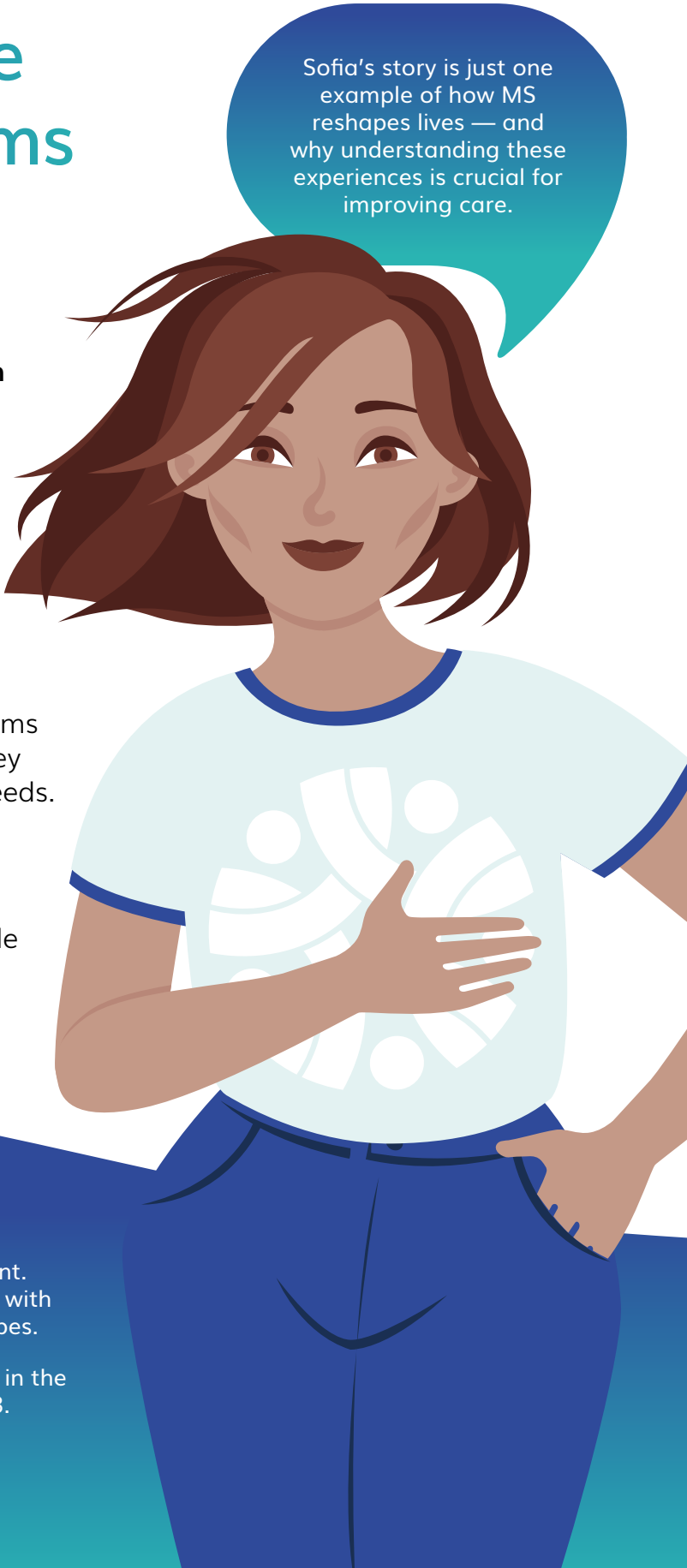


Impact of Multiple Sclerosis Symptoms (IMSS) in Italy

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 140,000 people in Italy and 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.



Sofia'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.



