

UNDERSTANDING CEREBRAL PALSY

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What is Cerebral Palsy?

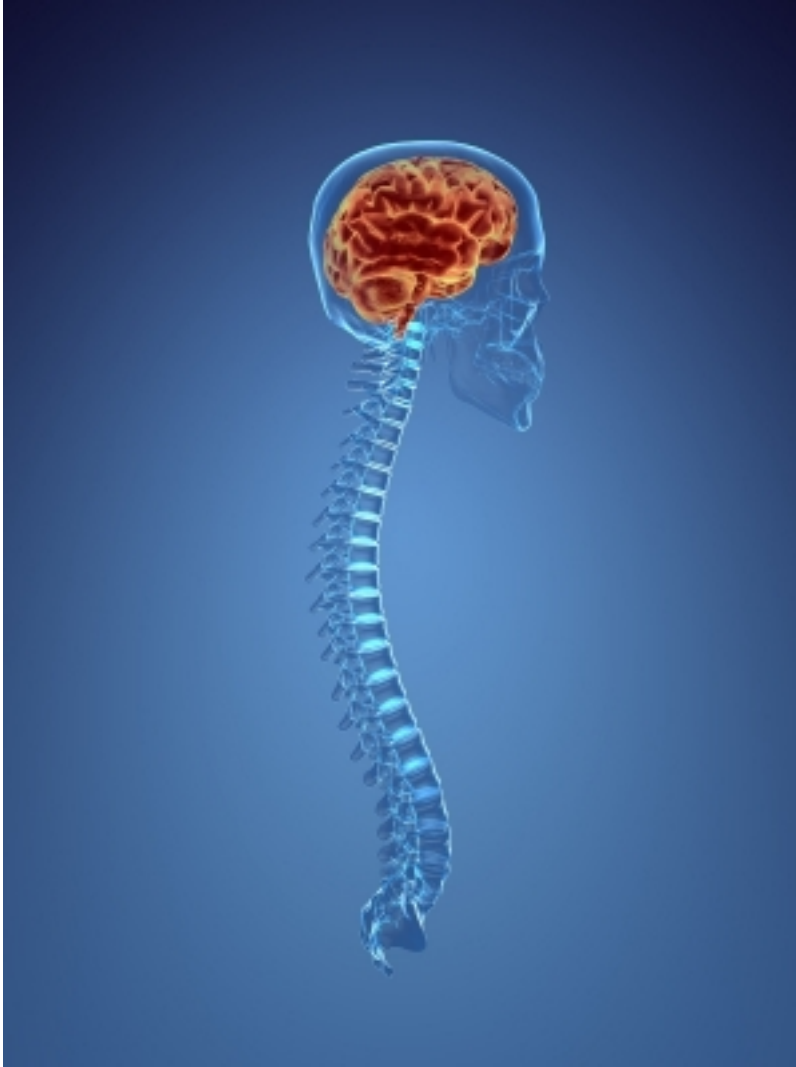


Cerebral palsy (CP) is a broad diagnostic term used to describe a problem with movement and posture that makes certain activities difficult. Although someone who has cerebral palsy may have problems moving his or her muscles, this is not because there is something wrong with the muscles or nerves. These difficulties are caused because of problems in the brain. CP can be the result of an injury to the brain during gestation or in the first year of life, or it occur when the brain does not develop properly during gestation. The injured or abnormal brain is unable to optimally control movement and posture.

Simply stated, “cerebral” refers to the brain, and “palsy” refers to muscle weakness and poor control. Although the brain itself will not get worse, people who have CP will usually change over time. Sometimes they will get better, and some patients will stay the same. Occasionally they will get worse, usually because of changing muscle tone or development of joint contractures.

There is currently no cure for CP; however there are different treatment options for people who have it. These options include therapy, medications, surgery, education and support. By taking advantage of these treatments, people with CP can improve their function, minimize the development of complicating issues and optimize the quality of their lives.

Who Does Cerebral Palsy Affect?



It is estimated that two out of every 1,000 newborn children will develop cerebral palsy and approximately 40% of those born with CP will have a severe case. Right now, about 10,000 babies and infants are diagnosed with the condition each year. In 2002, the number of CP cases in 8-year-old children was found to be one in 278. It is the most common motor disorder in children and is second only to autism as the most common disability in children.

What Causes Cerebral Palsy?

Cerebral Palsy does not have a single cause. There are many reasons why someone might have CP. An unborn child might have suffered an injury to the brain or had abnormal development of the brain tissue. These are called “prenatal” causes, meaning they happened before birth. These causes are responsible for about 70% of the cases of CP. Another 20% of the cases are caused by a brain injury that takes place during the birthing process, including low oxygen during delivery or complications of prematurity.

In the United States, about 10% of children who have CP developed it after they were born. This is called “acquired cerebral palsy.” The percentage of CP that is acquired is higher in under-developed countries. Acquired CP happens when there is brain damage during the first year of life. This damage can be caused by brain infections, like bacterial meningitis or viral encephalitis. It can also be caused by a head injury — such as that from a motor vehicle accident, a fall, or child abuse.

Sometimes, the actual cause of a particular child’s CP cannot be determined.

Although there may have been a brain injury or a brain development problem during gestation, the problems with motor control and posture may not be noticed until a baby’s motor skills develop to the extent to identify the condition. Thus, many children with CP are not diagnosed in the newborn period. However, the majority can be diagnosed in the first two years of life.

What Puts a Child at Risk for Developing Cerebral Palsy?



There are many risk factors for cerebral palsy. They can include:

- Premature (early) birth
- Low birth weight
- Maternal blood-clotting problems
- Inability of the placenta to provide the developing fetus with adequate oxygen and nutrients, due to abnormalities of the placenta
- RH or A-B-O blood type incompatibility between mother and infant
- Infection of the mother with viral diseases in pregnancy (e.g. rubella, cytomegalovirus, toxoplasmosis)
- Bacterial infection of the mother, fetus or infant that directly or indirectly attacks the infant's brain
- Prolonged low oxygen delivery to the baby during the birthing process
- Severe jaundice shortly after birth
- Having a major or minor birth defect
- Meconium aspiration (i.e. the baby pooping while in the uterus and breathing in the amniotic fluid that contains the poop, causing a pneumonia)
- An infant being distressed to the extent that an emergency caesarean delivery is needed
- Newborn seizures
- Newborn low blood sugar
- Multiple fetuses (e.g. twins, triplets...)

It is important to understand that even if a child does have a risk factor for CP, it does not mean that the child will develop it. It just means that the chance of the child having CP is increased. If a risk factor is present, it serves to alert parents and physicians to be very observant to the infant's development. Conversely, some children with CP have no risk factors.

How is Cerebral Palsy Diagnosed?

Parents are often the first to notice that their infant is not developing normally. Infants with cerebral palsy are often slow to roll over, sit, crawl, or walk. When an infant develops more slowly than usual, it is called developmental delay.

Some of the skills that infants should have include:

- Holding own head up when lying flat in a bed at 3 months
- Holding a sitting position without help and rolling over by 6 months
- Walking by 15 months
- Speaking several words by 18 months and 2 word phrases by 2 years of age

It is important for parents to alert their clinician if their child is not meeting these milestones and the clinician should initiate an evaluation to determine why the child's development is slow.

