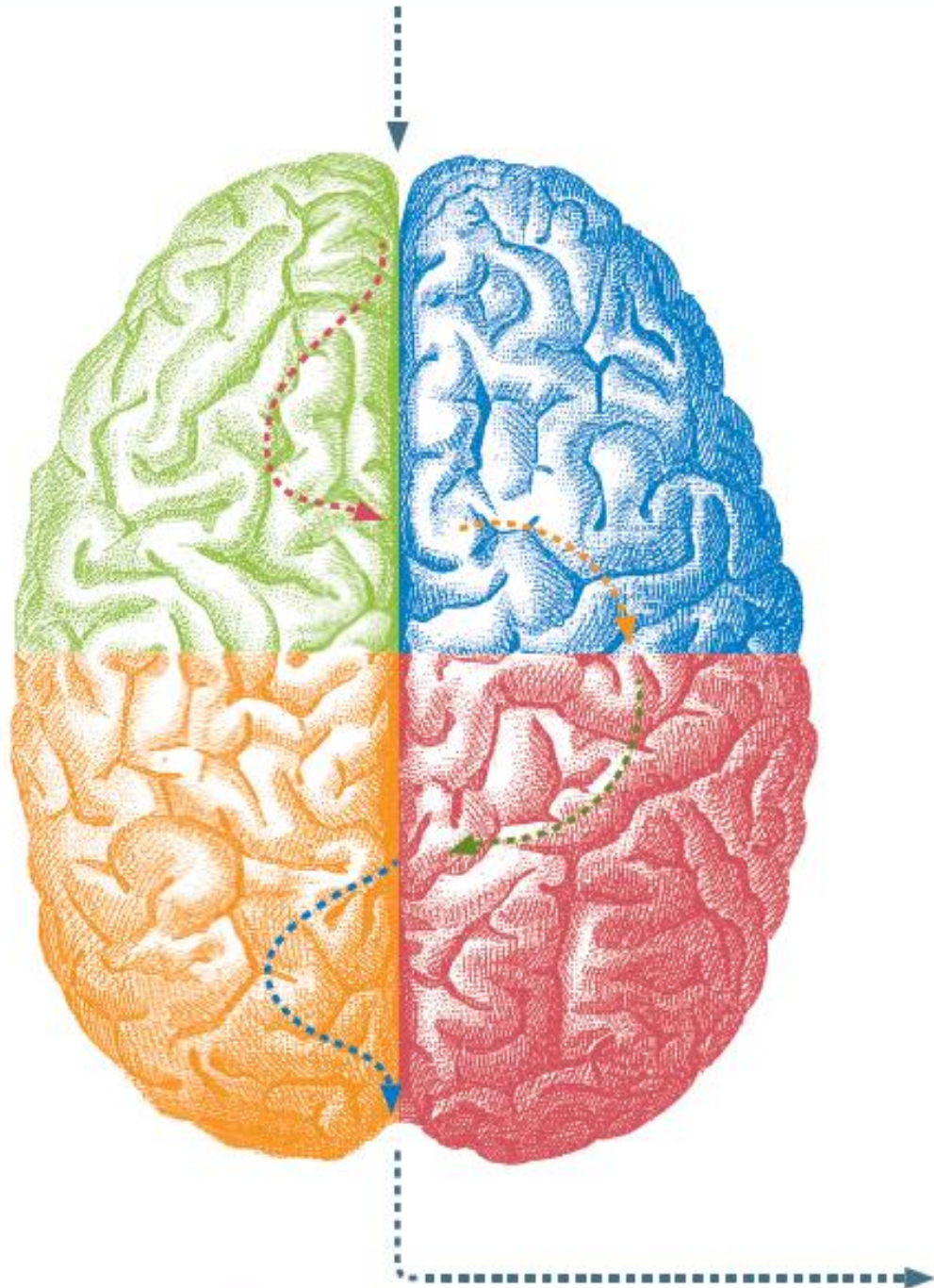


A Guide to

Cerebral Palsy



your pathway to understanding

*This edition of **A Guide to Cerebral Palsy** has adapted material from several excellent publications and websites, which outline the causes and effects of cerebral palsy:*

A Guide to Cerebral Palsy
Dr. A. Mervyn Fox
Canadian Cerebral Palsy Association, 1991

Cerebral Palsy - Facts and Figures
United Cerebral Palsy
(www.ucp.org)

Cerebral Palsy - Information kits for Educators and Parents
Cerebral Palsy Association of Manitoba, 1989

Cerebral Palsy Magazine
(www.cerebralpalsymagazine.com)

Children with Cerebral Palsy - A Parents' Guide
Elaine Geralis, 1998

National Institute of Neurological Disorders and Stroke
(www.ninds.nih.gov)

Ontario Federation of Cerebral Palsy
(www.ofcp.on.ca)

Published: 2006
Cerebral Palsy Association of BC
Written by Nan Colledge, 1999

2020 Addition Revised by: Dr. Ram Mishaal and Carolyn Chowne, Sunny Hill Health Centre at BC Children's Hospital

A Guide to
Cerebral Palsy

CEREBRAL PALSY ASSOCIATION OF BRITISH COLUMBIA



Cerebral Palsy Association
of British Columbia

3rd edition 2006

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The Cerebral Palsy Association of BC

Who We Are

The Cerebral Palsy Association of BC is an independent, not-for-profit Association directed by a volunteer Board of Directors that includes: those living with CP, parents of children and youth with CP, and interested community members.



We began in 1954, thanks to a group of concerned parents wanting the best possible opportunities for their children living with Cerebral Palsy. Today we provide: support, education and information to over 12,000 people across BC living with CP. This support is also extended to family members, professionals, students, other organizations, and community groups.

Our Mission

- To raise awareness of Cerebral Palsy in the community
- To assist those living with Cerebral Palsy to reach their maximum potential
- To work to see those living with Cerebral Palsy realize their place as equals within a diverse society

Guiding Principles

As the *Knowledge Centre* for Cerebral Palsy in the province of British Columbia, we are committed to the following Guiding Principles.

- We believe in providing accurate information concerning both the clinical and experiential aspects of living with Cerebral Palsy.
- We believe that all individuals living with Cerebral Palsy, *including*: family, friends, or others within the CP Community, should have equal access to programs and services that will both meet their present needs, and help them to achieve long term life goals.
- We believe that those living with Cerebral Palsy are part of the spectrum of human diversity, and therefore, do not need to be made to conform to a standardized norm. We believe in the *normality* of diversity.
- We believe that all people have unique skills and knowledge to offer society, thanks to differing age, ethnicity, cognitive ability, gender, and physical mobility.

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NOTES ON STYLES USED IN THIS GUIDES

To make this text easier to read:

The abbreviation – CP – is used to throughout in place of Cerebral Palsy.

CP affects roughly equal members of men and women. Rather than use “he/she”, “he” and “she” are used in alternating sections.