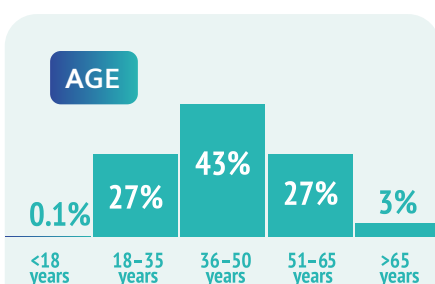
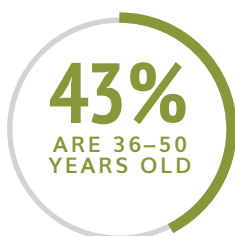
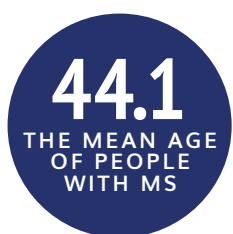
In Italy, 1,371¹ people with MS participated in the IMSS survey from May 5 to August 31, 2023.

A Life Changed by MS

Sofia had always been full of energy — a project manager and a passionate reader 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. Sofia tried to manage her symptoms, but they worsened. Everyday tasks became difficult. Her doctor first attributed this to stress and advised waiting. As months passed, uncertainty and pain took over. Eventually, she was referred to a neurologist who diagnosed her with MS.



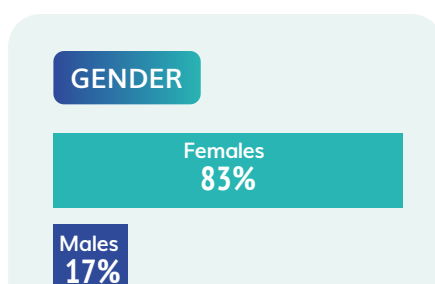
Participant demographics



People between **18-35** reported the most anxiety, depression/mood changes and cognitive impairment.

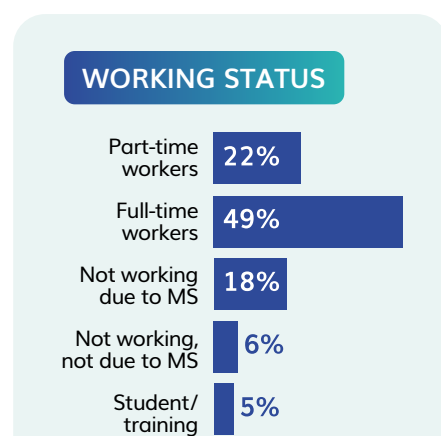
Individuals aged **36-50** reported spasticity problems and bladder control problems while reporting the highest sleep disturbances, dizziness and vision problems.

Between **51-65**, the lowest anxiety, but all other symptoms start to emerge significantly.



Females reported significantly fewer mobility problems and arm/hand problems but **more sleep disturbances, anxiety, cognitive impairment, dizziness, and speech problems** compared to males.

Males reported significantly fewer sleep disturbances, anxiety, dizziness, cognitive impairment, dizziness, and speech problems, but **more mobility impairment** than females.



Part-time workers experienced more spasticity problems.

Full-time workers reported less presence of symptoms.

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

Students and people in training reported the highest depression/mood changes, anxiety, and cognitive impairment.

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 Sofia, these questions resonate deeply. She eventually got her diagnosis, but the journey didn't end there. Her symptoms — fatigue, muscle weakness, tingling fingers, and bladder 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.

Sofia'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: early symptoms being disregarded, disjointed 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 Sofia across the continent.

Clinical situation

DIAGNOSIS AND SYMPTOM ONSET

57%

diagnosed between 18–35 yrs

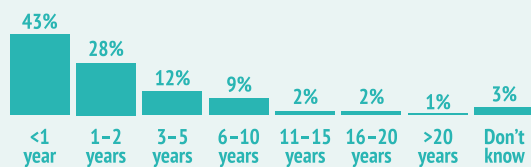
10.3 YEARS

average disease duration

1 in 3

have at least 1 additional illnesses

Delay from symptom onset to diagnosis



31.2

symptom onset age

AVERAGE DELAY OF 2.5 YEARS

33.8

average diagnosis age

TYPES OF MS

77%

RRMS, Relapsing Remitting MS

8%

PPMS, Primary Progressive MS

9%

SPMS, Secondary Progressive MS

6%

Unsure of their MS type

DISABILITY LEVELS

15% of the respondents had mild disability while 37% had moderate disability and 13% had severe disability. People living with PPMS reported the most severe disability (51%) while people with SPMS reported the most moderate disability (43%) and comparably high severe disability (49%)².

