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- “Cerebral Palsy Fact Sheet” by National Dissemination Center for Children with Disabilities (NICHCY)*, updated by Center for Parent Information and Resources
- “Cerebral Palsy: Hope Through Research” by the National Institute of Neurological Disorders & Stroke

Section 2: Strategies for Home and School  Information from various sources about the different approaches to managing Cerebral Palsy

- Excerpts from “Helping Your Child Learn Motor Skills,” Teaching Motor Skills to Children with Cerebral Palsy and Similar Movement Disorders by Sieglinde Martin, M.S., P.T.
- “Assistive Technology 101” by Family Center on Technology and Disability
- “Make Book Time Fun and Educational for Children with Cerebral Palsy (CP)” by Reach Out and Read, Inc. and Reading Rockets
- “Cerebral Palsy: Medical/Disability Information for Teachers” by Government of Alberta, Education

Section 3: How to work with professionals  Lists and articles about the particular service providers associated with Cerebral Palsy

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Section 4: Resources  Where to go for further information

- Materials in the Support for Families Library
- “Cerebral Palsy: Websites, Internet Forums, Books, Videos” by Christopher & Dana Reeve Foundation Paralysis Resource Center
- Evaluation
Acknowledgements

We would like to acknowledge the following organizations and authors used in this packet. All articles have been reprinted with permission.

National Dissemination Center for Children with Disabilities (NICHCY)* & Center for Parent Information and Resources (CPIR)
c/o Statewide Parent Advocacy Network
35 Halsey St., Fourth Floor, Newark, NJ 07102
(973) 642-8100, www.parentcenterhub.org

National Institute of Neurological Disorders & Stroke
National Institutes of Health
Bethesda, MD 20892
www.ninds.nih.gov

Sieglinde Martin, M.S., P.T. & Woodbine House
6510 Bells Mill Rd., Bethesda, MD 20817.
800-843-7323, www.woodbinehouse.com

Family Center on Technology and Disability
1825 Connecticut Ave, NW 7th Floor Washington, DC 20009

Reach Out and Read, Inc. & Reading Rockets
WETA Public Television
2775 S. Quincy St., Arlington, VA 22206
www.readingrockets.org

Government of Alberta, Education
Edmonton, Alberta. 2011.
www.learnalberta.ca/content/inmdict/html/cerebral_palsy.html

Michele Shusterman & CP Daily Living
www.cpdailyliving.com

United Cerebral Palsy & Cerebral Palsy International Research Foundation (CPIRF)
800-872-5827, www.ucp.org
212-520-1686, www.cpirf.org

Christopher & Dana Reeve Foundation Paralysis Resource Center
636 Morris Turnpike, Suite 3A, Short Hills, NJ 07078
800-539-7309, www.paralysis.org

*NICHCY lost funding in 2014, but CPIR has obtained and will continue to update many of NICHCY’S legacy publications.

Disclaimer: While many people have reviewed this packet for accuracy, policies, procedures and information like websites, agency names, addresses and phone numbers can change at any time. It is always a good idea to request copies of current policies from the agencies with whom you are working.

Additional Packets Available

Additional disability information packets and guides are available. Many are also available in Spanish and Chinese.

They include:
- ADHD
- Autism
- Behavior
- Down syndrome
- Learning Disabilities
- Mental Health
- Medical Home
- Transition from Early Intervention to Preschool

To request another packet or for more information please contact:

TEL: 415-920-5040
E-MAIL: info@supportforfamilies.org

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Section 1: Fact Sheets and Diagnosis

General Information
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.

**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 (eMedicine, 2009).

**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. *(March of Dimes, 2007)*

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** ([www.parentcenterhub.org/repository/ei-overview/](http://www.parentcenterhub.org/repository/ei-overview/)) | A system of services to support infants and toddlers with disabilities (before their 3rd birthday) and their families.
Special education and related services
(www.parentcenterhub.org/repository/steps/) | 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.” *IDEA’s definition of orthopedic impairment reads as follows:*

…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)]

To identify the EI program in your neighborhood, ask your child’s pediatrician for a referral. You can also call the local hospital’s maternity ward or pediatric ward, and ask for the contact information of the local early intervention program.

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. The symptoms will differ from person to person and change as children and their nervous systems mature.

(Healthcommunities.com, 2007)
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 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 Parents**

**Learn about CP.** The more you know, the more you can help yourself and your child. The resources and organizations listed at the end of this publication have a lot of information on CP to offer.

**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 listed at the end of this publication have a lot of information about CP to offer.

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 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.

Resources of More Information

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.

United Cerebral Palsy
1.800.872.5827
http://www.ucp.org/

Each of Us Remembers: Parents of Children with Cerebral Palsy Answer Your Questions
A 27-page guide from United Cerebral Palsy, 2013 edition

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

Medline’s interactive tutorial on CP
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.

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
What is Cerebral Palsy?

Cerebral palsy refers to a group of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination. Cerebral palsy (CP) is caused by damage to or abnormalities inside the developing brain that disrupt the brain’s ability to control movement and maintain posture and balance.
term **cerebral** refers to the brain; **palsy** refers to the loss or impairment of motor function.

Cerebral palsy affects the motor area of the brain’s outer layer (called the cerebral cortex), the part of the brain that directs muscle movement.

In some cases, the cerebral motor cortex hasn’t developed normally during fetal growth. In others, the damage is a result of injury to the brain either before, during, or after birth. In either case, the damage is not repairable and the disabilities that result are permanent.

Children with CP exhibit a wide variety of symptoms, including:

- lack of muscle coordination when performing voluntary movements (**ataxia**);
- stiff or tight muscles and exaggerated reflexes (**spasticity**);
- weakness in one or more arm or leg;
- walking on the toes, a crouched gait, or a “scissored” gait;
- variations in muscle tone, either too stiff or too floppy;
- excessive drooling or difficulties swallowing or speaking;
- shaking (**tremor**) or random involuntary movements;
- delays in reaching motor skill milestones; and
- difficulty with precise movements such as writing or buttoning a shirt.

The symptoms of CP differ in type and severity from one person to the next, and may even change in an individual over time. Symptoms may vary greatly among individuals, depending on which parts of the brain have been injured. All people with cerebral palsy have problems with movement and posture, and some also have some level of intellectual disability, seizures, and abnormal physical sensations or perceptions, as well as other medical disorders. People with CP also may have impaired vision or hearing, and language, and speech problems.

CP is the leading cause of childhood disabilities, but it doesn’t always cause profound disabilities. While one child with severe CP might be unable to walk and need extensive, lifelong care, another child with mild CP might be only slightly awkward and require no special assistance. The disorder isn’t progressive, meaning it doesn’t get worse over time. However, as the child gets older, certain symptoms may become more or less evident.

A study by the Centers for Disease Control and Prevention shows the average prevalence of cerebral palsy is 3.3 children per 1,000 live births.

There is no cure for cerebral palsy, but supportive treatments, medications, and surgery can help many individuals improve their motor skills and ability to communicate with the world.
What are the early signs?

The signs of cerebral palsy usually appear in the early months of life, although specific diagnosis may be delayed until age two years or later. Infants with CP frequently have *developmental delay*, in which they are slow to reach developmental milestones such as learning to roll over, sit, crawl, or walk. Some infants with CP have abnormal muscle tone. Decreased muscle tone (*hypotonia*) can make them appear relaxed, even floppy. Increased muscle tone (*hypertonia*) can make them seem stiff or rigid. In some cases, an early period of hypotonia will progress to hypertonia after the first 2 to 3 months of life. Children with CP may also have unusual posture or favor one side of the body when they reach, crawl, or move. It is important to note that some children *without* CP also might have some of these signs.

Some early warning signs:

In a Baby Younger Than 6 Months of Age
- His head lags when you pick him up while he’s lying on his back
- He feels stiff
- He feels floppy
- When you pick him up, his legs get stiff and they cross or scissor

In a Baby Older Than 6 Months of Age
- She doesn’t roll over in either direction
- She cannot bring her hands together
- She has difficulty bringing her hands to her mouth
- She reaches out with only one hand while keeping the other fisted

In a Baby Older Than 10 Months of Age
- He crawls in a lopsided manner, pushing off with one hand and leg while dragging the opposite hand and leg
- He cannot stand holding onto support

What causes cerebral palsy?

Cerebral palsy is caused by abnormal development of part of the brain or by damage to parts of the brain that control movement. This damage can occur before, during, or shortly after birth. The majority of children have *congenital cerebral palsy* CP (that is, they were born with it), although it may not be detected until months or years later. A small number of children have *acquired cerebral palsy*, which means the disorder begins after birth. Some causes of acquired cerebral palsy include brain damage in the first few
months or years of life, brain infections such as bacterial meningitis or viral encephalitis, problems with blood flow to the brain, or head injury from a motor vehicle accident, a fall, or child abuse.

In many cases, the cause of cerebral palsy is unknown. Possible causes include genetic abnormalities, congenital brain malformations, maternal infections or fevers, or fetal injury, for example. The following types of brain damage may cause its characteristic symptoms:

**Damage to the white matter of the brain (periventricular leukomalacia, or PVL).** The white matter of the brain is responsible for transmitting signals inside the brain and to the rest of the body. Damage from PVL looks like tiny holes in the white matter of an infant’s brain. These gaps in brain tissue interfere with the normal transmission of signals. Researchers have identified a period of selective vulnerability in the developing fetal brain, a period of time between 26 and 34 weeks of gestation, in which periventricular white matter is particularly sensitive to insults and injury.

**Abnormal development of the brain (cerebral dysgenesis).** Any interruption of the normal process of brain growth during fetal development can cause brain malformations that interfere with the transmission of brain signals. Mutations in the genes that control brain development during this early period can keep the brain from developing normally. Infections, fevers, trauma, or other conditions that cause unhealthy conditions in the womb also put an unborn baby’s nervous system at risk.

**Bleeding in the brain (intracranial hemorrhage).** Bleeding inside the brain from blocked or broken blood vessels is commonly caused by fetal stroke. Some babies suffer a stroke while still in the womb because of blood clots in the placenta that block blood flow in the brain. Other types of fetal stroke are caused by malformed or weak blood vessels in the brain or by blood-clotting abnormalities. Maternal high blood pressure (hypertension) is a common medical disorder during pregnancy and is more common in babies with fetal stroke. Maternal infection, especially pelvic inflammatory disease, has also been shown to increase the risk of fetal stroke.

**Severe lack of oxygen in the brain.** Asphyxia, a lack of oxygen in the brain caused by an interruption in breathing or poor oxygen supply, is common for a brief period of time in babies due to the stress of labor and delivery. If the supply of oxygen is cut off or reduced for lengthy periods, an infant can develop a type of brain damage called hypoxic-ischemic encephalopathy, which destroys tissue in the cerebral motor cortex and other areas of the brain. This kind of damage can also be caused by severe maternal low blood pressure, rupture of the uterus, detachment of the placenta, or problems involving the umbilical cord, or severe trauma to the head during labor and delivery.

**What are the risk factors?**

There are some medical conditions or events that can happen during pregnancy and delivery that may increase a baby’s risk of being born with cerebral palsy. These risks include:

**Low birthweight and premature birth.** Premature babies (born less than 37 weeks into
pregnancy) and babies weighing less than 5 ½ pounds at birth have a much higher risk of developing cerebral palsy than full-term, heavier weight babies. Tiny babies born at very early gestational ages are especially at risk.

**Multiple births.** Twins, triplets, and other multiple births -- even those born at term -- are linked to an increased risk of cerebral palsy. The death of a baby’s twin or triplet further increases the risk.

**Infections during pregnancy.** Infections such as toxoplasmosis, rubella (German measles), cytomegalovirus, and herpes, can infect the womb and placenta. Inflammation triggered by infection may then go on to damage the developing nervous system in an unborn baby. Maternal fever during pregnancy or delivery can also set off this kind of inflammatory response.

**Blood type incompatibility between mother and child.** *Rh incompatibility* is a condition that develops when a mother’s Rh blood type (either positive or negative) is different from the blood type of her baby. The mother’s system doesn’t tolerate the baby’s different blood type and her body will begin to make antibodies that will attack and kill her baby’s blood cells, which can cause brain damage.

**Exposure to toxic substances.** Mothers who have been exposed to toxic substances during pregnancy, such as methyl mercury, are at a heightened risk of having a baby with cerebral palsy.

**Mothers with thyroid abnormalities, intellectual disability, excess protein in the urine, or seizures.** Mothers with any of these conditions are slightly more likely to have a child with CP.

There are also medical conditions during labor and delivery, and immediately after delivery that act as warning signs for an increased risk of CP. However, most of these children will not develop CP. Warning signs include:

**Breech presentation.** Babies with cerebral palsy are more likely to be in a breech position (feet first) instead of head first at the beginning of labor. Babies who are unusually floppy as fetuses are more likely to be born in the breech position.

**Complicated labor and delivery.** A baby who has vascular or respiratory problems during labor and delivery may already have suffered brain damage or abnormalities.

**Small for gestational age.** Babies born smaller than normal for their gestational age are at risk for cerebral palsy because of factors that kept them from growing naturally in the womb.

**Low Apgar score.** The Apgar score is a numbered rating that reflects a newborn’s physical health. Doctors periodically score a baby's heart rate, breathing, muscle tone, reflexes, and skin color during the first minutes after birth. A low score at 10-20 minutes after delivery is often considered an important sign of potential problems such as CP.

**Jaundice.** More than 50 percent of newborns develop jaundice (a yellowing of the skin or whites of the eyes) after birth when **bilirubin**, a substance normally found in bile, builds up
faster than their livers can break it down and pass it from the body. Severe, untreated jaundice can kill brain cells and can cause deafness and CP.

**Seizures.** An infant who has seizures faces a higher risk of being diagnosed later in childhood with CP.

**Can cerebral palsy be prevented?**

Cerebral palsy related to genetic abnormalities cannot be prevented, but a few of the risk factors for congenital cerebral palsy can be managed or avoided. For example, *rubella*, or German measles, is preventable if women are vaccinated against the disease before becoming pregnant. Rh incompatibilities can also be managed early in pregnancy. Acquired cerebral palsy, often due to head injury, is often preventable using common safety tactics, such as using car seats for infants and toddlers.

**What are the different forms?**

The specific forms of cerebral palsy are determined by the extent, type, and location of a child’s abnormalities. Doctors classify CP according to the type of movement disorder involved -- spastic (stiff muscles), athetoid (writhing movements), or ataxic (poor balance and coordination) -- plus any additional symptoms, such as weakness (paresis) or paralysis (plegia). For example, hemiparesis (hemi = half) indicates that only one side of the body is weakened. Quadruparesis (quad = four) means all four limbs are affected.

**Spastic cerebral palsy** is the most common type of the disorder. People have stiff muscles and awkward movements. Forms of spastic cerebral palsy include:

- *Spastic hemiplegia/hemiparesis* typically affects the arm and hand on one side of the body, but it can also include the leg. Children with spastic hemiplegia generally walk later and on tip-toe because of tight heel tendons. The arm and leg of the affected side are frequently shorter and thinner. Some children will develop an abnormal curvature of the spine (scoliosis). A child with spastic hemiplegia may also have seizures. Speech will be delayed and, at best, may be competent, but intelligence is usually normal.

- *Spastic diplegia/diparesis* involves muscle stiffness that is predominantly in the legs and less severely affects the arms and face, although the hands may be clumsy. Tendon reflexes in the legs are hyperactive. Toes point up when the bottom of the foot is stimulated. Tightness in certain leg muscles makes the legs move like the arms of a scissor. Children may require a walker or leg braces. Intelligence and language skills are usually normal.

- *Spastic quadriplegia/quadriparesis* is the most severe form of cerebral palsy and is often associated with moderate-to-severe intellectual disability. It is caused by widespread damage to the brain or significant brain malformations. Children will often have severe stiffness in their limbs but a floppy neck. They are rarely able to walk. Speaking and being understood are difficult. Seizures can be frequent and hard to control.
Dyskinetic cerebral palsy (also includes athetoid, choreoathetoid, and dystonic cerebral palsies) is characterized by slow and uncontrollable writhing or jerky movements of the hands, feet, arms, or legs. Hyperactivity in the muscles of the face and tongue makes some children grimace or drool. They find it difficult to sit straight or walk. Some children have problems hearing, controlling their breathing, and/or coordinating the muscle movements required for speaking. Intelligence is rarely affected in these forms of cerebral palsy.

