Spinal Muscular Atrophy

Strategies that make a difference

Spinal muscular atrophy (SMA) is a neuromuscular disorder in which the nerve cells that control muscles die off. Typically, the weakness is more pronounced toward the core of the body than at the end of the limbs, and the legs are more affected than the arms. Individuals with SMA have normal sensation. Treatment consists mainly of surgery to manage spinal deformity and hip dislocation. There are four basic types of SMA. Only types II and III pertain to school-aged children. Type II is typically diagnosed between three and seven years of age. Students with Type II SMA can sometimes sit independently, but cannot stand or walk independently. Complications include spinal deformity and hip dislocation. Type III is usually diagnosed later in childhood. Students with Type III SMA may be able to walk independently. SMA is progressive and survival rates vary depending on the type and the age at diagnosis.

Implications for Planning and Awareness

- ☐ Meet with the student and parents early in the school year to discuss how the school can support this student's needs related to SMA. This could include finding out about:
  - the student's strengths, interests and areas of need
  - the student's specific symptoms
  - successful strategies used at home or in the community that could be used at school.
- ☐ In collaboration with parents and health care professionals, develop a written management plan that aligns with related jurisdictional policies and protocols. This should include specific information, such as:
  - symptoms that may affect the student at school and may require monitoring
  - the role of school staff
  - equipment and environmental modifications
  - when and what emergency measures should be taken.
- ☐ If the student is taking medications during the school day, discuss with the parents possible side effects. Follow school and/or jurisdictional policies and protocols in storing and administering medication.
- ☐ Work with the parents to carry out a risk assessment before field trips to determine potential hazards, and to plan for the student's safe and successful participation.
- ☐ Collaborate with the parents and student to consider if, and how, they would like to share specific information on SMA with peers. If they wish to do this, consultation with health care providers, such as school or community health nurses, may be helpful.

Your awareness needs to begin with conversations with the student's parents.

- ☐ Learn as much as you can about how SMA may affect learning and social and emotional well-being. Reading, asking questions and talking to qualified professionals will build your understanding and help you make decisions to support the student's success at school.
- ☐ Collaborate with the school and/or jurisdictional team to identify and coordinate any needed consultation and services, such as physical or occupational therapy.
- ☐ Determine and arrange for any equipment or classroom modifications that might be needed. This may include accommodations for mobility equipment (e.g., wheelchairs, standing frames, walkers), supportive seating, supportive toilet seats and/or mechanical lifts.
- ☐ Determine if any changes to school timetables or schedules will have to be made to accommodate the student's equipment and/or travel time from class-to-class.
- ☐ Develop a system for sharing information with relevant staff members about the student's condition and successful strategies.

Implications for Instruction

- ☐ Be aware that students with severe SMA may have numerous absences due to medical appointments or treatments, or fatigue.
- ☐ Develop a communication strategy between the home and school to stay informed about absences, and to keep the student and family connected to classroom learning.
- ☐ Provide the student with copies of notes and assignments. If possible, also provide the student with two copies of books, one for school and one for home.
- ☐ Provide adapted tools and materials, such as slant boards, adapted writing paper and pencils and specialized computer software, if weakness in the arms and hands make writing difficult.
- ☐ Provide alternative ways for the student to demonstrate learning.
- ☐ Provide additional time for transitions between classes, particularly in large schools. A trolley may assist in transporting books, laptop computers or other heavy items from room-to-room, if this is necessary.
- ☐ In collaboration with the student and parents, discuss the appropriate level and types of physical activity for the student. Alternatives to regular physical education may need to be considered.

Implications for Social and Emotional Well-being

- ☐ Engage the student and parents in planning for transitions between grade levels and different schools.
- ☐ Consider having a "key person" or mentor the student can check in with on a weekly or daily basis to assist with any goal setting, planning, self-monitoring and problem solving that may arise.
- ☐ Take steps to ensure the student does not feel left out during recess, intramural or other school activities; for example:
  - provide an alternative role, such as referee during physical education or intramural activities
  - provide alternative activities during recess, such as a friendship bench to sit on and meet with peers.

Parents know their children well and can offer insights on how to support their social and emotional well-being. There is strength in collaborating on strategies that could be used at home, at school and in the community.

As you consider the implications for this medical condition, think about the following questions:

1. Do I need further conversations with the parents to better understand this student's medical needs? ☐ Yes ☐ No
2. Do I need targeted professional learning? ☐ Yes ☐ No
   If yes, what specific topics and strategies would I explore?
3. Is consultation with jurisdictional staff required? ☐ Yes ☐ No
   If yes, what issues and questions would we explore?
4. Is consultation with external service providers required (e.g., Regional Educational Consulting Services, Student Health Partnership, Alberta Children's Hospital, Glenrose Hospital)? ☐ Yes ☐ No
   If yes, what issues and questions would we explore?
5. Is service to the student from an external provider required? ☐ Yes ☐ No
   If yes, what outcomes would be anticipated?

Links for further information:

Muscular Dystrophy Canada. "Educators." http://www.muscle.ca/index.php?id=73&L=0

MDA. Muscular Dystrophy Association. Spinal Muscular Atrophy. https://www.mda.org/disease/spinal-muscular-atrophy

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