



## The Learning Curve

*“Enhancing the Knowledge of DDDS Professionals”*

### Facts About Cerebral Palsy ...

(Article condensed from National Institute of Neurological Disorders and Stroke CP Information Page).

#### What is Cerebral Palsy?

The term cerebral palsy refers to any one of a number of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination but don't worsen over time. Even though cerebral palsy affects muscle movement, it isn't caused by problems in the muscles or nerves. It is caused by abnormalities in parts of the brain that control muscle movements. The majority of children with cerebral palsy are born with it, although it may not be detected until months or years later. The early signs of cerebral palsy usually appear before a child reaches 3 years of age. The most common are a lack of muscle coordination when performing voluntary movements (ataxia); stiff or tight muscles and exaggerated reflexes (spasticity); walking with one foot or leg dragging; walking on the toes, a crouched gait, or a “scissored” gait; and muscle tone that is either too stiff or too floppy. A small number of children have cerebral palsy as the result of brain damage in the first few months or years of life, brain infections such as bacterial meningitis or viral encephalitis, or head injury from a motor vehicle accident, a fall, or child abuse.

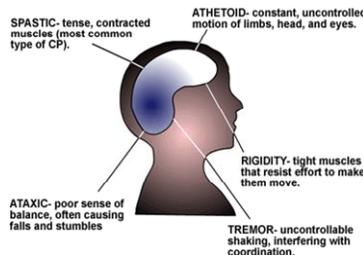
#### Is there any treatment?

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. Treatment may include physical and occupational therapy, speech therapy, drugs to control seizures, relax muscle spasms, and alleviate pain; surgery to correct anatomical abnormalities or release tight muscles; braces and other orthotic devices; wheelchairs and rolling walkers; and communication aids such as computers with attached voice synthesizers.

traumatic events in newborn babies' brains, such as bleeding, epileptic seizures, and breathing and circulation problems, which can cause the abnormal release of chemicals that trigger the kind of damage that causes cerebral palsy. To make sure children are getting the right kinds of therapies, studies are also being done that evaluate both experimental treatments and treatments already in use so that physicians and parents have valid information to help them choose the best therapy.

#### TYPES OF CEREBRAL PALSY



#### What can I do to support individuals with Cerebral Palsy?

If the person uses special equipment (for example, braces, wheelchair), know how the equipment works. Ask the individual with Cerebral Palsy (CP) to show you. For example, know how to operate the wheelchair that is, how to operate the brakes, how to maneuver it up and down curbs, and how to open and fold it.

- If you need some information from an individual with CP, be sure to ask the person. Do not direct your questions to another individual who is with them.

- An individual with CP often has difficulty speaking clearly. This does not mean they are mentally retarded.

- For people that have difficulty speaking, communication boards

#### What is the prognosis?

Cerebral palsy doesn't always cause profound disabilities. While one child with severe cerebral palsy might be unable to walk and need extensive, lifelong care, another with mild cerebral palsy might be only slightly awkward and require no special assistance. Supportive treatments, medications, and surgery can help many individuals improve their motor skills and ability to communicate with the world.

#### What research is being done?

Researchers are investigating the roles of mishaps early in brain development, including genetic defects, which are sometimes responsible for the brain malformations and abnormalities that result in cerebral palsy. Scientists are also looking at

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#### Did you know that...

- **8,000 – 10,000 babies and infants are diagnosed annually with Cerebral Palsy (CP).**

#### Cerebral Palsy (CP) Facts

- **Approx. 765,000 children and adults in the United States manifest one or more of the signs of CP.**

- **CP is identified in 1,200 – 1,500 preschool age children each year.**

- **CP is the second most common neurological impairment in childhood.**

- **45% of children with CP also develop mild or severe epilepsy**

- **Of congenital disorders, CP has the highest life-term costs per new case, averaging \$650,000 in 2003 dollars.**



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may be used. The boards may be electronic devices or a simple wood board with key words, the alphabet, or a combination of the two.