Ataxic cerebral palsy affects balance and depth perception. Children with ataxic CP will often have poor coordination and walk unsteadily with a wide-based gait. They have difficulty with quick or precise movements, such as writing or buttoning a shirt, or a hard time controlling voluntary movement such as reaching for a book.

Mixed types of cerebral palsy refer to symptoms that don’t correspond to any single type of CP but are a mix of types. For example, a child with mixed CP may have some muscles that are too tight and others that are too relaxed, creating a mix of stiffness and floppiness.

What other conditions are associated with cerebral palsy?

Intellectual disability. Approximately 30 – 50 percent of individuals with CP will be intellectually impaired. Mental impairment is more common among those with spastic quadriplegia than in those with other types of cerebral palsy.

Seizure disorder. As many as half of all children with CP have one or more seizures. Children with both cerebral palsy and epilepsy are more likely to have intellectual disability.

Delayed growth and development. Children with moderate to severe CP, especially those with spastic quadripareisis, often lag behind in growth and development. In babies this lag usually takes the form of too little weight gain. In young children it can appear as abnormal shortness, and in teenagers it may appear as a combination of shortness and lack of sexual development. The muscles and limbs affected by CP tend to be smaller than normal, especially in children with spastic hemiplegia, whose limbs on the affected side of the body may not grow as quickly or as long as those on the normal side.

Spinal deformities and osteoarthritis. Deformities of the spine—curvature (scoliosis), humpback (kyphosis), and saddle back (lordosis) -- are associated with CP. Spinal deformities can make sitting, standing, and walking difficult and cause chronic back pain. Pressure on and misalignment of the joints may result in osteoporosis (a breakdown of cartilage in the joints and bone enlargement).

Impaired vision. Many children with CP have strabismus, commonly called “cross eyes,” which left untreated can lead to poor vision in one eye and can interfere with the ability to judge distance. Some children with CP have difficulty understanding and organizing visual information. Other children may have defective vision or blindness that blurs the normal field of vision in one or both eyes.

Hearing loss. Impaired hearing is also more frequent among those with CP than in the
general population. Some children have partial or complete hearing loss, particularly as the result of jaundice or lack of oxygen to the developing brain.

**Speech and language disorders.** Speech and language disorders, such as difficulty forming words and speaking clearly, are present in more than a third of persons with CP. Poor speech impairs communication and is often interpreted as a sign of cognitive impairment, which can be very frustrating to children with CP, especially the majority who have average to above average intelligence.

**Drooling.** Some individuals with CP drool because they have poor control of the muscles of the throat, mouth, and tongue.

**Incontinence.** A possible complication of CP is incontinence, caused by poor control of the muscles that keep the bladder closed.

**Abnormal sensations and perceptions.** Some individuals with CP experience pain or have difficulty feeling simple sensations, such as touch.

**Learning difficulties.** Children with CP may have difficulty processing particular types of spatial and auditory information. Brain damage may affect the development of language and intellectual functioning.

**Infections and long-term illnesses.** Many adults with CP have a higher risk of heart and lung disease, and pneumonia (often from inhaling bits of food into the lungs), than those without the disorder.

**Contractures.** Muscles can become painfully fixed into abnormal positions, called *contractures*, which can increase muscle spasticity and joint deformities in people with CP.

**Malnutrition.** Swallowing, sucking, or feeding difficulties can make it difficult for many individuals with CP, particularly infants, to get proper nutrition and gain or maintain weight.

**Dental problems.** Many children with CP are at risk of developing gum disease and cavities because of poor dental hygiene. Certain medications, such as seizure drugs, can exacerbate these problems.

**Inactivity.** Childhood inactivity is magnified in children with CP due to impairment of the motor centers of the brain that produce and control voluntary movement. While children with CP may exhibit increased energy expenditure during activities of daily living, movement impairments make it difficult for them to participate in sports and other activities at a level of intensity sufficient to develop and maintain strength and fitness. Inactive adults with disability exhibit increased severity of disease and reduced overall health and well-being.

**How is cerebral palsy diagnosed?**

Most children with cerebral palsy are diagnosed during the first 2 years of life. But if a child’s symptoms are mild, it can be difficult for a doctor to make a reliable diagnosis.
Doctors will order a series of tests to evaluate the child’s motor skills. During regular visits, the doctor will monitor the child’s development, growth, muscle tone, age-appropriate motor control, hearing and vision, posture, and coordination, in order to rule out other disorders that could cause similar symptoms. Although symptoms may change over time, CP is not progressive. If a child is continuously losing motor skills, the problem more likely is a condition other than CP—such as a genetic or muscle disease, metabolism disorder, or tumors in the nervous system.

Lab tests can identify other conditions that may cause symptoms similar to those associated with CP.

Neuroimaging techniques that allow doctors to look into the brain (such as an MRI scan) can detect abnormalities that indicate a potentially treatable movement disorder. Neuroimaging methods include:

- **Cranial ultrasound** uses high-frequency sound waves to produce pictures of the brains of young babies. It is used for high-risk premature infants because it is the least intrusive of the imaging techniques, although it is not as successful as computed tomography or magnetic resonance imaging at capturing subtle changes in white matter—the type of brain tissue that is damaged in CP.

- **Computed tomography (CT)** uses x-rays to create images that show the structure of the brain and the areas of damage.

- **Magnetic resonance imaging (MRI)** uses a computer, a magnetic field, and radio waves to create an anatomical picture of the brain's tissues and structures. MRI can show the location and type of damage and offers finer levels of details than CT.

Another test, an electroencephalogram, uses a series of electrodes that are either taped or temporarily pasted to the scalp to detect electrical activity in the brain. Changes in the normal electrical pattern may help to identify epilepsy.

Some metabolic disorders can masquerade as CP. Most of the childhood metabolic disorders have characteristic brain abnormalities or malformations that will show up on an MRI.

Other types of disorders can also be mistaken for CP or can cause specific types of CP. For example, coagulation disorders (which prevent blood from clotting or lead to excessive clotting) can cause prenatal or perinatal strokes that damage the brain and produce symptoms characteristic of CP, most commonly hemiparetic CP. Referrals to specialists such as a child neurologist, developmental pediatrician, ophthalmologist, or otologist aid in a more accurate diagnosis and help doctors develop a specific treatment plan.

### How is cerebral palsy treated?

Cerebral palsy can’t be cured, but treatment will often improve a child’s capabilities. Many children go on to enjoy near-normal adult lives if their disabilities are properly managed. In
general, the earlier treatment begins, the better chance children have of overcoming developmental disabilities or learning new ways to accomplish the tasks that challenge them.

There is no standard therapy that works for every individual with cerebral palsy. Once the diagnosis is made, and the type of CP is determined, a team of health care professionals will work with a child and his or her parents to identify specific impairments and needs, and then develop an appropriate plan to tackle the core disabilities that affect the child’s quality of life.

**Physical therapy**, usually begun in the first few years of life or soon after the diagnosis is made, is a cornerstone of CP treatment. Specific sets of exercises (such as resistive, or strength training programs) and activities can maintain or improve muscle strength, balance, and motor skills, and prevent contractures. Special braces (called orthotic devices) may be used to improve mobility and stretch spastic muscles.

**Occupational therapy** focuses on optimizing upper body function, improving posture, and making the most of a child’s mobility. Occupational therapists help individuals address new ways to meet everyday activities such as dressing, going to school, and participating in day-to-day activities.

**Recreation therapy** encourages participation in art and cultural programs, sports, and other events that help an individual expand physical and cognitive skills and abilities. Parents of children who participate in recreational therapies usually notice an improvement in their child’s speech, self-esteem, and emotional well-being.

**Speech and language therapy** can improve a child’s ability to speak, more clearly, help with swallowing disorders, and learn new ways to communicate—using sign language and/or special communication devices such as a computer with a voice synthesizer, or a special board covered with symbols of everyday objects and activities to which a child can point to indicate his or her wishes.

**Treatments for problems with eating and drooling** are often necessary when children with CP have difficulty eating and drinking because they have little control over the muscles that move their mouth, jaw, and tongue. They are also at risk for breathing food or fluid into the lungs, as well as for malnutrition, recurrent lung infections, and progressive lung disease.

**Drug Treatments**

**Oral medications** such as diazepam, baclofen, dantrolene sodium, and tizanidine are usually used as the first line of treatment to relax stiff, contracted, or overactive muscles. Some drugs have some risk side effects such as drowsiness, changes in blood pressure, and risk of liver damage that require continuous monitoring. Oral medications are most appropriate for children who need only mild reduction in muscle tone or who have widespread spasticity.

- **Botulinum toxin (BT-A)**, injected locally, has become a standard treatment for overactive muscles in children with spastic movement disorders such as CP. BT-A
relaxes contracted muscles by keeping nerve cells from over-activating muscle. The relaxing effect of a BT-A injection lasts approximately 3 months. Undesirable side effects are mild and short-lived, consisting of pain upon injection and occasionally mild flu-like symptoms. BT-A injections are most effective when followed by a stretching program including physical therapy and splinting. BT-A injections work best for children who have some control over their motor movements and have a limited number of muscles to treat, none of which is fixed or rigid.

- **Intrathecal baclofen** therapy uses an implantable pump to deliver baclofen, a muscle relaxant, into the fluid surrounding the spinal cord. Baclofen decreases the excitability of nerve cells in the spinal cord, which then reduces muscle spasticity throughout the body. The pump can be adjusted if muscle tone is worse at certain times of the day or night. The baclofen pump is most appropriate for individuals with chronic, severe stiffness or uncontrolled muscle movement throughout the body.

**Surgery**

**Orthopedic surgery** is often recommended when spasticity and stiffness are severe enough to make walking and moving about difficult or painful. For many people with CP, improving the appearance of how they walk – their gait – is also important. Surgeons can lengthen muscles and tendons that are proportionately too short, which can improve mobility and lessen pain. Tendon surgery may help the symptoms for some children with CP but could also have negative long-term consequences. Orthopedic surgeries may be staggered at times appropriate to a child’s age and level of motor development. Surgery can also correct or greatly improve spinal deformities in people with CP. Surgery may not be indicated for all gait abnormalities and the surgeon may request a quantitative *gait analysis* before surgery.

**Surgery to cut nerves.** **Selective dorsal rhizotomy (SDR)** is a surgical procedure recommended for cases of severe spasticity when all of the more conservative treatments – physical therapy, oral medications, and intrathecal baclofen -- have failed to reduce spasticity or chronic pain. A surgeon locates and selectively severs overactivated nerves at the base of the spinal column. SDR is most commonly used to relax muscles and decrease chronic pain in one or both of the lower or upper limbs. It is also sometimes used to correct an overactive bladder. Potential side effects include sensory loss, numbness, or uncomfortable sensations in limb areas once supplied by the severed nerve.

**Assistive devices**

Assistive devices such devices as computers, computer software, voice synthesizers, and picture books can greatly help some individuals with CP improve communications skills. Other devices around the home or workplace make it easier for people with CP to adapt to activities of daily living. Orthotic devices help to compensate for muscle imbalance and increase independent mobility. Braces and splints use external force to correct muscle abnormalities and
improve function such as sitting or walking. Other orthotics help stretch muscles or the positioning of a joint. Braces, wedges, special chairs, and other devices can help people sit more comfortably and make it easier to perform daily functions. Wheelchairs, rolling walkers, and powered scooters can help individuals who are not independently mobile. Vision aids include glasses, magnifiers, and large-print books and computer typeface. Some individuals with CP may need surgery to correct vision problems. Hearing aids and telephone amplifiers may help people hear more clearly.

Complementary and Alternative Therapies

Many children and adolescents with CP use some form of complementary or alternative medicine. Controlled clinical trials involving some of the therapies have been inconclusive or showed no benefit and the therapies have not been accepted in mainstream clinical practice. Although there are anecdotal reports of some benefit in some children with CP, these therapies have not been approved by the U.S. Food and Drug Administration for the treatment of CP. Such therapies include hyperbaric oxygen therapy, special clothing worn during resistance exercise training, certain forms of electrical stimulation, assisting children in completing certain motions several times a day, and specialized learning strategies. Also, dietary supplements, including herbal products, may interact with other products or medications a child with CP may be taking or have unwanted side effects on their own. Families of children with CP should discuss all therapies with their doctor.

Stem cell therapy is being investigated as a treatment for cerebral palsy, but research is in early stages and large-scale clinical trials are needed to learn if stem cell therapy is safe and effective in humans. Stem cells are capable of becoming other cell types in the body. Scientists are hopeful that stem cells may be able to repair damaged nerves and brain tissues. Studies in the U.S. are examining the safety and tolerability of umbilical cord blood stem cell infusion in children with CP.

Are there treatments for other conditions associated with cerebral palsy?

Epilepsy. Many children with intellectual disability and CP also have epilepsy. In general, drugs are prescribed based on the type of seizures an individual experiences, since no one drug controls all types. Some individuals may need a combination of two or more drugs to achieve good seizure control.

Incontinence. Medical treatments for incontinence include special exercises, biofeedback, prescription drugs, surgery, or surgically implanted devices to replace or aid muscles.

Osteopenia. Children with CP who are unable to walk risk developing poor bone density (osteopenia), which makes them more likely to break bones. In a study of older Americans funded by the National Institutes of Health (NIH), a family of drugs called bisphosphonates, which has been approved by the FDA to treat mineral loss in elderly patients, also appeared to increase bone mineral density Doctors may choose to selectively prescribe the drug off-label to children to prevent osteopenia.
Pain. Pain can be a problem for people with CP due to spastic muscles and the stress and strain on parts of the body that are compensating for muscle abnormalities. Some individuals may also have frequent and irregular muscle spasms that can’t be predicted or medicated in advance. Diazepam can reduce the pain associated with muscle spasms and gabapentin has been used successfully to decrease the severity and frequency of painful spasms. Botulinum toxin injections have also been shown to decrease spasticity and pain. Intrathecal baclofen has shown good results in reducing pain. Some children and adults have been able to decrease pain by using noninvasive and drug-free interventions such as distraction, relaxation training, biofeedback, and therapeutic massage.

Do adults with cerebral palsy face special health challenges?

Premature aging. The majority of individuals with CP will experience some form of premature aging by the time they reach their 40s because of the extra stress and strain the disease puts upon their bodies. The developmental delays that often accompany CP keep some organ systems from developing to their full capacity and level of performance. As a consequence, organ systems such as the cardiovascular system (the heart, veins, and arteries) and pulmonary system (lungs) have to work harder and they age prematurely.

Functional issues at work. The day-to-day challenges of the workplace are likely to increase as an employed individual with CP reaches middle age. Some individuals will be able to continue working with accommodations such as an adjusted work schedule, assistive equipment, or frequent rest periods.

Depression. Mental health issues can also be of concern as someone with cerebral palsy grows older. The rate of depression is three to four times higher in people with disabilities such as cerebral palsy. It appears to be related not so much to the severity of their disabilities, but to how well they cope with them. The amount of emotional support someone has, how successful they are at coping with disappointment and stress, and whether or not they have an optimistic outlook about the future all have a significant impact on mental health.

Post-impairment syndrome. This syndrome is marked by a combination of pain, fatigue, and weakness due to muscle abnormalities, bone deformities, overuse syndromes (sometimes also called repetitive motion injuries), and arthritis. Fatigue is often a challenge, since individuals with CP may use up to three to five times the amount of energy that able-bodied people use when they walk and move about.

Osteoarthritis and degenerative arthritis. Musculoskeletal abnormalities that may not produce discomfort during childhood can cause pain in adulthood. For example, the abnormal relationships between joint surfaces and excessive joint compression can lead to the early development of painful osteoarthritis and degenerative arthritis. Individuals with CP also may have limited strength and restricted patterns of movement, which puts them at risk for overuse syndromes and nerve entrapments.

Pain. Individuals with CP may have pain that can be acute (usually comes on quickly and
lasts a short while) or chronic, and is experienced most commonly in the hips, knees, ankles, and the upper and lower back. Individuals with spastic CP may have an increased number of painful sites and worse pain than those with other types of cerebral palsy. Preventive treatment aimed at correcting skeletal and muscle abnormalities early in life may help to avoid the progressive accumulation of stress and strain that causes pain. Dislocated hips, which are particularly likely to cause pain, can be surgically repaired.

