NARRATIVE RESEARCH

2026 Narcolepsy Study Report

August 2026

Prepared for:

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

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Introduction and Summary of Findings

Introduction and Research Context

Mood Disorders Society of Canada (MDSC) is engaged in a wide range of products and initiatives designed to support the inclusion of persons with disabling mental illness and to lead public policy and program development in several capacities. MDSC recognizes that narcolepsy is a lifelong neurological disorder that can affect sleep, cognition, emotional well-being, employment, education, and overall quality of life. To advance understanding of the condition and support future policy, advocacy, and education initiatives, MDSC is interested in better understanding the experiences of Canadians living with narcolepsy and those who care for them. This research explores the challenges associated with diagnosis, treatment, symptom management, and daily functioning, while also identifying unmet needs, priorities for future treatment, and opportunities to improve care and support for individuals affected by narcolepsy.

More specific research objectives included:

- Understand the lived experience with narcolepsy
- Assess the impact of narcolepsy on daily life and on quality of life
- Evaluate current treatments – benefits, burdens, limitations
- Identify unmet needs and priority outcomes for patients
- Understand hypothetical expectations for a new treatment
- Capture economic, social, and practical burdens of the condition
- Document interactions with the health system & potential improvements
- Ensure equity considerations are reflected

This report presents the results of the study and includes an overview of the key findings, an analysis of the results from each question, and a description of the study methodology. The questionnaire and data tables are presented under separate cover. For each question, results are presented for the overall population under study.

As the study is based on a relatively small sample (n=47), including only four caregivers, findings should be interpreted as directional and considered with caution. The results reflect the views and experiences of survey participants only and cannot be assumed to represent those of the broader population of Canadians affected by narcolepsy.

Study Methodology

Mode
Online survey

Average Completion Time
23 minutes

Audience
Canadian adults aged 18 or older who have been diagnosed with narcolepsy, are experiencing symptoms of narcolepsy (without a diagnosis), or are caregivers of someone who has been diagnosed with narcolepsy.

Weighting
Results are not weighted.

47 completed surveys
(including 43 respondents with narcolepsy and 4 caregivers)

Margin of Error
As a non-probability sample of convenience, a margin of error is not applied to this study. Results cannot be extrapolated to the entire population.

Data Collection Dates
June 16 to August 3, 2026

Languages
The survey was offered in both English and French.

Sampling/Administration
MDSC distributed an open survey link through its social media networks and select partners.

Notes
Table references presented in the report refer to the detailed banner tables.

Summary of Objectives and Key Findings

Results of the **2026 Narcolepsy Study** indicate the following key findings:

Objectives	Key Findings
Understand the lived experience with narcolepsy	• The lived experience of narcolepsy is characterized by a long and often complex diagnostic journey, with most respondents reporting that it took at least six years, and frequently more than ten years, to receive a diagnosis after symptoms first appeared. • Before diagnosis, symptoms were commonly attributed to other conditions such as depression, chronic fatigue, anxiety, ADHD, or insomnia, suggesting that narcolepsy is often difficult to recognize and distinguish from other conditions. • Respondents also reported experiencing numerous symptoms simultaneously (an average of 7 symptoms), with many describing a combination of sleep-related, cognitive, emotional, and physical impacts, highlighting that narcolepsy affects far more than sleep alone and can permeate many aspects of daily functioning.
Assess the impact of narcolepsy on daily life and on quality of life	• Narcolepsy has a profound impact on quality of life, with respondents rating its effect an average of 8.2 out of 10 and two-thirds indicating that symptoms affect their lives a great deal. • The condition extends well beyond fatigue, affecting respondents' productivity, social relationships, emotional well-being, safety, employment, and educational participation. Many reported needing workplace or school accommodations, reducing their hours, or missing work, school, or volunteer commitments altogether. • The findings suggest that narcolepsy can shape how individuals work, learn, socialize, and manage daily responsibilities, resulting in a substantial overall burden on daily life.
Evaluate current treatments – benefits, burdens, limitations	• Respondents rely on a combination of medications, scheduled naps, lifestyle adjustments, workplace accommodations, and other coping strategies to manage symptoms, reflecting the need for a multifaceted approach to care. • While medications provide some benefit for certain symptoms, effectiveness ratings were generally moderate and varied considerably across symptom types, with emotional impacts, brain fog, and disrupted sleep remaining particularly difficult to manage. • Medication side effects were common and often affected mood, cardiovascular health, cognition, and sleep quality. • In addition, respondents reported challenges associated with dosing schedules, prescription monitoring requirements, obtaining refills, treatment affordability, and access to care, suggesting that current treatments often help manage symptoms but may not fully address the day-to-day realities of living with narcolepsy.

Summary of Objectives and Key Findings

Objectives	Key Findings
Identify unmet needs and priority outcomes for patients	• The findings point to significant unmet needs related to symptom control, treatment effectiveness, and quality of life. Respondents consistently identified the ability to remain awake, productive, and functional during the day as their highest priority. Improving sleep quality, reducing excessive daytime sleepiness, and improving cognitive functioning were also identified as key treatment goals. • The persistence of significant symptoms despite treatment, together with ongoing concerns about side effects and access to care, suggests that many respondents do not feel their current treatment approach allows them to function at the level they would like in work, school, family, and social settings.
Understand hypothetical expectations for a new treatment	• Respondents expressed strong interest in treatments that would provide meaningful improvements in daily functioning rather than simply reducing symptoms. Desired outcomes included increased energy and wakefulness, improved cognition and productivity, greater ability to work or study, and improved sleep quality. • Many also hoped that future treatments would help restore a sense of normalcy, independence, and emotional well-being, while reducing the burden associated with current medications, including side effects and treatment complexity. • These findings suggest that respondents are seeking treatments that improve both symptom management and overall quality of life.
Capture economic, social, and practical burdens of the condition	• Narcolepsy creates significant economic, social, and practical burdens that extend beyond direct healthcare costs. Respondents frequently reported expenses related to medications, travel for appointments, fatigue management, missed work or school, and reduced earning capacity. • Many also described the need for accommodations, changes in employment or educational participation, and ongoing time commitments associated with appointments, monitoring, and paperwork. • Social and emotional impacts were also substantial, including effects on relationships, mental well-being, and the need to rely on others for support. • Together, the findings suggest that the burden of narcolepsy extends into nearly every aspect of daily life and often affects entire households rather than only the individual living with the condition.

Summary of Objectives and Key Findings (cont.)

Objectives	Key Findings
Document interactions with the health system & potential improvements	• Managing narcolepsy often requires ongoing engagement with multiple healthcare professionals, particularly sleep specialists, neurologists, family physicians, and respirologists. • Despite regular interaction with the healthcare system, respondents frequently reported challenges, including ineffective treatments, long wait times, difficulty finding knowledgeable providers, referral requirements, travel burdens, and concerns that symptoms were not always taken seriously. • Together, these findings suggest opportunities to improve access to timely diagnosis, specialist care, treatment effectiveness, care coordination, and patient support throughout the healthcare journey.
Ensure equity considerations are reflected	• Although the sample is small, findings indicate that access to diagnosis, treatment, and support is not experienced equally by all respondents. Approximately one-third reported that personal circumstances or background factors had affected their access to care, while others identified concerns related to treatment affordability, insurance coverage, and geographic accessibility. • These findings suggest that barriers associated with income, coverage, location, and other circumstances may influence access to diagnosis and ongoing management, highlighting the importance of policies and programs that promote equitable access to treatment and support regardless of individual circumstances.

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Detailed Findings

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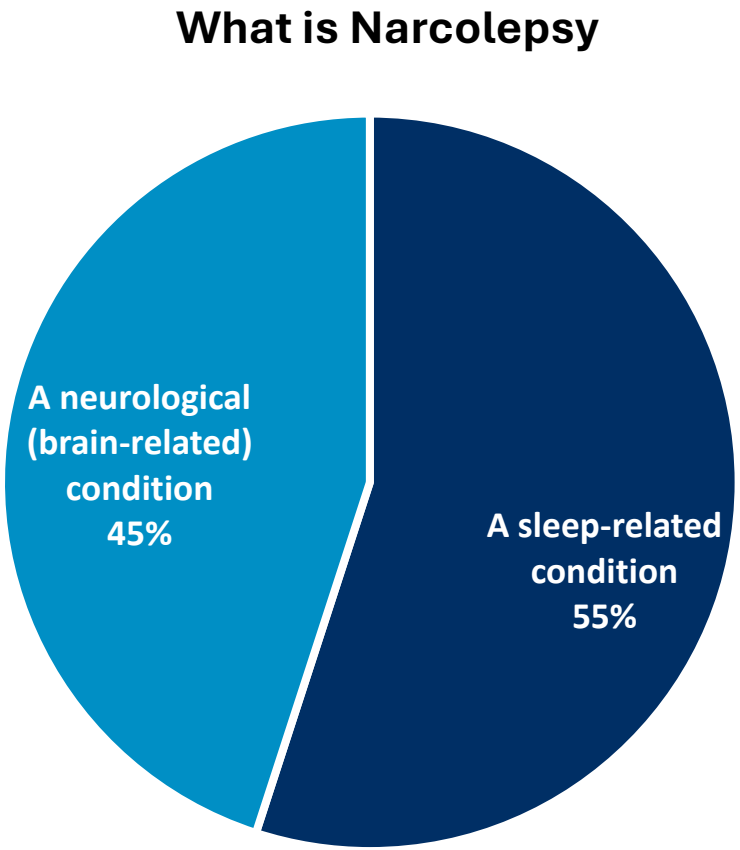
Awareness of Narcolepsy

Awareness of Narcolepsy

Narcolepsy is equally perceived as a sleep-related condition or a neurological (brain-related) condition.

Indicative of the survey target audience, all respondents have heard of the term narcolepsy. Among them, opinions are however divided with respect to what it is, between a sleep-related condition, and a neurological (brain-related) condition. (Tables 2 and 3)



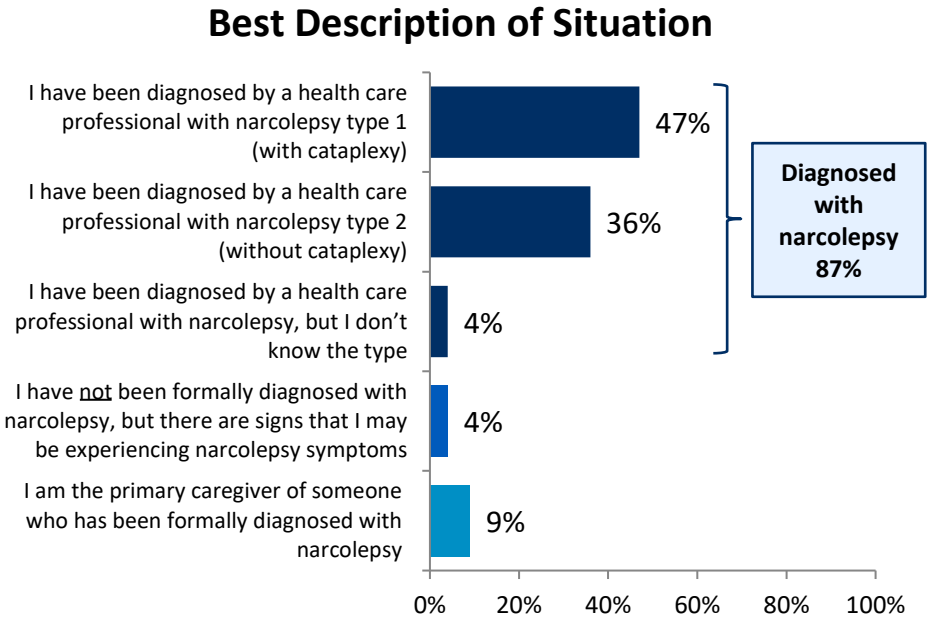
Q.3: Based on what you know, what is narcolepsy? (n=47) *Total aided mentions.*

Narcolepsy Experience and Diagnosis

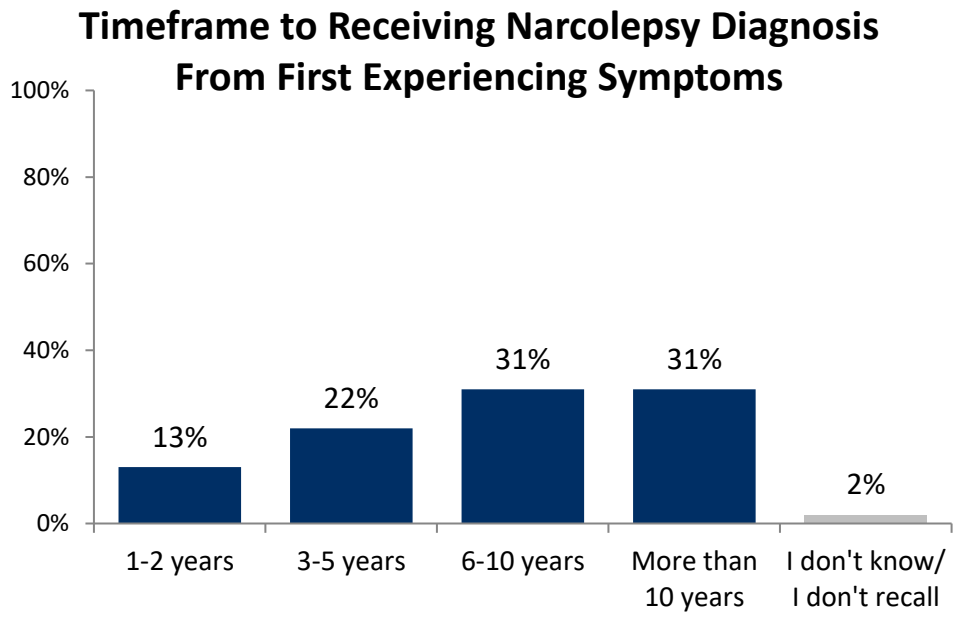
Survey perceptions are largely those of individuals who have been formally diagnosed with narcolepsy by a health care professional. A diagnosis was most often received at least six years from first experiencing narcolepsy symptoms.

The vast majority of respondents reported having received a formal diagnosis of narcolepsy from a health care professional. Among those diagnosed, respondents were divided between Type 1 and Type 2 narcolepsy. A small number reported experiencing signs or symptoms of narcolepsy without having received a formal diagnosis. Fewer than one in ten respondents identified as the primary caregiver of someone with a formal diagnosis of narcolepsy, while not having the condition themselves. (Table 4)

Where a formal narcolepsy diagnosis was received, respondents mentioned that it took them, or the person they care for, at least six years, or more than 10 years, to receive a diagnosis from first experiencing narcolepsy symptoms. (Table 6)



Q.4: Which of the following best describes your situation? Please select one response only that is most closely aligned with your closest experience with narcolepsy? (n=47) *Total aided mentions.*



Q.6: **[IF 'DIAGNOSIS' IN Q.4]** How long did it take for [you/the person you care for] from first experiencing symptoms to receiving a narcolepsy diagnosis? (n=45)

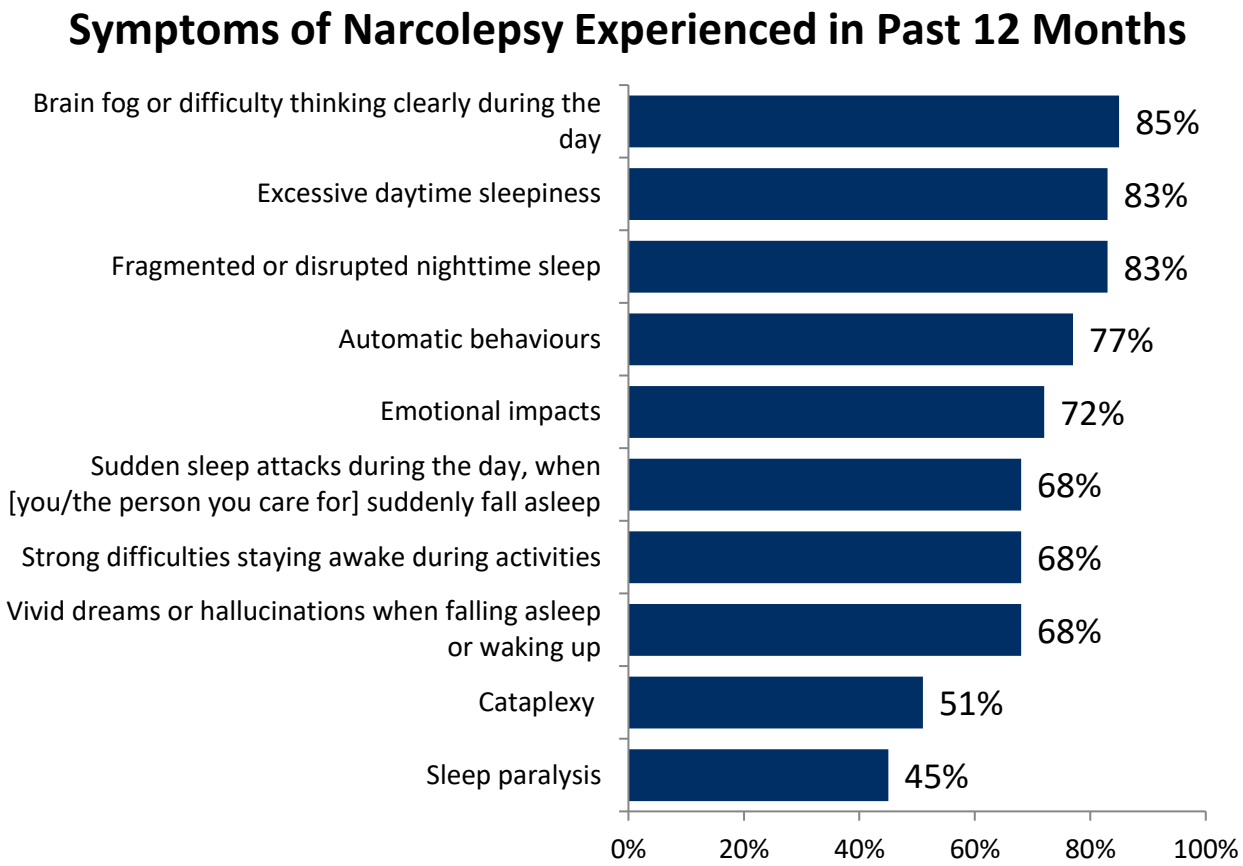
Symptoms Experienced

Narcolepsy is associated with a wide range of symptoms, with respondents reporting multiple sleep-related, cognitive, emotional, and physical impacts that affect daily functioning.

