IMSS

združenje multiple skleroze
slovenije

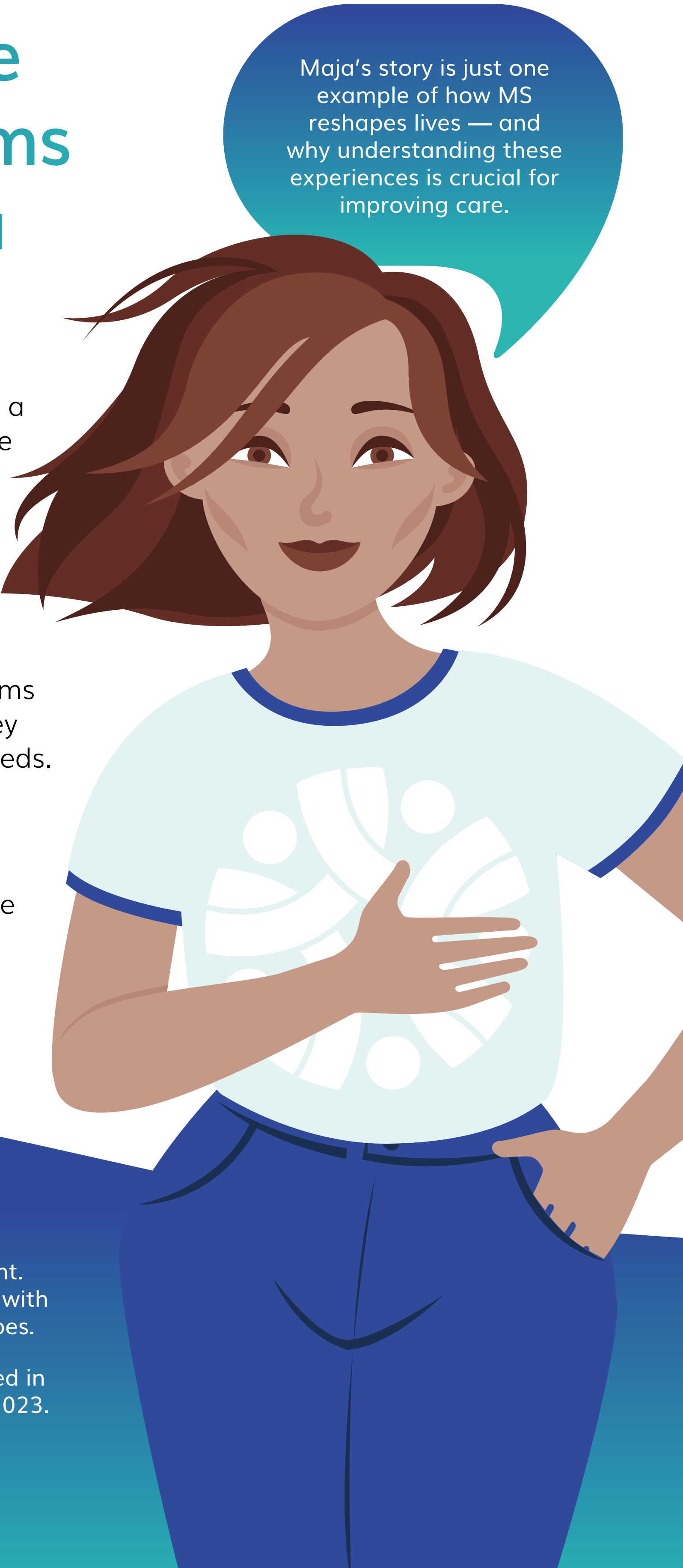
emsp EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Impact of Multiple Sclerosis Symptoms (IMSS) in Slovenia

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.



Maja'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 Slovenia, **618**[1] people with MS participated in the IMSS survey from May 5 to August 31, 2023.

A Life Changed by MS

Maja had always been full of energy — a pharmacist and a passionate runner in her free time. But at 29, 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 four and a half years, Maja lived with uncertainty, her daily life becoming a patchwork of pain, confusion, and questions without answers.