Other medical conditions. Adults have higher than normal rates of other medical conditions secondary to their cerebral palsy, such as hypertension, incontinence, bladder dysfunction, and swallowing difficulties. Scoliosis is likely to progress after puberty, when bones have matured into their final shape and size. People with CP also have a higher incidence of bone fractures, occurring most frequently during physical therapy sessions.

What research is being done?

The National Institute of Neurological Disorders and Stroke, (NINDS), a part of the National Institutes of Health (NIH), is the nation’s leading funder of basic, clinical, and translational research on brain and nervous system disorders. Another NIH agency, the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), also conducts and supports research on cerebral palsy.

Much of what we now know about CP came from research sponsored by the NINDS, including the identification of new causes and risk factors for cerebral palsy, the discovery of drugs to control stiff and spastic muscles and more precise methods to deliver them, refined surgical techniques to correct abnormalities in muscle and bone, and a greater understanding of how and why brain damage at critical stages of fetal development causes CP.

Many scientists think that a significant number of children develop CP because of mishaps early in brain development. They are examining how neurons (nerve cells) in the brain specialize and form the right connections with other brain cells, and they are looking for ways to prevent the factors that disrupt the normal processes of brain development.

Genetic defects are sometimes responsible for the brain malformations and abnormalities that cause cerebral palsy. Scientists are searching for the genes responsible for these abnormalities by collecting DNA samples from people with cerebral palsy and their families and using genetic screening techniques to discover linkages between individual genes and specific types of abnormality – primarily those associated with the process in the developing brain in which neurons migrate from where they are born to where they settle into neural circuits (called neural migration).

Scientists are scrutinizing events in newborn babies’ brains, such as bleeding, epileptic seizures, and breathing and circulation problems, which can cause the abnormal release of chemicals that triggers the kind of damage that causes cerebral palsy. For example, research has shown that bleeding in the brain unleashes dangerously high amounts of glutamate, a chemical that helps neurons communicate. However, too much glutamate
overexcites and kills neurons. By learning how brain chemicals that are normally helpful become dangerously toxic, scientists will have opportunities to develop new drugs to block their harmful effects.

Researchers are using **imaging techniques** and neurobehavioral tests to predict those preterm infants who will develop cerebral palsy. If these screening techniques are successful, doctors will be able to identify infants at risk for cerebral palsy before they are born.

Periventricular **white matter damage**—the most common cause of CP—is characterized by death of the white matter around the fluid-filled ventricles in the brain. The periventricular area contains nerve fibers that carry messages from the brain to the body’s muscles. NINDS-sponsored researchers are hoping to develop preventative strategies for white matter damage. For example, researchers are examining the role the brain chemicals play on white matter development in the brain. Another NINDS-funded project involves the development of a novel mouse model and cell-based therapies for perinatal white matter injury. Researchers funded by NINDS are studying a chemical found naturally in the body, called erythropoietin to see if it decreases the risk of CP in prematurely born infants.

NIH-funded scientists continue to look at new therapies and novel ways to use existing options to treat individuals with CP, including:

**Constraint-induced therapy (CIT)** is a promising therapy for CP. CIT typically involves restraining the stronger limb (such as the “good” arm in a person who has been affected by a stroke on one side of the body) in a cast and forcing the weaker arm to perform intensive activities every day over a period of weeks. A clinical study sponsored by the NICHD is examining the use of different dosage levels of daily training using either full-time cast immobilization vs. part-time splint restraint in improving upper body extremity skills in children with weakness on both sides of their body. Study findings will establish evidence-based practice standards to improve lifelong neuromotor capacity in individuals with CP.

**Functional electrical stimulation (FES)**—the therapeutic use of low-level electrical current to stimulate muscle movement and restore useful movements such as standing or stepping—is an effective way to target and strengthen spastic muscles. Researchers are evaluating how FES-assisted stationary cycling can improve physical conditioning and general lower extremity muscle strength in adolescents. **Robotic therapy** that applies controlled force to the leg during the swing phase of gait is may improve the efficacy of body weight supported treadmill training in children with CP. The results from this NICHD study will lead to an innovative clinical therapy aimed at improving locomotor function in children with CP.

**Botulinum toxin** (Botox), injected locally, has become a standard treatment in children with spastic movement disorders such as CP. Recent animal studies suggest Botox degrades bone but there are no studies of its skeletal consequences in humans. Other research shows a low intensity vibration treatment can improve bone structure in the lower extremity leg bones of children with CP. In a novel clinical study being conducted by NICHD, researchers are determining the effect of Botox treatment in conjunction with a
daily vibration treatment on bone mass and bone structure in children with spastic CP.

**Systemic hypothermia**—the controlled medical cooling of the body’s core temperature—appears to protect the brain and decrease the rate of death and disability from certain disorders and brain injuries. Previous studies have shown that hypothermia is effective in treating neurologic symptoms in term or late preterm babies less than one month old that are attributed to hypoxic-ischemia (HIE, brain injury due to a severe decrease in the oxygen supply to the body), which can cause quadriplegic CP, with or without movement disorder. In an effort to determine the most effective cooling strategies, NICHD-funded researchers are studying different cooling treatments to improve the chance of survival and neurodevelopment outcomes 18-22 months post-treatment in infants with neurologic symptoms attributed to HIE. Other researchers are examining if combined therapy using hypothermia and recombinant erythropoietin (a hormone that promotes the growth of new red blood cells and increases oxygen levels in the blood) is more effective than either therapy alone in treating neurodevelopmental handicaps in an animal model involving lack of oxygen before, during, or just after birth.

As researchers continue to explore new treatments for cerebral palsy and to expand our knowledge of brain development, we can expect significant improvements in the care of children with cerebral palsy and many other disorders that strike in early life.

**Where can I get more information?**

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN
P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424

Information also is available from the following organizations:

**United Cerebral Palsy (UCP)**
1825 K St NW
Suite 600
Washington, DC 20006
info@ucp.org
[http://www.ucp.org](http://www.ucp.org)
Tel: 202-776-0406 800-USA-UCP (872-5827)
Fax: 202-776-0414

**Pathways Awareness**
150 N. Michigan Avenue
Suite 2100
Chicago, IL 60601
friends@pathwaysawareness.org
[http://www.pathwaysawareness.org](http://www.pathwaysawareness.org)
Tel: 800-955-CHILD (2445)
Fax: 312-893-6621

**March of Dimes**
1275 Mamaroneck Avenue
White Plains, NY 10605
askus@marchofdimes.com
[http://www.marchofdimes.com](http://www.marchofdimes.com)
Tel: 914-997-4488 888-MODIMES (663-4637)
Fax: 914-428-8203

**Easter Seals**
233 South Wacker Drive
Suite 2400
Chicago, IL 60606
info@easterseals.com
[http://www.easterseals.com](http://www.easterseals.com)
Tel: 312-726-6200 800-221-6827
**Children's Neurobiological Solutions (CNS) Foundation**  
1223 Wilshire Blvd. #937  
Santa Monica, CA  90403  
info@cnsfoundation.org  
http://www.cnsfoundation.org  
Tel: (310) 889-8611

**Children's Hemiplegia and Stroke Assocn. (CHASA)**  
4101 West Green Oaks Blvd., Ste. 305  
PMB 149  
Arlington, TX  76016  
info437@chasa.org  
http://www.chasa.org  
Tel: 817-492-4325

**Cerebral Palsy International Research Foundation**  
186 Princeton Hightstown Road  
Building 4, 2nd Floor  
Princeton Junction, NJ  08550  
cpifr@cpifr.org  
http://www.cpifr.org  
Tel: 609-452-1200

**Pedal-with-Pete Foundation [for Research on Cerebral Palsy]**  
P.O. Box 1233  
Worthington, OH  43085  
pwp@pedal-with-pete.org  
http://www.pedal-with-pete.org  
Tel: 614-527-0202  
Fax: 330-673-1240

**Reaching for the Stars**  
3000 Old Alabama Road  
Suite 119 – 300  
Alpharetta, GA  30022  
info@reachingforthestars.org  
http://reachingforthestars.org/  
Tel: 855-240-7387

**Glossary**

*acquired cerebral palsy* — cerebral palsy that occurs as a result of injury to the brain after birth or during early childhood.

*Apgar score* — a numbered scoring system doctors use to assess a baby's physical state at the time of birth.

*asphyxia* — a lack of oxygen due to trouble with breathing or poor oxygen supply in the air.

*ataxia* — the loss of muscle control.

*athetoid* — making slow, sinuous, involuntary, writhing movements, especially with the hands.

*bilirubin* — a bile pigment produced by the liver of the human body as a byproduct of digestion.

*bisphosphonates* — a family of drugs that strengthen bones and reduce the risk of bone fracture in elderly adults.

*botulinum toxin* — a drug commonly used to relax spastic muscles; it blocks the release of acetylcholine, a neurotransmitter that energizes muscle tissue.
cerebral — relating to the two hemispheres of the human brain.

cerebral dysgenesis — defective brain development.

choreoathetoid — a condition characterized by aimless muscle movements and involuntary motions.

congenital cerebral palsy — cerebral palsy that is present at birth from causes that have occurred during fetal development.

contracture — a condition in which muscles become fixed in a rigid, abnormal position, which causes distortion or deformity.

developmental delay — behind schedule in reaching the milestones of early childhood development.

dyskinetic — the impairment of the ability to perform voluntary movements, which results in awkward or incomplete movements.

dystonia (dystonic) a condition of abnormal muscle tone.

gait analysis — a technique that uses cameras, force plates, electromyography, and computer analysis to objectively measure an individual's pattern of walking.

gestation — the period of fetal development from the time of conception until birth.

hemiparesis — paralysis affecting only one side of the body.

hypertonia — increased muscle tone.

hypotonia — decreased muscle tone.

hypoxic-ischemic encephalopathy — brain damage caused by poor blood flow or insufficient oxygen supply to the brain.

intracranial hemorrhage — bleeding in the brain.

intrathecal baclofen — baclofen that is injected into the cerebrospinal fluid of the spinal cord to reduce spasticity.

jaundice — a blood disorder caused by the abnormal buildup of bilirubin in the bloodstream.

kyphosis — a humpback-like outward curvature of the upper spine.

lordosis — an increased inward curvature of the lower spine.

orthotic devices — special devices, such as splints or braces, used to treat posture problems involving the muscles, ligaments, or bones.

osteopenia — reduced density and mass of the bones.
palsy — paralysis, or the lack of control over voluntary movement.

-paresis or -plegia — weakness or paralysis. In cerebral palsy, these terms are typically combined with other phrases that describe the distribution of paralysis and weakness; for example, quadriplegia means paralysis of all four limbs.

periventricular leukomalacia (PVL) — “peri” means near; "ventricular" refers to the ventricles or fluid spaces of the brain; and "leukomalacia" refers to softening of the white matter of the brain.  PVL is a condition in which the cells that make up white matter die near the ventricles. Under a microscope, the tissue looks soft and sponge-like.

placenta — an organ that joins a mother with her unborn baby and provides nourishment and sustenance.

quadriplegia — paralysis of both the arms and legs.

Rh incompatibility — a blood condition in which antibodies in a pregnant woman's blood attack fetal blood cells and impair an unborn baby’s supply of oxygen and nutrients.

rubella — (also known as German measles) a viral infection that can damage the nervous system of an unborn baby if a mother contracts the disease during pregnancy.

scoliosis — a disease of the spine in which the spinal column tilts or curves to one side of the body.

selective dorsal rhizotomy — a surgical procedure in which selected nerves are severed to reduce spasticity in the legs.

spastic (or spasticity) — describes stiff muscles and awkward movements.

spastic diplegia (or diparesis) — a form of cerebral palsy in which spasticity affects both legs, but the arms are relatively or completely spared.

spastic hemiplegia (or hemiparesis) — a form of cerebral palsy in which spasticity affects an arm and leg on one side of the body.

spastic quadriplegia (or quadriparesis) — a form of cerebral palsy in which all four limbs are paralyzed or weakened equally.

tremor — an involuntary trembling or quivering.


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- Parálisis Cerebral: Esperanza en la Investigación

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Last updated July 21, 2014
Section 2: Strategies for Home and School

Different management approaches for the specific disability from various sources
If you have read the preceding chapters, you may be wondering how it is possible for children with cerebral palsy or similar movement disorders to master the gross motor skills they need. If their difficulties with muscle tone, abnormal movement patterns, lack of motor control, muscle weakness, abnormal sensory awareness, and slowed development are due to a brain injury or a developmental defect of the central nervous system, what can help them overcome these problems? There are two answers:

1. The brain can, to a certain extent, recover from, or compensate, for injury, and
2. Parents and therapists can teach children the most effective ways to learn and practice motor skills.

**Neural Plasticity**

At birth, an infant's brain is not fully developed. During the first and second year of life, the brain is still growing, changing, and forming new connections. Therefore, it is possible that other cells may take over the work of the damaged cells. With stimulation and training, this is more likely to happen. This capacity of the brain to adapt to, and supplement for, a deficit is called neural plasticity.

As brain growth subsides, neural plasticity decreases. New research, however, indicates that some capacity for recovery remains throughout a person's life. Even if an adult suffers an injury to her central nervous system, other nerve cells may take over all or part of the function of the damaged cells. Special training as soon as possible after the injury makes this more likely.
Physical Therapy Treatment and Motor Learning

Another possible way children with cerebral palsy may acquire a basic skill such as crawling or sitting up is by training. How this training is done has evolved over the years. There are several sources of information that guide therapists when they work with children or advise their parents, caretakers, or teachers. One is a rapidly expanding body of knowledge called motor learning. The other sources are concepts and techniques developed by professionals intimately familiar with the characteristics, problems, and potentials of children with cerebral palsy or similar movement disorders.

Motor Learning

Physical education teachers, athletic trainers, and coaches specialize in teaching children and adults a great variety of motor skills we call sports. Children learn to swim, skate, dance, ski, horseback ride, do gymnastics, play tennis, and so on. They are not born with the ability to perform these sports. It is exposure to and training of the skills that lead to their mastery.

How quickly and how well a person learns a new sport depends on many factors. Aptitude, motivation, and opportunities for practice are important. But how well a sport is taught also plays a significant role. Scientists have been investigating how people learn a new motor skill and how to teach them best. As they asked questions, tested, got answers, and arrived at conclusions, they gained new insights and understandings. A whole field of study developed—the science of motor learning.

The knowledge of motor learning pertains to how a healthy person learns a physical skill. Does this knowledge apply to people with a neurological deficit? Does it apply to children with cerebral palsy? Some studies have tried to answer this question (Thorpe & Valvano, 2002). So far, there is no clear answer. Yet, at this time the general consensus is that insights gained in the field of motor learning may also explain how children with cerebral palsy learn basic motor skills (Shumway-Cook & Woollacott, 2001). The following section presents some of the findings.

PRINCIPLES OF MOTOR LEARNING TO KEEP IN MIND

1. Learning a new motor skill is an active process.

   It involves finding an efficient, consistent solution to a motor problem. What does this mean? Let’s use an example—your child is able to sit but is unable to get down from sitting. The motor problem she has to solve is how to move from sitting to the floor with ease and control. For a small child, the best way to do this is to turn to the side and place both hands on the floor. With her arms in a good position to guide her movements and soften the impact, she may now lower her trunk and slides down on her belly without getting hurt. The therapist will show you how to help your child perform this movement sequence. As you follow the instructions at home, your child will get acquainted with the movement pattern and her arm muscles may get stronger as she bears weight on them. But true skill learning will only happen if your child also participates with problem solving. When your child wants to move (there
is a toy on the floor she likes to play with), gets only some help from you, and does as much as possible on her own, then she takes part in the problem solving process and skill learning happens.

2. **Motivation is an important part of skill learning.**

   Therefore, before you practice a skill with your child, look for ways to motivate her. For instance, when your child is happily sitting and playing, it is not a good time to practice moving down to the floor. She will not be motivated to do so. Instead, wait until she is done playing and ready to get to the interesting toy you placed on the floor. Only if she wants to be on the floor will she be motivated to learn and try to perform the movement sequence of lowering herself out of sitting. Learning does not take place without motivation.

3. **Active exploration helps skill learning.**

   The more a child is allowed to actively explore and find solutions to motor problems, the more skills she will learn and the better she will learn them. You may believe that helping your child to move perfectly and smoothly from sitting to the floor will enhance good learning. This is not true. Padding the floor with an extra rug and allowing your child to do as much as possible on her own will further motor learning. Her movements may be choppy, and lack grace and fluency as she struggles on her own. Yet, do not worry; she will be learning. Motor skill learning requires many repetitions before you may expect efficiency and smoothness. You have to remember how often you had to bat a baseball or do a golf stroke before you got good at it.