Respondents with narcolepsy were asked which symptoms they had experienced in the past 12 months. On average, respondents reported experiencing 7 symptoms, highlighting the broad range of ways in which narcolepsy affects daily life. The most commonly reported symptoms included brain fog or difficulty thinking clearly during the day, excessive daytime sleepiness, and fragmented or disrupted nighttime sleep.

Many respondents also reported automatic behaviours (performing activities without later remembering them) and emotional and psychological impacts associated with their symptoms, such as feelings of anxiety, frustration, or low mood. Other commonly reported experiences included sudden sleep attacks during the day, significant difficulty staying awake during routine activities, and vivid dreams or hallucinations when falling asleep or waking up.

While somewhat less common, approximately half of respondents reported experiencing cataplexy (sudden muscle weakness triggered by emotions such as laughter or surprise) and sleep paralysis. (Table 5)



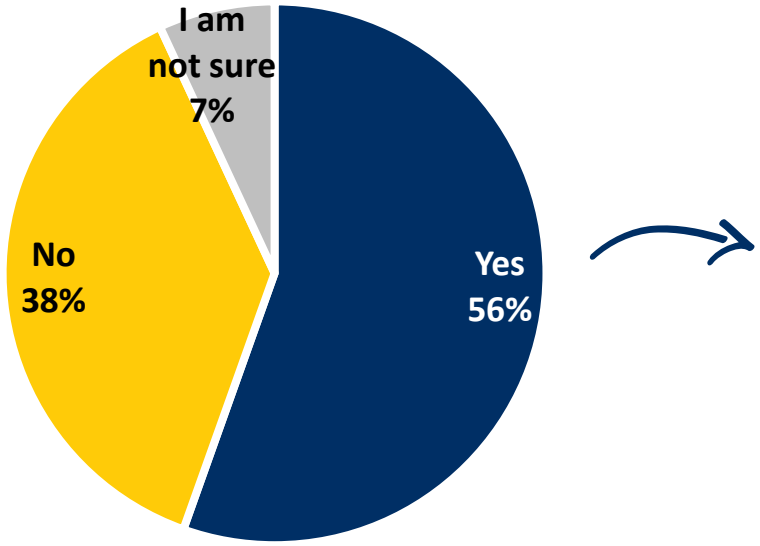
Q.5: **[IF 'EXPERIENCE WITH NARCOLEPSY' IN Q.4]** In the past 12 months, which symptoms of narcolepsy [have you/has the person you care for] experienced? (n=47) *Key aided mentions.*

Symptoms Attribution Prior to Narcolepsy Diagnosis

More than half of respondents experienced symptom misattribution before diagnosis, highlighting potential challenges in identifying narcolepsy.

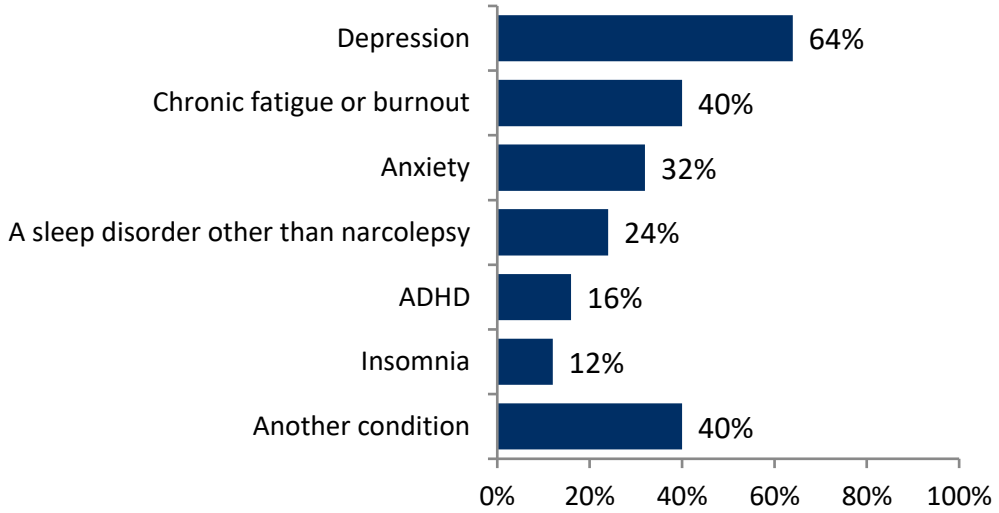
More than half of respondents with narcolepsy reported that their symptoms had been attributed to another condition before receiving a narcolepsy diagnosis. The conditions most commonly identified were depression, chronic fatigue or burnout, and anxiety, while smaller proportions reported that symptoms had been attributed to another sleep disorder, ADHD, or insomnia. (Tables 8 and 9)

Symptoms Attributed to Another Condition Prior to Narcolepsy Diagnosis



Q.8: **[IF 'DIAGNOSIS' IN Q.4]** Before receiving a narcolepsy diagnosis were the symptoms experienced by [you/the person you care for] ever attributed to another condition? (n=45)

Conditions Thought to Explain Narcolepsy Symptoms Before Diagnosis



Q.9: **[IF 'YES, SYMPTOMS ATTRIBUTED TO OTHER CONDITION' IN Q.8]** What condition(s) were the narcolepsy symptoms experienced by [you/the person you care for] attributed to, before narcolepsy was identified? (n=25) *Total aided mentions.*

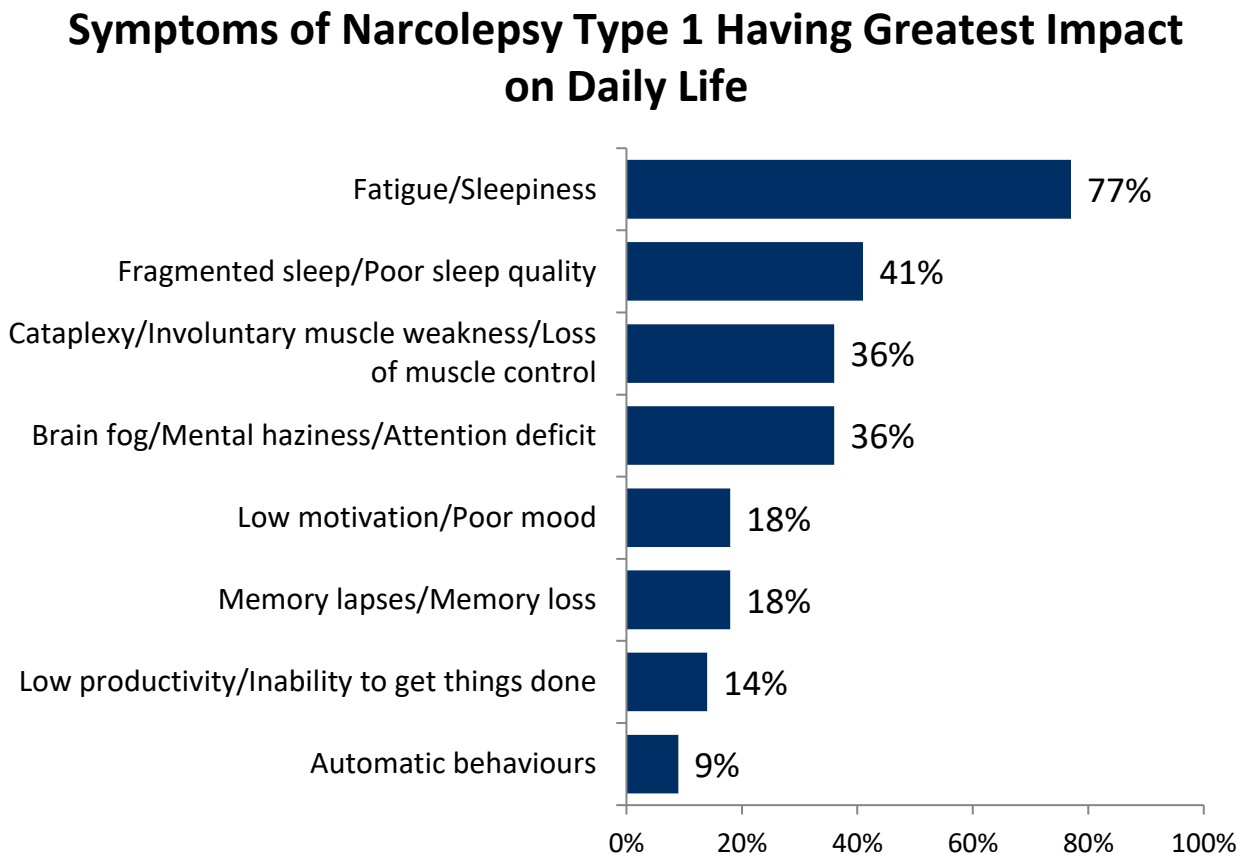
Most Impactful Symptoms of Narcolepsy Type 1 on Daily Life

Fatigue and sleepiness have the greatest negative impact on daily life among respondents with Type 1 narcolepsy.

Respondents with Type 1 narcolepsy were asked which symptoms had the greatest negative impact on their daily life. Fatigue or sleepiness was by far the most commonly reported symptom, highlighting the extent to which reduced energy and alertness can interfere with daily functioning. Fragmented sleep or poor sleep quality was also frequently mentioned, suggesting that respondents' daytime experiences may be compounded by difficulties achieving consistent, restorative sleep.

Other commonly reported impacts included cataplexy, involving involuntary muscle weakness or loss of muscle control, and brain fog, mental haziness, or attention deficits. These findings highlight that the effects of Type 1 narcolepsy extend beyond sleepiness and can also affect respondents' physical functioning and ability to think clearly or maintain attention.

While less common, respondents also mentioned low motivation or poor mood, memory lapses or loss, and low productivity or an inability to accomplish tasks. A small number identified automatic behaviours, involving performing activities without later remembering them, as having the greatest negative impact on daily life. (Table 7)



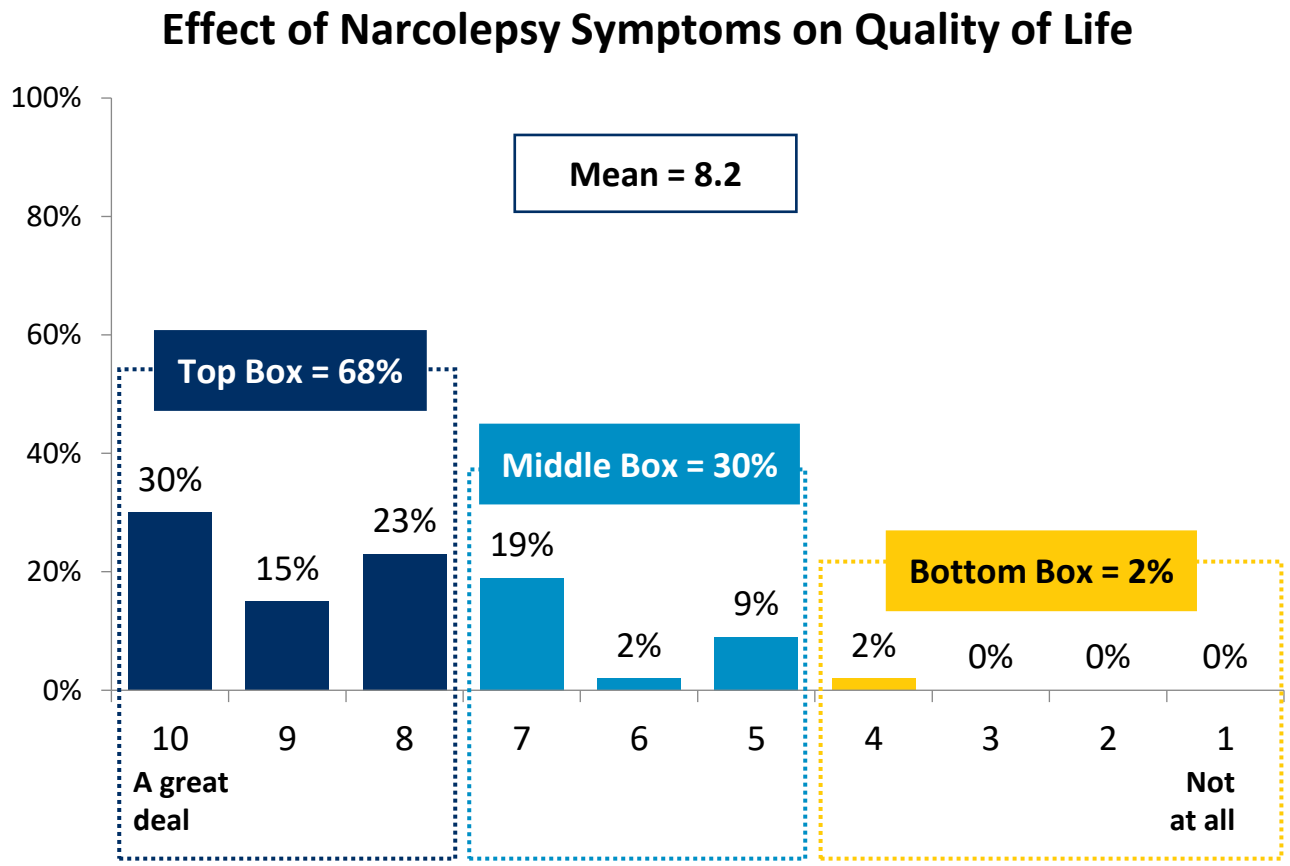
Q.7: **[IF 'DIAGNOSIS TYPE 1' IN Q.4]** Which symptoms of narcolepsy type 1 have the greatest negative impact on your daily life and why? (n=22) *Key unaided mentions.*

Impact of Narcolepsy Symptoms on Quality of Life

Narcolepsy symptoms have a substantial and widespread effect on quality of life, with nearly all respondents reporting at least a moderate impact.

Two-thirds of respondents rated the impact between eight and ten on a 10-point scale, including three in ten who indicated that symptoms affect quality of life a great deal. The average rating was 8.2, highlighting the considerable burden associated with living with narcolepsy.

