



NAVIGATING SCHOOL WITH NARCOLEPSY

Created by:

projectsleep



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WELCOME!

We are so glad you are here. This toolkit is designed for people living with narcolepsy and their loved ones to offer new tools, tips, and perspectives on navigating narcolepsy. Project Sleep created this toolkit as part of the **Narcolepsy Nerd Alert** series.

Narcolepsy Nerd Alert is an educational series diving deeper into specific topics relevant to narcolepsy. Each month, Project Sleep broadcasts a live event via Facebook, hosted by Julie Flygare, JD, Project Sleep's President & CEO.

After each live broadcast, we create a corresponding toolkit (like this one!) to capture our collective knowledge to help others down the road. Quotes featured throughout the toolkit are from panelists and participants who joined us for the live broadcast.

PLEASE NOTE

The **Narcolepsy Nerd Alert** series is intended for educational and awareness purposes and is not a substitute for medical attention. If anything in this toolkit sparks questions for you about your medical management, please bring those questions to your sleep doctor or narcolepsy specialist.



MEET THE PANELISTS



Kenya Gradnigo of Opelousas, Louisiana, was diagnosed with type 1 narcolepsy with cataplexy when she was eight years old. In 2015, she received Project Sleep's Jack and Julie Narcolepsy Scholarship as she began her undergraduate degree at Northwestern State University. Currently, Kenya is pursuing a Master of Social Work degree at Louisiana College.



Danielle Brooks of Dacula, Georgia, was diagnosed with type 1 narcolepsy with cataplexy during her freshman year of high school. She was awarded a Jack and Julie Narcolepsy Scholarship from Project Sleep as she started her undergrad degree at the University of Georgia in 2015. Danielle recently graduated from Georgia State University with a Master of Science in communication sciences and disorders, and is now working as a school speech language pathologist.



MEET THE HOST

Julie Flygare, JD, currently serves as President & CEO of [Project Sleep](#). She was diagnosed with narcolepsy with cataplexy in 2007 while in law school. Julie is an internationally recognized patient-perspective leader, an accomplished advocate, and the award-winning author of *[Wide Awake and Dreaming: A Memoir of Narcolepsy](#)*.



NAVIGATING SCHOOL WITH NARCOLEPSY

Students with narcolepsy and hypersomnia have the right to an equitable education.

On July 28, 2021, Project Sleep hosted the "Navigating School with Narcolepsy" live event to discuss how schools and families can work together to ensure opportunities for success. This toolkit is a compilation of the insights shared by panelists and community members from around the world.

- Watch the [Navigating School with Narcolepsy](#) Video
- Learn more about the [Narcolepsy Nerd Alert Series](#)



WHAT ACCOMODATIONS HAVE BEEN HELPFUL FOR YOU?



WHAT ADVICE WOULD YOU GIVE OTHER STUDENTS OR PARENTS?



ACCOMMODATIONS

There's no shame in seeking academic accommodations.

Is asking for accommodations a sign of weakness or strength?

It takes **strength** to pursue an education despite the challenges that come with narcolepsy. Managing symptoms, medications, side effects, and other complications can seriously impact one's academic career.

Is accepting accommodations letting narcolepsy win or taking control?

Making adjustments for narcolepsy means you're being smart and strategic; working with your narcolepsy to live your most successful life.

It can be difficult to adjust to a narcolepsy diagnosis while in school.

Before diagnosis, a student's grades and relationships with teachers and administrators may have suffered. School staff and administrators may not be knowledgeable about narcolepsy or know how to help.

It can be an uphill battle to gain accommodations.

Learning about legal protections, the accommodations process, and how accommodations work at different educational levels will empower students, parents, and doctors to work together.

Perseverance & communication are key.

While adjusting to symptoms and new treatments, it may take time to find a good schedule and accommodations that best meet your needs. This may be an evolving process and should be discussed during each doctor's visit. Educating school administrators and teachers will greatly improve a student's ability to manage their condition and succeed in school.

“ I didn't have a choice about taking accommodations at first because I was so young when I was diagnosed. As I got older, they turned out to be very helpful and I was very appreciative.

- Kenya

“ In law school I didn't want accommodations right away. After a few months I came back and said, 'Maybe I will take some accommodations.'

- Julie

“ I definitely couldn't have done as well in school without accommodations.

