

## ***Your Child's Journey***

### ***Birth to One year***

The goals for your child at this time are:

- Increase range of motion of the affected joints
- Maintain range of motion that was gained through splinting, casting, or positioning
- Positioning your child safely
- Teach you how to safely hold and handle your child

The amount of therapy and type of splints your child has depends upon your child's needs. You are a big part of your child's therapy. It is important that you feel comfortable handling, holding, and playing with your child. You will be doing the exercises at home with your child. It will help your child gain the best possible range of motion.

#### ***Range of Motion***

- Passive range of motion (PROM), or gentle stretching is important to do every day with your child. You can start right away. Your child may cry during stretching because it is uncomfortable. It does not mean they are necessarily in pain. It should not be painful. Stretch your child's joints 2-3 times a day. You can do it during bath time, diaper changes, or play time so your child is relaxed. Your physical and occupational therapist will teach you.
- Range of motion can also be improved through splinting, casting, and positioning. It holds that joint in the desired range for a longer period of time.
  - **Upper Extremity Splints:** They can be removed for bath and play time. Usually splints are worn during nights and naps so your child can start moving and playing during the day. They are usually made for your child's hands and arms. Full hand splints are made first. Some splints may be worn for about 18-20 hours depending on the goal. As your child grows, your occupational therapist will make new splints. Once your child is about 4-5 months old and can move their hand or arm more, a functional hand splint may be made. This splint allows your child to pick up toys and use their fingers and thumb. The functional hand splint is worn during the day and the full hand splint is worn at night.
  - **Lower Extremity Casts/Splints:** Babies with AMC are often born with clubfeet. They typically will be treated with the Ponsetti method which initially involves a series of long leg casts and a possible soft tissue surgery. It is followed by wearing orthotic shoes on a fixed bar (boots and bar). We also offer the French Functional Method, which is led by a physical therapist and involves stretches, taping, and the making of splints for the feet. The risk of your babies' clubfeet

recurring is very high and regardless of the initial method of treatment, it is very important that the parents, physician, orthotist, and physical therapist work together to insure the best fit of the braces/splints that are worn during the first few years of life.

### ***Strength***

- A therapist can tell how much strength your child has by watching your child move. If your child can roll over, they have good core strength. Your child's position of their hands and feet also can tell how much strength your child has. If your child's wrist stays in a bent (flexed) position, that means the muscles on the back of their hand (extensors) are weak.
- Your therapists and doctors will also look at your child in different positions: on their stomach, back, and side. This lets them see how your child can move their arms, legs, and trunk against gravity. It also lets them see which muscles are weak and which muscles are strong. Having one set of weak muscles and a set of strong muscles creates abnormal posture.
- You can help your child get stronger by playing with them in different positions. Playing on their side is the easiest way to play because it is not against gravity. Have them reach for toys, roll a ball, and pick up rattles.
- You can make reaching harder by having your child reach for toys on their back, on their stomach, and while sitting. A Baby Gym is great for having your child reach for toys while on their back. It also encourages them to kick their legs. You can increase their strength even more by having them play with heavier toys.
- It is important for your child to change positions throughout the day. This increases range of motion, hand and head development, and increases strength of all muscles.
- Give your child breaks and allow them to play in comfortable positions. You want them to enjoy playing. If you are giving your child a heavier toy, first give it to them when they are on their side. When they are able to pick it up while on their side, then give it to them on their back. Always give your child a chance to succeed at what they are doing first.

### ***Activities of Daily Living***

These are skills that your child does every day such as: bathing, toileting, dressing, eating, and moving from one place to another. When your child is young, you do this all for them. Limited movement in joints and abnormal positions can make this difficult for you.

- ***Oral Motor/Feeding:***
  - Some children with AMC will have a hard time eating and swallowing. You can make it easier for your child to swallow by holding their head and neck in line with their trunk and bending their head to their chest slightly. Supporting their chin and cheek can also improve their jaw control and cheek strength for sucking and swallowing.

