School Support

Narcolepsy is poorly recognized and seriously under-diagnosed. It is not uncommon for a child to be diagnosed with ADHD, Depression, behavioral disorders, sleep apnea, or even Schizophrenia before receiving the true Narcolepsy diagnosis.

With the help of the school, a student with narcolepsy can be successful.



- Teachers who know how to respond to EDS and Cataplexy can influence how fellow students and school staff respond to a student with Narcolepsy.
- Teachers should understand the child is not just being lazy.
- Teachers must ensure all accommodations are provided in the classroom and for state, district, and college entrance exams.
- Teachers can support the family through observations, related to medication, sleep, and behavior.

504 vs. IEP: What Does Your Child Need

Most children with Narcolepsy can be successful in the general education classroom with supports and accommodations through a 504 plan.

Section 504: Rehabilitation Act

- Federal *Civil Rights Law* that protects against discrimination-Vocational Rehabilitation Act of 1973
- Provides a plan for how the child will access the learning environment.
- Provides services/changes to the learning environment to level the playing ground for the child with a disability.
- Can continue to receive 504 accommodations in post-secondary education.

Eligibility: 1) Child ""has a physical or mental impairment which substantially limits one or more major life activities," (2) has a record of such an impairment, or (3) is regarded as having such an impairment. (34 C.F.R. §104.3(j)(1)).

Individualized Education Plan

- Federal Special Education Law-Individuals with Disabilities Education Act (IDEA).
- Provides a plan for the child's special education program at school.
- Provides individualized special education and related services to the child with a disability to meet the child's educational needs.
- IEP will discontinue when the student graduates (or ages out) of the K-I2 education system.

Eligibility: 1) Child has been identified as having one or more of the 13 specific disabilities listed under IDEA, and 2) the disability must affect the child's educational performance and/or ability to learn and benefit from the general education curriculum.



Accommodations

- Do not penalize for being tardy.
- Allow for short/scheduled naps
 (20-30 mins.) either in the
 classroom or a designated area. Do
 not wake up if the student falls
 asleep in class.
- Allow student to stand during class, move around, and have access to water. This can help the student to stay awake.
- Checks for comprehension of tasks, as student may experience microsleeps during instruction.
- Do not keep student in at break times to catch up on work. The student needs this time to move around and wake up.
- Allow for peer notetaking, teacher provided copy of notes, and/or recorded lectures, as student may experience microsleeps during lecture.
- Allow for preferential seating.
- Reduced assignments/tasks once the student demonstrates mastery.

Test Accommodations

- Schedule tests during times student is most awake.
- Allow for breaks during testing to move around and get water.
- Allow for extra time to accommodate naps

Impact on Childhood

Research shows that chronic excessive daytime sleepiness (EDS) among schoolaged children is associated with poorer academic functioning, school failure, school absenteeism/tardiness, and conduct problems. Additionally, EDS is associated with increased risk-taking behavior and impulsivity. Additional areas of impact include:

- Relationships (Personal/Educational)
- Making Friends
- Keeping Friends
- Family Relationships
- Emotional Wellbeing/Control
- School Activity Engagement
- Education/Sport Participation
- Career Choice/Job Retention
- Physical Wellbeing
- Public Safety- Driving



They have loved the stars too fondly to be fearful of the night!



Childhood
Narcolepsy and the
K-12 Education
System





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Taking Narcolepsy from the Shadows into the Light

What is Narcolepsy

Narcolepsy is an incurable, neurological sleep disorder where the brain is unable to regulate typical sleepwake cycles. Typical onset occurs between ages 10-20.

• Excessive Daytime Sleepiness (EDS)

The inability to stay awake and alert during the day.

• Cataplexy

A sudden, brief loss of muscle tone caused by experiencing strong emotions.

ullet Sleep Disruption

The breaking up of sleep by many awakenings. Poor-quality sleep at night: falling asleep easily, but having trouble staying asleep

• Sleep Paralysis

A brief inability to move or speak while falling asleep or waking up.

• Hypnagogic Hallucinations

Vivid dream-like events that occur while falling asleep or waking up. They can be experienced as multisensory hallucinations.

