

Understanding Cerebral Palsy: A Parent's Guide

Introduction

As a parent, you may have many questions regarding your child's cerebral palsy diagnosis. As you look for answers, you may encounter information about cerebral palsy, its causes, and possible treatments. All of these different opinions can make it challenging for a family to organize options and begin to choose a treatment plan that best fits the family.

We hope that this packet will help better prepare you to understand the information you receive about treatments for cerebral palsy, as well as give you the chance to look over the most recent professional opinions about cerebral palsy.

Westside Regional Center anticipates supporting your family as you proceed from your child's initial diagnosis to ongoing support throughout his or her lifetime.

What is Cerebral Palsy?

Cerebral palsy, also referred to as CP, is a disorder that affects body movement and muscle coordination. However, although it affects the muscles in our bodies, it is not caused by problems in the muscles themselves or the nerves. Cerebral palsy is caused by the failure of the brain to develop properly during pregnancy or damage to the brain, either before, during, or after birth. In fact, the word *cerebral* means having to do with the brain, while *palsy* means muscle weakness.

It is important to know that, while the severity of this disorder has a wide range (from a slightly awkward walk to whole body weakness requiring a wheelchair), cerebral palsy is usually classified into four categories.

The four major types of cerebral palsy are:

1. **Spastic cerebral palsy** occurs when muscles are extremely tight, causing stiff movement of the body. It is the most common form of cerebral palsy and accounts for a majority of CP cases. Doctors will often further describe this form of cerebral palsy based on what specific body parts are affected. Some examples include:
 - Spastic diplegia - in both legs, muscles are tight, which may make it difficult to walk
 - Spastic hemiplegia – only one side of the body is tight/stiff, and arms or hands might be more affected than legs
 - Spastic quadriplegia – arms, legs, and body are affected, which may make it difficult to walk and talk
2. **Athetoid cerebral palsy** involves slow, uncontrolled, writhing movements. It usually affects the arms, legs, hands or feet. In some cases, the muscles of the face or tongue are affected, causing drooling or grimacing.

3. **Ataxic cerebral palsy** affects depth perception and balance. This usually means that patients walk unsteadily with feet placed widely apart and have a difficult time with precise movement (i.e. buttoning a shirt).
4. **Hypotonic cerebral palsy** involves very low muscle tone and muscle weakness especially in the trunk and arms and legs, but with reflexes (such as the knee swing) that are stronger than normal.

Although doctors classify cerebral palsy into those four main categories, it is not unusual for patients to have symptoms of more than one of those major types. Therefore, you should be aware of mixed forms of cerebral palsy, where the most common tends to include spasticity and athetoid movements.

Although the symptoms of cerebral palsy may change over the course of the lifetime, the actual brain damage does not get worse. Also, you should remember that cerebral palsy is not contagious and cannot be passed from parent to child.

How did my child receive this diagnosis?

Most diagnoses of cerebral palsy take place before age 3. However, for children with mild cerebral palsy, it may not be diagnosed until they are 4 or 5 years-old. If a doctor suspects that a child has cerebral palsy, he or she will usually schedule an appointment to check up on the child's physical and behavior development. A doctor determines a diagnosis of cerebral palsy through a series of steps:

- **Carefully looking over the parents' and child's medical history.** This is an important first step – it allows the doctor to understand your own parental concerns, as well as review the results of your child's previous tests and medical history. It also helps the doctor to avoid repetitious testing, which can be very stressful to your child.
- **Assessing your child's development.** The doctor will usually ask about the age of your child when he/she first started to walk, crawl, or roll over. This will allow your doctor to see if there was any indication of cerebral palsy in your child's development history.
- **Examining the child's motor skills.** This is usually when the doctor checks to see if your child has unusual posture or abnormal muscle tone. These are some of the most characteristic symptoms of cerebral palsy and will play an important role in the diagnosis of your child.
- **Checking your child's reflexes and early development of hand preference.** Asking the parent if the child prefers to use one particular hand or overly uses

