Arthrogryposis: A Therapy Guide
What is Arthrogryposis (ar-thro-gry-POE-sis)?

Arthrogryposis (arthrogryposis multiplex congenita) is a condition where a child is born with multiple joint contractures. A contracture is when the muscles, tendons and ligaments in the body become tight and prevent normal movement. In some cases, children have only a few joints affected. They may have 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 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 them become as active as possible. We identify special needs at school, home and for transportation.

How is arthrogryposis treated?

Most children with arthrogryposis are treated with occupational and physical therapy (OT and PT). 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 OT and PT be like for my child?

Occupational Therapy (OT)

Your child’s occupational therapist will work 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”). The therapist will address eating, dressing, grooming, bathing, personal hygiene and using the bathroom. They 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.

Physical Therapy (PT)

Your child’s physical therapist 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.

What are orthoses (or-THOH-sees)?

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 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 the 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 the splint or brace 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 stimulates 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 your child can 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 child in a supported position. These stretches will help your child’s range of motion and 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 add stretches into daily activities. Think of stretching the arms when your child is feeding and the legs when changing their diaper. Gently move the limb to the point of resistance but without pain.
Upper extremities

- **Shoulder flexion**: Start with your child on their back. With your child’s thumb leading the way, slowly lift the arm forward and up over the head, **hold**, then bring the arm back down.

- **Shoulder external rotation**: Start with your child laying on their back. First, bring your child’s arm out to the side. Bend the elbow to make an L. Rotate their arm so the hand goes up towards the head with the palm facing forward.

- **Shoulder abduction**: Start with your child laying on their back and their arm by the side of their body. With the palm facing forward and the thumb leading the way, move the arm towards your child’s ear.

- **Elbow flexion**: Start with your child’s arm by the side of their body. Bend your child’s elbow. Hold the arm above the elbow with one hand. With your other hand, bring your child’s hand to their mouth keeping the palm facing up.

- **Forearm Supination**: Support your child’s elbow to make an L with one hand. Hold your child’s forearm just above the wrist with your other hand. Gently turn their forearm so that their palm is facing upward. Be careful not to twist your child’s wrist.

- **Wrist extension**: With one hand, support your child’s forearm, and with the other hold their hand like in the drawing. With their palm facing down, move your child’s hand up.
- **Finger extension**: With one hand, hold down the thumb and with the other hand, hold down the fingers like in the picture. Gently open your child's fingers and thumb so the hand is open and flat.

- **Finger flexion**: With one hand, hold the wrist and with the other hand, bend the fingers towards their palm.

### Lower Extremities

- **Hip Flexion**: Start with your child on their back. Slowly bend their knee up to the chest.

- **Hip Extension**: Start with your child on their side. Place one hand on the front of your child’s knee and the other on the child’s bottom. Bend the knee slightly and slowly stretch leg back.

- **Hip Adduction**: Start with your child lying on their back and the hips and knees straight. Move the leg towards the mid-line of the body.

- **Hip Abduction**: Start with your child lying on their back and the hips and knees straight. Start with the leg at the mid-line of the body. Then bring the leg away from the mid-line of the body.
- **Hip Internal Rotation**: Start with your child lying on their back and bend one leg 90 degrees at the knee and hip. Slowly rotate the leg at the hip so the foot moves away from the midline of the body.

- **Hip External Rotation**: Start with your child lying on their back and bend one leg 90 degrees at the knee and hip. Slowly rotate the leg at the hip so the foot moves towards the belly button.

- **Knee Flexion**: Start with your child on their tummy. With one hand on your child's bottom and the other hand below the ankle, slowly move the foot towards the bottom.

- **Knee Extension**: Start with your child on their back. Stabilize one leg by holding it down. With your other hand hold the opposite leg below the knee. Slowly lift that leg straight up.

- **Ankle Dorsiflexion**: Start with your child on their back and one knee straight. With your hand, hold the knee still. With your other hand, hold the foot in the palm of your hand. Slowly move their foot up towards your child's face.

- **Ankle Plantarflexion**: Start with your child on their back and the knee straight. Slowly move the foot down towards the table.
Ankle Eversion: Start with your child lying on their back and knee straight. With one hand, hold the knee still. With the other hand, rotate the foot so that it moves away from the midline of the body.

Ankle Inversion: Start with your child lying on their back and knee straight. With one hand, hold the knee still. With the other hand, slowly rotate 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 206-987-2114, option 2 or rehabclinicnurses@seattlechildrens.org.

Websites and support resources:

• Arthrogryposis Multiplex Congenital Support, Inc. amcsupport.org

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

• Arthrogryposis Association of Ireland arthrogryposis.ie

• The Arthrogryposis Group (TAG) arthrogryposis.co.uk

• Arthrogryposis – KidsHealth kidshealth.org/en/parents/arthrogryposis.html?ref=search
To Learn More
• Physical and Occupational Therapy
• 206-987-2113
• Ask your child’s healthcare provider
• seattlechildrens.org

Free Interpreter Services
• In the hospital, ask your 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.

Seattle Children’s offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children’s will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201. This handout has been reviewed by clinical staff at Seattle Children’s. However, your child’s needs are unique. Before you act or rely upon this information, please talk with your child’s healthcare provider.

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