Spinal Muscular Atrophy in Adults

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What is the adult form of Spinal Muscular Atrophy

SMA is a motor neuron disease which typically presents in infancy or childhood, and occasionally in adults, with a known genetic mutation in the majority of cases. Progressive muscle weakness is caused by degeneration of lower motor neurons (nerve cells that control muscles in the face and extremities). Adults with SMA may have had later onset and milder symptoms (Type 4 SMA), or may have had childhood onset with already limited function, severe weakness, contractures and scoliosis. In addition to muscle weakness and functional limitations, fatigue is a prominent symptom in adults with SMA, particularly in those with greater ability. This fact sheet will address adults living with SMA. (See the APTA Academy of Pediatric Physical Therapy for information about SMA in infants and children)

- Hypotonia (decreased muscle tone)
- Proximal muscle weakness, particularly the hip and shoulder
- Impaired function including altered gait pattern, difficulty rising from low surfaces and off of the floor, inability to run, and difficulty with
- Difficulty raising arms overhead and carrying heavy objects
- In more severe forms, people with SMA may be wheelchair users

Other symptoms frequently associated with the disease include:

- Skeletal deformities (scoliosis, hip dislocation, and joint contractures)
- Respiratory insufficiency
- Tongue fasciculations (muscle twitches)

Some of the pharmacological treatments for persons with SMA are available for adults, and research is ongoing. In addition, clinical management is focused on prevention and treatment of complications due to muscle weakness. An interdisciplinary team of providers is needed to address genetic, pulmonary, nutritional, musculoskeletal, and rehabilitation issues.

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How can physical therapy help adults with SMA?

The overall goal of physical therapy is to maximize function, strength and endurance. Interventions may include

- Stretching and range of motion, positioning, and bracing to prevent contractures
- Exercise prescription including strengthening, balance and aerobic (such as walking, recumbent cycling, or water aerobics) exercises
- Mobility aids such as walkers and wheelchairs to maintain independence
- Aquatic or body weight supported therapy to promote movement not possible against gravity
- Energy conservation techniques and fatigue management
- Fall prevention
- Caregiver training for transfers and bed mobility
- Home assessment and modification recommendations
- Equipment and self-care needs
- Assistive technology and accessibility
- Strategies for travelling

Your physician or neurologist can place a referral to physical therapy. Ask for guidance finding a therapist near you who works with clients who have neurological conditions.

References & Resources:

Mercuri E, Finkel RS, Muntoni F, et. al. Diagnosis and management of spinal muscular atrophy: Part 1: Recommendations for diagnosis, rehabilitation, orthopedic and nutritional care. Neuromuscul Disord. 2018 Feb;28(2):103-115. doi: 10.1016/j.nmd.2017.11.005.

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