Doctors are on the look-out for certain symptoms of cerebral palsy, such as:

- delays in head control (after 3-4 months), rolling over (after 6 months), sitting (after 7 months), crawling, smiling, and/or walking (after 15 months);
- weak or stiff muscles;
- favoring one side of the body during movement (before age 18 months);
- dragging a foot or leg during walking or walking on tip toes;
- drooling excessively;
- unusual posture or trouble moving from one position to another;
- difficulty swallowing or sucking;
- delayed speech;
- shaking a lot or having uncontrollable jerking of arms, legs or torso; and/or
- difficulty making precise movements.

the left or right side of his/her body will also give more evidence towards a diagnosis of cerebral palsy.

- **Making sure that your child's symptoms do not continuously worsen.** Though your child's exact symptoms can change over his/her *lifetime*, cerebral palsy is not progressive (i.e. the brain damage does not worsen). This is important because if your child is continuously losing motor skills, he/she might have another muscle disease or genetic disorder, not cerebral palsy.
- **Administering special tests.** These tests are given to your child to rule out other possibilities – other than cerebral palsy – for your child's movement problems or to learn about the brain damage that caused the cerebral palsy. These may include an MRI, or magnetic resonance imaging, scan which gives the doctor pictures of the brain to study or blood testing for genetic and other neurological disorders.
- **Searching for other conditions that are linked to cerebral palsy.** These related conditions can include epilepsy, mental retardation, speech and language problems, and problems with the muscles in the mouth, jaw or tongue (for example, problems swallowing). Testing for these are generally done only if the conditions are suspected, such as an EEG if epilepsy is suspected or developmental testing if mental retardation is suspected.

Your child may be evaluated by many doctors, including a pediatric neurologist, a pediatric orthopedist (bone/limb doctor) pediatric ophthalmologist (eye doctor), a pediatric ENT/otologist (ear doctor), and a developmental pediatrician in order to make sure that cerebral palsy is the right diagnosis and that your child gets the right treatments.

Evaluating Treatments

Before you explore the various treatments for cerebral palsy, here are some suggestions to help you evaluate your options for your child's therapy.

Determine whether this treatment is right for your child. No child with cerebral palsy is the same –children with CP often display a wide range of functioning and developmental differences. For example, some children will need a wheelchair to move around while others will only have slight tremors when they walk. For these reasons, one of the most important things to remember when thinking about treatments is to plan them specifically for your child. You must ask yourself, "Is the treatment right for my child? Which issues do I specifically want to address?" The best place to start is to have a complete assessment of your child's strengths, challenges, and needs by a team of medical professionals, including a physician, physical therapist, occupational therapist, and a speech therapist (this could be done, in part, by the medical professionals working within WRC or medical professionals that you already have). The exam would allow you to research treatments that specifically focus on the issues that are most important for your child.

Understand how much time and commitment the treatment will require. It is important to know that your family will play an important role in supporting and helping to carry out treatments. Therefore, many treatments may be stressful, not only for your child, but for your entire family. Some treatments may not have great benefit for your

child in his or her situation. When considering possible treatments, you should consider both the financial and emotional costs. *Does the benefit outweigh the costs for your child and family?* Also, if you decide to pursue a specific treatment, it is important that you know how to decide if the treatment is working. This allows you to monitor the progress of your child, so that you can decide whether or not you should continue or stop the treatment after a period of time.

