

School Accommodation Recommendations

Diagnosis: Spinal Muscular Atrophy (SMA)

SMA is a genetic disorder that involves the loss of muscle-controlling nerve cells, called motor neurons, in the spinal cord. The primary effect of SMA is on the muscles, which fail to receive the needed signals from the nerves. There are several different forms of SMA and thus, SMA can present in both genders and in childhood or adulthood dependent on which type of SMA a person has. Due to the progressive nature of this disease, and the fact that physical fatigue in people with SMA usually impacts them within 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 that this disease is not contagious, and does not make this student more of a health risk in school. Absences from school can accumulate, however, due to an increased risk of respiratory illness resulting from respiratory muscle weakness.

Within the school setting, the following aids, interventions, and supports are recommended for students with SMA to be able to fully access their school environment and excel academically and socially.

Physical Therapy

- Stretching
- Range of Motion exercises
- Safety training (on playground, etc.)
- Hallway safety
- Accommodating activities of daily living (ADL's) to changing physical needs (toileting, lunch time/cafeteria safety, etc)
- Adapted/modified Physical Education (see next section)

Physical Education (Adapted)

The modification of most activities can be done through consultation with the Physical Therapist, with the goal of this student's PE curriculum being recreation, rather than competition or increased strength & endurance. In many instances, schools will include a 'self-advocacy' goal within the student's IEP and then 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 activity.

Occupational Therapy

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

School Accommodations

- An additional set of text books should be provided to the student so that he/she does not need to transport heavy text books 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, this student's physical needs should be taken into consideration when designing his/her class schedule (classrooms should be close together to minimize distance travelled throughout the day, etc) to reduce muscle fatigue.
- Preferential seating in the classroom will allow a student with SMA to safely navigate the classroom and access his/her class environment.
- An Emergency Evacuation Plan should take the student's physical needs in to consideration. School personnel should be assigned to accompany him or her 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 in to consideration the needs of this student. 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? Etc.

Thank you . . .

for your commitment to your student. With your support, this student will successfully achieve his or her academic goals while also learning to adapt to his or her body's changing physical needs.

For more information regarding spinal muscular atrophy, please feel free to contact the Muscular Dystrophy Association at (800) 572-1717 or visit our website at www.mda.org.

Thank you.