Doctors diagnose CP by obtaining a complete medical history, reviewing the child's development and examining the child, paying special attention to the child's movements. In addition to checking for the most common symptoms – such as slow development, abnormal muscle tone and unusual posture – a doctor also has to make sure the child does not have something else that could cause similar symptoms.

Some children have hypotonia (low muscle tone), which means that their muscles are too relaxed. In this case, the baby may seem floppy. Other children have hypertonia (high muscle tone), which makes their muscles seem stiff. Sometimes a child can have hypotonia at birth that changes to hypertonia over the first few years of life. Children with CP may also have unusual posture or favor one side of their body.

What is most important to the doctor is making sure that the child's condition is not getting worse. Although CP symptoms may change over time, children who have it do not usually lose function. That means if a child does seem to be losing motor skills, the problem is probably not CP. It is more likely a genetic condition, muscle disease, metabolism disorder or tumor in the nervous system. A complete medical history, special medical tests, and, in some cases, repeated check-ups can help confirm whether or not the child has CP.

Once the diagnosis of CP has been made based on medical history and physical examination, your doctor may order tests to try to figure out the cause of the CP.

Some other tests a doctor might order include:

- **Cranial ultrasound.** This test is used for high-risk premature infants because it is the least intrusive of the imaging techniques. However, it is not as effective as the two methods described below at seeing small changes in “white matter” – which is the type of brain tissue that is affected in CP.
- **Computed tomography (CT) scan.** This technique creates images that show brain injury and major brain malformations. It is quicker to do, so a baby may not need to be sedated but it does not give as good of a picture of the brain structure as does an MRI scan. There are occasional reasons a CT scan might be preferred over an MRI scan. Examples include when there is a strong suspicion of certain viral infections during gestation, when a baby is too high risk to be sedated for an MRI scan or when an image is needed in an emergency, such as during an acute trauma event or suspected child abuse.
- **Magnetic resonance imaging (MRI) scan.** This test uses a computer, magnetic field, and radio waves to create a picture of the brain’s tissues and structures. Doctors prefer MRI imaging because it offers better detail and does not involve radiation. Most infants and young children will need to be sedated, as getting a good image requires the child to lie absolutely still during the scan.

What can CP be Confused with Clinically

Metabolic Disorders

On rare occasions, metabolic disorders can be mistaken for CP and some children will require additional tests to rule them out.

Specialized Knowledge and Training

To confirm a diagnosis of CP, a doctor may send a child to other doctors who have specialized knowledge and training, or to specialty clinics where these doctors work with a team of health professionals who specialize in working with children with CP and other developmental delays. These clinicians might be child neurologists, developmental pediatricians, genetic specialists, ophthalmologists (eye doctors), audiologists (hearing specialists) and physiatrists (rehabilitation specialists). Over time, other specialists like orthopedists (specialists in bone surgery, optimizing walking patterns and insuring optimal skeletal alignment), therapists, such as physical and occupational therapists and speech and language pathologists will be important members of the child's treatment team.

What Terms do Clinicians Use to Describe a Child's Motor Picture and What do They Mean?

As the clinical picture of cerebral palsy can be highly variable in severity and the area of the child's body affected by the condition, clinicians have tried to develop ways of describing the individual child's motor picture for easier communication among health professionals, as well as affording a prognosis and treatment. Traditionally, CP has been classified by the type of muscle tone, areas of the body that have been affected and severity of the impairments (mild, moderate and severe). Recently, a variety of new tools have been developed to describe a child's clinical picture. These include the Gross Motor Function Classification System, which has been used to classify CP in terms of a child's gross motor function and mobility at different age ranges.

Describing a Child's Cerebral Palsy

The terms below have historically been used by clinicians to describe the motor involvement in a child with CP. However, the reproducibility of these terms across clinical settings is sometimes a challenge.

Physiological Grouping

- **Muscle tone** may be increased or decreased in children with CP.
- **Spasticity** is one type of increased muscle tone. It is characterized by being velocity-dependent. This is determined by passively flexing and extending muscle groups across a joint. If a person has spasticity in the muscle being examined, the clinician will feel resistance to movement when it is ranged and the resistance will be more prominent if the limb is ranged quickly, compared to slowly. Children with spasticity often have more pronounced deep tendon reflexes, clonus (repetitive beats of the ankle when it is moved rapidly) and extensor plantar responses (the big toe turns up when the bottom of the foot is stroked). However, the latter are sometimes difficult to elicit in the infant and even in the older child with spastic CP. A satisfactory, reproducible system of grading muscle tone has never been developed, although the Ashworth and Tardieu scales are commonly used in research.

- **Dyskinesia** is defined as abnormal motor movements. When the patient with dyskinesia is totally relaxed lying on their back, a full range of motion and decreased muscle tone may be found. However, when they attempt voluntary movements, the dyskinesia becomes evident. Patients may have two different features of dyskinesia. The child with hyperkinetic or choreo-athetoid movements show purposeless, often massive involuntary movements with motor overflow, that is, the initiation of a movement of one muscle group leads to movement of other muscle groups. The child with dystonia manifests abnormal shifts of general muscle tone induced by movement. Typically, these children assume and retain abnormal and distorted postures in a stereotyped pattern. Dystonia creates resistance to range of motion at joints and high tone, but dystonia is not velocity-dependent so the resistance to range of motion will be significant even if the muscle is ranged slowly. However, the extent of dystonia can vary significantly, based upon the child's state of alertness and agitation. When the child is asleep, the dystonia may not be felt at all. If the child is upset and agitated, the dystonia will be prominent. Both types of dyskinesia may occur in the same patient.
- **Ataxias.** Patients with ataxias have poor coordination of voluntary movements. These patients may be hypotonic during the first 2 or 3 years of life. They commonly walk with a wide-based staggering gait and have poor accuracy when attempting to reach for something with their hands (called dysmetria).

Mixed Group

Sometimes, patients with CP have a complex picture with features of high and low muscle tone (e.g. low muscle tone in the trunk and high muscle tone in the extremities) and they may have a combination of spasticity and dystonia. Some of these patients may also have ataxia. Sometimes, clinicians will use the term "Mixed CP" to describe the child's clinical picture.

Anatomic Grouping

For children with spasticity, terms are sometimes used to describe the areas of the body involved. These terms include:

- **Diplegia** refers to involvement predominantly of the legs, although children with diplegia always have involvement in the arms to a lesser extent.

- **Quadriplegia** refers to dysfunction of all four extremities and either the arms/legs are involved equally or the arms somewhat more than the legs (in some children, one upper extremity might be less involved; the term triplegia then would be substituted).
- **Hemiplegia** refers to individuals with unilateral motor dysfunction; and in most children, the upper extremity is more severely involved than the lower.
- **Double hemiplegia** is an unusual situation that may occur where the upper extremities are much more involved than the lowers; the term double.

What are the Functional Classifications of Cerebral Palsy?

