



A Teacher's Guide to Neuromuscular Disease



Easy solutions for students may include the use of assistive technology.

Acknowledgments

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Introduction: A Teacher's Guide to Neuromuscular Disease

The Muscular Dystrophy Association (MDA) is committed to keeping families at the heart of all we do. We have created this booklet to help provide information and support to teachers of students with a neuromuscular disease. It is our goal that this booklet will help you better understand the challenges faced by children and adolescents affected by neuromuscular conditions, including muscular dystrophy, spinal muscular atrophy and Charcot-Marie-Tooth disease. This guide suggests general strategies to enhance your student's school experience both academically and socially, and it addresses school issues that may arise throughout K-12 education.

We understand that learning about the various challenges associated with neuromuscular diseases can be overwhelming. The good news is that these students also come with their own unique set of deep strengths, and your role in encouraging, supporting and motivating them draws on many of the skills you're already using with your diverse class of students.

A strong family-student-teacher team is the best approach to maximizing the school experience for children and teens with neuromuscular disease. The progressive nature of many neuromuscular diseases requires ongoing communication between school and home, so new challenges that arise can be solved in a timely manner or prevented altogether.

As an educator, you think big and set high expectations for all your students, and this should not change for those affected by neuromuscular disease. You have the opportunity to provide students affected by neuromuscular disease with the foundation for a life of independence and self-advocacy. Thanks to advances in scientific and medical research, many children living with neuromuscular disease will grow up to pursue higher education goals, and have careers, families and contributing roles in their communities.

It is important to note that every statement, strategy, accommodation and modification mentioned in this booklet may not apply to your student with a neuromuscular disease. It is our recommendation that you continue to have an open dialogue with the parents and the child or adolescent with whom you are working so you can better understand each student's specific needs.

You are not alone in this journey — MDA is here to provide assistance and support so our students with neuromuscular disease and our valued educators in hometowns across America can achieve success together inside the classroom and beyond.



Educators have the power to help provide students affected by neuromuscular disease with the foundation for a life of independence and self-advocacy.



A reasonable accommodation may include a student having a locker toward the end of a row for easier access.

What is a Neuromuscular Disease and Does It Affect the Ability to Learn?

Neuromuscular diseases are rare conditions that affect some part of the neuromuscular system, such as:

- the muscles
- nerves in the peripheral nervous system (e.g., arms and legs)
- the neuromuscular junction where the nerves and muscles meet
- nerves in the central nervous system (motor neurons in the spinal cord)

Most neuromuscular diseases are progressive in nature, and they typically result in muscle weakness and fatigue, among several other symptoms. Muscle weakness and fatigue can make it difficult for students to keep up with the physical and educational demands throughout the school day, but the appropriate accommodations can help compensate for this.

Some neuromuscular diseases are present at birth, some manifest in childhood, and others are adult-onset. Neuromuscular disorders may be passed down through family genetic lines, and in some cases, students may have an affected sibling, parent or another relative. At other times, there is no family history, and the disorder is the result of a spontaneous genetic mutation, an abnormal immune response or an unknown cause.

Life expectancy for those living with neuromuscular diseases varies by disease and severity. Medical interventions have resulted in increased life span and improved quality of life for many individuals. These interventions focus on treating or delaying symptom onset, enhancing physical mobility and social interactions, and preventing heart and lung complications. At present, there's no cure for most neuromuscular diseases, but there are now some treatments available for some types to further improve medical outcomes.

"I usually feel left out at recess when playing with my classmates because I can't run as fast as them. Sometimes I have kids that will slow down to be with me. Sometimes other kids give me weird looks when they see me walking, running or going up the stairs. When this happens, I just tell them "hi" and keep on going. If someone would ask me about it, I would just tell them that I have something wrong with my legs, and it is not a big deal."

— Amanda, a student living with a neuromuscular disease

Heart and respiratory complications, which are secondary effects of muscle deterioration, often are the cause of death. In winter, the increased susceptibility to (and life-threatening consequences of) respiratory infections may cause students to miss many days of school.

Like other students, children with neuromuscular diseases show a range of intellectual abilities, and many have higher-than-average intelligence. However, muscle weakness and fatigue can make it difficult for students to keep up with the physical demands of handwriting, moving between classrooms, organizing materials, etc.

A few neuromuscular diseases bring a higher-than-average risk of learning and intellectual disabilities. This may affect proficiencies in reading or mastering math concepts, being able to attend to a lesson or understanding instructions and classroom requirements.

Unlike muscle weakness in neuromuscular disease, cognitive effects do not worsen over time. Students benefit from appropriate accommodations for learning disabilities.

Students with neuromuscular diseases may qualify for special education services based on their orthopedic or learning disabilities, or both. Throughout their educational careers, most are placed in general education and some with supports.

