



Phoenix
Children's



Barrow
Neurological Institute

Cerebral Palsy Program



Cerebral Palsy Program

Welcome to the **Cerebral Palsy (CP) Program** at **Barrow Neurological Institute at Phoenix Children's**. This program is devoted to supporting all children with CP. Our mission is to provide excellent, personalized, multidisciplinary care dedicated to help your child move, function and feel better, while avoiding complications of chronic disability as they grow.

This booklet is designed for you and your family to learn more about cerebral palsy and get connected to your **Phoenix Children's healthcare team members**. You will also learn about important local and national resources to help you care for your child. At Phoenix Children's your child will receive the latest therapies and highest standard of care to help them reach their highest potential.



What is Cerebral Palsy?

Your doctor has just told you that your child has cerebral palsy. What is it? Cerebral palsy (commonly referred to as “CP”) is a group of movement disorders caused by damage to the area of the brain that controls muscles, coordination and balance. The damage can occur during pregnancy, at the time of birth, or within the first two years of the child’s life. CP is not a single disorder, and it looks different in each child. Once the damage happens, it will not get worse. However, the problems associated with cerebral palsy can get more severe as your child grows.

Cerebral palsy can result from:

- The brain not developing completely.
- An injury to the brain caused by not getting enough oxygen to the brain or bleeding on the brain.
- Seizures at birth or shortly after.
- Infections from the mother while she is pregnant.
- Infections after birth, such as encephalitis or meningitis.
- Exposure to drugs or other toxic substances.
- Trauma to the brain before the age of 2 years.

Often the exact cause of CP is not known. Some cases of CP are genetic, and researchers here at Phoenix Children’s are looking for possible links between genetics and the risk factors associated with the development of cerebral palsy.

Cerebral palsy is not curable. However, with early detection and ongoing medical care, we can help your child manage the symptoms of cerebral palsy and reach their maximal potential.

Known Risk Factors

- A child who is born as a twin, triplet, etc.
- A baby who is born early.
- A baby born with a low birth weight.
- A child who experienced complications during their delivery.
- A baby born to a mother who had an infection during pregnancy.



Diagnosis

The diagnosis of cerebral palsy happens when a child does not reach developmental milestones (roll over, sit up, crawl and walk) as expected and shows abnormalities in muscle tone and reflexes. Traditionally, CP is not diagnosed until the child is 1-2 years of age. However, recent research shows children can receive a diagnosis as early as 5 months or sooner when evaluated by a trained professional. In milder cases, a child may not be diagnosed until they are 3-5 years old. The diagnosis of cerebral palsy is made after:

- A complete medical history, including your child's development milestones.
- A physical examination that will include looking at the child's movements, muscle tone, posture and coordination. The doctor will look for differences between the right and left sides of the body, as well as differences between the child's arms and legs.
- Additional tests that may include magnetic resonance imaging (MRI), a brain ultrasound and/or a computed tomography (CT) scan.

Types of Muscle Tone/Movement Disorders

Cerebral palsy is classified into four main types depending on the area of the brain that is affected, the body parts primarily involved, and the movement disorder that is involved.

1. **Spastic cerebral palsy** is the type of muscle tone and/or movement disorder affecting around 80% of people with CP. It is associated with muscle stiffness, or muscles that cannot relax. Often patients with spastic cerebral palsy develop what is called a muscle contracture. A contracture is the shortening of a muscle that results in the loss of full range of motion at a joint. For example, if your child develops a knee flexion contracture, they may not be able to fully straighten the knee.

Description of spastic CP by body part:

- **Diplegia** primarily affects the legs.
 - **Quadriplegia** affects both arms and both legs.
 - **Hemiplegia** affects one arm and one leg on either the right or left side of the body.
2. **Athetoid, or dyskinetic, cerebral palsy** is associated with the inability to control movement. Often the child's movements will be involuntary and jerky. Drooling, swallowing problems and difficulty with speech are common with athetoid cerebral palsy. Muscle tone may be too tight or too loose and can vary throughout the day. These children may get stuck in postures.
 3. **Ataxic cerebral palsy** is associated with poor coordination, balance and sometimes tremors. People with ataxia also may have difficulty with movements that require a lot of control (buttoning a shirt or writing) or controlling hands and arms when reaching.
 4. **Mixed cerebral palsy** is the classification used for a child that has characteristics of more than one type of cerebral palsy. Spastic-dyskinetic CP is the most common type of mixed cerebral palsy.

