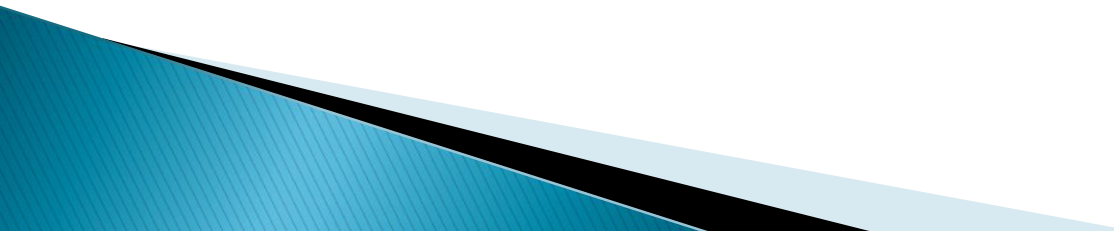


# Narcolepsy Accommodations: School & Work

Amy Dougrey, Med.  
Patient & Family Educator  
Boston Children's Hospital

# Table of Contents

- ▶ School Support
    - IEPs & 504 Plans
  - ▶ School Accommodations
  - ▶ College Accommodations
  - ▶ Workplace Accommodations
- 

# Misdiagnosis

WHY?

- \* Patients with narcolepsy are 4 times more likely than other patients to receive a misdiagnosis

- \* Mental health problem
- \* Epilepsy
- \* Insomnia/other sleep disorder

Kryger MH, 2002; Ohayon MM, 2013; Carter LP, 2013

- \* Lack of awareness by healthcare providers
  - \* 39% of PCP could identify narcolepsy symptoms
- \* Overlap of narcolepsy symptoms with other sleep disorders, medical and psychiatric symptoms
- \* Excessive daytime sleepiness/fatigue is becoming more common complaint due to sleep deprivation
- \* EDS may manifest as attention problems, memory issues, hyperactivity, behavior problems especially in children

Thorpy MJ, 2014; Rosenberg R, 2014

# Problematic Presentations

## Behavioral Problems

- ▶ Impulsive
- ▶ Emotionally labile
- ▶ Hyperactive
- ▶ Irritable/Talking back/Aggressive behaviors
- ▶ Appears to be smirking or sticking out tongue (cataplexy)

## Mood Problems

- ▶ Nearly 25–33% of pediatric patients report depression and/or anxiety
- ▶ Often called lazy, unmotivated
- ▶ Accused of being on drugs
- ▶ Not understanding what is happening to them
- ▶ Symptoms often develop in second decade of life when identity being formed; often impacting self-esteem

# School Problems

- ▶ High rate of academic difficulties among patients with untreated narcolepsy:
  - Difficulty paying attention, staying focused/easily distracted
  - May appear fidgety (as they are trying to stay awake)
  - Forgetful
  - May not complete tests or homework due to falling asleep
  - Look bored or disinterested (actually falling asleep)
  - Frequent requests to go to nurse's office

# School Support is Critical

- ▶ Even with treatment, students will have high degrees of sleepiness
  - Patients report chronically feeling like they have been sleep deprived for 1–2 nights
- ▶ Adequate support needed to prevent school failure (i.e. 504 Plan, IHCP, IEP)
- ▶ School and family support is needed to help student cope with diagnosis and potentially avoid co-morbid mood problems from developing

# 504 Plan vs. IEP

## 504 Plan

Section 504 of the Rehabilitation Act of 1973

- ▶ **Federal Civil Rights Statute** that says schools cannot discriminate against children with disabilities
- ▶ No Federal Funding
- ▶ Eligibility is determined if disability impacts a **major life activity** (breathing, seeing, learning, walking, etc.)
  - In 2008, SLEEPING was added to this list!
- ▶ Given **accommodations**, which make it possible for students to reach general education curriculum with appropriate supports and services
- ▶ “Levels the playing field”

