

# A Teacher's Guide to Neuromuscular Disease



**A Guide for  
Teachers and  
Families**

# Introduction



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.

This booklet is designed to:

- Provide information and support to teachers of students with neuromuscular diseases
- Help you better understand the challenges faced by children and adolescents living with neuromuscular conditions
- Suggest strategies to enhance these students' school experiences both academically and socially
- Address school issues that may arise throughout K-12 education

*“One day might be a good day and the next might not be. Educators need to be ready for the ever-changing lives of their students living with neuromuscular diseases.”*

— Jamie, MDA Ambassador

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. We recommend that you continue to have an open dialogue with the parents and child or adolescent with whom you are working so you can better understand that student's specific needs.

You are not alone in this journey. MDA is here to support educators and ensure that students with neuromuscular diseases can achieve success in the classroom and beyond.

## What is a neuromuscular disease?

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

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

Most neuromuscular diseases are progressive, meaning symptoms get worse over time. 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 a family's genes. At other times, there is no family history, and the disorder is the result of a spontaneous genetic mutation, abnormal immune response, or unknown cause.

Life expectancy for those living with neuromuscular diseases varies by disease and severity. Medical interventions have resulted in increased life spans and improved quality of life



for many individuals. Currently, there is no cure for most neuromuscular diseases, but treatments are available for some types to 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, student with a neuromuscular disease

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*Teachers can support students with neuromuscular diseases by creating inclusive learning environments, providing accommodations such as assistive technology or modified assignments, and fostering a supportive and understanding classroom culture.*

# Neuromuscular Diagnoses



The onset of a neuromuscular disease can range from birth through adulthood. The following neuromuscular diseases may affect children at some point during their educational journey. For more information about specific diagnoses and educator resources, please visit [mda.org/education](https://mda.org/education).

**Muscular dystrophies** are a group of diseases that cause weakness and degeneration of the skeletal muscles:

- Becker muscular dystrophy (BMD)
- Congenital muscular dystrophies (CMD)
- Duchenne muscular dystrophy (DMD)
- Emery-Dreifuss muscular dystrophy (EDMD)
- Facioscapulohumeral muscular dystrophy (FSHD)
- Limb-girdle muscular dystrophies (LGMD)
- Myotonic dystrophy (DM)

**Motor neuron disease** occurs when nerve cells called motor neurons progressively lose function, causing the muscles they control to become weak and then nonfunctional:

- Spinal muscular atrophy (SMA)

**Ion channel diseases** are associated with defects in proteins called ion channels. They typically involve muscular weakness, absent muscle tone, or episodic muscle paralysis:

- Andersen-Tawil syndrome
- Hyperkalemic periodic paralysis
- Hypokalemic periodic paralysis
- Myotonia congenita
- Paramyotonia congenita
- Potassium-aggravated myotonia

**Mitochondrial diseases** occur when structures that produce energy for a cell malfunction:

- Friedreich ataxia (FRDA)
- Mitochondrial myopathies

**Myopathies** are diseases of muscle in which the muscle fibers do not function properly, resulting in muscular weakness:

- Congenital myopathies
- Distal myopathies
- Endocrine myopathies
- Inflammatory myopathies
- Metabolic myopathies
- Myofibrillar myopathies (MFM)
- Scapuloperoneal myopathy

**Neuromuscular junction diseases** result from the destruction, malfunction, or absence of one or more key proteins involved in the transmission of signals between muscles and nerves:

- Congenital myasthenic syndromes (CMS)
- Lambert-Eaton myasthenic syndrome (LEMS)
- Myasthenia gravis (MG)

*“We had a teacher during homebound services from a major surgery. [The] teacher spent two hours per day at our home helping her. She learned about the disease and how it affected her daily. Teachers do not know what goes on in our daily life with a neuromuscular disease. I would recommend they research the student’s disease so they fully understand.”*

— Vicki, MDA Ambassador family

# Learning Disabilities

## Potential learning and intellectual exceptionalities

Like other students, children with neuromuscular diseases show a range of intellectual abilities, and many have higher-than-average intelligence. A few neuromuscular diseases bring a risk of learning and intellectual disabilities, such as autism, ADHD, or various processing disorders.

Children with some types of muscular dystrophy may experience learning disabilities, which can range from difficulties with executive functioning

and attention to challenges in reading, writing, or math, necessitating tailored educational strategies and support to address their unique learning needs effectively.

