Seattle Children's
HOSPITAL • RESEARCH • FOUNDATION

Patient and Family Education

Arthrogryposis: A Therapy Guide

What is Arthrogryposis?

Arthrogryposis (Arthrogryposis Multiplex Congenita) is a condition where a child is born with multiple joint contractures. A contracture occurs when the muscles, tendons and ligaments in the body become tight and prevent normal movement. In some cases children have only a few joints that are affected. They may have near normal range of motion. In most children with arthrogryposis, their hands, wrists, elbows, shoulders, hips, feet and knees are affected. In severe cases, nearly all body joints may be involved, including the jaw and back. Often children will also have muscle weakness which further limits their movement.

Our Arthrogryposis Clinic includes experts in Rehabilitation Medicine, Physical and Occupational Therapy, Education, Genetics, Orthopedics, Nursing, Nutrition and Social Work. We evaluate your child's abilities and develop recommendations to help your child become as active as possible. Comprehensive planning for children with arthrogryposis includes identifying special needs at school, home and for transportation. The arthrogryposis clinic takes place quarterly. For more information about the clinic dates and times contact the Rehabilitation Medicine scheduling at 206-987-2180.

How is arthrogryposis treated?

Most children with Arthrogryposis are treated with physical and occupational therapy. This improves a child's range of motion in their affected limbs and improves function. We encourage you to become an active participant in your child's therapy program and to do therapy at home on a daily basis.

What are the goals of therapy?

The main goal of therapy is to help your child achieve as much independence and function as they can. Exercises that include stretching and strengthening are a key part of the treatment plan. The therapist that treats your child is your guide and coach, but you play the most important role in your child's therapy. The stretches and activities you do at home will make the biggest impact on your child's mobility and function.

What will physical and occupational therapy be like for my child?

Physical Therapy

Your child's physical therapist (called "PT") will focus on gross motor skills, help your child learn to move and work on walking. They will work mostly with the legs, knees, hips, feet (called "lower extremities") and the trunk. Your child's therapist may talk with you about mobility devices and orthotics for your child and how to use them. Mobility devices help your child get around. They include things like crutches, walkers and wheelchairs.

Occupational Therapy

Your child's occupational therapist (called "OT") will work with your child on their fine motor skills and how they function in daily life. They will work mostly with the shoulders, elbows, wrists and hands (called "upper extremities"). Your child's OT will address eating, dressing, grooming, bathing, personal hygiene and using the bathroom. The OT will also help your child

with school and work skills, such as writing, drawing, using a computer, using scissors, books, driving and the tasks needed for play and leisure activity.

What are orthoses?

Orthoses are devices (splints or braces) that are put on the outside of your child's arms, legs or trunk. They help your child to remain stable, keep their joints aligned, provide a stretch and improve function. The splints or braces are made from lightweight metal and plastic or silicone rubber and are made by orthotists. Physical and occupational therapists also make orthoses and splints.

How are orthoses used?

Splints and braces are worn at different times of the day depending on their purpose and how it will help your child. Those that provide support and enhance function are used during daytime activities, such as walking, eating or writing. Others are made to help maintain range of motion, and their use may interfere with function. These are often used at bedtime or at other times when function isn't as important.

What other kinds of therapy could my child have?

Positioning

Positioning is holding joints in a stretched position through the use of splints, casts and foam wedges. This provides a prolonged stretch for gaining range of motion in the neck, shoulders and hips of infants.

Play

Play is truly a form of therapy for your child. Play will stimulate your child's cognitive development and can help you and your child form a positive relationship. Sometimes the play environment and how you play needs to be modified so that your child can be feel successful in exploring their world.

Exercises and stretches to do with your child

Range of motion

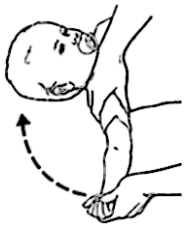
Do the stretches described and pictured below with your baby in a supported position. These stretches will maintain and promote your child's range of motion which will lead to better function.

Do all of the stretches that are marked with a ✓ 3 to 5 times per day. Hold each stretch for a few seconds. You can incorporate stretches into daily activities. Think of stretching the arms when your baby is feeding and the legs when changing the diaper. Gently move the limb to the point of resistance but without pain.