A further three in ten respondents provided a rating between five and seven, while almost no respondents felt that narcolepsy symptoms had little or no effect. Overall, the findings indicate that the impact of narcolepsy is not limited to managing individual symptoms but extends more broadly to respondents' overall well-being and ability to navigate daily life. (Table 10)



Q.10: **[IF 'EXPERIENCE WITH NARCOLEPSY' IN Q.4]** How much do narcolepsy symptoms affect [your quality of life/the quality of life of the person you care for]? (n=47)

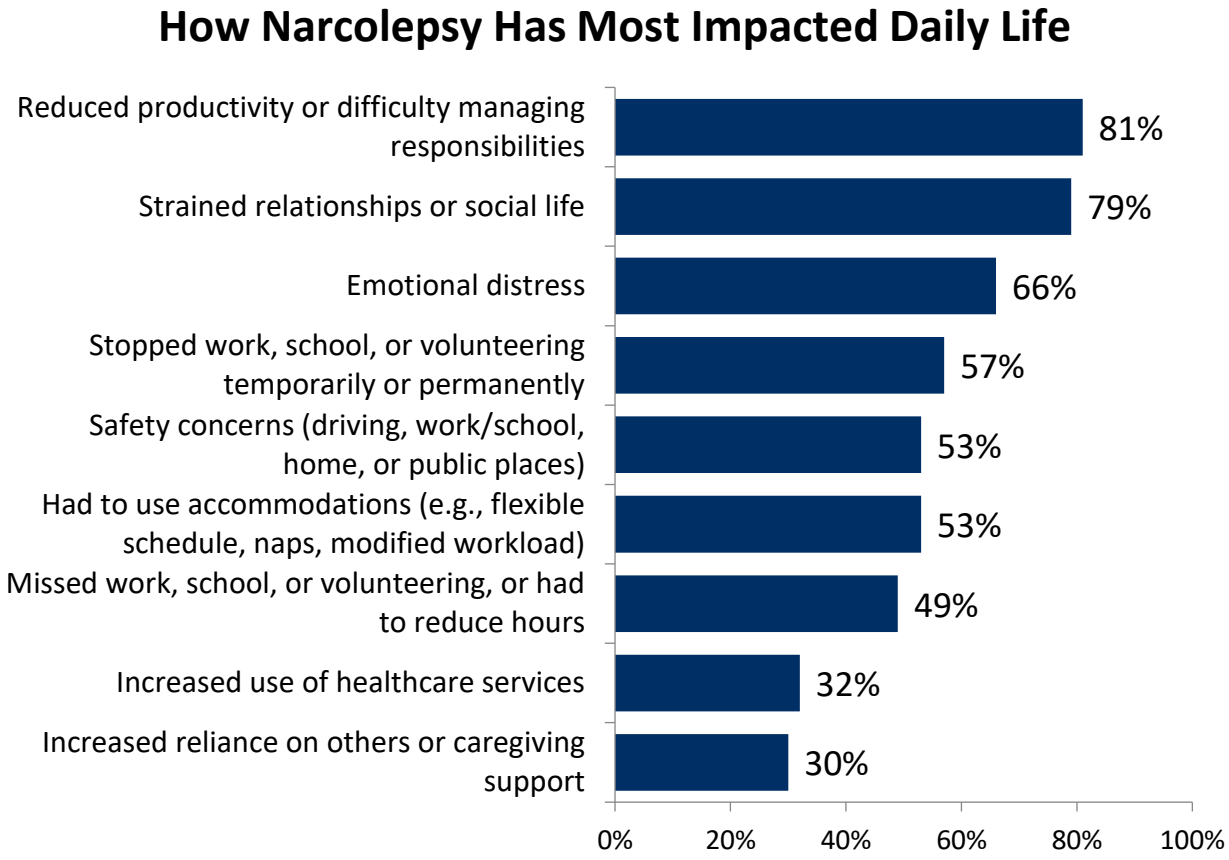
How Narcolepsy Impacts Quality of Life

Narcolepsy has a far-reaching impact on quality of life, affecting respondents' productivity, emotional well-being, relationships, safety, and ability to fully engage in daily activities.

Respondents who reported that narcolepsy symptoms had at least some impact on their quality of life (ratings of 2-10 on the 10-point scale) were asked how narcolepsy has affected their daily life, or that of the person they care for. The most commonly reported impacts were reduced productivity or difficulty managing daily responsibilities, strained relationships or social interactions, and emotional distress.

More than half also reported disruptions to work, school, or volunteer activities, including having to stop participation temporarily or permanently, miss time, or reduce their hours. Many also identified safety concerns while driving, working, studying, or going about daily activities, as well as a need for accommodations such as flexible schedules, daytime naps, or modified workloads.

While reported less frequently, a substantial minority indicated that narcolepsy had led to increased use of healthcare services and greater reliance on others for support or caregiving assistance. (Table 11)



Q.11: **[IF 'NARCOLEPSY IMPACTS DAILY LIFE' (RATINGS OF 2-10) IN Q.10]** How has narcolepsy most impacted [your daily life/the daily life of the person you care for]? (n=47) *Key aided mentions.*

Impact of Narcolepsy on Work, School, or Volunteering - Absenteeism

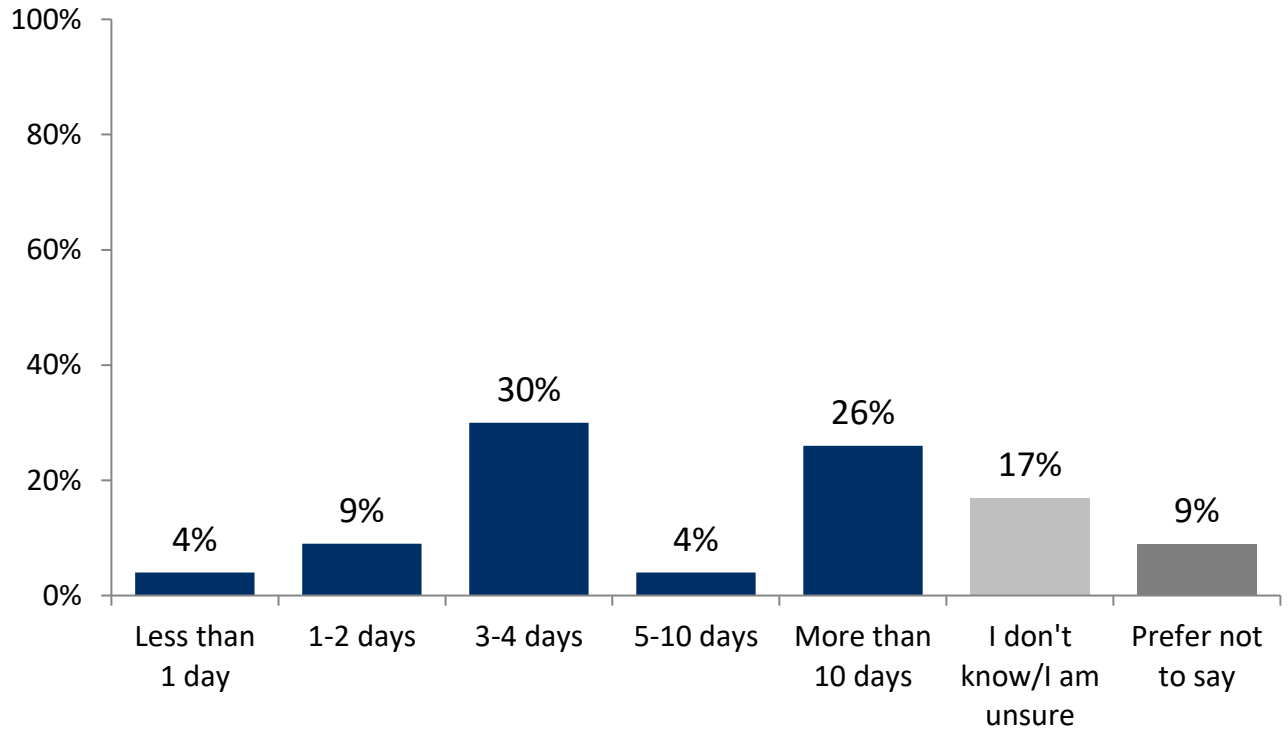
For many respondents, narcolepsy symptoms result in frequent absenteeism, underscoring the condition's impact on daily functioning and productivity.

Half of respondents whose narcolepsy has had an impact on their daily life report that their narcolepsy symptoms led them to miss work, school, or volunteering, or to reduce their hours. (Table 11)

Overall, these respondents are most likely to report 3-4 days or 10+ days of absenteeism per month due to narcolepsy. (Table 12)

49% missed work, school, or volunteering, or had to reduce hours

Days Missed Per Month Due to Narcolepsy Symptoms



Q.12: **[IF 'ABSENTEEISM' IN Q.11]** You mentioned that [you/the person you care for] had to miss work, school, or volunteering, or had to reduce hours. On average, how many days per month have [you/they] missed work, school, or volunteering in the past year because of [your/their] narcolepsy symptoms? (n=23)

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Treatment of Narcolepsy

Diagnosis of Narcolepsy

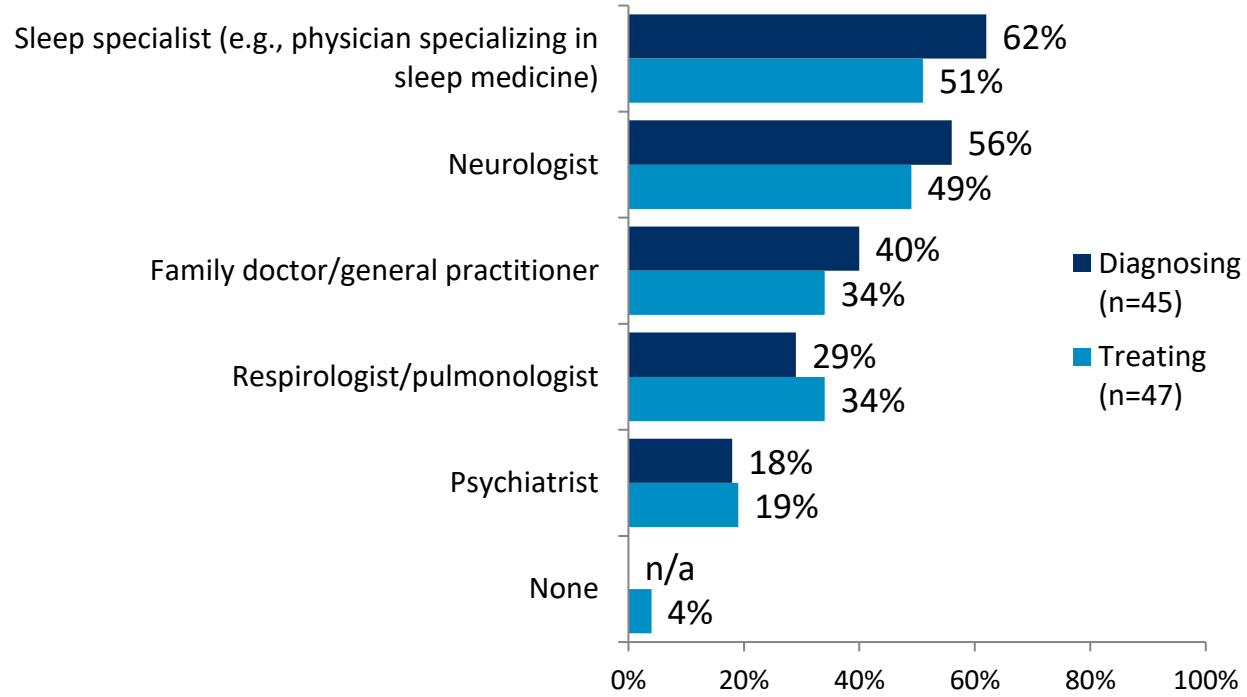
Sleep specialists and neurologists play the most prominent roles in both diagnosing and treating narcolepsy, while the involvement of several types of healthcare professionals reflects the multidisciplinary nature of care.

Sleep specialists and neurologists were the professionals most commonly involved in diagnosis, followed by family doctors or general practitioners. Respirologists or pulmonologists and psychiatrists were also involved for some respondents.

A similar pattern was reported for treatment, with sleep specialists and neurologists continuing to have the most prominent roles. Family doctors or general practitioners and respirologists or pulmonologists were each involved in treating one-third of respondents, while psychiatrists were less commonly involved.

Almost all respondents reported receiving treatment from at least one type of healthcare professional. Overall, the involvement of multiple healthcare specialties highlights the need for coordinated care that addresses the varied sleep-related, neurological, respiratory, and psychological aspects of narcolepsy. (Tables 13a, 13b)

Healthcare Professionals Involved in Diagnosing or Treating Narcolepsy



Q.13A: **[IF 'DIAGNOSIS' IN Q.4]** Which healthcare professionals have been involved in diagnosing narcolepsy [for yourself/for the person you care for]? | Q.13B: **[IF 'EXPERIENCE WITH NARCOLEPSY' IN Q.4]** Which healthcare professionals have been involved in treating narcolepsy [for yourself/for the person you care for]?

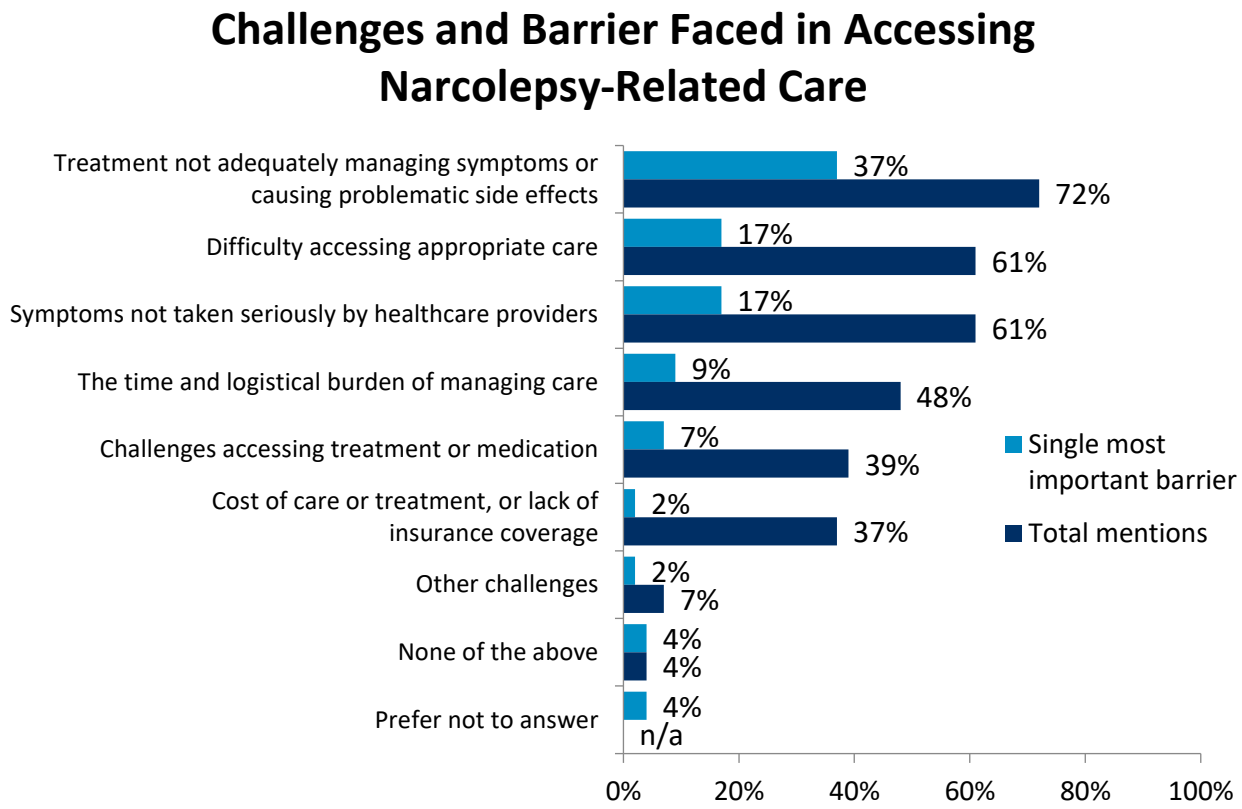
Barriers To Seeking Treatment

Narcolepsy care is often complicated by ineffective treatment and problematic side effects.

The most commonly reported challenge when seeking diagnosis or care for narcolepsy was that the treatment did not adequately manage symptoms or caused problematic side effects. Many respondents also experienced difficulty accessing appropriate care, including long wait times, referral requirements, challenges in finding a knowledgeable specialist, and travel or distance. An equal proportion reported that symptoms had not been taken seriously by healthcare providers, pointing to difficulties being heard and understood alongside challenges navigating the healthcare system.

Respondents also reported the time and logistical burden associated with appointments, paperwork, and taking time away from work or school. Challenges accessing treatment or medication and the cost of care, treatment, or insufficient insurance coverage were also common.

