

A Closer Look at Cerebral Palsy

Condition

Cerebral palsy is not a disease. It is a permanent physical condition that affects muscle coordination and body movement. A common description of cerebral palsy used by the medical community is ‘a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.’¹

Diagnosis

Cerebral palsy is often diagnosed within the first 12-18 months of life. Unless a child is born preterm and is followed by a specialty medical team from birth, signs of cerebral palsy are often first noticed by parents when they realize that their child is not meeting movement developmental milestones, looks stiff when they move, or shows a preference for using one side of their body. A diagnosis of cerebral palsy is confirmed by a neurologist or other specialty care physician.

Motor abilities of individuals with cerebral palsy can range from mild impairment of coordination and balance when running and climbing stairs to limited ability to move voluntarily. Some individuals with cerebral palsy walk without assistive devices and others use manual or powered wheelchairs for mobility. People with cerebral palsy may have challenges with other areas of functioning, such as vision, hearing, and communication.

¹ From: Rosenbaum, P., Paneth, N., Leviton, L., Goldstein, M., Bax, M., Damiano, D., Dan, B., Jacobsson, B. (2007) A report: the definition and classification of cerebral palsy April 2006. *Developmental Medicine & Child Neurology*. Feb; 109:8-14.

Intervention

The initial brain injury associated with cerebral palsy does not progress. However, the effects of the brain injury, such as muscle tightness, can evolve over time. Multi-disciplinary medical teams are involved in ensuring children with cerebral palsy optimize their health and ability to participate in meaningful activities. Rehabilitation intervention for people with cerebral palsy often includes therapies such as occupational, physical and speech and language therapy. These therapies focus on enhancing movement and communication to ensure that children can explore their environments, play, communicate, socialize, and participate in activities in their homes and communities. The ultimate goal of rehabilitation is to ensure that children and families can engage in the life activities that are important to them.

In addition to medical and therapy interventions, it is important to ensure that children with cerebral palsy and their families have access to services and supports in their communities that can enhance participation and inclusion in activities that are meaningful to them. For example, it is important that children with cerebral palsy are provided the opportunity to play and socialize with other children and that adults with cerebral palsy are supported to live in their own homes and engage in employment and leisure opportunities. Many families also value opportunities to connect and learn from other families who have life experience with cerebral palsy.

People with cerebral palsy can live full and meaningful lives if they are supported by an inclusive society that values them and acknowledges their right to participate and contribute. Many people with cerebral palsy have jobs, go to school, get married, raise families, and live in their own homes.

Embracing a Family Centred Approach

Family-centered service is focussed on enhancing family capacity through the development of relationships focused on empowerment, information sharing, and mutual respect. Ensuring a good fit between services and supports and family values and goals is foundational to supporting children with cerebral palsy and their families. Connecting parents with programs that provide family-centered services can promote positive mental health and reduce stress. To be family centered in your role, **listen** to the families describe what they need, ensure that you **share** relevant information with families and use language that is **respectful** and **caring**.

Since many parents who have infants and young children with cerebral palsy are unaware of specialized services and supports, you have an important role in sharing information about community programs and resources with them. For example, access to financial and service support for obtaining wheelchairs, walking aids, and communication devices, can drastically improve a child's abilities to move independently, and develop social, language, and play skills.

Other supports and programs that may be helpful for the child and their family are:

- **Early intervention-** Support programs for young children that provide early learning and various therapies aimed at maximizing developmental outcomes through learning, exploration and play.
- **Therapy-** Occupational therapy, speech and language pathology, physical (physio) therapy and recreation therapy are common services accessed by children with cerebral palsy.
- **General fitness programs-** Exercise specialists can create programs focussed on strength, flexibility, and endurance to contribute to reaching maximum potential for life enjoyment and participation.
- **Respite services-** Respite care is the provision of caregiving services so that families can ensure they have adequate time to fulfill their other life roles and live happy and successful lives.
- **Financial support –** Some programs offer financial support to families so that they can purchase equipment (e.g., wheelchairs, mechanical lifts, communication devices), attend medical appointments and cover the costs of extraordinary expenses of raising a child with a disability.