

# identifying disabilities

## WHEN YOUR CHILD HAS CEREBRAL PALSY

By Margaret "Muffi" Lavigne and Carl Gunderson, M.D.

### Editor's Note:

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*"For some of us, the diagnosis came as a complete surprise. We'd notice that our baby wasn't doing some things at the same age as other babies we knew, but we thought that, given time, she would catch up. For others of us, the diagnosis of cerebral palsy simply confirmed what we already suspected: our child had a problem that wasn't going to go away with time." \**

### WHAT IS CEREBRAL PALSY?

Cerebral palsy is a term used to describe a group of chronic conditions affecting body movement and muscle coordination. Children with cerebral palsy have suffered an injury to their brain, which has occurred either before they were born, in the first few months of life or during infancy. Thus, these disorders are not caused by problems in the muscles or nerves. Instead, the injury has in turn impaired the ability of their brain to control the voluntary muscles of their body.

Cerebral palsy itself is not progressive (i.e. brain damage does not get worse); however, secondary conditions can develop, such as muscle spasticity, which may get better, worse, or remain the same over time. Cerebral palsy is not communicable nor is it genetic. It is not a disease and should not be referred to as such. Although cerebral palsy is not "curable" in the accepted sense, training and therapy can help improve function.

The effect of this injury on the control of voluntary muscles usually takes one of two forms: weakness or involuntary movements. In those that are weak, the pattern of the weakness may be greatest in both legs (called diplegia), or more on one side than another (hemiparesis). There are other less common patterns involving three or more extremities. Since the weakness is due to brain injury, muscles often become hyperactive (spastic) and may become partially fixed in a contracted position (contractures). If the problem is involuntary movement, it may take the form of slow clumsy movements of the body and extremities (dyskinesia) or unsteadiness on reaching for things (ataxia).

Children with brain injuries leading to cerebral palsy may have other problems relating to their brains' injury such as epilepsy, visual disturbances, hearing deficits, or mental retardation. Many others will not. It is always best to proceed as if the movement disorder will be the only problem.

Cerebral Palsy is a very individualistic disability. Depending on the degree and type of cerebral palsy an individual has there is a whole continuum of effect — mild,

moderate, severely involved. Thus it is also never safe to assume that if you have seen one person with cerebral palsy, you have seen them all. This is also why cerebral palsy is often called a snowflake disability — there are never two people with cerebral palsy exactly alike.

### EARLY SIGNS

Early signs of cerebral palsy usually appear before 18 months of age, and parents are often the first to suspect that their infant is not developing motor skills normally. Infants with cerebral palsy are frequently slow to reach developmental milestones, such as learning to roll over, sit, crawl, smile, or walk. This is sometimes called developmental delay.

Some affected children have abnormal muscle tone. Decreased muscle tone is called hypotonia; the baby may seem flaccid and relaxed, even floppy. Increased muscle tone is called hypertonia, and the baby may seem stiff or rigid. In some cases, the baby has an early period of hypotonia that progresses to hypertonia after the first 2 to 3 months of life. Affected children may also have unusual posture or favor one side of their body.

Parents who are concerned about their baby's development for any reason should contact their physician, who can help distinguish normal variation in development from a developmental disorder.

### WHAT ABOUT TREATMENT?

"Management" is a better word than "treatment." It is important for parents to understand that nearly all of these brain injuries will not become any worse. Management consists of helping the child achieve maximum potential in growth and development. This should be started as early as possible with identification of the very young child who may have a developmental brain disorder.

Many children with cerebral palsy will be able to lead productive lives. They are often helped to do so by a wide range of educational and training programs (early intervention) provided by physical, occupational and/or speech therapists. Some children will benefit from surgical procedures designed to improve muscle and skeletal function. Others, especially those where spasticity is a major problem, may benefit from

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a variety of medical interventions including Botox and the Baclofin Pump. Again, please remember here, that cerebral palsy is an individualistic disability and what may work for one child may not for another.

As the child grows older, it may be necessary to make housing modifications such as widening doors or providing ramps instead of steps or the use of assistive technology. He or she may also require support services such as personal assistance services, continuing therapy, educational and vocational training, independent living services, counseling, transportation, recreation/leisure programs, and

employment opportunities, all essential to the developing adult. People with cerebral palsy can go to school, have jobs, get married, raise families, and live in homes of their own. Most of all, people with cerebral palsy need the opportunity for independence and full inclusion in our society. ■

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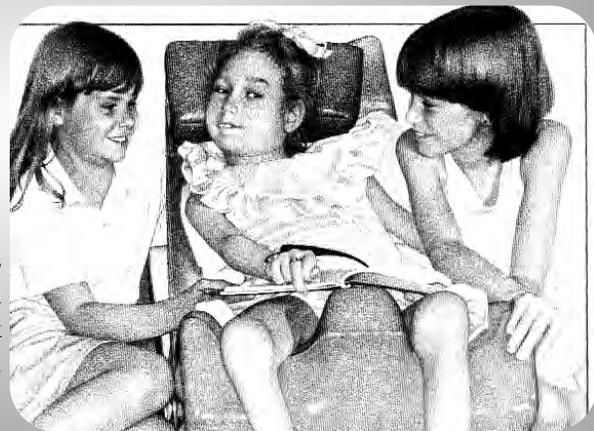
## HELPFUL ORGANIZATIONS

Founded in 1949, United Cerebral Palsy (UCP) is a nationwide network consisting of a central national organization, located in Washington, D.C. and over 100 independent, state and local non-profit affiliates. UCP is the leading source of information on cerebral palsy and is a pivotal advocate for the rights of all people with disabilities.

United Cerebral Palsy: [www.ucp.org](http://www.ucp.org)  
 Resources section of the UCP Web site:  
[www.ucp.org/ucp\\_generaldoc.cfm/1/3/43/43-43/5807](http://www.ucp.org/ucp_generaldoc.cfm/1/3/43/43-43/5807)

### VIRGINIA RESOURCES

Unfortunately, UCP does not have an affiliate in Virginia. To access the one-stop resource guides, visit the Resources section of the UCP Web site. Information seekers who need one-to-one information and referral service can contact Margaret "Muffi" Lavigne, UCP Information and Referral Coordinator at (800) 872-5827 or [mlavigne@ucp.org](mailto:mlavigne@ucp.org).



*Photographs courtesy of  
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 Assistive Technology Fair,  
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### Assistive Technology Catalogs

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