Participant demographics

44.7 THE MEAN AGE OF PEOPLE WITH MS

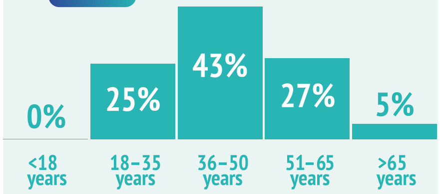
43% ARE 36–50 YEARS OLD

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

65% HAVE HIGH-LEVEL EDUCATION

84% LIVE WITH THEIR FAMILY

AGE



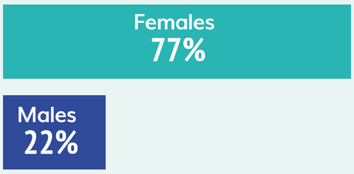
People between **18–35** reported low presence of all symptoms.

Individuals aged **36–50** experienced the lowest sleep disturbances.

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

Over 65, most of the problems reported between 51 and 65 continue, with the highest for all symptom.

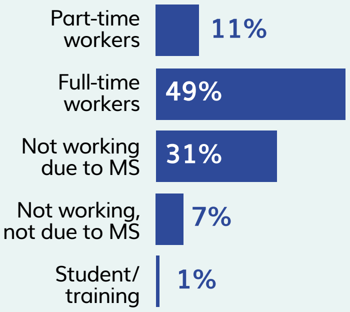
GENDER



Females reported significantly *fewer* mobility impairment, sexual problems and tremors, but *more* **sensory problems, dizziness, vision problems,** and **anxiety** compared to males.

Males reported significantly *fewer* sensory problems, but *more* **mobility impairment, sexual problems** and **tremors** than females.

WORKING STATUS



Part-time workers experienced the highest sensory problems and spasticity/muscle spasms.

Full-time workers reported significantly less symptoms.

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

People not working not due to MS reported more pain, mobility impairment and trouble swallowing.

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 Maja, these questions resonate deeply. Her diagnosis eventually came at age 34, but the journey didn't end there. Her symptoms — fatigue, cold sensitivity, balance problems, and sensory 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.

Maja'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 Maja across the continent.

Clinical situation

DIAGNOSIS AND SYMPTOM ONSET

54% diagnosed between 18–35 yrs

10.6 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 4.4 YEARS

34.1 average diagnosis age

TYPES OF MS

62%	17%	13%	8%
RRMS, Relapsing Remitting MS	**PPMS,** Primary Progressive MS	**SPMS,** Secondary Progressive MS	Unsure of their MS type

DISABILITY LEVELS

Overall, 14% of the respondents had mild disability while 39% had moderate disability and 21% had severe disability. People living with PPMS reported the most moderate (49%) disability and severe disability (46%) compared to RRMS while people with SPMS reported the most severe disability (71%)[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 (19%) and people with SPMS (34%)[3].

USE OF DMDs

82% of respondents have used **Disease Modifying Drugs** (DMDs), with 64% currently using them. 52% 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:

- 24% concerns about use
- 42% never being offered
- 12% physicians advising against them.

