



Spinal Muscular Atrophy

Symptoms

Varying degrees of progression in lack of muscle control and movement

Increased proximal muscle weakness

Cognitive, emotional and sensory nerves unaffected

Age of onset varies, but most often seen during infancy/toddler years

At risk for respiratory illnesses, spinal and bone deformities

About the Disorder

Spinal Muscular Atrophy (SMA) is a rare, inherited disease that is characterized by a progressive loss of muscle control, movement, and increased weakness due to the loss of motor neurons in the spinal cord. Proximal muscles (those closest to the spine) are most severely affected. Cognitive ability, emotional development, and sensory nerves are unaffected. SMA has a wide range of severity but all people with SMA will either never acquire or will progressively lose the ability to walk, stand, sit, and eventually move. The age of onset of SMA varies but most individuals show symptoms of the disease during infancy or toddler years. Respiratory illness is more common in individuals with SMA, as are spinal and bone deformities. A quality multidisciplinary approach to care which can include physical therapy, occupational therapy, respiratory therapy, nutritional care etc. can improve quality and length of life for the individual with SMA.

Different Forms of SMA:

Type I; Acute SMA (Werdnig-Hoffman Disease): The general age on onset of Type I is between birth and 6 months. It is characterized by generalized muscle weakness, weak cry, trouble swallowing and suckling, breathing distress, and inability to sit without support. Type 1 generally progresses more quickly than the other types of SMA.

Type II: The generally age of onset is between 6 and 18 months. Muscles closest to the center of the body such as the shoulders, hips, thighs, and upper back are most severely affected. Respiratory muscles may also be affected, and spinal curvature issues need to be monitored and treated appropriately. Type II usually progresses slowly.

Type III (Kugelberg-Welander Syndrome): The general age of onset is after 18 months, and similar to other forms, the muscles closest to the spine are most severely affected. The disease progresses slowly and the ability to walk can be maintained into adulthood and life span is generally not affected.

Most doctors consider the different SMA types to be on a continuum of severity and do not make rigid predictions about muscle weakness and life expectancy.



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Educational Implications

Given that cognitive abilities are generally not affected by this progressive muscle disorder, many of the educational implications center around the provision of accommodations to the environment and adaptations to equipment and materials in the educational setting. In addition to the examples listed below, the team should be aware of some of the following considerations: Students with Type I typically require wheelchairs and will require full access in and around the building and classroom, as well as modified desks and lockers. They may also require special transportation with a lift bus. Given the higher risk for respiratory illnesses, a school nurse should be considered as a possible team member, and an Individualized Health Plan (IHP) may need to be developed in addition to the IEP. Transition planning will need to take into consideration some of the physical/health/motor needs that may impact vocational/post-secondary options and start connecting the student and his/her family with the necessary resources and agency support to ensure success in adult settings.

Instructional Strategies and Classroom Accommodations

1. Meet frequently with parents to discuss student's current medical status, strengths, interests & needs
2. Prepare for frequent absences and have a plan in place to communicate with the student's family
3. Provide extra textbooks, notes, and assignments for home; or create electronic options
4. Provide adapted materials such as a slant-board, pencils, word processor/computer, software, etc.
5. Provide additional time for transitions
6. Determine the appropriate amount and type(s) of physical activity for the student

(Updated 2018)

Resources

Spina Muscular Atrophy
Foundation

<http://www.smafoundation.org/>

Cure SMA

<http://www.fsma.org/>

Muscular dystrophy Association

<http://www.mdausa.org/>

Gwendolyn Strong

Foundation/Never Give Up (SMA
Advocacy site)

<http://www.fightsma.org/>



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