The Gross Motor Function Classification System (GMFCS) for CP describes the ability of children, from birth to 18 years of age, to function and move around in their daily lives. The emphasis is on how well a child can sit, move between positions and walk. This is a five level classification system, based on function, mobility inside and outdoors and the need for assistive technology or devices to achieve mobility (such as walkers, crutches, canes and wheel mobility devices). The purpose of the classification system is to understand a child's current function and mobility to plan interventions to help allow him or her to be more independent in life. For a full description of the GMFCS, see the [CanChild Center](#).

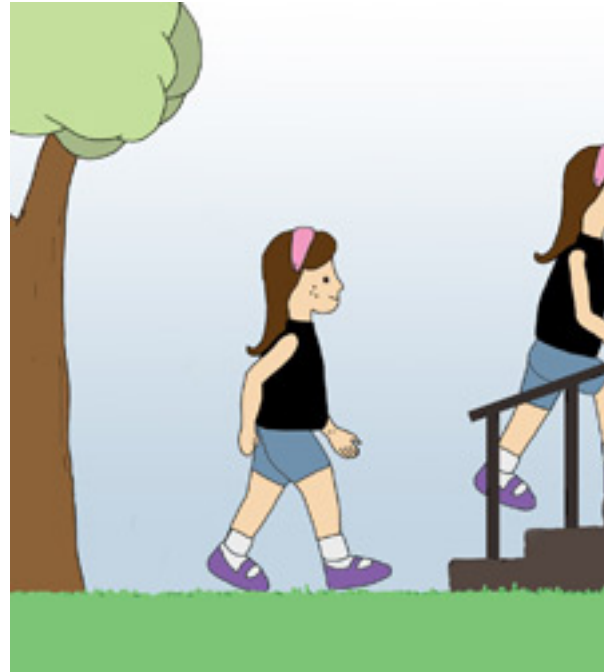


Level 1: Walks Without Limitations

- Uses no assistive devices (such as crutches)
- Can walk indoors and outdoors and climb stairs; no limits
- Can perform usual activities, such as running and jumping
- Has decreased speed, balance and coordination

Level 2: Walks With Limitations

- Is limited in outdoor activities
- Has the ability to walk indoors and outdoors and climb stairs with a railing
- Has difficulty with uneven surfaces, inclines or in crowds
- Has minimal ability to run or jump



Level 3: Walks Using a Hand-Held Mobility Device

- Walks with assistive mobility devices indoors and outdoors on level surfaces
- May be able to climb stairs using a railing
- May propel a manual wheelchair (with assistance needed for long distances or uneven surfaces)



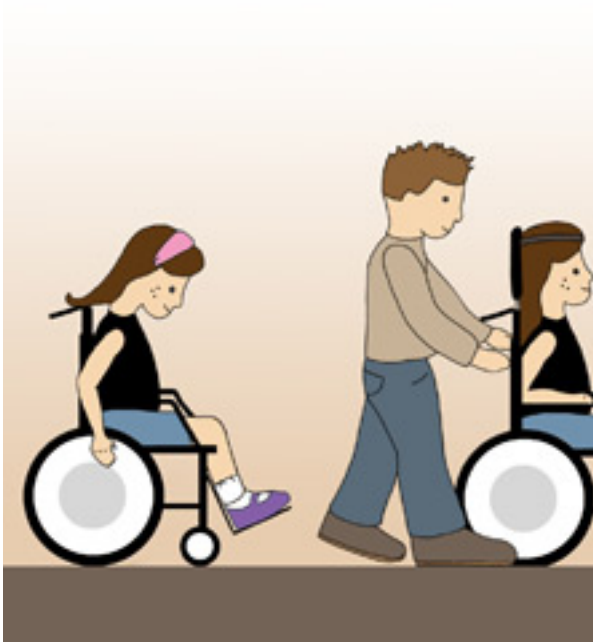
Level 4: Self-Mobility with Limitations; May Use Powered Mobility

- Self-mobility severely limited, even with assistive devices
- Uses wheelchairs most of the time and may propel their own power wheelchair



Level 5: Transported in a Manual Wheelchair

- Has physical impairments that restrict voluntary control of movement and the ability to maintain head and neck position against gravity
- Is impaired in all areas of motor function
- Cannot sit or stand on their own, even with equipment
- Cannot do independent mobility, though may be able to use a power wheelchair



Illustrations provided by: [Matthew Heern](#)

Can Cerebral Palsy be Prevented?



Certain medical advances (such as vaccines), nutrition and early and improved care of pregnant women have lowered the numbers of babies born with cerebral palsy in poorer countries. However, in developed countries (like the United States) the number of babies with CP has remained much the same over the last 50 years (Nelson, 2003). This is a complex issue, as certain causes of CP have been reduced (e.g. brain injury from neonatal jaundice or maternal rubella) but other causes have emerged (e.g. increased survival of very premature infants).

Today, More can be Done to Prevent CP Than Ever Before:

Rh Factor Test

Pregnant women who have an Rh-negative blood type can be treated to prevent problems with blood incompatibility with their infant while in the womb. All pregnant women are tested to determine their blood type. If a woman is found to be Rh negative, she can be immunized early in pregnancy and again within 72 hours of giving birth (or after the pregnancy terminates) to help reduce the risk of blood incompatibility during current or future pregnancies. Rh blood incompatibility can be a contributing factor to the development of CP.

If the woman who is Rh negative has developed an incompatibility with a baby's blood, various treatments can be used during and after pregnancy to optimize the baby's health and reduce the risk of CP for that child.

Treating Jaundice

Many babies develop jaundice (a yellow discoloration of the skin during the first few days of life). In many babies, this jaundice does not cause a problem and is a normal part of the body's maturation. However, sometimes the jaundice is severe because of underlying issues, such as blood group incompatibility, prematurity, or other concerns. The bilirubin in the blood (the substance that causes the yellow color) can cross into the brain and is toxic to certain brain cells, causing brain injury that could result in CP. If a baby is developing jaundice, the baby's clinician will monitor it and, if it is rising to a dangerous range, treat it by exposing the baby's skin to special lights ("phototherapy"), ensuring good hydration and, in severe cases, performing an "exchange blood transfusion."

Immunization and Prevention of Maternal Infection

Ensuring all women are immunized against rubella reduces the risk of congenital rubella, which can cause CP. Someday, vaccines may be developed against other infections that can happen during pregnancy and result in infant brain injury. These include cytomegalovirus (CMV) and toxoplasmosis. Until then, women can reduce their risk by avoiding these infections when possible (e.g. not changing a cat's litter box, as cats can carry toxoplasmosis and avoiding exposure to infants known to be secreting CMV virus). Maternal herpes infection can also result in infection in the infant, which, in some cases can result in brain infection causing brain injury related CP. If a mom has active herpes during delivery, the baby can be assessed and treated early, should infection occur.

Prenatal Care

It is important for women to get proper health care prior to conception, be evaluated by a high-risk perinatologist if they anticipate pregnancy complications and have early and continuous prenatal care throughout the pregnancy. Prematurity (being born too soon) may result in brain injury and subsequent CP.