4. **A demonstration may help your child.**

   A sibling may model for your child how to do a movement such as getting down from sitting or you may show her using a doll. If you do, emphasize the outcome of the movement sequence—in our example, it would be sliding onto the belly and reaching the toy. Researchers found that this is the way children learn best. Also, modeling a new skill smoothly and perfectly is not as helpful to a beginning learner as watching someone struggle to perform the skill.

5. **Variability helps skill learning.**

   Initially, your consistent help will make it easier for your child to perform a new movement sequence. As soon as your child improves, however, vary your approach. Try not to always help her in the very same way. Do not always place the toy she wants to get to in the very same spot. The more variable the practice, the better your child will learn the new skill.

6. **Practice a skill until it is well learned.**

   Just because your child successfully moved from sitting to her tummy once does not mean she has mastered the skill. Encourage her to practice until the skill is well learned. Only after a skill is well learned will your child always be able to do it. If it is not well learned, she may lose it again. When your child moves from sitting to the floor with ease and does so on her own during play, this skill is well learned. It is now part of her skill repertoire.
7. Transfer of learning may occur.
Transfer of learning means that learning one skill may help your child to learn another skill. When and how much transfer of learning occurs is important to know. Researchers found that the better a skill is learned and the more variably it is practiced, the more likely transfer of learning will happen. Also, the more alike two skills are, the more likely it is for transfer of learning to occur. For instance, if a child learns to move from sitting to the floor well, she may learn to push into sitting from being on the floor fairly quickly thereafter. Moving into sitting and moving out of sitting are two skills that share movement components. Therefore, mastery of one skill will help a child learn the other.

8. Some skills may have negative transfer effects.
A two-year-old child may teach herself to move from sitting to the floor by slowly rolling backwards. Doing so will not have a positive transfer effect in regard to moving into sitting. That is, it will not help her learn a related skill. If she tries to sit up using the same motor pattern she used rolling down, she will not succeed. It is only between 68 and 72 months of age that a typically developing child is able to sit up this way (Peabody Developmental Motor Scale, 2000). A child with cerebral palsy will not be able to do it any earlier. On the other hand, going down and sitting up by placing both hands forward and sideways is mastered by typically developing children between 7 to 9 months of age. Consequently, children with cerebral palsy are more likely to become successful when they use this same pattern.

9. Similar motor skills may need to be learned separately.
Research indicates that we learn motor skills more specifically than once was assumed. For instance, you may think that sitting on a chair and sitting on the floor are one and the same skill. In both situations the person sits, so it may be assumed that when she learns to sit, she becomes able to sit either on the floor or in a chair. In fact, this may not be true. Sitting on a chair and sitting on a floor may be two separate skills. To master them, both may have to be trained.

Specificity of learning and transfer of learning are interrelated concepts. At this time we do not yet know how they apply to many practical situations. Future research should tell us.

10. Feedback helps skill learning.
Through feedback, the child receives information about how she performed a task. Feedback may come in many forms. When your child moves from sitting on the floor to stomach-lying, she perceives how it feels to turn her body slightly to the side, put weight on her arms, bend her arms, and touch the floor with her belly. She will notice if she is able to reach the toy she wants to play with. She will see her parents’ smiling faces and hear their applause as she succeeds. All of this is helpful feedback.

Most parents like to give verbal feedback. They like to encourage and praise their children. Researchers asked the question of how often verbal feedback should be given. They found that steady verbal feedback is not as effective as intermittent feedback. Especially initially, verbal feedback may distract children from the task and may let them pay less attention to the feedback they receive from their senses. So, if you feel the urge to talk to and encourage your child, relax and do it only every once and a while. On the other hand, a loving smile or approving nod should always be helpful.
11. **Don’t ask your child to show off a new skill too soon.**

Researchers investigated the audience effect. They found that well-learned skills become better in front of an audience but a new skill may deteriorate. This explains why your child may not be able to demonstrate her newest trick to her grandparents or the therapist. After more practice, as the new skill becomes firmer, this should change.

12. **The more practice, the better.**

The more practice you can provide for your child, the more she learns. This makes sense, and motor learning research has confirmed it.

How much should you practice a skill with your child? Should you practice with her moving from sitting to the floor one time, then give her some free time, and later practice again? Or should you practice lots of time in a row with little rest in between? If you practice crawling with your child, should you take care that she practices only a short distance or should you encourage her to continue crawling as far as she possibly can? Researchers have looked into this. They found that it is all right to practice the same task again and again with little rest in between. They call it **massed practice.**

Even if a person got tired after many repetitions and did not do the task as well as before, researchers found that learning occurred. In fact, at times massed practice brings better learning than practice distributed over a longer period of time.

After a child has initially been reluctant to practice a new skill, it frequently happens that suddenly she really likes to practice. Whenever this happens, let your child practice as much as she wants to—you know she is learning. If, after many repetitions, she gets tired and does not do as well as before—you know she is still learning. You may have to watch her more closely for safety reasons, however. And don’t forget to praise and hug her afterwards. (Not in between, as that would interfere with her learning.)

13. **Ask the therapist how often to practice with your child each week.**

The optimal amount of time to practice exercises depends on the type of exercise. Stretching exercises have to be done every day. Fortunately, stretching does not take much time. Depending on how many stretches your child needs, a stretching program may be done in less than 5 to 15 minutes. (See Chapter 5 for information on stretching.) Strengthening exercises are effective if done three to four times a week. Skill and balance training does not have to be done on a specific schedule. Yet time on task matters. More practice will bring about more learning. If in doubt about the frequency and length of practice sessions, be sure to ask your child’s physical therapist.
“Road to Independence” Skills Guideline

**INITIAL SKILLS:**
- Brings hands together and plays in side-lying. *(photo 4.1)*
- Holds head in the middle, brings hands together, and plays in an infant seat. *(photo 4.2)*
- Holds head and looks around propped on forearms in stomach-lying. *(photo 4.3)*
- Lifts feet off the floor in back-lying and rolls over. *(photo 4.4)*
- Plays and moves about on stomach. *(photo 4.5)*
- Sits with both arms propped. *(photo 4.6)*
- “Bunny” from stomach-lying: child pulls both legs up and props on both arms. *(photo 4.7)*
**INTERMEDIATE SKILLS I:**

- Sits and stands holding onto a bar. *(photo 4.8a & 4.8b)*
- Pulls from bunny position to kneeling at a box and plays. *(photo 4.9)*
- Sits with some arm support and plays. *(photo 4.10)*
- Plays in bunny position. *(photo 4.11)*
- Plays in heel sitting and moves in/out of position. *(photo 4.12)*
- Sits without arm support and moves in/out of sitting. *(photo 4.13)*
INTERMEDIATE SKILLS II:
- Crawls on hands and knees. (photo 4.14)
- Sits well on a bench or chair. (photo 4.15)
- Pulls to stand at furniture, plays, and cruises. (photo 4.16)
- Walks with a walker. (photo 4.17)
- Walks with forearm crutches. (photo 4.18)
- Walks stairs with assistance.

ADVANCED SKILLS:
- Stands without Support. (photo 4.19)
- Walks without support. (photo 4.20)
- Walks up and down stairs, walks up and down curbs, and may run.
Frequently Asked Questions

Q. “How long will it take our son Hayden to learn each skill?”
A. This varies greatly from child to child. Hayden may learn a few skills rather quickly, while others may require weeks or even months of daily practice.

Q. “Should we work with Hayden on one skill at a time?”
A. In general, it is good to work on several skills at a time. As mentioned you may want to work on sitting and kneeling at the same time and practice standing with arm support also on the same day. Some times, however, it helps to concentrate on one skill and practice it over and over (see massed practice). This all varies depending on circumstances. Your child’s physical therapist will give you guidance for specific situations. She will explain which skills need to be practiced more than other skills.

Q. “Does Celeste have to crawl in order to walk?”
A. Children with developmental delays or cerebral palsy may learn to walk with a walker without first being able to crawl. Yet, crawling will help Celeste in many ways. It teaches her coordinated reciprocal arm and leg movements and strengthens her hip, shoulder, and arm muscles. Few children walk independently without ever crawling. An exception is the child with hemiplegia whose arm is seriously affected by cerebral palsy. She will be unable to crawl, but still progress to independent walking.

Q. “Does Celeste have to walk with a walker before she walks on her own?”
A. No. Not all children with cerebral palsy walk with a walker first, but many do.

Q. “Our son Mohsen has hemiplegia. Only one side of his body is affected by cerebral palsy. How will he develop gross motor skills?”
A. On his own, Mohsen will rely mostly on his stronger arm and leg. By doing so, he may learn most skills almost as quickly as children without cerebral palsy until it is time to walk. Now the abnormal muscle tone, the lack of coordination, and the weakness of the affected leg may delay the onset of walking. Nevertheless, he will progress to independent walking.

   It is best for Mohsen to receive physical therapy early. It will assure that he uses his affected arm and leg as much as possible and does not “neglect” them. Even though it is not essential that children with hemiplegia crawl, they benefit a great deal from crawling. The more Mohsen crawls, the stronger and more coordinated his affected arm and leg become. For the rest of his life, he will benefit from crawling.
What Is Assistive Technology?

Assistive technology is any kind of technology that can be used to enhance the functional independence of a person with a disability. Often, for people with disabilities, accomplishing daily tasks such as talking with friends, going to school and work, or participating in recreational activities is a challenge. Assistive Technology (AT) devices are tools to help to overcome those challenges and enable people living with disabilities to enhance their quality of life and lead more independent lives.

Assistive technology can be anything from a simple (low-tech) device such as a magnifying glass, to a complex (high-tech) device, such as a computerized communication system. It can be big — an automated van lift for a wheelchair — or small — a Velcro attached grip attached to a pen or fork for example, for eating and writing. Assistive technology can also be a substitute — such as an augmentative communication device that provides vocal output for a child who cannot communicate with her voice.

Meeting Challenges with Assistive Technology

Assistive technology helps to level the playing field for individuals with disabilities by providing them a way to fully engage in life's activities. An individual may use assistive technology to travel about, participate in recreational and social activities, learn, work, communicate with others, and much more.

Here are several examples of AT that enables people with disabilities to enter into the community and interact with others.

- For greater independence with mobility and travel, people with physical disabilities may utilize mobility aids, such as wheelchairs, scooters, and walkers. Adapted car seats and vehicle wheelchair restraints promote safe travel.
- Hand-held GPS devices help persons with visual impairments navigate busy city streets and utilize public transportation.
- Building modifications at work sites, such as ramps, automatic door openers, grab bars, and wider doorways mean fewer barriers to employment, businesses, and community spaces, such as libraries, churches, and shopping malls.
- Special computer software and hardware, such as voice recognition programs and screen enlargement programs, enable persons with mobility and sensory impairments to carry out educational or work-related tasks.
- Education and work aids such as automatic page turners, book holders, and adapted pencil grips enable children to participate in classroom activities.
- Bowling balls with hand-grips and one-handed fishing reels are a few examples of how technology can be adapted for sporting activities. Light-weight wheelchairs have been designed for organized sports, such as basketball, tennis, and racing.
- Accessibly designed movie theaters provide closed captioning and audio description for moviegoers with hearing and visual difficulties.
- Devices to assist a person with daily living tasks, such as cooking, dressing, and grooming, are available for people with special needs. For example, a medication dispenser with an alarm can be set to remind a person with memory loss to take daily medication. A person with use of only one hand can use a one-handed cutting board and a cabinet mounted can opener to cook meals with improved independence and safety.
Choosing the Right Assistive Technology Device(s) for Your Child

To determine the assistive technology needs of a child, an AT assessment should be conducted. The assessment can be conducted by the school, an independent agency, or an individual consultant. This assessment should take place in a child’s customary environments – home, school, and community.

It is important that the assessment address the child’s strengths as well as his/her weaknesses. It is key, when discussing how the child participates in his/her world, to hear the perspectives of teachers, parents and siblings, as well as that of the child. The discussion should not be limited merely to what skills the child possesses but should include the ways in which a child communicates, what he likes and dislikes, and what kind of strategies and interventions are helpful in interacting with the child. Consideration must be taken on how a child’s need for AT might change depending on the environment, for example on the playground, the classroom, a friend’s house or in a public place like a mall or library. This type of input will provide clues as to what technology might work and how well your child will respond to it.

The end result of an assessment is a recommendation for specific devices and services. Once it is agreed that assistive technology would benefit a child, issues related to design and selection of the device, as well as maintenance, repair, and replacement of devices should be considered. Training (to use the device) and ongoing technical assistance is necessary not only for the child, but also for family members, teachers, service providers, and other people who are significantly involved in a student’s life. It is also important to integrate and coordinate any assistive technology with therapies, interventions, or services provided by education and rehabilitation plans and programs.

Acquiring assistive technology does not just happen once in a lifetime. The type of devices your child needs may change depending on the child’s age, abilities, physical status, and features of the immediate environment. Change in your child’s life may necessitate a re-assessment of his or her assistive technology needs.

Learning More about Assistive Technology

Parents can help to identify potential AT for their child if they learn about the choices that are available. A good place to start is often with speech-Language therapists, occupational therapists and school professionals. There are many organizations that provide AT information and training to consumers and families such as parent training and Information centers (PTI’s), community technology centers, state assistive technology programs and rehabilitation centers. If possible you should visit an AT center with your child to see and try out various devices and equipment. Some AT centers offer lending programs that allow families to borrow devices for a trial period.

The Family Center on Technology and Disability (FCTD) offers a wide range of assistive technology resources for disability organizations, AT providers, educators and families of children with disabilities. Families are always welcome to visit the FCTD web site (www.fctd.info) to find other AT and disability organizations and to learn more about assistive technology.

The following list includes several organizations that offer a various resources on AT.

Abledata  -  www.abledata.com
Assistivetech.net  -  www.assistivetech.net
AbilityHub  -  www.abilityhub.com
PACER Center - Simon Technology Center - http://www.pacer.org/stc/
Technical Assistance Alliance for Parent Centers - www.taalliance.org
Association of State Technology Act Programs - www.ataporg.org/stateatprojects.asp
Helping your child love books

You’ll find sharing books together is a great way to bond with your son or daughter and help your child’s development at the same time. **Give your child a great gift that will last for life—the love of books.**

CP affects your child’s brain. This may cause difficulty with muscle tone and control. Your child may have delays speaking or have speech that is hard to understand. Reading with your child and having your child name objects in the book or read aloud to you can strengthen his speech skills.

Tips for reading with your infant or toddler

Each time you read to your child, you are helping his brain to develop. Reading to your child helps him understand that there are words and pictures on the page. **So—you’ve planted the seed to reading that will stay with your child throughout his life.**

Since young children have short attention spans, try reading for a few minutes at a time at first. Then build up the time you read together. Your child will soon see reading time as fun time and learning time!

Check off the things you can try:

- Buy books or borrow books from the library that have thick, sturdy pages.
- Find books that have rhymes like a Mother Goose nursery rhymes book.
- Clap your hands and help your baby clap along to the rhythm of the words.
- Read aloud. Talk about the pictures and read the text. Help your toddler point to objects you name in the book.

Some suggested books for your infant

**Fisher Price** makes **Stroller Strap Books.** The straps make the books easy to handle and the sturdy pages stay open and are easy to turn. Some titles include:

- *Ears, Nose & Toes!*
- *Touch and Feel*
- *I Love My Family*

Some suggested books for your toddler

**E-Z Page Turners** is a series of books made by **Innovative Kids.** These books are specially designed to help little ones turn the pages. You can buy them online or ask your child’s occupational therapist for help finding this brand. Some titles include:

- *Trucks*
- *Opposites*
- *Mommies and Babies*
Helping your preschooler or school-age child love books

Remember, when you read to your child often and combine reading time with cuddle and play time, your child will link books with fun times together.

Check off the things you can try:

- Find books on topics that interest your child, such as books on animals or sports.
- Position your child next to you on the couch. If your child is in a wheelchair or special chair, sit close enough so he can see the book and hear you. Ask your child’s occupational and/or physical therapist about special tools to help your child prop up the book.
- Find books that have buttons to press that make sounds. Buy audio books that your child can start or stop by pressing a button.
- Read aloud and talk about the pictures. Ask your child to name objects or read aloud.
- Praise your child’s efforts at reading!