QUALITY OF LIFE

The majority of respondents had no or slight problems, while 6.3% were experiencing moderate or severe problems affecting their quality of life. The quality of life deteriorated more among people with PPMS (14%) and people with SPMS (24%)³.

USE OF DMDs

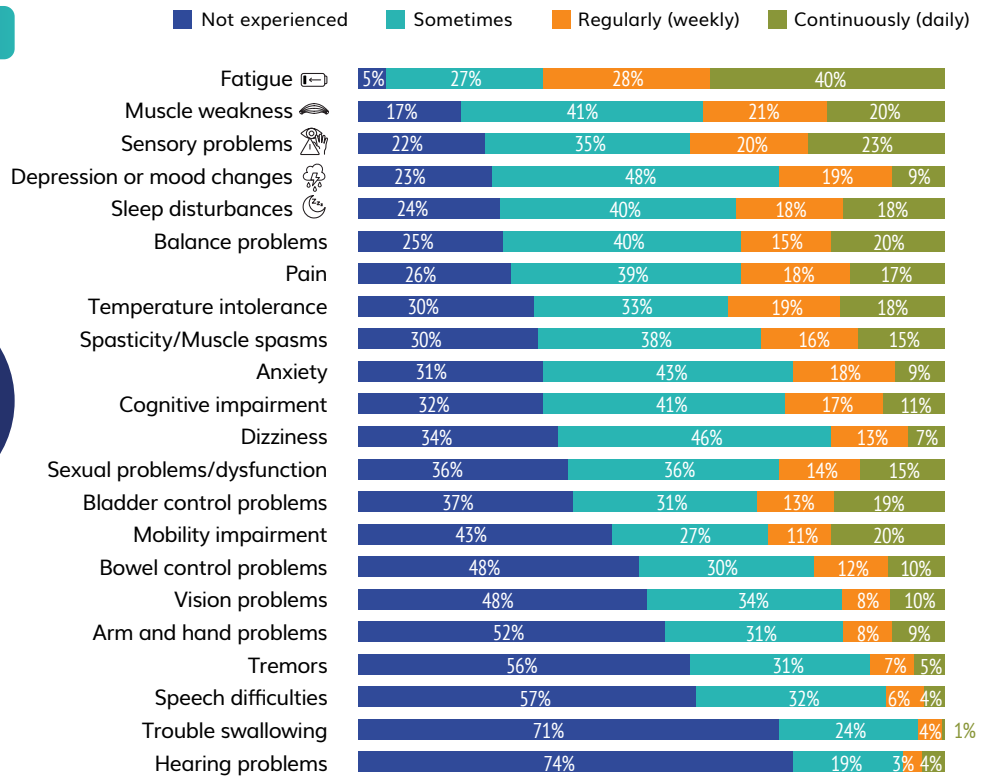
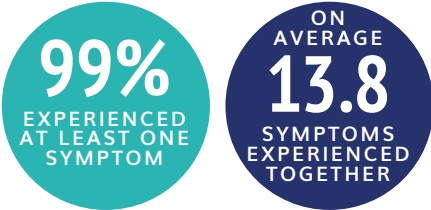
88% of respondents have used **Disease Modifying Drugs** (DMDs), with 76% currently using them. Among non-users, the main reasons were:

- 15% concerns about use
- 39% never being offered
- 10% physicians advising against them.

