

Living with **Cerebral Palsy**



Living with
Cerebral Palsy

An information and resource manual for British Columbia

CEREBRAL PALSY ASSOCIATION
OF BRITISH COLUMBIA

*2006 addition adapted & edited by:
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*Contains A Guide To Cerebral Palsy
by Nan Colledge, 1999 (with expanded content)*

*A project of the Cerebral Palsy Association of British Columbia
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FUNDING GRACIOUSLY PROVIDED BY:

Royal Canadian Legion Nakusp Br. #20

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Burnaby Host Lions Club

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PREFACE

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THE CEREBRAL PALSY ASSOCIATION: A BRIEF HISTORY

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 believed that all people have unique skills and knowledge to offer society thanks to differing age, ethnicity, cognitive ability, gender, and physical mobility.



HOW TO USE THIS MANUAL

The *Living with Cerebral Palsy Manual* has been designed to provide information for those living with Cerebral Palsy, their family members, caregivers, educators, friends, and the general public who wish to learn more about this condition. We acknowledge the reality that Cerebral Palsy impacts people, in changing ways, throughout their lives, and have tried to produce a manual that reflects this continuum, addressing different areas of concern for people with CP in all stages of life.

Section 2: What is Cerebral Palsy?, offers general information about the condition, how it is caused, and offers various medical definitions and treatment options.

Section 3: Parenthood, provides information relevant to those who have a child with CP. Topics range from inclusive education to advocacy and family related issues.

Section 4: Adolescence, is concerned with issues related to body image, self esteem, sexuality and post secondary education.

Section 5: Aging with CP, offers adults strategies for staying mentally and physically fit as they age.

Section 6: Resource Guide, provides descriptions and contact information of organizations that provide services and information for those with disabilities. This Resource Guide is an extensive index that lists both governmental and non-governmental agencies.

The manual also contains a detailed list of relevant media relating to CP and disability issues. While this manual may not provide the answers to all of your CP related question, it is our aim to provide the user with a basic foundation of knowledge so that they can better understand life with Cerebral Palsy.



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.

Editorial Notes:

To make this text easier to read:

- The abbreviation “CP” is used throughout in place of Cerebral Palsy.
- CP roughly affects equal numbers of men and women. Rather than use “he/she”, “he” and “she” are used in alternating sections.

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WHAT IS CEREBRAL PALSY?

Cerebral Palsy is the result of an injury to the developing brain at any time during pregnancy, at birth, or until the age of three. 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 them to the spinal cord — only the brain's ability to control the muscles.

Cerebral = of the brain Palsy = lack of muscle control

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.

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 problems (“failure to thrive”)
- Seizures or epilepsy
- Learning disabilities
- Hearing impairment
- Vision problems



COMMON MISCONCEPTIONS ABOUT CP

Myth: CP is genetic.

Fact: CP is *not* genetic. It cannot be passed from parent to offspring. It is the result of injury to the developing brain before, during, or after birth.

Myth: CP is hereditary.

Fact: 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 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.

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. On the other hand, 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 a disease.

Fact: CP is *not* a 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 usually the primary cause of death.

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

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

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

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.



HOW MANY PEOPLE HAVE CEREBRAL PALSY?

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.

WHAT CAUSES CEREBRAL PALSY?

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 not 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.

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:

- Multiple births (twins or triplets)
- A damaged placenta which may interfere with fetal growth
- Infections (e.g., rubella)
- Poor nutrition
- Exposure to toxic substances, including nicotine and alcohol
- Maternal diabetes, hyperthyroidism or high blood pressure
- Premature dilation of the cervix leading to premature delivery
- 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., gonorrhea, herpes...)