The following steps can help prevent premature births:

- Reducing exposure of pregnant women to virus and other infections
- Recognizing and treating bacterial infection of the reproductive and urinary tracts
- Avoiding unnecessary exposure to X-rays, drugs, alcohol, cigarettes and medications

- Controlling maternal health problems, such as diabetes, anemia and hypertension
- Optimal maternal nutrition, including maternal vitamin supplements
- Ensuring optimal evaluation for women who have had miscarriages or prior premature infants. In some cases, treatments can be offered to reduce the risk of recurrence (e.g. hydroxyprogesterone treatment in women with high risk of premature delivery, treatments for cervical incompetence or uterine malformations)
- Early recognition and treatment of preterm labor. With early recognition, the preterm labor can sometimes be stopped. If not, treating mothers who are 23-32 weeks of gestation and have anticipated delivery with magnesium sulfate may provide some neuro-protection for the infant. However, guidelines regarding this are still emerging, so obstetric practices vary across centers.

Birth Asphyxia Treatment

Birth asphyxia (having low oxygen delivery to the brain during the birth) is a risk factor associated with the development of CP. If an infant is suspected of having low oxygen delivery to the brain during the birthing process, it is critical that the infant receives the best possible medical stabilization and support to minimize the extent of brain injury. Some specialized neonatal intensive care units will provide emerging treatments (e.g. neonatal head or body cooling) to reduce the risk of CP.

Reduce risk of head injury

Since anything that causes brain injury can result in CP, ensuring optimal safety for infants is important in prevention. This includes not shaking infants (to avoid brain injury from shaken baby syndrome), providing families supports to reduce the potential for child abuse, ensuring proper restraint in vehicles (e.g. car seats), reducing risks of falls, optimal vaccination (to reduce risk of meningitis from certain germs) and ensuring early recognition of infections that affect the nervous system (e.g. meningitis and encephalitis).

Common Health Problems Associated With Cerebral Palsy

Certain health problems are more common in individuals with cerebral palsy.

Drooling

Drooling can cause severe skin irritation, bad breath, create a social barrier and can contribute to lung issues. Drooling results from problems with swallowing, such as difficulty with coordination or reduced frequency of swallows. It is not caused by excessive saliva production. Drooling should be openly discussed with a doctor as part of routine health management. In some cases, oral hygiene and the use of bibs to absorb the saliva is adequate for management.

Certain medications can reduce the amount of saliva produced, which, in some cases, helps reduce the extent of drooling. However, not all children tolerate or benefit from these medications. A speech therapist can help to teach the child better oral coordination and encourage swallowing frequency. But often, while the child swallows more frequently during therapy, they may not continue this outside of therapy sessions. Botox can be injected into the major salivary glands, which inhibit nerve endings and reduce the amount of saliva produced. However, this treatment is somewhat invasive, has to be repeated every 3-6 months and can sometimes result in excessive dry mouth. Surgery to remove major salivary glands may be an option when issues are severe.

Nutrition

Poor nutrition can be associated with serious health problems in children with CP. Chewing and swallowing difficulties, which occur in about one-third of all cases, are most responsible for the problems with under nutrition. In some cases, the use of oral motor therapy, optimizing positioning and frequency of feeding and the use of high-density supplements can optimize growth and nutrition.

However, for other children, a feeding tube (usually placed through the abdominal wall into the stomach, using an endoscope or surgery) is important to support optimal hydration and nutrition. Some children with CP may develop obesity. In some cases, this is due to lifestyle choices; while in other cases, it may be due to overzealous treatment of under nutrition with oral supplements or a feeding tube. In addition to issues with over and under nutrition, children with CP can be at risk for deficient intakes of certain micro-nutrients, protein and fiber. In particular, iron deficiency, inadequate calcium intake and sub-optimal Vitamin D levels have occurred with increased frequency. It is critical that all children with CP have ongoing nutritional assessments by a clinician skilled in this area.

Bladder Dysfunction

Bladder dysfunction can also be a serious health problem for children with CP and may require treatment from a physician who specializes in bladder function. Incomplete bladder emptying (resulting in urinary tract infections), increased accidents due to bladder muscle-tone abnormalities, bed wetting, stress incontinence and dribbling are all issues that may occur with increased frequency in children with CP.

Gastrointestinal Issues

Gastroesophageal reflux (food in the stomach being able to sneak back up the esophagus) is a common problem in children with CP and is usually treated by adjusting feeding schedules, optimal positioning, acid-blocking medication and sometimes other medication to help stomach motility.

Constipation

Constipation is a common complication of CP. Many factors may contribute to constipation, including reduced fiber and fluid intake, reduced mobility, the impact of certain medications on intestinal motility (e.g. seizure medications), weak abdominal muscles, difficulty coordinating the act of pooping and sub-optimal positioning for pooping. All of these factors should be addressed when treating constipation.

Puberty

Information about pubertal development in CP is somewhat limited. Overall, children with CP should be expected to pass through puberty at similar ages to the general population. However, one cross-sectional survey of children with moderate to severe CP showed that there was a caveat. First, a subset of children with CP develops pubic hair earlier than the general population, without other signs of puberty, such as breast development. This is likely not true puberty but a benign condition known as premature adrenarche. Additionally, there seems to be a subset of children with CP who do start puberty (indicated by breast development) slightly earlier and a subset that finishes puberty slightly later than the general population.

It is important for teens with CP to receive all the usual care that is typical for teens (e.g. treatment of acne, cognitively appropriate information on substance abuse, sexuality and safety information, standard immunizations, management of menstrual issues, like pain or excessive bleeding). Some girls with CP may benefit from medical suppression of menses. Fertility rates have not been evaluated in individuals with CP but many individuals with CP have had children.

Respiratory Issues in Cerebral Palsy

Oral motor challenges and gastroesophageal reflux may both contribute to chronic aspiration of saliva, food and/or refluxed gastric contents into the lungs. This may cause illness with pneumonia or lead to an injury in the lungs called “chronic lung disease.” Evaluation and management by a specialist skilled in lung function (e.g. a pulmonary specialist) is important for all children with recurrent pneumonias or other chronic respiratory issues.

Sleep

Sleep issues are common in children with CP and may include difficulty with falling asleep, separating from parents at bedtime and staying asleep due to pain, seizures, respiratory or gastrointestinal issues, not breathing adequately in sleep (a condition call sleep hypoventilation), changes in respiratory patterns during sleep due to brain function (e.g. central sleep apnea) or having obstruction of the airway during sleep (sleep obstructive apnea). If a child with CP is having difficulty with sleep, it should be discussed with the health care provider and, in some cases, involvement of a certified sleep doctor or evaluation with a sleep study may be indicated.

Pain and Cerebral Palsy

Hip pain in children with CP is a very common problem. Only recently has general pain in children with CP been recognized and studied. According to a questionnaire, two-thirds of the parents felt that their children experienced pain for at least several days during the month before the completion of the questionnaire. But it can be difficult to tell when children with CP are in pain if they have limitations in their communication skills (Nolan et al., 2000). Research regarding pain management specific to CP is limited.