- Danielle



KEY TIPS

- Know what accommodations you want **before** starting the process with your school.

“ I don't think we can expect a school to know what the right accommodations are, in part because narcolepsy is relatively rare, but also because everyone's different. - Julie

- Think about what you would need on your **worst** days.

“ When I'm writing down which accommodations I'm going to ask for, I have to think back to my worst days. They're not fun to think about, but when they happen you want to be prepared. Even if you only need them once or twice throughout the year, it's best to have accommodations as a safety net. - Danielle

- "It's okay to be **delayed**, just not **denied**."

“ I was held back a semester because I was having so many bad days while trying to adjust. I called my mom crying and she said, 'Kenya, it's okay to be delayed, just not denied.' Some of us do have to take a break from school and it's okay. - Kenya

- Address concerns **before** problems arise.
- Put everything in **writing** when interacting with your school district.

“ Parents, please make copies of everything. Start the folder for the journey. - Ricky



DOES NARCOLEPSY QUALIFY AS A DISABILITY?

- Determining who qualifies as a student with a disability is an **individualized evaluation** made on a case-by-case basis.
- Federal law defines an individual with a disability as "any person who has a mental or physical impairment that substantially limits one or more **major life activity**."
- **What are "major life activities?"**
 - Major life activities include caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.
 - In 2008, new activities were added: eating, **sleeping**, standing, lifting, bending, reading, concentrating, thinking, and communicating.
 - While narcolepsy affects many aspects of life, the **inclusion of sleeping** as a major life activity is helpful for students with narcolepsy and other sleep disorders to gain a favorable determination toward receiving accommodations.
- A narcolepsy diagnosis does not, by itself, qualify any individual as "disabled" under the law. This evaluation is always an individualized process that considers the student's **unique circumstances**.



ACCOMMODATIONS PROCESS

How does the accommodations process begin?

At the elementary and secondary school level, the process to determine if a child qualifies as disabled begins with an evaluation conducted by the school's Section 504 committee. Anyone can refer a child for consideration for evaluation, including a doctor, parent, teacher, or school nurse.

What information is used in conducting an evaluation?

Schools must consider a variety of sources. A single source of information, like a doctor's letter, cannot be the only information considered. The committee will look at grades over the past few years, teachers' reports, information from parents and medical providers, standardized test scores, discipline reports, and attendance records. No formalized testing is required.

Who determines if a student qualifies for accommodations?

School administrators and teachers use the information gathered during evaluation 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 (often known as a 504 plan).

**See the Appendix for more information about
Section 504 of the Rehabilitation Act of 1973.**



ACCOMMODATIONS PROCESS

There are **three main factors** to discuss with school personnel in any accommodations discussion:

Basic narcolepsy facts

Lack of awareness about narcolepsy and misperceptions may lead to exaggerated concern or lack of concern from school officials. See the Resources section of this toolkit for links to fact sheets and other educational materials.

How narcolepsy affects the student

No two people with narcolepsy are exactly the same. Some may experience great improvements with proper diagnosis and treatment, while others struggle to find adequate therapies to manage symptoms, side effects, and other complexities. Some individuals may find short naps restful while others do not. Cognitive functioning, brain fog, and memory issues severely affect some students. It's important to clearly communicate how narcolepsy affects you in order to identify the accommodations that will be most helpful.

Accommodation suggestions

Students, parents, and doctors can discuss what accommodations will be helpful and bring suggestions to the school. Requesting specific adjustments is a key factor in getting meaningful accommodations.



ACCOMMODATION EXAMPLES

These are just a few types of accommodations that may be helpful for a student with narcolepsy. What works best may be a creative combination of some of these ideas.

- Test timing coordinated with wakefulness
- Limited hours of testing per day
- Note-taking support or "smart pen"
- Seating assignment and ability to stand
- Class scheduling and priority registration
- Extended time for homework and final papers
- Excused absences
- A place and time to nap

“ Multiple choice tests trigger my cataplexy, so I get open question tests instead. - Forever Brain Fog

“ In law school I was able to get priority registration. This helped me get into some of the more engaging, conversational classes as opposed to lectures. - Julie

“ My time capacity for testing was three hours, so for the ACT I had one section of the test a day. It took me two weekends to take the test, but it was very helpful. - Danielle

“ I took all my tests at a standing desk. I had a chair if I wanted to sit, but standing helped me stay alert. - Danielle

More educational accommodation ideas are listed at the end of this toolkit.



