IMSS

Savez društava
multiple skleroze
Hrvatske

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

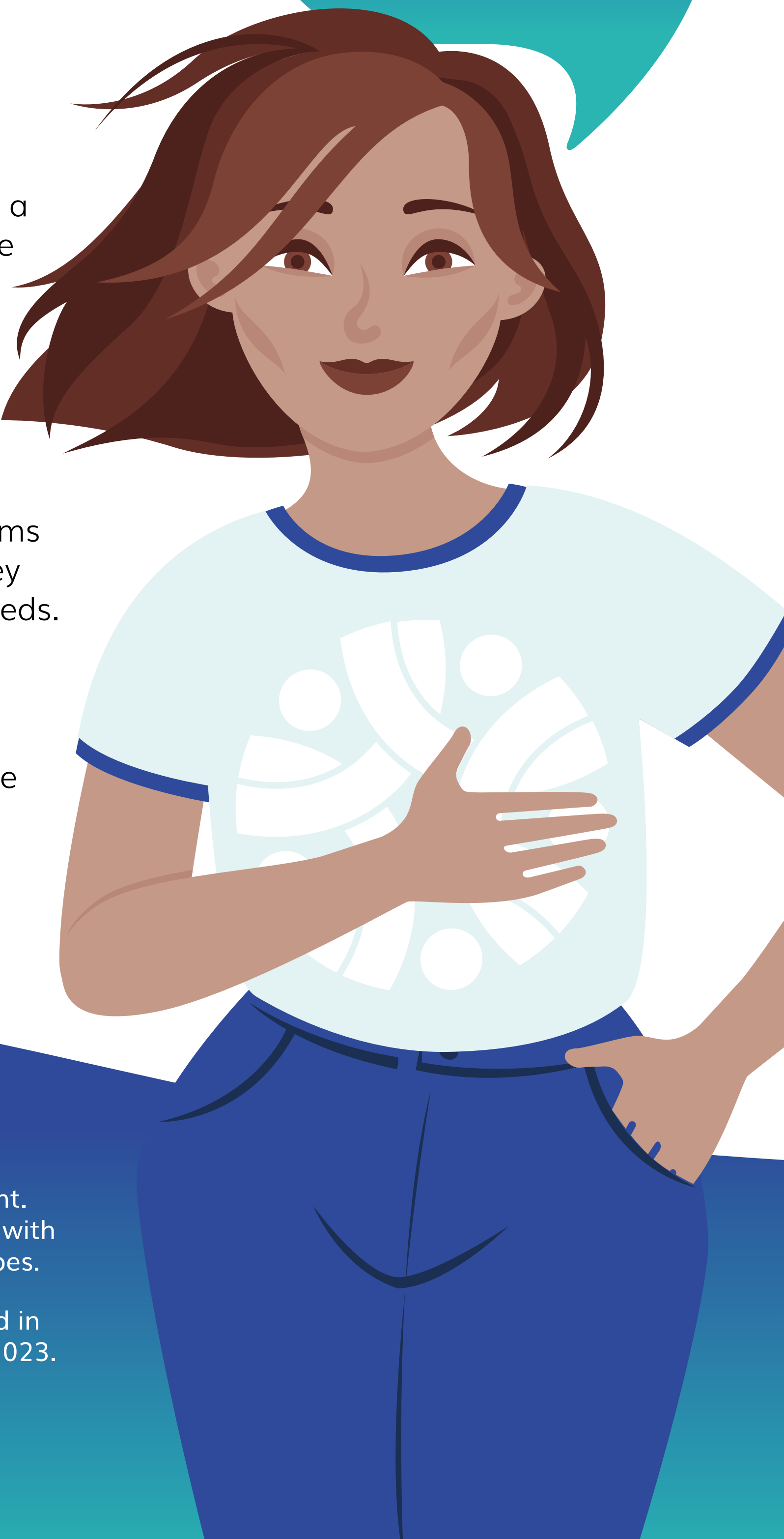
Impact of Multiple Sclerosis Symptoms (IMSS) in Croatia

Mia'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 Croatia, **224**[1] people with MS participated in the IMSS survey from May 5 to August 31, 2023.

