multiple Sclerosis Symptoms (IMSS) in Portugal

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 Portugal, **785**[1] people with MS participated in the IMSS survey from May 5 to August 31, 2023.

A Life Changed by MS

Maria had always been full of energy — a mother, an interior designer, and a passionate baker 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, Maria lived with uncertainty, her daily life becoming a patchwork of pain, confusion, and questions without answers.

Participant demographics

44.6
THE MEAN AGE OF PEOPLE WITH MS

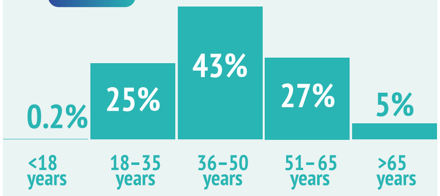
43%
ARE 36–50 YEARS OLD

DUE TO MS
1 in 5
ARE NOT WORKING

65%
HAVE HIGH-LEVEL EDUCATION

83%
LIVE WITH THEIR FAMILY

AGE



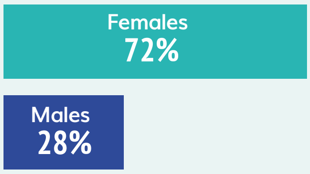
People between **18–35** reported the fewest symptoms, except for anxiety.

Among individuals aged **36-50**, trouble swallowing was reported the least.

Between **51-65**, symptoms increase, with the exception of anxiety.

Over 65, increase in balance problems, muscle weakness, bladder and bowel issues, sexual problems, mobility impairments, arm and hand difficulties, speech challenges, and trouble swallowing.

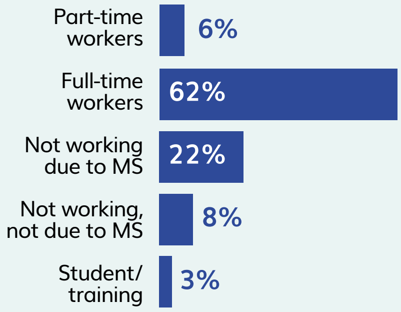
GENDER ‡



Females reported significantly *less* mobility impairment and trouble swallowing, but *more* **fatigue, pain, cognitive impairment, anxiety,** and **dizziness** compared to males.

Males reported significantly *less* fatigue, pain, anxiety and dizziness, but *more* **mobility impairment** than females.

WORKING STATUS



Part-time workers experienced the highest fatigue, pain, depression, mood changes, and anxiety.

Full-time workers reported fewer symptoms.

People not working due to MS reported the most symptoms, except for anxiety.

People not working not due to MS reported high levels most 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 Maria, these questions resonate deeply. Her diagnosis eventually came at age 34, but the journey didn't end there. Her symptoms — fatigue, sensory problems, pain, and sleep 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.

Maria'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 Maria across the continent.

Clinical situation

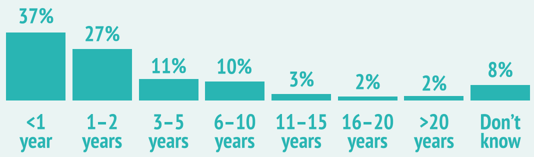
DIAGNOSIS AND SYMPTOM ONSET

56% diagnosed between 18–35 yrs

10.3 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 3.1 YEARS

34.3 average diagnosis age

TYPES OF MS

72% **RRMS,** Relapsing Remitting MS

13% **PPMS,** Primary Progressive MS

8% **SPMS,** Secondary Progressive MS

7% **Unsure of their MS type**

DISABILITY LEVELS

18% of the respondents had mild disability while 34% had moderate disability and 11% had severe disability. People living with PPMS reported more moderate (56%) and severe disability (23%) compared to RRMS. People with SPMS reported the most severe disability (57%)[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 SPMS (23%)[3].

USE OF DMDs

84% of respondents have used **Disease Modifying Drugs** (DMDs), with 77% currently using them. 63% reported *less* than a 1-year delay to start DMDs, while 10% experienced delays of 6 years or more. Among non-users, the main reasons were:

- 22% concerns about use
- 52% never being offered

ON AVERAGE **1.7** YEARS DELAY BETWEEN DIAGNOSIS AND DMD START

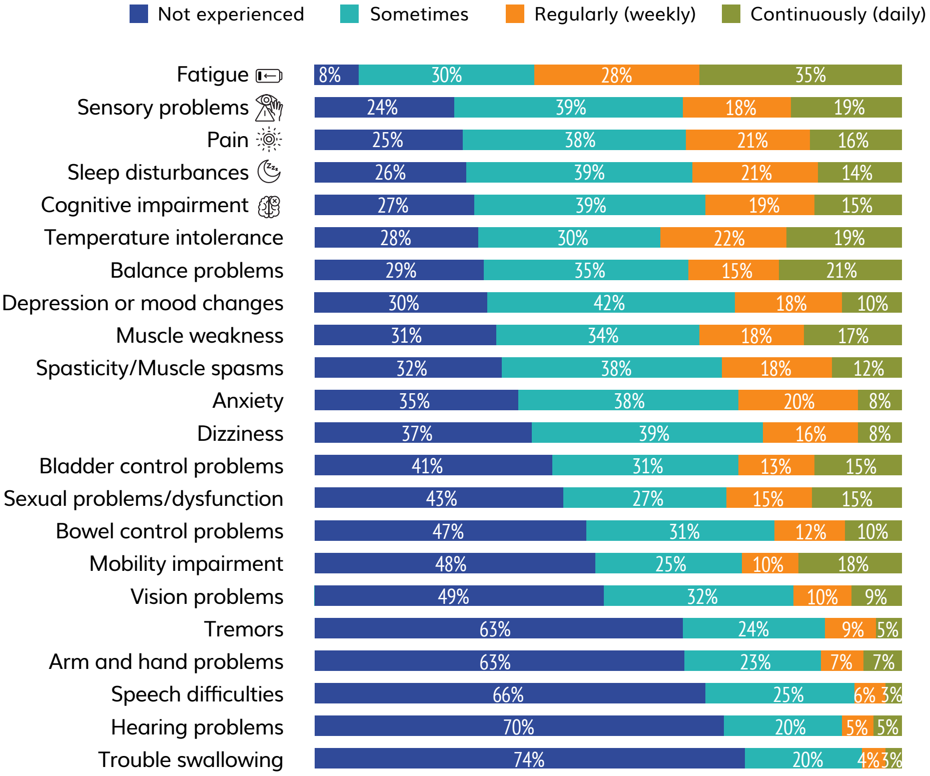
Symptoms

PRESENCE AND PREVALENCE

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

99% EXPERIENCED AT LEAST ONE SYMPTOM

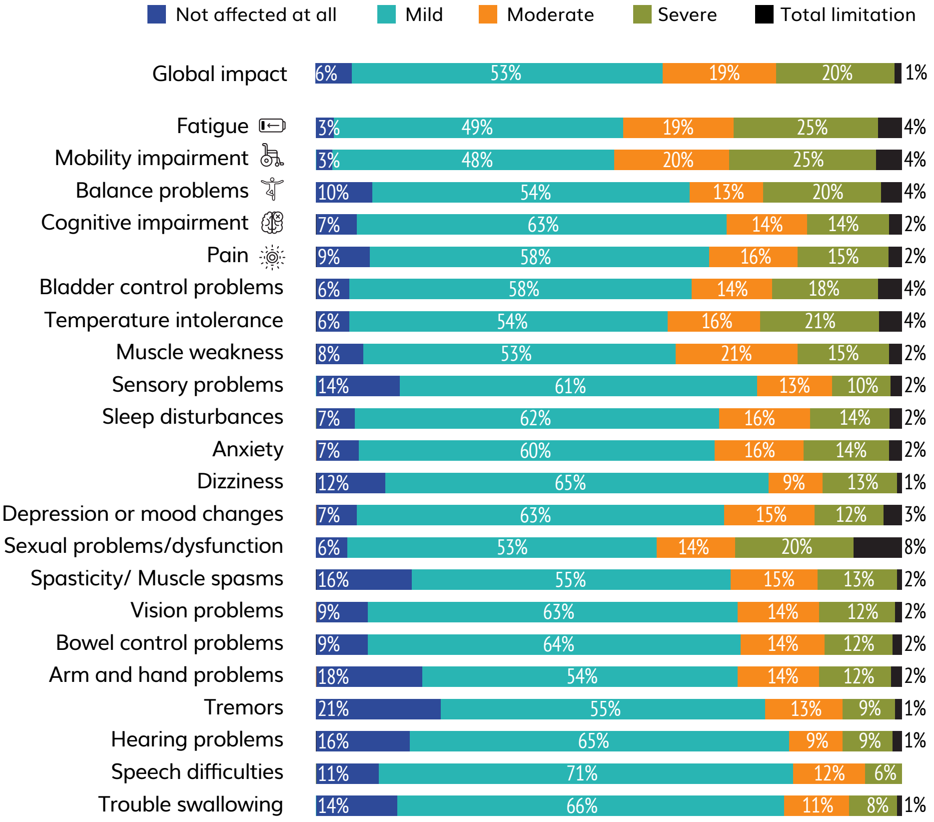
ON AVERAGE **13** SYMPTOMS EXPERIENCED TOGETHER



SEVERITY AND IMPACT

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

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



Treatment and care

CARE FOR SYMPTOMS

81% HAVE ANY CARE/ TREATMENT

19% don't use any care /treatment. The *top reasons* for not using a specific treatment were having no need, they cannot afford this treatment, or treatment was not offered to them.