INTRODUCTION

Every person who has Cerebral Palsy (CP) is unique. CP describes a variety of movement disorders, ranging from mild to severe, with differing causes affecting individuals in many ways. If you are new to Cerebral Palsy, you may find yourself struggling with a bewildering number of medical and technical terms.

In Canada, people with disabilities have access to one of the widest ranges of support and therapy services, equipment, medical intervention, educational and employment opportunities in the world. While having CP does present some additional challenges, it does not need to be a barrier to leading an enjoyable and productive life. Being well informed about the options and opportunities available is a first step to successfully facing these challenges.



“After I’ve been tucked into bed at the end of the day, what matters most is whether or not I’m happy with who I am and what I’ve achieved, disability and all”.

- T. VAN DER KAMP

What is Cerebral Palsy?

Cerebral palsy is the result of an injury to the developing brain at any time during pregnancy, birth, or until the age of two. The injury to the brain interferes with messages from the brain to the body affecting body movement and muscle coordination. CP does not damage a child's muscles or the nerves connecting to them to the spinal cord – only the brain's ability to control muscles.

Depending on how much of the brain was affected, the effects of CP vary widely from individual to individual. At its mildest, CP may result in a slight awkwardness of movement or hand control. At its most severe, CP may result in virtually no muscle control, profoundly affecting movement and speech.

Cerebral = of the brain

Palsy = lack of muscle control

Depending on which areas of the brain have been injured, one or more of the following may occur:

- Muscle tightness or spasm
- Involuntary movement
- Difficulty with *gross motor skills* such as walking or running
- Difficulty with *fine motor skills*, for example, writing and speaking
- Abnormal perception and sensation

These effects may cause associated problems, for instance, difficulties in eating and swallowing, poor bladder and bowel control, and breathing problems.

Many, but not all, individuals who have CP have secondary medical conditions and disabilities:

- Growth problem (failure to thrive)
- Seizures or epilepsy
- Learning disabilities / cognitive impairment
- Hearing impairment
- Vision problems

COMMON MISCONCEPTIONS ABOUT CP

Myth: CP is hereditary

Fact: While there might be some genetic components, CP is *not* inherited from one generation to the next

Myth: CP is life-threatening.

Fact: People diagnosed with CP can have a normal life span.

Myth: CP is usually the primary cause of death.

Fact: Because CP is *not* sickness or disease, and *not* progressive, it is not the primary cause of death

Myth: CP is a disease.

Fact: CP is *not* sickness or disease that can be passed on from one individual to another or be cured. It is a life-long condition.

Myth: CP is progressive.

Fact: Injury to the brain is a one-time event, so the condition *will not* worsen, change or expand, although the *effects* of CP may change over time. Some may improve; for example, a child whose hands are affected may be able to gain enough hand control to write and to dress himself. Alternatively, muscles may tighten and can cause problems in the hips and spines of growing children. This may require orthopedic surgery to correct.

Myth: CP is always preventable.

Fact: There are measures that may be taken to prevent some cases of CP. However, despite best efforts of parents and physicians, children are still being born with CP.

Myth: The physical disabilities of CP are an indication of level of intelligence.

Fact: People with CP can have difficulty with speaking, but this *does not* equate low intelligence or low cognitive levels for their age. Many people living with CP have average to above average intelligence levels.

Myth: CP means limb paralysis.

Fact: The muscles in limbs affected by CP are *not* paralyzed. Pain, heat, cold and pressure are felt but there can be diminished sensation.

HOW MANY PEOPLE HAVE CP?

It is difficult to estimate exactly how many people live with CP. Many people with mild CP are never diagnosed, while others may have multiple disabilities, which overshadow their CP.

Worldwide, more than 15 million people have CP. In Canada, it is estimated that one out of every 500 babies, and up to one in three low-birth-weight babies, are affected to some extent. Presently, there are over 50,000 Canadians living with CP.

A large number of risk factors, individually or in combination, can injure the developing brain, which in turn may produce CP. Risk factors are not causes but variables which, when present, increase the chance of something occurring – in this case, CP. Just because a risk factor is present does not mean CP will occur; nor does the absence of a risk factor mean that CP will occur. If a risk factor is present, it serves to alert parents and physicians to be even more observant to the infant's development – before, during, and after birth.

WHAT INCREASES THE RISK OF CEREBRAL PALSY?

Risk factors that can lead to birth complications resulting in CP include the following:

DURING PREGNANCY:

Anything, which tends to produce a low birth weight baby, will increase the likelihood of CP.

Factors during pregnancy which may increase the risk of CP include:

- Premature delivery
- Multiple births (twins or triplets)
- A damaged placenta which may interfere with fetal growth
- Infections (e.g. rubella)
- Poor nutrition
- Exposure to toxic substance, including nicotine and alcohol
- Maternal diabetes, hyperthyroidism or high blood pressure
- Biochemical genetic disorders
- Chance malformations of the developing brain
- Rh or A-B-O blood type incompatibility between mother and infant
- Sexually transmitted diseases (e.g. gonorrhoea, herpes...)

DURING LABOUR:

- Premature delivery
- Abnormal positioning of the baby (such as breech or transverse lie) which makes delivery difficult
- Small pelvic structure
- Rupture of the amniotic membranes leading to fetal infection
- Prolonged loss of oxygen during the birthing process
- Effects of anesthetics or analgesics
- Severe jaundice shortly after birth
- Low Apgar score

POST-NATAL (0-2 YEARS OLD) RISK FACTORS:

CP can occur if a child suffers from an injury to the brain due to:

- Infection such as meningitis
- Brain hemorrhages
- Nervous system malformations
- Head injury such as falls or car accidents
- A lack of oxygen (asphyxia) due to accidents such as drowning
- Poisoning



In some cases, a difficult labour may lead to a lack of oxygen to the brain, which can be an important contributing factor in the development of CP. Other people with CP may be born prematurely. Still other families sail through straightforward pregnancies and deliveries, only to have their child diagnosed with CP “out of the blue”.

Every person with CP asks, “Why did this happen to me?” and every parent of a child with CP asks, “Did I do anything wrong?” In some instances, these questions will never be answered to your satisfaction. As one mother said, “When I stopped saying ‘why me?’ I was ready to accept my son's CP and look to the future”.

“Finding out your child has a disability: it’s not the end of the world.”

- DR. MARK NAGLER, PH.D.

IS CEREBRAL PALSY PREVENTABLE?

Several of the risk factors for CP are preventable or treatable:

- Safety campaigns give advice on protecting children from accidents and injury. Head injury can be prevented by regular use of child safety seats when riding in a car or use of helmets during bicycle rides. In addition, common sense measures around the household – close supervision during bathing and keeping poison out of reach – can reduce the risk of accidental injury.
- Newborns with jaundice can be treated effectively with phototherapy.
- Rh incompatibility is easily identified by a simple blood test routinely performed on expectant mothers. Pregnant women are tested for the Rh factor and, if Rh negative, they can be immunized within 72 hours of giving birth. This prevents any adverse consequences of blood incompatibility in a subsequent pregnancy.
- Rubella, or German measles, can be prevented if women are vaccinated against this disease before becoming pregnant.
- Women should begin getting regular medical care they know they are pregnant, and should avoid smoking, alcohol, and other drug abuse. Education programs stress the importance of optimal well-being prior to conception and adequate prenatal care.