When asked to identify the single biggest barrier to narcolepsy-related care, ineffective treatment or problematic side effects were mentioned most often. Overall, the findings suggest that receiving care does not necessarily resolve the challenges faced by respondents, as many continue to experience unmet needs related to treatment effectiveness, recognition of symptoms, and access to knowledgeable and affordable care. (Tables 14 & 15)



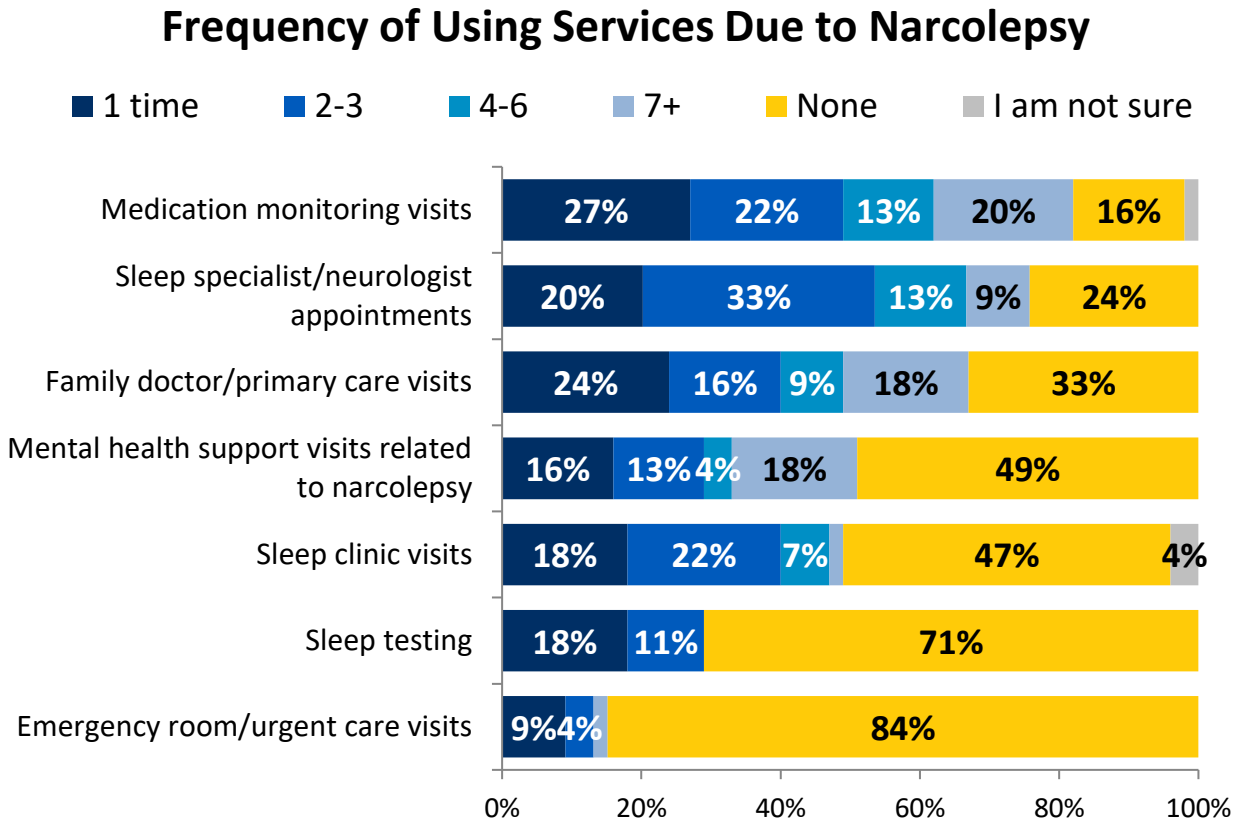
Q.14: **[IF 'HEALTHCARE DIAGNOSIS OR CARE' IN Q.13A AND/OR IN Q.13B]** Have [you experienced] any of the following challenges [been experienced by the person you care for] when looking for a diagnosis or care for narcolepsy symptoms? (n=46) Total aided mentions. | Q.15: **[IF 'CHALLENGES ACCESSING CARE' IN Q.14]** What is the single biggest barrier [you face/faced/the person you care for faces/faced] in accessing narcolepsy-related care? (n=46) *Key aided mentions.*

Use of Health Care Services Because of Narcolepsy

Narcolepsy-related healthcare use is concentrated in ongoing specialist care and medication monitoring, while emergency and diagnostic services are used less frequently.

Medication monitoring was the most widely used service within the past 12 months, with most respondents reporting at least one visit and many requiring repeated visits. Sleep specialist or neurologist appointments were also common, with more than half of respondents attending these services at least twice. Sleep clinic and family doctor or primary care visits were used by many respondents, although generally less frequently.

Mental health support related to narcolepsy was accessed by half of the respondents, including nearly two in ten who reported seven or more visits in the past year. This indicates that, for some respondents, managing narcolepsy involves ongoing psychological support alongside medical care. In contrast, most respondents had not used emergency or urgent care or undergone sleep testing during the past year. Overall, the findings highlight that narcolepsy care often requires regular monitoring and continued engagement with specialist and primary care services. (Tables 16a to 16g)



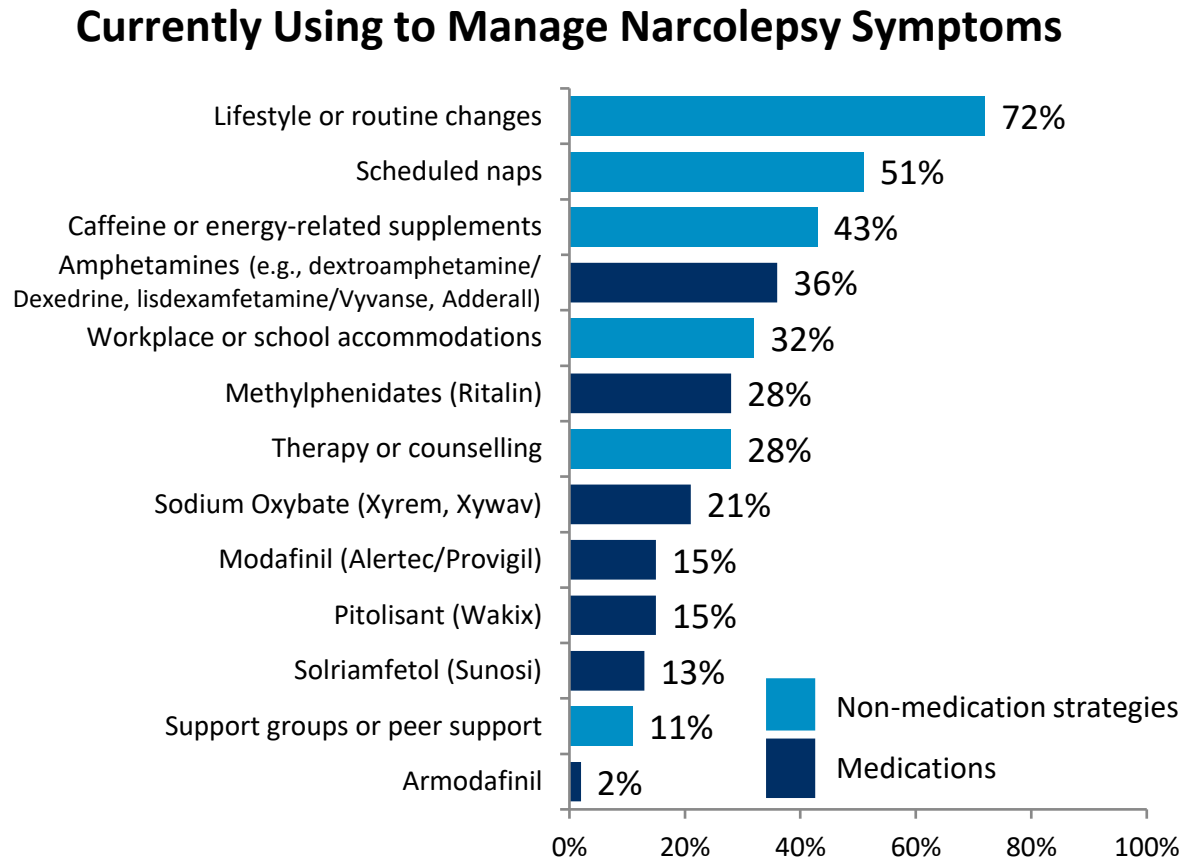
Q.16a-g: **[IF 'WAS TREATED FOR NARCOLEPSY' IN Q.13B]** In the past 12 months, approximately how many times have [you/the person you care for] used each of the following services because of narcolepsy (including follow-up and monitoring)? (n=45)
Values of 2% or less are not labelled.

Current Treatments or Strategies Used to Address Narcolepsy Symptoms

Managing narcolepsy often involves combining daily routine changes with medication and other supports.

Respondents were asked which treatments or strategies they were currently using to manage narcolepsy symptoms. Lifestyle or routine changes, such as maintaining a sleep schedule or planning activities, were most common, while half of the respondents mentioned scheduled naps. Many respondents also relied on caffeine or energy-related supplements, workplace or school accommodations, and therapy or counselling, demonstrating how symptom management can extend into daily routines, work, education, and emotional well-being.

Respondents also reported using a range of medications, most commonly amphetamines and methylphenidates, while smaller proportions used sodium oxybate, modafinil, pitolisant, solriamfetol, or armodafinil. Overall, the findings show that respondents often draw on multiple approaches to manage narcolepsy symptoms, with non-medication strategies playing an important role alongside prescribed treatments. (Table 17)



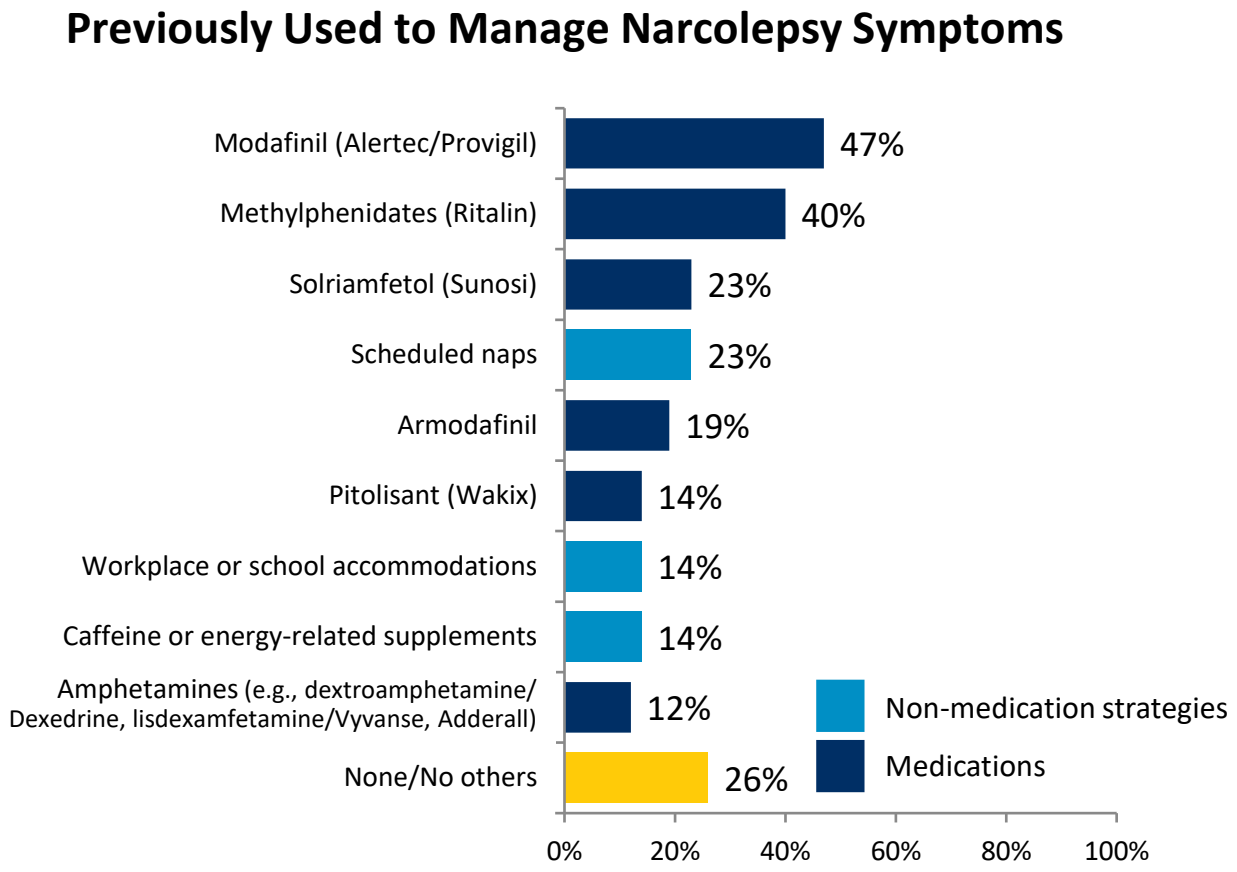
Q.17: **[IF 'EXPERIENCE WITH NARCOLEPSY' IN Q.4]** What treatments or strategies [are you/is the person you care for] currently using to manage narcolepsy symptoms? Select all that apply. (n=47) *Key aided mentions.*

Past Treatments or Strategies Used to Address Narcolepsy Symptoms

Past approaches to managing narcolepsy were primarily medication-based, highlighting the need to try different treatments over time.

According to respondents, Modafinil and methylphenidates were the most commonly reported previous treatments, followed by solriamfetol and armodafinil. Other medications previously used included pitolisant, amphetamines, and sodium oxybate.

Some respondents had also previously used non-medication strategies, most commonly scheduled naps, followed by workplace or school accommodations and caffeine or energy-related supplements. Lifestyle or routine changes, support groups or peer support, and therapy or counselling were mentioned less often. Approximately one-quarter had not used any other treatments or strategies, while the range of approaches reported by others suggests that managing narcolepsy can involve trying multiple options over time. (Table 17a)



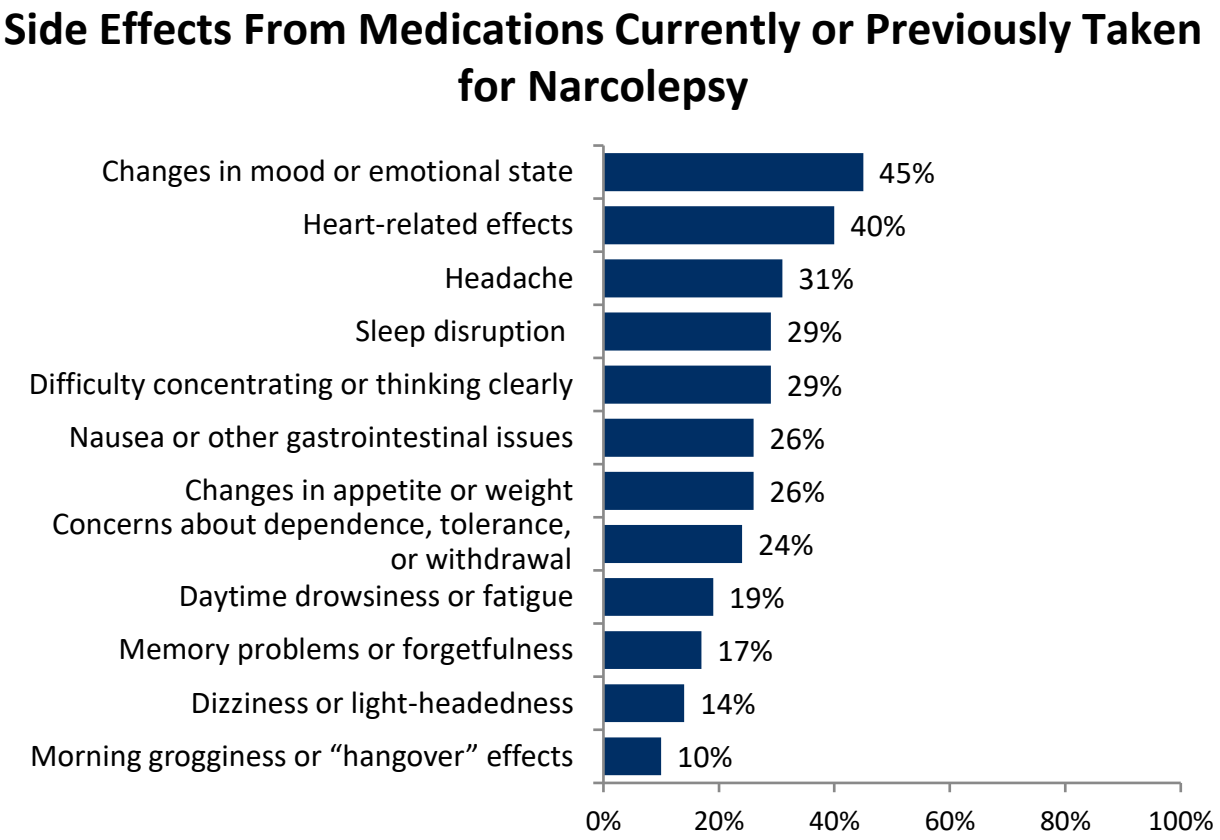
Q.17a: **[IF 'EXPERIENCE WITH NARCOLEPSY' IN Q.4]** What [other] treatments or strategies [have you/has the person you care for] used in the past, to manage narcolepsy symptoms? Select all that apply. (n=43) *Key aided mentions.*

Most Bothersome Side Effects from Medication

Medication side effects can add emotional, physical, and cognitive challenges to managing narcolepsy.