- A person with CP who uses a communication board will point to the letters to spell out words and/or point to the key words, in order to communicate with you. Be sure to allow the individual time to communicate their wants, needs, and thoughts.
- The electronic devices are similar to police scanners. They have up to 100 different phrases and words on them. The person stops the beam of light when it reaches the desired word, letter or phrase.
- Most individuals with CP learn as quickly as anyone else and most can do many things.
- Keep in mind the person may have limitations in movements. Spastic motions can make it hard to control or hold a pencil or spoon or be neat when writing or eating. CP can also affect a person's ability to climb, lift, pull, balance, carry, stand, reach, or turn.
- Avoid tension and fatigue situations. These increase rigidity in muscles making it difficult or impossible to do tasks that the person can do when the muscles are relaxed.
- More time may be required to complete a project.

#### **What are some of the special Health Challenges for Adults with Cerebral Palsy?**

Before the mid-twentieth century, few children with cerebral palsy survived to adulthood. Now, because of improvements in medical care, rehabilitation, and assistive technologies, 65 to 90% of children with cerebral palsy live into their adult years. This increase in life expectancy is often accompanied by a rise in medical and functional problems – some of them beginning at a relatively early age – including the following:

**Premature aging.** The majority of individuals with cerebral palsy will experience some form of premature aging by the time they reach their 40's because of the extra stress and strain the disease puts upon their bodies. The developmental delays that often accompany cerebral palsy 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 cerebral palsy

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. Early retirement may be necessary for others.



**Depression.** Mental Health issues can also be of concern as someone with cerebral palsy grows older. The rate of depression is three or 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.** Most adults with cerebral palsy experience what is called post-impairment syndrome, 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 cerebral palsy use three to five times the amount of energy that able-bodied people use when they walk and move about.

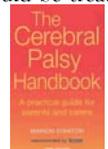
**Osteoarthritis and degenerative arthritis.** Musculoskeletal abnormalities that may not produce discomfort during childhood can cause pain in adulthood. For example, the abnormal relationships between joint surfaces and excessive joint compression can lead to the early development of painful osteoarthritis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

**Pain.** Issues related to pain often go unrecognized by health care providers since individuals with cerebral palsy may not be able to describe the extent or location of their pain. Pain can be acute or chronic, and is experienced most commonly in the hips, knees, ankles, and the upper and lower back. Individuals with spastic cerebral palsy have an increased number of painful sites

and worse pain than those with other types of cerebral palsy. The best treatment for pain due to musculoskeletal abnormalities is preventive – correcting skeletal and muscle abnormalities early in life 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. If it is managed properly, pain does not have to become a chronic condition.

**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. Curvature of the spine (scoliosis) is likely to progress after puberty, when bones have matured into their final shape and size. People with cerebral palsy also have a higher incidence of bone fractures, occurring most frequently during physical therapy sessions. A combination of mouth breathing, poor hygiene and abnormalities in tooth enamel increase the risk of cavities and periodontal disease. 25 to 39% of adults with cerebral palsy have vision problems; 8 to 18% have hearing problems.

Because of their unique medical situations, adults with cerebral palsy benefit from regular visits to their doctor and ongoing evaluation of their physical status. It is important to evaluate physical complaints to make sure they are not the result of underlying conditions. For example, adults with cerebral palsy are likely to experience fatigue, but fatigue can also be due to undiagnosed medical problems that could be treated and reversed.



#### **Cerebral Palsy Resources – Books, Videos, and Websites:**

##### **[Cerebral Palsy Books](#)**

#### **Web links regarding Cerebral Palsy:**

##### **[Cerebral Palsy Links](#)**

##### **[Cerebral Palsy: Hope Through Research](#)**

**A.I. du Pont Hospital – “Cerebral Palsy A Guide to Care” web link:**

##### **[Cerebral Palsy: a Guide for Care \(Alfred I. Dupont Institute\)](#)**