

Cerebral Palsy

NICHCY Disability Fact Sheet #2
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Jennifer's Story

Jen was born 11 weeks early and weighed only 2½ pounds. The doctors were surprised to see what a strong, wiggly girl she was. But when Jen was just a few days old, she stopped breathing and was put on a ventilator. After 24 hours she was able to breathe on her own again. The doctors did a lot of tests to find out what had happened, but they couldn't find anything wrong. The rest of Jen's time in the hospital was quiet, and after two months she was able to go home. Everyone thought she would be just fine.

At home, Jen's mom noticed that Jen was really sloppy when she drank from her bottle. As the months went by, Jen's mom noticed other things she didn't remember seeing with Jen's older brother. At six months, Jen didn't hold her head up straight. She cried a lot and would go stiff with rage. When Jen went back for her six-month checkup, the doctor was concerned by what he saw and what

Jen's mom told him. He suggested that Jen's mom take the little girl to a doctor who could look closely at Jen's development. Jen's mom took her to a developmental specialist who finally put a name to all the little things that hadn't seemed right with Jen—cerebral palsy.

What is CP?

Cerebral palsy—also known as CP—is a condition caused by injury to the parts of the brain that control our

ability to use our muscles and bodies. *Cerebral* means having to do with the brain. *Palsy* means weakness or problems with using the muscles. Often the injury happens before birth, sometimes during delivery, or, like Jen, soon after being born.

CP can be mild, moderate, or severe. Mild CP may mean a child is clumsy. Moderate CP may mean the child walks with a limp. He or she may need a special leg brace or a cane. More severe CP can affect all parts of a child's physical abilities. A child with moderate or severe CP may have to use a wheelchair and other special equipment.

Sometimes children with CP can also have learning problems, problems with hearing or seeing (called *sensory problems*), or intellectual disabilities. Usually, the greater the injury to the brain, the more severe the CP. However, CP doesn't get worse over time, and most children with CP have a normal life span.



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How Common is CP?

Cerebral palsy occurs in approximately 2 per 1000 live births. This frequency rate hasn't changed in more than four decades, even with the significant advances in the medical care of newborns.¹

What Are the Signs of CP?

There are four main types of CP:

- *Spastic CP* is where there is too much muscle tone or tightness. Movements are stiff, especially in the legs, arms, and/or back. Children with this form of CP move their legs awkwardly, turning in or scissoring their legs as they try to walk. This form of CP occurs in 50-75% of all cases.

- *Athetoid CP* (also called *dyskinetic CP*) can affect movements of the entire body. Typically, this form of CP involves slow, uncontrolled body movements and low muscle tone that makes it hard for the person to sit straight and walk. This form occurs in 10-20% of all cases.

- *Ataxic CP* involves poor coordination, balance, and depth perception and occurs in approximately 5-10% of all cases.

- *Mixed CP* is a combination of the symptoms listed above. A child with mixed CP has both high and low tone muscle. Some muscles are too tight, and others are too

loose, creating a mix of stiffness and involuntary movements.²

More words used to describe the different types of CP include:

- *Diplegia*—This means only the legs are affected.

- *Hemiplegia*—This means one half of the body (such as the right arm and leg) is affected.

- *Quadriplegia*—This means both arms and legs are affected, sometimes including the facial muscles and torso.

Is There Help Available?

Yes, there's a lot of help available, beginning with the free evaluation of the child. The nation's special education law, the Individuals with Disabilities Education Act (IDEA), requires that all children suspected of having a disability be evaluated *without cost to their parents* to

determine if they *do* have a disability and, because of the disability, need special services under IDEA. Those special services are:

- **Early intervention** | A system of services to support infants and toddlers with disabilities (before their 3rd birthday) and their families.
- **Special education and related services** | Services available through the public school system for school-aged children, including preschoolers (ages 3-21).

Under IDEA, children with CP are usually found eligible for services under the category of "Orthopedic Impairment." We've included IDEA's definition of orthopedic impairment in the box below.