Some suggested books for your preschooler or school-age child

- *Harold and the Purple Crayon* by Crockett Johnson
- *We Are Going on a Bear Hunt* by Helen Oxenbury
- *The Napping House* by Audrey Wood

How children can learn more about cerebral palsy

Read these books:

- *Brothers and Sisters* by Laura Dwight
- *Living with a Brother or Sister with Special Needs* by Donald Meyer and Patricia Vadasy (Ages 4–10)
- *Views from Our Shoes* by Donald Meyer (Ages 8–12)

How parents can learn more about cerebral palsy

Read these books:

- *Children with Cerebral Palsy: A Parent’s Guide* edited by Elaine Geralis
- *Reflections from a Different Journey* by Stanley Klein

Contact these groups for more information:

- Centers for Disease Control and Prevention—(800) CDC-INFO or www.cdc.gov/actearly
- Easter Seals—(800) 221-6827 or www.easter-seals.org
- National Dissemination Center for Children with Disabilities—(800) 695-0285 or www.nichcy.org
- National Institute of Neurological Disorders and Stroke, National Institutes of Health—www.ninds.nih.gov
- United Cerebral Palsy Association—(800) 872-5827 or www.ucp.org
- Siblings Support—www.siblingsupport.org
- University of Michigan Health System—www.med.umich.edu/yourchild/topics/specneed.htm
Cerebral Palsy

Cerebral palsy (CP) refers to a group of disorders that result from injury to the developing brain, and can affect movement and muscle coordination. Depending on which areas of the brain are damaged, CP can cause one or more of the following: muscle tightness or spasms, involuntary movement, difficulty with gross motor skills such as walking or running, difficulty with fine motor skills such as writing or doing up buttons, and difficulty with perception and sensation. Individuals with CP may have cognitive, speech and language disorders, visual and hearing impairments and/or learning disabilities. The parts of the body that are affected and the severity of impairment can vary widely. CP is not progressive, but can seem to change as the child grows.

Implications for Planning and Awareness

☐ Meet with the student and parents early in the school year to discuss how the school can support this student’s needs related to cerebral palsy. This could include finding out about:
  – the student’s strengths, interests and areas of need
  – the student’s specific symptoms
  – successful strategies used at home or in the community that could be used at school.

☐ In collaboration with the parents and health care professionals, develop a written management plan that aligns with related jurisdictional policies and protocols and could include specific information, such as:
  – symptoms and associated disorders that may affect the student at school
  – the role of school staff
  – equipment and modifications
  – when emergency measures should be taken.

☐ If the student is taking medications during the school day, discuss with the parents possible side effects. Follow school and/or jurisdictional policies and protocols in storing and administering medication.

☐ Work with the parents to carry out a risk assessment before field trips to determine potential hazards and to plan for the student’s safe and successful participation.

☐ Collaborate with the parents and student to consider if, and how, they would like to share specific information on cerebral palsy with peers. If they wish to do this, consultation with health care providers, such as school or community health nurses, may be helpful.

☐ Learn as much as you can about how cerebral palsy may affect learning and social and emotional well-being. Reading, asking questions and talking to qualified professionals will build your understanding and help you make
Collaborate with the school and/or jurisdictional team to identify and coordinate any needed consultation and services, such as speech-language, occupational or physical therapy.

Arrange for any equipment or classroom modifications that might be needed, as recommended by a specialist. This may include accommodations for mobility equipment (e.g., wheelchairs, standing frames, walkers), supportive seating, supportive toilet seats and/or mechanical lifts.

Determine if any changes to school timetables or schedules will have to be made to accommodate the student’s equipment and/or travel time from class-to-class.

Develop a system for sharing information with relevant staff members about the student’s condition and successful strategies.

**Implications for Instruction**

- Give clear, brief directions. Give written or visual directions as well as oral ones. Allow extra time for oral responses.
- Break tasks and assignments into short, easy-to-manage steps. Provide each step separately and give feedback along the way.
- Provide checklists, graphic organizers, visual referents and examples to help the student plan ahead and to stay on-task.
- Teach strategies for self-monitoring, such as making daily lists and personal checklists for areas of difficulty.
- Use instructional strategies that include memory prompts.
- Teach strategies for what to do while waiting for help (e.g., underline, highlight or rephrase directions; jot down key words or questions on sticky notes).
- Provide extra time for tasks or reduce the amount of written work required.
- Provide alternatives to writing for the student to demonstrate learning. If handwriting continues to be difficult for the student, reduce expectations for copying, provide extra time for written work and explore the use of a dedicated word processor and writing software.

**Implications for Social and Emotional Well-being**

- Engage the student and parents in planning for transitions between grade levels and different schools.
- Provide clear expectations, consistency, structure and routine for the entire class. Rules should be specific, direct, written down and applied consistently.
- Consider ways to adapt play activities and structure opportunities for play with peers. Teach the entire class modified versions of common recess games, and/or assign a recess or break buddy.
- If the student uses an alternative form of communication, like a communication book or device, make sure it is available to him or her at recess and lunchtime.
- If required, teach peers how to interact with the student using the communication device or book.
☐ Use low-key cues, such as touching the student’s desk to signal the student to think about what he or she is doing without drawing the attention of classmates.

☐ Provide support in transitioning from one activity or place to another. Cues, routines and purposeful activity during transitions may be helpful.

☐ Monitor for signs of anxiety or depression, such as visible tension, withdrawal, changes in grooming habits, missing or coming late to class, fatigue or incomplete assignments.

☐ Support the development of self-advocacy skills, so students feel comfortable and confident asking for what they need and expressing their preferences.

☐ Consider having a “key person” the student can check in with on a weekly (or daily basis) to assist with planning, self-monitoring and problem solving of any concerns or issues that may arise.

As you consider the implications for this medical condition, think about the following questions:

1. Do I need further conversations with the parents to better understand this student’s medical needs?  ☐ Yes  ☐ No

2. Do I need targeted professional learning?  ☐ Yes  ☐ No
   If yes, what specific topics and strategies would I explore?

3. Is consultation with jurisdictional staff required?  ☐ Yes  ☐ No
   If yes, what issues and questions would we explore?

4. Is consultation with external service providers required (e.g., Regional Educational Consulting Services, Student Health Partnership, Alberta Children’s Hospital, Glenrose Hospital)?  ☐ Yes  ☐ No
   If yes, what issues and questions would we explore?

5. Are further assessments required to assist with planning for this student?  ☐ Yes  ☐ No
   If yes, what questions do I need answered?

6. Is service to the student from an external provider required?  ☐ Yes  ☐ No
   If yes, what outcomes would be anticipated?

Links for further information:


Please note:
These websites are for information only and the user is responsible for evaluating the content and appropriate uses of the information.
Section 3: How to Work with Professionals

Articles about the service providers associated with the specific disability
Mom's introduction

One of the more important pieces of advice I have received regarding our daughter’s therapy and treatment came from our developmental pediatrician. During one of our visits he said to us, “Michele, if there was a cure [for CP] everyone would be in line to receive it.” What he meant was that he sees so many parents blindly run from one treatment, experiment, and/or therapeutic activity to another trying to find that “secret cure” when, in fact, CP does not have a “secret cure” or magic therapy that will fix everything.

He always tried to impart the importance of creating balance amidst the sea of not knowing. He has consoled, encouraged, and guided us through this journey and without his guiding words, our journey would have been much more difficult.

It is important for you to find competent and compassionate physicians like him to rely upon and to help you create a reasonable therapy and treatment schedule for your child (and for you the parent/caregiver). This is easier said than done but I have found that my intuition and my personal observations of Maya have been invaluable. This becomes particularly important when dealing with the pressure to do anything and everything to help your child. This pressure, coupled with the guilt you may feel as a parent for not doing enough to help your child, can be overwhelming. During your child’s early years, you will probably hear a lot about the importance of early therapy. You hear this because the brain has the most flexibility, or ability to change, during this time. This ideology generated a lot of anxiety for my family and I am sure it does the same for many other parents. Don't make yourself crazy as you try to think of and do everything under the sun to help your child. This may be a lifelong journey for your child and as his or her guide, it is important to pace yourself as best as you can. Remember these words as you face each day.

Dad's introduction

I want to do everything possible for my daughter. Throughout Maya’s seven years, my wife and I have introduced her to many different therapies and therapists, both successfully and unsuccessfully, and have (for the time being) found a path that we think is helping her develop new abilities. One of the most difficult aspects on our journey has been figuring out which therapies to try, which therapies to continue, and which therapies to stop. None of these have been easy decisions because many therapies have limited or no formal research, standards of care for cerebral palsy have
not yet been established and some interventions which may be more effective with more frequent visits, may not be covered by insurance. In addition to being a father, I am a physician, and I hope my knowledge and experience provide a unique perspective on this issue. My goal is to combine my personal experiences with the latest available research on therapies for children with CP.

After spending a portion of my spare time reviewing the data regarding all therapy options for people with cerebral palsy, I have concluded that there is no “gold standard” type of therapy for CP. In other words, no one type of therapy has enough study evidence to support it above the other types of therapy.

Types of treatment/therapies

We begin with the three primary approaches currently used to treat the symptoms commonly associated with CP. We continue with a comprehensive alphabetical list of additional treatments and approaches. Some have been researched and others have not. This is not an exhaustive list and we are not providing an endorsement, nor making a statement by listing or not listing a particular therapy or treatment. Instead, this list is intended to provide a broad overview of some commonly used approaches for treating the symptoms of CP, and to give information about alternative therapies/approaches we have repeatedly heard about from other parents. It’s important to keep in mind that certain treatments listed focus on relieving specific aspects of one type of cerebral palsy (such as spasticity) and would not necessarily be appropriate for another type. Always consult with your own or your child's doctors and professional therapists for further guidance and information that applies to your unique situation.

Conventional Therapies:

Physical Therapy (PT)

Physical therapy addresses the child's abilities in the areas of gross motor skills and mobility. Initial evaluations for physical therapy include assessing a child's posture, sensory processing, muscle tone and coordination, developmental skills, and adaptive equipment. Direct physical therapy goals and activities are individually established based on the evaluation. They may include learning to sit, crawl, walk, climb steps, or throw and catch a ball. Activities include exercises for strengthening, range of motion and balance. Simple ball games, tricycle riding and outdoor play are used to improve coordination and endurance. Physical therapists often work with the family and local durable medical equipment vendors to identify, order, and maintain adaptive equipment to assist the child's sitting stability, posture, and/or mobility. Typical equipment includes

http://cpdailyliving.com/types-of-therapy
orthotics, activity chairs, car seats, walkers, special strollers or wheelchairs. Physical therapists also work with the child’s physicians when the child has problems with skin breakdown, contractures, or other orthopedic problems.

It’s helpful for parents to become familiar with the GMFCS scale (www.canchild.ca/en/measures/gmfcs.asp). This scale was developed as an objective way to assess gross motor function in children with cerebral palsy. It’s intended to replace the very subjective terms of "mild", "moderate", and "severe".

Thank you to the Meyer Center for Special Children (www.meyercenter.org) for contributing to this summary.

The following are some commonly used approaches and support roles of physical therapists treating people with CP. Each therapist will differ slightly in their education, training, and preferences for how they wish to approach treating the individual.

1. Stretching

2. Neuro-developmenta Treatment (NDT) (www.ndta.org)

3. Resistance/Strength Training

4. Robotics-i.e. Locomat (www.ric.org/conditions/pcs-specialized/lokomat/index.aspx)

5. Treadmill Training

6. Aquatic Exercise Therapy -Here is an excellent overview of Aquatic Exercise Therapy provided by CanChild of Canada. (http://cpnet.canchild.ca/en/resourcesGeneral/KeepingCurrent_AquaticExercise_final.pdf)

The following is a blog post I wrote interviewing our daughter’s PT about Physical Therapy and CP. (http://cpdailyliving.com/physical-therapy-and-cp-an-interview)

Occupational Therapy (OT)

When a professional recommends occupational therapy (referred to as OT), especially for a child, the caregivers’ initial response is often one of wondering what sort of occupation a young child might need. Occupation refers to all of the “jobs” that make up our daily life, whether you are one or eighty one. OT will evaluate a child’s ability to perform self care, play, and work (school) skills at an age-appropriate level. These are referred to as ADL’s-activities of daily living. Through a comprehensive evaluation the OT can begin to identify issues that interfere with the child’s performance. This may
include problems with strength, abnormal muscle tone, eye-hand coordination, visual perceptual skills, and sensory processing skills. The goal of OT is for the child to participate as actively and fully as possible in all areas of ADL’s- self-care, play, and school skills.

An OT’s academic background is heavy in life sciences including gross anatomy and neuro-anatomy, as well as psychology, human growth and development, and treatment of disabilities across the lifespan. An OT addresses how the whole person is affected by his or her injury or disability, and specifically how it affects his or her ADL’s.

Pediatric OT’s often use a variety of approaches in assessing and treating children, including neuro-developmental treatment (NDT), sensory processing, and motor learning approaches. Therapy is child directed and based on activities that are meaningful and purposeful to that specific child.

OT’s also assess and incorporate various tools and adaptive equipment to increase independence. Examples include specialized feeding utensils, adaptive scissors and writing utensils, splints, and adaptations to clothing such as zipper pulls, button hooks, and reachers.

Pediatric specialists may also provide cranio-sacral therapy (CST), constraint therapy, kinesiotaping, therapeutic listening programs, sensory integrative (SI) therapy, vision related therapies (for visual motor and visual perceptual difficulties), Bal-a-Vis-X, Brain Gym, Interactive Metronome, and feeding related therapy.

Written collectively by the occupational therapy department at the Meyer Center for Special Children.

**Constraint Induced Movement Therapy (CIMT)**

Constraint induced movement therapy (CIMT) is a therapeutic approach dedicated to help children and adults who have limited movement on one side of their body due to an injury in the brain. This applies mainly to adults with strokes and to children with cerebral palsy (CP). These individuals develop “learned non-use” as they neglect the affected limb and perform activities only with the unaffected limb. In CIMT, a constraint is applied to the unimpaired (or less impaired) hand or wrist while the patient undergoes intensive training with the impaired limb. The goal is to improve activity level and usage of the impaired limb.

This therapy was initially developed in the 1900s during experiments with monkeys. Then in the 1960s, CIMT was applied to adult stroke patients with some beneficial results. The therapy is thought to increase the neural connections in the area of the brain that controls the affected side. With the recent development and validation of brain plasticity ([http://merzenich.positscience.com/?page_id=143](http://merzenich.positscience.com/?page_id=143)), this type of therapy has
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gained attention and popularity. Because of the success in adults with strokes, this therapy has recently been applied to children with hemiplegic CP. CIMT is often given in an intensive series of lessons over 1-2 weeks and frequently in a fun environment that motivates the child to use the affected side.

**Speech-Language Therapy**

Speech-language pathologists (SLP) evaluate communication skills and treat speech and language disorders. This includes receptive and expressive language, auditory processing, memory, articulation, fluency, oral-motor development, and feeding skills. The speech pathologist may also screen a child's hearing and make a referral for further evaluation if needed.

Structured activities are used to teach specific language concepts of vocabulary and grammar, articulation and phonological training. Computers may be used to teach new concepts or reinforce previously learned information, and therapists may also use auditory/listening training. Speech pathologists may incorporate and teach alternative ways of communicating which include manual sign language, picture communication boards, and/or voice output communication devices.

Speech disorders include:

- **Articulation disorders**: difficulties producing sounds in syllables or saying words incorrectly to the point that listeners can't understand what's being said.
- **Fluency disorders**: problems such as stuttering, in which the flow of speech is interrupted by abnormal stoppages, repetitions (st-st-stuttering), or prolonging sounds and syllables (ssssstuttering).
- **Resonance or voice disorders**: problems with the pitch, volume, or quality of the voice that distract listeners from what's being said. These types of disorders may also cause pain or discomfort for a child when speaking.
- **Dysphagia/oral feeding disorders**: these include difficulties with drooling, eating, and swallowing.

Language disorders can be either receptive or expressive:

- **Receptive disorders**: difficulties understanding or processing language.
- **Expressive disorders**: difficulty putting words together, limited vocabulary, or inability to use language in a socially appropriate way.