A Life Changed by MS

Mia had always been full of energy—a mother, a photographer and a passionate hiker in her free time. But at 30, 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 four long years, Mia 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

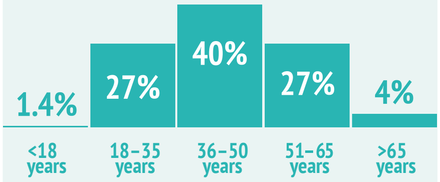
40% ARE 36–50 YEARS OLD

DUE TO MS **1 in 5** ARE NOT WORKING

65% HAVE HIGH-LEVEL EDUCATION

82% LIVE WITH THEIR FAMILY

AGE



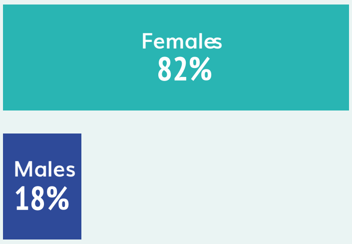
People between **18–35** reported the least balance problems, pain, sleep disturbances, muscle weakness, spasticity, bladder and bowel problems, sexual problems, mobility impairment and tremors.

Individuals aged **36–50** experienced the most sleep disturbances and the least tremors.

Between **51-65**, the most dizziness, bladder and bowel problems.

Over 65, most of the problems reported between 51 and 65 continue.

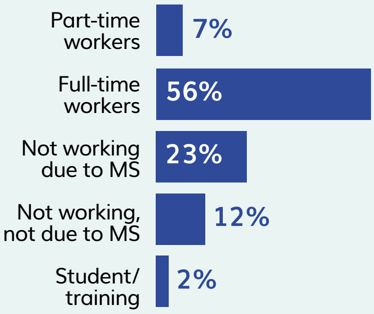
GENDER



Females reported *fewer* speech difficulties but *more* **cognitive impairment** compared to males.

Significant differences between genders were not observed for most symptoms.

WORKING STATUS



Full-time workers significantly reported the least presence of almost all symptoms.

The sample size of all other groups was too small to draw any conclusions.

Understanding MS Across Europe

The 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 Mia, these questions resonate deeply. Her diagnosis eventually came at age 34, but the journey didn't end there. Her symptoms—fatigue, sensory problems, mood changes, 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 to help people like her.

Mia'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, they could push for policies that prioritize comprehensive, equitable care for people like Mia across the continent.

Clinical situation

DIAGNOSIS AND SYMPTOM ONSET

57% 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

29.5 symptom onset age

AVERAGE DELAY OF 4 YEARS

33.7 average diagnosis age

TYPES OF MS

72% **RRMS,** Relapsing Remitting MS

10% **PPMS,** Primary Progressive MS

10% **SPMS,** Secondary Progressive MS

8% Unsure of their MS type

DISABILITY LEVELS

22% of the respondents had mild disability while 42% had moderate disability and 11% had severe disability. Disability was most common in RRMS (46%), while severe disability was highest in SPMS (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. Quality of life declined most significantly in SPMS (77%) and PPMS (32%)[3].

USE OF DMDs

82% of respondents have used **Disease Modifying Drugs** (DMDs), with 64% currently using them. 38% reported *less* than a 1-year delay to start DMDs, while 16% experienced delays of 6 years or more. Among non-users, the main reasons were:

- 38% concerns about use
- 14% never being offered
- 9% physicians advising against them
- 43% mentioned 'other reasons', prompting further investigation.