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

Symptoms

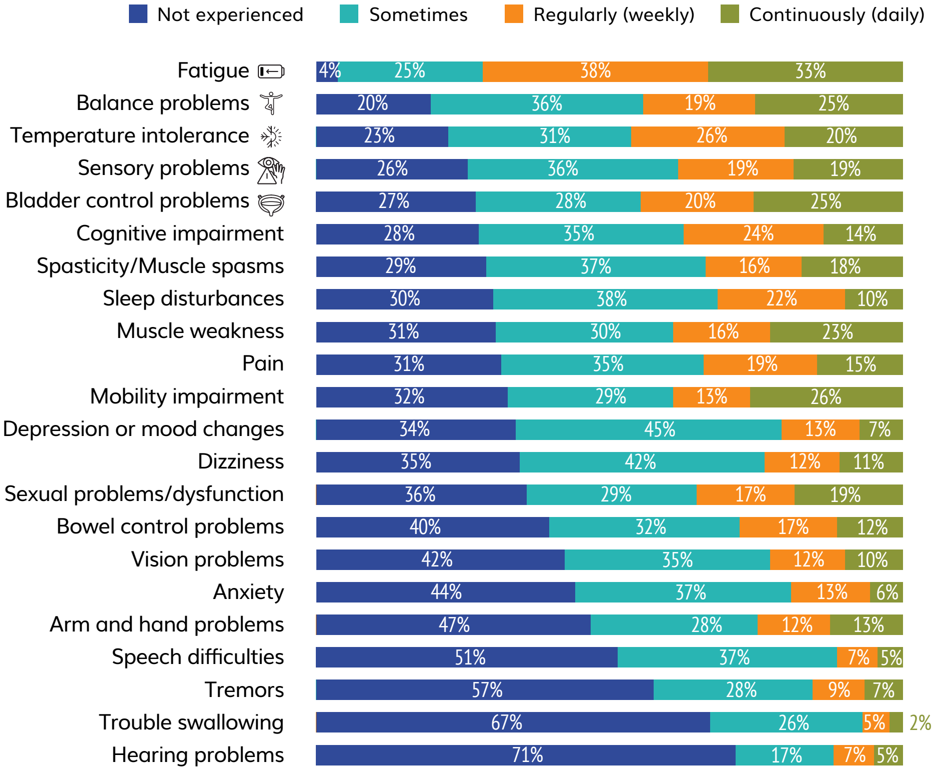
PRESENCE AND PREVALENCE

The symptoms reported the *most* were **fatigue, balance problems, heat or cold intolerance, sensory problems,** and **bladder control problems.**

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

99% EXPERIENCED AT LEAST ONE SYMPTOM

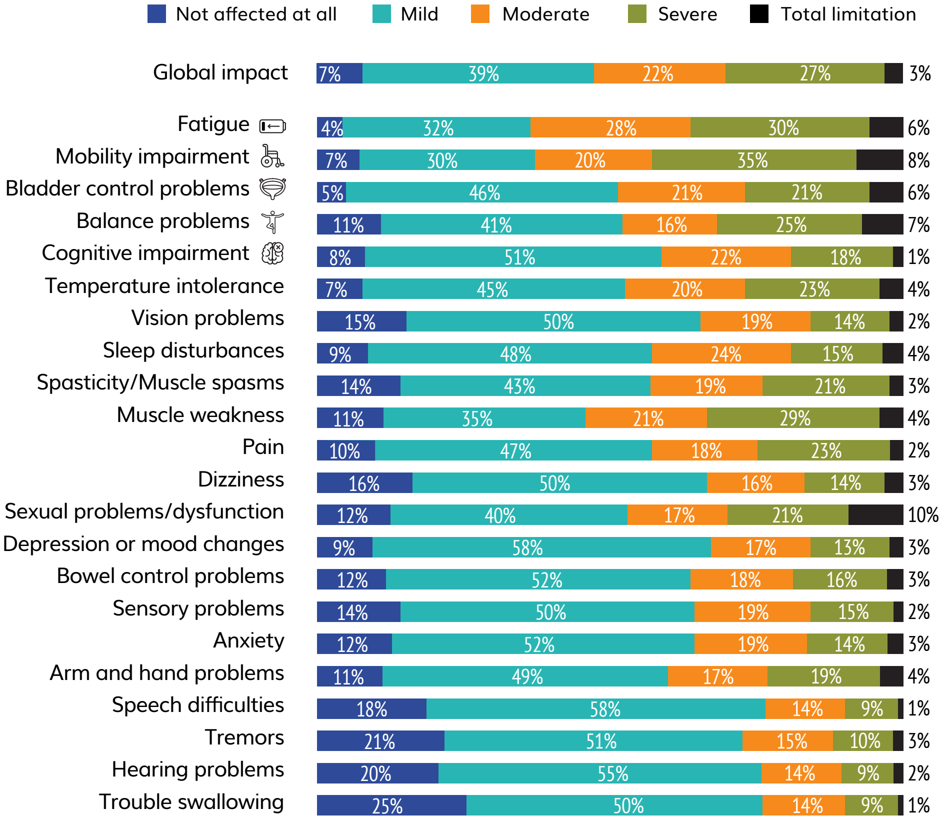
ON AVERAGE **14** SYMPTOMS EXPERIENCED TOGETHER



SEVERITY AND IMPACT

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

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



Treatment and care

CARE FOR SYMPTOMS

87%
HAVE ANY CARE/ TREATMENT

13% 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
6.5
TREATMENTS OR CARE

People with MS reported using 6.5 treatments or care on average for their symptoms.