These measures have undoubtedly prevented many children from a brain injury resulting in CP. Other developments – such as neonatal intensive care – have enabled very low birth weight babies to survive. However, despite the best efforts of parents and physicians, children may still be born with CP. As research uncovers more about the causes of CP, doctors and parents will one day be further equipped to help prevent this condition.

DIAGNOSIS OF CP

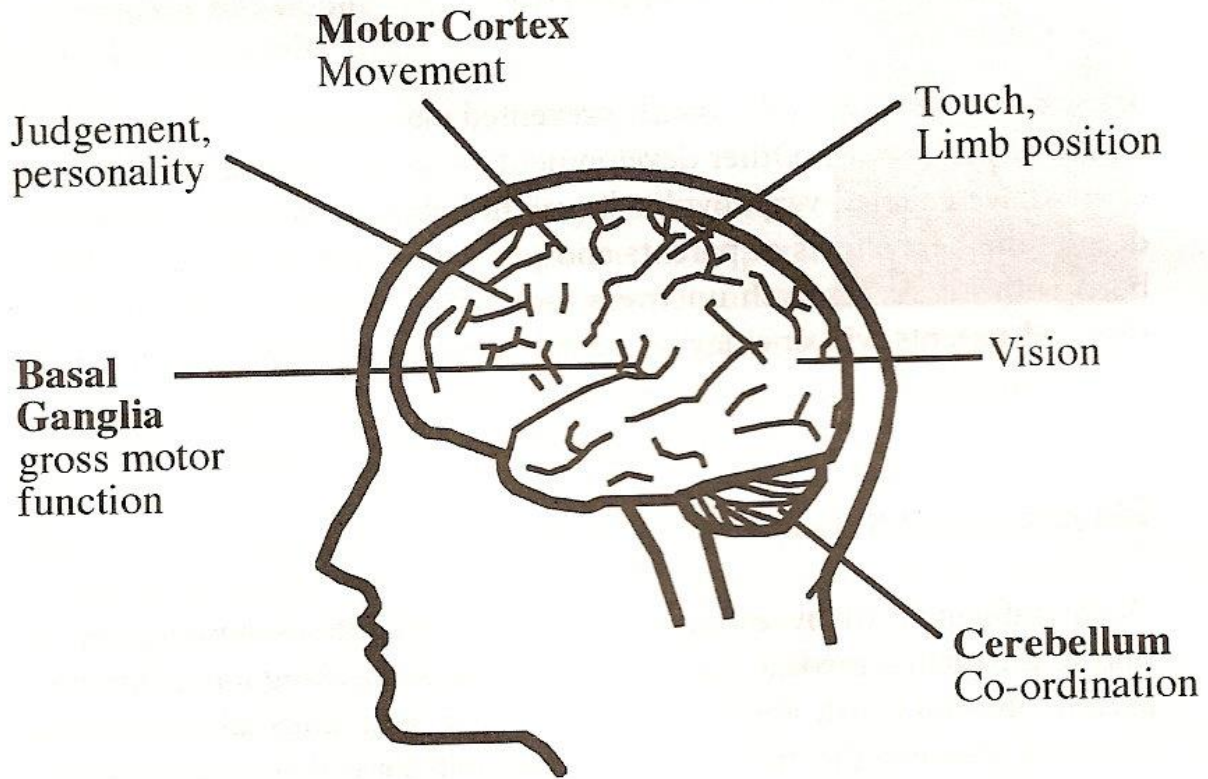
Doctors diagnose CP by testing an infant’s motor skills and looking carefully at the infant’s medical history. In addition to checking for symptoms of slow development, abnormal muscle tone, and unusual posture, a physician also tests the infant’s reflexes and looks for early development of hand preference.

The doctor may also order specialized tests to learn more about the possible cause of CP. Brain imaging such as MRIs (Magnetic Resonance Imaging) can identify lesions in the brain.

Current knowledge enables some children, who are considered at risk of having CP to be diagnosed very early. However, in some cases it will be months, and sometimes years, before a diagnosis is confirmed.

A child with CP will probably be delayed in reaching her “milestones” such as rolling over, sitting and standing. A baby may feel unusually stiff or floppy. A diagnosis of CP is unlikely to be given until the child’s progress is observed over a period of time and other conditions are ruled out. Many parents report that this waiting period – when they know their child is not developing at the same speed as her peers, yet not knowing why – is particularly stressful.

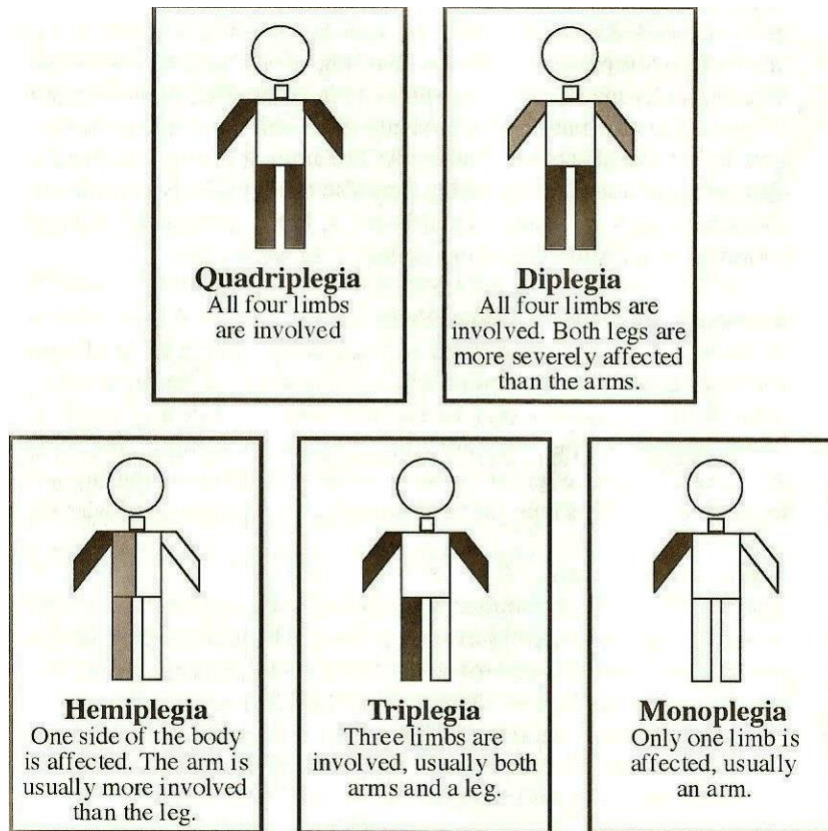
THE HUMAN BRIAN



TYPES OF CP

Just as there are many different causes of CP, CP also takes many forms. Every person with CP is a unique individual, but is likely to be classified as having a particular type of CP. Classification is related to the type of movement disorder and/or by the number of limbs involved.