ON AVERAGE **4.5** TREATMENTS OR CARE

People with MS reported using 4.5 treatments or care on average for their symptoms.

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

Lifestyle changes

- Physical activity 40%
- Personal life modifications 37%
- Dietary changes 30%
- Quitting smoking 7%

Medication for symptom management

- Prescription medication 67%
- Non-prescription medication 12%

Therapy/treatments

- Physical therapy 25%
- Psychological therapy 15%
- Bladder and bowel management 9%
- Neuro-cognitive rehabilitation 6%
- Occupational therapy 3%
- Speech therapy 1%

Social support

- Friends and family 22%
- Other people with MS 6%
- Formal sessions with social worker 2%

Complementary and alternative therapies

- Dietary supplements 12%
- Alternative medicine 12%
- Meditation 9%
- Other alternative therapy 6%
- Mindfulness 5%

Other

- Diaries and applications 10%
- Assistive devices 10%
- Home modification 10%
- At-home massage devices 5%
- Other 2%
- Service/support animals 1%

Surgery 1%

INVOLVEMENT OF PROFESSIONALS

ON AVERAGE **4.1** HEALTHCARE PROFESSIONALS

People with MS had 4.1 healthcare professionals on average taking care of their MS. 70% reported that their healthcare professionals are coordinating together.

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

Neurologist/ MS neurologist	99%
Nurse/MS nurse	69%
General practitioner	53%
Physiotherapist	36%
Clinical psychologist/ psychiatrist	34%
Neuro-ophthalmologist	24%
Urologist	21%
Dietitian	16%
Rehabilitation physician	11%
Social worker / social care specialist	8%
Occupational therapist	7%
Neuro-radiologist	6%
Gastroenterologist	6%
Speech therapist	3%
Pain specialist	3%
Neuro-otologist	3%
Spasticity specialist	1%
Other professional	9%

CAREGIVER PRESENCE AND ASSISTANCE

79% have no need for assistance

12% do not have caregivers but need assistance

9% have caregivers

Of those caregivers, **83%** were a family, partner, or friend. **24%** were paid professionals*.

83% ARE A FAMILY, PARTNER OR FRIEND

ON AVERAGE **31.2** HOURS/ WEEK

The caregivers supported people with MS for 31.2 hours per week on average. **93%** 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 (23%) while people with RRMS reported the most not having and not needing a caregiver (86%). People with PPMS reported not having but needing one (30%).

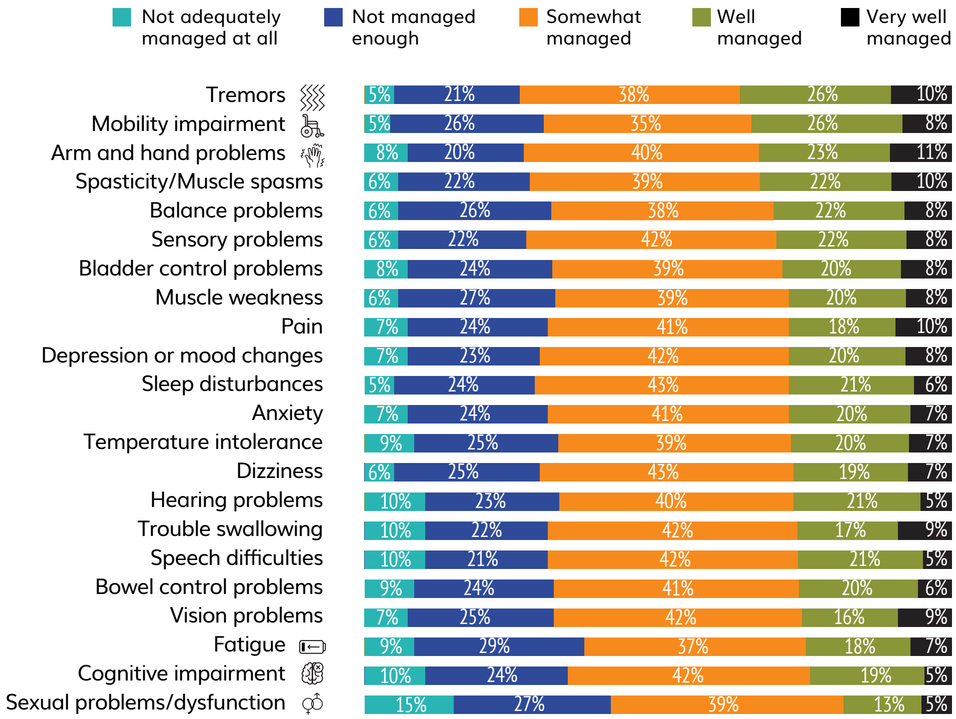
Satisfaction with management of symptoms

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

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

1 in 3

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 Maria, 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%, prefer not to say: 0.1%

References: [1] Among respondents, 55% were MS society members, 12% were linked but not members, and 33% 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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