**Strategies:**

- **Language intervention activities**: The SLP will interact with a child by playing and talking, using pictures, books, objects, or ongoing events to stimulate language development. The therapist may also model correct pronunciation and use repetition exercises to build speech and language skills.
- **Articulation therapy**: Articulation, or sound production, exercises involve having the therapist model correct sounds and syllables for a child, often during play.

http://cpdailyliving.com/types-of-therapy
activities. The level of play is age-appropriate and related to the child’s specific needs. The SLP will physically show the child how to make certain sounds, such as the "r" sound, and may demonstrate how to move the tongue to produce specific sounds.

- **Oral-motor/feeding and swallowing therapy:** The SLP will use a variety of oral exercises — including facial massage and various tongue, lip, and jaw exercises — to strengthen the muscles of the mouth. The SLP also may work with different food textures and temperatures to increase a child's oral awareness during eating and swallowing.

*Information from this section has been compiled from Nemours.org and the Meyer Center for Special Children parent handbook.

**Alcohol/Phenol Nerve Blocking**

Nerve blocking is used as a way of reducing spasticity (muscle tightness) by disrupting/blocking the overactive nerve signal from the brain to the muscles. The nerve block involves dissolving the fatty coating or myelin sheath wrapped around the nerve, while the nerve itself remains intact. This approach requires more precision than the use of Botox since specific nerves are being targeted rather than the larger muscles themselves.

**Aquatic Exercise Therapy-See Physical Therapy**

**Botox**

Botox is a brand name for botulinum toxin type A (BTA) which is frequently used to temporarily treat muscle stiffness in people with cerebral palsy. BTA is injected into specific muscles in order to relax the tight muscles associated with spastic forms of cerebral palsy. It is thought that decreasing the muscle stiffness will allow for better stretching of shortened muscles, increased range of motion and opportunities to strengthen muscles that work opposite to the muscle that has been injected (source CanChild). Over the last 25 years, BTA has been used to treat many neuromuscular conditions including strabismus (crossed eyes) and vocal cord spasm. Although BTA has been used in the last ten years in children (and adults) with cerebral palsy, administration protocols often vary among physicians (i.e some treat under anesthesia only while others don't) There are different types of physicians who may administer botox as a treatment for CP including physiatrists and orthopedic surgeons. For more information about Botox and CP you may wish to fish the CanChild website (www.canchild.ca/en/canchildresources/botulinumtoxininchildren.asp).
Select the Dorsal Rhizotomy (SDR)

Although still considered a controversial surgery, SDR has been a surgical intervention used for certain presentations of cerebral palsy for many years. It involves cutting specific nerves of the spinal cord in order to more permanently reduce spasticity. Below is a description of the way the surgery has been conducted at St. Louis Children's Hospital since 1991:

"SDR begins with a 1- to 2-inch incision along the center of the lower back just above the waist. The spinuous processes and a portion of the lamina are removed to expose the spinal cord and spinal nerves. Ultrasound and an x-ray locate the tip of the spinal cord, where there is a natural separation between sensory and motor nerves. A rubber pad is placed to separate the motor from the sensory nerves. The sensory nerve roots that will be tested and cut are placed on top of the pad and the motor nerves beneath the pad, away from the operative field. After the sensory nerves are exposed, each sensory nerve root is divided into 3-5 rootlets. Each rootlet is tested with EMG, which records electrical patterns in muscles. Rootlets are ranked from 1 (mild) to 4 (severe) for spasticity. The severely abnormal rootlets are cut. This technique is repeated for rootlets between spinal nerves L1 and S1/S2.

When testing and cutting are complete, the dura mater is closed, and fentanyl is given to bathe the sensory nerves directly. The other layers of tissue, muscle, fascia, and subcutaneous tissue are sewn. The skin is closed with glue. There are no stitches to be removed from the back. Surgery takes approximately 4 hours. The patient goes to the recovery room for 1-2 hours before being transferred to the Neurology/Neurosurgery Floor."

Intensive therapy protocols follow surgery.

Functional Vision Assessment & Intervention Programs

Developmental Optometry

Developmental/behavioral optometry is based upon the principle that vision is dynamic. In this approach vision is a learned process and can be developed or improved upon at any age. Optometrists practicing developmental optometry have had postgraduate training beyond the Doctor of Optometry (O.D.) degree. Their continuing education emphasizes the use of lenses, prisms, and vision therapy to enhance a patient's visual capabilities, reduce visual stress and potentially prevent and rehabilitate vision problems.
Cortical Visual Impairment and the CVI Range Assessment and Intervention Program

Cortical visual impairment is a neurological condition that is the leading cause of visual impairment of children in the US and the First World and is commonly seen in people with cerebral palsy (Good, Jan, Burden, Skoczenski, & Candy, 2001, p. 56). It is not an eye condition. Resulting from damaged or malformed visual pathways and/or visual processing centers of the brain, CVI presents very differently than other types of visual impairment. Whereas a typical visual impairment can be diagnosed with an eye exam and vision testing, CVI often presents with a normal eye exam that does not explain the individual’s significant lack of visual function.

The CVI Range developed by Dr. Christine Roman, is an assessment NOT a replacement for an eye exam. It helps to describe how the child sees and provides a common language for describing levels of function. The Range is a change model and is supposed to be used to develop appropriate interventions leading to improvement. Dr. Roman’s approach is to develop more vision in the brain so the individual continues to make progress in the range and in turn his/her functional vision. The educator/professional uses the range to monitor changes in visual processing, and adapt the individual’s environment to correspond with those visual processing improvements.

Dr. Roman has a goal of getting all children to 7 out of 10 on the range and, although most people with CVI naturally improve over time, Dr. Roman says progress is dependent on what can be done to foster improvement, as well as to offer support as early as possible.

What are the differences between Developmental Optometry Principles and the CVI Range?

Although developmental optometry and the CVI Range may be based on the similar idea that vision is dynamic (rather than traditional models that believe vision is unchangeable) and may have some crossover in their efforts, their approaches to improving functional vision are very different. Developmental optometry services are provided by a Doctor of Optometry and take place in an office setting. They often address ocular impairments that affect visual perception. These include evaluating and addressing how the eyes work together, visual tracking, accommodation/focusing and visual motor integration. Developmental optometrists may also address other aspects of visual perception, which do have some crossover into areas addressed by the CVI Range. They use eye exercises and different types of lenses and prisms to treat their patients.

This differs from Dr. Roman’s approach with the CVI Range. The CVI Range is intended to capture and address specific characteristics associated with CVI and related visual...
processing problems. The CVI Range is intended to be part of the student's IEP and therefore free and part of an appropriate education. Although a developmental optometrist may be trained in using the CVI Range, it may be administered by educators, therapists, and early interventionists and even parents. The CVI Range Assessment and Intervention Program is the only known objective measure and intervention program for CVI at this time.

For more information about CVI you may wish to read two blog posts I wrote on the topic:


CVI Part Two: Dr. Christine Roman's CVI Range Assessment (http://cpdailyliving.com/cvi-part-two-dr-romans-cvi-range-assessment)

The Perkins School for the Blind (www.perkins.org/resources/webcasts/cvi-and-the-evaluation-of-functional-vision.html) offers excellent information and resources about CVI including many videos featuring Dr. Roman.

Additional and/or Experimental Interventions:

Adeli Suit

The Adeli suit (also known as the Polish Suit, Therapy Suit, and Therasuit) is a modified piece of equipment from the Soviet Space Program. It was originally developed to counteract long-term weightlessness in space where a lack of gravity can cause atrophy of the muscles. Through wearing the suit, which consists of supporting elements including a vest, shorts, knee caps, and footwear linked by a set of elastic ties, an artificial force is created on the body. The suit holds the body in proper physical alignment and the child goes through various exercises while wearing the suit. It also works to normalize the child’s proprioceptive sense, which allows the child to understand where his/her body is in space. The therapy was initially started in Russia and has spread to other parts of the world. In some European facilities the suit is used as part of intensive physiotherapy for several days at a time over a period of 4 weeks.

Anat Baniel Method (ABM)

Written by Lisa Shusterman PhD, Anat Baniel Practitioner for Children, and Maya's grandmother:
The Anat Baniel Method (ABM) helps children with special needs learn through gentle movement. This approach emerged from the work of Moshe Feldenkrais, an Israeli physicist who developed the Feldenkrais Method. Anat Baniel was mentored by Feldenkrais and demonstrated an extraordinary gift in her ability to facilitate transformational changes particularly in children. Eventually Feldenkrais appointed her as the leader and expert in applying his work to children. Over the years Anat Baniel built upon her knowledge of the Feldenkrais technique and developed her own unique approach called the Anat Baniel Method*. ABM accesses the remarkable capacity of the human brain to form new connections and new patterns. It enhances learning by using techniques such as movement with attention, variation and flexible goals. The process wakes up the brain and facilitates the growth of new brain pathways, which help the brain perform at a higher, more complex level.

Children with CP often miss out on the rich learning that occurs through random movement. Through random movement, a typical child learns about herself, her body in space, how to move different parts of her body to accomplish an intended action, and how to be in the world. ABM gives the brain of the child with CP the information that the typical child gets automatically.

ABM sessions are called lessons, practitioners are called teachers and clients are called students. At a lesson, the student, fully clothed, lies down or sits on a padded table. The teacher slowly and gently moves the student’s body in specific and comfortable ways. Unlike some other treatments, ABM is completely free of pain. Comfort is integral to the learning.

In children, the brain is almost always ready to form new patterns that can improve functioning and quality of life. Intervention can start at any time, but the earlier, the better.

In Anat Baniel’s new book, Kids Beyond Limits, she explains how ABM works and what parents can do on their own to boost their child’s learning. It is a great resource for understanding special needs and for finding ways to help children progress. When parents, in daily interaction with their child, apply the ABM principles, the child becomes a better learner.

To find out more about the Anat Baniel Method visit www.anatbanielmethod.com.

Biofeedback

The best description I have found for biofeedback is written by Bette Runck, staff writer, Division of Communication and Education, National Institute of Mental Health. Here it is in its entirety:

"Biofeedback is a treatment technique in which people are trained to improve their
health by using signals from their own bodies. Physical therapists use biofeedback to help stroke victims regain movement in paralyzed muscles. Psychologists use it to help tense and anxious clients learn to relax. Specialists in many different fields use biofeedback to help their patients cope with pain.

Chances are you have used biofeedback yourself. You've used it if you have ever taken your temperature or stepped on a scale. The thermometer tells you whether you're running a fever, the scale whether you've gained weight. Both devices "feed back" information about your body's condition. Armed with this information, you can take steps you've learned to improve the condition. When you're running a fever, you go to bed and drink plenty of fluids. When you've gained weight, you resolve to eat less and sometimes you do.

Clinicians reply on complicated biofeedback machines in somewhat the same way that you rely on your scale or thermometer. Their machines can detect a person's internal bodily functions with far greater sensitivity and precision than a person can alone. This information may be valuable. Both patients and therapists use it to gauge and direct the progress of treatment.

For patients, the biofeedback machine acts as a kind of sixth sense which allows them to "see" or "hear" activity inside their bodies. One commonly used type of machine, for example, picks up electrical signals in the muscles. It translates these signals into a form that patients can detect: It triggers a flashing light bulb, perhaps, or activates a beeper every time muscles grow tenser. If patients want to relax tense muscles, they try to slow down the flashing or beeping.

Like a pitcher learning to throw a ball across a home plate, the biofeedback trainee, in an attempt to improve a skill, monitors the performance. When a pitch is off the mark, the ballplayer adjusts the delivery so that he performs better the next time he tries. When the light flashes or the beeper beeps too often, the biofeedback trainee makes internal adjustments which alter the signals. The biofeedback therapist acts as a coach, standing at the sidelines setting goals and limits on what to expect and giving hints on how to improve performance.

The goal with CP or other neurologic injuries is that through biofeedback, a child will be able to use these "extra signals" to better control his/her movements.

**Canine Assistants/Service Dogs**

Assistant dogs provide support to children and adults with a wide range of physical, cognitive, and/or developmental disabilities. They may help owners in a variety of ways including performing daily tasks, alerting owners who are deaf or hard of hearing to important sounds, providing companionship, support, and motivation, and/or monitoring and warning owners about oncoming seizures.
For more general information you may wish to visit the Assistance Dogs International website. (www.assistancedogsinternational.org)

**Chinese Scalp Acupuncture**

Chinese scalp acupuncture (CSA) is a contemporary acupuncture technique combining Chinese acupuncture with knowledge of anatomy, physiology, and pathology of the cerebral cortex. The more general acupuncture therapy is often called body acupuncture. There are four types of Chinese scalp acupuncture techniques. In scalp acupuncture, very short, fine needles are placed on the scalp to achieve the desired therapeutic effects on the different parts of the body.

**Conductive Education**

Contributed by Jennifer Lyman. Jennifer describes herself first as a parent advocate. She has a child who has CP. She holds an MS in Health and Human Performance with Certifications in Recreation Therapy, Conductive Education, and Alternative Access for Communication and Powered Mobility.

Conductive Education was developed by Dr. Andras Peto in Budapest, Hungary in 1945. According to the Colorado Foundation of Conductive Education, Dr. Peto believed that movement disorders in children with cerebral palsy were due to problems of learning, and that a motor disabled child could develop new physical skills through repetition of those movements. From this belief he developed Conductive Education, a multidisciplinary education model for children and adults with non-progressive neurologically based motor impairments. Conductive Education (CE) has now become an education and rehabilitation tool around the world. It tends to be more popular in Europe and Australia, however in the United States and Canada private programs and even some public schools have adopted the model.

Conductive Education is taught in a group classroom setting by a trained “Conductor.” A Conductor has a four year degree from the Peto Institute, (www.peto.hu/en/) which basically encompasses learning about the motor, sensory, speech, and processing of individuals with neurologically based motor impairments. Conductive Education classes vary in frequency and duration depending on the type of program (i.e. after school, summer camp), however most are 3-4 hours long, 5 days a week for 3-4 weeks at a time. The research has shown that participants in CE who have 3 weeks in a program, then 3 weeks off, transfer skills more efficiently than those who are in a program throughout the year. Prior to the beginning of a session, the conductor will evaluate and match participants according to age and ability. For example, a class may consist of a group of 5-7 year old quadriplegic children working on similar physical, academic and social skills. The Conductor then designs the lessons and tasks based on the needs of the individuals in the class. Basic principals of CE include Group Interaction, Task Series, Rhythmic Intention, Self Speak and Specialized Equipment.
Although all classes are different, all will incorporate these principals. The lesson relies on these principals in combination with Focus, Intensity, Repetition and Personal Motivation to help the individual learn to function differently. These are key components to the current understanding of neuroplasticity.

The difficulty with Conductive Education is that it has been introduced in the US as a therapy instead of an educational model and therefore is compared to other therapies. The reality is that it is an educational tool and should be compared accordingly.

**CranioSacral Therapy**

The Upledger Institute describes CranioSacral therapy for children in the following way, "It is a light-touch therapy shown to be effective in supporting the central nervous system so that your child's body can self-correct and heal naturally." Therapists use a light touch and monitor the rhythm of the fluid that is flowing around the central nervous system to detect potential problems.

They use gentle hands-on techniques to release any tensions that may be affecting your child's brain and spinal cord. The Upledger Institute reports that because of its gentle, non-invasive qualities, it seamlessly accommodates other therapies developed by early-intervention medical teams.

**Check with your child's neurologist and/or doctors to make sure this therapy is appropriate for your child and there are no contraindications. I would think (but do not know) this would be particularly important if your child has an active neurological hemorrhage or shunt.**

For further information see the Upledger Institute website: [www.upledger.com](http://www.upledger.com)


**Deep Brain Stimulation**

From the Mayo Clinic: "Deep brain stimulation involves implanting electrodes within certain areas of your brain. These electrodes produce electrical impulses that regulate abnormal impulses. Or, the electrical impulses can affect certain cells and chemicals within the brain. The amount of stimulation in deep brain stimulation is controlled by a pacemaker-like device placed under the skin in your upper chest. A wire that travels under your skin connects this device to the electrodes in your brain."

Deep brain stimulation is used to treat a number of neurological conditions, such as:

- Essential tremor
- Parkinson’s disease
• Dystonia

**More in depth DBS research investigating its use in CP is still needing to be conducted but there appears to be emerging evidence that it may be helpful for dyskinetic forms of cerebral palsy.