DURING LABOUR:

Factors during labour, which may increase the risk of CP, include:

- 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 anaesthetics or analgesics
- Severe jaundice shortly after birth
- Low Apgar score

POST-NATAL (0 – 3 YEARS OLD) RISK FACTORS:

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

- Infections such as meningitis
- Brain hemorrhages
- Nervous system malformations
- Head injury following falls, car accidents or abuse
- A lack of oxygen (asphyxia) due to accidents such as drowning
- Poisoning
- Seizures
- A difficult labour
- A lack of oxygen to the brain
- A premature birth
- No known cause (straightforward pregnancy and delivery followed by a diagnosis of 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 most 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.”



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 driving 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 as soon as they know they are pregnant, and should avoid smoking, alcohol consumption, and 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 CEREBRAL PALSY

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.

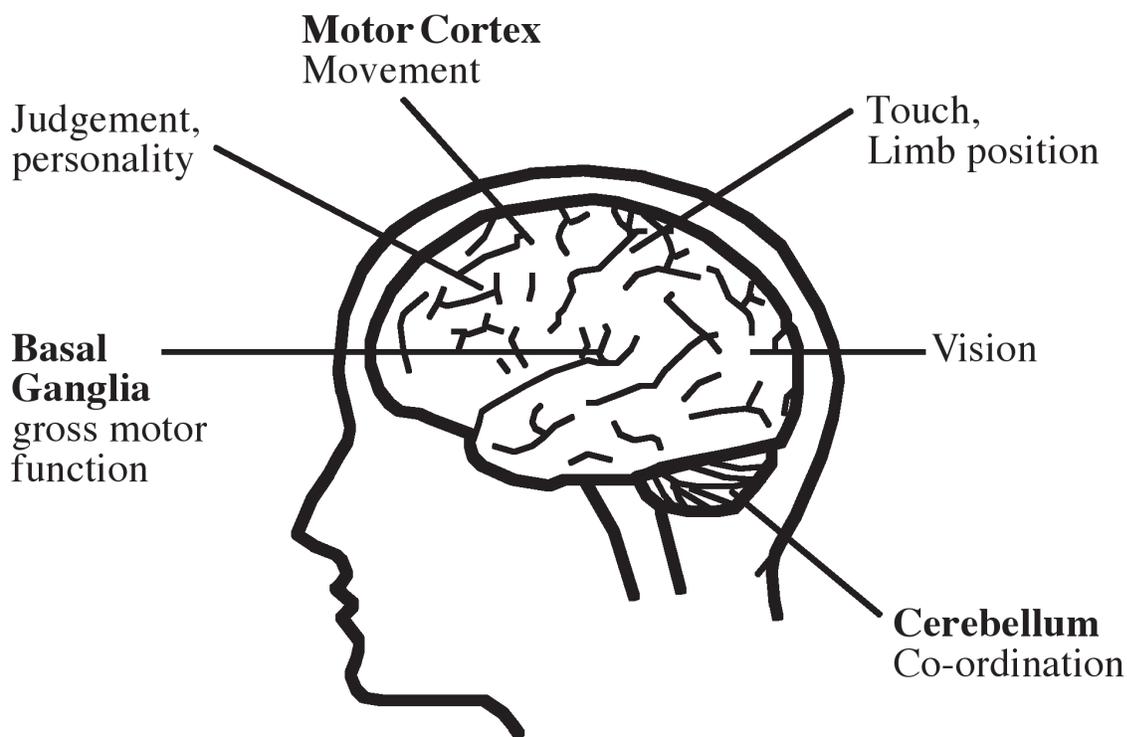
The doctor may also order specialized tests to learn more about the possible cause of CP. CAT Scans (Computerized Axial Tomography) and MRI (Magnetic Resonance Imaging) can identify lesions in the brain. This technology enables some children who are considered at risk of having CP to be diagnosed very early. However, for the majority of people with CP it will be months, and sometimes years, before a diagnosis is confirmed.



It should be noted that in many cases, physicians may be hesitant to make a diagnosis of CP until the child reaches 18 – 24 months of age, for fear of a misdiagnosis because a delay in development that occurs early in the child’s life can later disappear (i.e., the child catches-up).

