IMSS

Nationale Belgische
Multiple Sclerose Liga
Ligue Nationale Belge
de la Sclérose en Plaques

emsp
EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

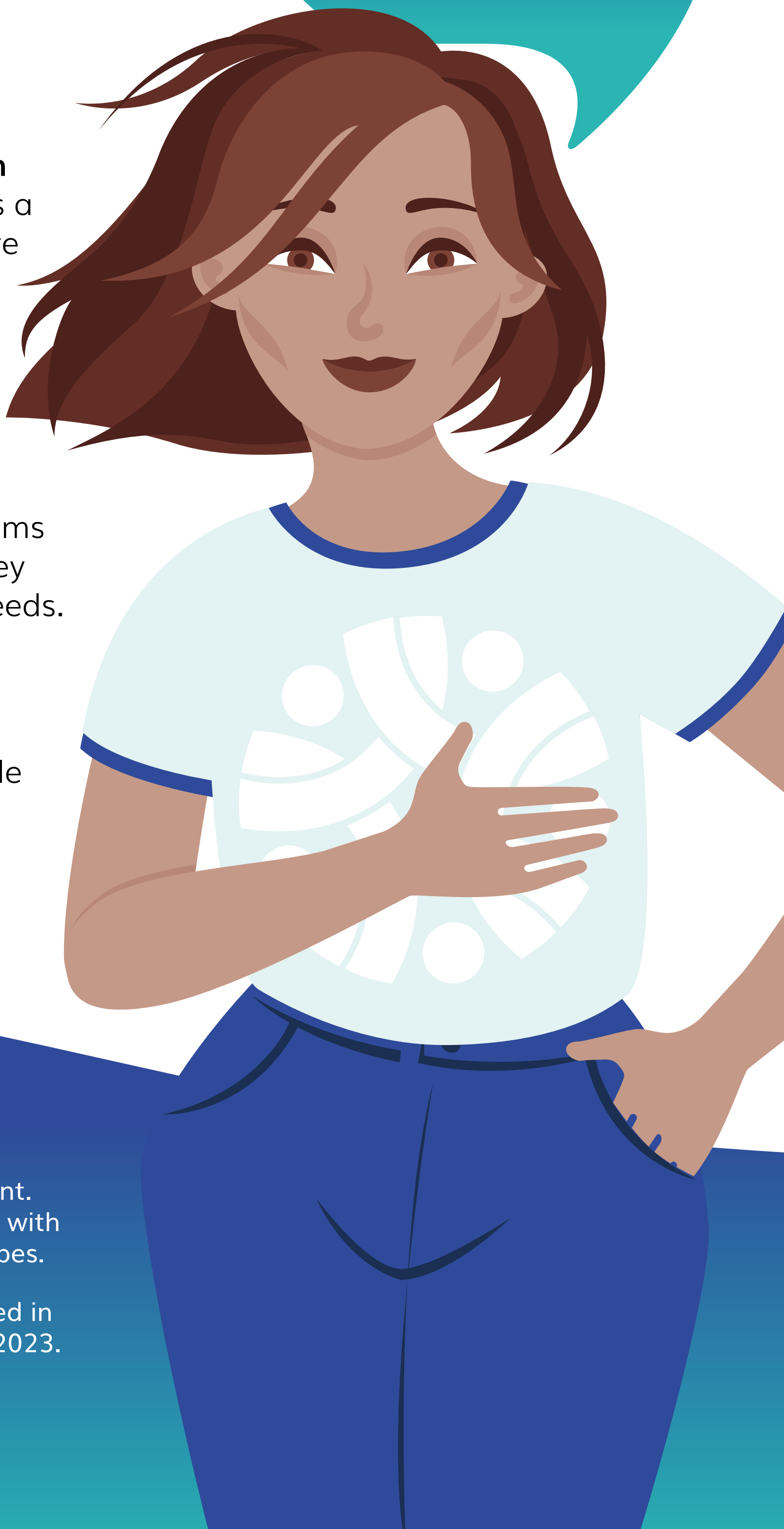
Impact of Multiple Sclerosis Symptoms (IMSS) in Belgium

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.