## IEP

Individualized Education Program

- ▶ **Individuals with Disabilities and Education Act (IDEA)** makes sure that children with disabilities have access to a **Free and Appropriate Public Education (FAPE)**
- ▶ Federal Funding
- ▶ Progress Reports, Services, Accommodations, Goals and Objectives
- ▶ **Modifications and Accommodations**
- ▶ Tailored to meet the needs of each individualized student

# Educational Plans

- ▶ A 504 Plan is strongly recommended to all patients with narcolepsy
  - Brings awareness of diagnosis to teachers/school staff
  - Permits helpful school and testing accommodations that can be utilized when necessary
  - Allows student to better access the general education curriculum
  - Takes the pressure off of the student and helps them get sufficient amount of sleep
- ▶ Individualized Health Care Plan (IHCP)
- ▶ Individualized Education Program (IEP) may be needed if education needs to be modified and accommodated



# 504 Plan Process

- ▶ Anyone can refer a child for consideration for 504 Plan, including a doctor, parent, teacher, or school nurse
- ▶ Schools must consider a variety of sources when determining the need for accommodations through a 504 Plan
  - Doctor's Letter/Clinic Notes
  - Grades
  - Teacher reports
  - Information from parents
  - Standardized test scores
  - Discipline reports
  - Attendance records
- ▶ No formalized testing is required
- ▶ School administrators and teachers use the information gathered during the process to decide whether a student qualifies as disabled. If a student is determined to have a disability, the committee will assess the student's educational needs and develop a plan for accommodations

# Letters from Provider



Boston Children's Hospital  
Clinical Assistant in Child Neurology



HARVARD MEDICAL SCHOOL  
Assistant Professor, Dept of Neurology

6/13/22

To Whom it May Concern,

I am writing you in regards to STUDENT (DOB XX-XX-XXXX). STUDENT is my patient in the Sleep Neurology Clinic at Boston Children's Hospital who we suspect has narcolepsy (G47.411). She is awaiting confirmatory lab and sleep study testing (this may not be done till late summer/fall).

Narcolepsy is a rare disease condition that is caused by loss or reduction in a neuro-hormone called "hypocretin". Deficiency in hypocretin results in loss of ability to maintain wakefulness during daytime hours and paradoxically, very fragmented nocturnal sleep. In addition to daytime sleepiness, patients with narcolepsy can have hallucination like events before and after sleep and cataplexy, a symptom that causes loss of muscle tone with and without emotion. Patients with narcolepsy have normal intelligence but may have difficulty sustaining attention and vigilance to tasks because of the sleepiness. Simply said, patients cannot control their need to sleep during the day and this is worse in passive situations (such as classroom lecture).

We suggest a number of accommodations be implemented into her school day at this time to maximize academic success given her severe daytime sleepiness.

1. Include 1-2 study periods during the academic day. This allows patients to get more work done while medications are active and permits time for naps as needed.
2. Schedule a 30 minute nap during the day if needed (some patients benefit from this nap after lunch and/or mid-morning). It would be helpful, if there could be a place STUDENT could take this uninterrupted nap such as nurse's office if needed.
3. Be able to chew gum/drink cool water during class/test taking or be able to walk around or stretch when feeling sleepy in order to maintain alertness
4. Request extra time for completion of tests/projects. STUDENT needs to keep 9-10 hours for sleep at night and this can be difficult if she is overwhelmed by homework responsibility.
5. Maintain light to moderate exercise daily as exercise as this helps improve daytime sleepiness. Ideally, gym would be in afternoon and classes that require more attention would be scheduled in the morning.
6. She has no activity restrictions and no sports restrictions

STUDENT and her family can decide if any of these suggestions should be incorporated into a 504 plan. STUDENT is a very bright, intelligent young woman and we hope to avoid academic difficulties because of her daytime sleepiness. Please do not hesitate to contact me if you have any questions or concerns

- Symptoms of narcolepsy
- Current treatment options
- How narcolepsy effects quality of life
- Highlight student's unique circumstances, if necessary
- Suggest specific accommodations

# When is an Evaluation Necessary?

\*A Special Education Team Evaluation is only necessary once the TEAM exhausts all other interventions\*

**Step One:** A teacher / paraprofessional notes that their student is struggling, so they start to collect data and implement their own interventions (i.e. extra help, individualized attention, fidget toys, student placement, peer partnerships, etc.)