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 BRAIN

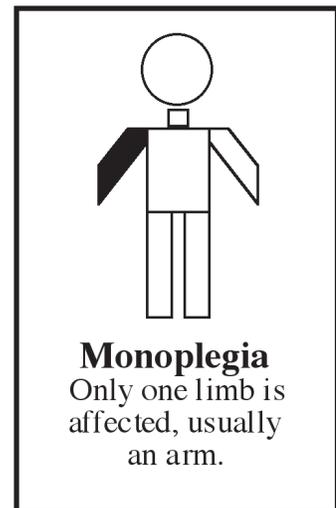
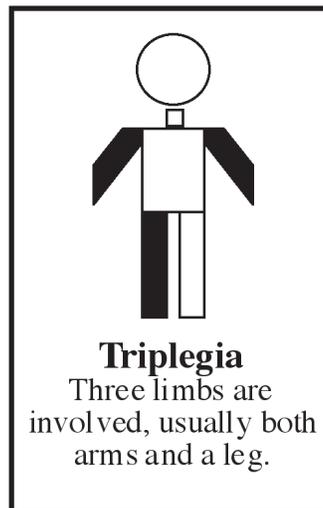
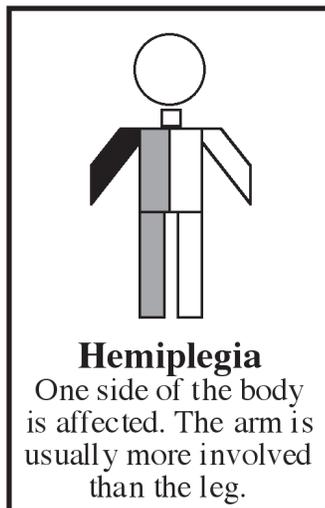
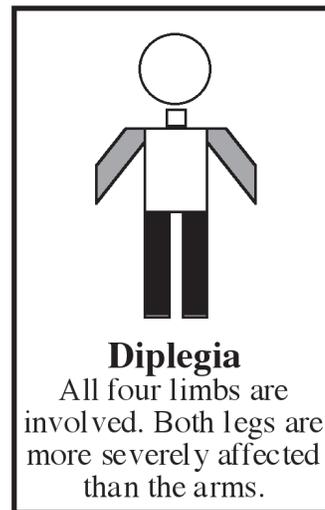
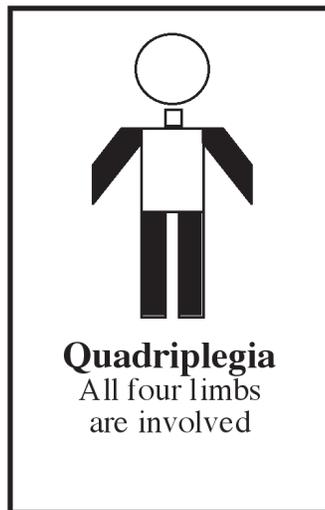




TYPES OF CEREBRAL PALSY

Just as there are many causes of CP, it can also take 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 affected.

CLASSIFICATION BY NUMBER OF LIMBS INVOLVED





CLASSIFICATION BY MOVEMENT DISORDER

The location of the brain injury will determine how movement is affected.

Spastic Cerebral Palsy

Spastic CP is the most common type, affecting about 75% 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. Spastic muscles become active together and block effective movement. This muscular “tug-of-war” is called *co-contraction*. Spasticity may also involve difficulty in controlling the 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 with time (i.e., aging), but may also change with environmental conditions, such as weather (cold/heat...), lighting (sunlight, halogen lighting...), and stimulants (pop, coffee...) to name a few.

Athetoid (Dyskinetic) Cerebral Palsy

Athetoid 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. This type affects about 25% of those diagnosed with CP.

Ataxic Cerebral Palsy

Ataxic CP is the least common type, affecting about 5–10% of the CP population, and is caused by damage to the cerebellum. 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.

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.

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.



