IMSS

MSL
LLSP & FSPL
Multiple Sclérose
Lëtzebuerg

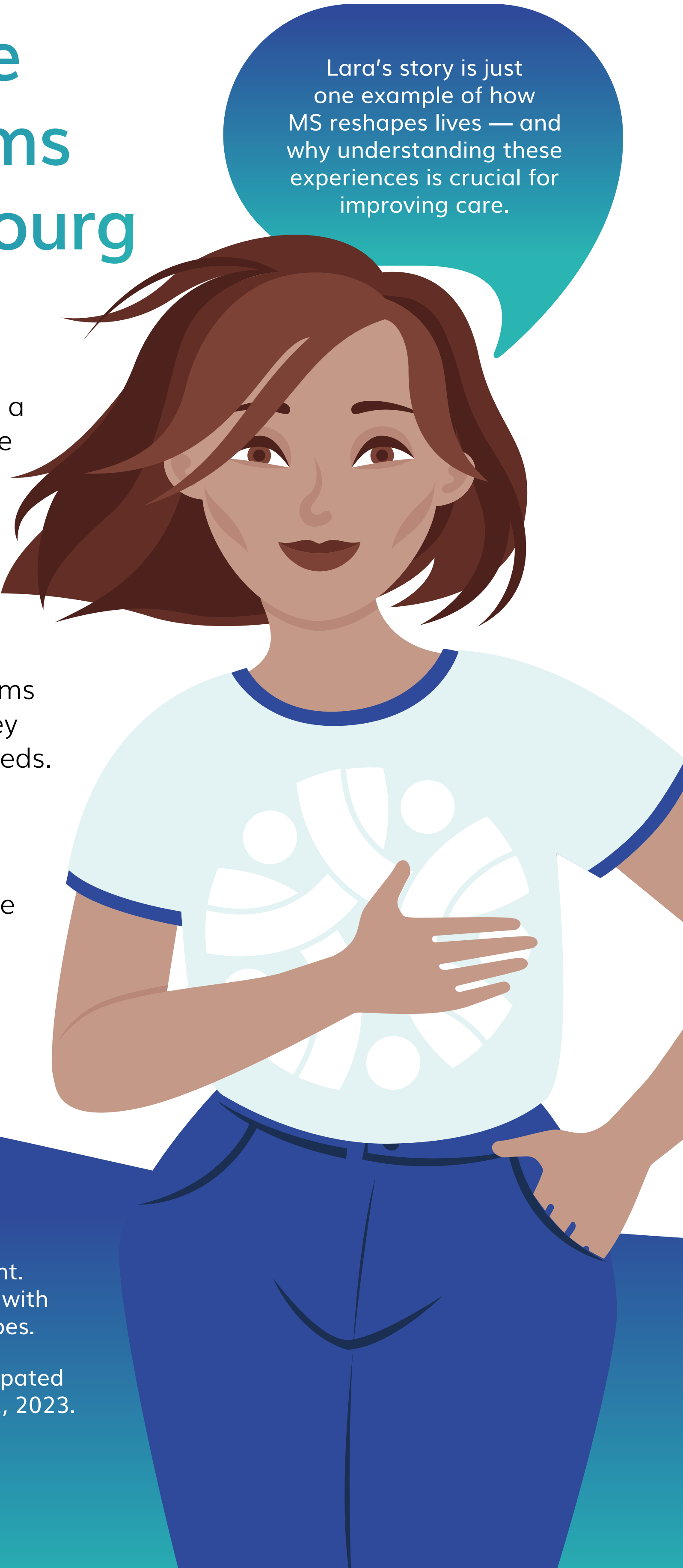
emsp
EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Impact of Multiple Sclerosis Symptoms (IMSS) in Luxembourg

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 Luxembourg, **119**[1] people with MS participated in the IMSS survey from May 5 to August 31, 2023.

A Life Changed by MS

Lara had always been full of energy — a teacher and a passionate runner in her free time. But at 30, 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 long years, Lara 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

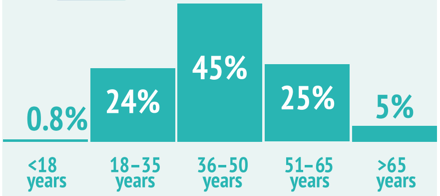
45%
ARE 36–50 YEARS OLD

DUE TO MS
1 in 5
ARE NOT WORKING

65%
HAVE HIGH-LEVEL EDUCATION

81%
LIVE WITH THEIR FAMILY

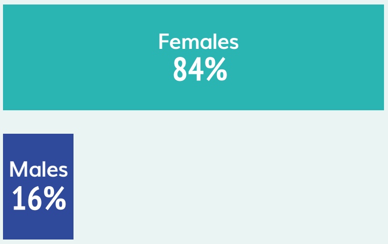
AGE



People between **51 and 65** experienced the most symptoms compared to other age groups, with the exception of depression and mood changes that was higher among people with MS aged between **36 and 50** years.

It was not possible to draw conclusions about other age groups and related symptoms, possibly due to the small sample size.

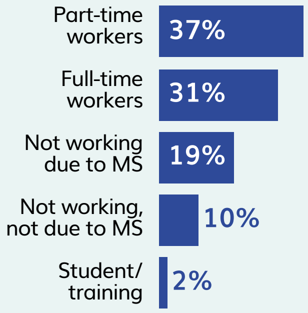
GENDER



There were no significant differences in the presence of symptoms between males and females, with the exception of **females** experiencing *more* **sleep disturbances.**

This could possibly be due to the sample size as it was too small to draw any conclusions.

WORKING STATUS



There were no significant differences in the presence of symptoms between people with MS with different working status. This could be due to the small sample size dispersed across different groups.

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 Lara, these questions resonate deeply. Her diagnosis eventually came at age 34, but the journey didn't end there. Her symptoms — fatigue, walking difficulties, sensory problems, and pain — 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.

Lara'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 Lara across the continent.

Clinical situation

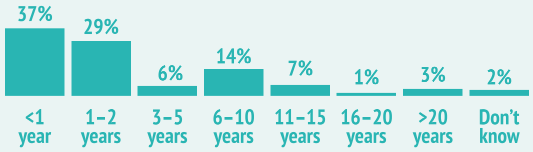
DIAGNOSIS AND SYMPTOM ONSET

56%
diagnosed between 18–35 yrs

10.5 YEARS
average disease duration

2 in 5
have at least 1 additional illnesses

Delay from symptom onset to diagnosis



30.2
symptom onset age

AVERAGE DELAY OF 3.5 YEARS

33.8
average diagnosis age

TYPES OF MS

64%
RRMS,
Relapsing Remitting MS

15%
PPMS,
Primary Progressive MS

13%
SPMS,
Secondary Progressive MS

8%
Unsure of their MS type

DISABILITY LEVELS

23% of the respondents had mild disability while 39% had moderate disability and 11% had severe disability. People living with PPMS reported more moderate (48%) and severe disability (30%) compared to RRMS while people with SPMS reported the most moderate disability (52%) and most severe disability (38%)[2].

QUALITY OF LIFE

The majority of respondents had no or slight problems, while 9% were experiencing moderate or severe problems affecting their quality of life. The quality of life deteriorated more among people with PPMS (20%) and people with SPMS (25%)[3].

USE OF DMDs

83% of respondents have used **Disease Modifying Drugs** (DMDs), with 67% currently using them. 63% reported *less* than a 1-year delay to start DMDs, while 18% experienced delays of 6 years or more. Among non-users, the main reasons were:

- 64% concerns about use
- 17% never being offered
- 9% physicians advising against them.

ON AVERAGE
1.5
YEARS DELAY BETWEEN DIAGNOSIS AND DMD START

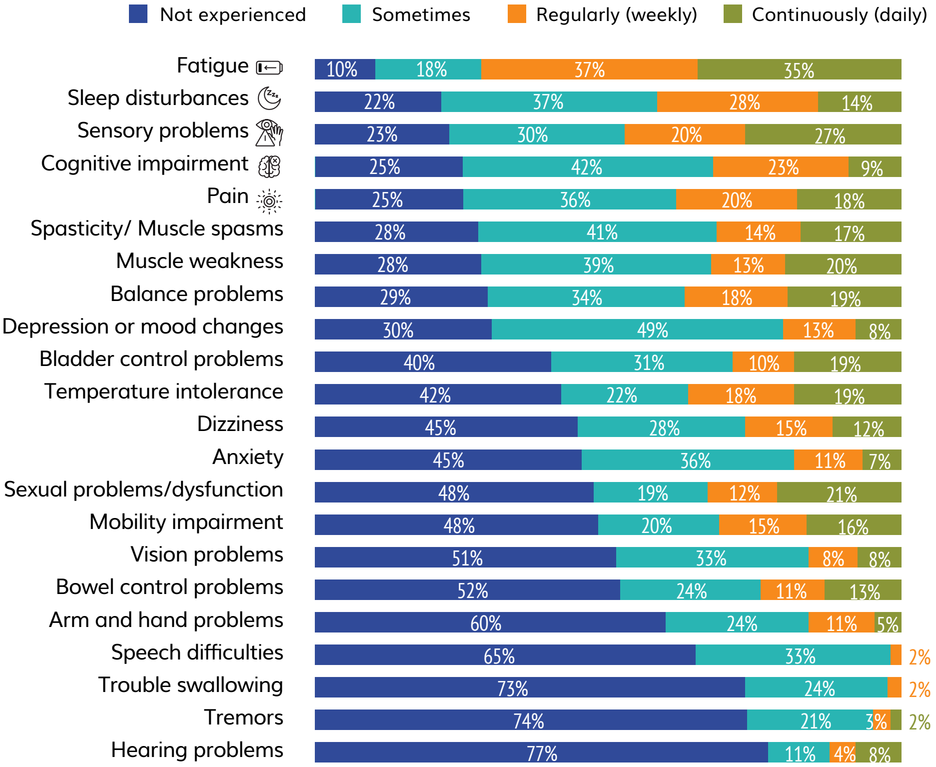
Symptoms

PRESENCE AND PREVALENCE

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

98%
EXPERIENCED AT LEAST ONE SYMPTOM

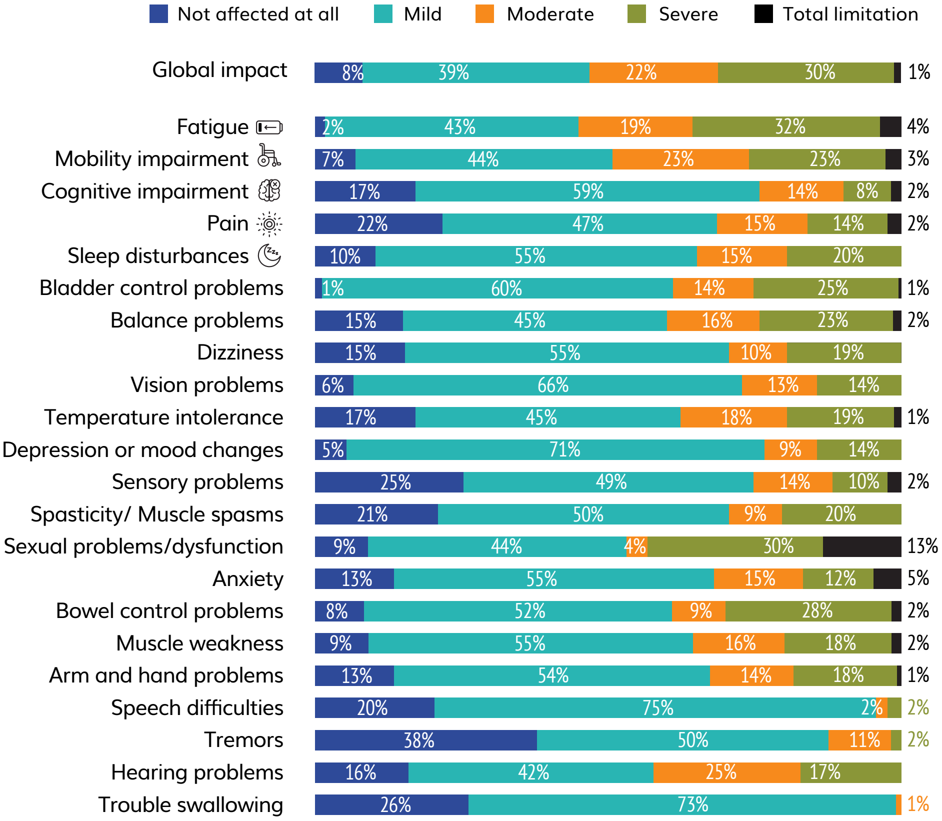
ON AVERAGE
12.6
SYMPTOMS EXPERIENCED TOGETHER



SEVERITY AND IMPACT

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

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



Treatment and care

CARE FOR SYMPTOMS

92%
HAVE ANY CARE/ TREATMENT

8% don't use any care /treatment. The *top reasons* for not using a specific treatment were having no need, treatment was not offered to them, or they do not want to use any care.

ON AVERAGE
5.3
TREATMENTS OR CARE

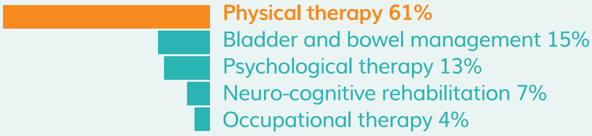
People with MS reported using 5.3 treatments or care on average for their symptoms.

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

Lifestyle changes

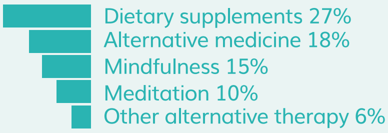
Medication for symptom management

Therapy/treatments



Social support

Complementary and alternative therapies



Other

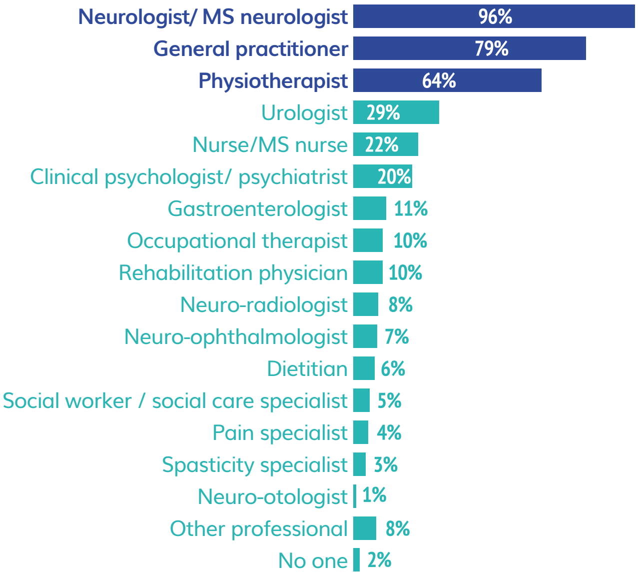
Surgery 1%

INVOLVEMENT OF PROFESSIONALS

ON AVERAGE
3.9
HEALTHCARE PROFESSIONALS

People with MS had 3.9 healthcare professionals on average taking care of their MS. 44% reported that their healthcare professionals are coordinating together.

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



CAREGIVER PRESENCE AND ASSISTANCE

78% have no need for assistance

13% do not have caregivers but need assistance

9% have caregivers

Of those caregivers, **77%** were a family, partner, or friend. **35%** were paid professionals*.

4 in 5
ARE A FAMILY, PARTNER OR FRIEND

ON AVERAGE
12.7
HOURS/ WEEK

The caregivers supported people with MS for 12.7 hours per week on average. **89%** of respondents mentioned that the carer was of **great or good** help to them.

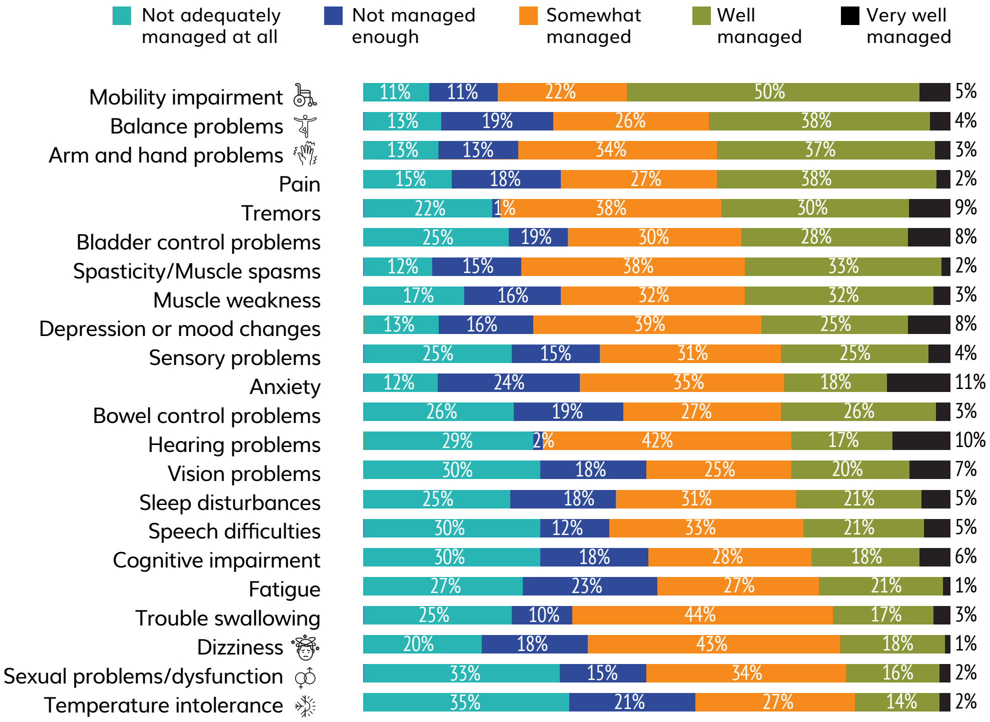
People living with SPMS reported having a caregiver equally to people living with PPMS (17%). Both people living with SPMS and PPMS reported needing a caregiver (23%, 32% respectively). People with RRMS reported the most not having and not needing a caregiver (87%).

Satisfaction with management of symptoms

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

The *least* well managed symptoms were **heat and/or cold intolerance, sexual problems/dysfunction,** and **dizziness.**

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 Lara, 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, 61% were MS society members, 9% were linked but not members, and 30% 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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