**Step Two:** The interventions don't seem to help, so the teacher brings their student to an Educational Support Team-type group that most schools have. This EST panel will create a 6-8 week intervention plan with specific accommodations and supports in an attempt to bring that student back up to grade-level. Teachers will collect **DATA** and review after EST Plan period

**Step Three:** If the teachers notice improvement, they may continue with supports and interventions. If effective progress is still not noted, the EST Team may tweak plan and try another angle and set of accommodations/support; using what works and eliminating what they feel doesn't

**Step Four:** After second/third intervention period has been completed, and effective progress has NOT been noted (with the support of the specified accommodations and interventions), the Team should *THEN* move towards speaking with the family about an Initial Special Education Evaluation to determine if their education needs to be **modified** and if more services, supports and accommodations are warranted in order to help that student access the general education curriculum

# TEAM Evaluation

- ▶ No matter who makes the referral, PARENT/LEGAL GUARDIAN must give their consent in writing
- ▶ The school must contact parent within five\* school days of receiving referral to let them know if the district will conduct the Team Evaluation to determine whether or not that student is eligible for Special Education services
- ▶ Evaluations must be completed within 30\* school days of parental consent.
  - Parents have right to receive all SPED Evaluation Reports two days prior to Team Meeting; parents need to request these
- ▶ TEAM meeting (Eligibility Meeting) must be held within 45\* days of consent

**\*ALL TIMELINES ARE SUBJECT TO CHANGE DEPENDING ON YOUR STATE\***



# What Parents Can Ask School District to Evaluate

**Psychological Evaluation:** Cognitive Abilities

**Academic Evaluation:** Assess basics of math, reading and writing

**Occupational Therapy Evaluation:** Fine Motor, Visual Motor and Sensory

**Physical Therapy Evaluation:** Gross Motor Skills

**Speech and Language:** Social Skills, Expressive & Receptive Communication, Vocabulary, Pragmatics, Sign Language, Augmentative Communication Devices, Feeding, Swallowing, etc.

**Assistive Technology Assessment:** determines what software/tech tools will best support child's access to curriculum



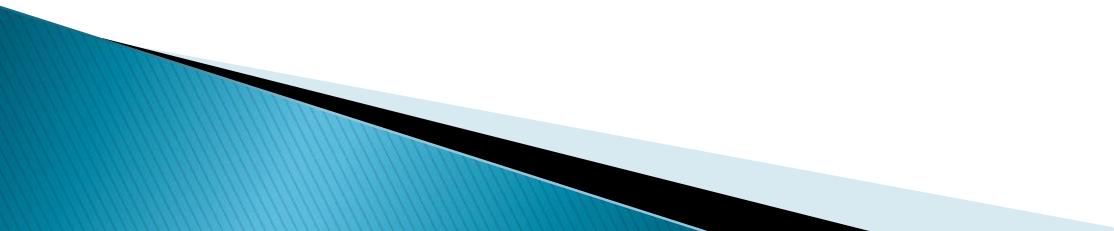
# Determining Eligibility

- 1) Does the child have a disability?
- 2) Does the disability cause ADVERSE EFFECT?
- 3) Does the student require specially designed instruction (modifications to curriculum) to make **EFFECTIVE PROGRESS** in order to access the general education curriculum?

IF Eligible – Team will develop IEP

IF Ineligible – This may result in 504 Plan or continued accommodations; but not SPED

\*Please note: There are a lot of accommodations listed that are geared more toward elementary school-aged students. Clearly, not all accommodations will be socially acceptable or appropriate for older students, so please take into consideration what the student feels comfortable with and continue to think outside of the box in order to find strategies and tools that work for each individual.