TREATMENT AND MANAGEMENT OF CP

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 independent lives. The word “management” is much preferred to “treatment,” as management refers to minimizing and preventing deformities, and helping the child achieve his maximum potential in growth and development. 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, and
- 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/paediatrician, orthopaedist, physiotherapist, occupational therapist, speech and language therapist, social worker, psychologist, and educator. See **The Professional Team (p.35)** 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.

“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*

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

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

THERAPIES FOR CP AND SECONDARY ASSOCIATED CONDITIONS

Physical Therapy (PT) aims to help people achieve their potential for physical independence and mobility. PT uses exercise and activities to improve range of motion and other gross motor functions. Correct positioning and teaching alternate ways of movement such as the use of walkers and wheelchairs are also important.

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 Pathology (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 require a nonverbal communication system. Alternative communication systems include low-technological picture and symbol boards, to high-technological eyegaze systems, blissymbol boards, and electronic voice synthesizers.

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 can help relax muscles, increase body posture and balance, decrease muscle spasms, and increase circulation.

Biofeedback techniques can 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 variable, rhythmic, and repetitive. Hippotherapy can improve balance, posture, mobility, and function.

Hyperbaric Oxygen Therapy (HBOT) involves breathing 100% oxygen under pressure in a special chamber. HBOT can help heal damaged tissues, decrease swelling, and improve circulation.

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

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

Neurobiofeedback involves training the brain to help improve its ability to regulate bodily functions. It helps with seizures, lowers stress and anxiety, helps deal with depression, and manages pain and emotions.

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.

Sensory Integration Therapy helps to develop better sensory perception. The therapy, which is guided by the child and their interests, can improve balance and steady movement, as well as help children learn sequences of movements.



Orthotic & Splints

Most children with CP will be prescribed orthotics, casts or splints to supplement their therapy programs. These should be custom made for your child as 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 CP, such as seizures. Drugs may also be prescribed to control spasticity, particularly following surgery. Medications used most often include:

- Diazepam (Valium): acts as a general relaxant of the brain and body
- Baclofen (Lioresal): blocks signals sent from the spinal cord to contract the muscles
- Dantrolene (Dantrium): interferes with the process of muscle contraction

Anticholinergic drugs — including Trihexyphenidyl, Benztropine, and Procyclidine Hydrochloride — are sometimes prescribed to help reduce abnormal movements in individuals with athetoid CP.

Injections

Occasionally physicians may use alcohol “washes” — or injections of alcohol into a muscle — to reduce spasticity for a short period. This technique is most often used when physicians want to correct a developing contracture.

Botox has been proven effective for the use in the treatment of many other hyperactive, spastic muscle conditions and has been studied extensively in Cerebral Palsy to treat muscle stiffness in children two years of age or older.

Today, Botox is used in the treatment of dynamic equines foot deformity due to spasticity in pediatric Cerebral Palsy patients, two years of age or older for the following reasons:

- Significantly improved gait pattern
- Improvement in ankle position
- Reduction in equinus
- The improved gait pattern enables patients to perform daily personal activities more independently
- Decreased pain in stiff muscles
- Reduction in spasticity makes patient care easier
- Shown to help delay surgery until the child is older



Children best suited to Botox treatments are those:

- Two years of age or older
- With muscle stiffness interfering with function
- Where calf length maintenance is required
- Who require early, conservative treatment
- Where improvement in gait is desired (toe walkers)
- Supported by a physiotherapy program
- With pain in stiff muscles

How will Botox help with overall treatment?

Botox can help by reducing the over activity of muscles very quickly. In fact, most people begin to see results within the first two weeks after injection.

Excerpt from: Cerebral Palsy and the Role of Botox. Allergan, 2002

Surgery

Surgery may be recommended when contractures are severe enough to cause movement problems.

It is important to understand that opinions will vary from doctor to doctor; therefore, it is recommended that as parents of children with CP you:

- get opinions and advice from various sources (not just doctors)
- seriously consider the benefits and consequences of a particular surgery before proceeding
- consult with and consider the opinion of your child, and ensure that he understands how he will be affected by surgery in the near and long-term future

Orthopedic and Soft-tissue surgery can help to 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. When the child has finished growing, bone surgery may help to 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 by reducing the amount of stimulation that reaches leg muscles via nerves. It can reduce spasticity in some patients, particularly those who have spastic diplegia. This surgery is irreversible and permanent.