Changes in mood or emotional state, such as irritability, anxiety, or low mood, were the most commonly reported side effects of narcolepsy medication, followed by heart-related effects such as increased heart rate or changes in blood pressure. Headaches, disrupted sleep, and difficulty concentrating or thinking clearly were also common concerns.

Other bothersome side effects included nausea or gastrointestinal issues, changes in appetite or weight, and concerns about dependence, tolerance, or withdrawal. Some respondents also reported daytime drowsiness or fatigue, memory problems, dizziness, and morning grogginess. Almost all respondents identified at least one bothersome side effect, highlighting the challenge of balancing symptom management with the broader effects of medication on daily well-being. (Table 18)



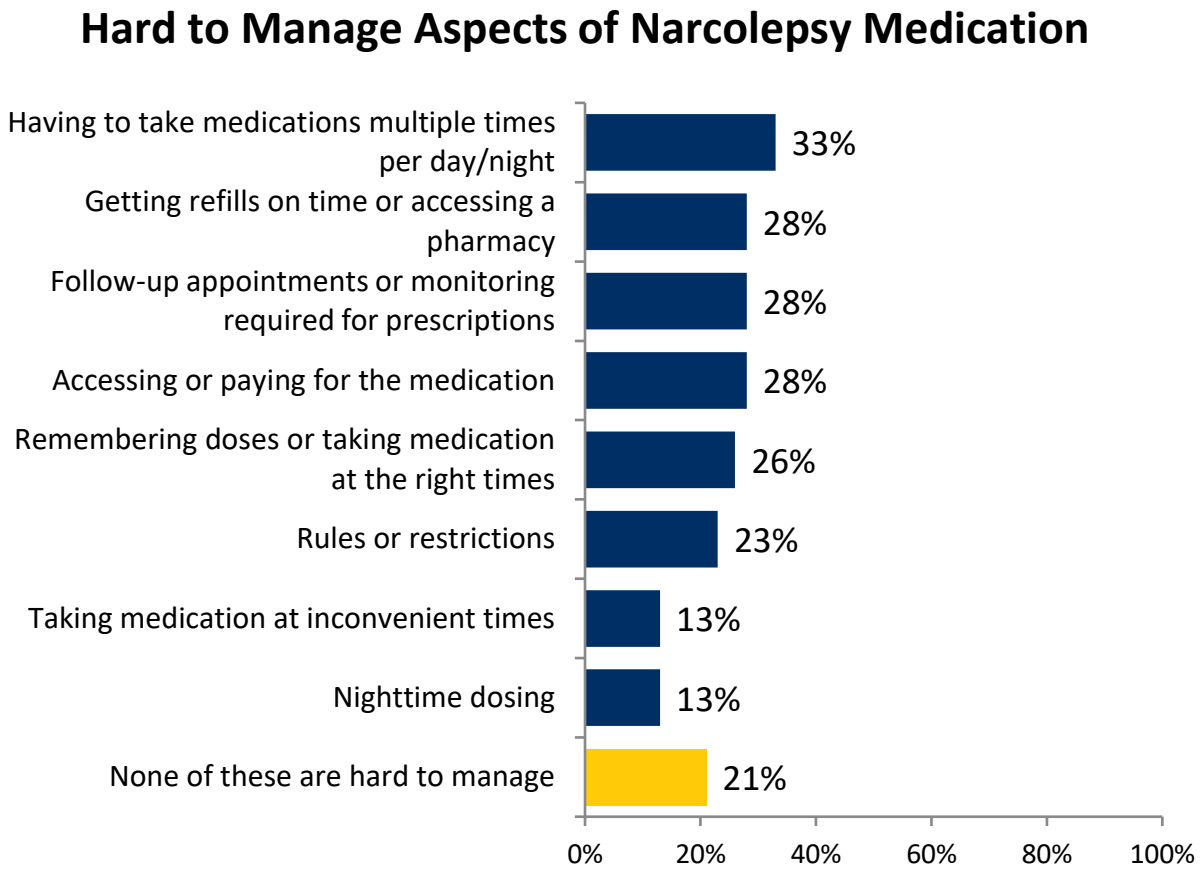
Q.18: **[IF ‘MEDICATION TAKEN’ IN Q.17 AND/OR Q.17A]** Which side effects from narcolepsy medications currently taken or taken in the past are most bothersome to [you/the person you care for]? Please select up to four side effects that are the most bothersome to [you/the person you care for]. (n=42) *Key aided mentions.*

Aspects of Managing Narcolepsy Medication Hard to Manage

Managing narcolepsy medication can add logistical, financial, and administrative demands to living with narcolepsy.

Respondents who had taken narcolepsy medication were asked which aspects they found difficult to manage. Taking medication multiple times during the day or night was the most common challenge. Many respondents also experienced difficulties obtaining timely refills or accessing a pharmacy, attending follow-up appointments or monitoring required for prescriptions, and accessing or paying for medication. Remembering doses or taking medication at the correct times and navigating rules or restrictions for controlled medications were also common challenges.

Fewer respondents reported difficulties related to inconvenient or nighttime dosing, needing assistance from another person, or travel and storage requirements. One in five respondents did not find any of these aspects difficult. (Table 19)



Q.19: **[IF 'MEDICATION TAKEN' IN Q.17]** Which aspects of managing narcolepsy medication, if any, [do you/does the person you care for] find hard to manage? Please select all that apply. (n=39) *Key aided mentions*.

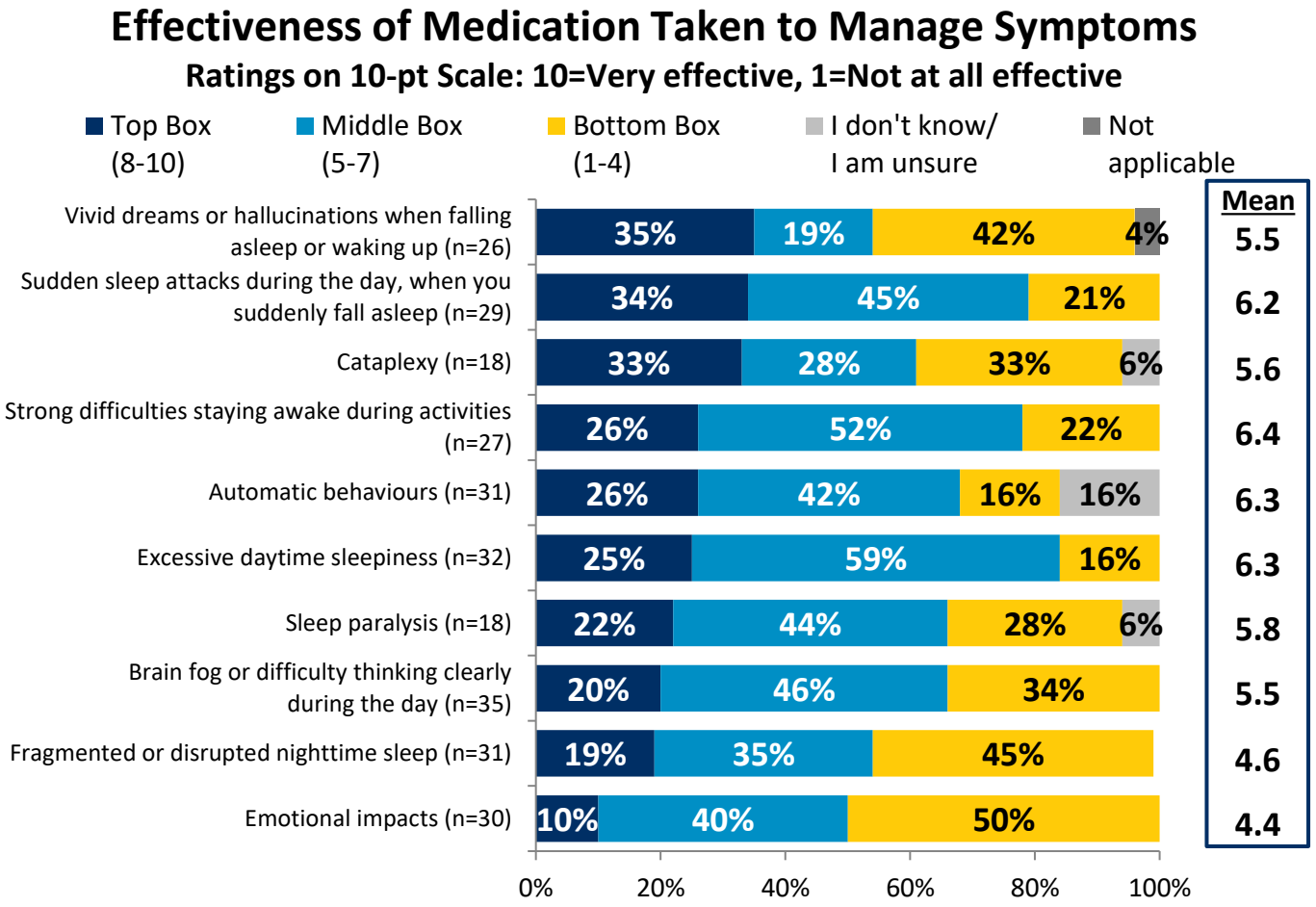
Effectiveness of Most Recent Narcolepsy Medication

The most recent medication provided limited effectiveness across narcolepsy symptoms, particularly for emotional impacts.

Respondents who take or have taken medication(s) to address their narcolepsy symptoms were asked to rate, on a scale of one to ten, how effective their most recent medication is at managing their various symptoms. Medication was most likely to be rated highly effective for vivid dreams or hallucinations, sudden daytime sleep attacks, and cataplexy. However, only one-third of respondents managing these symptoms provided a rating of eight to 10, indicating that even the most effectively managed symptoms often remained insufficiently controlled. Effectiveness was lowest for fragmented or disrupted nighttime sleep and emotional impacts such as anxiety, frustration, or low mood, for which the respondents were more likely to rate in the bottom box.

Although perhaps not most *highly* effective, medication is most *widely* effective at managing the inability to stay awake during activities, automatic behaviours, excessive sleepiness, and daytime sudden sleep attacks.

Overall, the findings point to substantial gaps in symptom management, with the most recent medication seldom providing a high level of effectiveness across the varied impacts of narcolepsy. (Tables 20a to 20j)



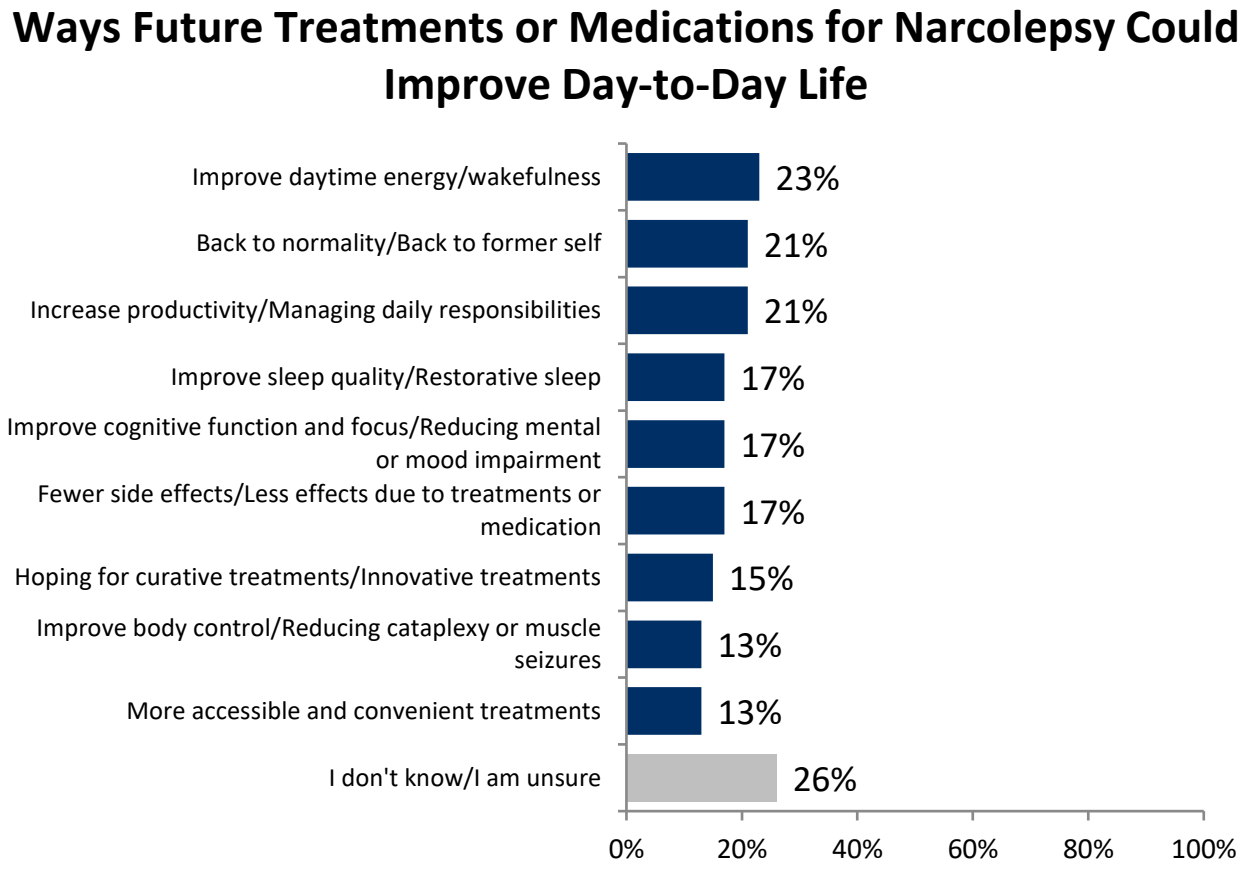
Q.20a-j: **[IF 'MEDICATION TAKEN' IN Q.17 AND 'EXPERIENCED SYMPTOMS' Q.5]** How effective is/was the most recent medication [you/the person you care for] took in managing the following narcolepsy symptoms? *Responses of 'I don't know/I am unsure' and 'Not applicable' were excluded from the calculation of the Mean.*

Expectations for New Treatment

Respondents hope future treatments will help restore energy, independence, and a greater sense of normalcy in daily life.

The most common hopes for future treatments included improving daytime energy and wakefulness, feeling more like their former selves, and being better able to manage daily responsibilities and remain productive. Respondents also hoped for more restorative sleep, improved cognitive function and focus, and fewer medication side effects.