Other Health Problems

In addition to the mentioned problems above, patients with CP often have other health problems including:

- Muscle and skeletal issues, including contractures, scoliosis and hip dislocation
- Seizures
- Vision and hearing concerns
- A higher risk of pressure sores
- Dental care concerns, including identifying a dentist skilled in caring for children with special needs, orthodontic issues and a higher risk for cavities if there are challenges with providing regular oral care.

Other Concerns

Due to brain injury or abnormal brain development, many children with CP have associated learning concerns, including specific learning disabilities or intellectual disabilities (a globally lowered intelligence). Children with CP may also have a higher risk of difficulties with focus, impulse control or managing activity levels (ADHD). Some children with CP may also have challenges with communication development in a pattern consistent with a diagnosis of autism.

Speech and language challenges may occur in this group of children. Contributing factors include oral motor dysfunction (difficulties with motor control of the oral muscles), hearing impairments and cognitive concerns.

Mental health concerns, including behavioral challenges, difficulties with emotional regulation, anxiety and depression may occur in individuals with CP. Unfortunately, these often go unrecognized or untreated due to the challenges in recognizing and treating these conditions in children with disabilities. If a parent has any concern, evaluation by a mental health professional skilled in “dual diagnosis” (the combination of a mental health issue and developmental disability) is important.

What Other Diagnoses are Similar to Cerebral Palsy?

Cerebral palsy can be confused with other medical conditions. It is especially important to consider other causes that might have different treatments. Taking a careful medical history exam can often identify distinguishing features of these “other” diagnoses. Clinical clues to consider carefully include:

- Is there an absence of difficulties at or around the time of birth that account for the developmental motor and associated abnormalities?
- Is the child having a decline in motor function, intellectual ability or degree of high muscle tone over time that is not explained by an orthopedic issue/growth/or change in health status?

One of the diagnoses that can appear like CP is a progressive movement disorder called Dopa responsive dystonia (DYT5). This rare genetic disorder occurs, due to impaired production of a neurochemical called DOPA. This results in a progressive increase in muscle tone and physical limitations and can resemble CP. Patients with this condition typically do not have cognitive challenges but may have progressive and severe spasticity or dystonia. A large number of these individuals also have variation in their tone during the day. These children and adults often respond to very low dose DOPA supplement and have significant improvement in their symptoms.

Another genetic disorder that is confused with CP early in the course of the disorder is Glutaric aciduria type 1. The distinguishing feature of this condition is progression of the movement disorder with the child developing chorea (rapid random movements). Also, imaging of the brain reveals a distinctive pattern of abnormalities in the temporal area. While reversal of the symptoms is not anticipated, specific medical interventions may limit further progression of the condition.

Instability of the spinal column is also an important consideration. This possibility should be strongly considered if an individual has progressive spasticity, deterioration of motor function, sensory changes and progressive bowel and bladder abnormalities. The spinal cord can be injured directly by the increased movement of the bone vertebra. This may be as high as the cervical area or at any point along the spine. Intervention to stabilize the spine is critical to stopping the progression. Reversal of the new neurological findings is frequently not possible but, again, the intervention may stop the deterioration.

Other slowly progressive disorders are occasionally misdiagnosed as CP. These are predominantly rare diagnoses that have other symptoms that help separate them from individuals with CP. For example, several have an associated loss of cognitive skills. These patients do not have a stable, predominantly motor problem but, instead, deteriorate across several domains (e.g. cognitive, behavioral, fine and gross motor). Imaging (MRI preferably) may reveal changes that are consistent with the diagnosis. Examples of such diagnoses include:

- Metachromatic Leukodystrophy
- Pelizaeus-Merzbacher disease
- Rett's Syndrome should be considered when the symptoms of motor delay and spasticity are combined with autistic features and non-purposeful hand movements

Cerebral Palsy Treatment



There is no one therapy that works for every child who has cerebral palsy. If your doctors have decided that your child does have CP, a team of health care professionals can help identify specific needs and then develop a treatment plan to help improve your child's quality of life.

Although CP cannot be cured, treatment will often improve a child's capabilities. Many children with CP go on to enjoy near normal adult lives if their disabilities are properly managed. In general, the earlier that treatment begins, the better chance the child has of overcoming developmental disabilities, or of learning new ways to accomplish the tasks that challenge them. Your doctor will determine which, if any, of these treatments might be appropriate for your child.

Who is on the Team?

Doctors may include:

- Neonatologists
- Pediatricians
- Developmental Pediatricians
- Neurologists
- Orthopedists
- Physiatrists (Physical Medicine and Rehabilitation)
- Ophthalmologists
- Neurosurgeons
- Gastroenterologists
- Urologists
- Otolaryngologists (Ear, Nose and Throat Physicians)
- Genetic specialists

Other health care professionals may include:

- Physical and Occupational Therapists
- Speech Language Pathologists
- Social Workers
- Nurses
- Audiologists
- Psychologists
- Nutritionists/Dietitians
- Orthotists
- Recreational Therapists
- Music Therapists

Providers outside of the health care profession:

- Teachers
- Specialists in adaptive computer access
- Legal consultants to aid with understanding the individual's rights within the educational and healthcare systems
- Financial specialists to guide in planning for the child and families financial future
- Vocational rehabilitation specialists

What are Some Therapy Options?



General Comments on Therapy Services

Children may receive specialized assessments by therapists to help determine prognosis or need for treatment. Therapists in a clinic, hospital, early-intervention program or school may perform these assessments. Some therapies focus on gross and fine motor skills, some focus on activities of daily living, some on communication and others on developing recreation or vocation. Assessments and interventions will focus on range of motion, strength, motor control, balance, coordination, functional skills, endurance and mobility, including walking (gait). Following medical or surgical treatment, therapy can enhance motor function and speed recovery. This may include instruction in methods to transfer in and out of bed, use of equipment, such as braces, splints, wheelchairs and walkers and exercises for stretching, strengthening and improving function. Therapy programs may be recommended to optimize communication and feeding.

The focus of therapy changes as children age. For example:

Children with CP are delayed in acquisition of motor skills to varying degrees, but usually reach their maximum potential for independent mobility by age 6. The focus of therapy changes from development of motor skills to promotion of health and achievement of independence with adaptations as needed.

Short-term intensive therapy is often used to address specific issues, such as recovery from surgery, self-care and use of technology.

As children grow and develop, the need for individual therapy is reduced. They may become more responsible for performing individual exercises and activities to move toward their goals. Therapists can design a home or school program that incorporates education, recreation, social inclusion and participation in extracurricular activities (e.g. athletics). When possible, activities should be enjoyable and lay the foundation for lifelong health, function and participation. It is important to realize that the therapist should be considered a 'coach' and continued work at home will lead to the best result.

As individuals mature, they may require support services, such as personal assistance services, educational and vocational training, independent living services, counseling, transportation, recreation/leisure programs and employment opportunities, all essential to the developing adult.

People with CP can go to school, have jobs, get married, raise families and live in homes of their own. Most of all, people with CP need the opportunity for independence and full inclusion in our society.