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



Adaptive Equipment

An enormous range of aids and adaptive equipment is 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 synthesizers
- Head sticks and key guards for computers
- Specialized computer hardware and software

Daily Living Aids include:

- Electronic door openers
- Largehandled eating utensils
- Grab sticks
- Environmental control systems

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

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INTRODUCTION

Cerebral Palsy not only affects the person who has been diagnosed with the condition but ultimately impacts the lives of everyone involved in that person's life; no one feels this impact more greatly than the parent. Whether you learn of your child's disability all at once or gradually as your child ages, the reality of the challenges you and your child may face can seem overwhelming. However, the future is brighter than ever for children with Cerebral Palsy. New advancements in medicine and technology have greatly increased opportunities in education and greater collaboration between professionals and parents have given children a head start in achieving independence and living full and rewarding lives. This section is designed to answer some of the most pressing questions facing a parent whose child has Cerebral Palsy.

IMPACT ON THE 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; however, they may still face a mixture of conflicting/negative emotions such as love, anger, hope, 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.

The following are two real life accounts offering some insight on what it is like to have a child with CP.



PARENT TESTIMONIALS

WELCOME TO HOLLAND

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this... when you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guide books and make your wonderful plans: the Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!?", you say. "What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very, very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland.



A PARENT'S PERSPECTIVE

By Cal Lambeth

My daughter was born nine weeks prematurely after my two-week stay in 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 being premature can create.

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. 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 their 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 dependent, 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 marvellously I was coping. I felt neither marvellous, 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 “aloneness” 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 FATHER’S ROLE

By Conrad van der Kamp

Recently I was 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 wheelchair, 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 to 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 instructions. “Sometime, if you want, Dad, I could use ...”, 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 at least 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.



EMOTIONAL IMPACTS OF CEREBRAL PALSY

Upon receiving the initial diagnosis that your child has Cerebral Palsy you have undoubtedly experienced a mix of painful and often conflicting emotions. You may feel overwhelmed with feelings of anger, sadness, and guilt. These reactions while often extreme and powerful are all very normal when learning about the challenges you and your family will face. Recognizing how you feel is an important step in realizing that with time, education, and support your world will not always seem so dark and that Cerebral Palsy is something you and your family are very capable of overcoming.

“ Our first reaction was devastation, denial, anger and disbelief. We wondered if it could be fixed”

— *Parent of a Child with CP*

Described below are typical emotions associated with the grieving process. You may identify with some or all of these characteristics.

Shock

Many parents go into a state of shock when they learn their child has Cerebral Palsy. They may feel completely numb and detached from the world around them feeling as if events around them are happening to someone else.

Denial

Can be the refusal to accept your child’s diagnosis, to believe that your child will grow out of this condition, or that getting another opinion will somehow change their condition.

Grief

After the initial shock of the diagnosis has worn off and you’ve come to realize your child’s condition is in fact very real, grief is often the most powerful emotion to emerge. People grieve for themselves, their families and the relationships that will be forever changed. Parents also mourn the loss of the ideal child they had always imagined. Feelings of despair and sadness are often associated with this period.

Guilt

You may feel as if you are responsible for your child’s Cerebral Palsy. However, as described in previous sections of this manual, there are a multitude of factors that can cause Cerebral Palsy. It is often impossible to determine the exact cause of the condition. It is important to believe that you did not cause the condition, and there was nothing you or anyone else could have done to prevent it.

**Anger**

Blaming yourself or others, such as doctors and other healthcare workers, for your child's condition. You may wonder why this has happened to you and your child. You may resent other families who do not have a child with a disability. You may even become angry with your child feeling as if that they have burdened you with this condition. Whether your anger is justified or not it is a very typical reaction.