Classification By Number of Limbs Involved



“The most important factor in a family’s success is the motivation to succeed”.

- DR. MARK NAGLER, PH.D

CLASSIFICATION BY MOVEMENT DISORDER

The location of the brain injury may influence how movement is affected.

Spastic Cerebral Palsy

Spastic CP is the most common type, affecting about 70% of the CP population, and is caused by injury to the motor cortex. Spastic muscles are tight and stiff, which limit movement. Normal muscles work in pairs – when one group contracts, the other group relaxes to allow free movement in the desired direction. Spasticity may also involve difficulty in controlling mouth and tongue. Spasticity may be very mild and affect only a few movements, or very severe and affect the whole body. The amount of spasticity usually changes over time (i.e., aging), but may also be affected by pain, stress, illness, and excitement etc.

Dyskinetic Cerebral Palsy

Dyskinetic CP affects about 15% of the CP population and there are 3 sub-types:

1. Choreoathetoid CP
2. Dystonic CP
3. Ataxic/Hypotonic CP

Dyskinetic CP results from damage to the basal ganglia in the midbrain, and leads to difficulty in controlling and coordinating movement. Uncontrollable movements may be fast and jerky or slow and writhing. People with this type may have trouble sitting or walking. They may also have a hard time speaking due to problems controlling the face and tongue muscles.

Dystonia is abnormal muscle contractions that look like twisting, jerking or stiffening of the arms, legs or whole body that is followed by relaxation.

Ataxic/Hypotonic Cerebral Palsy

Ataxic CP is the least common type. People with this type have a disturbed sense of balance and depth perception (i.e., they have difficulty judging how close or far away things are). They may also have difficulty walking, often walking with a limp, and difficulty with tasks requiring small, coordinated movements such as writing or reaching and grasping objects smoothly. Hypotonia also called ‘low tone’ and causes overly relaxed muscle. The arms and legs move very easily and appear floppy.

Mixed-type cerebral palsy

When areas of the brain affecting both muscle tone and voluntary movement are affected, a diagnosis of “Mixed -type CP” may be given. Usually the spasticity is more obvious at first, with involuntary movement increasing as the child develops. This affects about 15% of the CP population.

The classifications of movement disorder and number of limbs involved are usually combined (e.g. spastic diplegia). These technical words can be useful in describing the type and extent of CP, but they are only labels. A label does not describe an individual.

Gross Motor Function Classification System (GMFCS)

The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. Distinctions are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement. The focus of the GMFCS is on determining which level best represents the child's or youth's present abilities and limitations in gross motor function. Emphasis is on usual performance in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability).

General Headings for Each Level

LEVEL I - Walks without Limitations

LEVEL II - Walks with Limitations

LEVEL III - Walks Using a Hand-Held Mobility Device

LEVEL IV - Self-Mobility with Limitations; May Use Powered Mobility

LEVEL V - Transported in a Manual

MANAGEMENT OF CEREBRAL PALSY

CP is not a curable condition. However, there is much that can be done to lessen the effects of CP and to help people lead as independently as possible. The word "management" is much preferred to "treatment," as management refers to minimizing and preventing complications, and helping the child achieve his maximum potential in growth, development and participation. The earlier management begins, the better chance a child has of overcoming developmental challenges and learning new ways to accomplish difficult tasks.

There is no standard therapy that works for all people. Specific interventions for CP are based on:

- Your child's age, overall health, and medical history
- The extent of the condition
- The type of CP
- Your child's tolerance for specific medications, procedures or therapies.
- Expectations for the course of the condition
- Your opinion or preference as parents/caregivers

Once your child's unique needs and impairments are identified, a team of health care professionals will work together to create an individual intervention plan to address your child's needs. A typical intervention team may include a physician/pediatrician, orthopaedist, physiotherapist, occupational therapist, speech and language therapist, social worker, psychologist, and educator. See **The Professional Team (p.28)** for further information. Families or caregivers of individuals with CP are also key members of the intervention team, and should be involved in all steps of planning, making decisions, and applying treatments.

Individual/Family Supports

People living with CP and their families, may need support to adjust to this condition and all it entails. Parents and relatives may be angry their child has CP or they may feel guilty or overwhelmed. Brothers and sisters of children with Cp may also need extra support.

Talking to a social worker, psychologist, or family therapist may help. In addition, many people with CP and their families may find encouragement through support groups or simply interacting with other people living with CP.

NOTE: For information on local and on-line support groups, please contact the CP Association of BC, or visit www.bccerebralpalsy.com.

“Essential to every age, every challenge, every crisis, are the connections we have formed with other parents of children with disabilities. These connections come naturally: in clinic lines, preschool pickups, and all other occasions when we parents are shepherding our children with disabilities through life.”

- M. Somoza, parent of twin girls with CP

Most Commonly Used Therapies:

Physical Therapy (PT) also called Physiotherapy, aims to help people achieve their potential for physical independence and mobility. Physical Therapy uses exercise and activities to improve range of motion, strength and other gross motor functions.

Occupational Therapy (OT) designs purposeful activities to increase independence through fine motor skills. OTs help children to use adaptive equipment such as feeding, seating and bathroom aids.

Speech/Language Therapy (SLP) aims to help children communicate with others. A child may only need help to overcome a slight articulation problem, or she may not be able to communicate verbally and may require a non-verbal communication system. Alternative communication systems include low-technological picture and symbol boards, to high-technological eye-gaze systems, blissymbol boards, and voice output devices.

Other Therapies

Acupuncture involves inserting specially designed fine needles into specific areas of the body for therapeutic uses, to relieve muscle pain, or as a regional anesthetic.

Aquatic Therapy involves PT in a warm water pool. It is not necessary to know how to swim to do aquatic therapy. It may help relax muscles, improve body posture and balance, and decrease muscle spasms, and increase circulation.

Biofeedback techniques may improve control over body movements by increasing the concentration of mind over body.

Conductive Education does not involve directly changing a certain disability; rather it involves teaching those with motor disabilities to carry out coordinated and integrated actions through properly-guided, understandable education applied to daily routines and play. (Peto Institute)

Hippotherapy involves therapeutic horseback riding. A horse's walk provides sensory input through movement that is viable, rhythmic, and repetitive. Hippotherapy may improve balance, posture, core strength and range of motion.

Massage Therapy can benefit people living with CP by helping them relax tense muscles, relieve muscle spasms and cramps, strengthen muscles, keep joint flexible, and increase circulation.

Music Therapy uses music for the treatment of secondary, developmental or behavioral disabilities.

Recreation Therapy uses sports and leisure activities as a form of therapy. Recreational therapists work with children on such activities as dancing, swimming, horseback riding, art, horticulture, and any other hobby the child is interested in. Other activities may also include traditional sports with or without equipment aids.