# Accommodations



- ▶ Whole Class Movement Breaks
- ▶ Individual Movement Breaks
- ▶ Naps
- ▶ Classroom Environment
- ▶ Sensory Stimuli to Maintain Wakefulness
- ▶ Curriculum



# Whole Class Movement Breaks

It has been discussed that movement helps to fight off fatigue and stimulate the brain, therefore we encourage teachers to allow walks, breaks, and give their students access to a variety of tools that encourage such movement

- Incorporating movement through stretching, dancing, yoga, etc.
  - [GoNoodle.com](http://GoNoodle.com)
  - [ThinkingMoves.com](http://ThinkingMoves.com)
  - [StandUpKids.org](http://StandUpKids.org)
- Incorporating movement in classroom teaching through kinesthetic learning

# Individual Movement Breaks

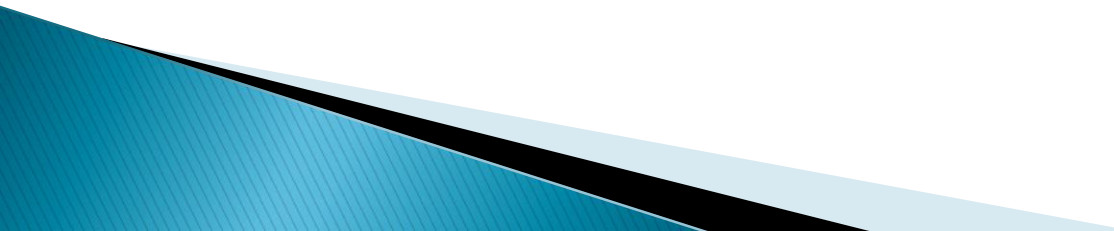
- ▶ Access to stand-up desks
- ▶ Notes to Nowhere: These are ready-made, teacher-produced notes that are given to students when an adult notices the need for movement. These notes have a simple message written inside and are either stapled or enclosed in an envelope (so students can't see message). The student takes note to designated adult somewhere in building, who upon receipt opens, reads, signs and sends the student back to their classroom. (Note to Nowhere usually says: *"Joey needs a break. Please sign and send back to room 205."*)
- ▶ Classroom helper (paper passer-outer, hand out materials, note deliverer, etc.)
- ▶ Older students should be permitted to take walks, get up and move their bodies

# Naps

## ▶ Incorporate Naps

- Schedule naps (ex. Two 15–20 minutes at nurses office or other designated space)
  - If allowed to sleep longer, sometimes it is difficult to wake child
- Naps are most often needed around 10 am and after lunch

# Classroom Environment

- ▶ Cool environment (allow fan and/or air-conditioning if possible)
  - ▶ Access to movement breaks, therabands/bungee cords, fidget toys, disco seats, wobble stools, etc. – anything that promotes movement
  - ▶ Allow patient to sit in front of class if attention needed (or back of class in order to take brief naps)
  - ▶ Allow student to chew gum and/or keep cool water at their desk
  - ▶ Allow student to leave a sweatshirt and/or blanket at school for naps in order for more comfort
  - ▶ Create a designated nap area (i.e. Beanbag chair, pillows, blankets, etc.)
- 

# Sensory Stimuli

## Sensory Stimuli to Maintain Wakefulness

- Access to therabands/bungee cords around the legs of chairs
- Access to a standing desk
- Ability to use disco seat
- Fidget Toys (squeeze/squishy balls, silly putty, twist and lock blocks, etc.)
- Velcro placed on underside of desk in order for student to touch and run fingers over it
- Sitting on exercise ball (If student is prone to falling asleep or cataplexy, they may fall; please take into consideration)
- Ability to color and draw