Acceptance

Eventually these other emotions will become less dominant as you slowly begin to accept your child's condition.

You may have experienced some or all of these emotions at one point or another, but it is important to remember that learning of a child's CP affects every parent and family differently. Accepting and adjusting to your child's Cerebral Palsy is a lifelong and often complex process. At times it may seem a lonely and difficult task. You have the right to grieve, to feel sad and to be angry. You also have the right to learn about and advocate your needs and the needs of your child.

YOUR RIGHTS AS A PARENTS

The Right To Feel Angry

Nothing in life prepares one for being disabled, and when it is your child who has a disability, it seems all the more unfair. You did not ask for this, and there is very little you can do to change it. Your sense of control over your own life and the life of your child is at risk. Be angry, but use your anger to get the best services you can for your child.

The Right To Seek Another Opinion

Everyone is told today that it makes good sense to seek a second opinion before having surgery, investing money, or buying a used car. It should not be any different for you and your child whether you are looking for medical care or an educational program. If you hear of a new treatment that might help your child, why shouldn't you look onto it?

The Right To Privacy

Many parents have talked about the effects a child with a disability in the family has on family members' privacy because a disabled child suddenly brings into the family circle a series of professionals who examine, give advice, and sometimes even judge actions of individual family members. Some aspects of your life are simply no one else's business. If you do not want to discuss something, or if you do not want your child's picture taken, it is your right to say "No".



The Right to Keep Trying

Parenting is not easy, but all parents try to do the best job they can. It may become harder when well-meaning people tell you that you have to set goals that your child will never be able to reach, or that you must stand back and accept the fact that your daughter has multiple disabilities and will never be able to walk. There is nothing wrong with you if you are not willing to give up.

The Right to Stop Trying

Friends and professionals have also told parents that they do not work often enough or long enough with their children. You are the one who lives with your child; you are the one who is being asked to do one more thing. If you cannot do it tonight that is your decision.

The Right To Set Limits

There are limits to what one person can do; you shouldn't expect yourself to think about your child all the time. And your child shouldn't expect to be the centre of attention. You have limits, and your child has limits; learn to recognize both, and give yourself a chance to examine the situation before responding in anger or out of fatigue.

The Right To Have Fun

Therapy and educational activities at home are certainly beneficial but you and your child need time to fool around, laugh and have fun.

The Right To Be Unenthusiastic

No one expects you to be “turned on” all of the time. Sometimes you feel sad. If other people take that as a sign that you're “not adjusting” or that you're “not accepting your child's disability”, that is their problem. No one is excited about work every day; it can be tedious one day and new and interesting the next. The same is true of parenting: there will be days when your child will bring you great joy and others you may feel less than enthusiastic.

The Right To Be Annoyed With Your Child

There are days when you like your child and days when you don't, but that does not mean that you don't love them. Children with Cerebral Palsy are just as capable of being difficult as other children, and they too should be disciplined.

The Right To Time Off

You need time to yourself, with your spouse/partner and other family members. There are many parts to your life, and each deserves as much attention and nurturing as your child with CP.



The Right To Be The Expert In Charge

You spend the most time with her, have lived with her longer than anyone else, and know what works and doesn't. Support personnel may come and go, but you are the person with experience and first-hand knowledge about your child. As the expert, you have the right to be in charge of your child's educational, social, and medical decisions — at least until she is able to be.

HAVING A SIBLING WITH A DISABILITY

Many people with CP have siblings who may not have a disability. Siblings in all families have their share of difficulties; however, having a brother or sister with a disability may raise certain issues:

- Embarrassment due to the sibling's behaviour or appearance
- Guilt about not having a disability
- Fear the child might develop the disability
- Anger or jealousy over the amount of attention brother or sister receives
- Isolation because they feel no one else can relate to their situation
- Feeling extra pressure to excel in order to make up for sibling's disability
- Need for information about the sibling disability or illness

While there are adjustments to be made on the part of an able-bodied sibling in dealing with the disability of their brother or sister research has shown that they

- Gain insight into the human condition as a result of growing up with a sibling with a disability
- Develop a certain level of maturity as a result of coping with a sibling's disability
- Develop a strong sense of family unity
- Are more patient and compassionate towards others because of their sibling's unique needs

Having a sibling with CP may at times be a difficult process as parents naturally devote a lot of time and energy into caring for their child with a disability. However, for parents, it is important to spend time with and consider the unique needs of their other children as well.