What is Muscle Tone?

During your medical visits, you will hear your physicians and therapists talk about your child's **muscle tone**. Muscle tone refers to how stiff or loose your child's muscles are. When certain areas of the brain are damaged, it can cause abnormal muscle tone such as:

- **Spasticity or hypertonia** – Stiff or tight muscles that tend to spasm. It may be difficult for the child to move their arms and legs.
- **Rigidity** – Arm and leg muscles are extremely tight and resist movement in all directions.
- **Hypotonia** – Also referred to as low muscle tone. It may be described as loose or floppy muscles.



Children with cerebral palsy also may have involuntary movements:

- **Ataxia** – Poor muscle control causing difficulties in walking, balance, hand coordination (shaking or tremors), swallowing, speech and eye movements.
- **Athetosis** – Involuntary writhing movements particularly in hands, arms, mouth and feet; slow and continuous.
- **Chorea** – Fidgety movements that are random and involuntary.
- **Dystonia** – Abnormal postures, twisting or repetitive movements in one or more parts of the body.

Classification Systems

Doctors will use assessment tools and classification systems when diagnosing your child. These systems determine levels of ability and guide your care team on what therapies and assistive devices will help your child the most. These levels may change over the course of your child's development and will be reassessed as they age.

Here are the five classification systems of cerebral palsy:

- Gross Motor Function Classification System (**GMFCS**)
- Manual Ability Classification System (**MACS**)
- Eating and Drinking Ability Classification System (**EDACS**)
- Communication Function Classification System (**CFCS**)
- Visual Function Classification System (**VFCS**)

Effects of Cerebral Palsy

Each child with CP is unique and will have varied degrees of injury to the brain. Some symptoms will have primary, secondary and associated neurological effects. Many of these effects can be slowed or corrected with early interventions and closely monitored care.

Primary effects

- Abnormal reflexes
- Problems with balance and movement control
- Abnormal muscle tone (too stiff or too floppy)

Secondary effects

- Shortened and tight muscles (contractures)
- Lack of flexibility in the joints
- Differences in length between the right and left legs
- A curve in the spine (scoliosis)
- Hip shifting out of the socket (you will hear terms such as hip dysplasia, subluxation or dislocation)
- Foot and ankle deformities
- Crouched, or flexed-knee, gait
- Fatigue with movements and walking
- Pain

Neurological effects

(depending on the location of the brain injury)

- Impaired thinking skills
- Attention difficulties
- Learning disabilities
- Seizures (epilepsy)
- Visual problems
- Hearing problems
- Problems with swallowing or sucking
- Problems with speech (dysarthria)
- Drooling
- Bladder problems
- Constipation
- Breathing problems
- Tooth cavities
- Poor nutrition



Treatments and Therapies

The best way to treat children with cerebral palsy is with a coordinated care approach. This means that a team of medical providers will work together to help your child maximize their abilities. The team also will develop a treatment plan to minimize the problems that can occur or develop because of cerebral palsy. Coming to scheduled doctor appointments is important so that we can monitor changes in your child and treat new issues as soon as they begin to develop.

You will have access to many treatment options to manage the impairments caused by your child's cerebral palsy. These include physical, speech and occupational therapy. Therapy can help your child learn to move about in their environment, use hands and upper limbs for self-help and communicate more effectively.

- **Physical therapy (PT)** is focused on maintaining muscle flexibility and on improving strength, balance and coordination. In physical therapy, your child will work on developing gross motor skills, such as the ability to roll, sit, crawl, stand, walk and/or use a wheelchair or other equipment.
- **Occupational therapy (OT)** will help your child develop the fine motor skills necessary to perform daily tasks at home such as dressing, hygiene and feeding. Occupational therapists also may address perceptual and sensory problems.
- **Speech and language therapists** can help your child control the facial mouth muscles involved in chewing and swallowing, as well as in speaking and nonverbal communications.

