



Diagnosis: Spinal Muscular Atrophy (SMA)

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. There are several different types of SMA; it can present in both genders and in childhood or adulthood, depending upon the type. Due to the progressive nature of this disease, and the fact that physical fatigue in children with SMA usually impacts them while in the school environment, it is imperative that educational professionals who work with students with SMA be aware of their diagnosis, needs and abilities.

It is important that school health officials understand 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.

To learn more about SMA, visit mda.org/disease/spinal-muscular-atrophy.

In the school setting, the following aids, interventions and supports are recommended for students with SMA so they are able to fully access their school environment and have the opportunity to excel academically and socially.

Physical Therapy

Physical therapy enables children with SMA to make maximum use of healthy muscle function, helping them maintain independence and prevent the onset of muscle contractures. This is a list of accommodations students may need during the school day:

- Stretching
- Range-of-motion exercises
- Safety training (on playground, etc.)
- Hallway safety
- Accommodating activities of daily living (ADLs) to changing physical needs (toileting, lunch/time/cafeteria safety, etc.)
- Adapted/modified physical education (see next section)

Physical Education (Adapted)

Modifications for most activities can be done by consulting with the physical therapist, with the goal of the student's PE curriculum being recreation, rather than competition or increased strength and endurance. In many instances, schools will include a "self-advocacy" goal within the student's IEP (Individualized Education Plan) 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. Many students with SMA use assistive devices such as manual or power wheelchairs. They also may require modified written assignments or computer technology that maximizes fine motor skills or utilizes voice command/dictation typing systems.

School Accommodations

Every child is unique and has different physical needs. The following are accommodations to consider in the classroom/school environment:

- An additional set of textbooks should be provided to the student so they do not need to transport heavy textbooks to and from school (or from one classroom to another).
- If the school has multiple levels, the student should have access to an elevator.
- If the student is able to walk, the student's physical needs should be taken into consideration when designing their class schedule (classrooms should be close together to minimize distance traveled throughout the day to reduce muscle fatigue, etc.).
- Preferential seating in the classroom will allow a student with SMA to safely navigate the classroom and access their class environment.
- An emergency evacuation plan should take the student's physical needs into consideration. School personnel should be assigned to accompany the student during an emergency. If the school has multiple levels, a "safe room" should be established with the local fire department.
- Field trips and school events should take the student's needs into consideration. For example, how far will students have to travel from the bus to the front door? Is the field trip destination wheelchair-accessible? Is there a wheelchair lift on the bus? Have chaperones been informed of this student's needs?

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 the Muscular Dystrophy Association at **800-572-1717** and **ResourceCenter@mdausa.org**. Visit **mda.org** for additional resources.

