Introduction

Children with rare or undiagnosed conditions – such as narcolepsy – are members of neighborhood schools across the country. School can, and should, be a great place for everyone, including those with unique medical conditions, to access their education.

Narcolepsy can affect children differently, and children who have it vary greatly in intelligence, behavior, medical issues, and educational needs. In this resource, we offer tips and strategies for children who have narcolepsy. We will also describe specialized educational supports and ways to work with your child’s school to ensure a collaborative approach is created to ensure your child has access to their education.
Meeting a Child’s Individual Needs

When a child has a rare disease, the road to a diagnosis can be long and complex. Some children with narcolepsy may never receive a diagnosis of narcolepsy. Instead, they may have a general diagnosis, or be labeled as lazy, unmotivated, or staying up too late at home. A medical diagnosis may help open some doors for educational services by explaining the student’s constellation of symptoms and behaviors are neurological and not intentional in nature. That being said, if a student is not yet diagnosed, but is unable to access their education, caregivers should be proactive by reaching out to the school for accommodations or modifications to ensure the student can access their education.

Medical Information That May Prove Helpful for Effective Advocacy

1) Sleep Log

A sleep log is a tool for evaluating aspects of an individual’s sleep habits, finding ways to improve the quality and quantity of sleep a person gets, or investigating the effectiveness of a new or changed treatment. It is important to start the sleep log a few weeks before starting any new or changed medication or therapy, so that you become accustomed to the process and establish a base line for comparison. Over time, the individual may begin to see patterns emerge. A sleep log is one of the best ways to provide the accurate and objective information a doctor or school needs to know to make important decisions about treatment and educational planning.

You can print copies of a sleep log from learnaboutnarcolepsy.org or use a notebook to record the most common and useful data:

- Sleep and wake times, naps, triggers, and duration of cataplectic events
- Medication including prescription, over the counter, homeopathic and herbal preparations, times, and dosages

2) Epworth Sleepiness Scale (ESS) & Swiss Narcolepsy Scale (SNS)

The Epworth Sleepiness Scale (ESS) is a tool to help determine how likely you are to fall asleep in everyday situations. The ESS helps measure the degree of daytime sleepiness that you experience and can provide valuable information when advocating for your child for educational accommodations or modifications.

<table>
<thead>
<tr>
<th>Situation</th>
<th>Chance of dozing (0-3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sitting and reading</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>Watching television</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>Sitting inactive in a public place – for example, a theater or meeting</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>As a passenger in a car for an hour without a break</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>Lying down to rest in the afternoon</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>Sitting and talking to someone</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>Sitting quietly after lunch (when you’ve had no alcohol)</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>In a car, while stopped in traffic</td>
<td>0 1 2 3</td>
</tr>
</tbody>
</table>

**Total Score**

0 = would never doze; 1 = slight chance of dozing; 2 = moderate chance of dozing; 3 = high chance of dozing

Johns MW. Sleep. 1991;14:540.

The Swiss Narcolepsy Scale (SNS) is a tool used to measure a person’s symptoms and determine if they have narcolepsy with cataplexy. The SNS is made up of five brief questions:

1. How often are you unable to fall asleep?
2. How often do you feel bad or not well rested in the morning?
3. How often do you take a nap during the day?
4. How often have you experienced weak knees/buckling of the knees during emotions like happiness or anger?
5. How often have you experienced sagging of the jaw during emotions like happiness or anger?
3) Letter(s) from your child’s doctor(s) that contain the following information:

a. Name and date of birth of child
b. Diagnosis
c. Explanation of the diagnosis
d. Explain how the child is specifically impacted
   i. Fatigue?
   ii. Inability to stay awake?
   iii. Difficulty focusing, concentrating, paying attention, taking notes?
   iv. Inability to wake up in the morning and make it to school on time?
v. If the child has cataplexy, explain cataplexy and how it impacts the child.
e. What accommodations/modifications are recommended to level the playing field with neuro-typical students? (See list of possible accommodations listed later in this article)
f. List doctor’s credentials (i.e., specialty, special training, any board certifications, years in practice)

What to Do If You Think Your Child May Need Services and/or Support

If you think that your child is not developing at the same pace or in the same way as most children his or her age, a good place to start is with your child’s pediatrician.