Upper extremities

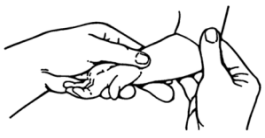
- ❑ Shoulder flexion: Slowly lift the arm forward and over the head. Hold for a few seconds, and then bring the arm back down.

- ❑ Shoulder external rotation: First, bring the arm straight out to the side with the elbow bent. Slowly turn the arm so that the palm is facing up.



- ❑ Shoulder abduction: Slowly bring arm out to the side of your baby's body. While keeping your baby's arm flat on the surface, gently bring it up towards your baby's ear.

- ❑ Elbow flexion: Begin to bend your baby's elbow, bring the hand up to the mouth keeping the palm facing up.



- ❑ Forearm Supination: Support your baby's elbow at 90 degrees with one hand, and hold your baby's forearm just above the wrist with your other hand. Gently turn their forearm so that their palm is facing upward. Hold this position briefly. Be careful not to twist your baby's wrist.

- ❑ Wrist extension: Gently bring your baby's wrist up and back.

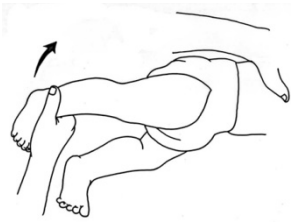
- ❑ Finger extension: Gently open your baby's fingers and thumb so the hand is open and flat.

- ❑ Finger flexion: Gently bend each finger into the palm, one at a time.

Lower Extremities

- ❑ Hip Flexion: with your baby on their back slowly bend the knee up to the chest.

- ❑ Hip Extension: with baby lying on their side, bend the knee slightly and slowly stretch leg back. Place one hand on the front of your baby's knee and the other on the baby's bottom.



- ❑ Hip Adduction: with your baby lying on their back and the hips and knees straight, bring the leg **towards** the mid-line of the body.

- ❑ Hip Abduction: with baby lying on their back and the hips and knees straight, bring the leg **away** from the mid-line of the body.

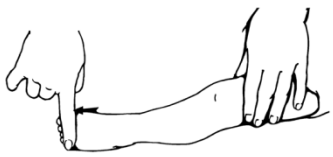
- ❑ Hip Internal rotation: with your baby lying on their back and one leg bent, slowly rotate leg so the foot moves away from the body.

- ❑ Hip External Rotation: with your baby lying on their back and one leg bent, slowly rotate leg so the foot moves towards the center of the body.

- ❑ Knee Flexion: Lay your baby on their tummy; slowly bring the foot towards the bottom.

- ❑ Knee Extension: Lay your baby on their back; slowly lift the leg straight up.

- ❑ Ankle Dorsiflexion: with your baby lying on their back and the knee straight, slowly bring the foot up towards the face.



- ❑ Ankle Plantarflexion: have your baby lying on their back and the knee straight; slowly move the foot down towards the table.

- ❑ Ankle Eversion: have your baby lying on their back and knee straight; slowly stretch the foot so that it moves away from the midline of the body.

- ❑ Ankle Inversion: with your baby lying on their back and knee straight, slowly stretch the foot so that it moves towards the midline of the body.

What support groups and resources are there for families?

There are a number of websites and parent support groups for families who have a child with arthrogryposis. The groups can be helpful to parents in learning what to expect in the future and connecting with other families with the same challenges.

Every quarter during our Arthrogryposis clinic, Children's Rehabilitation (called "Rehab") staff host a midday luncheon for families who have children with arthrogryposis. This is a time to meet other families, share a meal together and learn from staff and one another. For more information, contact Rehabilitation Medicine scheduling at 206-987-2180.

Websites and support resources:

- Arthrogryposis Multiplex Congenital Support, Inc.
  www.amcsupport.org

- The Australian Arthrogryposis Support Group (TAAG)
  www.taag.org.au

- Arthrogryposis Association of Ireland
  www.arthrogryposis.ie

- The Arthrogryposis Group (TAG)
  www.arthrogryposis.co.uk

- Avenues: A national support group for arthrogryposis multiplex
  www.avenuesforamc.com

- Community of Interest for Arthrogryposis
  www.iga-ev.de/iga/info_en

To Learn More

- Physical and Occupational Therapy 206-987-2113
- Your child's healthcare provider
- www.seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your child's nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.

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