Management and Treatment of Cerebral Palsy

Although there is no cure for cerebral palsy, there are a variety of treatments that can help make sure your child achieves his or her potential – physically, mentally, and emotionally. Your child’s symptoms can usually improve with early, intensive management, which works on functioning, capabilities, and quality of life. WRC has included a brief look at some of these therapies:

- **Physical therapy** to improve walking, stretch muscles, and prevent deformities
- **Occupational therapy** to develop strategies for everyday living, with a focus on activities such as dressing.
- **Speech therapy** to help with any swallowing problems or speech impediments
- **Braces** to help compensate for muscle imbalance and can help with posture and walking
- **Mechanical aids** (such as wheelchairs or walkers) to increase mobility
- **Communication aids** (such as computers) can help with communication for the more severely impaired
- **Medications** to help with muscle contractions, reduce shaking, and relax muscles. The most commonly prescribed drugs muscle relaxants, like Baclofen, or injections into the muscles to relax them, such as with Botox or botulinum toxin. Medications may also be needed for seizures or epilepsy, if present.
- **Surgery** to correct anatomical abnormalities or release tight muscles

Ideally, you and your doctors should share information back and forth. You should be partners in the care of your child and you should decide on the treatment plan together, with a focus on your child’s and family’s needs. The best management strategy for cerebral palsy involves a team approach that includes parents and caregivers, doctors and other health professionals. Many times, the best care is given in a cerebral palsy multi-disciplinary clinic, where all of the specialists come together at one place and time to plan for your child. The table below lists the role of each medical professional:

| Care provider | Roles/responsibilities |
|--|---|
| Primary physician | <ul style="list-style-type: none"> ▪ address specific systems problems and lead the treatment team, putting the plan in place ▪ bring together advice from all specialists ▪ follow carefully as the child goes through treatment to make sure it is the best care |
| Geneticists (specialty doctor) | <ul style="list-style-type: none"> ▪ evaluate genetic syndromes |
| Pediatric neurologist (specialty doctor) | <ul style="list-style-type: none"> ▪ diagnose and treat brain and nerve problems |

| | |
|--|---|
| Pediatric orthopedists (specialty doctors) | <ul style="list-style-type: none"> ▪ diagnose and treat specific muscle problems |
| Pediatric gastroenterologists (specialty doctors) and nutritionists | <ul style="list-style-type: none"> ▪ diagnose and treat feeding or swallowing problems |
| Rehabilitation medicine specialist (specialty doctors) and Physical therapists | <ul style="list-style-type: none"> ▪ design and implement treatments to develop and maintain muscles; help to do activities like walking, sitting, and balancing |
| Occupational therapists | <ul style="list-style-type: none"> ▪ teach fine motor skills necessary daily activities, such as dressing or writing |
| Speech and language therapists | <ul style="list-style-type: none"> ▪ work with those who have difficulty communicating or swallowing |
| Social workers | <ul style="list-style-type: none"> ▪ connect children and family members to needed community and education programs |
| Psychologists | <ul style="list-style-type: none"> ▪ provide therapy and support for stresses arising from the demands of CP |
| Educators | <ul style="list-style-type: none"> ▪ respond to any school issues that are related to CP or any other conditions |

What to expect medically

With good care, many people with cerebral palsy will live completely independently. About one-fourth of children with cerebral palsy have a mild form with little difficulty in walking or other activities. About half of children with cerebral palsy have moderate impairments and will need some assistance throughout their lives. About one-fourth of children have severe cerebral palsy so that they will need extensive assistance and will not be able to walk. Of the three-quarters of people with cerebral palsy who do walk, many will require assistive equipment.

Your child's primary doctor should continue to provide your child with regularly-scheduled medical care and preventive screenings. However, people with cerebral palsy are at higher risk for certain medical complications. Your child may have some of these or may develop them over time, but not every person with CP has these problems. The more severe the cerebral palsy, such as spastic quadriplegia, the more likely the child is to develop complications. These include:

- ***Seizures/epilepsy*** Generally about one-third of those with cerebral palsy have epilepsy, but up to 60% may eventually have one or more seizures. A pediatric neurologist should be consulted for this problem.
- ***Mental Retardation*** Cerebral palsy does not mean that your child's mental function is less than other children. Only one-third to one-half (30-50%) of people with cerebral palsy have mental retardation as well. It is important that you know that standardized tests that use verbal responses can underestimate intelligence in those with cerebral palsy.