Maria'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 Belgium, **565**[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 midwife 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

44.3
THE MEAN AGE OF PEOPLE WITH MS

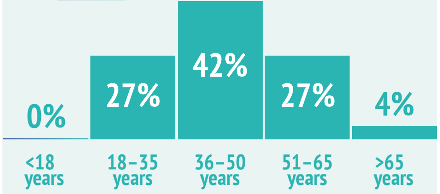
42%
ARE 36–50 YEARS OLD

DUE TO MS
1 in 3
ARE NOT WORKING

65%
HAVE HIGH-LEVEL EDUCATION

77%
LIVE WITH THEIR FAMILY

AGE



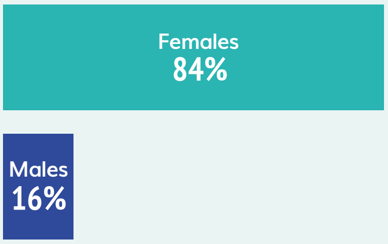
People between **18–35** reported the fewest symptoms.

Individuals aged **36–50** experienced the highest levels of anxiety.

Between **51-65**, the most sensory problems, sleep disturbances, pain, sexual issues, vision problems, and tremors.

Over 65, increased spasticity, muscle spasms, mood changes, muscle weakness, heat/cold sensitivity, bladder and bowel problems, mobility impairment, arm and hand issues, and swallowing difficulties.

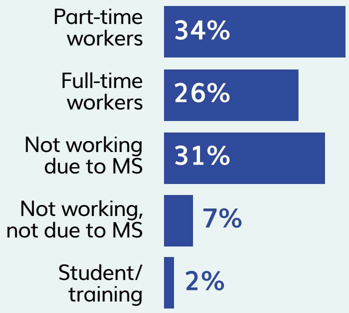
GENDER[‡]



Females reported *fewer* balance problems and sexual dysfunction but *more* **fatigue, sleep disturbances,** and **anxiety** compared to males.

Males reported significantly *fewer* fatigue, sleep disturbances, and anxiety, but *more* **balance problems, sexual dysfunction,** and **mobility impairment** than females.

WORKING STATUS



Part-time workers experienced lower levels of muscle weakness, bowel problems, mobility impairment, and arm/hand issues.

Full-time workers reported significantly fewer symptoms.

People not working due to MS reported higher rates of bowel problems and mobility 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 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 anxiety — 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

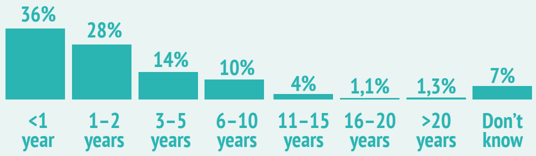
DIAGNOSIS AND SYMPTOM ONSET

59% diagnosed between 18–35 yrs

10.4 YEARS average disease duration

1 in 3 have at least 1 additional illnesses

Delay from symptom onset to diagnosis



30.6 symptom onset age

AVERAGE DELAY OF 2.8 YEARS

33.8 average diagnosis age

TYPES OF MS

73% **RRMS,** Relapsing Remitting MS

13% **PPMS,** Primary Progressive MS

8% **SPMS,** Secondary Progressive MS

7% **Unsure of their MS type**

DISABILITY LEVELS

Overall, 16% of the respondents had mild disability while 48% had moderate disability and 12% had severe disability. Those with PPMS reported higher moderate (56%) and severe (33%) disability rates, while SPMS had the highest severe disability (54%)[2].

QUALITY OF LIFE

The majority of respondents had no or slight problems, while 10% were experiencing moderate or severe problems affecting their quality of life. Quality of Life declined most for those with PPMS (28%) and SPMS (38%)[3].

USE OF DMDs

88% of respondents have used **Disease Modifying Drugs** (DMDs), with 74% currently using them. 68% reported *less* than a 1-year delay to start DMDs, while 9% experienced delays of 6 years or more. Among non-users, the main reasons were:

- 39% concerns about use
- 25% never being offered
- 17% physicians advising against them.