ON AVERAGE **3** YEARS DELAY BETWEEN DIAGNOSIS AND DMD START

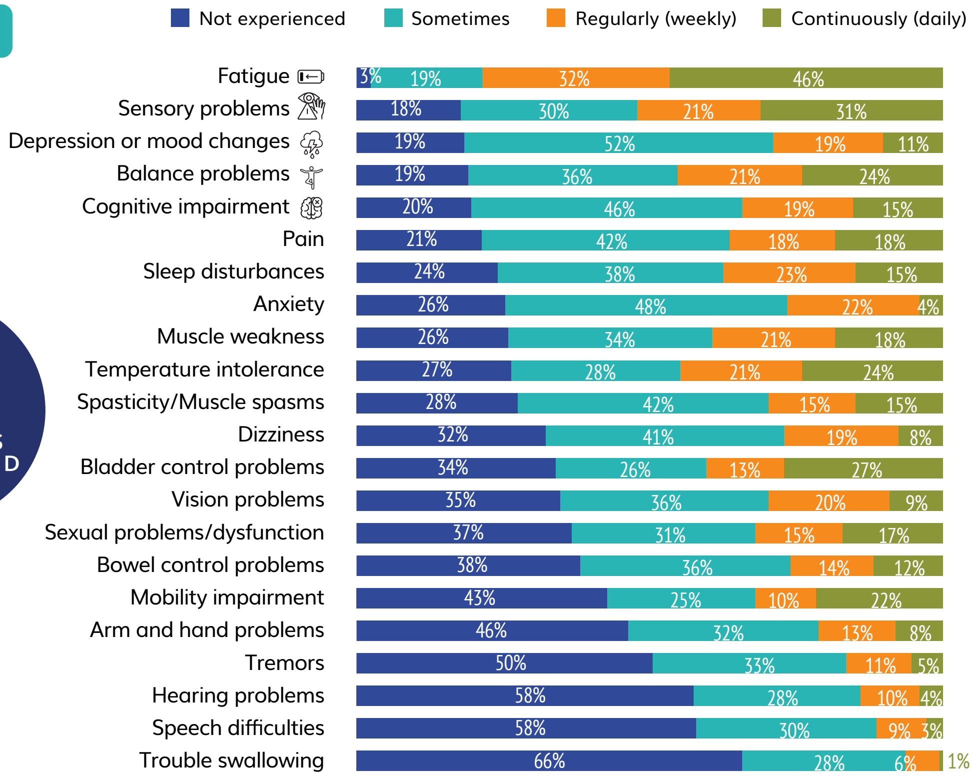
Symptoms

PRESENCE AND PREVALENCE

The symptoms reported the *most* were **fatigue, sensory problems, depression/mood changes, balance problems** and **cognitive impairment.**

99%
EXPERIENCED AT LEAST ONE SYMPTOM

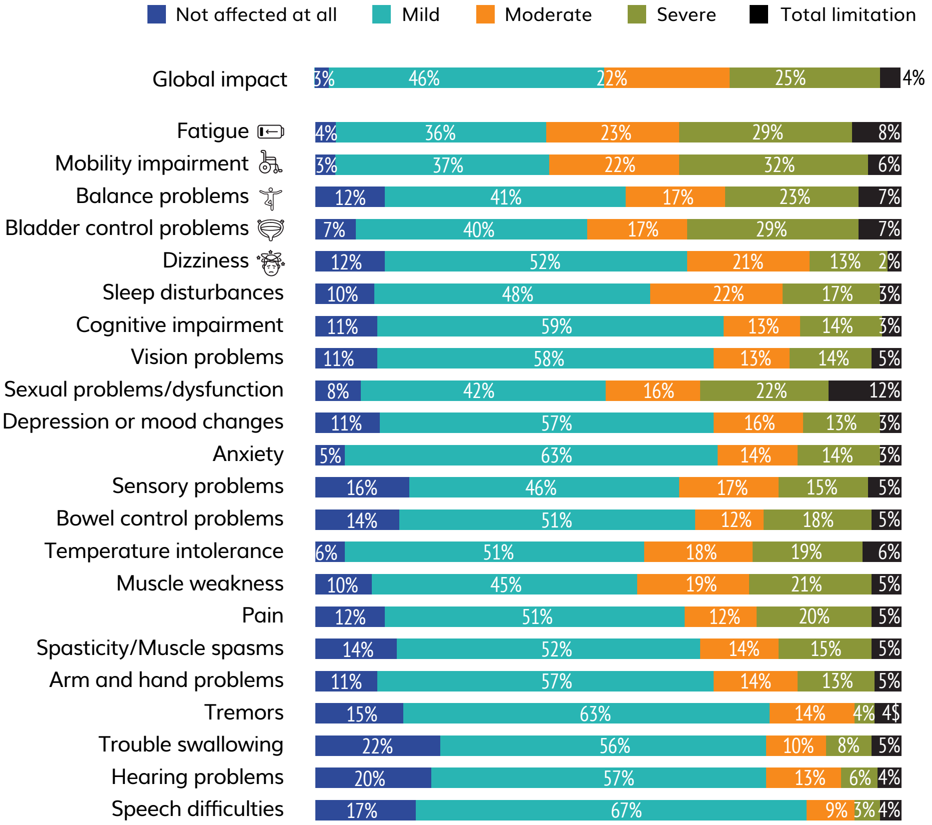
ON AVERAGE
14.7
SYMPTOMS EXPERIENCED TOGETHER