Students with neuromuscular diseases may qualify for special education services based on their orthopedic needs or learning disabilities, and they will benefit from appropriate accommodations.

Neuromuscular diseases are generally not associated with a decrease in cognitive abilities over time.



# Challenges

## Potential challenges for students with neuromuscular diseases:

### 1. Missing school for medical management

Most students with neuromuscular diseases have appointments with their team of doctors, nurses, and other specialists. A student may need to attend one to several appointments per year, some of which may involve travel out of town. Frequent or extended absences may require tutoring or remedial assistance for missed classroom time.

Students may have scheduled surgeries, procedures, or hospitalizations that result in planned school absences. The time for recovery and rehabilitation varies, and when possible, this should be discussed in advance to establish a plan for missed classroom time.

### 2. Environmental accommodations

Muscle weakness and fatigue can make it difficult for students with neuromuscular diseases to keep up with school's physical demands. They may also require equipment, such as a wheelchair, walker, or orthotic device, to assist in their movement.

Allowing students more time to travel between classes or permitting them to begin their

transitions early are common accommodations made for students with physical disabilities.

Making the classroom environment accessible for those with physical disabilities is another important way educators can support their students.

Here are some tips:



**Consider** the environment from the student's perspective — how would you open a door, use a locker, etc.?



**Arrange** furniture to create wide, clear paths for easy navigation.



**Use** desks and tables that can be adjusted to different heights to accommodate various needs.



**Provide** materials in multiple formats (e.g., digital, large print, audio) to accommodate diverse learning needs.



**Ensure** that nearby restrooms are wheelchair accessible, with proper support bars and enough space to maneuver with mobility equipment.

*"I've missed a lot of class time throughout school because of appointments and illnesses. Yet, I am immensely grateful for the understanding and flexibility my teachers consistently demonstrated with assignments and deadlines. Their support in making assignments digital and moving deadlines has been pivotal to my academic achievements."*

— AJ, MDA Ambassador

### 3. Challenges with respiratory muscles

Some neuromuscular diseases affect the lungs, making it difficult for the student to breathe comfortably and effectively or clear secretions from their airway.

Students with known respiratory complications may need interventions during the school day to help maintain their pulmonary health. Examples include using a cough-assist device, suctioning, portable ventilator, or an inhaler. A school nurse or educational assistant should be trained to support the student with their medical equipment.

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 symptoms are noted at school, any concerns should be discussed with the student's parents/guardians with encouragement to seek medical evaluation.

### 4. Challenges with the heart

Some neuromuscular diseases can cause heart complications. These may include thickening (fibrosis) and weakening of the heart muscles, resulting in less effective pumping (cardiomyopathy). Sometimes, the heart rhythm may be altered.

Symptoms of cardiomyopathy include fatigue, lethargy, swelling in the legs and feet, cold extremities, digestive problems, and poor circulation. Some medications used to address cardiac complications associated with neuromuscular diseases may alter heart rate and blood pressure.

A student with heart complications 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.

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*Children with neuromuscular diseases may require specialized medical care, including regular monitoring, physical therapy, orthopedic devices, and/or medications to manage their symptoms and slow disease progression.*



# IEPs and 504 Plans

## The teacher's role in IEPs and 504 plans

IEPs (Individualized Education Programs) and 504 plans are legal documents designed to support students with exceptionalities in the educational setting. They document the student's disability and outline legal protections, individualized support, and any accommodations or modifications the student may need to be successful at school.

The choice between an IEP and a 504 plan depends on the individual needs of the student and the nature of their disability. Students with neuromuscular diseases may qualify for either an IEP or 504 plan:

- **IEPs** offer a comprehensive set of services, including specialized instruction and measurable goals. IEPs provide a higher level of support.
- **504 plans** primarily focus on providing reasonable accommodations and modifications to ensure equal access. They generally do not include specialized instruction.

As the teacher of a student with a disability, you have access to the student's education plan and may be considered a part of their educational planning team. The student's primary caregivers, teachers, and other educational providers, such as physical therapists, occupational therapists, and special education teachers, are considered IEP or 504 plan team members.

It is recommended that you read through the student's plan, as it will give you more background on their disability and how you can best support them.