**Anything that promotes movement in a positive, non-distracting way!**

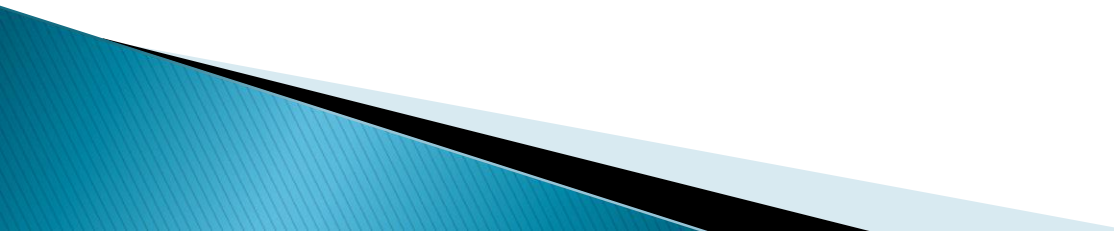


# Curriculum

- Kinesthetic and interactive learning. Incorporating movement into the curriculum
- Have notes and or lessons provided to student in case they miss important information
- For younger kids, flexibility with homework. Sometimes they can barely make it through the day, let alone homework
- Extra time to make up homework
- Study period/block
- Morning classes/afternoon activity
- Encouraging gym/recess
- Modified homework schedule (i.e. odd problems)
- Stop clock/timer
- Allow recording of lessons/lectures
- Modified classwork
- Priority scheduling – first period study hall for kids who can't wake up, or mid-day study hall if you need a nap time. The most difficult classes at their most alert time of day (Middle to college-aged students)

# Standardized Testing Accommodations

At the start of high school, it's important to start thinking about accommodations for standardized tests like the ACT, SAT, and AP exams. It's a good idea to begin this process early. Having accommodations at school will not guarantee accommodations for all standardized tests, but it can be helpful. Providing diagnosis documentation, explaining how narcolepsy affects you, and asking for specific accommodations are key. There are different requirements for each exam, so check with the School Guidance Counselor or look at the ACT and College Board (SAT) websites for detailed information.



# College Accommodations

- ▶ **You are responsible for disclosing your condition to your school** so you can receive accommodations. It's best to start the process as early as possible
- ▶ To find out how to request accommodations, visit the college's website or contact their disability center. If you are unsure about the correct procedure, get in touch with a counselor or admissions officer
- ▶ To request narcolepsy accommodations, you'll need to provide documentation from a healthcare professional that confirms your diagnosis. It should also include which academic accommodations are necessary for your condition and your individual needs. Speak with your doctor ahead of time to discuss which accommodations would be most beneficial
- ▶ If you qualify, you'll receive an official letter outlining which accommodations you've received
- ▶ You have the option to get in touch with your professors. You can email each teacher, request an in-person appointment, or even just take 5 mins to chat with them after your first day of class. Give your professors information about narcolepsy and tell them how you plan to be successful in their class



# Narcolepsy Considerations in College

- ▶ **Learn your sleepiness schedule**
  - Ask yourself these questions:
    - Do I become more tired in the morning or evenings?
    - What do I eat that makes me want to take a nap?
    - How many hours am I awake until I start to feel tired?
    - What activities help to make me feel more alert?
    - What are the activities that make me tired?
- ▶ Take advantage of the disability center on campus. A disability center provides students with tools and resources to help them be successful in college. Every disability center is different, so make sure you ask about all the services that they offer. Even if what they provide doesn't help, it is good to meet people who want you to succeed

# College Accommodations

- ▶ Extended time on tests/quizzes
- ▶ Priority scheduling: Ability to sign up for classes ahead of general population in order to get classes during the time of day when most alert
- ▶ Multi-day testing
- ▶ Flexible deadlines on assignments
- ▶ Note-taking assistance, ability to record lectures, take pictures
- ▶ Exempt from tardies and absences
  - This isn't always recommended, but sometimes college classes are only offered at a certain time which may not be an optimal time (i.e., 8:00 AM)
- ▶ Find a place to nap on campus
- ▶ Highlighted textbooks. If it's challenging to remain alert when you read, you may be able to request a highlighted textbook that allows you to focus on important information and reduce the amount of reading
- ▶ Classes in first-floor classrooms or in buildings with elevators if you have cataplexy
- ▶ Text-to-Speech and Speech-to-Text software
- ▶ Find a study partner and/or study group
- ▶ Access to class notes/PowerPoint prior to class.
  - When the lecture is over, you can chat with your professor to get the information you missed.