Feldenkrais

**Functional Integration (FI) is the individualized hands-on mode of the Feldenkrais Method. It is a non-medical movement modality. During FI lessons the student is guided through a series of positions and gentle movements (fully clothed), all within the easy range of motion. Staying within this range allows him to experience more completely what is possible for him at that given moment. He experiences himself as “whole”, which improves his self-image. When movements within this range occur that he has not experienced before, new connections are formed and new movements that seemed impossible before then emerge. The intelligent nervous system “chooses” the ones that are more pleasant and efficient. These replace the more stressful, difficult patterns, and when they “work” they are reinforced and become part of daily life.**

It is postulated that moving more freely with less wasted effort makes daily life less stressful and more enjoyable for the child with CP. Because the Feldenkrais Method focuses on the relationship between movement and thought, increased mental awareness and creativity may accompany physical improvements.

To learn more about the Feldenkrais Method visit and to find a practitioner near you visit: [www.feldenkrais.com](http://www.feldenkrais.com).

Written by Jane Ella Matthews, Feldenkrais Practitioner, LMBT, and retired special education teacher.

Hyperbaric Oxygen Therapy

Hyperbaric oxygen is an established treatment for a variety of medical problems: wound healing, carbon monoxide poisoning, and decompression sickness. To provide the treatment, a person is placed in a hyperbaric oxygen (HBO) chamber. This chamber delivers oxygen at increased atmospheric pressures thereby increasing oxygen delivery to injured tissues in the body. In the last 20 years it has been used intermittently for the treatment of cerebral palsy, targeting the injured tissues in the brain. The goal of the therapy in CP is to provide increased oxygenation to the part of the brain between the injured brain tissue and the healthy brain tissue. The theory is that increasing oxygen delivery to these cells will reactivate the dormant cells in the brain and stimulate regrowth of the damaged tissues. This regrowth will then, in theory, lead to decreased physical limitations. Costs range from $100-$400 per treatment. Potential side effects from the treatment include ear problems due to increased pressure and an increase in
seizures.

Masgutova Neurosensorimotor Reflex Integration-MNRI

This section was contributed by Andrea Bowers who is a movement and learning specialist. She is both an Anat Baniel Method Practitioner, Feldenakrais Method Practitioner and has taken courses with Dr. Masgutova who developed MNRI. Andrea is also the parent of a young adult son with cerebral palsy.

Dr. Svetlana Masgutova began researching the function of reflexes after she had success helping traumatized children using information from a method called “Brain Gym”. Brain Gym focuses on integrating early reflexes to help children who are atypical in development. Masgutova’s exploration of reflexes, the brain, and learning led her to develop the Masgutova Neurosensorimotor Reflex Integration (MNRI) program she teaches at the university in Poland and in private courses in the US and other countries.

She identifies reflexes as a blueprint for learning voluntary movement and are key to establishing a connection in the brain linking the lower (reflex) and upper (voluntary) parts of the brain. Masgutova has developed a list of human reflexes including some that she herself has identified.

In healthy infants reflexes appear at ordered times. Some reflexes appear near or at birth and some appear at 2 months, 6 months etc. therefore, what is considered “normal” in reflex evaluations depends on the age of the child being observed. Each reflex has a specific trigger and consistent motor response that continues to be active for a finite period of time. The repetition of the same motor response gives the baby an opportunity to learn to repeat it as voluntary movement.

“Integration” of a reflex indicates that a connection has been made between different levels of the brain. The reflex has achieved its function and becomes inactive, becoming secondary to higher brain activity unless called upon in an emergency situation. It is suspected that voluntary motor skills learned without the reflex foundation are not as robust and can be much more easily overwhelmed by stresses and environmental factors.

If typical development is not occurring due to abnormal brain functioning or a limitation in learning a reflex can be present in a pathologically strong way, hijacking the person’s nervous system and eliminating the possibility to experience other reflexes. In an extreme case, no matter which trigger is activated the pathological reflex responds. Masgutova has identified specific reflex groups that are consistently not integrated in some conditions such as ADD and autism. She continues to research connections between other limiting conditions and reflexes.

In workshops and family camps Masgutova teaches parents and professionals to
identify the state of each reflex by using tests she has devised that create a trigger and 
an observable reaction. Repetitive exercises are then used to normalize the person’s 
un-integrated reflexes. The specialist or parent triggers the reflex then physically moves 
the child through the correct reaction pattern.

Masgutova and her teams of core specialists teach 3 to 4 day workshops open to 
parents, professionals, and people who wish to continue her programs to qualify as a 
core specialist. There are workshops in Dynamic and Postural Reflex (the basic theory 
class) as well as Facial, Tactile, Upper Limbs and many others.

Family camps are intensives of 4 days to two weeks where children receive individual 
lessons 6 times per day. The lessons are from a variety of modalities that Masgutova 
believes contribute towards her goal of integrating reflexes and establishing higher brain 
function.

At camps or in private lessons Masgutova herself does the full evaluations on each 
child, usually up to 2 hrs per day, and a home program is designed and taught to 
parents by her assistants. Children who do not tolerate the exercises well can be 
worked with in their sleep. Four months is the minimum amount of time recommended 
for expecting change.

It is recommended that children return every 4 to 6 months for re-evaluation and further 
intensives, as well as seeking private sessions with a local MNRI specialist if one is 
available.

You may wish to visit the Svetlana Masgutova Educational Institute website 
(http://masgutovamethod.com)

You may visit Andrea's website at: www.AndreaLBowers.com

**Selective Percutaneous Myofascial Lengthening (SPML) Surgery**

An outpatient surgery used to treat spasticity and tight tendons by releasing tight bands 
of tendon where muscle and tendon overlap called the myofascia. When the myofascia 
is cut, the muscle under it can more easily stretch and lengthen. Percutaneous refers to 
the small incisions made in the myofascia during this procedure. There are several parts 
of the body where the Percs SPML procedure may be used and include at the back of 
the ankle for calf and heel cord tightness and spasticity, behind the knee for hamstring 
tightness and spasticity, and in the groin area for scissoring gait and groin spasticity. 
The Percs (SPML) method has been developed over the last 20 years by Dr. Roy 
Nuzzo of Summit NJ.
Stem Cell Applications

Where are we in our quest for applying stem cells to treat CP? The following lecture from CP Alliance (www.youtube.com/watch?v=fRjH6aZlG1w&feature=youtu.be) in Australia was held on May 21, 2013. It discusses the states of affairs in our quest to find if stem cells can help people with cerebral palsy. Here is my summary blog post on the CP Alliance telecast May 2012 telecast. (http://cpdailyliving.com/update-on-stem-cells-cerebral-palsy-summary-of-the-cp-alliance-webcast)

Cure CP is a US based and parent run non-profit focused on funding CP research. They have a question and answer page with information about stem cells. www.curecp.org/faq/php

Here is a great resource from the ISSR (International Society for Stem Cell Research). The web address is: www.isscr.org. It offers information to help separate fact from fiction as it relates to understanding the application of stem cell therapy/medicine.

Therapeutic Riding/Hippotherapy

Therapeutic riding uses equine-assisted activities for the purpose of supporting the cognitive, physical, emotional and social well-being of people with disabilities. Experiencing the rhythmic motion of a horse moves the rider's body in a manner similar to a human gait. As a result, riders with physical needs often show improvement in flexibility, balance and muscle strength. This is because the horse is providing input in ways the rider may not be able to receive otherwise. In addition to the physical benefits, horseback riding also provides an outdoor recreational opportunity for children and the associated psychological and social benefits. During a session, a child will be placed on a horse that is commensurate with the child’s size. The horse and child are then assisted by two side walkers who walk alongside the horse and a horse leader who walks in front. They provide stability and guidance while the child is on the horse. Riding classes are usually taught by an instructor with a strong equine background, as well as an understanding of various disabilities.

Equine assisted training for children with disabilities falls into two separate categories: therapeutic riding and hippotherapy. Hippotherapy involves a licensed therapist providing speech-language, occupational, physical therapy, or psychotherapy combined with equine movement in an effort to help a child with disabilities. In this setting, a trained therapist sets therapy goals and guides the child through a series of activities designed to help the child achieve greater independence in movement, postural stability, and strength. On the other hand, therapeutic riding involves a riding instructor with no medical background teaching a child with special needs to ride a horse. The therapeutic riding sessions do not focus on specific therapeutic interventions or therapy goals.

http://cpdailyliving.com/types-of-therapy
In an effort to bring the benefits hippotherapy to a greater number of children, certain centers will sit a child on a machine that is designed to stimulate the movements of a horse.

Here is a link to PATH International (www.pathintl.org) which can help you locate a therapeutic riding center near you.

For information about Hippotherapy you may visit the American Hippotherapy Association's website. (www.americanhippotherapyassociation.org)

Yoga

The classical techniques of Yoga date back more than 5,000 years. It is a system of physical and mental exercise. The word Yoga means "to join or yoke together", and it brings the body and mind together into one harmonious experience.

The whole system of Yoga is built on three main structures: exercise, breathing, and meditation. The body is looked upon as the primary instrument that enables us to work and evolve in the world, and so a Yoga student treats it with great care and respect. Breathing techniques are based on the concept that breath is the source of life in the body. The Yoga student gently increases breath control to improve the health and function of both body and mind. These two systems of exercise and breathing then prepare the body and mind for meditation, allowing the student to cultivate a quiet mind that allows silence and healing from everyday stress. –Adapted from www.americanyogaassociation.org

There are over one hundred different schools of yoga! There is one program I am aware of that has been specifically designed for children with special needs. It's called "Yoga for the Special Child" by Sonia Sumar. There may be more formal programs out there, and there certainly are instructors who have experience working with children and adults who have physical impairments.

Adapted from the online article, "Types of Treatments/Interventions" from CP Daily Living. Reprinted with permission from CP Daily Living. For the complete article, which includes more detailed descriptions with research studies and personal experiences from parents, visit http://cpdailyliving.com/types-of-therapy.
Adolescents with cerebral palsy (CP) often face difficulties transitioning from pediatric to adult primary and specialty healthcare providers willing/able to manage routine and complex care effectively. The recommendations below provide guidance for medical professionals to minimize the frustrations and stresses of adolescent patients and to support continuing good health and quality of life as they mature into adults.

1. Explain and discuss special healthcare needs your patient has and may have in the future.

2. Institute concrete plans for transition to adult healthcare services by mid-adolescence.

3. Identify adult primary (e.g. Internal or Family Medicine, OB/GYN) and specialized (e.g. Physiatry, Orthopedics, Therapeutic) healthcare options.

4. Inform of possible changes in healthcare insurance coverage.

5. Consider emotional attachments to past providers and build bridges to future providers.

6. Promote independence and personal responsibility for healthcare when feasible.

7. Discuss sexuality in general and as specific to CP.

8. Encourage exercise and healthy eating habits, providing specific suggestions to individuals and/or their families and caregivers.

O’Ryan Case, MPH
United Cerebral Palsy

James A. Blackman, MD, MPH
Cerebral Palsy International Research Foundation

January 2014
Section 4: Resources

Where to go for further information
## Cerebral Palsy

### Bibliography

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<td>Taking Cerebral Palsy To School [Childrens] (6th Book In Our &quot;Special Kids In School&quot; Series)</td>
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| **Bound Materials** | **Specific Disabilities -- Cerebral Palsy** | Cerebral Palsy Information packet | LANGUAGE |

| **Kits** | **Specific Disabilities -- Cerebral Palsy** | Living With Cerebral Palsy [childrens] (Living Well) | CHILDREN 362.196836 21 GRAY, SUSAN HEI GRAY |
The following excerpt has been taken from the Christopher & Dana Reeve Foundation Paralysis Resource Center website.
http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453213/k.7D62/Cerebral_Palsy.htm#

Cerebral Palsy

Cerebral palsy refers to a group of conditions that affect control of movement and posture. Due to damage to one or more parts of the brain that control movement, an affected person cannot move his or her muscles normally. Symptoms range from mild to severe, including forms of paralysis.

With treatment, most children can significantly improve their abilities. Although symptoms may change over time, cerebral palsy by definition is not progressive, so if increased impairment occurs, the problem may be something other than cerebral palsy.

Many children with cerebral palsy have other problems that require treatment. These include mental retardation; learning disabilities; seizures; and vision, hearing and speech problems.

Cerebral palsy usually is not diagnosed until a child is about 2 to 3 years of age. About 2 to 3 children in 1,000 over the age of three have cerebral palsy. About 500,000 children and adults of all ages in this country have cerebral palsy.

The three major types of cerebral palsy:

**Spastic cerebral palsy.** About 70 to 80 percent of affected individuals have spastic cerebral palsy, in which muscles are stiff, making movement difficult. When both legs are affected (spastic diplegia), a child may have difficulty walking because tight muscles in the hips and legs cause legs to turn inward and cross at the knees (called scissoring). In other cases, only one side of the body is affected (spastic hemiplegia), often with the arm more severely affected than the leg. Most severe is spastic quadriplegia, in which all four limbs and the trunk are affected, often along with the muscles controlling the mouth and tongue. Children with spastic quadriplegia have mental retardation and other problems.

**Dyskinetic cerebral palsy.** About 10 to 20 percent have the dyskinetic form, which affects the entire body. It is characterized by fluctuations in muscle tone (varying from...
too tight to too loose) and sometimes is associated with uncontrolled movements (which can be slow and writhing or rapid and jerky). Children often have trouble learning to control their bodies well enough to sit and walk. Because muscles of the face and tongue can be affected, there also can be difficulties with sucking, swallowing and speech.

**Ataxic cerebral palsy.** About 5 to 10 percent have the ataxic form, which affects balance and coordination. They may walk with an unsteady gait and have difficulty with motions that require precise coordination, such as writing.

There are many things that occur during pregnancy and around the time of birth that can disrupt the normal development of the brain and result in cerebral palsy. In about 70 percent of cases, brain damage occurs before birth, although it also occurs around the time of delivery, or in the first months or years of life.

Some of the known causes include:

**Infections during pregnancy.** Certain infections in the mother, including rubella (German measles), cytomegalovirus (a mild viral infection), and toxoplasmosis (a mild parasitic infection) can cause brain damage and result in cerebral palsy.

**Insufficient oxygen reaching the fetus.** For example, when the placenta is not functioning properly or it tears away from the wall of the uterus before delivery, the fetus may not receive sufficient oxygen.

**Prematurity.** Premature babies who weigh less than 3 1/3 pounds are up to 30 times more likely to develop cerebral palsy than full-term babies.

**Complications of labor and delivery.** Until recently, doctors believed that asphyxia (lack of oxygen) during a difficult delivery was the cause of most cases of cerebral palsy. Recent studies show that this causes only about 10 percent of cases.

**Rh disease.** This incompatibility between the blood of the mother and her fetus can cause brain damage, resulting in cerebral palsy. Fortunately, Rh disease usually can be prevented by giving an Rh-negative woman an injection of a blood product called Rh immune globulin around the 28th week of pregnancy and again after the birth of an Rh-positive baby.

**Other birth defects.** Babies with brain malformations, numerous genetic diseases, chromosomal abnormalities, and other physical birth defects are at increased risk of cerebral palsy.

**Acquired cerebral palsy.** About 10 percent of children with cerebral palsy acquire it after birth due to brain injuries that occur during the first two years of life. The most common causes of such injuries are brain infections (such as meningitis) and head injuries.
Cerebral palsy is diagnosed mainly by evaluating how a baby or young child moves. Some children with CP have low muscle tone, which can make them appear floppy. Others have increased muscle tone, which makes them appear stiff, or variable muscle tone (increased at times and low at other times).

The doctor also may suggest brain-imaging tests such as magnetic resonance imaging (MRI), computed tomography (CT scan), or ultrasound. These tests sometimes can help identify the cause of cerebral palsy.

**How is cerebral palsy treated?**

A team of health care professionals works with the child and family to identify the child’s needs. The team may include pediatricians, physical medicine and rehabilitation physicians, orthopedic surgeons, physical and occupational therapists, ophthalmologists, speech/language pathologists, and social workers and psychologists.

The child usually begins physical therapy soon after diagnosis. This enhances motor skills (such as sitting and walking), improves muscle strength, and helps prevent contractures (shortening of muscles that limits joint movement). Sometimes braces, splints or casts are used along with therapy to help prevent contractures and improve function of the hands or legs. If contractures are severe, surgery may be recommended to lengthen affected muscles.