YOUR ADVOCACY TEAM

Who should you have on your team as you're getting accommodations?

Student + Parents + Sleep Specialist

Students and parents should educate themselves on narcolepsy and find tools to communicate effectively, such as the narcolepsy fact sheets linked in the Resources section of this toolkit. A doctor's report is an important part of the review documentation, as school personnel may know little about narcolepsy.

“ I had one roommate who was part of my team. She knew my condition, and was right there with anything I needed to help me along the journey.
- Kenya

“ I was diagnosed at 14, so my parents were a big part of the first accommodations meetings. As I got older, I started taking over the conversation while my parents were still present so I could learn advocacy skills. If you don't have supportive parents or they're not there, I recommend having someone like a friend or another advocate in the meeting, to have another set of ears and to make sure you're being heard.
- Danielle

What should be included in a doctor's report?

A doctor's report can educate the Section 504 committee on the symptoms of narcolepsy, current treatment options, and effects on quality of life. Furthermore, the doctor's report can highlight your unique circumstances and suggest specific accommodations. The accommodations suggested in the report should be consistent with what you are requesting.



HIGH SCHOOL V. COLLEGE V. GRADUATE SCHOOL

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 the ACT and College Board (SAT) websites for detailed information.

College may offer:

- Greater scheduling flexibility
- Classes that stimulate personal interests and fit various learning styles
- Classes with final exams versus final papers
- A wide variety of clubs and interest groups
- Alternative housing accommodations
- Greater diversity and opportunities to find community

“ The transition from high school to college was a little rough in the beginning. Having a new environment, new people, and changing medications made the transition harder. Once everything got on the right track it was easier.

- Kenya

“ Communicate with your professors. Even if they don't understand, provide them information.

- Danielle

“ I didn't really have choices with when my grad school classes were, so I needed the accommodation of a safe place to take a nap and time to nap during the day.

- Danielle



RESOURCES

Here are some of our favorite resources. We look forward to hearing what our fellow #NarcolepsyNerds find most useful for navigating school with narcolepsy!

PATIENT ORGANIZATIONS

- Major US Organizations:
 - [Hypersomnia Foundation](#)
 - [Narcolepsy Network](#)
 - [Project Sleep](#)
 - [Wake Up Narcolepsy](#)
- International Organizations:
 - Listed on Project Sleep's [World Narcolepsy Day webpage](#)

RESOURCES

- [ADA.gov](#)
- [College Board & ACT websites](#)
- [US Department of Education, Office of Civil Rights](#)
- [Hidden Disabilities](#) - Office of Civil Rights
- [Narcolepsy Quick Facts](#)
- [Narcolepsy Infographic](#)

REFERENCES

- [Title II of the Americans with Disabilities Act of 1990](#). 42 U.S.C. §12101 et seq.
- [Section 504 of the Rehabilitation Act of 1973](#), as amended. 29 U.S.C. § 794.
- [ADA Amendments Act of 2008](#) (Public Law 110-325, ADAAMA)
- [The Civil Rights of Students with Hidden Disabilities under Section 504 of the Rehabilitation Act of 1973](#)—Pamphlet.1995, U.S. Department of Education.



APPENDIX

What is Section 504?

Section 504 of the Rehabilitation Act of 1973 is an anti-discrimination, civil rights act prohibiting discrimination based on disability. Section 504 requires public school districts and other institutions of higher education receiving Federal Financial Assistance to provide a "free appropriate public education" to each qualified student with a disability. Title II of the Americans with Disabilities Act of 1990 extends this prohibition against discrimination to a wide range of additional state and local government services, programs, and activities (including public schools) regardless of whether they receive any Federal Financial Assistance.

Who is covered by Section 504?

Section 504 covers students who are "qualified" (which is generally between ages 3 and 22 years of age, depending on the program, and must have a disability). Federal law defines an individual with a disability as "any person who has a mental or physical impairment that substantially limits one or more major life activity."

Determining if a student has a physical or mental impairment that substantially limits a major life activity under Section 504 is an individualized evaluation made on a case-by-case basis. Interestingly, "substantially limits" is not defined in Section 504, but the Amendments Act of 2008 (Amendments Act) provided guidance stating that the determination "is intended to afford a broad scope of protection to eligible persons."