ON AVERAGE **1.4** YEARS DELAY BETWEEN DIAGNOSIS AND DMD START

Symptoms

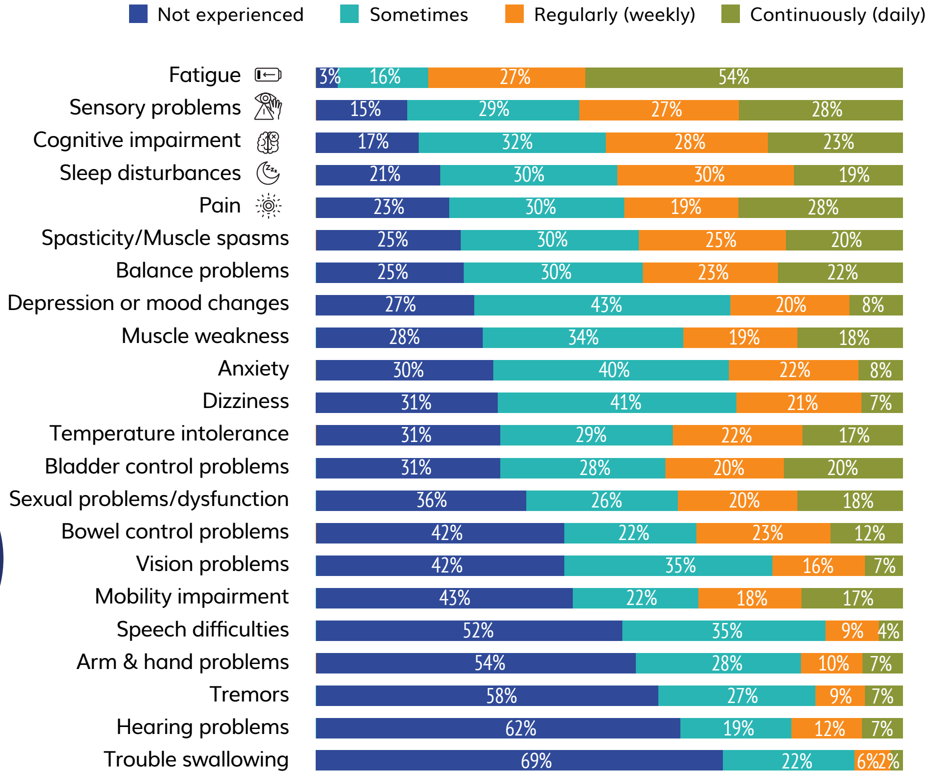
PRESENCE AND PREVALENCE

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

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

99% EXPERIENCED AT LEAST ONE SYMPTOM

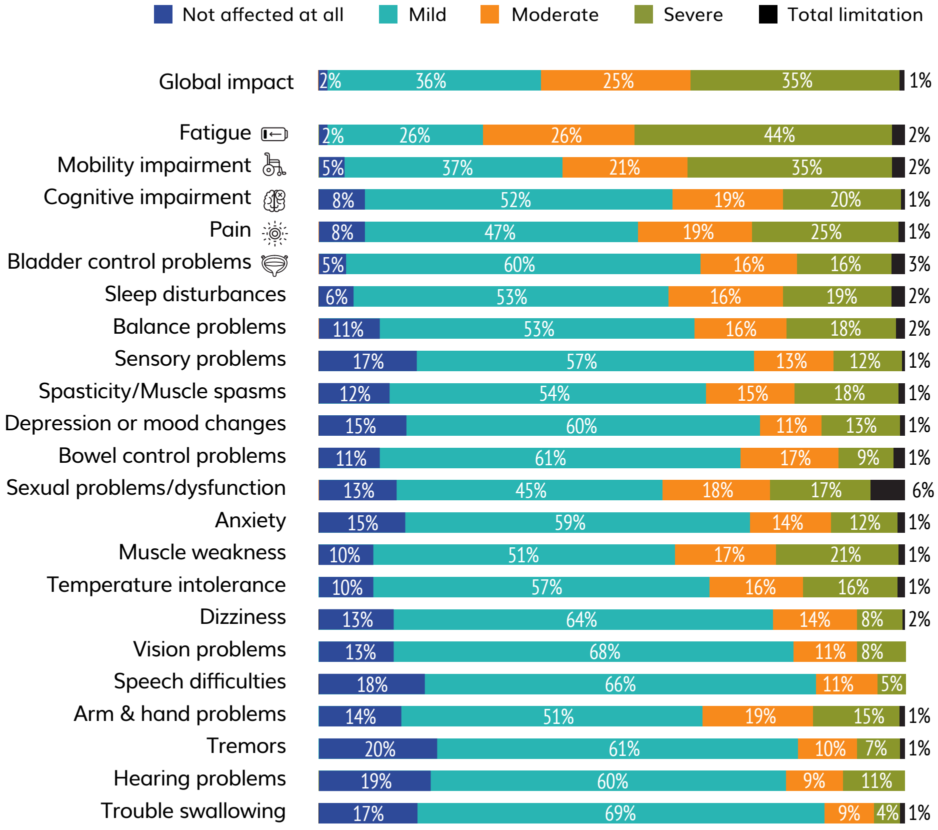
ON AVERAGE **14** SYMPTOMS EXPERIENCED TOGETHER



SEVERITY AND IMPACT

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

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



Treatment and care

CARE FOR SYMPTOMS

89%
HAVE ANY CARE/ TREATMENT

11% 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
5.9
TREATMENTS OR CARE

People with MS reported using 5.9 treatments or care on average for their symptoms.

