What is Narcolepsy?

Narcolepsy is an incurable, neurological sleep disorder where the brain is unable to regulate typical sleep-wake 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.

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.

Taking Narcolepsy from the shadows into the Light!

Impact on Childhood

Research shows that chronic excessive daytime sleepiness (EDS) among school-aged 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 & Keeping Friends
- Family Relationships
- Emotional Wellbeing/Control
- School Activity Engagement
- Education/ Sport Participation
- Career Choice/ Job Retention
- Physical Wellbeing
- Public Safety- Driving

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Social media links:
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-12 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.