* Hyperbaric Oxygen Therapy (HBOT) involves breathing pressurized 100% oxygen in a special chamber. Current evidence does not support this hyperbaric oxygen therapy in its effectiveness in improving body function. There are possible side effects and demonstrated risks of receiving this type of therapy.

* HBOT is highly sought after as marketing around this often claims a miracle cure and very expensive.

Orthotics & Splints

Most children with CP will be prescribed orthotics, casts or splints to supplement their therapy programs. They help to provide stability, keep joints in position, and help stretch muscles.

Medications

Your child may take medication for secondary conditions sometimes associated with her CP, such as seizures. Drugs may also be prescribed to control spasticity, dystonia and other dyskinetic movements. Medications used most often includes:

- Dantrolene (Dantrium): interferes with the process of muscle contraction. Generally not prescribed for children.

- Benzodiazepines (such as clonazepam, diazepam/valium): acts as a general muscle relaxant at the central nervous system.
- Baclofen (Lioresal): works mostly at the spinal cord level and acts as a muscle relaxant

Anticholinergic drugs – including Trihexyphenidyl, Bzotropine, and Procyclidine Hydrochloric – are sometimes prescribed to help reduce abnormal movements in individuals with dyskinetic CP.

Injections

Botox

Occasionally, physicians use injections of toxins such as alcohol or botulinum toxin into the muscle – in order block the nerves that activate these muscles and to reduce spasticity for a short period.

Your physician may suggest the use of injections for specific goals such as tolerating splints, etc.

Hip Surveillance

Hip surveillance helps us to ensure that children at risk for hip displacement receive appropriate screening to allow for early and appropriate management. Consult your child's physician or physiotherapist.

Surgery

Surgery may be recommended when contractures, or bony deformities, are severe enough to cause movement problems, pain or physiological challenges.

Orthopedic: Bony and soft tissue surgery can help counter the damaging effects of spasticity on the spine, hips and legs. Surgery can lengthen or transfer tendons, enabling the child to move more easily. Bone surgery may help reposition and stabilize bones.

Neurosurgery involves surgery on the spine's nerve roots, which control muscle tone. *Selective dorsal root rhizotomy* aims to reduce spasticity in the legs. It can reduce spasticity in some patients, particularly those who have spastic diplegia. This surgery is irreversible and permanent.

Intrathecal Baclofen Therapy (ITB Pumps) is a surgical procedure where an ITB Pump is implanted into the abdomen with a catheter leading to the spinal canal.

Pain and Sleep

People with CP may experience pain or sleep difficulties. This should be discussed with your physician and therapists as there are a variety of treatment options.

Nutrition

It is important to ensure adequate nutrition to help maintain good health status and support growth and development. Some people with CP will need additional nutritional support and supplements such as Vitamin D.

Adaptive Equipment

An enormous range of aids and adaptive equipment are now available for people with disabilities. As the number of elderly people in Canada increases, more daily living aids are coming onto the market.

Mobility Devices include:

- Wheelchairs (manual, power and sports)
- Scooters
- Specially made bicycles and tricycles
- Walkers and crutches

Communication Devices include:

- Symbol boards
- Voice output devices
- Head sticks and key guards for computers
- Specialized computer hardware and software



Daily Living Aids include:

- Electronic door openers
- Large-handled eating utensils
- Grab sticks
- Environmental control systems

Some equipment is available through provincial health and social service systems. These vary across the country. Your local Cerebral Palsy Association can advise you what is available in your area.

Educational Supports

Many children with CP will also have some type of learning disability. Assessment by a psychologist, and the support of special educators can reduce the impairing effects of a learning disability.

Canada has some of the world's best early intervention programs. Children with CP will often start their education early to help improve their mobility and communication skills before starting school. The availability of early intervention programs are often subject to government funding and trained professionals.

In BC, children with CP receive an integrated education enabling them to mix with their peers in their neighborhood school. A child with mild CP may simply require minor program adjustments. For example, he may need a little more time to write an exam if his hand control is poor. A child with more severe disabilities may require considerable support from resource staff and teaching assistants.

Children should have an Individualized Education Plan (IEP), which assesses the child's performance, sets goals and specifies which supports are required. The amount of support offered, and the commitment to successful integration, varies widely between school boards and individual schools. A good partnership between parents and educators will help children to achieve their goals.

“Developing a positive attitude is very important, and although children with disabilities will inevitably become aware of their limitations, they should always be encouraged to take on new challenges”

.
- DR. MARK NAGLER, PH.D.

LIVING WITH CP

Impact on Family

Raising a child with CP can be a challenge for everyone in the family. Parents love their child deeply and often are prepared to do whatever is necessary to help their child achieve their potential. They may, however, still face a mixture of conflicting emotions such as love and anger, hope and despair, guilt and frustration. Brothers and sisters of a child living with CP will also be greatly affected. Some children may feel resentful and neglected as their parents spend a great deal of time with their sibling with a disability. Parents will need to support their able-bodied children and help them understand and adjust to this new situation.

Raising a child with any disability will mean making changes in the family. Understanding the challenges, they'll face, and committing to facing them together, will provide the family with a strong foundation to stand on and a secure base of support for all family members.

Growing Up with CP

CP doesn't have to stop children from going to school, making friends or doing things they enjoy; however, they may have to do things a little differently.

People with CP are also able to dance, play basketball, ski, cycle, etc. For the child with CP this can reduce the amount of physical therapy a child needs and receives. Remember, having CP does not mean a person is unhealthy.



*Paul Gauthier
Paralympic gold medalist*

Interdependent Living

People living with CP are usually able to live independently in the community either with or without assistance. Adaptations in the home, such as stairlifts and grab bars, can be made to make it more user-friendly. Advanced technology, can help enable people living with CP to be productive, contributing members of society.

CP is not a life-threatening condition, and in itself, is no barrier to leading a long, satisfying life. People with CP enjoy many of the milestones the most people enjoy, including fulfilling careers, a university education, a social life and marriage.

Women with CP are as biologically and physically capable of having children, as they are of caring for and loving them. Arrangements can be made to make pregnancy and the birthing process safer and easier for someone with CP. As well, many adaptations can be made around the home to enable caring for the child easier for parent(s) with CP.

A person living with CP has to cope with both *disabilities* and *barriers*. A *disability* is a physical loss of function such as walking or difficulty with hand control or speech. A *barrier* is the degree to

which that disability puts a person at a disadvantage in daily life; for instance, someone who is very short-sighted may be considered to have a *disability*, but she is unlikely to consider this a *barrier* if she has corrective lenses. A *disability* may prevent someone with CP from climbing stairs, but this will only be a *barrier* if the building she wants to enter is not wheelchair-accessible.

Key elements to minimize the barriers experienced include:

- Management and Treatment
- Access – being able to enter and use public buildings, washrooms, and transportation devices (to name a few)
- Attitudes – prejudice and teasing can be very damaging to a person with CP, as can many misperceptions and myths concerning their abilities and intelligence

It is important to remember to that people with disabilities are people first and share similar needs, desires and drives as the rest of us!