Others expressed interest in curative or innovative treatments, better control of cataplexy or involuntary muscle weakness, and treatments that are easier to access and use. Improved social lives and relationships, and more affordable treatment, were mentioned less often. One in four were unsure how future treatments could improve daily life. Overall, respondents' hopes extend beyond symptom relief to regaining greater consistency, functioning, and control in everyday life. (Table 21)



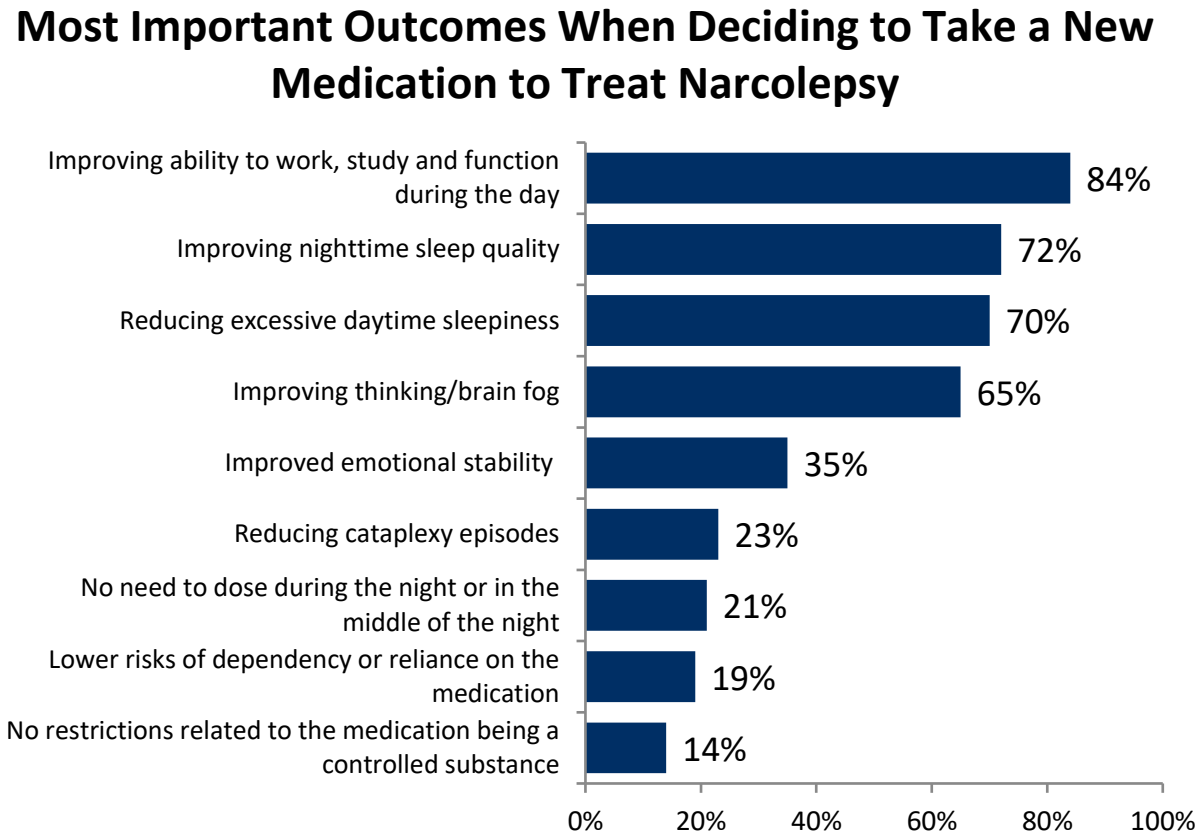
Q.21: **[IF 'EXPERIENCE WITH NARCOLEPSY' IN Q.4]** In what ways would you hope future treatments or medications for narcolepsy would improve [your day-to-day life/the life of the person you care for]? (n=47) *Key unaided mentions*.

Important Outcomes of New Medication

Respondents prioritize treatments that improve daily functioning, sleep quality, alertness, and cognitive clarity.

Respondents were asked which outcomes would be most important when considering a new medication for narcolepsy. The ability to work, study, and function during the day was the most important outcome. Improving nighttime sleep quality, reducing excessive daytime sleepiness, and alleviating cognitive impairment, or 'brain fog,' were also key priorities, underscoring the need for treatments that address both nighttime sleep and daytime functioning.

Improved emotional stability was important to about one-third of respondents, while others prioritized reducing cataplexy episodes, avoiding nighttime dosing, and lowering the risk of dependence or reliance on medication. Fewer daily doses, caregiver assistance, and special storage requirements were less commonly prioritized. (Table 22)



Q.22: **[IF 'SELF EXPERIENCE WITH NARCOLEPSY' IN Q.4]** If a new medication were available to treat narcolepsy, which of the following outcomes would be most important in your decision to consider taking this new medication? Please select up to 5 responses, based on what you would want the new medication to do. (n=43) *Key aided mentions*.

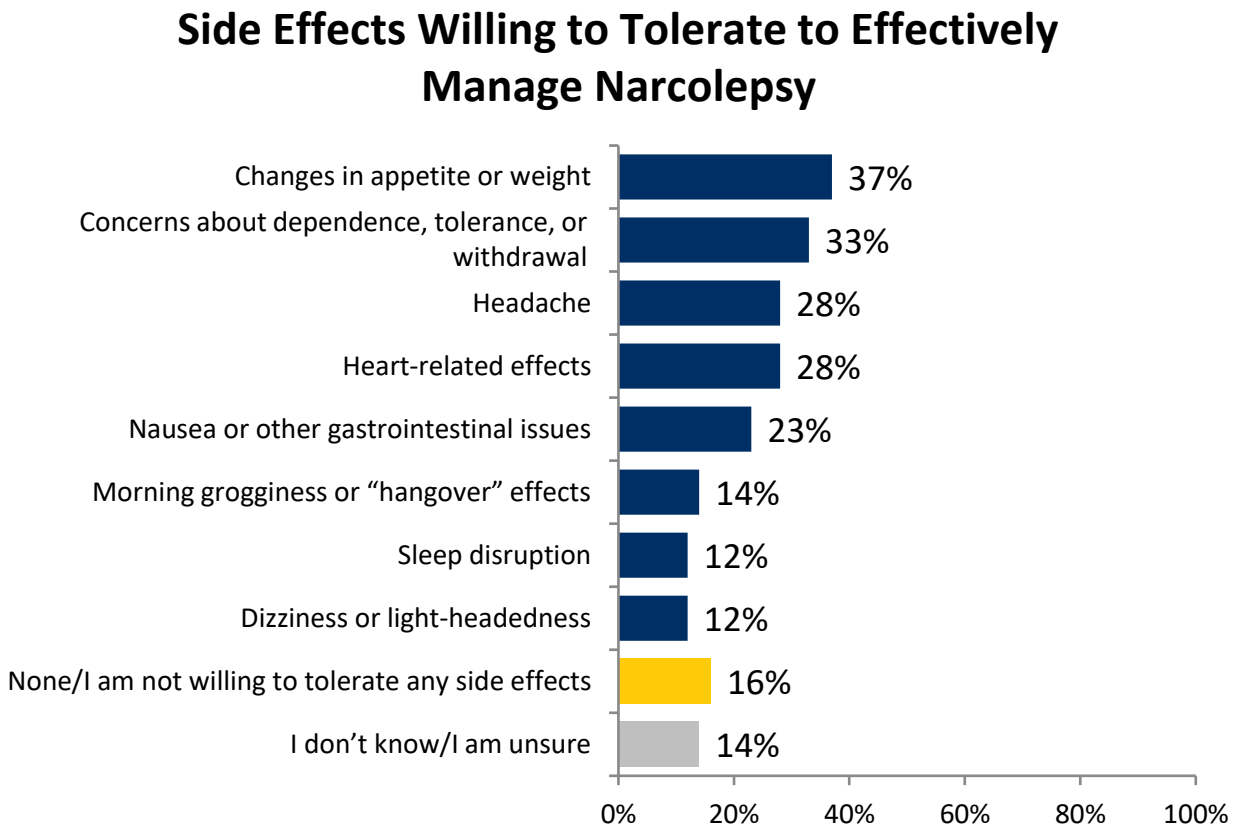
Side Effects of New Medication

Respondents are more willing to tolerate physical side effects than effects that could further impair daily functioning.

Respondents who experience narcolepsy symptoms were asked what side effects they would be willing to tolerate in a hypothetical medication that could effectively manage their narcolepsy symptoms. Changes in appetite or weight were most commonly considered acceptable, followed by concerns about dependence, tolerance, or withdrawal. Some respondents were also willing to tolerate headaches, heart-related effects, and nausea or other gastrointestinal issues.

Fewer respondents were willing to accept morning grogginess, sleep disruption, or dizziness. Very few were willing to tolerate daytime drowsiness, changes in mood, difficulty thinking clearly, memory problems, or coordination difficulties.

This suggests respondents are particularly reluctant to accept side effects that resemble existing narcolepsy symptoms or undermine the alertness, cognitive clarity, and functioning they hope treatment will improve. However, this should be interpreted directionally due to the low frequency of the responses. (Table 23)



Q.23: **[IF 'SELF EXPERIENCE WITH NARCOLEPSY' IN Q.4]** Knowing that all medications may have side effects, which side effects would you be willing to tolerate if a medication that effectively manages your narcolepsy were available? Please select all that apply. (n=43) *Key aided mentions.*

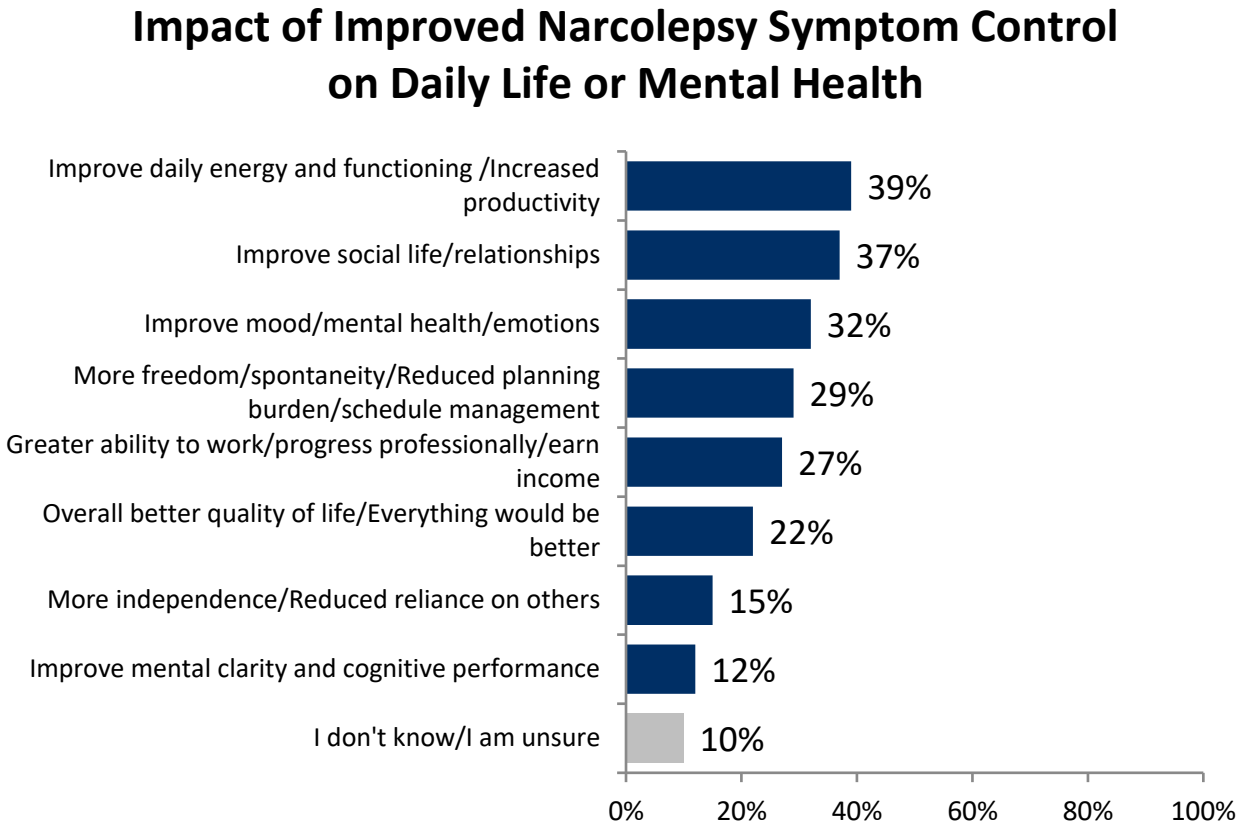
Effect of New Medication on Sleepiness and/or Cataplexy

Better treatment of excessive daytime sleepiness and cataplexy could improve respondents' functioning, relationships, and mental well-being.

Respondents were asked how better treatment of excessive daytime sleepiness or cataplexy would change daily life or mental health. The most anticipated benefits were greater energy, improved daily functioning and productivity. Many respondents also expected stronger social lives and relationships, improvements in mood, mental health, and emotional well-being.

Other anticipated benefits included greater freedom and spontaneity, with less need to plan daily activities around symptoms, as well as an improved ability to work, progress professionally, and earn income. Respondents also felt that better symptom control could improve overall quality of life, increase independence, reduce reliance on others, and support clearer thinking.

Overall, the findings demonstrate that better treatment could have benefits extending well beyond symptom control, helping respondents participate more fully and independently in everyday life. (Table 24)



Q.24: **[IF 'EXPERIENCE EXCESSIVE DAYTIME SLEEPINESS AND/OR CATAPLEXY' IN Q.5]** If [your/the] excessive daytime sleepiness and/or cataplexy associated with narcolepsy [experienced by the person you care for] were better treated, how do you think this would change [your/their] daily life or mental health? (n=41) *Key unaided mentions.*

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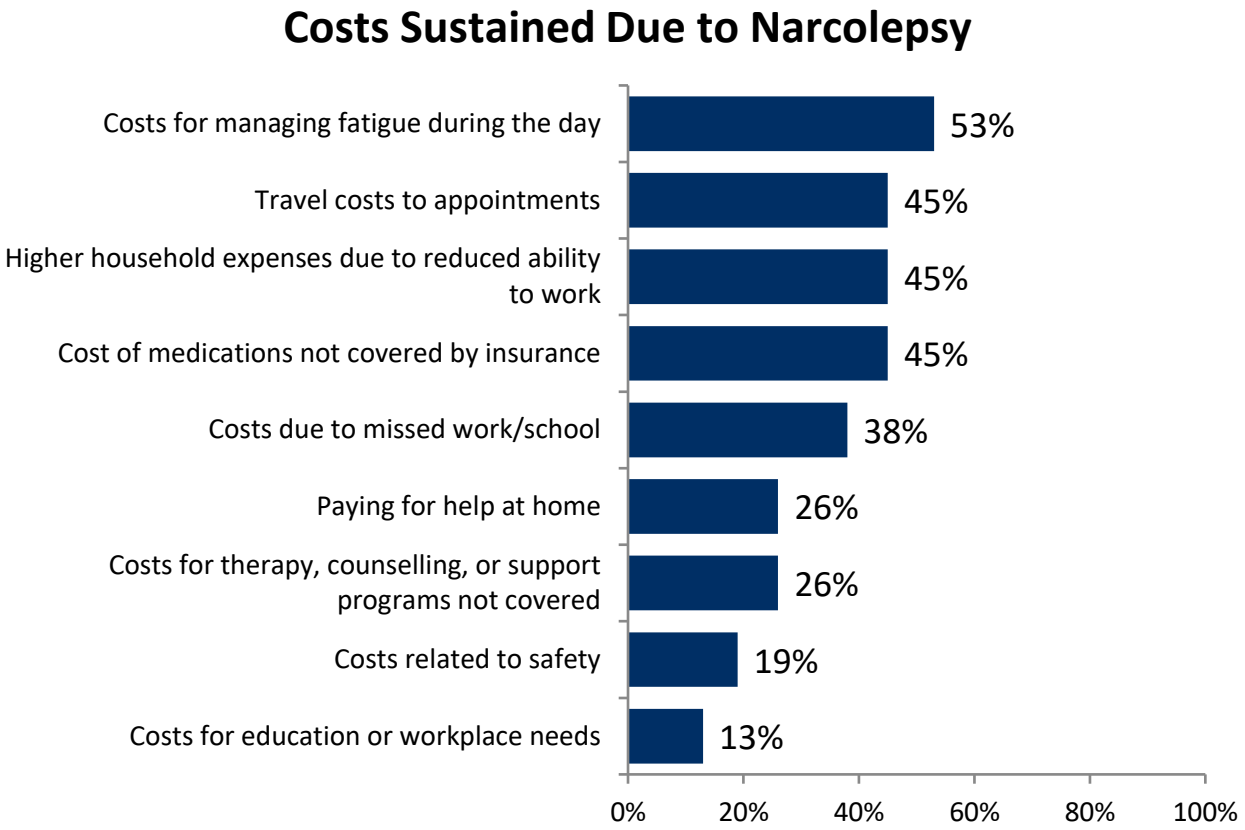
Impact of Narcolepsy on Finances and Time

Costs Incurred Due to Narcolepsy

Narcolepsy creates financial pressures through both the direct costs of managing the condition and its impact on respondents' ability to work.

Costs associated with managing daytime fatigue, such as caffeine, energy products, or related supplies, were most common. Many respondents also reported travel costs for appointments, medication expenses not covered by insurance, and higher household expenses resulting from a reduced ability to work.