Equipment Options

Children who have trouble sitting, walking, standing or moving independently deserve mobility solutions that are designed specifically for them. To help your child achieve their goals, therapists may provide and instruct you on the use of assistive devices, including walkers, braces, splints, crutches, adaptive utensils or communication boards. The Seating and Mobility Clinic will help your child get properly fitted for the best equipment to help them participate in activities. A pediatric physiatrist, adaptive seating specialists and physical therapists can teach you the best ways to position your child to optimize function and prevent, or minimize, deformities.

Orthotics (braces or splints)

An orthotic (or orthosis) is a splint or brace applied on the outside of the body that can help control, guide or limit movement at specific joints in the body. Splints may help to stretch tight joints. For example, an ankle foot orthotic (AFO) is often prescribed to be worn on the back of the lower leg and under the foot. Usually molded out of plastic, an AFO helps control the motion and position of the foot and ankle and can indirectly help with knee control. These are usually custom made at a brace shop (orthotist) requiring two visits, one to measure/take molds, and one to deliver the final fitting.

Wheelchairs

If your child has trouble walking or sitting in a comfortable position, they may benefit from a medical wheelchair. Properly fitted equipment, such as a wheelchair, enable the child to explore their environment and learn. At the Seating and Mobility Clinic, you will learn about different chair options, frame size, positioning options and insurance coverage.

Medications

There are several medications that can help decrease spasticity (stiff and tight muscles) by blocking the abnormal signals from the brain to the involved muscles. These medications are given orally, through a feeding tube or injected. You and your doctor will discuss the best options for your child based on their unique symptoms and complications. Your doctor can describe the benefits of the drug, as well as the short- and long-term side effects.

- **Oral and feeding tube medications** commonly used to treat spasticity include baclofen, diazepam, dantrolene, tizanidine and trihexyphenidyl.
- **Injected medications**, such as botulinum toxin (Botox®), Dysport® and phenol, can be targeted to specific muscles. They can be very effective in relaxing spastic muscles for several months at a time. For some children, this can be an in-office procedure with or without sedation. For others, it will be done in the outpatient surgery center.

Healthy Hips

As noted above, some children with CP may have trouble standing or walking, or they may have tight or stiff muscles around the hip. This can affect how the hip joint develops. Your child's doctors will monitor their hips at regularly scheduled times. This is done by physical examination (while asking the child about pain and monitoring mobility of the hip) and hip X-rays. This hip surveillance allows your child's healthcare team to find hip displacement early and help your child before the hip becomes dislocated.



Who Should I Contact with Questions?

Throughout your care at Phoenix Children's, your child with CP will be seen by many doctors and therapists. It can sometimes get confusing about whom you should call and when. Your "Home Base" for the Cerebral Palsy Program is the Physical Medicine & Rehabilitation (PM&R) department. This team of doctors and medical staff will provide ongoing support throughout childhood and adolescence to help your child function at their highest potential.

During clinic visits at PM&R, your child will be evaluated by leaders in their field of spasticity and muscle tone management. We may offer injection therapies and/or medications to help with spasticity and dystonia, provide bracing or splinting prescriptions, as well as mobility solutions in our Seating and Mobility Clinic. This team also works closely with other specialty areas such as neurology, orthopedics, neurosurgery and physical/occupational/speech therapy to maximize your child's motor and cognitive outcomes.

You will have direct access to the cerebral palsy nurse program coordinator, who is dedicated to helping patients and families navigate through the CP Program and coordinate care with all of your child's providers here at Phoenix Children's. The nurse program coordinator is available to answer any questions.

