



Symptoms

Normal Intelligence

Normal speech

Intact sensation

Muscle weakness

Internal rotation deformity of the shoulder

Extension and pronation deformity of the elbow;

Volar & ulnar deformity of the wrist

Finger in fixed flexion and thumb-in-palm deformity

Flexed, abducted, externally rotated hips, often with dislocation

Flexion deformity of the knee

Club foot deformity

Arthrogryposis

About the Disorder

Arthrogryposis is a non-progressive congenital musculoskeletal disorder characterized by the presence of multiple joint contractures (limitation of the range of motion of a joint) at birth. There may be as many as 10 to 20 different arthrogrypotic disorders, all with similar joint manifestations. In some cases, only a few joints may be affected. However, in classic cases of Arthrogryposis Multiplex Congenita (AMC) which occur in one of every 3,000 live births, the hands, wrists, elbows, shoulders, hips, feet, and knees are affected by joint contractures, muscle weakness, and fibrosis. In more severe cases, joints in the back and jaw can be affected as well.

There are many different causes of AMC, but typically it is a result of either problems with joint growth and development, decreased fetal movement (not enough room in the uterus to move), or problems with spinal development in the first 3 months of pregnancy. A diagnosis of AMC can sometimes be made during pregnancy. Ultrasounds at approximately 20 weeks gestation may show abnormal position of joints or lack of movements in joints and limbs indicating the disorder. Otherwise, the diagnosis can be made by an orthopedist based on clinical symptoms and findings. Muscle biopsies, blood tests, and clinical findings help rule out other possible disorders and provide evidence for AMC.

The primary joints involved (in order of decreasing prevalence) include the foot, hip, wrist, knee, elbow, and shoulder. AMC is typically symmetrical and involves all four extremities with some variation seen. Other associated conditions include scoliosis, lung hypoplasia (underdevelopment) leading to respiratory problems, slowed growth, midfacial hemangioma (benign tumor of dilated blood vessels), facial and jaw deformities, respiratory problems, and abdominal hernias.

There is no cure for AMC; however, there are treatments that can assist individuals in being as independent as possible. For many, physical therapy, splinting and bracing has proven to be beneficial to strengthen muscles and improve range of motion. If these traditional treatments do not produce positive results, surgery may be necessary. AMC is not a progressive disorder, so it will not worsen with age. However, medical and therapeutic intervention are critical for children to prevent joints from stiffening as they grow. Cognition and speech are typically normal, functional mobility is realistic, and individuals are typically able to live productive, independent lives.



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Educational Implications

Children with AMC usually possess normal intelligence and speech. The student may need support in dealing with self image and acceptance from his/her peers. Physical therapy, occupational therapy, and adaptive physical education will be needed to address the student's specific needs. Assistive equipment may be necessary as well as an adapted classroom environment. Due to limited mobility, the student may need additional hall passing time. The student may need academic services provided when absent for long periods of time due to scheduled surgeries.

Instructional Strategies and Classroom Accommodations

Staff may need to provide:

- Curriculum modifications (extra time for assignments, modifications to length of assignment, no time limits, alternative ways to test and get information, adapted materials and environment, extended passing time, support from resource room) and possible support from PT/OT/DAPE.
- May need assistance at lunch.
- May not be able to write or inability to write as fast as other students. The student may need to do work orally, use a computer for written assignments, may need alternative note taking methods, or other handwriting accommodations.
- May become tired easily from walking or other motor activities. Should be allowed more time to get from one place to another.
- May need assistance with daily classroom activities such as getting books out of book bag, etc.
- Check to see if the student can walk up steps.
- An Individual Health Care Plan and Emergency Evacuation Plan should be developed and implemented.

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Resources

Avenues

<http://www.avenuesforamc.com>

Wheeless' Textbook of Orthopedics

<http://www.medmedia.com/012/110.htm>

Orthoseek

<http://www.orthoseek.com/articles/0/arthrogryposis.html>

The National Rehabilitation Information Center

<https://www.naric.com/>

National Organization for Rare Diseases

<https://rarediseases.org/rare-diseases/arthrogryposis-multiplex-congenita/>



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