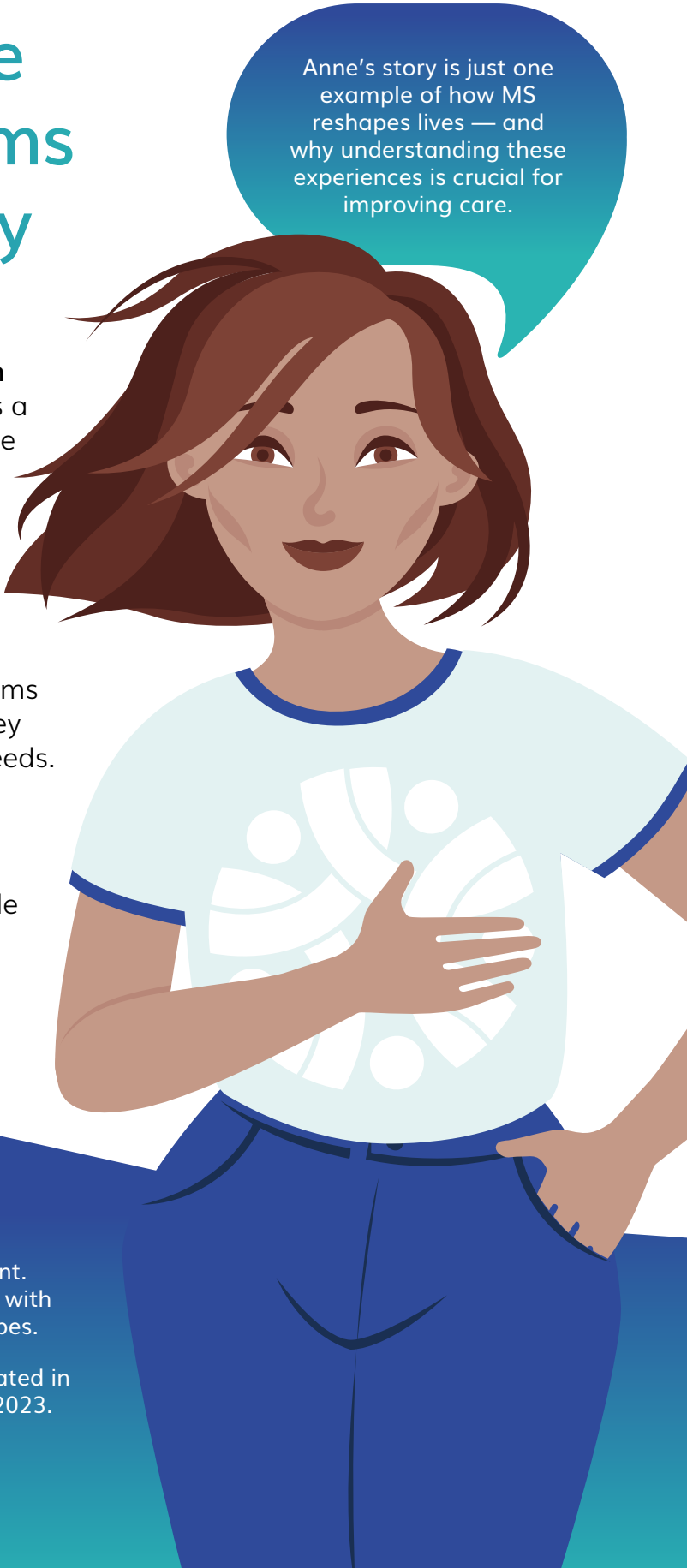


# Impact of Multiple Sclerosis Symptoms (IMSS) in Germany

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.



Anne'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.



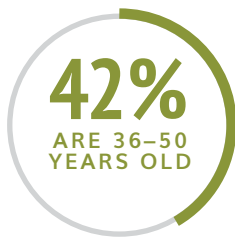
In Germany, 2019<sup>1</sup> people with MS participated in the IMSS survey from May 5 to August 31, 2023.

# A Life Changed by MS

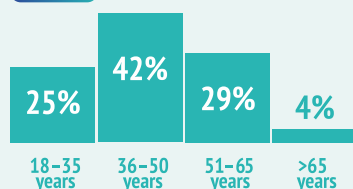
Anne had always been full of energy — a nurse and a passionate camper in her free time. But at 31, her life took an unexpected turn. She started noticing strange sensations in her legs, followed by bouts of overwhelming fatigue. Over time, these symptoms grew harder to ignore. Tasks she once did effortlessly became a struggle. Her doctor ran tests, but the results were inconclusive. For three long years, Anne lived with uncertainty, her daily life becoming a patchwork of pain, confusion, and questions without answers.



## Participant demographics



### AGE



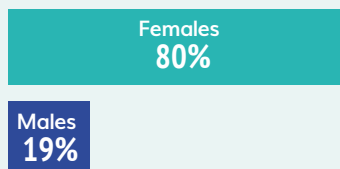
People between **18-35** reported the fewest symptoms across various domains.

Individuals aged **36-50** experienced the highest sleep disturbances.

Between **51-65**, sensory issues, balance problems, and mobility impairments became more prominent.

**Over 65**, these issues persisted, with the highest levels of balance problems, spasticity, muscle weakness, bladder and bowel problems, mobility impairment, and sexual dysfunction.

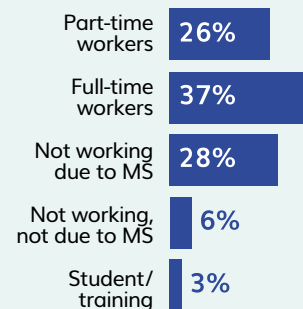
### GENDER †



**Females** reported significantly fewer tremors but more **sensory problems, cognitive impairment, sleep problems, depression or mood changes, heat/cold intolerance, pain, anxiety** and **hearing problems** comparing to males.

**Males** reported significantly fewer sensory problems, cognitive impairment, sleep disturbances, depression or mood changes, heat/cold intolerance, pain, dizziness, anxiety and hearing problems, but more **mobility problems and tremors** than females.

### WORKING STATUS



**Part-time workers** reported high sleep disturbances, anxiety, and mood changes.

**Full-time workers** reported least presence of symptoms.

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

**People not working not due to MS** reported balance problems, spasticity, muscle weakness, bladder problems and mobility impairment.

**Students and people in training** reported highest anxiety.

# 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 Anne, these questions resonate deeply. Her diagnosis eventually came at age 34, but the journey didn't end there. Her symptoms — fatigue, sensory problems, trouble with her memory, 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.

Anne'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 Anne across the continent.

## Clinical situation

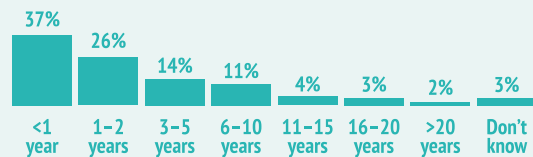
### DIAGNOSIS AND SYMPTOM ONSET

**56%** diagnosed between 18–35 yrs

**10.5 YEARS** average disease duration

**1 in 2** have at least 1 additional illnesses

#### Delay from symptom onset to diagnosis



**30.5** symptom onset age

**AVERAGE DELAY OF 3.4 YEARS**

**34** average diagnosis age

### TYPES OF MS

**69%** RRMS, Relapsing Remitting MS

**10%** PPMS, Primary Progressive MS

**15%** SPMS, Secondary Progressive MS

**6%** Unsure of their MS type

### DISABILITY LEVELS

21% of the respondents had mild disability while 46% had moderate disability and 15% had severe disability. People living with PPMS reported more moderate (53%) and severe disability (37%) compared to RRMS. People with SPMS reported the most severe disability (52%)<sup>2</sup>.

### 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. The quality of life deteriorated more among people with PPMS (21%) and people with SPMS (29%)<sup>3</sup>.

### USE OF DMDs

86% of respondents have used **Disease Modifying Drugs** (DMDs), with 74% currently using them. 66% 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:

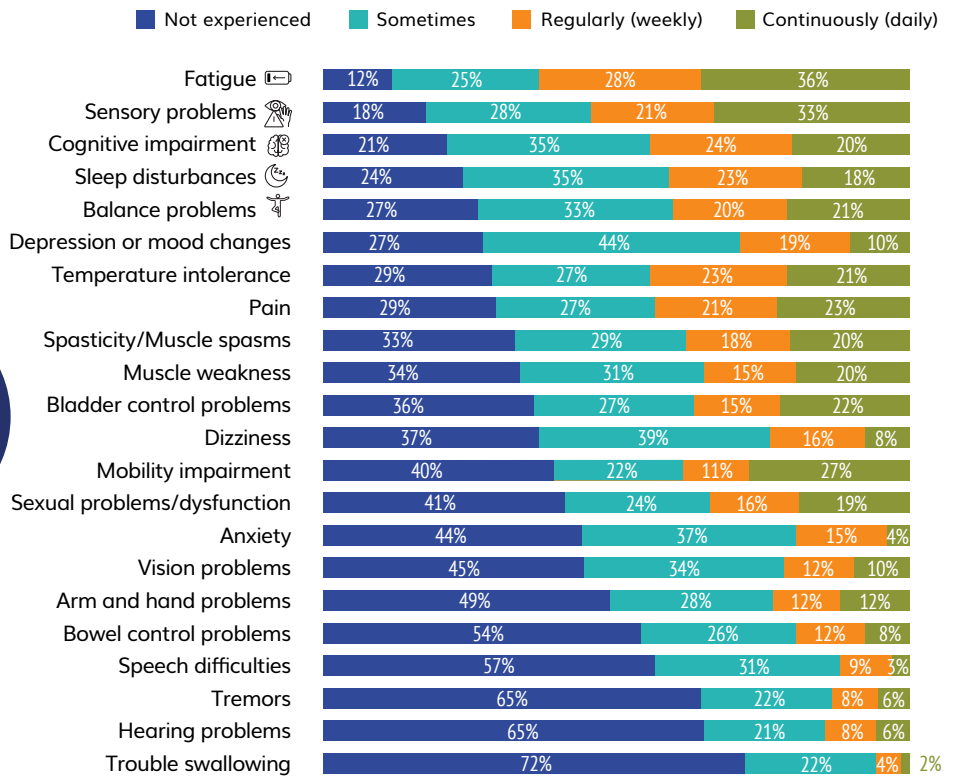
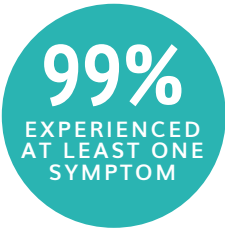
- 42% concerns about use
- 24% never being offered
- 19% physicians advising against them.

**ON AVERAGE 1.5 YEARS DELAY BETWEEN DIAGNOSIS AND DMD START**

# Symptoms

## PRESENCE AND PREVALENCE

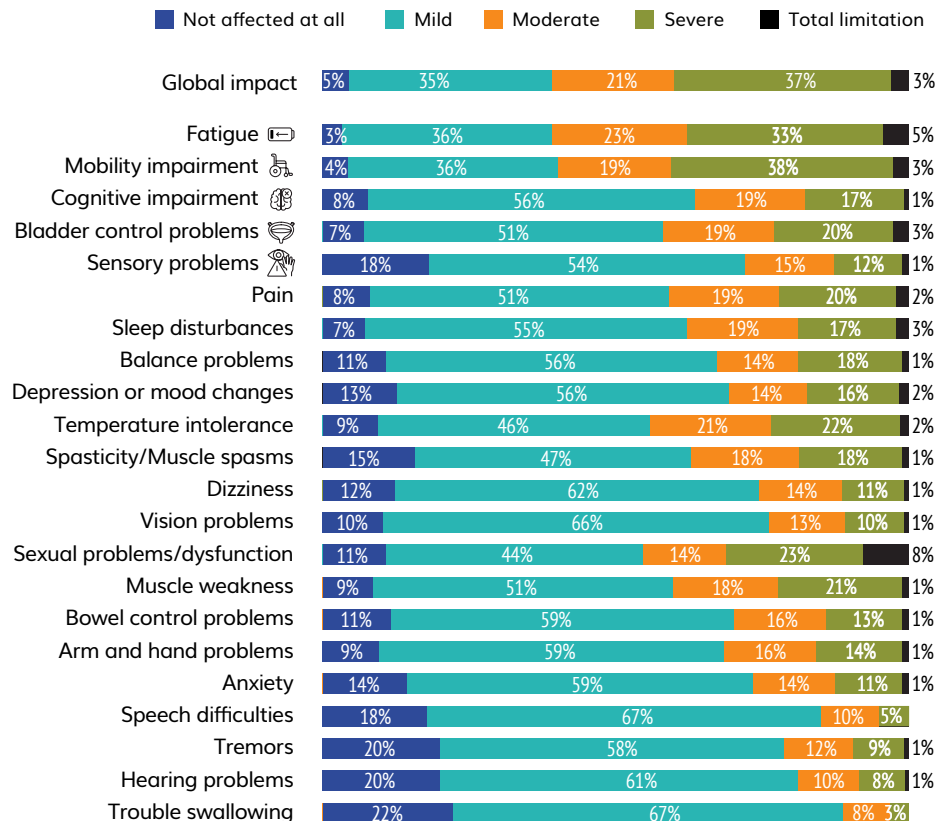
The symptoms reported the most were **fatigue, sensory problems, cognitive impairment, sleep disturbances, and balance problems.**



## SEVERITY AND IMPACT

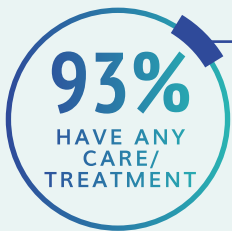
The symptoms that were affecting the daily lives of people with MS were **fatigue, mobility impairment, bladder control problems, sleep disturbances and cognitive impairment**<sup>4</sup>.

The top 3 most debilitating symptoms were **fatigue, mobility impairment, and cognitive impairment**<sup>5</sup>.



# Treatment and care

## CARE FOR SYMPTOMS



**7% 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 it takes a lot of time to take an appointment.



People with MS reported using 6 treatments or care on average for their symptoms.

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

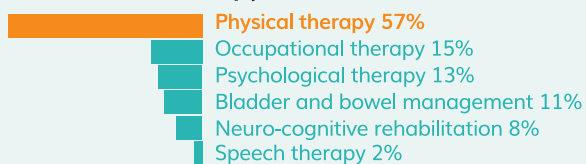
### Lifestyle changes



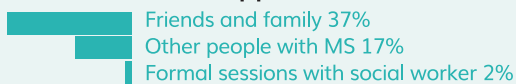
### Medication for symptom management



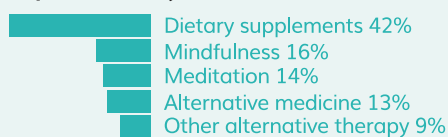
### Therapy/treatments



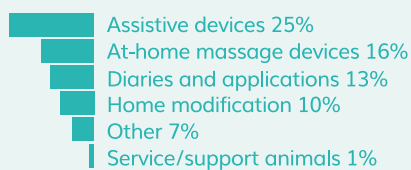
### Social support



### Complementary and alternative therapies



### Other



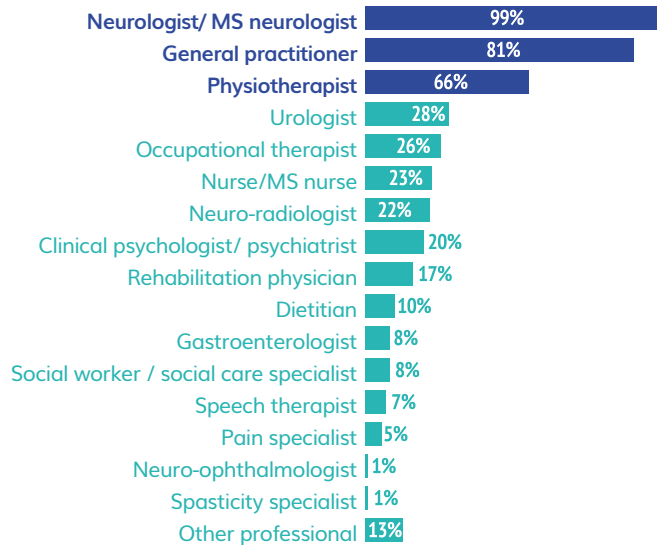
**Surgery 1%**

## INVOLVEMENT OF PROFESSIONALS



People with MS had 4 healthcare professionals on average taking care of their MS. 43% reported that their healthcare professionals are coordinating together.