- Set aside special time to spend with your child
- Encourage open communication and expression regarding their feelings surrounding their sibling's disability
- Provide opportunities to meet with other siblings of children with disabilities and treat them as children — they are not therapists or adult caretakers



THE PROFESSIONAL TEAM

Most hospitals, treatment centres 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 loss 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 Physician (ENT): 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 preschool programs.

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

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

Neurologist: Specializes 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: Specializes 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.

Orthopaedist: A surgeon who specializes in disease and abnormalities of the locomotor system (bones, muscles, joints and tendons). In addition to performing surgery, an orthopaedist can recommend special footwear or braces. An orthopaedist 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.

Paediatrician: Specializes in the health, development and diseases of children. Paediatric Neurologists have expertise in the diagnosis and treatment of brain disorders, including epilepsy. Developmental Paediatricians 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 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 counselling and referral services to assist families in coping with the additional challenges of raising a child with a disability.

Speech and 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 the urinary organs in females and the urinary tract and sex organs in males. Also called a urological surgeon.

PARENTS AS CO-THERAPISTS

While the professional team plays an important and invaluable role in helping your child to develop, it is important to remember that you and your family are the greatest single resource that your child has. The period of time your child spends with their therapists may not be enough to make significant progress if it is not followed up at home. It is important that the parents take part in their child's therapy sessions for several reasons:

- To listen to the suggestions that the therapists make
- To consider how these ideas can fit into your family's daily life
- To contribute further information so that the therapists can create the most beneficial program based upon the specific needs of your child and family

It is important for everyone involved that the parents and therapy team members are able to communicate openly with each other, so that each understands the other's point of view and reasons behind the successes or failures of the activities. If parents do not understand, or have concerns regarding treatment plans or the activities involved, they need to be able to express these concerns to their therapist.



HELPING YOUR CHILD TO DEVELOP

Physical Movement

If your child is given proper support at an early age she can be better helped to develop. The first three years are vital ones, as your child needs to learn key fundamental movements. Learning key movements such as how to protect themselves, establishing balance, and how to shift positions to be more comfortable, will lead to greater independence.

Speech and Communication

Some children with Cerebral Palsy speak differently, perhaps with great effort or slowly using a few words at a time. Others may use the assistance of symbol boards or computerized devices to communicate. This does not mean they are incapable of understanding appropriate language. Conversation at an age appropriate level will help your child understand adult ideas and concepts thus helping them to grow. Children with CP should be encouraged to think for themselves; encourage your child to make choices about her life, even if they may be small decisions.

Learning and Perceptual Difficulties

Some children with Cerebral Palsy have learning and perceptual difficulties. They may have difficulty determining where an object is in relation to another (i.e. above, below, behind, in front of, etc.); telling left from right; building structures (i.e. a tower from blocks); or being able to tell the differences between sizes, shapes, and distances. Difficulty in concentrating, low-motivation, and sensory problems (i.e. high tone hearing loss or the inability to see similarities and differences in objects), may also occur.

Progress may be made in reducing the effect of learning and perceptual disabilities before a child reaches the regular school system. Pre-school programs in which teachers have been trained to handle these disabilities have proven to be an effective approach. Also, parents might ask their occupational therapist, doctors or other health care workers for information about things they can do to encourage development.

EDUCATION

Before you found out your child had Cerebral Palsy you probably had given some thought about their future education; attending the community elementary school with the other neighborhood children, then following the path through to high school and beyond. While finding out your child has CP may have changed your perception of a typical education for your child, there are many services and programs available at both the primary and second-



ary level to provide the opportunity for your child to grow and develop. Having a child with a disability may seem overwhelming but with proper planning, strong communication with school staff can go a long way to ensuring the educational process is a rewarding one. The following section discusses some strategies to help make the transition from home to school an easier process for both you and your child.