Disability is a loss of function	Barrier is the effect of that disability in daily life
--	--

A PARENT’S PERSPECTIVE

by Cal Lambeth

My daughter was born nine weeks prematurely after my two-week stay in the hospital with ruptured membranes. She had to be resuscitated in the delivery room. She had no breathing difficulties and was soon transferred out of the intensive care nursery. Five weeks later, still a month ahead of schedule, we took her home.

I remember that time as a difficult one of adjustment. She was our first baby. Things just hadn't gone according to “script.” I felt both she and I had been cheated out of those important nine weeks in the womb. These negative feelings were those of many new mothers and they did not relate to any anxiety about her long-term health. Rather naive, I had considered that her birth circumstances were either “do” or “die.” She would be born and survive with no further problems, or she would die (probably from breathing difficulties). I was unaware of the increased risk of many disabling conditions which prematurity creates.

Over time I began to notice “things” about her. She was irritable and colicky. She couldn’t seem to master breast feeding as her tongue kept thrusting out. Her head control was very poor. She kept arching her back to look over her head. For a time we all found this amusing, thinking that the ceiling fascinated her. Her right hand remained almost always clenched. Her legs seemed stiff and her feet scissored. Gradually, private little fears began to creep in, but I held them off as merely relating to her prematurity.

Because of her premature birth she became involved in a study of lung maturity. This necessitated follow-up with certain health professionals over the course of the year after her birth and it was as a result of this study that we received a diagnosis. When she was about 11 months old, a pediatrician at one of these meetings merely said, “You’re aware that she has Cerebral Palsy.” She was described as “mild to moderate.” I was absolutely devastated. I remember clutching her and sobbing, “My poor baby!” It was like a scene from a bad movie and I still remember it vividly.

Later, doctors apologized for this rather blunt and unprepared announcement. It seemed that they had been concerned about her condition for some time but were monitoring it and didn't want to say anything until they were sure of the diagnosis. Although I appreciated this goodwill, I questioned the withholding of this information. They couldn't shield me forever, and in my opinion, my daughter was losing valuable time in which to begin physiotherapy.

Thus began our lives as "Parents of a Special Needs Child." Those were bleak days. I was despondent, panic stricken, and felt that life would never be good again. My career plans were destroyed. Looking back at this time I realize how bitter and hostile I was. I found it difficult to maintain close relationships with people who had children similar in age to my daughter. I wanted to scream when they complained that their child was "into everything" while mine lay flat on the floor, unable to sit or crawl. I also felt angry when people told me how marvelously I was coping. I felt neither marvelous, nor that I was coping well; furthermore, it seemed that this was an indication of their view that my child was a burden – privately, I felt this way myself at times. I suppose this all represented a fairly typical and predictable process.

Although I presented a bold front to those around me, the truth of the matter was that I was depressed and frightened. I was fortunate to have a family which offered physical help and a listening ear. Not everyone is so lucky. I strongly felt the need to talk to others about their own experiences. My first thought was to look up "Cerebral Palsy" in the telephone directory. I took a deep breath and called the number of the Cerebral Palsy Association, determined to be strong and in control. Shortly into the conversation I broke down, but the woman I spoke to was kind. She offered the information that her husband had CP and that they were expecting their first child. These words gave me a new sense of what the future could hold. CP was not a death sentence. My child could grow up, be happy, and lead a life of purpose. At least the possibility was there. From this conversation I received information about parent support groups which I attended for a time and found valuable. But the most important fact was that I had taken some action. This small step had helped to allay the sense of "aleness" and had given me a renewed sense of control.

Our family is now much like any other - enjoying the excitement of new achievements and the ups and downs of child rearing. It would be wrong to claim that all of the emotional and psychological hurdles have been overcome. As our child matures new challenges present themselves. We are always seeking new ways to adapt her physical environment to allow greater independence. We want to encourage self-esteem, and pleasure in new achievements. We are not experts in these matters, but have learned to rely upon our common sense and the knowledge and expertise of those we trust.

A PARENT'S PERSPECTIVE

By Conrad van der Kamp

Recently I asked: so what's the special role of a Dad in the life of a child with CP? What's the role of a Dad in any child's life? It's all about providing, safeguarding, teaching, hugging tightly and encouraging. And it's also about encouraging from the sidelines and standing back when your child stumbles. It involves making room and letting go.

Letting go is pretty tricky, especially when the child faces unusual obstacles and a little help would help so much. Do you want a hand with that sleeve? You want me to cut that sandwich? How about I proofread that essay? I know you can do that transfer, but it's so much faster if I just... and so on. When our daughter was little I would swing her in and out of cars, into her wheelchairs, and into bed. When she got older, I could still lift her in and out of cars. It was just easier; faster and

easier. Well yes, maybe easier, but maybe not so smart. Not so smart for my back in any case, but also not smart as a way to affirm the young woman that she had become. I had to learn, and am still learning, to adapt her rhythms and her timing; learning to let her lead.

It was the same with schooling – I wanted to wade in, shape everybody up, and have them really see this soft-spoken plucky girl instead of the wheelchair. I wanted to guard her from offhand cruelty, from casual inattention, and from well meant but patronizing gestures. At the same time, I wanted to constrain her to act “normal”, talk “normal”, and to disappear into the crowd. Well I couldn’t accomplish any of those. In the end I came to acknowledge that she was pretty good herself at dealing with all the indignities. She was pretty darn good at ‘skipping’ to her goals and awfully darn good at reading people along the way.

So now I sit at the table in her cheery, bright apartment, while one of the attendants she has hired is bustling about. My daughter gives me



Tammy van der Kamp

instructions. “Sometimes, if you want, Dad, I could you...”, and pretty soon I’m fixing a loose cupboard door, or maybe I’m just digging some bulbs into her patio border, happy that I’m still in the game. I can still fix things a little bit. Then the thought crosses my mind that maybe she figures she’s the one helping me by giving me some tasks. I straighten up and scratch my head for a moment, trying to get used to that idea, and then I get on with the digging.

AGING AND CP

No two people, including those with CP, will experience the aging process in quite the same way; however, one thing is certain, like all of us, those will slow down as they age.

- Their energy levels won't be as high as they used to be
- They won't be able to accomplish things the ways they used to
- They may not remain as independent as they would like to be

People with CP are considered to have a normal life expectancy; however, the physical challenges of CP may intensify with age; for instance, increased spasticity, fatigue, loss of strength, and declining mobility. In addition, adults living with CP may deal with many of the usual physical problems of aging at much earlier age than people without disabilities.



This person now uses a scooter to their mobility. A lifetime of crutch walking has contributed to an overuse injury to her shoulders.

Further, research indicates that as they age adults with CP are susceptible to such problems as:

- Chronic pain
- Physical fatigue
- Arthritis – because of repetitive motions such as pushing wheelchairs or leaning on canes
- Osteoporosis – which may lead to such secondary complications as hip fractures
- Bowel and bladder problems
- Increased respiratory problems
- Decreased reproductive and sexual functioning

Like many aging people, those with CP may face greater isolation and loneliness because of their physical inability to get around as easily as others. Their decreased mobility can sometimes put them at greater risk for abuse and victimization. This abuse can be physical, financial, sexual or emotional in nature.