Your therapist may refer you to a nutritionist if you need to change the thickness or temperature of your child's formula. If you have any questions or concerns, always ask your speech and/or occupational therapist.

- **Bathing:**

- It is important for all children to be placed in a safe, upright position during bath time. Children with AMC may have difficulties with this because of abnormal posture or limited movement. Bath supports can be purchased commercially or made by your therapist. Bath supports can help better support your child's trunk, neck, and head during bath time to make it safe and fun. This is a good time for stretching your child's arms and legs.

- **Transportation:**

- It is important for all children to ride in a car seat. Nothing should ever be added to a car seat unless it was crash tested in that car seat. This could compromise the fit of the car seat. However, very thin pieces of foam can be added for better neck and head support as long as it does not interfere with the harness or fit of the car seat. Always contact the car seat company to ensure the safety with any additional add ins to the car seat. Adaptive car seats may be purchased as well. Contact [SafeKids.org](http://SafeKids.org) for further information on car seat safety.
- Thicker foam inserts can be added to strollers to make the stroller rides more comfortable.

### ***Gross Motor Skills***

- Any movement your child does is a motor skill. For example: rolling, crawling, reaching, and kicking. The most important skill that will be looked at is your child's head control. It is important for your child to hold their head up. Next will be trunk control. This is important for sitting upright and balance. You can give your child a lot of trunk support in sitting by placing your hands high on the trunk. As your child's trunk gets stronger you can move your hands down lower. This allows your child to use their trunk muscles to hold certain positions.
- Your child should start rolling when they are about 5 months old. You can encourage your child to roll by having them reach for toys while laying on their back or stomach.
- If your child starts to show other patterns of movement in attempt to move, it should not be discouraged. You need to encourage this movement because they are able to explore this way. Always put them in different positions to encourage them to work other muscles as well. For example: if your child is scooting on their back to move from one place to another this is working on their back muscles; put them on their stomach so they can also work on their head and trunk control.



## ***Toddler to Preschool Years***

This is a very important time in your child's life. They begin to move around and interact with other children. During this time your therapist's will focus on mobility, play skills, and activities of daily living skills. The frequency of therapy is usually decreased as your child gets older.

### ***Range of Motion***

As your child gets older, their range of motion must be preserved. Your child may continue to need gentle range of motion exercises to be performed every day. This can easily be incorporated into your daily routine (during bath time, right before bed, or in the morning). Night splints may also be continued through these years to assist with maintaining the range of motion. Full hand, wrist, elbow, long leg, knee extension, and ankle dorsiflexion splints are often worn at night.

### ***Strength Interventions***

Play activities will be incorporated during strengthening exercises. This will encourage your child to participate, as well as make it more fun and enjoyable. Different positions and activities that will be encouraged are:

- Tall kneeling: This is a great position for hip and pelvic strengthening. This position strengthens the muscles that are used during standing and walking. If your child has limited knee range of motion, a foam wedge will help in making this position possible.
- Grasping: Grasping helps to strengthen your child's hand muscles. Some hand strengthening activities are: water play with squeeze toys and sponges, cutting with adaptive scissors, and resistive blocks and pegs.

### ***Gross Motor Activities***

Your child's ability to roll, crawl, scoot, and walk will all be addressed by your therapists. It is important for your child to learn how to roll from their back to their stomach and transition from sitting to standing before crawling and walking are addressed. Your therapist will work on adaptive methods to help your child attain their own successful method of mobility. Practicing with your child at home is very important for success. Furniture, pillows, and adaptive equipment help your child be independent in mobility. Ride on toys can be helpful tools to allow your child to have independent mobility at home.

### ***Activities of Daily Living***

These activities include everything that your child does on a daily basis such as: feeding, dressing, bathing, toileting, and playing. It is important for your child to learn how to do these activities around the same time other children learn these skills; however, a child will not learn if they do not want to do the skill on their own. It is just as important for your child to want to dress themselves in order for them to have the motivation to participate. Dressing themselves

requires a lot of effort and therefore they need to want to be able to do this skill in order to want to practice it. Your occupational therapist will provide your child with adaptive tools to use in order to make these skills easier for your child to perform if needed. Not all children with AMC will need adaptive tools. Some children will need more assist than others.