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

Lifestyle changes

- **Personal life modifications 47%**
- **Physical activity 47%**
- Dietary changes 35%
- Quitting smoking 7%

Medication for symptom management

- **Prescription medication 67%**
- Non-prescription medication 26%

Therapy/treatments

- Physical therapy 38%
- Psychological therapy 14%
- Bladder and bowel management 10%
- Occupational therapy 10%
- Neuro-cognitive rehabilitation 4%
- Speech therapy 1%

Social support

- **Friends and family 47%**
- Other people with MS 22%
- Formal sessions with social worker 2%

Complementary and alternative therapies

- Dietary supplements 43%
- Alternative medicine 26%
- Meditation 18%
- Mindfulness 10%
- Other alternative therapy 9%

Other

- Assistive devices 24%
- At-home massage device 19%
- Home modifications 15%
- Other 7%
- Diaries and applications 6%
- Service/support animals 4%

Surgery 2%

INVOLVEMENT OF PROFESSIONALS

ON AVERAGE
4.4
HEALTHCARE PROFESSIONALS

People with MS had 4.4 healthcare professionals on average taking care of their MS. 67% reported that their healthcare professionals are coordinating together.

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

Neurologist/ MS neurologist	98%
General practitioner	90%
Nurse/MS nurse	69%
Physiotherapist	47%
Occupational therapist	24%
Clinical psychologist/ psychiatrist	24%
Rehabilitation physician	20%
Urologist	17%
Neuro-radiologist	8%
Social worker / social care specialist	8%
Neuro-ophthalmologist	8%
Gastroenterologist	8%
Pain specialist	5%
Speech therapist	3%
Dietitian	3%
Spasticity specialist	1%
Other professional	6%
No one	1%

CAREGIVER PRESENCE AND ASSISTANCE

71% have no need for assistance

18% do not have caregivers but need assistance

10% have caregivers

Of those caregivers, **63%** were a family, partner, or friend. **49%** were paid professionals*.

3 in 5
ARE A FAMILY, PARTNER OR FRIEND

ON AVERAGE
53.5
HOURS/ WEEK

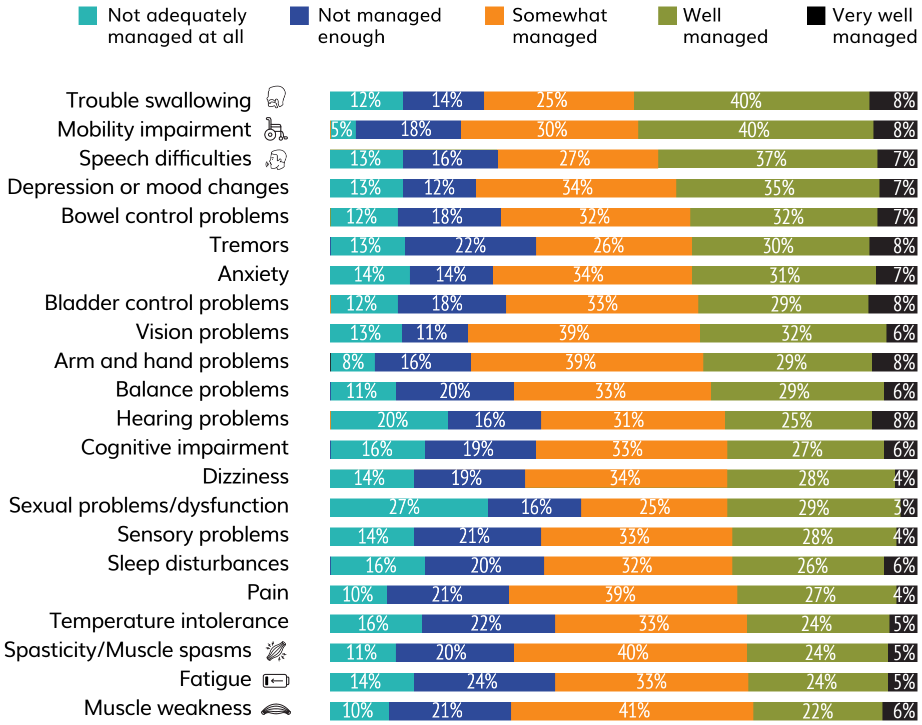
The caregivers supported people with MS for 53.5 hours per week on average. **94%** of respondents mentioned that the carer was of **great or good** help to them.

People living with SPMS reported having a caregiver (33%) or needing one (41%) while people with RRMS reported the most not having and not needing a caregiver (85%).

Satisfaction with management of symptoms

The *most* well managed symptoms were **trouble swallowing, mobility impairment,** and **speech difficulties.**

The *least* well managed symptoms were **muscle weakness, fatigue,** and **spasticity / muscle spasms.**



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 Maja, 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: 0.4%

References: [1] Among respondents, 93.3% were MS society members, 3.3% were linked but not members, and 3.4% 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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