INCLUSIVE EDUCATION

Children with disabilities are first and foremost, children, and as such they are entitled to participate and be included in their local school system. Often this inclusion requires specialized knowledge, equipment, programs and staff members. Above all, it requires a partnership between home and school to be most effective.

Rights and Responsibilities

You as a parent have inherent rights and responsibilities in your child's education.

Parents have the Right:

- To work in partnership with the schools
- To be informed and involved in education decisions that affect their child
- To be consulted and be given consent regarding the type and results of any assessment your child receives
- To have your concerns listened to and responded to in a timely and confidential manner
- To have access to your child's file
- To be involved with your child's individual education plan (IEP)
- To appeal decisions made in regard to their child's (education)

Parents have the Responsibility:

- To be aware of school policies, rules and routines as they relate to all students
- To share relevant information on their child with appropriate personnel
- To share concerns openly and immediately with appropriate personnel
- To respond to notes, memos or requests from the school in a prompt manner
- To describe concerns objectively

You've known your child all their life, and now it's time to entrust them to the school system for several hours of every day. How well this transition is accomplished, and their successful adjustment throughout school years, will depend to a very large extent on the relationship between home and school. There are things that you can do to make sure this relationship is positive from the start. School personnel are the experts on education; parents are the experts on their own child. Co-operation and mutual respect between all those concerned with the child is essential.



PREPARING FOR SCHOOL

Don't wait until the first day of school to present your child to the school — and the school to your child! The teacher and principal need time to plan and prepare in order to do their best meeting your child's educational needs. As well, your child will be much more at ease if they have visited the classroom and met their teacher beforehand.

Do some creative observing of your child, and let the teacher know what you have discovered. Is she easily distracted by other children? Can she follow verbal instructions? What forms of discipline do you find work best? Does she have a special interest or ability that she can share with the other children? Put your observations and suggestions in writing, and give them to the teachers when you first meet with them. Be open to questions and suggestions from the teacher and principal.

If you can, be a frequent visitor. If you have time, volunteer to help in the school — not necessarily in your child's classroom, as that may make your child or their teacher uncomfortable.

If you are dissatisfied with what is happening to your child in school, talk first with the classroom teacher. If you feel that your concerns are not being addressed, request a meeting with the teacher and principal. If all parties enter into this process with a cooperative and positive attitude, most problems will be resolved at this level. If you are still not comfortable with what has happened, there is a special education consultant in every school district.

Any student who has a significant physical or visual disability which restricts development can be referred to SET-BC. After assessment by their community-based team, he may be provided with technology services, such as computers, special access systems and programs that will enhance his ability to participate in the classroom experience. The initial referral to SET-BC must be processed through the school; a parent or guardian may request that the school initiate the referral process. Teachers, particularly those of behaviourally challenged children, have a strategy that works in most cases — “Catch them doing something right” — and praise them for it. This works for anyone! Let your child's teacher and principal know when things are going well. Give praise where it is due — it improves the relationship, and makes people much more receptive to listening to suggestions.

Building A Partnership with the School

- You may not have a background in education, but you do know your child. You are the expert and as such you should be an important part of the school's efforts to provide your child with an educational program that will meet his or her individual needs.



- Participate — attend teacher conferences, parent group meetings, and school functions. Always attend IEP meetings, so you can give ideas, suggestions, and negotiate a program for your child. Volunteer at your child’s school. If you are unable to volunteer at the school, make yourself known to key people and students.
- Not all teachers feel qualified to work with children with disabilities. Some may be quite nervous about teaching your child. Cultivate a good relationship with your child’s classroom teacher. Don’t hesitate to ask them if they would like some of the resources you have, or take time to seek out appropriate resources. They may not know about them or have time to access them.
- