

# Walking disorders in MS: how do they impact patients' quality of life? Results from an observational study conducted via an online patient community



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## Conclusions

- MS patients with EDSS between 4 and 7 experience daily difficulties, such as walking difficulties, difficulties climbing stairs, difficulties linked to fatigue and loss of balance.
- These difficulties impact patients' quality of life; particularly social, professional and family life.
- Walking related problems also impact patients' caregivers, as most MS patients rely on the help of their family and friends to perform some activities, for example walks outside their home, cleaning, cooking and for medical care (e.g. attending medical appointments).
- Overall walking impairment weighs heavily on patients and their relatives, in particular at higher EDSS states.
- Considering the impact on quality of life, MS patients have significant expectations to improve their walking disorders.

## Introduction

- Multiple Sclerosis (MS) is a neurodegenerative disease, characterized by inflammation leading to demyelination and axonal loss<sup>1</sup>.
- Symptoms of MS such as spasticity, loss of balance or muscle weakness may progressively lead to irreversible disabilities, greatly impacting patients' overall quality of life<sup>2</sup>.
- Nearly half (45%) of patients reported experiencing mobility difficulties within a month of diagnosis and nearly all patients (93%) report difficulties within 10 years<sup>3</sup>.

## Objectives

- To assess the impact of walking disability on MS patients' quality of life
- To identify patients' expectations regarding walking impairment

## Methods

### Carenity.com

- CARENITY is an international online patient community devoted to people with chronic diseases.
- It allows patients and caregivers to share their experiences, to access medical information and to participate in online surveys, generating real-world patient insights.

### Survey

- An online questionnaire was submitted to the members of the Carenity French MS community.
- The questionnaire had been proofread by one MS patient with walking disabilities.
- The questionnaire was self-reported, including clinical data such as EDSS level.

### Inclusion and exclusion criteria

- Adult MS patients with EDSS (Expanded Disability Status Scale) between 4 and 7.
- Patients receiving PR-fampridine were excluded from survey

### Online survey data collection

- From January to February 2018.

## Results

### Respondents' profile

- 100 MS patients answered the questionnaire.

♀ 83% ♂ 17% Mean age : 52.4 y.o

	18-30 y.o	31-40 y.o	41-50 y.o	51-60 y.o	61-70 y.o	70+ y.o
	2%	14%	27%	31%	21%	5%
	Relapsing-remitting MS	Secondary progressive MS	Primary progressive MS	Do not know		
	48%	23%	21%	8%		

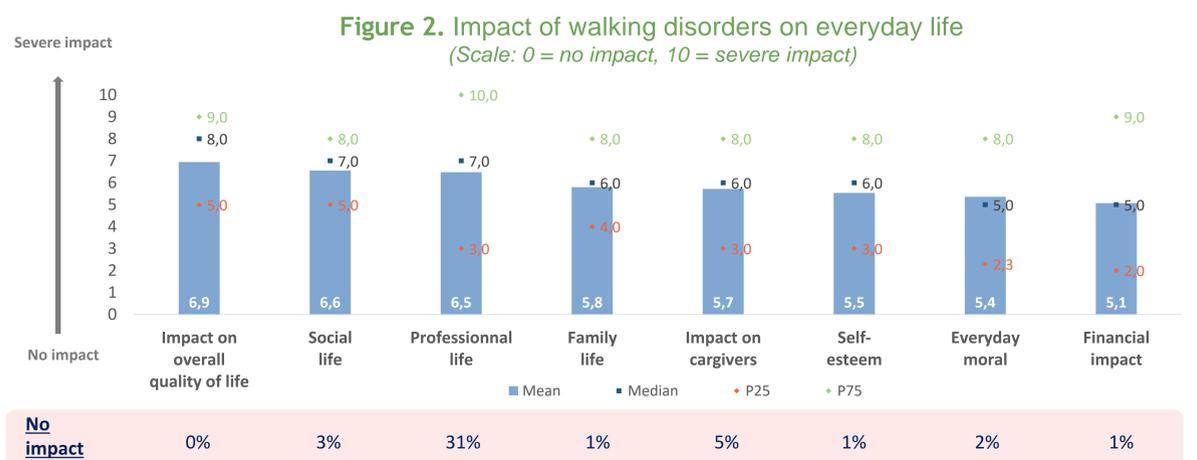
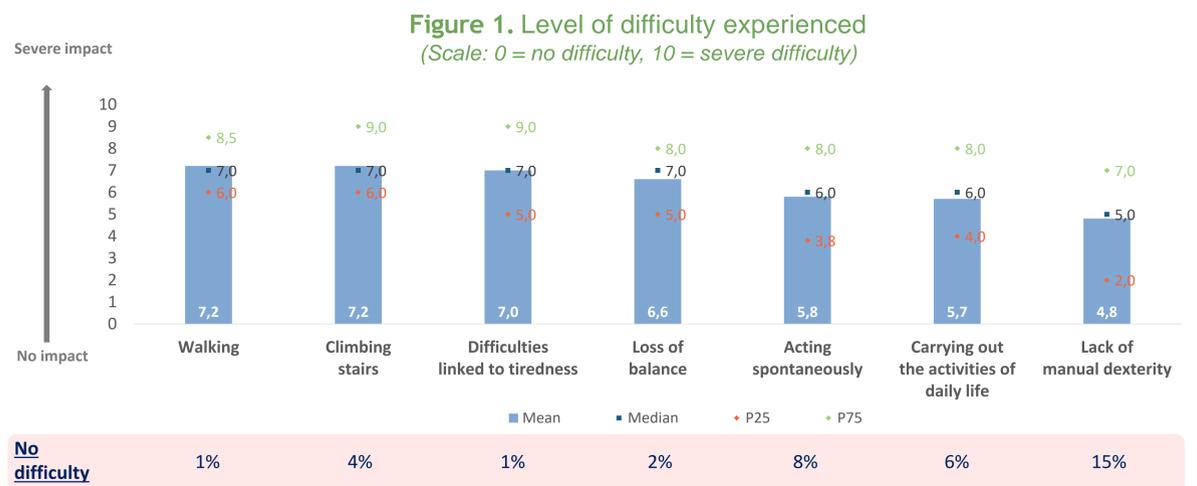
- 71% had an EDSS of 4 or 5 and 29% of 6 or 7.

### Impact of walking impairment on Quality of Life

- On a scale from 0 to 10, more than 50% of patients considered that walking impairment had a large impact on their quality of life (median = 8/10).
- Social life was the most impacted aspect, followed by professional and family life.
- The main difficulties reported were: walking, climbing stairs, imbalance and difficulties linked to fatigue (median= 7/10, p75 between 8 and 9/10).
- The severity of walking impairment was higher at higher EDSS levels.
- 69% of patients also experience autonomy loss: 49% are supported by their relatives for walks outside their home, 46% with cleaning and 25% with cooking. Patients with higher EDSS were shown to require more assistance (63% for patients with EDSS 4 or 5, 83% with EDSS 6 or 7).

### Patients' expectations regarding walking impairment

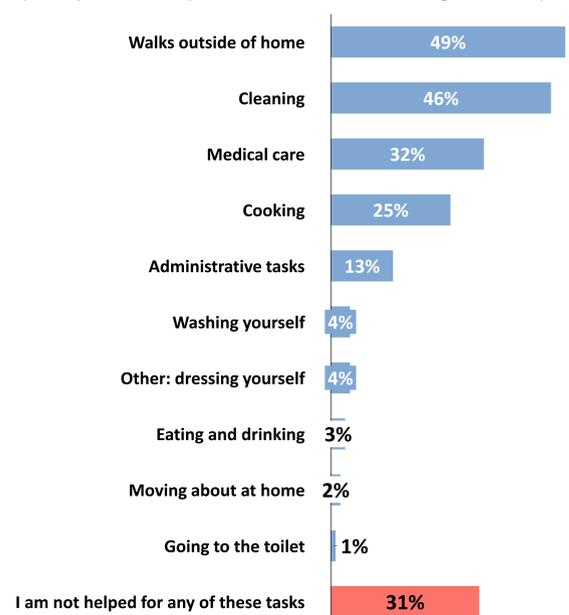
- Walking greater distances (64%), having a better balance (47%), being less tired (47%) and having less muscle pain (41%) are the most expected improvements.
- If their gait function improved, patients spontaneously report the activities they would be able to perform more easily, including physical activities, walks outside their home and activities of daily living at home.



	Median (p75)	Impact on overall QoL	Social life	Professional life	Family life	Impact on close ones	Self-esteem	Everyday moral	Financial impact
EDSS 4 and 5 n=71	7.0 (9.0)	7.0 (7.0)	7.0 (10.0)	7.0 (10.0)	5.0 (7.0)	5.0 (7.0)	5.0 (7.8)	5.0 (8.0)	4.0 (8.0)
EDSS 6 and 7 n=29	9.0 (10.0)	7.5 (10.0)	10.0 (10.0)	7.5 (10.0)	8.0 (9.3)	8.0 (9.0)	8.0 (9.0)	8.0 (9.0)	7.0 (9.0)

**Table 1. Impact of walking disorders on everyday life (by EDSS)**  
(Scale: 0=no impact, 10=severe impact)

**Figure 3. Help provided by family and caregivers**  
(% of patients helped for one of the following activities)



**Figure 4. Desired improvements**