To access early intervention services for a child up to his or her 3rd birthday, consult NICHCY's *State Resource Sheet* for your state

Definition of "Orthopedic Impairment" under IDEA

Under IDEA, cerebral palsy is considered an "orthopedic impairment," which is defined as:

...a severe orthopedic impairment that adversely affects a child's educational performance. The term includes impairments caused by a congenital anomaly, impairments caused by disease (e.g., poliomyelitis, bone tuberculosis), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures).

[34 CFR §300.8(c)(9)]

(available online at: <http://www.nichcy.org/families-community/states/>). You'll find a listing for early intervention under the first section, State Agencies. The agency listed there will be able to put you in contact with the early intervention program in your community.

To access special education services for a school-aged child, get in touch with your local public school system. Calling the elementary school in your neighborhood is an excellent place to start.

What About Treatment?

With early and ongoing treatment the effects of CP can be reduced. Many children learn how to get their bodies to work for them in other ways. For example, one infant whose CP keeps him from crawling may be able to get around by rolling from place to place.

Typically, children with CP may need different kinds of therapy, including:

- *Physical therapy (PT)*, which helps the child develop stronger muscles such as those in the legs and trunk. Through PT, the child works on skills such as walking, sitting, and keeping his or her balance.

- *Occupational therapy (OT)*, which helps the child develop fine motor skills

such as dressing, feeding, writing, and other daily living tasks.

- *Speech-language pathology (S/L)*, which helps the child develop his or her communication skills. The child may work in particular on speaking, which may be difficult due to problems with muscle tone of the tongue and throat.

All of these are available as related services in both early intervention programs (for very young children) and special education (for school-aged children).

Children with CP may also find a variety of special equipment helpful. For example, braces (also called AFOs) may be used to hold the foot in place when the child stands or walks. Custom splints can provide support to help a child use his or her hands. A variety of therapy equipment and adapted toys are available to help children play and have fun while they are working their bodies. Activities such as swimming or horseback riding can help strengthen weaker muscles and relax the tighter ones.

New medical treatments are being developed all the time. Sometimes surgery, Botox injections, or other medications can help lessen

the effects of CP, but there is no cure for the condition. It's also important to understand that cerebral palsy is not contagious, not inherited, and not progressive.³ The symptoms will differ from person to person and change as children and their nervous systems mature.⁴

What About School?

A child with CP can face many challenges in school and is likely to need individualized help. Fortunately, states are responsible for meeting the educational needs of children with disabilities.

As we've said, for children up to the 3rd birthday, services are provided through an early intervention system. Staff work with the child's family to develop what is known as an Individualized Family Services Plan, or IFSP. The IFSP will describe the child's unique needs as well as the services the child will receive to address those needs. The IFSP will also emphasize the unique needs of the family, so that parents and other family members will know how to help their young child with CP. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income.



For school-aged children, including preschoolers, special education and related services will be provided through the school system. School staff will work with the child's parents to develop an Individualized Education Program, or IEP. The IEP is similar to an IFSP in that it describes the child's unique needs and the services that have been designed to meet those needs. Special education and related services, which can include PT, OT, and speech-language pathology, are provided at no cost to parents.

In addition to therapy services and special equipment, children with CP may need what is known as *assistive technology*. Examples of assistive technology include:

- *Communication devices*, which can range from the simple to the sophisticated. Communication boards, for example, have pictures, symbols, letters, or words attached. The child communicates by pointing to or gazing at the pictures or symbols. Augmentative communication devices are more sophisticated and include voice synthesizers that enable the child to "talk" with others.

- *Computer technology*, which can range from electronic toys with special switches to sophisticated computer programs operated

by simple switch pads or keyboard adaptations.