Students with neuromuscular diseases may have an IEP (Individualized Education Program) outlining educational goals, strategies and supports. Also, these students, if they do not have an IEP, will qualify for a Section 504 accommodation and/or health plan.



Neuromuscular diseases are progressive in nature. A child may experience fatigue throughout the day.



“Communicate with the student and family ahead of time to discuss goals for the [IEP] meeting and possible issues that the family, student and team would like to discuss and resolve. This lessens anxiety, builds relationships and leads to a meeting that is more successful in meeting the needs of the student.”

— Tammy, mom of a child living with a neuromuscular disease



Students with physical disabilities may benefit from two sets of textbooks: one for home and one for school.

Tips for Health and Well-Being in the Classroom

It is important to note that not all students with neuromuscular diseases will have acute health concerns, but depending upon the student's specific diagnosis, the following should be considered to help ensure success in the school setting.

Prevent the spread of germs with good handwashing:

Most neuromuscular diseases do not impact the immune system; however, children with compromised respiratory function (due to muscle weakness of the diaphragm) may have more difficulty recovering from common illnesses (e.g., cold, cough and strep throat). Additionally, in conditions for which corticosteroids are prescribed, these medications may cause weakened immune systems.

- Students with compromised respiratory function may need to avoid classrooms with high rates of communicable diseases, as they can become life-threatening.
- Developing classroom habits that limit the spread of germs creates a healthy environment for all students. Examples include: not having a community pencil sharpening station, not sharing writing utensils or glue sticks, covering the mouth/nose with a tissue or one's arm when sneezing or coughing, cleaning workspaces between students, and scheduling a specific time to encourage and demonstrate good handwashing techniques.

Proper nutrition can help the body sustain good health:

The goal for most children is to eat a healthy, well-balanced diet to sustain normal growth and development. Proper nutrition is essential for muscle health and focus in the classroom.

- Some neuromuscular disorders are treated with corticosteroids, such as prednisone, that often stimulate appetite, which can lead to excessive weight gain. Potential weight gain due to corticosteroid treatment can be further compounded by limitations on exercise and physical activity experienced by many with neuromuscular disorders. A customized dietary plan may be necessary to promote healthy food choices and avoid high-calorie or carbohydrate-dense meals and snacks.
- Students with extensive muscle weakness may need help setting up their lunch (e.g., opening cartons, cutting food into pieces), and they may require assistance from an attendant with eating and drinking. They may eat more slowly and need frequent fluids to avoid choking and aspiration. They may feel fatigued from the effort of eating and require longer lunch periods to complete their meal.
- Students who cannot eat and drink safely (due to high risk of choking or aspiration) may need liquid nutrition delivered through a medically placed tube to sustain proper nutrition. If this is the case, it is important to ask if the student can or should not have anything to eat or drink.

Gastrointestinal complications manifest in many different ways:

Smooth muscles of the GI tract from the mouth to the colon may be affected by a neuromuscular disease. This can cause either constipation or diarrhea, and sometimes constipation will be related to urinary problems (accidents or need for frequent urination).

- Students with constipation or diarrhea may require a specific diet or medications to make bowel movements occur more normally. They may require scheduled restroom breaks during the day and need more time in the restroom. They also may require more time walking to and from the restroom.

Exercise and activity recommendations may include

modifications or adaptations: The type of neuromuscular disorder is very important when considering exercise and activity. Exercise and activity limitations are primarily dependent upon the specific diagnosis and pattern of muscle weakness.

- In general, most children should be encouraged to remain active to the greatest degree possible given their diagnosis. Activities may need to be adapted, and in some cases, restricted to prevent falls; likewise, activities that lead to fatigue or discomfort may need to be adapted or avoided so as not to hinder the student's ability to participate in the classroom experience.
- A licensed physical therapist or physical education (PE) teacher trained in developmental adaptive PE can identify appropriate modifications to prevent excessive wear and tear on muscles and/or excessive fatigue. More research is needed in this area, but most students with muscular dystrophy and related neuromuscular diseases should not lift weights or participate in strengthening activities. These activities may hasten muscle breakdown in some types of neuromuscular disease.
- Competitive, timed tests of strength and endurance may not be helpful to enhancing self-esteem for students with any type of disability involving muscles and mobility. It is not appropriate to rate progress in relation to peers or national standards when students have progressive conditions that weaken muscle strength and limit mobility.
- Many students with neuromuscular diseases are at risk for joint contractures. Daily stretching and range-of-motion activities (at school or at home) are appropriate. Stretching and scheduled rest at school when physically tired may reduce discomfort and allow greater focus in the classroom.
- Students with neuromuscular diseases that affect the peripheral nerves (e.g., Charcot-Marie-Tooth disease) may have decreased sensation and strength in the extremities (primarily toes, feet and lower legs but may also affect the hands and forearms). This places them at risk for sprained ankles, calluses or skin breakdown on the feet, as well as difficulty running and with some fine motor skills. They may not have the ability to feel extreme temperatures, placing them at risk for frostbite or burns.