Therapy Services

Physical Therapy:

A physical therapist will focus on helping children with strength, balance, flexibility and the coordination required for motor skills and functional mobility, including rolling, sitting, crawling and walking. They also select, fabricate, modify and train children and families in the use of adaptive equipment.

Occupational Therapy:

Occupational therapists focus on the development of fine motor skills and on optimizing upper body function and improving posture. An occupational therapist helps a child master the basic activities of daily living, such as eating, dressing, and using the bathroom alone. Fostering this kind of independence boosts self-reliance and self-esteem and also helps reduce demands on parents and caregivers. They can also address difficulties with feeding and swallowing. They will use exercise, facilitated practice, alternative strategies and adaptive equipment to promote independence.

Speech and Language:

Speech and language therapists (also known as speech therapists or speech-language pathologists) diagnose and treat the communication disorders associated with CP. They use a program of exercises to teach children how to overcome specific communication difficulties. A speech therapist works with your child on the receptive (understanding) part of speech and language, as well as the expressive part. Speech therapists help improve your child's ability to speak clearly or communicate using alternative means, such as an augmentative communication devices or sign language. They may also help with difficulties related to feeding and swallowing. Speech interventions often use a child's family members, teachers and friends to reinforce the lessons learned in a therapeutic setting. This kind of indirect therapy encourages people who are in close daily contact with a child to create opportunities for him or her to use their new skills in conversation, learning and play.

Psychology:

Psychologists can help children and families cope with the special stresses and demands of CP. In some cases, psychologist may also oversee therapy to address unhelpful or destructive behaviors. The two most common forms of therapy that psychologists provided for children with CP are behavior therapy and cognitive therapy. Psychologists may also evaluate cognitive function, such as an evaluation for a learning disability, intellectual disability, ADHD and autism.

Vision and Hearing Aids:

Depending on how your child's eyes are affected, he or she may need eyeglasses or surgery to correct vision. Some children will benefit from consultation with a vision specialist to determine what types of adaptations in their environment will optimize the use of their visual skills. This is particularly important for children with visual field defects, cortical vision impairments and low vision.

Hearing aids may help correct hearing problems and children with hearing impairments should be followed by an audiologist who can monitor hearing status and prescribe/adjust hearing aids. Consultation with a hearing specialist may be important to determine environmental modifications in the classroom and home that will help the child with impaired hearing have optimal function.

Orthotics:

A variety of orthotics, braces or splints may be recommended for your child. These may be used on your child's legs, arms, hands or trunk. Some of these supports are used to help function, such as with improved walking, sitting or standing. The purpose of other types of orthotics is for additional stretching or positioning of a joint.

Assistive Technology



Assistive technology means “any equipment purchased ...off the shelf or custom made, that is used to improve function in persons with disabilities” (Technology-Related Assistance for Individuals with Disabilities Act of 1988). Simple technology can be used to assist with skills (e.g. modified eating utensils). Complex technology can substitute or replace abilities that do not exist (e.g. power chairs for walking or electronic speech aids for talking). Learning to use the equipment may include education from a therapist or teacher, depending on the technology. Assistive Technology may help children move more easily, control their environment, perform activities of daily living with more independence or communicate successfully.

Assistive Devices for Communication

Some children may use sign language, some use picture books and some will use computerized software programs to communicate and learn. The computer is probably the most dramatic example of a communication device that can make a big difference in the lives of children with cerebral palsy. If a child has a computer and a voice synthesizer, a child can communicate successfully with others. Communication for a child with CP is essential.

Assistive Technology Options for Motor Function, Positioning, and Activities of Daily Living

- Braces (orthotics) and splints
- Mobility devices
- Canes
- Walkers
- Wheelchairs (manual or powered)
- Powered scooters
- Positioning devices
- Seats
- Stenders
- Sidelyers
- Wedges
- Adapted eating equipment
- Bath chairs
- Electronic home aids (door openers, devices to turn on lights)
- Vision aids (magnifiers, large text print books)
- Hearing aids (telephone amplifiers)

Additional Support Services

- Personal assistance, such as in-home nursing care or aides
- Educational and vocational training
- Independent living services
- Counseling
- Transportation
- Recreation/leisure programs
- Employment opportunities and support

Where are Services Provided?

- Inpatient and outpatient services
- Hospitals
- Special clinics or outpatient offices (may be affiliated with hospitals or may be private or free-standing)
- Early-intervention services (birth to three years)
- Homes
- Community locations
- Day care settings
- Other settings or programs when participating along with peers
- School-based services (ages 3 - 21 years)
- Public schools

What are Some Muscle Tone Management Options for Cerebral Palsy?

Oral Medication:

Medications are usually used as the first line of treatment to relax tight or overactive muscles. While easy to use and appropriate to consider for children who need only mild reduction in muscle tone or for children with widespread spasticity, the use of oral medication for the management of abnormal tone has been somewhat disappointing in that impacts are often not ideal. For spasticity, dantrolene, baclofen, diazepam and tizanidine have been used. Other medications, such as Artane have been used for dystonia and there are some preliminary reports of success with modafinil. There has been very limited success in using medications to treat dyskinesias, including dystonia, athetosis and hemiballismus.

Botulinum Toxin:

Botulinum Toxin A therapy (Botox, Allergan, Corporation, Irvine, CA) is FDA approved for strabismus, hemifacial spasm, cervical dystonia, severe primary axillary hyperhidrosis and cosmesis (wrinkles). Although approved throughout the world for treatment of spasticity in children with CP, it is not approved by the FDA for this use in the United States. It has been used as an off-label drug for this indication since the late 1980s. There are other preparations on the market, including Dysport and Myobloc, which is Botulinum Toxin B and acts through a different mechanism than does Botulinum Toxin A.

Extensive literature exists to show that botox is effective for children and adults who have spasticity and/or dystonia. A combination of muscle weakening and strengthening of the antagonist muscle may minimize or prevent contracture development with bone growth. This type of intervention is used when a limited number of muscles are causing deformities, such as spasticity of the gastrocnemius muscle causing a child to walk on their toes or hamstring spasticity being responsible for a crouched gait. Recovery of the muscle tone occurs because of the sprouting of the nerve terminals, a process which peaks at approximately 60 days.

Botox use in the upper-extremity spasticity has been shown to improve cosmesis and function, although the evidence is not conclusive.

Selective Dorsal Rhizotomy:

Selective dorsal rhizotomy (SDR) involves the cutting of approximately 50% of the dorsal sensory roots from the spinal cord, thereby decreasing the muscle tone in the lower extremities. As a result of the decrease in the muscle tone, discomfort or pain may be alleviated and sitting posture and/or gait may improve. The ideal candidate is a child who has normal or near-normal strength in the lower extremities, has good trunk strength, who has not developed fixed contractures and whose alteration of tone will lead to the desired improvements in function. Combining the data from three separate studies that compared physical therapy with SDR revealed a direct relationship between the percentage of dorsal root tissue transected and functional improvement. SDR+PT are efficacious in reducing spasticity in children with spastic diplegia and have a small positive effect on gross motor function.