What are major life activities under Section 504?

"Major life activities" include caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. In 2008, new activities were added to this list: eating, **sleeping**, standing, lifting, bending, reading, concentrating, thinking, and communicating. While narcolepsy affects many aspects of life, the inclusion of sleeping as a major life activity is helpful for students with narcolepsy and other sleep disorders to gain a favorable determination toward receiving accommodations.



APPENDIX

It was also added in 2008 that **mitigating measures** (such as medication) cannot be considered in making the determination. This is especially helpful for students with narcolepsy. As narcolepsy's effects on quality of life are often underappreciated by outsiders, the fact that ameliorating factors like medication will no longer be considered in the determination is helpful.

The Office of Civil Rights has also acknowledged that some students have "hidden disabilities" that are not readily apparent to others. These students, regardless of their intelligence, may be unable to fully demonstrate their ability or attain educational benefits equal to that of non-disabled students.

Who determines if a student qualifies under Section 504?

According to federal regulations, "placement decisions are to be made by a group of persons who are knowledgeable about the child, the meaning of the evaluation data, placement options, least restrictive environment requirements, and capable facilities." Without a definitive "list" of qualifying conditions, school administrators and teachers must use their collective, professional judgment to make the determination.

Who initiates the Section 504 process for accommodations?

Anyone can refer a child for consideration for evaluation under Section 504, including a doctor, parent, teacher, or school nurse. If a parent or doctor refers a student for evaluation, the school district must also have reason to believe that the child is in need of services under Section 504.

If a parent initiates a request for evaluation and the school district denies the request, the school district must provide the parent with notice of their procedural rights under Section 504, so that parents can file a complaint with the school district Section 504 coordinator or with the appropriate regional Office for Civil Rights.

Do accommodations extend to extra curriculums?

Yes, school districts must provide equal opportunity in areas such as counseling, physical education and/or athletics, transportation, health services, recreational activities, specific interest groups and clubs.



ACCOMMODATION IDEAS

This list was compiled directly from students with narcolepsy at all grade levels including elementary, secondary school, college, and graduate school. Every student with narcolepsy is different. Every school is different. What works best for each student may be a creative combination of these ideas.

Managing EDS - Nap Accommodations:

- Providing a designated area for scheduled nap time
- Going to the nurse when a nap is needed
- Walking out of class for fresh air whenever necessary
- Staying in the classroom at break times to sleep
- Designating a reserved cubicle in the library to nap anytime
- Leaving the classroom if a sleep attack is coming or for any other reason
- A study hall period to nap daily

Note-Taking:

- Allowed to anonymously assign a classmate to take notes and use their own notes as well in order to grasp concepts better
- Teachers provide copies of their notes
- Using a "smart pen" that records audio with writing

Day-to-day in classroom:

- Snacking in class if stomach is upset from medication
- Providing tutors who understand if student is late - knowledgeable about difficulties with sleep and EDS
- Ability to participate in extra-curricular activities
- Opportunities to revise material at a time that suits student best

Homework:

- Limited homework
- Extra time to make up homework



ACCOMMODATION IDEAS

Absenteeism:

- Allowed to be late if sleep is an issue
- Absences excused
- Providing one doctor's note for the semester or year, especially if the student is newly diagnosed and trying new medications

Class Schedule:

- Arranging classes so that less engaging or more difficult ones occur while medication/alertness is still strong
- In a block schedule system, the ability to come in second period
- Priority scheduling – first period study hall for those with trouble waking up, or mid-day study hall for nap time

Alternatives to standard classroom:

- Virtual school programs
- Online classes to make up credits to graduate
- Summer classes

Testing/Final Papers:

- Extra time for tests
- Regularly scheduled breaks during tests
- Mark in book only–no answer sheet to bubble
- Separate room for testing
- Air conditioning
- Tests & quizzes first thing in the morning
- Seat placement next to a window for natural light
- Standing while taking tests
- Limiting testing time per day
- For ACT, one test per day
- Extensions for all final papers
- Extra time on all deadlines



THANK YOU!

We are so grateful that you took the time to check out this toolkit!

Project Sleep is a 501(c)(3) nonprofit organization dedicated to raising awareness about sleep health and sleep disorders.

More resources at: www.project-sleep.com