Symptoms

PRESENCE AND PREVALENCE

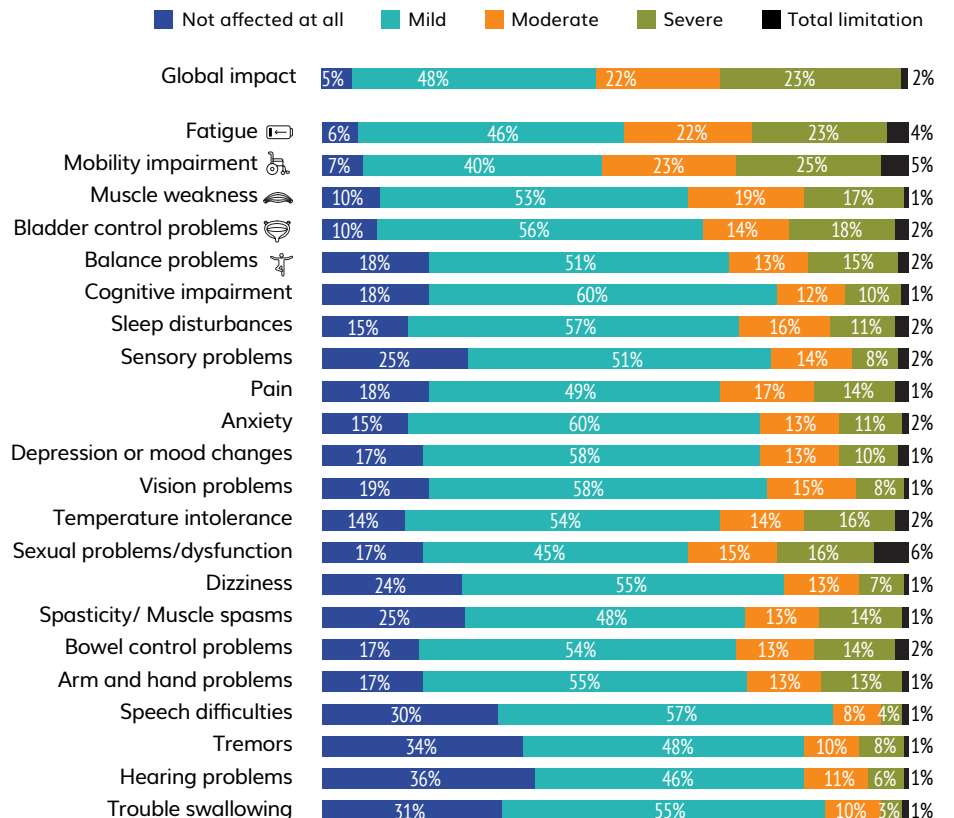
The symptoms reported the most were **fatigue, muscle weakness, sensory problems, depression/mood changes, and sleep disturbances.**



SEVERITY AND IMPACT

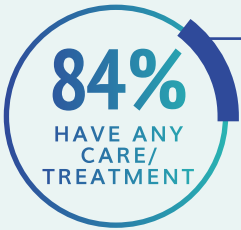
The symptoms that were affecting the daily lives of people with MS were **fatigue, mobility impairment, muscle weakness, bladder control problems, and temperature intolerance**⁴.

The top 3 most debilitating symptoms were **fatigue, mobility impairment, and muscle weakness**⁵.



Treatment and care

CARE FOR SYMPTOMS



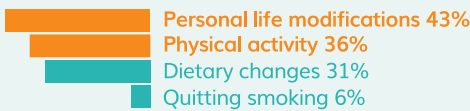
16% don't use any care /treatment. The top reasons for not using a specific treatment were treatment was not offered to them, having no need, or they cannot afford this treatment.



People with MS reported using 4.7 treatments or care on average for their symptoms.

