

Arthrogryposis

Ages 0-3

What kind of professionals will my child need?	<p>General physician – addresses the overall health of your child</p> <p>Clinical geneticist – addresses the genetic aspects of arthrogryposis</p> <p>Audiologist and Ophthalmologist – addresses any visual and hearing impairments</p> <p>Orthopedic surgeon – addresses musculoskeletal issues your child may encounter</p> <p>Physical Therapist – addresses musculoskeletal and mobility impairments</p> <p>Occupational Therapist – helps your child interact with the environment and learn independence</p> <p>Speech Therapist - helps your child learn how to use and strengthen throat and face muscles to help your child breathe, eat, and communicate more effectively</p> <p>Psychologist - addresses the emotional and social health of your family</p>
What other conditions may affect my child?	<p>Musculoskeletal problems such as joint contractures and scoliosis are the most common musculoskeletal problems found with arthrogryposis. Severity varies from child to child, but can often be addressed with physical therapy and surgery.</p> <p>Hearing and Vision impairments vary from child to child; addressing possible hearing or visual impairments helps with other areas of development as well</p> <p>Developmental delays, especially in motor development and motor control occur.</p> <p>Respiratory issues such as respiratory infections are common and should be treated early; respiratory weakness should also be noted when receiving anesthesia.</p> <p>Digestive difficulties due to swallowing problems are common and getting the proper nutrition is difficult; surgery may be needed to help with feeding. Constipation is also common and can be treated with diet modifications and medication.</p> <p>Congenital heart disease such as ventricular and atrial septal defects can be repaired surgically early in the baby's life.</p> <p>**It is important to know that these conditions are more common in individuals with arthrogryposis, but a diagnosis of arthrogryposis does not mean that your child will develop them.**</p>
What kind of surgeries will my child need?	<p>Surgery is not always necessary, but can be helpful depending on what kind of impairments your child may have. This is a list of a few options, but consult your doctor for more information</p> <ul style="list-style-type: none">• Tetonomies (lengthening of muscle tendons) and capsulotomies (lengthening of the joint capsule) are performed to relieve joint contracture (stiffening of the joint) in order to improve mobility. These are done in severe contractures and can be performed early in development.

	<ul style="list-style-type: none"> • Hip surgery can be performed if a hip abnormality and contracture significantly impairs mobility; this also prevents scoliosis. Sometimes this is followed by knee or foot surgery later in life. • Cardiac surgery may be necessary to repair any septum defects in the heart
<p>What therapies are available?</p>	<p>Drug therapy is not used to treat Cri du Chat directly, but may be used for associated medical issues like gastric issues and behavioral problems.</p> <p>Speech therapy helps your child learn to use throat and face muscles properly to communicate, eat, and breathe properly.</p> <p>Physical therapy helps keep muscles strong and flexible, and joints mobile, which is important for children with arthrogryposis. PT helps specifically with joint contractures and limb abnormalities to help your child with walking and using gross motor skill to kick a ball or ride a bike. Early intervention is important to ensure proper development of your child.</p> <p>Occupational therapy helps to teach your child how to care for him/herself and establish independence. This can range from toileting to dressing to writing.</p> <p>Special braces and splinting is used in conjunction with PT to help compensate for muscle imbalance and improve mobility of an affected limb or stiff joint. These are especially helpful in preventing scoliosis and upper limb mobility. Early intervention is often recommended with splinting.</p> <p>Water therapy or aqua therapy reduces the pressure on the child’s bones and joints, enabling them to move more freely than they can on land. It helps increase muscle strength, improve coordination, increase endurance, and relieve stress.</p>
<p>What kind of assistive devices are available?</p>	<p>Adaptive devices are commonly used for children with arthrogryposis, especially to help with proper body positioning and mobility. Please use the informational list of adaptive devices, consult your physician, or check out the websites listed below.</p> <p>Wheelchair – used to make getting around easier and can also help in correcting posture and body position</p> <p>Car seats, stroller, and push chairs – help with proper positioning and posture while doing everyday activities</p> <p>Orthotics (particularly for the foot) – to correct some bone deformations and make walking easier, prevent hip migration, and prevent joint contractures</p> <p>Tricycles – not only for recreational use, but also used for physical therapy purposes</p> <p>Walkers and gait trainers – help support your child while walking (and learning to walk)</p>

	<p>Toileting chairs, Sleeping aids, Table and chairs, Bathing aids –used to make everyday activities more manageable</p> <p>Special handles and grips - for eating utensils, pens, pencils, making it easier for your child to hold things.</p> <p>Communication aids – such as a book or poster to spell out messages, and specialized computers that can talk for your child if he/she is difficult to understand.</p> <p>Computer technology – can help with multiple daily activities, like scanning documents, typing, pointing, etc. This can be very helpful if your child is non-verbal.</p> <p>Helpful websites: http://pattersonmedical.com/ http://www.ottobockus.com/ http://www.especialneeds.com/home.php</p>
What sort of expectation should I have for my child's intellectual development?	Children with arthrogryposis usually have more physical developmental delays than intellectual. However, there are many links between motor and cognitive development. There is no way to predict your child's intellectual capability; consult with your doctor on ways to encourage and monitor development.
What sort of expectation should I have for my child's physical development?	Physical development depends on the severity of arthrogryposis. Any major malformations are normally surgically correctable. It is important to monitor your child's physical health as he/she grows in order to ensure the best outcomes. Again, it is impossible to tell what any child will be capable of; consult with your doctor for more information on how to best care for your child.