Costs related to missed work or school were also common, further highlighting the financial consequences of symptoms that interfere with daily functioning. Some respondents paid for help at home or for therapy, counselling, or support programs not covered by insurance, while others experienced costs related to safety, education, or workplace needs. Only a small proportion reported none of these costs, indicating that the financial impact of narcolepsy is widespread and extends across healthcare, employment, household support, and everyday symptom management. (Table 25)



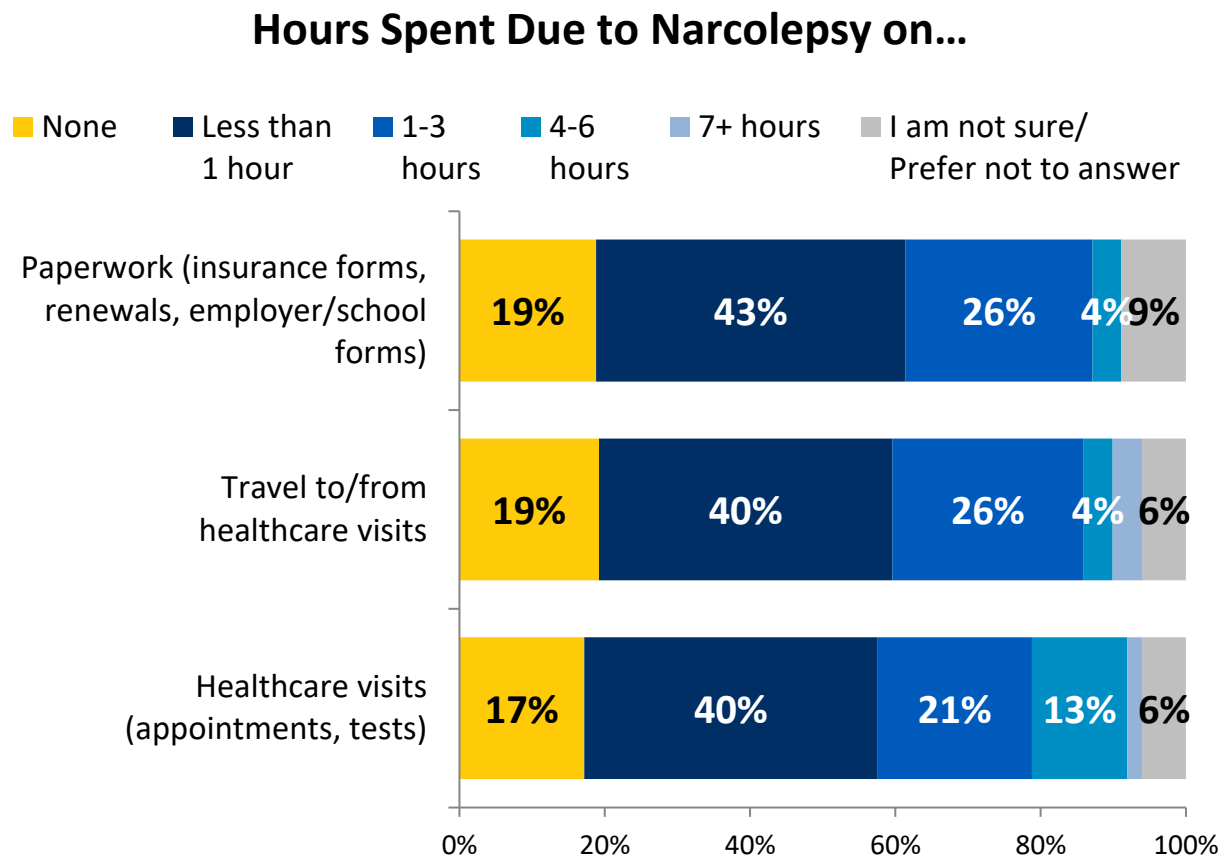
Q.25: **[IF 'EXPERIENCE WITH NARCOLEPSY' IN Q.4]** In the past 12 months, which of the following costs have [you and your household/the person you care for and their household] had because of narcolepsy? Select all that apply. (n=47) *Key aided mentions.*

Time Spent Managing Narcolepsy

For most respondents, the monthly time spent managing narcolepsy-related healthcare is limited.

Respondents were asked how much time they typically spend each month on healthcare visits, travel to and from appointments, and paperwork because of narcolepsy. Across all three activities, most respondents spent three hours or less per month, including a sizeable minority who spent less than one hour. Healthcare visits were somewhat more time-intensive, with some respondents spending four to six hours per month on appointments and tests.

About one in five respondents spent no time travelling to healthcare visits or completing related paperwork, while a similar proportion reported no time spent attending healthcare visits. (Tables 26a to 26c)



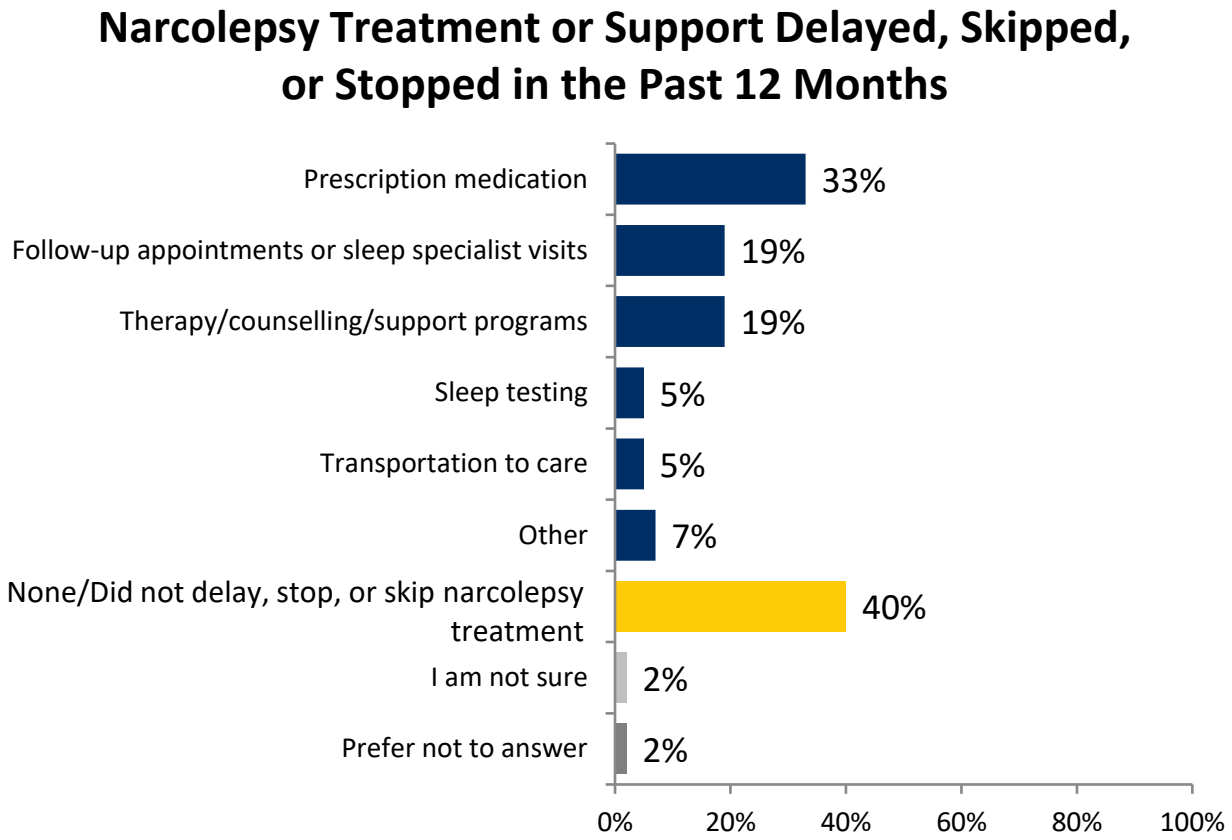
Q.26a-c: **[IF 'EXPERIENCE WITH NARCOLEPSY' IN Q.4]** In a typical month, about how many hours [do you/does the person you care for] spend because of narcolepsy on: (n=47) *Values of 2% or less are not labelled.*

Delayed Treatment or Support

Barriers related to cost, stigma, treatment complexity, or effectiveness led many respondents to interrupt narcolepsy care.

Prescription medication was the most commonly affected treatment that respondents had delayed, skipped, or stopped in the past 12 months due to barriers, followed by follow-up appointments or sleep specialist visits and therapy, counselling, or support programs. Fewer respondents had interrupted sleep testing or transportation to care.

While four in ten respondents had not delayed, skipped, or stopped any treatment or support, the findings indicate that many experienced barriers that disrupted some aspect of their care. Interruptions to medication, specialist follow-up, and emotional support may make it more difficult to manage symptoms consistently and receive ongoing care. (Table 27)



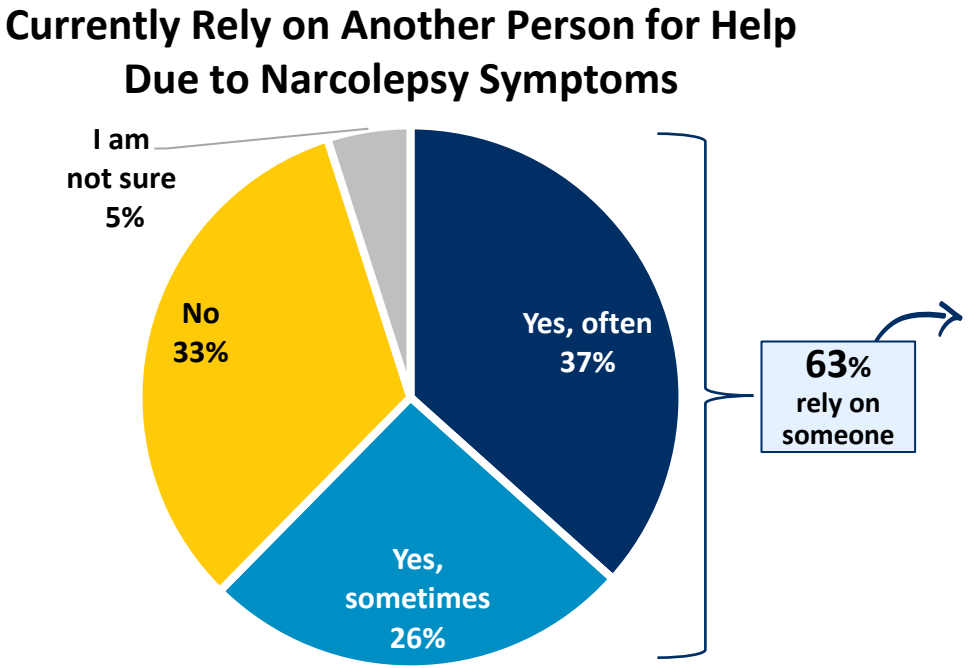
Q.27: **[IF 'TREATMENT USED' IN Q.17]** What narcolepsy treatment or support, if any, did [you/the person you care for] delay, skip, or stop in the past 12 months because of the cost, stigma, complexity of regimen, or lack of effectiveness? Select all that apply. (n=43) *Total aided mentions.*

Support/Impact on Caregiving

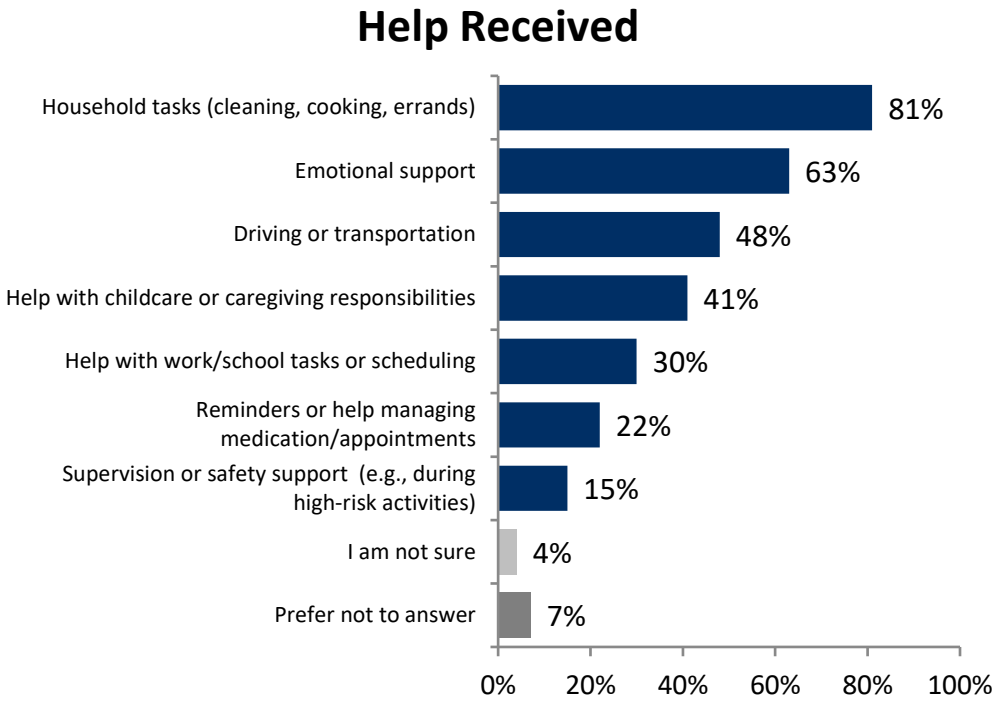
Support/Help Received

Many respondents rely on others to help manage the daily impacts of narcolepsy.

Two-thirds of respondents reported relying on another person for help because of narcolepsy symptoms, including more than one-third who often required support. Among those receiving help, assistance with household tasks such as cleaning, cooking, and running errands was most common, followed by emotional support. Respondents also relied on others for driving or transportation and help with childcare or other caregiving responsibilities. Some received assistance with work or school tasks, scheduling, medication, or appointments, while fewer required supervision or safety support during higher-risk activities. (Tables 28 and 29)



Q.28: **[IF 'SELF EXPERIENCE NARCOLEPSY' IN Q.4]** Do you currently rely on another person for help because of your narcolepsy symptoms? (n=43)

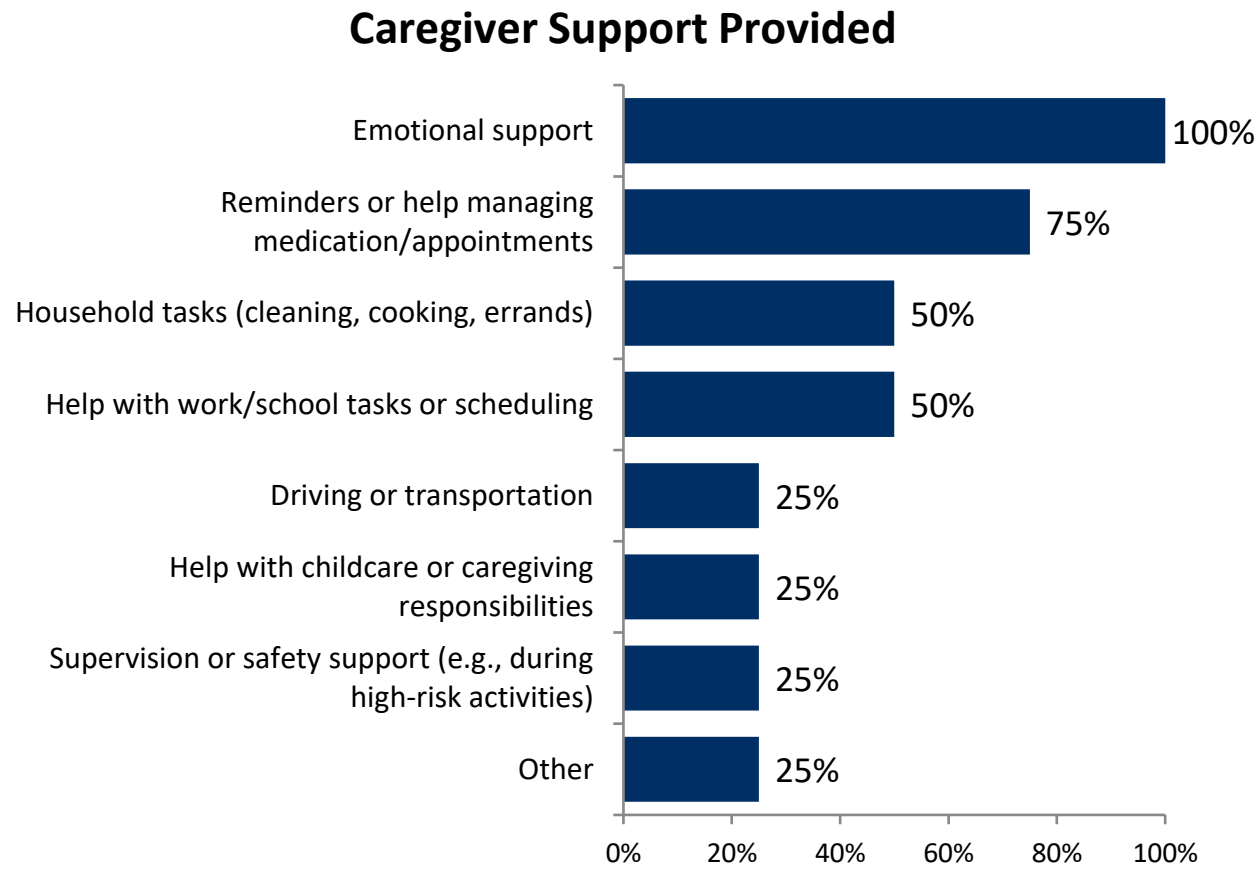


Q.29: **[IF 'YES, OFTEN OR SOMETIMES RELY ON ANOTHER PERSON' IN Q.28]** What kind of help do you receive? Select all that apply? (n=27) *Key aided mentions.*

Caregiver Involvement

Support related to narcolepsy can involve varied caregiver responsibilities.

