

Supporting Children with Narcolepsy at School

What is Narcolepsy?

Narcolepsy is a chronic neurological disorder that affects the brain's ability to control sleep-wake cycles. It results in persistent and excessive daytime sleepiness and, in some cases, cataplexy.

Cataplexy is the sudden loss of muscle tone, leading to weakness and loss of voluntary movement, that can be triggered by strong emotions. Type 1 narcolepsy occurs with cataplexy, whereas Type 2 does not.



More than half of narcolepsy patients have symptoms before age 20, which often go undiagnosed or misdiagnosed for years. Common symptoms include disturbed nighttime sleep, insomnia, and hallucinations, and in children, may also include:

- ▶ Hyperactivity
- ▶ Irritability and aggression
- ▶ Difficulty remembering, and difficulty thinking
- ▶ Impulsiveness or restlessness during the day and at night
- ▶ The need for longer or multiple naps
- ▶ Atypical cataplexy (e.g., facial or jaw and eyelid weakness, tongue protrusion, neck extension, or slurred speech)

Narcolepsy Support at School

Narcolepsy is an invisible illness that is often misinterpreted in children as laziness or lack of motivation. Teachers can mistake symptoms as behavioral or cognitive problems, and even many adolescents with narcolepsy report difficulty performing in school.

Narcolepsy can have a significant impact on a child's academic life, so communication and support from schools are critical. Reasonable accommodations at school for children with narcolepsy are covered under the Americans with Disabilities Act. For K-12 students, academic accommodations are based on individualized evaluations and can be set through a 504 Plan or an Individualized Education Program (IEP). Children may benefit from one or both plans.

1 A **504 Plan** proposes how a child will access the learning environment and specifies accommodations for every class.

- ▶ Covered under Section 504 of the Rehabilitation Act
- ▶ Provides accommodations for a student to learn in a traditional classroom
- ▶ Requires referral by doctor, parent, teacher, or school nurse to the school's Section 504 committee
- ▶ Parent/guardian must consent to have child evaluated

2 An **Individualized Education Program (IEP)** provides a plan for a child's special education program and sets goals based on ability.

- ▶ Covered under the Individuals with Disabilities Education Act (IDEA)
- ▶ Provides a plan for specialized instruction or special education
- ▶ Requires assessment by a licensed school psychologist
- ▶ Parent/guardian must consent to have child evaluated

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Additional accommodations may range based on age, treatment plans, and learning environment capacities. These may include whole-class or individual movement breaks, scheduled naps, access to standing desks or sensory stimuli, note-taking assistance, and extra time on tests.



Tips for Seeking Accommodations:

- Learn how accommodations work at different educational levels (K-12 and college)
- Record interactions in writing when engaging with your child's school
- Educate teachers and school counselors about narcolepsy
- When reviewing accommodations, consider what your child needs on their hardest day
- Periodically re-evaluate your child's needs and change accommodations as necessary

Tips for Supporting Caregivers:

Serving as a caregiver to a child with a chronic condition like narcolepsy can be overwhelming. It is important to find ways to support yourself, such as:

- Connecting with peer support groups, websites, or chats
- Asking your child's clinical team about financial and educational resources
- Planning breaks and opportunities for self-care
- Asking for and accepting help from family, friends, and professional services

Additional Resources

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- **SWHR Narcolepsy Toolkit: A Woman's Empowerment Guide:** https://swhr.org/swhr_resource/narcolepsy-toolkit-a-womans-empowerment-guide
- **Wake Up Narcolepsy Accommodations for School and Work:** <https://www.wakeupnarcolepsy.org/accommodations-for-school-work>
- **Project Sleep Navigating School with Narcolepsy:** <https://project-sleep.com/new-nerd-alert-navigating-school-with-narcolepsy>

References

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