Intrathecal Baclofen Infusion (ITB):

Baclofen, a GABA agonist, administered intrathecally (next to the spinal cord) via an implanted pump (ITB) has been helpful to patients whose muscle tone is generalized and interfering with function. As Baclofen does not cross the blood-brain barrier very effectively, large doses must be used orally to achieve success, compared to administering Baclofen intrathecally. Often, the patient on oral medication develops side effects, such as sedation. These side effects are less common with ITB since small doses of medication are delivered directly at the site of action. Patients who have generalized tone interfering with activities, such as hygiene, transferring from a chair to a bed or just maintaining a safe upright position are excellent candidates for ITB treatment. Although the complication rate, including infection and Baclofen withdrawal symptoms (occurring as a result of catheter breakage or leakage), is about 50%, parent satisfaction is extremely high with this type of intervention. Once the complication is corrected, more than 90% of the parents/caretakers/patients request that the pump be re-implanted or the catheter be replaced.

Certain patients are poor candidates for ITB treatment and may be affected adversely. This includes patients with significant underlying muscle weakness impacting their gait. SDR and/or ITB in these patients are contraindicated, as the procedure will cause additional muscle weakness, possibly causing an ambulatory patient to become non-ambulatory.

See [What are the Surgical Options Manage Tone.](#)

What are the Surgical Options?

Orthopedic surgery is often recommended when spasticity and stiffness are severe enough to make walking and moving about difficult or painful. The spine is monitored for scoliosis, and the hips for progressive dislocation. In younger children, lengthening of or transferring contracted tendons may suffice. This surgery is typically supplemented by bracing to prevent early recurrences. For older children with bony deformities, corrective osteotomies (cutting and resetting of the bony alignment) may be required. If surgery becomes necessary, it is wise to do as much as possible at one setting (single event multilevel surgery (SEMLS)), both to keep multiple levels in balance, as well as to avoid having to operate too frequently through childhood. Indications for surgery are generally different in ambulatory, as opposed to non-ambulatory children.

Ambulatory Children:

The goal here is to improve walking, though the spine and hips must still be monitored as in the non-ambulatory child. Typically, the children are ambulating but with some issues, such as toe walking, a poor stride length, scissoring (hips crossing over while walking) or crouching (the knees bent while walking). At times, the feet may not be aligned with the way that the child is walking and there may be toeing in or toeing out. Instrumented three-dimensional gait analyses may be helpful in identifying which muscles are contributing to the abnormalities, and examinations can determine if there are twists in the bones that need to be addressed. Scissoring may be caused by tight adductor muscles of the hips or flexion at the knees, as well as and internal rotation at the hips. A crouched gait may be related to simple weakness or balance issues, or can be due to contractures of the hips and/or knees. For the ankle level, the issues are tightness or weakness of the triceps surae, or both. In the past, heel cords were released as necessary, but now we recognize that the gastrocnemius may be tight without the soleus being involved. The latter is important in lifting the heel at the end of stance ('push off') so when possible it must be preserved. Otherwise, there is a risk of further crouching at the ankle as the child ages. The exception is the child with hemiplegic, where toe walking may be treated (after conservative measures, such as casting and or botulinum toxin) by tendon Achilles lengthening, without concern for later crouching which is a risk only for children with both lower extremities involved (i.e. diplegia).

Non-ambulatory Children:

The goal is to promote ease of care by preventing contractures, the development of significant scoliosis and progressive hip subluxation.

This is done to promote useful sitting and transfers, if possible, and to prevent pain and pressure difficulties, which may eventually accompany poor sitting postures and subluxed hips. To ensure good sitting height and lung development, scoliosis surgery is postponed as late as possible by sitting modification and, at times, bracing. Likewise, hip abduction bracing or chair 'pom pom' modifications may be useful to control hip subluxations. X-rays monitor both of these areas. Spinal fusion may be offered for curves in older children that exceed 50 degrees when sitting. The mere presences of hip and knee contractures in individuals who utilize a wheelchair are not in itself an indication for surgery. For progressive hip subluxation, iliopsoas release and adductor tendon lengthening may stabilize the situation, but when there is bony deformity of the hip joint itself, or when spasticity is particularly severe, proximal femoral varus osteotomy (cutting and redirecting the thigh bone) and/or acetabuloplasty (deepening or reorientation of the socket) may be necessary. For foot deformities, the goal is to perform procedures that allow the child to wear comfortable shoes and to be able to place them properly in a wheelchair foot platform. This may require tendon lengthening, particularly the triceps surae (heelcord) and the posterior tibialis muscles (responsible for inverting or turning the foot in), but may require bony realignments and fusions in more severe cases.

Rotational Problems:

Although not readily apparent to the untrained eye, the position of the foot with respect to the leg is helpful in extending the knee. When distorted, this relationship is often referred to as 'lever arm' disease. Likewise, the position of the knee with respect to the axis of the hips is also important in gait progression so there is not excessive 'kneeing in.' Why correct such deformities? Severe kneeing in or scissoring may impede one leg from moving ahead of the other. Further, if an otherwise uninvolved individual were to attempt to walk in a crouched manner, he or she would experience great fatigue in a short amount of time. Similarly, if they were to take half steps all day long, they would likewise feel very fatigued. Half steps or a shorted stride may result from tight hamstrings. Thus, correction of such abnormalities may result in a more efficient gait, with a greater stride length, greater self-selected velocity and less fatigability.

As there can be a combination of bony deformity and soft tissue contractures, along with weakness, deciding how much and which abnormalities to address can at times be challenging. Once a decision to address a gait aberration has been made, the trend among orthopedic surgeons is to do more at a single sitting and not less. This discussion did not touch on some of the nuances, such as hyperextension of the knees or patella alta, but when severe and symptomatic, these abnormalities may at times require complex reconstruction as well.

What Happens To Someone With Cerebral Palsy Over Time?

This condition encompasses a wide variety of causes, severity and associated issues. Some individuals have severe impairments in motor function, while others have mild impairments. Some have learning issues, vision problems or hearing concerns. Some children with cerebral palsy will show improvement, some will remain the same, and some will get worse due to medical complications or orthopedic issues. Such diversity means that outcomes vary. There are some caveats that help to guide evaluation of prognosis:

- The child's motor (movement) abilities at age 2 can often predict how well the child will walk and move as he or she ages. However, since every child with CP is different, it is not easy to make a prediction of whether or not a child will make progress.
- Children with low IQs do not do as well with children with higher IQs.
- Children who undergo treatment often do better than children who are not treated.

People with CP need the opportunity for full inclusion in society and optimal independence. Regardless of condition severity, all children with CP should take part in their community and attend school. Many people who have CP hold jobs, get married, raise families and live in independently as adults.

10 Myths and Misunderstandings about Cerebral Palsy

1) My Child's Future is Limited.

A child born with cerebral palsy or other disabilities has never had a more promising future. With early intervention services available from birth, and public school education in the “least restrictive environment” made mandatory, children with disabilities have the best shot ever for a quality education and greater achievement in life. But all services are not provided equally throughout the country. Parents will be the chief advocates for their child.

2) Caring for my Child with Disabilities Will Place Enormous Stress on my Family.