- **Self-Feeding:**

- Finger feeding is the first developmental feeding skill that your therapist will focus on with your child. The first step is for your child to practice grasping small finger foods. He/she may use his thumb and first finger to pinch the food, or will pinch the food in between two fingers, or will need adaptive equipment. The next step is bringing the food to his/her mouth. Many children use the edge of table to help bring their hands closer to their mouth. Your child may need an elbow block to help position his/her hand closer to the mouth.
- Utensils are difficult to grasp for children with AMC. There are a variety of adaptive equipment tools for feeding that may help your child perform this skill successfully. Your child may need a lot of encouragement with this skill because there is a lot of trial and error until the correct adaptive tool, method, and/or equipment is found for your child. Your child may need a foam built up handle on the utensil to make it easier to grasp, or custom made splint that will hold the utensil for your child. Your occupational therapist will also work with your child on the correct position for them to be in to make this easier for your child. A feeder seat may help your child stay in an upright sitting position when eating. This allows them to focus on eating rather than sitting upright. Sitting alone and eating are hard skills and may have to be done separate at first if your child has difficulty.

- **Dressing:**

- Each child will dress and undress themselves differently. It is important for them to be motivated to dress themselves because it may require a lot of effort. Modified clothing with Velcro instead of buttons, loose fitting clothes, zipper pulls, a dressing tree, and sock aides can help make dressing easier for your child if it is difficult. Dycem is a resistive material that can also help with dressing and eating. It prevents plates from moving on the table. It also can be taped to the wall and help with pulling up and down pants.

- **Toileting:**

- You do not need to postpone toileting for your child. If they announce that they need to use the restroom, it is time to start training. Independence in toileting depends on their ability to walk, stand, sit down, and put on/take off their pants. You will need to assist your child a lot along the way, however encourage



## ***Early School Years***

When your child reaches school age, it is important for them to be included in decisions. Important decisions such as: surgical plans, changes in therapy, and types of adaptive equipment that they will be using. Their therapist will also set some therapy goals based on what your child wants to accomplish.

### ***Range of motion***

Daily range of motion exercises begins to decrease at this age and the need for surgery may be discussed with your doctor. Gentle stretching along with splinting is needed to help maintain a new position after surgery. Passive range of motion measurements will be taken in order to determine whether your child needs to continue or discontinue splints. These measurements will be monitored to ensure that a decrease in splinting time does not cause a loss of range of motion.

### ***Strengthening***

Muscle strengthening will be continued based on your child's goals with his/her therapist. Functional activities such as: scooting, standing, and swimming will be encouraged for your child to participate in daily. A specific muscle strength evaluation should be performed. This will let your therapist know if your child is using his/her stronger muscles to substitute for the weaker muscles. Many children do this to allow them to be more functional. If your child has a specific weak muscle, then your therapist will encourage activities that will specifically strengthen that muscle.

### ***Activities of Daily Living***

- **Self-Feeding**

Your child may have mastered the ability to self-feed with or without an adaptive device. Eating soup without spilling, cutting meat, opening containers, and opening chip bags are difficult two-handed tasks to master. Your child may need help to manage his or her lunch at school. Another child or teacher can assist them. Bringing lunch from home that is easy for them to open and eat by themselves is another good option.

- **Bathing**

As your child grows, toileting and bathing without help becomes more important. Some adaptive equipment that will make it easier for your child to bathe are: tub-transfer bench, shower bench, hand-held shower, grab bars in tub or shower, wall mounted soap dispenser, and long-handled brush for washing his/her hair.

- **Toileting**

Toileting without assist is very important at this age. You as a parent, your child's therapist, and the school will be involved in determining the easiest way for your child to use the bathroom at school. Some of the following questions should be asked: can he/she open the door to the bathroom, are there grab bars in the stalls, is the toilet paper accessible and can your child wipe him/herself, and is there a teacher available if your child needs help? Adaptations to your child's pants may be necessary (Velcro, snap, elastic waist bands, ect.) to help your child master this skill.