Coping With the Aging Process

A lifestyle that involves regular exercise and proper nutrition is important for everyone, including those with disabilities. Exercise may just seem like one more thing to fit into a schedule already overwhelmed by the demands of everyday life: work, school, medical appointments and social activities. A good general fitness level will help maintain range of motion and flexibility. Exercise to improve cardiovascular fitness can also improve endurance and physical strength, thus helping to offset age-related changes that lead to fatigue.

When dealing with fatigue, people with CP can take steps to make sure they don't get over-tired. They should realize their limits and take breaks or rest when feeling tired or in pain.

Methods to lessen pain include: avoiding physical exertion, taking pain medications such as Diazepam or over-the-counter analgesics or using interventions such as tendon-release Morphine or Baclofen pumps. Psychological counseling and biofeedback may help to reduce pain. People with CP feeling lonely or isolated may also benefit from participation in leisure activities targeting people with disabilities, from counseling, or by sharing their feelings with someone they trust.

Everyone needs a proper attitude, knowledge, and skills to make well-informed decisions concerning their health and well-being. Adults with disabilities need to learn to take an active role in their personal health management. It is well known that stresses associated with aging are lessened if a person is able to maintain a positive personal attitude, is involved in meaningful activities and has developed a supportive environment. For a person living with CP it is wise to seek information, to plan for age-related changes, and to be an active participant in his health care and lifestyle choices.

WHAT RESEARCH IS BEING DONE ON CP?

Research programs across North America care looking for ways to prevent CP, to reduce its effects, and to improve the quality of life for people with CP. Research questions being addressed include:

- What are the factors that predispose the developing brain to injury? Can these factors be eliminated or minimized?
- How do associated risk factors relate to the severity of CP?
- What are the causes of injury to the developing brain? Can the developing brain be protected? What are the causes of developmental delays and "failure to thrive"?
- Why is a low birth weight in full-term and premature infants an important risk factor for CP? How do infections, hormonal problems, etc. increase the chance of a premature birth?
- Can CP be diagnosed before birth and/or better diagnosed shortly after birth? Can current diagnostic aids be improved to give more accurate results in the diagnosing of CP?
- Can the injured brain cells of persons with CP be "repaired" or re-grown?
- Which treatments are most effective in dealing with the physical limitations of CP? How effective are existing treatment/management strategies?
- What are the effects of aging on the person with CP?
- Based on new developments in the medical, surgical, behavioral, and bioengineering sciences, what improvements can be made in the quality of life people with CP?

- What are the social and emotional effects on the child growing up with CP? How can she be helped to develop a positive self-image?
- What obstacles does society create for persons with disabilities (including CP)? How can these be overcome?
- Identification of genetic causes

“I like to throw a monkey wrench into those preconceived notions of what a person with a disability can accomplish. It’s fun, and I try not to gloat”.

- T. VAN DER KAMP

WEB SITES

Web sites change quickly and this information will date. The following may be good starting points to link you further information and other organizations.

www.vcpgv.org

Web site of the Voice of the Cerebral Palsied of Greater Vancouver.

www.cerebralpalsymagazine.com

Web site for the official *Cerebral Palsy Magazine* printed quarterly every year, focusing on issues concerning CP.

www.ucp.org

National homepage of United Cerebral Palsy, the leading source of information and advocacy for people with CP in the United States.

www.ninds.nih.gov

Research information from the National Institute of Neurological Disorders and Stroke of Maryland.

www.scope.org.uk

Scope, formerly The Spastics Society, is the largest charity working people with disabilities in the U.K.

www.aacpdm.org

Website for The American Academy for Cerebral Palsy and Developmental Medicine.

www.diversityworld.com

Diversity World offers information and resources concerning employment issues for persons with disabilities.

www.yourcpf.org

Cerebral Palsy Foundation

YOUR KNOWLEDGE CENTRE

- Knowledgeable BC Cerebral Palsy staff are available to answer your questions about CP, CPA-BC services, and other relevant community supports.
- Our Library contains books and videos concerning Cerebral Palsy that are useful to parents, professionals and those living with CP.
- Through public speaking we work to raise awareness of Cerebral Palsy and to remove attitudinal barriers experienced by those living with CP, by providing presentations and workshops to schools, community groups etc.
- Our Website provides general information about Cerebral Palsy and links you to others living with CP and those groups serving those with Cerebral Palsy.
- *The Roundtable* is available to all members of the Association. It is produced on a quarterly basis and will keep you up-to-date as to what is going on in the Association and the larger disability.
- Educational Bursaries: These are awarded to students living with Cerebral Palsy who are planning to pursue post-secondary education or attend institutions of higher learning during the following year.



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THE PROFESSIONAL TEAM

Most hospitals, treatment centers and community programs use a team approach to therapy. The professionals in the team are highly trained in specific aspects of CP, but you know your child best. If you have a child with CP, he may benefit from a consultation with some of the following specialists.

Audiologist: Identifies and measures hearing losses and the health of the organs of hearing. Audiologists can fit and manage hearing aids, and perform listening tests on children who have difficulty paying attention.

Dentist: Specializes in the care and treatment of teeth and gums. The spasticity and feeding difficulties of CP can lead to dental problems. Children with CP should see a dentist before or during their fourth year. Try to see a dentist who is familiar with CP.

Ear, Nose & Throat (ENT) Physician: Can diagnose and treat problems in hearing, feeding, swallowing and drooling. ENT physicians may be consulted about problems with severe or repeated ear infections, enlarged tonsils or adenoids. Also known as otolaryngologists.

Early Childhood Educator (ECE): Translates recommendations from your child's therapists into practical, enjoyable, play experiences. The ECE enables children with CP to attend regular daycare or pre-school programs.

Kinesiologist: Helps to improve movement quality and uses specialized athletic and recreational programs to provide good experience of the body motion.

Neonatologist: A pediatrician who specializes in the care of newborn infants.

Neurologist: Specialize in the diagnosis and treatments of disorders of the nervous system.

Neurosurgeon: Performs surgery on the brain, spinal cord and other nervous tissue.

Nutritionist or Dietician: Specialize in feeding and nutritional needs. Children who have difficulty feeding may need special nutritional supplements. A nutritionist may also recommend a diet to prevent constipation in children with weak abdominal muscles.

Occupational Therapist (OT): Designs purposeful activities to help your child develop fine motor skills and become independent. They also help clients learn skills for day-to-day living (such as dressing, grooming, or cooking), school and work. OTs may recommend and provide training in adaptive equipment such as bathroom aids, seating and mobility systems and adapted toys. They can advise on wheelchair accessibility issues at home or school.

Ophthalmologist: A doctor specializing in disorders of the eye and vision.

Optometrist: Examines, measures and treats visual defects by means of glasses or contact lenses.

