

Cerebral Palsy



NICHCY Disability Fact Sheet—No. 2


◆ 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.



NICHCY is the
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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 mental retardation. 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.

❖ How Common is CP? ❖

About 500,000 people in America have some form of CP. Each year 8,000 infants and nearly 1,500 preschool-age children are diagnosed with CP.

❖ What Are the Signs of CP? ❖

There are three 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 is the most common form of CP.

- *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.

- *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.

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.

❖ 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.

Children younger than three years old can benefit greatly from *early intervention services*. Early intervention is a system of services to support infants and toddlers with disabilities and their families. For older children, *special education and related services* are available through the public school to help each child achieve and learn.

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.

The child 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.

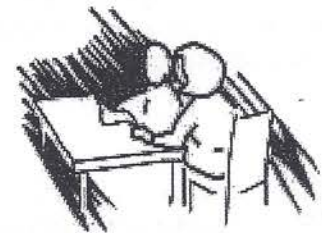
◆ Tips for Parents ◆



- 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!

◆ 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.



❖ 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.

For children up to age three, 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 Individuals with Disabilities Education Act (IDEA) guides how early intervention services and special education and related services are provided to children with disabilities. 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 congenital anomaly (e.g. clubfoot, absence of some member, etc.), impairments caused by disease (e.g., poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures)." 34 Code of Federal Regulations §300.7(c)(8)

❖ Resources ❖

Geralis, E. (1998). *Children with cerebral palsy: A parents' guide* (2nd ed.). Bethesda, MD: Woodbine House. (Phone: 800.843.7323. Web: www.woodbinehouse.com)

Kelker, K.A., & Holt, R. (2000). *Family guide to assistive technology*. Cambridge, MA: Brookline Books. (Phone: 800.666.2665. Web: www.brooklinebooks.com)

Miller, F., & Bachrach, S.J. (1998). *Cerebral palsy: A complete guide for caregiving*. Baltimore, MD: Johns Hopkins University Press. (Phone: 800.537.5487. Web: www.press.jhu.edu)

Videos to rent: *My Left Foot* and *Gaby: A True Story*.

❖ Other Web Sites ❖

www.ninds.nih.gov—site of the National Institute of Neurological Disorders and Stroke at the National Institutes of Health

www.dreamms.org—a non-profit information clearinghouse on assistive technology

www.lburkhart.com—ideas and instructions for adapting toys for use by children with CP

❖ Organizations ❖

United Cerebral Palsy Associations, Inc.
1660 L Street, NW, Suite 700, Washington, DC 20036
202.776.0406; 202.973.7197 (TTY); 800.872.5827 (V/TTY)
www.ucp.org

Easter Seals—National Office
230 W. Monroe Street, Suite 1800, Chicago, IL 60606-4802
312.726.6200; 312.726.4258 (TTY); 800.221.6827
www.easter-seals.org



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