- **Personal Hygiene**

Your child will begin to show interest in brushing his/her own teeth. Lever style faucet handles, built up handles on toothbrushes, electric toothbrushes, and automatic toothpaste dispenser will help make this task easier.

### ***Gross Motor Skills***

As your child begins school, it is important to know his/her ability to walk or propel a wheelchair. Surgery is sometimes performed at this age to help your child to walk without an assistive device or sit in a wheelchair better. After this surgery, intensive physical therapy will be needed for gait training. The focus will be on strengthening and stretching exercises along with orthotic fitting and training and gait training with assistive devices. Children who can walk may not be able to walk long distances. They may need a rolling walker or manual wheelchair to use at school or on family outings. Some children need a power wheelchair for mobility. They may use a joy stick or head controls to control their power wheelchair. If your child needs a wheelchair, a wheelchair evaluation will be done with your therapist and an Assistive Technology Professional (ATP) to decide what kind of wheelchair is right for your child.

### ***Upper Extremity Functions***

When your child begins school, an important skill for them to have is writing and typing on the computer. Writing and typing is a hard skill to master for any child because it requires effort, time, and legibility. Adaptive writing aides can make it easier for your child to hold onto the pencil. Some children will need a mouth wand that they can hold in their mouth to write or type with. Different settings on the computer may be needed to make it easier for your child to type. Talk to your child's teacher to see if any accommodations can be made for your child. Some options are: notes given to them by the teacher, writing their name and a short response to questions, a smaller amount of things to write.

### ***Recreation***

It is important for children to be involved in activities outside of school. They will make new friends and develop good social skills. Swimming, biking, horseback riding, and adaptive sports can be good ways for your child to increase their strength, endurance, and social skills.



## ***Teenage Years***

Just like any teenager, your child will begin to notice the difference between their body and their friends' bodies. It is extremely important for children at this age to be involved in their treatment plans. Your child will not see Occupational and Physical therapy on a regular basis at this age unless they had surgery, want to learn how to do something, or for school related goals.

### ***Home Exercise Programs***

It is important to continue with stretching and strengthening exercises. Your child can learn a self-stretching and strengthening exercise program. Splints are usually not worn at this age, but they are needed after surgery or if your child's range of motion has decreased. Your child will be taught how to put on and take off their own splint. At this age, it is very important for your child to eat a well-balanced diet. It is hard to walk without an assistive device if your child has extra weight on his/her body. A nutritionist can assist you with any questions and/or concerns.

### ***Activities of Daily Living***

Your child may continue to need assist with fasteners as they get older. Adaptations to clothing's such as: snaps instead of buttons, Velcro instead of snaps, and Velcro shoes will help your child be independent in dressing. Shoes and socks are also difficult for older children. A long-handled shoe horn and a sock aide can help make this easier for your child. Shaving and make-up also become important as your child grows. Built up handles on lipstick and on electric razors are some adaptive ways your child can do these things. Small bursts of occupational therapy may be needed to work towards some of these goals if they are not already met.

### ***Kitchen Skills***

It is important for your child to move around in the kitchen safely to get food for themselves. It may be hard for your child to reach plates and cups in high or low cupboards. Moving important kitchen items to places where your child can easily reach is important. Your child may also need a rolling cart to place all the items in until he or she has everything they need to make their meal. Children with arthrogryposis have weak hands and it makes it difficult to hold a lot of items at once. Other adaptive tools such as: an electric can opener, adaptive knives, and built up utensils will make cooking possible for your child.

### ***Recreation and Independent Living***

Participation in swimming, biking, and walking activities is still encouraged at this age. You should also encourage your child to learn other sports or activities. There are a lot of adaptive sport opportunities. Your therapist is a good resource Your child may also have an interest in driving at this age. A driving evaluation should be done to determine if accommodations and modifications are indicated. The website is [AOTA.org](http://AOTA.org). In the *search box* type, "find a driving specialist" to find one near your home.

