

# Wellness Tips for Narcolepsy Across the Lifespan

# LIVING WELL WITH NARCOLEPSY

## Emotional Wellbeing

Managing narcolepsy and its symptoms can be very challenging, and sometimes, overwhelming. Both men and women with narcolepsy experience higher rates of depression and anxiety.

**57%** of women with narcolepsy experience depression<sup>14</sup>  
**32%** of women with narcolepsy experience anxiety<sup>11</sup>

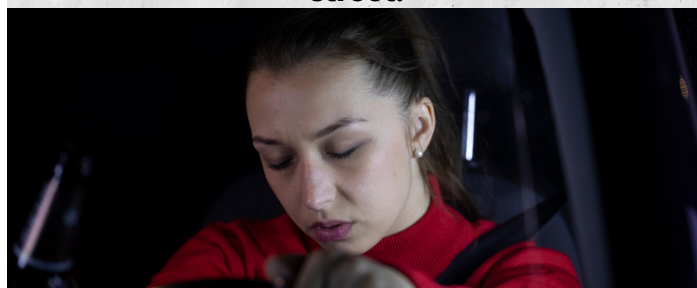
Schedule time with your health care provider to discuss any concerns or challenges you are experiencing. Together, you can create a plan to support your mental health and wellness. Seeking counseling, therapy, and online support can make a big difference in the quality of your life.

- 1 Seek care and support.** Connecting with other people who have narcolepsy can help support you along your journey and introduce you to others who may have similar experiences.
- 2 Share your experience.** Consider talking about your narcolepsy symptoms and how they affect your day-to-day life. While it is important to share your challenges, it is also helpful to discuss your goals and successes with trusted family, friends, and coworkers. Many people are not familiar with narcolepsy, so educating them can spread awareness and create support.
- 3 Communicate openly.** Sharing openly about your experience with friends, loved ones, and your medical team gives them the opportunity to understand your journey with narcolepsy.
- 4 Ask for help.** Your support network wants to help you but may need to be told exactly what you need and when. Tell them how they can help during a cataplexy or sleep attack or express how they can support you in general.

## Safety Tips for Driving

Narcolepsy can lead to safety issues and increased risk of accidents. It is important to gauge what activities tend to make you sleepy and when to avoid them. Car accidents can be common among people with narcolepsy, especially during long road trips or while driving on the highway. Consult with your health care provider to determine whether your symptoms are well-managed and stable enough for you to drive safely.

**Up to 30-50% of individuals with narcolepsy have reported accidents or near accidents that involved falling asleep while cooking, smoking, running machinery, and crossing the street.**<sup>19</sup>



Individuals with narcolepsy are **3-4x** more likely to be in a car accident<sup>19</sup>

If you do get behind the wheel:

- Take short breaks and schedule naps during long trips
- Take turns driving with someone else
- Avoid driving at night or after a big meal
- Consider alternative transportation options (public transportation, taxis, or ride shares)

# NARCOLEPSY AND STUDENT LIFE

Adults and adolescents experience symptoms of narcolepsy similarly; however, if undiagnosed, **excessive daytime sleepiness (EDS)** can be mistaken as restlessness, irritability, or misbehavior among children and teens.

**80%** of adolescents with narcolepsy have cataplexy<sup>10</sup>

Adolescents with narcolepsy type 1 (NT1) often show a more subtle version of **cataplexy** – mild weakness, half-closed eyes, slight tongue protrusion, and a wobbly walk. They are also more likely to be overweight and start puberty early (before 8 or 9 years old).



## School Accommodations

Due to the effects of EDS and cataplexy, adolescents may experience challenges with school, such as frequent tardiness, falling asleep in class or while studying, forgetfulness, and brain fog. Still, with proper treatment, a consistent routine, and adequate support, adolescents can be very successful in their educational pursuits.

Under the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA), K-12 public schools are required to create special accommodations for students with a disability. Narcolepsy is an eligible condition for this accommodation, allowing students to participate in specialized education plans, such as a [504 Plan](#) and/or an [Individualized Education Plan \(IEP\)](#).

Qualifying for narcolepsy accommodations will likely involve having the student with narcolepsy undergo an evaluation and provide a note from their health care provider(s). Once qualified, the student and their parents must collaborate with their providers and the school faculty and staff (administrators, teachers, and nurse) to determine which accommodations should be put in place to best help the student succeed in their school environment.

**Remember, every student is different.  
Figuring out what works best for you will  
depend on your individual symptoms,  
needs, and goals for school.**



Example accommodations for school and learning might include:

- Help with note-taking, shared notes, or recordings of class to review again later
- Audio versions of textbooks
- Flexible scheduling of classes and tests (e.g., when student is most alert)
- Flexible deadlines for assignments
- Extra time or short breaks during tests
- Separate and comfortable (e.g., natural light, air conditioned) testing room

### **Students with narcolepsy graduate from college at similar rates to those without.**<sup>19</sup>

Many colleges and universities offer support to students with disabilities, typically through a student support services or resource center. When transitioning into higher education, find out what services your potential school has. Additional accommodations to promote your success at college might include:

- Priority scheduling of classes
- Alternative course formats (e.g., online, asynchronous, practicum)
- Independent dorm room



### **Helpful Tips for Teens with Narcolepsy**

- Take a brief nap after school, but not too close to bedtime
- Prioritize your sleep, even if that means limiting after-school activities
- Keep your bedroom comfortable (e.g., quiet, dark, and cool)
- Limit the use of electronics late at night and in the bedroom
- Communicate openly and regularly with teachers, classmates, and school administration
- Create a daily bedtime routine
- Prioritize exercise and a healthy diet
- Do not overuse caffeine and avoid energy drinks

# WOMEN WITH NARCOLEPSY IN THE WORKPLACE



Narcolepsy can present certain challenges and safety concerns in the workplace, especially for jobs that require operating heavy machinery or driving long distances. Women who fear losing their job or who prefer to keep their condition private might have difficulty disclosing their narcolepsy diagnosis to an employer. If you decide that you would like to tell your employer about your narcolepsy or another medical condition, the following tips can provide some guidance.

## Workplace Accommodations

Under the Americans with Disabilities Act (ADA), employers are required by law to provide reasonable accommodations in the work setting for those who are eligible and have received approval. Your employer is responsible for creating and maintaining a safe and healthy work environment for all employees, including those with disabilities.

Before meeting with your supervisor or human resources department, consider preparing a list of your symptoms, how they affect your ability to function at work, and treatments or actions you are taking to address them, especially as it relates to your job. You may also want to ask your health care provider for a letter describing your symptoms to help your employer better understand how they can support you. Conversations might feel uncomfortable at first, but do not be afraid to advocate for the support you need to be safe and successful in your job.

Individuals with narcolepsy take **2.5x** as many short-term disability days<sup>20</sup>

Examples of workplace accommodations include:

- Flexible work hours
- A designated nap space
- Scheduled nap breaks
- A wake-promoting workspace (e.g., a standing desk with natural light)
- Working from home, if possible

## Helpful Work-Life Balance Tips for Narcolepsy

- Optimize your workspace (e.g., get a standing desk, stay cool)
- Stay active while working (e.g., chew gum, stand, walk around, or stretch)
- Schedule tasks throughout the day according to your alertness (e.g., break up mundane tasks across your day)
- Take a brief nap after work, but not too close to bed time
- Maintain a consistent sleep schedule, even on the weekends
- Limit the use of electronic devices right before naps or late at night
- Consider getting an occupational therapist evaluation for more personalized recommendations

# NARCOLEPSY AND MOTHERHOOD

## Planning for a Family

Many women worry about whether they will pass narcolepsy onto their children. While there is a genetic component to narcolepsy, most people develop narcolepsy without any family history. If this is a concern, consider talking to your health care provider.

**10%** of individuals with NT1 have a close relative with similar symptoms<sup>21</sup>

## Treatment Modifications During Pregnancy

Treatment of narcolepsy during pregnancy is a multi-layered process that engages multiple health care professionals. It might be helpful to connect your provider for your pregnancy (e.g., obstetrician/gynecologist) with your other health care providers (e.g., neurologist) to coordinate care while pregnant. For high-risk pregnancies, you might be referred to a maternal-fetal medicine specialist for additional expertise.



**1/3** of women report worse symptoms during pregnancy<sup>22</sup>



Studies have not provided conclusive data about medications' impact on developing and newborn babies, so there are no clinical guidelines available. Many health care providers will suggest that women trying to conceive or who are pregnant or breastfeeding reduce or stop medications for narcolepsy, especially stimulants.

This deferment could result in a woman with narcolepsy going without treatment for years at a time to pursue childbearing. It is possible to manage narcolepsy in ways other than with medication. However, it is important to balance and monitor the potential health risks and benefits for both mother and baby throughout the pregnancy.

## Cataplexy and Childbirth

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 during pregnancy. While cataplexy can be triggered by strong emotions, attacks during labor are rare.<sup>23</sup>

**Narcolepsy itself does not increase the risk for adverse birth outcomes, and most women deliver vaginally without any complications.**<sup>22,23</sup>



## Care and Safety After Birth

New mothers may experience changes in symptoms, particularly due to unpredictable sleep patterns and stressors that come with caring for a newborn. Additional support from your family and friends is extremely important during the postpartum period. It is also important to regularly check in with your provider to adjust your narcolepsy care plan as needed to best manage your symptoms and ensure that you and your newborn are safe and healthy.

There are no formal guidelines concerning breastfeeding while taking narcolepsy medications; the research data is very limited. It is important to remember that different providers will have different recommendations and your decision should be made by weighing your own personal preferences, symptom severity, and overall experience with narcolepsy.



# NARCOLEPSY AND THE MENOPAUSE TRANSITION



As a woman gets older, her ovaries produce less of the hormone estrogen and her menstrual cycle begins to change and eventually stops, resulting in menopause.

During the menopause transition, or perimenopause, this decline in estrogen affects the body's ability to regulate its temperature. Many women experience vasomotor symptoms, such as hot flashes, night sweats, and sleep disturbances. Trouble sleeping can also result from other underlying conditions that commonly develop during perimenopause, such as insomnia, restless legs syndrome, and obstructive sleep apnea. These disruptions can be especially challenging for women living with narcolepsy. Therefore, prioritizing sleep is extremely important in managing your narcolepsy during menopause.

In addition to managing your narcolepsy symptoms and maintaining good sleep hygiene, below are some approaches to address hot flashes:

- Staying cool with light, layered clothing and bedding
- Cooling devices (e.g., handheld and wearable devices, cooling gel bed toppers)
- Cognitive behavioral therapy and mindfulness strategies
- Hormone therapy
- Other medications that may help manage hot flashes (e.g., low-dose antidepressants, anticonvulsants, hypertension drugs, bladder relaxants)

## Tips for Good Sleep Hygiene

- **Maintain a consistent sleep schedule, even on the weekends**
- **Limit the use of electronic devices right before naps or late at night**
- **Keep your bedroom comfortable (e.g., quiet, dark, and cool)**
- **Avoid large meals, caffeine, and alcohol before bed**
- **Exercise daily**

To learn more about menopause and managing vasomotor and other symptoms, see the [\*\*SWHR Menopause Preparedness Toolkit\*\*](#).