

# Diagnosis: Spinal Muscular Atrophy

**Spinal muscular atrophy (SMA)** is a genetic disorder that involves the loss of muscle-controlling nerve cells, called motor neurons, in the spinal cord. In SMA, the muscles fail to receive the necessary signals from the nerves, which can cause symptoms such as muscle weakness, limited mobility, breathing problems, or difficulty eating and swallowing.

There are several different types of SMA. It can present in all genders and in childhood or adulthood, depending on the type. SMA is a progressive disease that can impact a child's school experience.

Due to the progressive nature of this disease and the fact that physical fatigue in children with SMA usually impacts them in the school environment,

it is important for education professionals who work with students with SMA to be aware of their diagnosis, needs, and abilities. Please be aware that this disease is not contagious and does not pose a health risk to the school. However, absences from school can accumulate due to an increased risk of respiratory illness resulting from respiratory muscle weakness.

Educators should consider the following aids, interventions, and supports for a student with SMA in the school setting. These supports can help the student fully access their school environment so they can excel academically and socially.

For more information on supporting students with neuromuscular disease, please check out MDA's Teacher's Guide on [mda.org/education](https://mda.org/education).



**A Guide for  
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## Physical therapy

Physical therapy enables children with SMA to make maximum use of healthy muscle function, helping them to maintain independence and prevent the onset of muscle contractures. Accommodations a student needs throughout the school day may include:

- Stretching
- Range-of-motion exercises
- Accommodating activities of daily living (ADLs) to changing physical needs (toileting, lunchtime/cafeteria safety, etc.)
- Safety training (on the stairs, in the hallways, and on the playground)
- Use of a mobility device, such as a manual or power wheelchair



## Physical education (adapted)

Modifications for most activities can be found by consulting with the student's physical therapist. The student's PE curriculum should emphasize recreation over competition and focus on increasing their strength and endurance.

In many instances, schools will include a "self-advocacy" goal within the student's Individualized Education Plan (IEP) and will involve the student in the planning of modified PE activities (in collaboration with the PE teacher, occupational therapist, physical therapist, or other school personnel). In some circumstances, physicians may require that a student be excused from PE activities.



## Occupational therapy

For students with SMA, an assistive technology evaluation should be provided. In addition, an occupational therapy consultation for body positioning, seating, and gross and fine motor function is recommended.

They also may require modified written assignments or computer technology that maximizes fine motor skills or utilizes voice command/dictation typing systems.



## School accommodations and modifications

Every child is unique and has different needs. The following are possible accommodations or modifications to consider:

- **Accessibility:** Ensure that all facilities, classrooms, and other areas are wheelchair accessible. This may include ramps, elevators, accessible restrooms, and designated parking spaces.
- **Accessibility training:** Offer training and awareness programs for faculty, staff, and students to promote understanding and inclusion of individuals with disabilities.
- **Accessible materials:** Ensure that all course materials, including textbooks, handouts, and online resources, are available in accessible formats, such as large print, electronic text, or audio formats. An additional set of textbooks may be helpful so the student does not have to transport heavy books back and forth.
- **Emergency evacuation plan:** Develop a personalized emergency evacuation plan to ensure the safety of the student in the event of an emergency or evacuation.
- **Extended test-taking time:** Offer extended time for exams or alternative testing arrangements such as oral exams.
- **Field trips and extracurricular activities:** Make sure to consider accessibility when planning a field trip or extracurricular activity. Have a plan for transportation and make sure the destination is accessible so that the student can participate in all aspects of the activity.
- **Flexible attendance policies:** Allow flexibility in attendance requirements to accommodate medical appointments or illness.
- **IEP or 504 plan:** Working with the student, the student's parents/guardians, educational professionals, and healthcare providers, develop an individualized plan outlining specific accommodations and support services tailored to the student's needs.
- **Note-taking assistance:** Arrange for note-taking assistance through a peer note-sharing program, a designated note-taker, or access to lecture recordings.
- **Peer support:** Encourage the formation of a support network through peer mentoring or disability support groups. Encouraging students to join after-school clubs and sports is another way to build peer support and develop friendships.
- **Physical environment:** The student's physical needs should be taken into consideration when designing their class schedule. For example, classrooms should be close together to minimize fatigue with traveling. If classes are on different floors, the student should have access to an elevator. Seats within the classroom should be arranged to accommodate the student's comfort and accessibility needs. This may include adjustable desks or tables.

# A Message From MDA

Thank you for your commitment to your student(s) living with spinal muscular atrophy (SMA). With your support, your student(s) will have the opportunity to achieve their academic goals while also learning to adapt to their changing physical needs. For more information about SMA, and for additional support, contact MDA's Resource Center at **833-ASK-MDA1 (275-6321)** or **ResourceCenter@mdausa.org**. Visit **mda.org** for additional resources.

Muscular Dystrophy Association is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For over 70 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.

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**+** To learn more about SMA, visit [mda.org/disease/spinal-muscular-atrophy](https://mda.org/disease/spinal-muscular-atrophy).