

Narcolepsy and Maternal Health



What is Narcolepsy?

Narcolepsy is a chronic neurological disorder that affects the brain's ability to regulate sleep-wake cycles. It results in persistent and excessive daytime sleepiness and, in the case of Narcolepsy Type 1 (NT1), also results in cataplexy. Individuals with narcolepsy may also experience:

- Disturbed nighttime sleep
- Sleep-related hallucinations
- Temporary sleep paralysis
- Memory issues
- Difficulties concentrating

The exact cause of narcolepsy is unknown, and while there is a genetic component to narcolepsy, most people develop narcolepsy without any family history.

10% of individuals with NT1 have a close relative with similar symptoms ¹

Cataplexy is a sudden loss of muscle tone that can be triggered by strong emotions (e.g., fear, anger, stress, joy, laughter), resulting in weakness or involuntary movements.

Certain sleep disorders, like narcolepsy, affect women differently, in part, due to natural biological processes, such as menstruation, pregnancy, and menopause.

Women with narcolepsy who are considering planning for a family should have early conversations with their health care providers about how their symptoms and treatment plan may impact conception, pregnancy, breastfeeding, and parenting.

Impacts of Narcolepsy on Pregnancy

Treatment Modifications During Pregnancy. Because there are limited studies about the impacts of narcolepsy medications on the developing baby, many health care providers will suggest reducing or stopping medications, especially stimulants, while pregnant or breastfeeding. Some women are able to manage their symptoms using non-medical approaches (e.g., strategic napping and improved sleep hygiene), whereas, for others, deferring medication might result in worse symptoms.

Discussing the potential risks, benefits, and changes to your treatment plan should be a collaborative decision between you and your health care team.



79% of women report stopping narcolepsy medications during pregnancy ²

1/3 of women report worse symptoms during pregnancy ³

Potential Complications. Women with cataplexy are at higher risk for gestational diabetes, anemia, and weight gain during pregnancy; however, these conditions can be well-managed and do not generally lead to further complications. **Cataplexy attacks during labor are rare – less than 1% of women with narcolepsy experience cataplexy attacks during labor.** ⁴

Birth Outcomes. Narcolepsy, itself, does not increase the risk for adverse birth outcomes, and most women deliver vaginally without any complications. Research does suggest that women with narcolepsy have slightly higher rates of cesarean sections.

Care and Safety After Birth. Managing narcolepsy, its symptoms, and motherhood can be challenging, and sometimes, overwhelming. New mothers may experience changes in symptoms, particularly due to unpredictable sleep patterns and stressors that come with caring for a newborn. **It is important to note which activities tend to make you sleepy and when to modify them or ask for help while caring for your newborn.**



60% of mothers with narcolepsy say caring for their newborn was impacted by their symptoms ⁴

There are many layers to managing narcolepsy during pregnancy and postpartum. Consider connecting your pregnancy care provider (e.g., OB/GYN, midwife, etc.) with your narcolepsy care providers (e.g., sleep doctor, neurologist, etc.) to better coordinate your care during this time. Communicating regularly and openly with your health care team and creating a personal support network can also help during the transition into motherhood.

Wellness Tips for Mothers with Narcolepsy	
Pregnancy	Postpartum
<ul style="list-style-type: none"> • Allow for frequent naps and rest to counteract fatigue • Consider adjusting your sleep positions and improve sleep hygiene to promote better sleep • Monitor for symptoms of restless legs syndrome or obstructive sleep apnea that can also develop during pregnancy • Create a birth plan that takes into consideration your narcolepsy symptoms • Inform the hospital about your narcolepsy diagnosis when you go into labor 	<ul style="list-style-type: none"> • Schedule naps for when your newborn is asleep • Re-evaluate medication management with your health care providers to further optimize symptom control • Identify spaces to reduce the risk of accidents or falls in case of a cataplexy attack while caring for your newborn (e.g., change or feed your newborn on the floor) • Request help from family, friends, or paid professionals (e.g., postpartum doula), to assist around the house or for caring for your newborn



During pregnancy, it is recommended that women sleep on their left side with legs slightly curled, to relieve the weight placed on the uterus, spine and back muscles. Some women also find that placing pillows between their knees and under their belly helps.

Resources

- Hypersomnia Foundation: <https://www.hypersomnifoundation.org/parenthood>
- Narcolepsy Nerd Alert: <https://project-sleep.com/narcolepsy-nerd-alert-pregnancy>
- Wake Up Narcolepsy Support Groups: <https://heypeers.com/organizations/2>

References

1. Narcolepsy Fact Sheet. National Institute of Neurological Disorders and Stroke. <https://www.ninds.nih.gov/health-information/patient-caregiver-education/fact-sheets/narcolepsy-fact-sheet> Accessed 21 Jul 2022.
2. Pascoe M, Carter LP, Honig E, Bena J, Foldvary-Schaefer N. J Clin Sleep Med. 2019 Oct 15;15(10):1421-1426.
3. Narcolepsy & Pregnancy. European Narcolepsy Network. <http://www.eu-nn.com/narcolepsy-and-pregnancy> Accessed 21 Jul 2022.
4. Maurovich-Horvat E, Kemlink D, Högl B, et al. J Sleep Res. 2013 Oct;22(5):496-512.