Students are encouraged to remain active and part of mainstream extracurricular activities.

“Teaching a child with a neuromuscular disease is just that — teaching a child. It is not teaching a disease. Each child is unique, as are their strengths and weaknesses, abilities and limitations. Do not let the disease stop you from getting to know the child and giving that child the same opportunities to show their abilities that are afforded to every other child.”

— Angela, mom of a child living with a neuromuscular disease



You may need to collaborate with your school district's bus service to ensure safe transportation to and from school.

Muscles for breathing can be weakened: This can make it difficult to effectively move air in and out of the lungs, and clear secretions from the airway with coughing. Not all students with neuromuscular diseases will have impaired breathing, so it is important to inquire about the student's respiratory status.

- Reduced respiratory function and airway clearance (i.e., cough) can result in a simple cold that can progress rapidly into pneumonia.
- Symptoms of respiratory problems may include frequent headaches, mental dullness, difficulty concentrating or staying awake in the classroom, or frequent colds/coughs that don't seem to resolve. (If these are noted at school, this should be discussed with the student's parents with encouragement to seek medical evaluation.)
- For students with known respiratory complications, interventions during the school day to help maintain good health may be needed. Examples may include use of a cough-assist device, suctioning or even a portable ventilator.
 - **Cough-assist machines and suctioning:** These machines help bring up lung secretions to keep the bronchial system free of infection.
 - **Assisted ventilation:** Help with breathing may be given either through an external mask or "sipper" tube, or by way of a tracheostomy (trach) in which a tube is inserted directly into the airway to deliver air to the lungs.

The heart is a muscle too: Complications involving the heart can occur in some types of neuromuscular disease. This may include fibrosis (thickening) and weakening of muscles in the heart, resulting in less effective pumping (cardiomyopathy). Other times, the heart rhythm may be altered.

- Symptoms of cardiomyopathy may include fatigue, lethargy (lack of energy), swelling in the legs and feet, cold extremities, digestive problems and poor circulation. If these are occurring, the student may need more time to complete work or receive a reduced volume of work. It is common for the student to require positioning to help with circulation, such as elevating the feet.
- Some medications used to address cardiac complications associated with neuromuscular disease may alter heart rate and blood pressure. Occasionally, a school nurse will be enlisted to check these periodically, so the student does not miss school for such monitoring.

"Be open-minded, be flexible, be patient with a student who has a neuromuscular disease."

— Kevin and Julie, parents of a child with neuromuscular disease

Missing school for appointments and medical management

can be expected: For most students with a neuromuscular disease, there will be appointments with their neuromuscular team of doctors, nurses, physical therapist (PT), occupational therapist (OT) and other specialists. Frequent or extended absences may require tutoring or remedial assistance for missed classroom time.

- Depending on the specific neuromuscular disease, a student may need to attend one to several appointments per year, and some appointments may involve travel out of town. The student should continue appointments with their primary care providers for standard pediatric care, as well as treatment for common childhood illnesses and injuries.
- With advances in research, some students participate in clinical trials or other research opportunities to advance scientific and medical knowledge of neuromuscular disorders. These may require long-distance travel and can be quite tiring for the student and family. Clinical trials involving research for new medications or therapies can involve medical appointments as frequently as once a week.
- Students may have scheduled surgeries, procedures or hospitalizations that result in planned school absences. For example, a surgery for heel-cord contractures may require a few days of hospitalization and recovery, while a surgery to correct scoliosis may mean several weeks of missed school. The time for recovery and rehabilitation varies and should be discussed in advance to establish a plan for missed classroom time when possible.

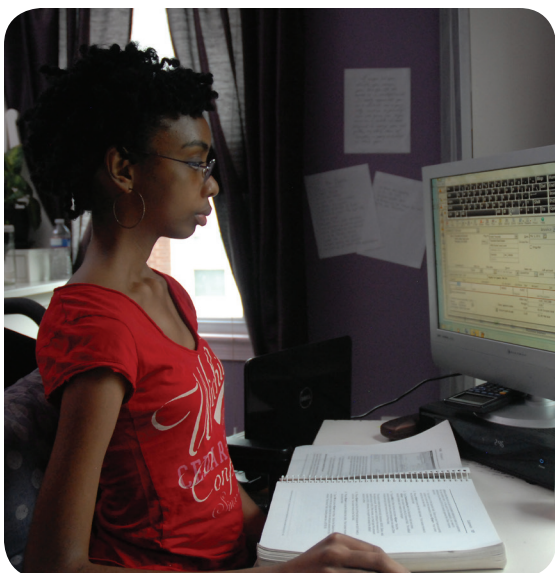


Physical and occupational therapists are important team members with which to consult on IEP/504 plans for students with neuromuscular diseases.