Caregivers were asked what types of support they provide to a person with narcolepsy. As the sample size is very small (n=4), these results should be interpreted with caution and used only as directional. The most common types of assistance provided include emotional support, reminders or assistance with medication and appointments, household tasks, and help with work/school tasks or scheduling. (Table 29a)

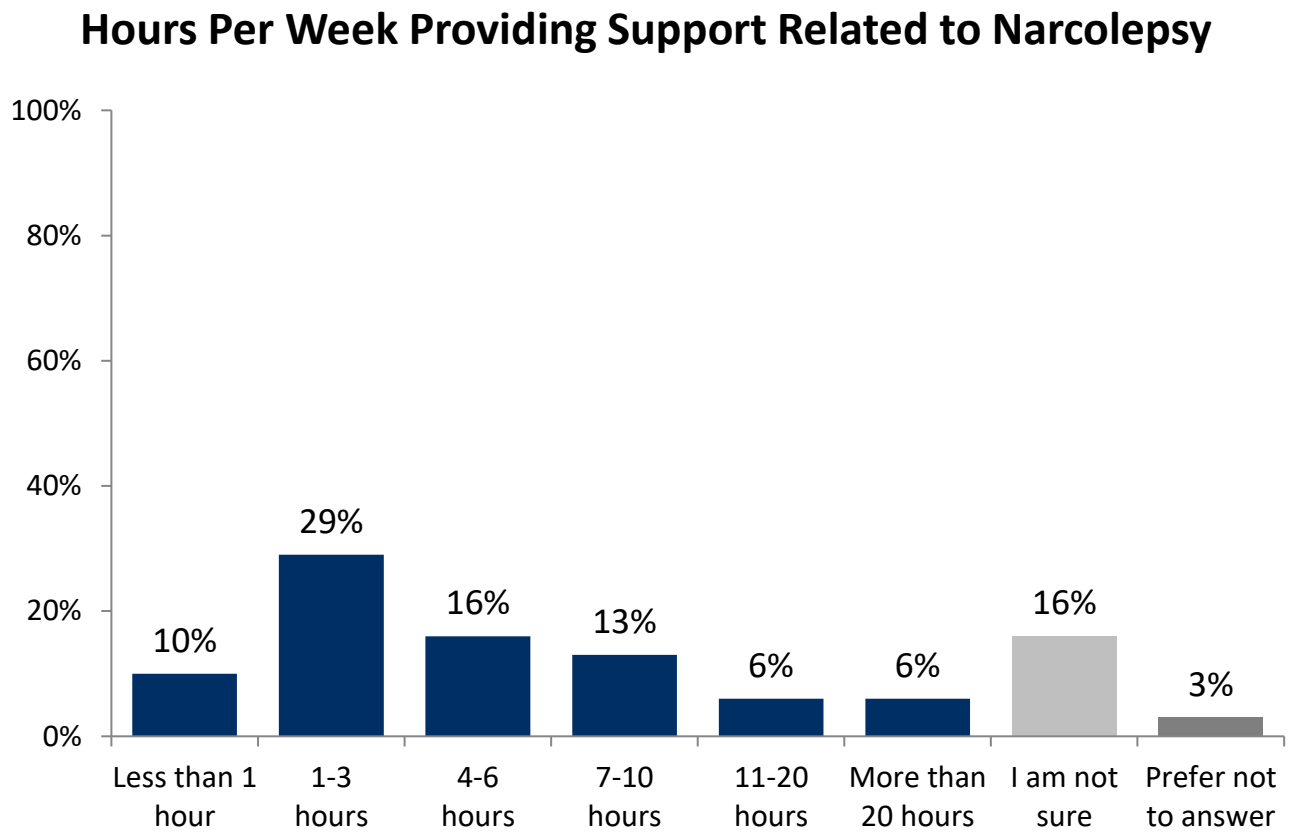


Q.29A: **[IF 'CAREGIVER' IN Q.4]** What type of support do you provide as a caregiver to the person with narcolepsy? (n=4) *Total aided mentions.* **Caution: Small sample size.*

Caregiver Involvement

Support related to narcolepsy involves a weekly time commitment.

Across caregivers and respondents receiving help (n=31), the time spent providing narcolepsy-related support varied considerably. While support most commonly required one to three hours per week, some reported four to ten hours, and a smaller number required more than ten hours. (Table 30)



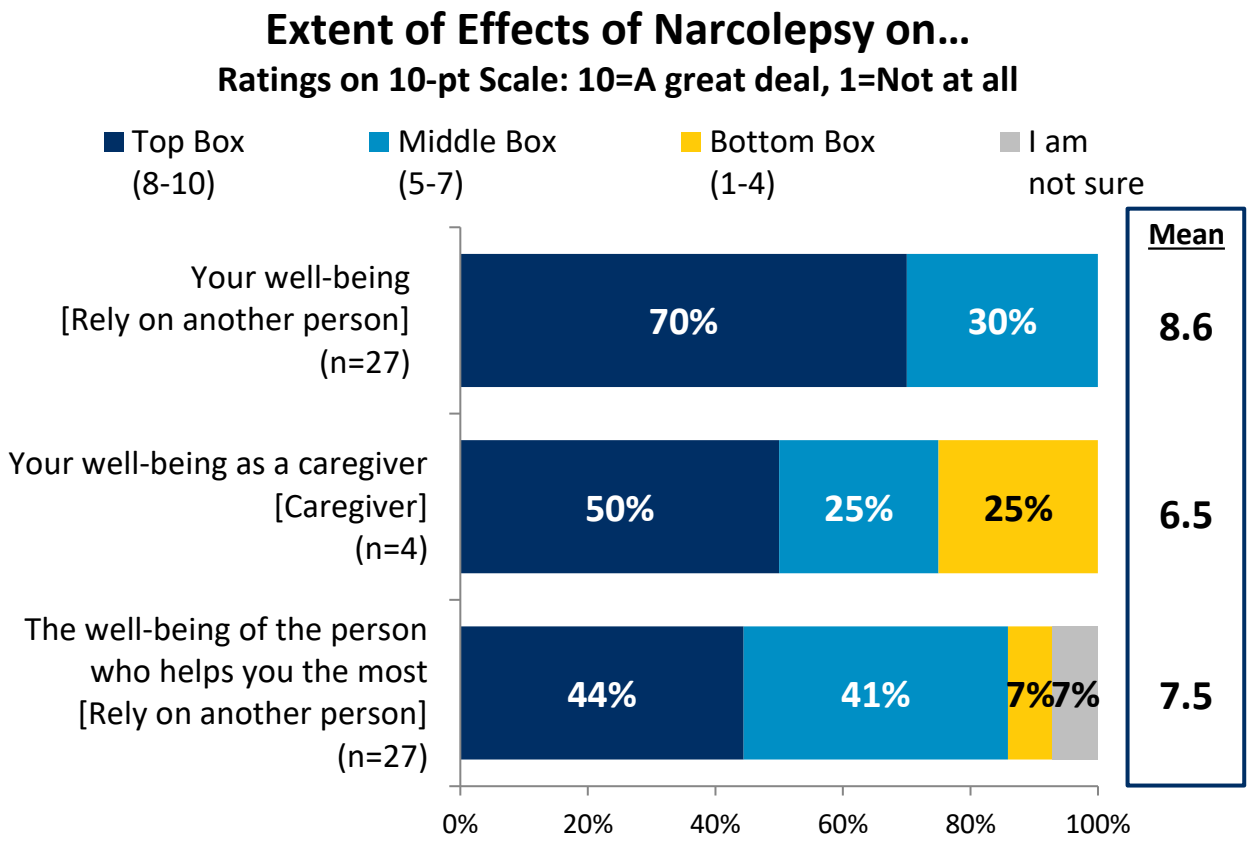
Q.30: **[IF 'CAREGIVER' IN Q.4 OR 'YES, OFTEN OR SOMETIMES RELY ON ANOTHER PERSON' IN Q.28]** About how many hours per week [do you/does the person (or people) helping you] spend providing support related to narcolepsy? (n=31)

Effects on Caregivers

Narcolepsy affects the well-being of respondents and the people who support them.

Respondents who rely on another person for help were asked how much narcolepsy had affected their own well-being and the well-being of the person who helps them most. Seven in ten reported a substantial impact on their own well-being, with an average rating of 8.6 out of 10. The impact also extended to support providers, with many respondents indicating that the well-being of the person who helps them most had been affected. The few caregivers who completed a survey (n=4) also reported that the help they provide has impacted their own well-being, to varying degrees.

Overall, the findings indicate that the burden of narcolepsy can extend beyond respondents to affect the well-being and daily commitments of those providing support. (Tables 31a to 31c and Table 32)



Q.31a-c: **[IF 'CAREGIVER' IN Q.4 OR 'YES, OFTEN OR SOMETIMES RELY ON ANOTHER PERSON' IN Q.28]** To what extent has [your narcolepsy/the narcolepsy of the person you care for] affected*: Responses of 'I am not sure' were excluded from the calculation of the Mean.*

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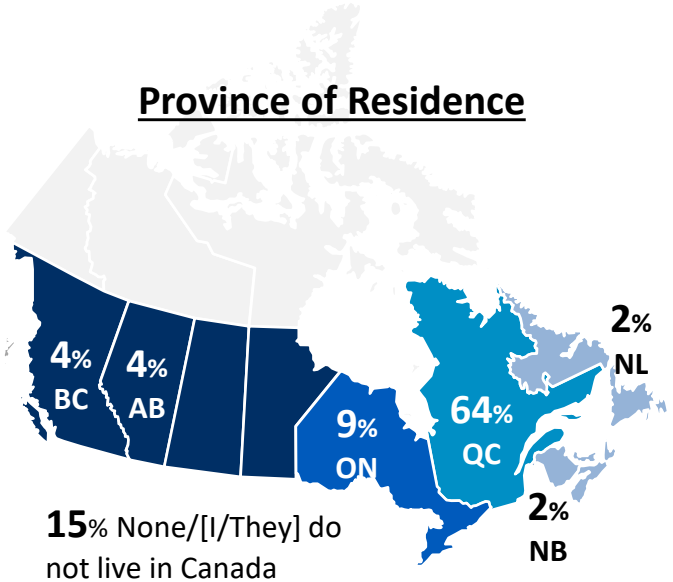
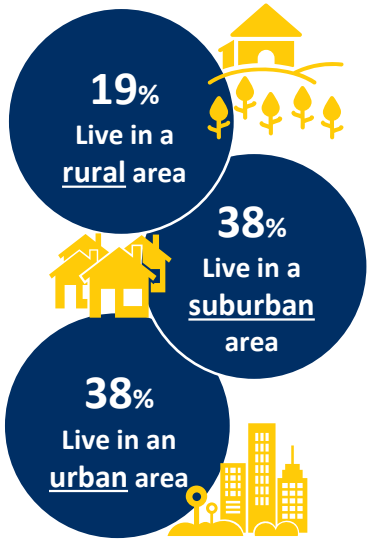
Respondent Profile

Demographic Profile (n=12-47)

Province of Residence



15% None/[I/They] do not live in Canada



4% I don't know/I am unsure

Education

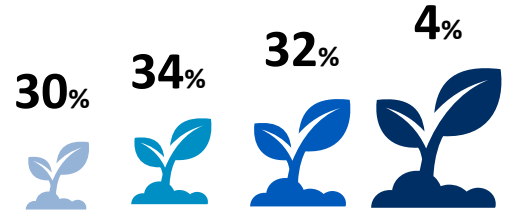
23%	High school or less
2%	Some college
19%	Graduated college
15%	Some university
28%	Graduated university
9%	Post Graduate
4%	Prefer not to say

Gender

83% Woman

17% Man

Age



Background or Circumstances

16%	Live in a low-income household
7%	Member of a racialized community
7%	Identify as 2SLGBTQ+
7%	Live in a rural or remote community
67%	None of the above
5%	Prefer not to answer

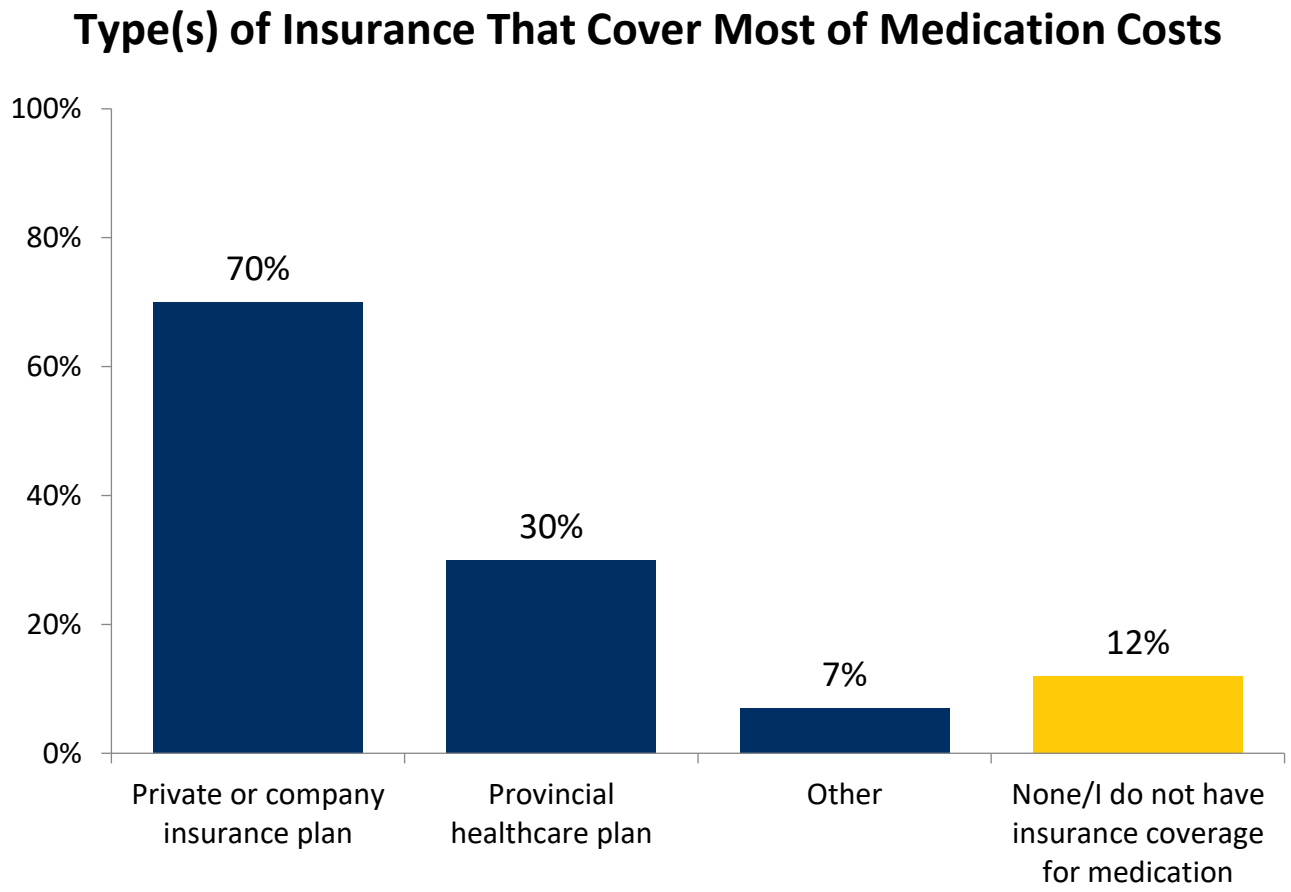
Background or circumstances factors have affected their ability to access diagnosis, treatment, or support for narcolepsy

33% say yes

Health Coverage

Private or company insurance plans are the primary source of medication coverage, although some respondents remain without coverage.

Private or company insurance plans, such as employer-sponsored coverage, were most common, while one-third relied primarily on a provincial healthcare plan. A small number used other sources, such as free samples, clinical trials, or catastrophic drug coverage. However, one in ten respondents did not have insurance coverage for medication. (Table 39)



Q.39: And finally, which of the following types of insurance covers most of your medication costs? (n=43)

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Every insight tells a story.