SEVERITY AND IMPACT

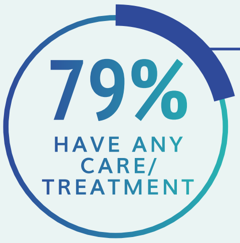
The symptoms that were affecting the daily lives of people with MS were **fatigue, mobility impairment, anxiety, heat/cold sensitivity** and **bladder control problems**[4].

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



Treatment and care

CARE FOR SYMPTOMS



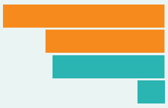
21% don't use any care /treatment. The *top reasons* for not using a specific treatment were having no need, they cannot afford this treatment or treatment was not offered to them.

ON AVERAGE
6.1
TREATMENTS OR CARE

People with MS reported using 6.1 treatments or care on average for their symptoms.

The *most* used treatments were*: **prescription medication, personal life modifications, dietary supplements, physical therapy,** and **support from friends and family.**

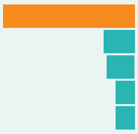
Lifestyle changes


Personal life modifications 48%
Physical activity 35%
Dietary changes 33%
Quitting smoking 8%

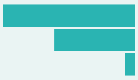
Medication for symptom management


Prescription medication 48%
Non-prescription medication 31%

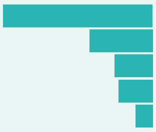
Therapy/treatments


Physical therapy 39%
Psychological therapy 9%
Bladder and bowel management 8%
Neuro-cognitive rehabilitation 6%
Occupational therapy 6%

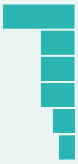
Social support


Friends and family 39%
Other people with MS 24%
Formal sessions with social worker 3%

Complementary and alternative therapies


Dietary supplements 44%
Alternative medicine 19%
Mindfulness 11%
Meditation 10%
Other alternative therapy 5%

Other

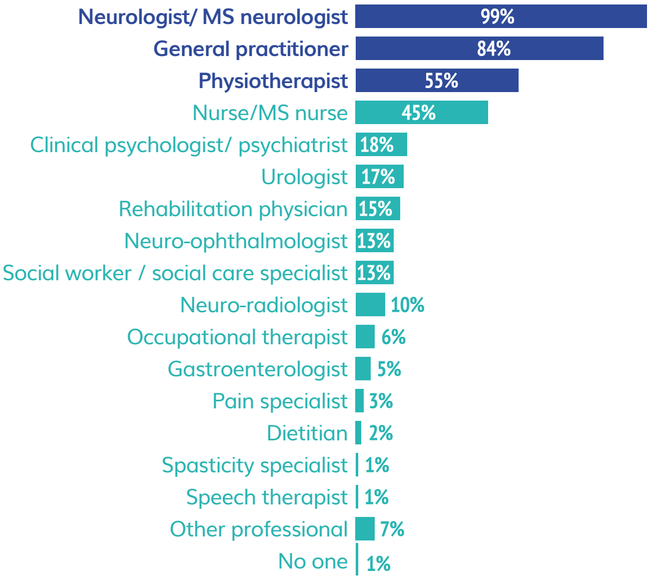

Assistive devices 11%
At-home massage devices 10%
Home modification 10%
Service/support animals 10%
Diaries and applications 7%
Other 5%