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

Medication for symptom management

- Prescription medication 67%
- Non-prescription medication 27%

Lifestyle changes

- Personal life modifications 51%
- Physical activity 45%
- Dietary changes 27%
- Quitting smoking 7%

Therapy/treatments

- Physical therapy 57%
- Psychological therapy 17%
- Bladder and bowel management 12%
- Neuro-cognitive rehabilitation 8%
- Occupational therapy 4%
- Speech therapy 2%

Social support

- Friends and family 38%
- Other people with MS 16%
- Formal sessions with social worker 6%

Complementary and alternative therapies

- Dietary supplements 30%
- Alternative medicine 15%
- Meditation 13%
- Mindfulness 12%
- Other alternative therapy 6%

Other

- Assistive devices 21%
- Diaries and applications 13%
- Home modification 13%
- At-home massage devices 10%
- Other 3%
- Service/support animals 2%

Surgery 1%

INVOLVEMENT OF PROFESSIONALS

ON AVERAGE
5
HEALTHCARE PROFESSIONALS

People with MS had 5 healthcare professionals on average taking care of their MS. 68% 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	91%
Nurse / MS nurse	61%
Physiotherapist	59%
Urologist	30%
Clinical psychologist / psychiatrist	27%
Social worker / social care specialist	26%
Rehabilitation physician	18%
Occupational therapist	14%
Gastroenterologist	14%
Neuro-ophthalmologist	13%
Dietitian	10%
Neuro-radiologist	9%
Pain specialist	7%
Neuro-otologist	4%
Speech therapist	4%
Spasticity specialist	1%
Other professional	13%

CAREGIVER PRESENCE AND ASSISTANCE

63% have no need for assistance

12% do not have caregivers but need assistance

25% have caregivers

Of those caregivers, **80%** were a family, partner, or friend. **33%** were paid professionals*.

4 in 5
ARE A FAMILY, PARTNER OR FRIEND

ON AVERAGE
13.3
HOURS/ WEEK

The caregivers supported people with MS for 13.3 hours per week on average. **73%** of respondents mentioned that the carer was of **great or good** help to them.

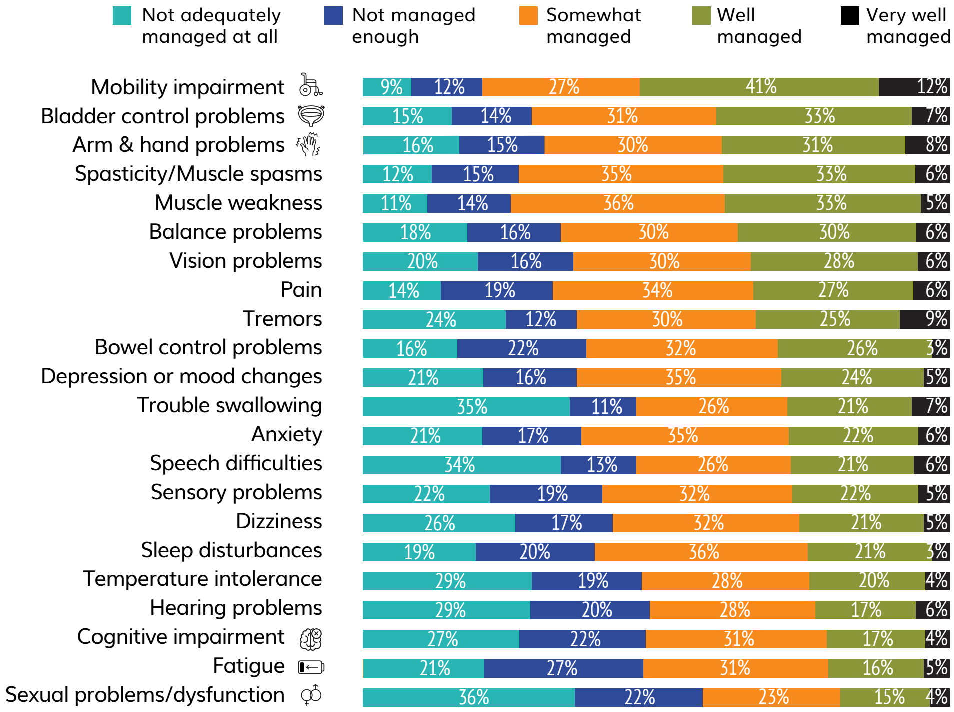
Caregiver needs were most among SPMS respondents (58% having, 14% needing). 69% with RRMS reported not having/needing caregiver.

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 **cognitive impairment.**

3 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 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%

References: [1] Among respondents, 68% were MS society members, 10% were linked but not members, and 22% 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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