For children under three years of age, your pediatrician may refer you to the early intervention program in your area to evaluate your child for developmental delays or disability. You may also contact early intervention directly. To find the program in your area, ask your pediatrician or visit the Early Childhood Technical Assistance Center website (ectacenter.org/contact/ptccoord.asp). It is highly recommended that any and all requests made for support or services be in writing. If you make a phone call, follow up this call with written documentation as to who you spoke with, the date of the call, what was said, and your next steps.

For children over three years old, if you suspect your child has narcolepsy or a challenge that impacts learning, including academic, physical, behavioral, or emotional challenges, you have two options. You can request a 504 plan meeting or you can make a referral to determine eligibility for special education and related services. Educators, therapists (physical, occupational, speech), service providers, and/or doctors can also request a meeting be held, where you will participate along with school staff and personnel. Requests for a 504 plan meeting or a referral to determine eligibility for special education and related services should be made in writing. If you are requesting a 504 plan meeting, you need to state your child has a disability that impacts his/her major life activities (i.e., sleep, staying awake, focus, concentration, being able to wake up and get to school on time, difficulty taking notes). If you are making a referral to special education and related services, you need to include why you think your child may need special education services and should list all areas of suspected disability. Providing examples of types of situations that are challenging to your child will be helpful. Note, some schools may have forms to request a 504 plan meeting or a referral to special education online.

After your request for either a 504 plan meeting or a referral to special education, a team, including key staff and parents/legal guardians, will meet to determine if the child is eligible for either a 504 plan (student must have disability that substantially limits the ability to learn and participate in the general education classroom) or an Individualized Education Plan (IEP) (evaluations must show child has a disability that requires specialized instruction).

Narcolepsy: Should I Request a 504 Plan Meeting or Make a Referral to Special Education

Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 701 et seq, is a civil rights law that prohibits discrimination against individuals with disabilities. Section 504 ensures equal access to education for students with disabilities and if the student qualifies, they may receive accommodations and modifications needed to level the playing field with neuro-typical peers. As of January 1, 2009, Section 504 incorporates the American Disabilities Act of 2008 (ADAAA) by reference and applies to all public school students. The ADAAA broadens the definition of disability under Section 504. To qualify for a 504 plan, you must show your child has a disability (i.e., narcolepsy) that impacts a major life activity (i.e., sleeping, staying awake, focus, concentration). Learning is not the only major life activity a school district must consider when determining eligibility under Section 504. Section 504 requires equal access and opportunity and a school should determine the student’s needs in order to provide equal opportunity to participate in school, as well as the school’s programs (i.e., after school clubs and sports, field trips). If a student is deemed eligible for a 504 plan, accommodations must be made (i.e., no penalty for lateness to school caused by inability to wake up on time, notes provided, no more than two tests in one day, place to take a nap at school).
If your child is having difficulty academically, emotionally, behaviorally, and/or socially, you should make a referral to determine if your child is eligible for special education and related services. Once this referral is made, the school district will want to conduct an evaluation. The Individuals with Disabilities Education Act, 20 U.S.C. 1400 et seq, includes the Child Find mandate. Child Find, see 20 U.S.C. 1412(a)(3) requires all school districts to identify, locate, and evaluate all children with disabilities, starting at birth. Child Find applies to all children who reside within a State, including children in both public and private schools, regardless of the severity of their disabilities. This mandate includes all children who are suspected of having a disability, even children who are receiving passing grades and are “advancing from grade to grade.” (34 C.F.R. 300.111(c)). This law does not require children to be “labeled” or classified by their disability. (20 U.S.C. 1412(a)(3)(B); 34 C.F.R. 300.111(d)).