Caring for a child with disabilities does place substantial stress on a family, challenging family members in every aspect of their lives. However, more and more resources exist to help reduce this stress. Most states now offer family support programs with a range of services, including respite, counseling, parent training, cash subsidy programs, and recreational and after-school activities. Government funded respite services are available in most communities, ranging from in-home assistance to overnight care. Also, local non-profit organizations, such as United Cerebral Palsy affiliates provide parent and sibling support groups, resources centers and learning libraries, information, referral aid and assistive technology services. These are often in addition to concrete services, which include programs for early intervention, preschool and school-age special education, adult recreation, and residential care, as well as healthcare, employment assistance, and more.

3) My Child Will Never be Able to Walk.

When a child is very young, it is generally too soon to make a judgment about his or her long-term physical abilities. There are many complex issues that will come into play from a healthcare and rehabilitation perspective. A child's self-motivation for physical independence also plays a key role. A parent can get connected by networking with other parents, as well as by asking their pediatrician to recommend an agency, hospital, or clinic that can provide the orthopedic evaluations comprehensive medical care and physical therapy.

4) My Child Will Never be Able to Communicate.

All children communicate in one form or another. Many children benefit from ongoing speech therapy. For a child who has limited speech or difficult-to-understand speech, there are an increasingly wide array of augmentative/alternative speech systems available. Young children learn with simple communication boards, basic “yes/no” switches and sign language. As children grow older and gain the ability to operate more complex communication systems, they typically graduate to more sophisticated and high-tech electronic devices. From the parent’s perspective, it is important to find an educational program or in-house service that is savvy about speech therapy and augmentative communication systems and introduces these services at the earliest point possible. Your local school district or county health department can direct you to speech and augmentative communication services in your community.

5) My Child Will Never Have Friends who are Non-Disabled.

Throughout their lives, children with disabilities have constant, natural opportunities to interact with youngsters who are non-disabled, such as play groups and family gatherings. Many preschool settings are now integrated and children who have disabilities learn side-by-side with their typically developing peers. When they graduate from preschool, they may go on to inclusionary public school settings.

6) My Child Will Never Hold Down a Job.

Your child’s future in terms of both supported and mainstream employment is brighter than ever. With the 1997 renewal of the Individuals with Disabilities Education Act (IDEA), we will continue the progress made in the educational arena guaranteeing an appropriate and inclusionary education for individuals with disabilities. Too, the widespread availability of transitional services between school and the work world increase the likelihood of success for individuals with disabilities in the workplace. The statistics speak for themselves: 20 years after IDEA, 57 percent of young people with disabilities as compared with 33 percent of older individuals with disabilities are cumulatively employed within five years of leaving school.

7) My Child Will Never be Able to get Around the Community.

The 1990 Americans with Disabilities Act (ADA) guarantees the accessibility of public systems by people with disabilities, and mandates alternative transportation systems when public transportation, such as subways, cannot be made readily accessible. And for adults who choose to live in small group programs in the community, specially trained staff provide instruction to promote independent traveling. Many programs also have accessible vans and other vehicles to assist in using community resources.

8) My Child Won't Have a Normal Life in the Community.

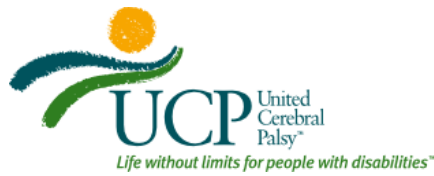
Children with CP and other disabilities have the potential for a childhood, adolescent, and adult life that is satisfying, challenging and, from almost every perspective, similar to everyone else's. Depending on their degree of disability, they may eventually live on their own or in a small supervised group settings. They may marry and have children of their own. They will face the emotional highs and lows and challenging life circumstances that every person faces at various points in their lives. Most importantly, they will have a choice in selecting the lifestyle and living situation that they prefer.

9) Society Will Never Accept my Child.

A child born with disabilities today enters a world where attitudes are light years ahead of society 20 years ago. In most communities across America, we have experienced 20 to 25 years of deinstitutionalization and community living. Individuals who have disabilities are visible everywhere -- in school, in the workplace, and in every possible public venue. Most Americans have had some personal experiences with one or more persons who have disabilities – many through volunteer work and many others in every aspect of day-to-day life. Further, the ADA – which mandates physical accessibility for public buildings, public spaces, and transportation – has also served to heighten awareness of those with physical disabilities. While we do not live in a perfect world, we do live in a society that is far more accepting and in tune to the needs of those with physical and cognitive challenges.

10) My Child Will Never be Independent.

Today there exists an incredible variety of assistive devices and services that enhance the independence of individuals with CP. There are also simple modifications that can be made to a person's home, school and work environments to facilitate independence and productivity. Lowering the clothes bar and shelves in a closet, widening doorways and installing hand-held showers, all make it possible for a child who has CP to actively participate in self-care activities. Adapted utensils and appliances enable a child to have access and independence in feeding and food preparations. Other assistive technology devices, ranging from alternative communication systems to computer adaptations, to adapted toys, enhance independence in all areas of a child's life. Through the federal "Tech Act" Technology Related Assistance for Individuals with Disabilities (TRAID) Centers have been established in every state, offering free information and referral for assistive technology devices and systems.



Cerebral Palsy Resources

More Information about Cerebral Palsy is Available on the Following Websites:

United Cerebral Palsy

www.ucp.org

American Academy for Cerebral Palsy and Developmental Medicine

www.aacpdm.org

National Information Center for Children and Youth With Disabilities

www.nichcy.org

National Institute of Neurological Disorders and Stroke

www.ninds.nih.gov

Centers for Disease Control and Prevention (CDC)

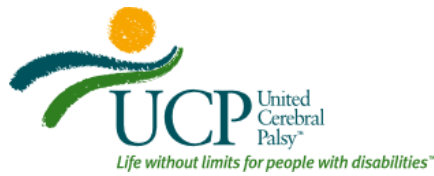
www.cdc.gov

Reaching for the Stars

www.reachingforthestars.org

Cerebral Palsy International Research Foundation

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



Meet Dr. Lisa

My Child Without Limits partnered with Dr. Lisa Samson-Fang in fall 2012 where she took on the role as Medical Director providing consultative support for the website.

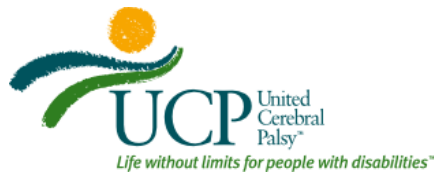
Dr. Lisa is a General and Developmental Behavioral Pediatrician at Bryner Pediatrics Clinic and Shriners Hospital For Children in Salt Lake City. Her clinical practice provides primary health care with emphasis upon caring for children with special health care needs in a medical home model. She is a member of the American Academy of Pediatrics, the Ambulatory Pediatric Society, the American Board of Pediatrics and the American Academy of Cerebral Palsy and Developmental Medicine.

About Us

MyChildWithoutLimits.org is an authoritative early intervention resource for families of young children ages 0-5 with developmental delays or disabilities, and professionals looking for a single, trusted, aggregate source of information that relates to their needs and interests. My Child Without Limits is a program of United Cerebral Palsy (UCP).



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