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

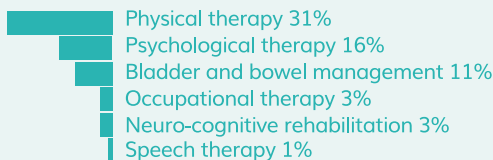
Lifestyle changes



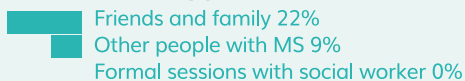
Medication for symptom management



Therapy/treatments



Social support



Complementary and alternative therapies



Other



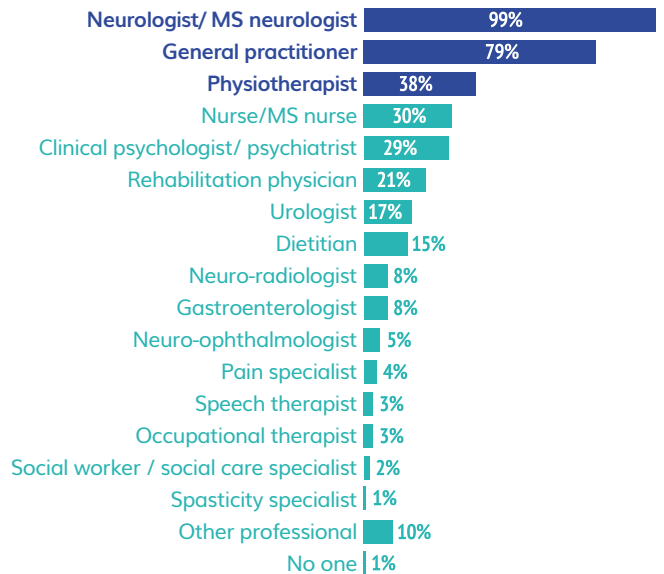
Surgery 1%

INVOLVEMENT OF PROFESSIONALS



People with MS had 3.7 healthcare professionals on average taking care of their MS. 48% reported that their healthcare professionals are coordinating together.

The most involved professionals were **neurologist, general practitioner and physiotherapist***



CAREGIVER PRESENCE AND ASSISTANCE



76% have no need for assistance

12% do not have caregivers but need assistance

13% have caregivers

Of those caregivers, **92%** were a family, partner, or friend. **15%** were paid professionals*.



The caregivers supported people with MS for 16.7 hours per week on average. **84%** of respondents mentioned that the carer was of **great or good** help to them.

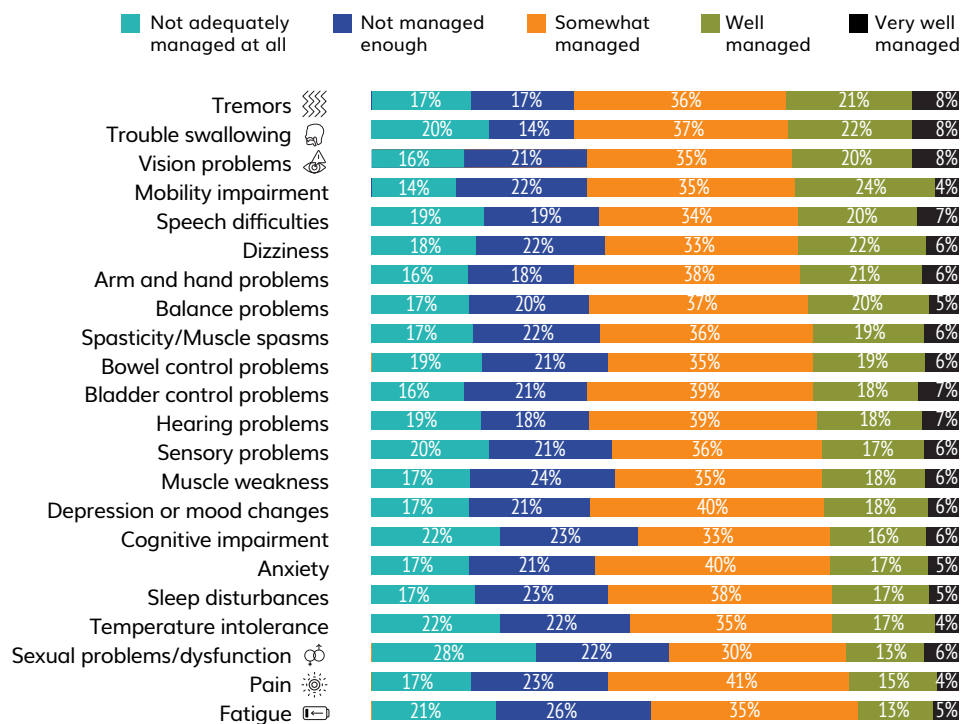
People living with SPMS and PPMS reported similar caregiver needs: having a caregiver (39% vs 38%) or needing one (both 22%) while people with RRMS reported the most not having and not needing a caregiver (83%).

Satisfaction with management of symptoms

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

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

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 Sofia, 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%, don't know: 0.2%.

References: ¹Among respondents, 25.7% were MS society members, 34% were linked but not members, and 40.3% 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).

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