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*Educational plans for children with neuromuscular diseases should address their specific learning needs by providing accommodations and support services. This ensures that students can access a quality education and reach their full potential.*





## Considerations in creating education plans

When creating educational plans for students with neuromuscular diseases, it's essential to consider several specific factors to ensure their needs are adequately addressed:



**Mobility and accessibility:** Assess the student's mobility limitations and ensure that the school environment is physically accessible.



**Assistive technology:** Identify and provide appropriate assistive technology devices or tools that can aid the student in accessing the curriculum and participating in classroom activities.



**Physical accommodations:** Adjustable desks, seating with adequate support, and modified classroom layouts can accommodate mobility aids like wheelchairs or walkers.



**Medical support:** Work closely with the student's medical team to understand their specific medical needs, including any required medications, therapies, medical interventions, and staff training.



**Social and emotional support:** Offer support services, such as counseling or peer mentoring, and provide opportunities for the student to socialize with peers and participate in extracurricular activities.



# Accommodations and Modifications

## Common educational accommodations and modifications

Accommodations and modifications are common ways to support students with disabilities on their educational journeys. Students with neuromuscular diseases are often provided with these supports so they can be successful in school.

**Accommodations focus on providing support within the existing curriculum, while modifications involve changes to the curriculum itself.**

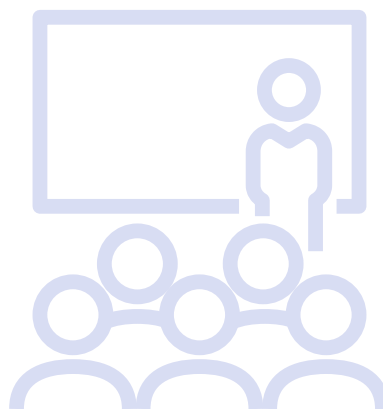
Some common accommodations and modifications are provided below. However, it is important to speak with the student and their caregivers and complete a review of the student's educational plan to best support them.

## Common educational accommodations include:

- Providing electronic books and materials and/or another set of textbooks for the student's home
- Providing additional time to complete assignments and assessments and to travel in the hallways
- Rearranging the classroom and existing school environment (doorways, library, etc.) to be accessible to students with physical disabilities
- Providing a locker located on the end of a row and a different type of lock if needed
- Providing assistance with putting on and/or taking off outdoor clothing
- Organizing 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.

## Common educational modifications include:

- Allowing alternative opportunities for the student to demonstrate understanding and comprehension
- Allowing the use of assistive technology, such as voice recognition software or screen readers
- Arranging for the student to have a notetaker, as well as teacher-provided outlines, notes, or transcripts
- Offering alternative physical education opportunities
- Evaluating weather during recess times for extreme heat and cold and offering indoor activities if necessary
- When a student is unable to participate in outdoor recess, allowing another student to participate in the designated indoor recess activity so the child does not feel excluded



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**+ For additional information, including disease-specific school accommodations, physical therapy recommendations, planning tips, and related resources, visit MDA's K-12 Educational Resources page at [mda.org/services/educational-resources](https://mda.org/services/educational-resources).**

# Well-Being

## Supporting student health and well-being

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

### 1. Environmental considerations

Most neuromuscular diseases do not impact the immune system. However, some children with neuromuscular diseases have compromised respiratory function. This may be due to muscle weakness of the diaphragm or prescription treatment containing corticosteroids. These students may have more difficulty recovering from common illnesses. Students with compromised respiratory function may need to avoid classrooms with high rates of communicable diseases, which can become life-threatening.

Developing classroom habits that limit the spread of germs creates a healthy environment for all students:

- Schedule a specific time to encourage and demonstrate good handwashing techniques.
- Avoid communal use of classroom materials (sharing books, writing instruments, etc.).
- Teach all students to cover their mouths/noses with a tissue or an arm when sneezing or coughing.
- Clean workspaces daily and/or between students.



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*Follow any specific precautions or guidelines recommended by healthcare professionals to support overall well-being and minimize the risk of infections or complications.*

## 2. Nutrition considerations

Some neuromuscular disorders are treated with corticosteroids, which often stimulate appetite. This can lead to weight gain, and exercise and physical activity limitations can compound weight gain. 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, providing a straw), and they may require an attendant's assistance 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.

## 3. Gastrointestinal considerations

A neuromuscular disease may affect the smooth muscles of the GI tract from the mouth to the colon. This can cause either constipation or diarrhea. Sometimes, constipation is related to urinary problems (accidents or the 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.