INVOLVEMENT OF PROFESSIONALS

ON AVERAGE
3.9
HEALTHCARE PROFESSIONALS

People with MS had 3.9 medical professionals on average taking care of their MS. 57% of people with MS 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

14% do not have caregivers but need assistance

10% have caregivers

Of those caregivers, **86%** were a family, partner, or friend. **41%** were paid professionals*.

86%
ARE A FAMILY, PARTNER OR FRIEND

ON AVERAGE
15.6
HOURS/ WEEK

The caregivers supported people with MS for 15.6 hours per week on average. **85%** of respondents mentioned that the carer was of **great or good** help to them.

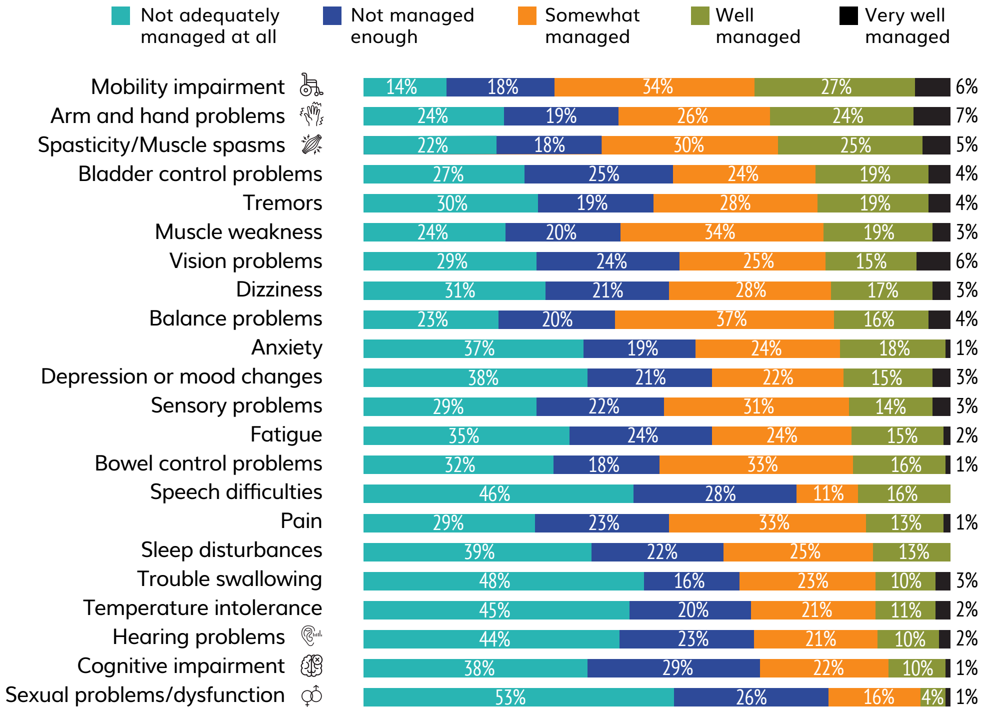
People with SPMS frequently had (42%) or needed caregivers (33%), compared to 88% of people with RRMS who reported not needing a caregiver.

Satisfaction with management of symptoms

The *most* well managed symptoms were **mobility impairment, arm and hand problems,** and **spasticity/muscle spasms.**

The *least* well managed symptoms were **sexual problems/dysfunction, cognitive impairment,** and **hearing 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 Mia, 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, 55% were MS society members, 19% were linked but not members, and 26% 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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