- ***Orthopedic problems*** These problems may include curves in the spine, dislocated hips, or brittle bones that can lead to fractures. Children with cerebral palsy may also experience pain or other unusual sensations and perceptions. They also may have later physical development than other children/adolescents. An orthopedic doctor should address these problems.
- ***Lung or respiratory problems*** These problems may include drooling; asthma, pneumonia, chronic lung disease and other lung problems. A pulmonary doctor should be involved with these problems..
- ***Gastrointestinal problems*** Children with cerebral palsy may develop constipation or diarrhea, usually from problems with mobility. Also, if in a wheelchair, children will be at risk for obesity but a healthy diet and exercise can lessen the risk. A pediatric gastroenterologist doctor and/or nutritionist should be consulted for these problems.
- ***Other problems*** These include ulcers and sores, especially if a wheelchair or other adaptive equipment is used; there may also be declines in vision, hearing, or speech, so these should be checked frequently.

Many of these conditions can be avoided or minimized with good medical care, exercise and activity, equipment use, and therapies. Your doctors should assess your child for these conditions and they should be treated promptly. People with CP may have difficulty communicating that they are having problems, such as pain. As family members, you should look out for signs that your child could be in pain and point these out to your doctor.

As people with cerebral palsy get older, they have a higher risk for some age-related conditions. You and your doctors should watch for depression, arthritis, pain, high blood pressure, bladder problems, swallowing difficulties, bone fractures, cavities, and gum disease. Regular doctor visits are recommended throughout the lifetime of individuals with cerebral palsy, with special attention paid to pain. Also, children and adults with cerebral palsy should exercise regularly and be regularly monitored to determine their ability to get around and perform daily living skills. Most people with cerebral palsy live as long as those without cerebral palsy and with technology advancing at a rapid pace, every child with cerebral palsy can be aided to live a more full and fulfilled life.

Resources at WRC

- Health and Medical Department (310-258-4254)
- Equipment Clinic
- Family Resource Center (310-258-4063)
- Service Coordination
- Support Groups – Birth to Five Parent, Teen Social Group, Networking and Social Group
- Trainings & Events – self advocacy, consumer discussion, and behavior management

Resources in the Community

- American Academy for Cerebral Palsy and Developmental Medicine, <http://www.aacpdm.org>, (847) 698-1635
- California Assistive Technology Services, P.O. Box 1325, Simi Valley, CA 93062, <http://www.catsca.org>, (800) 390-2699
- Children's Hemiplegia and Stroke Association, 4101 West Green Oaks Blvd., Suite 305, PMB 149, Arlington, TX 76016, <http://www.hemi-kids.org>, info437@chasa.org, (817) 492-4325
- Easter Seals, 230 West Monroe St., Suite 1800, Chicago, IL 60606, <http://www.easterseals.com>, info@easterseals.com, (312) 726-6200
- National Institute of Neurological Disorders and Stroke, <http://www.ninds.nih.gov>, (800) 352-9424
- United Cerebral Palsy, 1660 L Street, NW, Suite 700, Washington, DC 20036, <http://www.ucp.org>, national@ucp.org, (800) USA-5UCP
- United Cerebral Palsy of Los Angeles, Ventura, and Santa Barbara Counties, 6430 Independence Ave., Woodland Hills, CA 91367, mail@ucpla.com, (818)782-2211

References

Cerebral Palsy: Hope Through Research. Retrieved October 2, 2007, from The National Institute of Neurological Disorders and Stroke Web site:

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

Cerebral Palsy in Children: What You Should Know. Retrieved October 2, 2007, from the American Family Physician Web site: <http://www.aafp.org/afp/20060101/101ph.html>

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

Krigger, K. (2006, Jan 1). Cerebral Palsy: An Overview. *American Family Physician*, 73(1), 91-100.

The National Dissemination Center for Children with Disabilities. (2003, October). Cerebral Palsy. *Disability Fact Sheet*, 2.

Zeldin, A. et al. Cerebral Palsy. Retrieved October 2, 2007, from eMedicine Web site: <http://www.emedicine.com/NEURO/topic533.htm>