

Narcolepsy

A PATIENT-FRIENDLY GUIDE AND CHECKLIST

Narcolepsy is a chronic neurological disorder that disrupts the brain's ability to regulate sleep and wake cycles. People with narcolepsy experience excessive daytime sleepiness and may suddenly fall asleep at inappropriate times, regardless of how much rest they get at night.

Types of Narcolepsy

Narcolepsy Type 1:

Excessive sleepiness with cataplexy (*sudden loss of muscle tone triggered by strong emotions, including laughter or surprise*)

Narcolepsy Type 2:

Excessive sleepiness **without** cataplexy

Narcolepsy often coexists with other conditions, including:

- **Depression and anxiety**
- **Attention and memory problems**
- **Obesity or metabolic challenges**
- **Other sleep disorders (like sleep apnea or insomnia)**
- **Headaches or migraines**

Core Symptoms of Narcolepsy

Narcolepsy can look different from person to person. The core symptoms include:

- **Excessive Daytime Sleepiness:** Feeling overwhelmingly sleepy during the day, even after a full night's sleep
- **Sudden Sleep Attacks:** Falling asleep unexpectedly at inappropriate times
- **Cataplexy (Type 1):** Sudden loss of muscle strength during strong emotions
- **Disrupted Nighttime Sleep:** Frequent awakenings or restless sleep at night
- **Sleep Paralysis:** Temporary inability to move or speak while falling asleep or waking up
- **Vivid Hallucinations at Sleep Transitions:** Seeing or hearing things that aren't there, especially when falling asleep or waking up

Impact on Daily Life

Narcolepsy can have a broad impact on quality of life, including:

- **Academic or work difficulties due to sleepiness and trouble focusing**
- **Challenges with personal relationships and social activities**
- **Safety concerns, especially with driving or operating machinery**
- **Decreased confidence and self-esteem**

Many people with narcolepsy face skepticism or misunderstanding from others, who may wrongly assume symptoms are due to laziness, lack of willpower, or poor habits. It's important to remember: **Narcolepsy is a neurological medical condition—not a weakness or character flaw.**

With the right diagnosis, treatment, and support, people with narcolepsy can thrive at school, work, and in their personal lives.

Next Steps for Patients and Families

- 1. Keep a Sleep Diary:** Record sleep patterns, daytime sleepiness, and any episodes of muscle weakness, hallucinations, or sleep paralysis
- 2. Consult Your Healthcare Provider:** Share your observations
- 3. Advocate for Yourself:** Consider saying, "I've experienced severe daytime sleepiness and unexpected sleep episodes. Can we discuss narcolepsy or other sleep disorders?"

Treatment and Support: What Helps

Treatment is highly individualized but may include:

- **Medications to help stay awake during the day or improve nighttime sleep**
- **Lifestyle changes: regular sleep schedule, planned naps, exercise, and healthy eating**
- **Support at school or work (*accommodations & adaptations, garnering understanding from teachers/employers*)**
- **Counseling or support groups**

Key Takeaways

- ✓ Narcolepsy is a neurological condition, not a character flaw.
- ✓ Symptoms can be subtle, varied, and sometimes mistaken for other issues.
- ✓ Early recognition and proper management can vastly improve quality of life.
- ✓ You are not alone—support is available.

Narcolepsy Symptom Checklist *(For Your Next Appointment)*

You can hand this checklist to your clinician and say:

"I've been very sleepy, and I'm worried I might have narcolepsy or another sleep disorder. Can we talk about these symptoms and next steps?"

1. Daytime Sleepiness

Over the last 3 months:

- I feel very sleepy most days, even if I think I slept enough
- I doze off or "nod off" when I don't mean to (*TV, reading, meetings, class*)
- I feel *"tired all the time"* or like I can't stay alert

How many days per week are you very sleepy? _____

2. Sudden Weakness With Emotions *(Cataplexy)*

When I laugh, get excited, surprised, or angry, my muscles sometimes:

- Feel weak in my knees
- Make my head drop or jaw go slack
- Make me drop things
- Make me collapse or fall
- During these episodes, I am awake and aware but can't move for a short time

How often does this happen? _____

3. Nighttime Sleep

- I often wake up many times during the night
- My sleep feels light and unrefreshing
- I have very vivid or intense dreams
- I wake feeling like I did not sleep deeply

Usual bedtime: _____ Usual wake time: _____

Estimated hours of sleep per night: _____

Narcolepsy Symptom Checklist *(Continued)*

4. Sleep Paralysis & Hallucinations

- I have woken up and been unable to move or speak for seconds to minutes
- As I fall asleep or wake up, I sometimes see or hear things that feel real but are dream-like (*people, shapes, voices, sounds*)

How often? _____

5. Naps

- I often need to nap in the daytime
- Naps help me feel better for a short time
- I fall asleep very quickly when I try to nap

How many naps per day? _____ Typical nap length: _____ minutes: _____

6. Mood, Thinking, and Other Conditions

Check any that apply:

- Depression (*feeling down, loss of interest, hopelessness*)
- Anxiety (*worry, panic, social fear*)
- Feeling lonely or avoiding people because of my tiredness
- Trouble focusing or paying attention
- Memory problems or "*brain fog*"
- Weight gain that is hard to explain
- Headaches or migraines
- Restless/uncomfortable legs at night or leg jerks in sleep

Have you ever been told you're "*lazy,*" "*unmotivated,*" or "*always tired,*" even though you feel you are trying your best?

- Yes No