Drugs may be used to ease spasticity or to reduce abnormal movement. Unfortunately, oral drug treatment is often not very helpful. Sometimes injection of drugs directly into spastic muscles is more helpful, and the effects may last several months. A new type of drug treatment is showing promise in children with moderate to severe spasticity affecting all four limbs. During a surgical procedure, a pump is implanted under the skin that continuously delivers the anti-spasmodic drug baclofen.

For some children with spasticity affecting both legs, selective dorsal rhizotomy may permanently reduce spasticity and improve the ability to sit, stand and walk. In this procedure, doctors cut some of the nerve fibers that are contributing most to spasticity. This procedure usually is done when a child is between 2 and 6 years of age.

Research suggests that cerebral palsy results from incorrect cell development early in pregnancy. For example, a group of researchers has recently observed that more than one-third of children with cerebral palsy also have missing enamel on certain teeth. Scientists are also examining other events -- such as bleeding in the brain, seizures, and breathing and circulation problems -- that threaten the brain of a newborn baby. Some investigators are conducting studies to learn whether certain drugs can help prevent neonatal stroke, and other investigators are examining the causes of low birth-weight. Other scientists are exploring how brain insults (like brain damage from a shortage of oxygen or blood flow, bleeding in the brain, and seizures) can cause the abnormal release of brain chemicals and trigger brain disease.
Sources:

United Cerebral Palsy, March of Dimes, National Institute of Neurological Disorders and Stroke

Web Sites

www.ucp.org
United Cerebral Palsy
1-800-872-5827
info@ucp.org
1660 L Street Suite 700
Washington, DC 20036
UCP's mission is to advance the independence, productivity, and full citizenship of people with cerebral palsy and other disabilities, through a commitment to the principles of independence, inclusion, and self-determination.

http://cpirf.org
Cerebral Palsy International Research Foundation
1025 Connecticut Ave., Suite 701
Washington, DC 20036
202-496-5060
Formerly UCP Research and Educational Foundation, no longer affiliated with UCP.

www.modimes.org
The March of Dimes Birth Defects Foundation
914-997-4488
1275 Mamaroneck Avenue
White Plains, NY 10605
Features resources and connections to address four major problems threaten the health of America's babies: birth defects, infant mortality, low birth weight, and lack of prenatal care.

The National Institute of Neurological Disorders and Stroke
Offers fact sheets on CP.

http://www.disaboom.com/Health/Cerebral-Palsy.aspx
Disaboom: Cerebral Palsy

http://www.aacpdm.org/index?service=page/Home
The American Academy for Cerebral Palsy and Developmental Medicine (AACPDM)
414-918-3014
info@AACPDM.org
555 E. Wells Street Suite 1100
Milwaukee, WI 53202
AACPD is a multidisciplinary scientific society devoted to the study of cerebral palsy and other childhood onset disabilities, to promoting professional education for the treatment and management of these conditions, and to improving the quality of life for people with these disabilities. The Academy was founded in 1947 "to foster and stimulate professional education, research, and interest in the understanding of these conditions and in improving the care and rehabilitation of affected persons." The diversity of the six founding members (an orthopedic surgeon, a neurologist, two pediatricians, a neurosurgeon and a physiatrist) signified the necessity for an interchange of ideas and experiences among all of those who provide care for patients with cerebral palsy. The foresight of our founders is reflected by the Academy's increasing membership of specialists in these and other disciplines. The scope of the Academy's interests has expanded from an initial focus on cerebral palsy into related areas of developmental medicine, including spina bifida, neuromuscular disease, traumatic brain injury and other acquired disabilities, genetic disorders, communications problems, and specific learning disabilities.

www.stlouischildrens.org
The Cerebral Palsy Center at St. Louis Children’s Hospital
314-454-6000
The Center is known for its spasticity management program using rhizotomy.

http://www.uclaccp.org/
Center for Cerebral Palsy at UCLA
310-825-5858
mgreenberg@mednet.ucla.edu
1000 Veteran Avenue
Room 22-64
Los Angeles, CA 90095-1795
Is an interdisciplinary clinic for the medical management of movement disorders in children with cerebral palsy.

http://gait.aidi.udel.edu/gaitlab/cpGuide.html
Cerebral Palsy: A Guide for Care from the Alfred I. DuPont Institute in Wilmington, Delaware

www.theCPGroup.org
The CP Group
Information for those with CP as well as an online forum where messages and questions can be exchanged.

http://www.familyvillage.wisc.edu/lib_cerp.htm
Family Village—Cerebral Palsy
Includes chat room listings and a variety of resources including international information and non-English speaking resources.
MedlinePlus—Cerebral Palsy

www.reachingforthestars.org
Reaching for the Stars, Inc.
770-561-5950
info@reachingforthestars.org
3000 Old Alabama Road Suite 119-300
Alpharetta, GA 30022
A non-profit organization started by parents of children with CP. Creating a research foundation centered on the belief that leading-edge research by progressive scientists, physicians, and therapists can lead to a cure of CP.

Kids Health for Kids: Cerebral Palsy

http://www.cpparent.org/
CPParent Resource Center
CPParent is a group of parents, caregivers and others who work with children with cerebral palsy.

http://www.uhms.org
The Undersea and Hyperbaric Medical Society (UHMS)
410-257-6606
uhms@uhms.org
10020 Southern Maryland Blvd. Suite 204
Dunkirk, MD 20754
It provides information to improve the scientific basis of hyperbaric oxygen therapy. There are more than 2,500 hyperbaric scientist and physician members around the world.

http://www.thecpnetwork.org
The Cerebral Palsy Network
They are a non profit corporation consisting of parents and individuals across the globe who share an interest in CP.

http://www.cpisra.org/
Cerebral Palsy International Sports and Recreation Association
CPISRA is committed to enhancing the opportunities for people with cerebral palsy or a related neurological condition to participate in the sport or leisure activity of their choosing.

http://www.cprf.org/
Cerebral Palsy Research Foundation
5111 East 21st Street N.
Wichita, KS 67208
316-688-1888
Providing people with disabilities customized services, supports and technologies, with an emphasis on employment and training options, to facilitate their chosen economic and personal independence.

Origins of Cerebral Palsy

Suits Me Latex-Free Swimwear
Phone: 352-666-1485

Chat Rooms/Message Boards

Yahoo offers several cerebral palsy message groups for connecting to the greater CP community. Click on “groups” on the home page and search for “cerebral palsy”.

The CP Group
Information for those with CP as well as a forum where messages can be exchanged.

The following books and videos are available for free loan from the PRC library. For more information, please see www.paralysis.org and click the Lending Library tab.

Books

Appleton, Andrew B. The Disabled Father: The Story of a Father and His Son. Lincoln, Neb.: iUniverse, 2005. Appleton’s son has CP.


Barker, George A. Jr. Moon Gate Dreams: A Quest for Romance and Adventure Beyond the Moon Gate. Bend, Ore.: Maverick Publications, 1997. Barker was left quadriplegic from a mosquito bite that gave him encephalitis. Diagnosed with a form of CP.


Joel, Gil S. *So Your Child Has Cerebral Palsy*. Albuquerque, NM: University of New Mexico Press, 1975.


See the Adult Volume, Chapter 3 for info specific to Cerebral Palsy.

Killilea’s daughter Karen was born with CP.

A continuation of Karen’s life story.


Kramer details her experience raising son Seth who has CP.


McHugh’s brother had CP and mental retardation.


Nixon’s autobiography.


The author has all 5 types of CP which is rare. Biography.


Rose, Colleen. **Step by Step: Real Life Experiences with Cerebral Palsy.** Toronto: Rose Publishing, 1995. Rose’s daughter Lisa has CP.


Stamer, Marcia, PT. **Posture and Movement of the Child with Cerebral Palsy.** Therapy Skill Builders, 2000.


Swinford, Beth E. **Traveling Uphill in a Wheelchair: Growing Up with Cerebral Palsy.** 1996.


Wambach, Timothy. **Keep on Keeping On: How a Little Kid With Nothing to Lose Helped a Big Kid find it All.** Advantage Inspirational, 2995. Wambach is inspired by his friend Mike Berkson who has CP.


**Children’s Books**

-Aiello, Barbara and Jeffrey Shulman. *It’s Your Turn at Bat*. Frederick, MD: Twenty-First Century Books, 1988. The Kids on the Block Book series. Fiction. Mark, a fifth-grader with CP, discovers that the money for the baseball team’s jerseys is missing. Includes a Q&A section on living with CP.


-Mikaelsen, Ben. **Petey**. New York: Hyperion, 1998. Fiction. In 1922, Pete who has CP is institutionalized and thought to be an idiot. Sixty years later, he befriends a boy and shares with him the joy of life.


- Scott, Rosanna. **Peter and Friends at Camp.** Hollidaysburg, Penn.: Jason & Nordic Publishers, 2006. Peter has juvenile rheumatoid arthritis and Dalton has cerebral palsy. Together they attend camp for the first time.


-Wanous, Suzanne. Sara’s Secret. Minneapolis, MN: Carolrhoda Books, 1995. Fiction. Sara is afraid that if her schoolmates find out her brother has CP, they won’t like her. She brings her brother to class to explain about CP.


Videos

- **Body & Soul: Diana & Kathy.** New York: Welcome Change Productions, 2007. DVD 40 minutes. [www.dianaandkathy.com](http://www.dianaandkathy.com) Two friends, one has Down syndrome and the other has cerebral palsy, advocate for better housing for people with disabilities.

- **Breaking Bad. The Complete First Season.** Sony, 2008. 3 DVDs. TV series on AMC. The main character’s teen son has CP which affects his mobility and speech.

- **Catching My Breath: The Life and Races of Athlete Ken Thomas.** Canadian Learning Co., 2008. DVD 48 minutes. Ken Thomas is a Canadian wheelchair racer.


• Cerebral Palsy: What Teachers Need to Know. Houston, TX: Digital 2000 Inc. Phone 1-800-334-1523.


• A Day At a Time. New York: Filmmaker’s Library, 1992. 58 min. The portrait of four siblings, two of whom have CP and are twins. The more severely disabled twin must have surgery.

• Door to Door. Warner Home Video, 2002. 91 minutes in VHS and DVD Based on the true story of Bill Porter who has CP and becomes a top door to door salesman for his company.

• Handling, Positioning & Feeding Children with Cerebral Palsy/Techniques for Parents and Professionals. Distributed by AOTA.

• If I Can’t Do It. Boston, MA: Fanlight Productions, 1998. 57 minutes The story of Arthur Campbell Jr.’s life with CP. He was sheltered by his family for the first 38 years of his life. He later lived independently and became a disability rights activist.

• My Left Foot. HBO Video/Miramax Films, 1990. 103 minutes. VHS and DVD. Based on the true story of Christy Brown, a poet who communicates with his left foot.

• King Gimp. Princeton, NJ: Films for the Humanities & Sciences, 1999. 50 minutes. Oscar-Award winning documentary of Dan Keplinger, filmed over thirteen years. VHS and DVD

• The King of Arts. Baltimore, Md.: University of Maryland at Baltimore School of Medicine, 2007. DVD 10 minutes. Documentary of Dan Keplinger’s art work.

• The King’s Miracle. Baltimore, Md.: University of Maryland at Baltimore School of Medicine, 2004. DVD 7 minutes. Focuses on Dan Keplinger’s life after he is featured in King Gimp. He is an artist and travels to speak on arts and disabilities.

• May’s Miracle: A Retarded Youth with a Gift for Music. New York: Filmmakers Library, 1994. Leslie was blind, retarded and had CP when his adoptive mother found out he had a gift for music. Documentary


- **Rachael, Being Five.** University of Maryland Video Press, 200?. DVD 28 minutes.

- **Rachael in Middle School.** University of Maryland Video Press, 200?. DVD 28 minutes.

- **Revel in the Light: The Story of Rebecca Beayni.** Scarsborough, Ont.: MasterWorks Productions, DVD. 12 minutes.

- **Rory O’Shea Was Here.** Universal. 2005 105 min. The two lead characters are wheelchair users (one with CP and the other has Duchenne muscular dystrophy). They live together with the help of an aid. Drama.

- **Storytelling.** New Line Cinema, 2002. 90 minutes. DVD Drama Features a male college student who has CP.

- **Test of Love.** Universal City, Calif.: MCA Home Video, 1984. 93 minutes. Drama about a teen with CP. Based on a true story.

- **Touched by Love.** RCA/Columbia, 1984 VHS 95 minutes. Based on the book To Elvis, With Love. A young girl with CP starts a correspondence with Elvis Presley.

- **Waddie Welcome: A Man Who Cannot Be Denied.** University of Georgia. Distributed by Program Development Associates, 1997. 26 minutes. Waddie lived with his family for 60 years until his last relative died. He was then placed in a nursing home. The film focuses on community-based care and person-centered planning that enabled him to find another home in the community to live in.

The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It
should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see your physician or other qualified health care provider promptly. Always consult with your physician or other qualified health care provider before embarking on a new treatment, diet or fitness program. You should never disregard medical advice or delay in seeking it because of something you have read in this message.
Since 1982, Support for Families has offered information, education, and parent-to-parent support free of charge to families and professionals of children with any kind of disability, concern, or special health care need in San Francisco.

All services are free of charge:

- Phone Line & Drop-In Center
- Information & Resources
- Resource Library
- Support Groups
- Parent Mentor Program
- Educational Workshops
- Family Special Events
- Short-term Counseling
- Community Outreach & Satellites

SUPPORT FOR FAMILIES OF CHILDREN WITH DISABILITIES

1663 Mission St, 7th Floor
San Francisco, CA 94103
415-282-7494
415-920-5040 (Phoneline)
info@supportforfamilies.org
www.supportforfamilies.org

HOURS
MWF 9:30am – 4:30pm
TTH 12:30pm – 8:30pm

PUBLIC TRANSIT
BART: 16th St Mission (3 blocks to 13th)
MUNI: 14 Mission, 49 Van Ness, Van Ness Metro Station
1. Are you a:  **PARENT/CAREGIVER**  **PROFESSIONAL**  **OTHER**  (CIRCLE ONE)

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<th>Neutral</th>
<th>Disagree</th>
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<td>Helped increase my knowledge about my child’s needs or disability, and/or the needs of children with disabilities and their families</td>
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<td>4</td>
<td>3</td>
<td>2</td>
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<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
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<tr>
<td>Helped increase my knowledge of resources or services</td>
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<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>N/A</td>
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<tr>
<td>Helped provide strategies to advocate for my child and/or children I serve as well as participate in the decision-making process</td>
<td>5</td>
<td>4</td>
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(The following questions are for Parents/Caregivers Only)

| Helped increase my ability to communicate with professionals | 5   | 4   | 3   | 2   | 1   | N/A |
| Helped increase my knowledge of parent participation activities at the school as well as school reform | 5   | 4   | 3   | 2   | 1   | N/A |

(The following questions are for Professionals Only)

| Helped increase my ability to communicate with families and service providers | 5   | 4   | 3   | 2   | 1   | N/A |
| Helped increase my knowledge of family-centered care | 5   | 4   | 3   | 2   | 1   | N/A |

3. On a scale of 1 to 5, with 5 being the best, how would you rate the value of this packet?

- Great Value 💎 [ ] 5
- Agree [ ] 4
- Neutral [ ] 3
- Disagree [ ] 2
- Strongly Disagree [ ] 1
- Little Value 💙

**Comments:**

4. On a scale of 1 to 5, with 5 being the best, how would you rate the quality of this packet?

- Great Quality 💎 [ ] 5
- Agree [ ] 4
- Neutral [ ] 3
- Disagree [ ] 2
- Strongly Disagree [ ] 1
- Little Quality 💙

**Comments:**

5. Would you recommend this packet to others? [ ] Yes [ ] No

6. What did you find most useful?

7. What did you find least useful?

8. Any other articles or information you would like to see?

9. Has this information made it more likely that special education issues can be resolved without having to go to Fair Hearing? [ ] Yes [ ] No [ ] Not Applicable

   If not, why not?

(Optional Information) Name:  Phone Number:

_Evaluations help us improve our services and report back to our funders, which allows us to continue to provide our services - including these packets - free of charge. Please complete and return this evaluation in one of four ways:_

1. Mail this evaluation to our office by folding this sheet of paper into thirds (see other side of page).
2. Scan or take a photo of this evaluation and email it to newsletter@supportforfamilies.org
3. Fax this evaluation to 415-282-1226
4. Or fill out the evaluation online: www.surveymonkey.com/s/sfcd-info-packet

THANK YOU!