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



## CAREGIVER PRESENCE AND ASSISTANCE



**71%** have no need for assistance

**12%** do not have caregivers but need assistance

**17%** have caregivers

Of those caregivers, **90%** were a family, partner, or friend. **17%** were paid professionals\*.



The caregivers supported people with MS for 16.4 hours per week on average. **57%** of respondents mentioned that the carer was of **great or good** help to them.

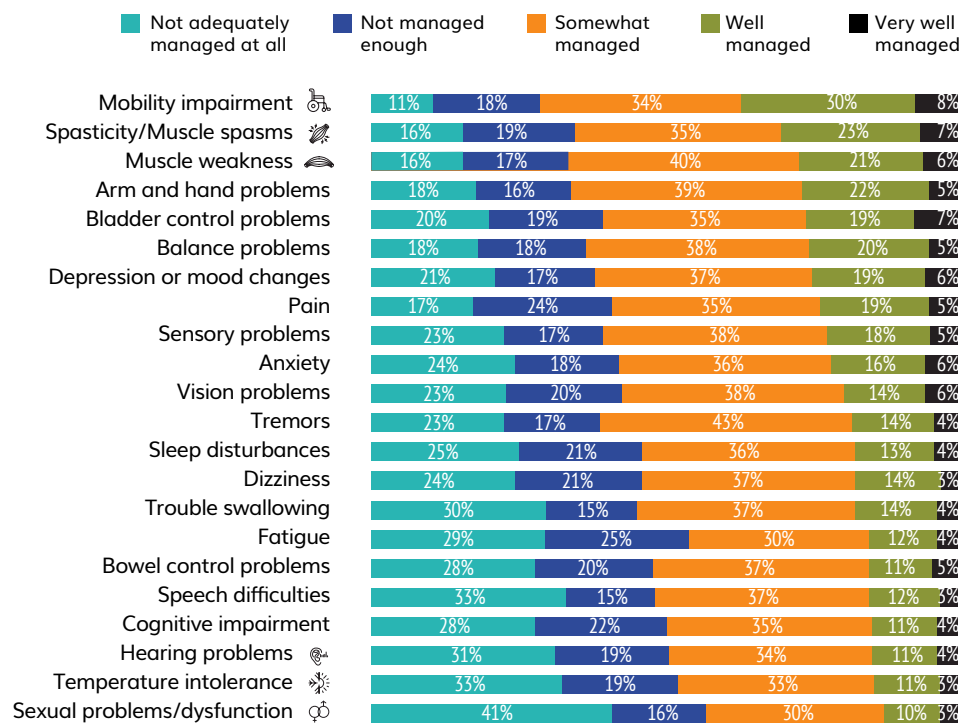
People living with SPMS reported having a caregiver (49%) or needing one (16%) while people with RRMS reported the most not having and not needing a caregiver (82%).



# Satisfaction with management of symptoms

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

The least well managed symptoms were **sexual problems/dysfunction, heat and/or cold sensitivity or intolerance, hearing problems and cognitive impairment.**



## 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 wait years for answers. 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 Anne, 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: 0.2%, prefer not to say 0.3%.

**References:** <sup>1</sup>Among respondents, 49% were MS society members, 14% were linked but not members, and 37% had no society affiliation. <sup>2</sup>Measured by the PDDS: Patient-Determined Disease Steps, provided for use by the NARCOMS Registry: [www.narcoms.org/pdds](http://www.narcoms.org/pdds). NARCOMS is supported in part by the Consortium of Multiple Sclerosis Centres (CMSC) and the CMSC Foundation. <sup>3</sup>Measured by EuroQOL Research Foundation: EQ-5D-5L. <sup>4</sup>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). <sup>5</sup>The '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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