# Campus Living

- ▶ Roommate vs. Single
  - Think about your sleep schedule
  - Do you need a shaking alarm that will vibrate your bed or light alarms that will flash a strobe light for waking up in the morning?
- ▶ Bathroom attached to room
- ▶ Access to air conditioner
- ▶ Talk to Campus Housing and Campus Safety
  - Alert them to your needs/medications in case of emergency, etc.

# Advocates

- ▶ When to think about an advocate:
  - Just because
  - When school is not following plan; i.e. 504/IEP
  - When you're starting to pursue Special Education
- ▶ Where to find them:
  - Your state's Department of Education
  - Online search
  - Family/Friend referrals

# Narcolepsy in the Workplace

**The American with Disabilities Act (ADA) only protects you if your employer knows about your condition**

- ▶ You are not required to disclose your narcolepsy to an employer. But if you do not inform your supervisor, your sleepiness may be seen as laziness or lack of motivation
- ▶ Employers can and will deny requests that provide an “undue burden” on the organization
  - Your company may be required to make reasonable accommodations for you under the Americans with Disabilities Act. Reasonable accommodations often cost the employer no money
- ▶ You may be required to provide a doctor’s note that confirms your workplace needs when you request some accommodations
- ▶ Know your rights under the American with Disabilities Act and the Families and Medical Leave Act (FMLA)

# Work Accommodations

- ▶ Schedule short nap breaks of 15-20 minutes every 3 to 4 hours during day
- ▶ Take a nap at lunch
- ▶ Permission to stand during meetings
- ▶ Permission to get up and walk around when sleepy
- ▶ Move your desk near a window so natural light can help keep you awake or have access to full-spectrum lighting
- ▶ Use a wellness room, or new mothers nursing room as a nap space
- ▶ Flexible arrival time, or moving to a morning or afternoon shift to allow for a regular sleep schedule
- ▶ Move less interesting tasks to times when you are most alert
- ▶ Flexible working hours to avoid peak traffic
- ▶ Work from home, if possible
- ▶ Not taking closing/opening shifts where you close one night and open the next morning
- ▶ Keep a consistent shift rather than a rotating shift
- ▶ You may also need to work with your doctor to change the timing and doses of your medications to fit your work schedule
- ▶ Shifts scheduled for when you're most alert or the option to work on a flexible schedule
- ▶ Breaks that meet your needs, whether that's longer ones or shorter, more frequent ones
- ▶ The option to break up repetitive, monotonous tasks throughout the day to help you stay alert
- ▶ Scheduled walks at various times during the day to help with your energy and alertness
- ▶ A standing desk
- ▶ Work instructions provided both verbally and in writing, so you don't miss anything
- ▶ Permission to record meetings, so you can watch/listen later at your own pace
- ▶ Flex-Time. Paid time off to arrive late to work due to difficulties transitioning to wakefulness. This can be granted through intermittent FMLA protections. These protections kick in after working for a company for more than a year and for more than 1,250 accumulated hours

# Driving

- ▶ In a survey of 64 narcolepsy patients, 48% reported falling asleep while driving
  - 25% reported a car crash due to drowsy driving
  - Only 4% stopped driving after an accident
- ▶ National Institutes of Health (NIH) website reports patients with untreated narcolepsy have 10 x increased risk of having a car accident than general population
- ▶ Each state has different laws surrounding driving guidelines
  - Massachusetts– physician is required to report if there are concerns of impaired driving/public safety
    - Licenses may be given back in specific time period if patient shows improvement in sleepiness (usually with treatment)
  - New Jersey – mandatory physician reporting; citizen reporting
  - Colorado – Patient required to report condition

Parkes J. (1983)

[http://www.ninds.nih.gov/disorders/narcolepsy/detail\\_narcolepsy.htm](http://www.ninds.nih.gov/disorders/narcolepsy/detail_narcolepsy.htm)

# FINAL THOUGHTS

- ▶ If you think you or your child do not need accommodations...you do. It is better to ask for them and not use them, than to struggle
  - ▶ Think about what you/your child needs on your/their WORST day?
  - ▶ There is no cure for narcolepsy, but treatments needs to be tailored to the individual patient
- 