If accommodations will not be enough to enable your child to successfully access their education, testing in all areas of suspected disability is essential and required by both federal and state law.

**Educational Testing May Provide Helpful Information for Effective Advocacy**

It is important to understand as much as possible about narcolepsy and any other suspected learning challenges to provide input to the school team at the school meeting. Some of the areas of testing districts may administer include:

- Cognitive (i.e., assesses students learned reasoning and problem solving abilities through a battery of verbal, quantitative, and nonverbal test items; sometimes referred to as intellectual testing, which attempts to measure a child’s potential for learning and to understand how a child processes information)
- Academic Achievement (i.e., measures a child’s current academic achievement; what has the child learned to date)
- Social-emotional Functioning (i.e., testing to identify social and personal strengths and weaknesses)
- Processing (i.e., to determine how a child makes sense of information; areas that may be measured include auditory processing, visual processing, visual-motor skills, memory functioning, and executive functioning)
- Speech and Language (i.e., assesses student’s communication skills and may look at receptive, expressive, pragmatic, articulation, and voice quality)

You must provide written consent for any testing to commence and the consent must be informed.

Many children have co-morbid disabilities, meaning more than one disability that impact a student’s ability to access their education. Schools need to understand that many children have more than one barrier to learning and that co-morbid challenges have a compounding effect. For example, if a child constantly falls asleep in class and misses notes and instruction time, the child may become panicky and anxious wondering how they are going to catch up and pass needed exams and tests. The anxiety can be increased by a fear of teasing and bullying by peers, being left sleeping in class after the bell has rung, and being wrongly perceived as lazy. They may also have an inability to get to school on time every day, and develop concerns that teachers and peers do not understand their disability. Schools and parents need to work collaboratively and often creatively to implement either a 504 plan (accommodations) or an IEP (specially designed instruction with measurable goals and objectives which may include modifications).

Here are some steps that you may take to ensure appropriate modifications are being made for your child.

- Track data (i.e., grades, progress reports, tardies) over time to document educational growth as well as areas of weakness in need of support
- Keep a notebook at home and record the amount of extra time spent on school work outside of the school day
- Keep track of the amount of time you spend helping your child each night after school, as well as hours of help provided by tutors, if applicable
- Record situations where services have not been delivered according to Individualized Education Programs (IEP) or 504 plan specifications; if for example, your child is being penalized for being late to school because they overslept, your child should not be punished or lose credits if the lateness is directly linked to your child’s narcolepsy
- Make sure teaching strategies being used are appropriate for the child. For example, if tests will be open book based on notes and your child slept through most of the class, your child should be provided with notes for each class so they are not penalized for their disability
Narcolepsy: What Accommodations (504 Plan)/Modifications (IEP) are Possible?

Accommodations or modifications must be specific to address the unique needs of your child. You should speak with your child, school staff, and providers to determine what may work for your child.

Here are some ideas to consider:

- A safe, private place to take a short nap while at school
- Ability to go to the nurse as needed
- Extended time on tests and assignments
- Testing in private area so student can get up and walk around or stand
- Preferential seating
- Reduced homework or classwork
- Notes and study outlines for every class
- Modified or flexible class schedules (important classes scheduled when your child is most alert)
- Priority scheduling
- No penalty for lateness to school
- Ability to leave classroom and walk around if sleep attack approaching
- Snack/drink in classroom
- Accommodations on standardized testing (i.e., testing over several days; extended time; ability to take breaks)

Knowledge is the Key to Effective Advocacy

The more you and your child can learn about narcolepsy and the impact it has on day to day functioning, the better you will be able to effectively advocate for accommodations or modifications needed to be successful in school. If you disagree with the evaluations conducted by the district, you have a right to an Independent Educational Evaluation (IEE) paid for at district expense (see 34 C.F.R. 300.502). Be sure to learn as much as possible about narcolepsy, as well as laws that protect students with narcolepsy, namely Section 504 and the IDEA.

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