Orthopedist: A surgeon who specializes in disease and abnormalities of locomotor system (bones, muscles, joints and tendons). In addition to performing surgery, an orthopedist can recommend special footwear or braces. An orthopedist might also be called on to predict, diagnose, or treat muscle problems associated with CP.

Orthotist: Designs specialized mechanical devices, such as braces and shoe supports to support or supplement weakened or abnormal joints or limbs.

Pediatrician: Specializes in the health, development and diseases of children. Pediatric Neurologists have expertise in the diagnosis and treatment of brain disorders, including epilepsy. Developmental Pediatricians are experts in the diagnosis and management of developmental and behavioral disorders. They examine how a child is growing or developing in relation to other children of the same age.

Physiatrist: A doctor specializing in physical medicine and rehabilitation. They help to restore optimal function to people with injuries to the muscles, bones, tissues, and the nervous system.

Physical Therapist (PT): Helps with mobility, strength and physical independence. PTs focus on gross motor functions, strategies to reduce spasticity, help children move correctly, and teach alternate ways of movement such as walkers or wheelchair mobility.

Podiatrist: Diagnoses and treats disorders and diseases of the foot.

Psychiatrist: A doctor who diagnoses and treats mental, emotional and behavioral disorders. They can prescribe medication whereas a psychologist cannot.

Psychologist: Provides assessment, consultation and interventions for learning, behavior, and socializing or emotional adjustment difficulties.

Recreational/Sports Therapist: Uses sports and leisure activities such as a form of therapy. They work with children on such activities as dancing, swimming, horseback riding, art, horticulture, and any other hobby the child is interested in.

Rehabilitation Engineer and Technologist: Brings knowledge of modern technology to the design, construction and maintenance of adaptive devices including wheelchairs, augmentative communication devices, and environmental control aids.

Social Worker: Provides supportive counseling and referral services to assist families in coping with the additional challenges of raising a child with a disability.

Speech-Language Pathologist: Helps children to develop their verbal communication. Can recommend and provide training in the use of augmentative communication equipment, and can assist with chewing and swallowing difficulties. Also called a speech therapist.

Urologist: A specialist in diseases of urinary organs in females and the urinary tract and sex organs in males. Also called a urological surgeon.

GLOSSARY

Analgesic: A medication that reduces or eliminates pain.

Anesthetic: A medication that causes temporary loss of bodily sensations.

Apgar score: A system of evaluating a newborn's physical condition by assigning a value (0, 1, or 2) to each of five criteria: heart rate, respiratory effort, muscle tone, response to stimuli, and skin color.

Arthritis: Inflammation of a joint or joints resulting in pain and swelling.

Asphyxia: Lack of oxygen due to trouble with breathing or poor oxygen supply in the air.

Baclofen: A medication that acts as a muscle relaxant and is used to treat spasticity.

Basal ganglia: The part of the brain responsible for gross motor functioning.

Cerebellum: The part of the brain responsible for the regulation and coordination of complex voluntary muscular movement as well as the maintenance of posture and balance.

Cerebral: Relating to the two hemispheres of the human brain.

Computerized axial tomography (CAT): An imaging technique that uses X rays and a computer to create a picture of the brain's tissues and structures.

Congenital: Present at birth

Contracture: A condition in which muscles become rigid, abnormal position causing distortion and deformity.

Diabetes: Any of several metabolic disorders marked by excessive urination and persistent thirst.

Dysarthria: Problems with speaking caused by difficulty moving or coordinating the muscles needed for speech.

Electroencephalogram (EEG): A technique for recording the pattern of electrical currents inside the brain.

Electromyography: A special recording technique that detects muscle activity.

Epilepsy: A disorder of the central nervous system characterized by loss of consciousness and convulsions.

Failure to thrive: A condition characterized by lag in physical growth and development.

Fine motor skills: Control over actions that have to do with smaller movements such as reaching and grasping.

Gait analysis: A technique that uses camera recording, force plates, electromyography, and computer analysis to objectively measure an individual's pattern of walking.

Gross motor skills: Control over actions that help children get around in the environment, such as crawling, standing and walking.

Hyperthyroidism: overactive thyroid gland resulting in an increased metabolic rate, an enlargement of the thyroid gland, rapid heart rate, and high blood pressure.

Hypertonia: increased tone/extreme tension of muscles.

Hypotonia: Decreased tone/reduced tension of muscles.

Hypoxic-ischemic encephalopathy: Brain damage caused by poor blood flow or insufficient oxygen supply to the brain.

Jaundice: A blood disorder caused by the abnormal buildup of bile pigments in the bloodstream.

Magnetic Resonance Imaging (MRI): An imaging technique which uses radio waves, magnetic fields, and computer analysis to create a picture of body tissues and structures.

Motor cortex: Part of the brain responsible for movements of the face, neck and trunk, and arm and leg.

Neonatal hemorrhage: Bleeding of brain blood vessels in a newborn.

Orthotic devices: Special devices, such as splints or braces, used to treat problems of the muscles, ligaments, or bones of the skeletal system.

Osteoporosis: A disease in which the bones become extremely porous (holes), are subject to fracture (break), and heal slowly.

Paresis or plegia: Weakness or paralysis. In Cerebral Palsy, these terms are typically combined with another phrase that describes the distribution of paralysis and weakness, e.g., paraparesis.

Palsy: Paralysis, or problems in the control of voluntary movement.

Phototherapy: The treatment of a disorder, especially of the skin, by exposure to light, including ultraviolet and infrared radiation.

Reflexes: Movements that the body makes automatically in response to a specific cue.

Rh incompatibility: A blood condition in which antibodies in a pregnant woman's blood can attack fetal blood cells, impairing the fetus's supply of oxygen and nutrients.

Rubella or German measles: A viral infection that can damage the nervous system in the developing fetus.

Seizure: A sudden attack, spasm, or convulsion.

Selective dorsal root rhizotomy: A surgical procedure in which selected nerves are severed to reduce spasticity in the legs.

Spastic diplegia: A form of Cerebral Palsy in which both arms and both legs are affected, the legs being more severely affected.

Spastic hemiplegia (or paraparesis): A form of Cerebral Palsy in which spasticity affects both legs but the arms are relatively or completely spared.

Spastic quadriplegia (or quadriparesis): A form of Cerebral Palsy in which all four limbs are affected equally.

Strabismus: Misalignment of the eyes.

Ultrasonography: A technique that uses the reflections of high-frequency sound waves to construct an image of a body organ (a sonogram) commonly used to observe fetal growth.

CP ASSOCIATIONS IN CANADA

BRITISH COLUMBIA

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Calgary, ABORIGINAL T3J 5C8

Tel: 403.543.1161
Fax: 403.543.1168
Toll Free: 1.800.363.2807

E-mail: admin@cpalberta.com
www.cpalberta.com

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Fax: 306.373.2665

E-mail: saskcpa@shaw.ca
<http://members.shaw.ca/saskcpa/>

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Winnipeg, MB R3C 3X1

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