*“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*

# Extracurricular Activities



## Exercise and activity considerations

Most children should be encouraged to remain active to the greatest degree possible given their diagnosis. Depending on the type of neuromuscular disease a person has, their physical abilities will be impacted in different ways. Because of this, exercise and activity limitations are primarily dependent upon a student's specific diagnosis and pattern of muscle weakness.

Many students with neuromuscular diseases are at risk for joint contractures. Daily stretching and range-of-motion activities (at school or home) are appropriate.

Students with neuromuscular diseases that affect the peripheral nerves may have decreased sensation and strength in the extremities. This places them at risk for sprained ankles, calluses, or skin breakdown on the feet, as well as difficulty with running and some fine motor skills.

*“When my daughter started third grade, her teacher encouraged her to join an after-school running club. I never would have considered signing her up without this teacher’s encouragement, but she joined and she loves it! It means a lot to me that this particular teacher saw past my daughter’s wheelchair and included her in a meaningful way.”*

— Kathleen, MDA Ambassador family

## Exercise and activity modifications

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.

Here are some points to consider:

- Activities may need to be adapted and, in some cases, restricted to prevent falls.
- Activities that cause fatigue or discomfort may need to be adapted or avoided so the student can participate in the classroom experience.
- Stretching and scheduled rest times when the student is tired may reduce discomfort and allow them to focus more in the classroom.
- It is not appropriate to rate progress in relation to peers or national standards for students with physical disabilities, including progressive conditions that weaken muscles and limit mobility.

# Tips for Teachers and Staff

## 1. Build a strong home-school connection.

A strong family-student-teacher team is the best approach to maximizing the school experience for children and teens with neuromuscular diseases. Establish a relationship with the student's parents or caregivers and encourage open communication. The student and their family have the most knowledge about the diagnosis, the student's abilities, and appropriate accommodations.

## 2. Be open-minded.

Students with neuromuscular diseases often can complete nearly every activity and develop many skills. Brainstorm with parents/guardians and your school support team to determine how to engage all students in the learning process. Knowledge of essential skills can be demonstrated in a variety of ways.

## 3. Be inclusive.

Inclusive educational practices ensure that children of all backgrounds and ability levels are given the opportunity to learn in the same classroom environment. An inclusive classroom is supportive of all students, not just those with disabilities, as it creates a supportive and accepting learning environment.



## 4. Encourage the student.

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

## 5. Plan ahead.

Prepare your classroom's environment and practices to ensure they are supportive of an inclusive classroom setting. If an accommodation or modification is needed for an activity or lesson, ensure that this is planned and prepared for ahead of time.

### Children's Books about Neuromuscular Disease

- *DMD and Me* by Chris Harmon and Sue Nuenke
- *I Have Muscular Dystrophy and It's Okay!* by Dr. William M. Bauer & Mallory Bauer
- *Dan and DMD* by Joseph Yasmeh (Author), Liora Yasmeh (Illustrator)
- *I'll Walk with You* by Carol Lynn Pearson
- *The Abilities in Me* series by Gemma Keir
- *The Diagnosis: Epic Battle With Muscular Dystrophy* by Luke Dalien

# About MDA

Muscular Dystrophy Association (MDA) is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For nearly 75 years, MDA has led the way in accelerating research, advancing care, and advocating for the support of our families. MDA's mission is to empower the people we serve to live longer, more independent lives.

If you have additional questions or need more information, contact MDA's Resource Center at **833-ASK-MDA1 (833-275-6321)** or **[ResourceCenter@mdausa.org](mailto:ResourceCenter@mdausa.org)**.

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## Join the Community


 Instagram: @mdaorg

 Facebook: MDAorg

 LinkedIn: Muscular Dystrophy Association

 X: @MDAorg

 Advocacy X: @MDA\_Advocacy

 YouTube: [YouTube.com/MDA](https://www.youtube.com/MDA)

 TikTok: @mdaorg

 Twitch: MDA\_LetsPlay

 Discord: MDA Let's Play

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**+ To learn more about neuromuscular diseases and MDA's programs, visit [mda.org](https://mda.org).**

DISCLAIMER: This resource is meant to inform and educate the community. The information presented is not intended to replace discussions with medical specialists, and it should not be considered medical or legal advice. Please consult with your healthcare provider or legal advisor for information specific to you.