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Ages 4-12

From the ages of 4-12 you will need to continue using the same information as above about what doctors to consult, therapies, and adaptive devices available, so please refer back to the chart for ages 0-3. This chart includes additional things you may need to do after your child turns 4.

What kind of doctors will my child need?	Continue with regular appointments with your Primary Care Physician, Orthopedic Surgeon/neuromusculoskeletal medicine, Pediatric Neurologist/Neurosurgeon, Nutritionist, and Psychologist.
What kind of surgeries will my child need? When?	Again, surgery is not always necessary, but may be helpful to correct musculoskeletal problems. It is important that you continuously check in with your orthopedic surgeon as your child grows to monitor any changes that may occur or need to be corrected. The surgeries described above are still important to consider at all ages. As your child grows, various skeletal problems may occur and sometimes surgery is available to help correct them and improve mobility. Osteotomies (bone corrective surgery) can be performed after your child develops to correct problems that may arise.
What kind of therapies are available?	This is not an exhaustive list, but continue with therapies listed above and consider these types of therapies as your child gets older: <ul style="list-style-type: none"> • Massage therapy – may help to relax tense muscles, improving mobility. • Counseling – to help modify behavioral and emotional difficulties in

	<p>children and in your family life too.</p> <ul style="list-style-type: none"> • Hippotherapy – a new type of therapy which involves interacting with horses to aid in achieving normal balance, improving posture, movement, muscle strength, and overall coordination.
What will my child do for school?	<p>Going to school is important for emotional and social development of your child. Your child has a right to attend public school and receive the same free education as every other child. Before sending them to school, you should know if your child has a learning disability or physical disability that may impair their learning. If he/she does, then they qualify for special education assistance. Depending on the school district, your child may be “mainstreamed” and placed in general education classes with everyone their age, but with a modified work to accommodate their learning disability. This is known as “inclusion” in the public schools. Your child may also be placed in a special education classroom with other students who qualify for special education accommodations.</p> <p>Additional information about Individualized Education Programs (IEP): US Department of Education</p>
What else can I do?	<ul style="list-style-type: none"> - Keep regular appointments with doctors and therapists - Make sure your child stays active - Monitor any changes in your child’s health, especially musculoskeletal changes - Enjoy your child!

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Ages 13-18

What new challenges will my child experience as he/she gets older?	<p>Puberty can be a difficult time, but it may be especially challenging for teens with arthrogyryposis. Some patients develop skeletal changes secondary to the original deformities; these may include scoliosis and deformed bones in the hand and foot, and they worsen the patient's overall condition. Limbs may undergrow after long-standing contractures. External genitalia are often abnormal (eg, cryptorchidism, absent labia majora) because of abnormal hip position.</p> <p>Continue with regular appointments with your doctors to monitor your child’s health and consider how other therapies, surgeries, and adaptive devices described above may help your child.</p>
What else can I do?	<ul style="list-style-type: none"> - Keep regular appointments with doctors and therapists - Enjoy your child!

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Ages 19 and beyond

What new challenges will my child experience as he/she gets older?	<p>Although arthrogyryposis is not a progressive disease, it is important to continue with regular appointments with your doctors to ensure that musculoskeletal changes are monitored and treated when necessary.</p>
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References

1. Arthrogryposis: information. Arthrogryposis Multiplex Congenita Support, Inc. 2011. Available at: <http://www.amcsupport.org/AMCInfo.htm>. Accessed on: April 9, 2011.
2. Bamshad, M., Van Hees, A.E., Pleasure, D. Arthrogryposis: a review and update. *Journal of Bone and Joint Surgery* 2009. 92: 40-46.
3. Medscape reference: Arthrogryposis. Medscape 2011. Available at: <http://emedicine.medscape.com/article/941917-overview>. Accessed on: April 9, 2011.
4. My Child has Arthrogryposis. Children's Hospital Boston 2011. Available at: <http://www.childrenshospital.org/az/Site594/mainpageS594P0.html>. Accessed on April 7, 2011.
5. My Child's Special Needs. US Department of Education. Available at: <http://www2.ed.gov/parents/needs/speced/iepguide/index.html>. Accessed on: April 2, 2011.
6. Arthrogryposis. Avenues: A National Support Group for Arthrogryposis Multiplex Congenita 2011. Available at: <http://www.avenuesforamc.com/publications/pamphlet.htm#4>. Accessed on: April 5, 2011.