# What's TRENDing: Narcolepsy and Pregnancy

**April 2026**

Narcolepsy is a chronic neurological sleep disorder characterized by excessive daytime sleepiness that can significantly impact daily functioning and quality of life. Some individuals may also experience cataplexy, disrupted nighttime sleep, sleep paralysis, and hallucinations. Narcolepsy is often underdiagnosed and misunderstood, leading to delays in diagnosis and treatment.[1,2]

PWN4PWN (People with Narcolepsy for People with Narcolepsy) is a patient-led nonprofit created by and for individuals living with narcolepsy and IH. The organization provides connection, education, and advocacy while fostering a supportive community for those navigating these invisible sleep disorders. TREND Community is a community-powered data analytics company that transforms lived patient experiences into actionable insights. This report is a qualitative analysis of registry data from individuals with narcolepsy related to pregnancy, with the goal of elevating patient voices, deepening understanding of their experiences, and informing care and research.

## DATA SOURCES

*PWN4PWN Registry (N=673), Napchat (N=236)*

**TIME RANGE:** *October 2016-March 2025*

| RESPONDENTS WITH DIAGNOSIS PRIOR TO PREGNANCY: | TYPE: |
|---|---|
| n=34 | NT1: n=5<br>NT2: n=5<br>IH: n=2<br>Undisclosed: n=22 |

## CO-MORBIDITIES

The six most common co-morbidities are: **anxiety, asthma/allergies, fibromyalgia, idiopathic generalized epilepsy, depression (non-postpartum), postpartum depression/anxiety**. In the word cloud below, the size of the six words represents their frequency.


**Figure 1. Top 6 Most Frequently Mentioned Co-Morbidities**

These findings highlight the complex health profiles of individuals with narcolepsy during pregnancy and emphasize **the need for comprehensive, multidisciplinary care during the perinatal period**.

## MIXED EXPERIENCES AND GAPS IN OBSTETRIC AWARENESS (n=34)

- Among 34 participants, 21 **(62%)** said narcolepsy **influenced** their decision to become pregnant (6 fully, 12 partially, 3 slightly), while 12 **(35%)** said it **did not influence** their decision at all and 1 (3%) did not specify.
- 97% of pregnant participants across both types reported that their **obstetrician DID NOT have any medical background on narcolepsy**.
- 55.8% reported experiencing **negative attitudes from healthcare professionals** related to narcolepsy and parenting.
- 41.2% described **raising their children as a positive experience** while 26.47% said their parenting experience was neutral, and 8.8% reported a negative parenting experience.
- These findings suggest a range of experiences and highlight a **gap between patient needs and provider knowledge**.

***"I wondered if I could handle being a mom while managing narcolepsy and cataplexy."***


[1]National Institute of Neurological Disorders and Stroke. *Narcolepsy Fact Sheet; Hypersomnia Information Page.* National Institutes of Health. Updated 2023. Accessed February 11, 2026. https://www.ninds.nih.gov/health-information/disorders/narcolepsy; https://www.ninds.nih.gov/health-information/disorders/hypersomnia

[2]American Academy of Sleep Medicine; Hypersomnia Foundation. *Narcolepsy; Idiopathic Hypersomnia Overview.* Sleep Education by AASM; Hypersomnia Foundation. Accessed February 11, 2026. https://sleepeducation.org/sleep-disorders/narcolepsy/; https://www.hypersomniafoundation.org/idiopathic-hypersomnia/

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## MEDICATION BEFORE, DURING AND AFTER PREGNANCY

- Of the 34 individuals with a diagnosis of narcolepsy prior to pregnancy, 29 (85%) took medication at the time of conception, 13 (38.2%) took medication during pregnancy, and 4 (11.7%) took medication while breastfeeding. See Figure 2.
- **Stimulant medications** were the most commonly reported treatments across all stages of pregnancy, particularly Adderall, Vyvanse and methylphenidate.
- **Oxybates** were mainly used by individuals with NT1.
- Some participants also reported taking **antidepressants** such as sertraline or escitalopram alongside their narcolepsy medications.
- These findings suggest that many families stopped or adjusted treatment during pregnancy and postpartum, likely balancing symptom management with concerns about medication safety for their baby.

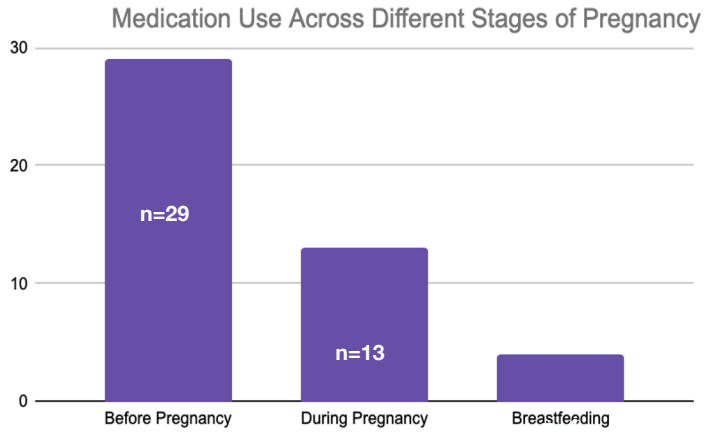


**Figure 2. Medication Use Across Different Stages of Pregnancy**

***"During my pregnancy, I had to advocate not only for myself, but also for my baby while educating my healthcare team about narcolepsy."***

## CATAPLEXY MAY INFLUENCE DELIVERY OUTCOMES

- Three out of the five individuals who reported having NT1 reported that **cataplexy affected their delivery**, and some required a cesarean section.
- One out of the two individuals who reported having IH reported that cataplexy **did not affect** their delivery.
- These findings suggest that **delivery complications may be specific to NT1 and related to cataplexy.** While more exploration is needed, this begins to highlight the importance of planning and coordination between sleep specialists and obstetric care teams during pregnancy.

## CONCLUSION

Pregnancy was common among individuals with narcolepsy, though experiences varied by subtype. Medication use often decreased during pregnancy, reflecting efforts to balance symptom management with safety concerns. Cataplexy-related delivery complications were reported primarily among those living with NT1, where cesarean delivery was often required. Most participants reported limited provider knowledge of narcolepsy, and many experienced negative healthcare attitudes. Despite these challenges, the majority described parenting as a positive or neutral experience.These findings demonstrate a clear gap in obstetric knowledge and care coordination for patients with narcolepsy, representing a potential risk to maternal health outcomes. Addressing these gaps through targeted provider education, clinical guidance, and improved coordination between sleep and obstetric care teams is essential to improving safe pregnancy management for this population.