Sheila Birlin, MSN, BSN, RN, CPN
Cerebral Palsy Nurse Program Coordinator
602-933-3998

Learn more at: <https://phoenixchildrens.org/centers-programs/cerebral-palsy>

Recommended Books for Your Child

- *Roll with It* by Jamie Sumner
- *Taking Seizure Disorders to School: A Story About Epilepsy (Special Kids in School)* by Kim Gosselin and Moss Friedman
- *Taking Cerebral Palsy to School* by Mary Elizabeth Anderson
- *All the Way to the Top: How One Girl's Fight for Americans with Disabilities Changed Everything* by Annette Bay Pimentel
- *Rolling Along: The Story of Taylor and his Wheelchair, A Rehabilitation Institute of Chicago Learning Book* by Jamee Riggio Heelan
- *Rainbow of Friends* by P. K. Hallinan
- *Private Eye Romeo Riley, The Boy Who Saw Too Much* by April M. Whitt



Additional Resources

Educating families about cerebral palsy is an important part of our treatment approach. We want you to be an integral part of the team. Together, we can help your child reach their fullest capabilities. Here is a list of other resources to help you on this journey:

The Adolescent Transition Project

The Adolescent Transition Project is a resource for teens and young adults with special healthcare needs to aid in a successful transfer to adulthood and independence.

Website: <http://depts.washington.edu/healthtr/>

Arizona Bridge to Independent Living (ABIL)

ABIL offers and promotes programs designed to empower people with disabilities to take personal responsibility so they may achieve or continue independent lifestyles within the community.

Website: <https://ability360.org>

Arizona Early Intervention Program (AzEIP)

The Arizona Early Intervention Program, also known as AzEIP (pronounced Ay-zip), is a statewide system of supports and services for families of children (from birth to 3 years old) with disabilities or developmental delays. These state agencies are part of the AzEIP system:

- Department of Economic Security (DES)
- DES/Arizona Early Intervention Program (AzEIP)
- DES/Division of Developmental Disabilities (DDD)
- Arizona Department of Health Services (ADHS)
- Arizona State Schools for the Deaf and the Blind (ASDB)
- Arizona Department of Education (ADE)
- Arizona Health Care Cost Containment System (AHCCCS)

Phone: 602-532-9960

Website: <https://des.az.gov/services/developmental-disabilities/early-intervention/contact>

Arizona Long Term Care System (ALTCS)

ALTCS is the State of Arizona's Medicaid program that provides long term services, at little or no cost, to financially and medically eligible Arizona residents who are aged, blind or disabled or have a developmental disability.

Phone: 602-417-6000

Website: <https://www.azahcccs.gov/Members/GetCovered/Categories/DD-ALTCS.html>

Additional Resources

Cerebral Palsy Research Network

CP Research Network focuses on optimizing the lifelong health and wellness of people with cerebral palsy and their families through high-quality research, education and community programming. Check out their helpful tool kit.

Website: <https://cprn.org>

Division of Developmental Disabilities (DDD)

The Division of Developmental Disabilities is Arizona's state agency that provides support and services for eligible people who have autism, cerebral palsy, epilepsy or mental retardation, or who have substantial life limitations in functioning.

Phone: 602-542-0419

Website: <https://des.az.gov/ddd/>

Got Transition

Got Transition is an organization that aims to improve the transition from pediatric to adult healthcare through the use of new and innovative strategies for health professionals and youth and families.

Website: <https://www.gottransition.org>

Beacon Group

Beacon Group provides variety of employment-related programs, as well as the education and socialization necessary for our clients to lead meaningful, productive lives.

Website: <https://beaongroup.org/>

Raising Special Kids

The mission of Raising Special Kids is to improve the lives of children with disabilities by providing families with parent-to-parent support, training, information and individual assistance. Programs and services are offered free of charge, in English and Spanish, and without regard to the child's disability, age, family income, qualifying conditions or other eligibility factors.

Phone: 602-242-4366

Website: <https://raisingspecialkids.org>

Supplemental Security Income (SSI)

The Supplemental Security Income (SSI) program pays benefits to disabled adults and children who have limited income and resources.

Phone: 1-800-772-1213

Website: <http://www.ssa.gov>

Additional Resources

United Cerebral Palsy of Central Arizona (UCP)

UCP is committed to creating possibilities and nurturing opportunities for children and adults with disabilities. UCP is a leader in providing therapies, independent living services, inclusive and integrated educational based programs, innovative social opportunities and basic research. They also support families as they face the daily challenges of raising a child with a disability and hope for Life Without Limits for their child.

Phone: 602-943-5472

Website: <https://ucpofcentralaz.org>

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