2026 NARCOLEPSY STUDY

ONLINE SURVEY with Canadian adults 18+ diagnosed with narcolepsy, experiencing symptoms without a diagnosis, or caregivers of someone diagnosed. Open link via MDSC social media networks & select partners from June 16 to August 3, 2026.

47 Completed surveys › **43** People with narcolepsy **4** Caregivers

1 EXPERIENCE & DIAGNOSIS

87% FORMALLY DIAGNOSED

47% Type 1 | **36%** Type 2 | **4%** Type unknown

TIME TO DIAGNOSIS

Years	13%	22%	31%	31%
n=45	1–2	3–5	6–10	>10

SYMPTOMS PAST 12 MONTHS

7.0 on average

Brain fog	85%
Daytime sleepiness	83%
Disrupted nighttime sleep	83%
Automatic behaviours	77%
Emotional impacts	72%
Sudden sleep attacks	68%
Trouble staying awake	68%
Dream-like hallucinations when falling asleep or waking up	68%
Cataplexy	51%
Sleep paralysis	45%

56% *had symptoms attributed to another condition:* n=45

64%	Depression
40%	Chronic fatigue/burnout
32%	Anxiety
24%	Sleep disorder other than narcolepsy
16%	ADHD
12%	Insomnia
40%	Another condition

n=25

2 IMPACT OF NARCOLEPSY

IMPACT ON QUALITY-OF-LIFE **8.2/10**

68% High 8-10 | **30%** Mid 5-7 | **2%** Low 1-4

IMPACTS ON DAILY LIFE

Reduced productivity	81%
Strained relationships	79%
Emotional distress	66%
Stopped work or school	57%
Safety concerns	53%
Needed accommodations	53%
Missed work/school/ volunteering/reduced hours	49%
More healthcare use	32%
More reliance on others	30%

Days Missed per Month

n=23	4%	9%	30%	4%	26%
	<1	1–2	3–4	5–10	10+

GREATEST NEGATIVE IMPACTS OF TYPE 1

Top 5 n=22

77%	Fatigue/sleepiness
41%	Fragmented sleep
36%	Cataplexy
36%	Brain fog
18%	Low mood/motivation
18%	Memory lapses
14%	Low productivity

IMPACT ON OWN WELL-BEING **8.6/10**

Top Box 8–10	
Own well-being (n=27)	70%
Caregiver well-being (n=4)	50%
Helper's well-being (n=27)	44%

3 MANAGING NARCOLEPSY

89% *currently use/have used medication*

MOST BOTHERSOME SIDE EFFECTS

Mood/emotional changes	45%
Heart-related effects	40%
Headache	31%
Sleep disruption	29%
Difficulty concentrating	29%

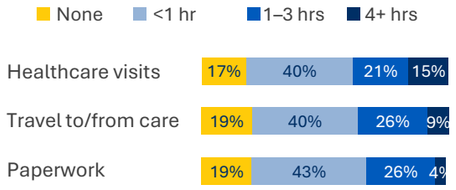
Top 5 n=42

HARD-TO-MANAGE MEDICATION ASPECTS

33%	Multiple daily/nightly doses
28%	Refills/pharmacy access
28%	Follow-up/monitoring
28%	Accessing/paying for it
26%	Remembering doses

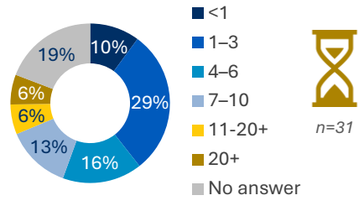
Top 5 n=39

MONTHLY TIME SPENT DUE TO NARCOLEPSY



63% *rely on another person for help* n=43

WEEKLY SUPPORT HOURS



n=31

HELP RECEIVED

Top 5 *Rely on others, n=27*

Household tasks	81%
Emotional support	63%
Driving or transportation	48%
Childcare or caregiving	41%
Work or school tasks	30%

TOP COSTS SUSTAINED

Fatigue management **53%**, Travel to care **45%**, Higher household expenses due to reduced work **45%**, Uncovered medications **45%**, Costs due to missed work/school **38%**

4 DIFFICULTIES MANAGING

CARE ACCESS CHALLENGES

n=46

Treatment ineffective/Side effects	72%
Inappropriate care access	61%
Symptoms not taken seriously	61%
Time/Logistical burden	48%
Treatment/medication access	39%
Cost/Lack of coverage	37%

33% say ***background or circumstances factors*** such as low-income, member of a racialized community, identify as 2SLGBTQ+, rural or remote residents ***affected ability to access diagnosis, treatment, or support*** n=12

5 DESIRED OUTCOMES OF NEW TREATMENT

84% ***Improve ability to work, study & function during the day***

Top 5 n=43

72%	Better nighttime sleep quality
70%	Reduce daytime sleepiness
65%	Improve thinking/less brain fog
35%	Better emotional stability

70% ***willing to tolerate at least 1 side effect if new medication effectively manages narcolepsy*** n=43

SIDE EFFECTS WILLING TO TOLERATE

37%	Appetite/weight changes
33%	Dependence/tolerance concerns
28%	Headache
28%	Heart-related effects
23%	Nausea/GI issues

Top 5

Mood Disorders Society of Canada
Société pour les troubles de l'humeur du Canada

IMPORTANT Small, unweighted convenience sample. Findings are directional, reflect survey participants only, and cannot be assumed to represent all Canadians affected by narcolepsy. n sizes vary by question.

NARRATIVE RESEARCH