The ability of the brain to find new ways of working after an injury is remarkable. Even so, it can be

difficult for parents to imagine what their child's future will be like. Good therapy and handling can help, but the most important "treatment" the child can receive is love and encouragement, with lots of typical childhood

Tips for Parents

- Learn about CP. The more you know, the more you can help yourself and your child. See the list of resources and organizations at the end of this publication.
- Love and play with your child. Treat your son or daughter as you would a child without disabilities. Take your child places, read together, have fun.
- Learn from professionals and other parents how to meet your child's special needs, but try not to turn your lives into one round of therapy after another.
- Ask for help from family and friends. Caring for a child with CP is hard work. Teach others what to do and give them plenty of opportunities to practice while you take a break.
- Keep informed about new treatments and technologies that may help. New approaches are constantly being worked on and can make a huge difference to the quality of your child's life. However, be careful about unproven new "fads."
- Learn about assistive technology that can help your child. This may include a simple communication board to help your child express needs and desires, or may be as sophisticated as a computer with special software.
- Be patient, keep up your hope for improvement. Your child, like every child, has a whole lifetime to learn and grow.
- Work with professionals in early intervention or in your school to develop an IFSP or an IEP that reflects your child's needs and abilities. Be sure to include related services such as speech-language pathology, physical therapy, and occupational therapy if your child needs these. Don't forget about assistive technology either!

experiences, family, and friends. With the right mix of support, equipment, extra time, and accommodations, all children with CP can be successful learners and full participants in life.



Tips for Teachers

- Learn more about CP. The resources and organizations at the end of this publication will help you.
- This may seem obvious, but sometimes the “look” of CP can give the mistaken impression that a child who has CP cannot learn as much as others. Focus on the individual child and learn firsthand what needs and capabilities he or she has.
- Tap into the strategies that teachers of students with learning disabilities use for their students. Become knowledgeable about different learning styles. Then you can use the approach best suited for a particular child, based upon that child’s learning abilities as well as physical abilities.
- Be inventive. Ask yourself (and others), “How can I adapt this lesson for this child to maximize *active, hands-on* learning?”
- Learn to love assistive technology. Find experts within and outside your school to help you. Assistive technology can mean the difference between independence for your student or not.
- Always remember, parents are experts, too. Talk candidly with your student’s parents. They can tell you a great deal about their daughter’s or son’s special needs and abilities.
- Effective teamwork for the child with CP needs to bring together professionals with diverse backgrounds and expertise. The team must combine the knowledge of its members to plan, implement, and coordinate the child’s services.



References

¹ eMedicine. (2009, March). *Cerebral palsy*. Available online at: <http://emedicine.medscape.com/article/310740-overview>

² United Cerebral Palsy. (2001). *General information: Cerebral palsy facts and figures*. Available online at: www.ucp.org/ucp_channel.doc.cfm/1/11/10427/10427-10427/447

³ Healthcommunities.com. (2007, December). *Cerebral palsy*. Available online at: www.neurologychannel.com/cerebralpalsy/index.shtml

⁴ *Ibid.*

Resources and Organizations are listed on the next page.





Organizations and Resources

United Cerebral Palsy

1.800.872.5827

<http://www.ucp.org/index.cfm>

Find an incredible wealth of information and connections at UCP, including the chapters working in your state and publications and resource pages for parents and professionals in English and in Spanish.

Medline

This service of the National Institutes of Health is an excellent place to learn about CP and keep on top of the latest medical treatments and therapies. Two web pages in particular to visit are:

- Medline's CP fact sheet
www.nlm.nih.gov/medlineplus/cerebralpalsy.html
- Medline's interactive tutorial on CP
www.nlm.nih.gov/medlineplus/tutorials/cerebralpalsy/htm/index.htm

The CDC | Centers for Disease Control and Prevention

1.800.CDC.INFO

Information in English and Spanish.

<http://www.cdc.gov/ncbddd/dd/ddcp.htm>

NINDS | National Institute on Neurological Disorders and Stroke

1.800.352.9424

Information in English and Spanish.

http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm

4MyChild

1.800.469.2445

<http://www.cerebralpalsy.org/>

Woodbine House

1.800.843.7323

Visit this commercial publisher to connect with a book series on CP, including a guide for parents; a children's book; and a guide to teaching motor skills to children with CP.

Read more about these resources at:

<http://www.woodbinehouse.com/Cerebral-Palsy.12.0.0.2.htm>

Cerebral Palsy Guide

This guide offers extensive information on CP from a medical perspective.

<http://gait.aidi.udel.edu/gaitlab/cpGuide.html>



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