“I wish Sara’s teachers knew that even though she is not as affected by her neuromuscular disease as some other children, she still faces obstacles and difficulties. She has issues with fine motor skills that can result in slower writing time, as well as hand fatigue. She also has contractures in the tendons in her legs, which affect her gait and ability to climb stairs. She will never be able to do everything in PE the same way other children can, but she is always determined to do her best and give 100 percent.”

— Angela, mom of a child living with neuromuscular disease





Begin discussing a student's plans for postsecondary education one to two years before high school graduation.

Tips for Teachers and School Personnel

These tips have been provided by individuals with neuromuscular diseases. When teaching and working with students with neuromuscular diseases, remember the following:

Don't make assumptions.

- If you have questions about something, ask the student or the parents. The student and their family have the most knowledge about the disorder, the student's abilities and appropriate accommodations.

Encourage open communication.

Plan ahead (see below).

Be open-minded.

- Nearly every activity and skill can be completed by students with neuromuscular disease. It is especially helpful if you can think outside the box, and brainstorm with the student's parents to determine how the student can be fully engaged. Knowledge of essential skills can be demonstrated in a variety of ways.

Be inclusive.

- If notes or outlines will benefit the entire class, give them to every student, as some accommodations can help everyone succeed.
- If you ask students who are physically able to assist you, also ask students who are affected by neuromuscular disease or other types of disabilities.
- Make sure class seating allows for everyone to participate, and that no one is left off to the side or isolated from the group.

"Teachers are responsible for providing students with the academic skills and accommodations to be lifelong learners. Students with neuromuscular diseases who receive accommodations actively participate in classroom activities and excel at learning. Neuromuscular diseases can manifest in different ways. Don't forget to accommodate for the students who you cannot visually identify their symptoms, and for those who you can visually determine their symptoms, keep in mind that they want to be treated just like their peers."

— Tammy, mom of a child living with a neuromuscular disease

Common educational accommodations:

- Provide electronic books and materials and/or another set of textbooks for the student's home.
- Provide additional time to complete assignments and assessments and to travel in the hallways.
- Allow for alternative opportunities for the student to demonstrate understanding and comprehension.
- Arrange for the student to have a notetaker, as well as teacher-provided outlines, notes or transcripts.
- Assist with classroom and school modifications that will enhance the student's independence.
- Organize specialized transportation to and from school, including field trips. Be sure to discuss with the parent/guardian possible accommodations needed to get on and off the bus.
- Ensure safe and clear access for entering and exiting the school building.
- Evaluate weather during recess times for extreme heat and cold and offer indoor activities if necessary. When a student is unable to participate in outdoor recess, allow another student to participate in the designated indoor recess activity so the child does not feel excluded.
- Provide a locker located on the end, and be aware that accommodations for a different type of lock may be needed.
- Provide assistance with putting on and/or taking off outdoor clothing.

For additional information, including disease-specific school accommodations sheets, physical therapy recommendations and how to plan ahead, as well as tips and related resources, visit MDA's K-12 Educational Resources page at mda.org/services/educational-resources.

"I often wish I could just be like every other student and come to school on the first day of school with my backpack and new school supplies and just think about hanging out with my friends. That isn't a luxury I have if I want to be able to function and learn on my first day of class. I have to prepare months ahead for my first day of school.

— Halie, a student living with a neuromuscular disease



Students with neuromuscular diseases may need more time to complete homework and other assignments, so help them plan accordingly.





MDA Is Here to Help

MDA is ready to help teachers and school staff by providing resources and support. Be sure to visit the MDA disease list to learn more about your student's specific diagnosis. Muscular dystrophy and related life-threatening diseases weaken muscle strength and severely limit mobility. Find out who gets these diseases, what causes them, what the symptoms and life expectancy are for individuals affected by them, and how MDA research is leading the way to treatments and cures. Learn more at mda.org/disease/list.

If you have additional questions, contact the MDA National Resource Center at ResourceCenter@mdausa.org or **800-572-1717** (select option 1). MDA's trained resource specialists are available Monday through Friday from 8 a.m. to 5:30 p.m. Central time to provide information, resources and one-on-one support.

About MDA

MDA is leading the fight to free individuals — and the families who love them — from the harm of muscular dystrophy, ALS and related diseases that take away physical strength, independence and life. We use our collective strength to help kids and adults live longer and grow stronger by finding research breakthroughs across diseases; caring for individuals from day one; and empowering families with services and support in hometowns across America. Learn how you can fund cures, find care or champion the cause at mda.org.



For Strength,
Independence & Life

Muscular Dystrophy Association

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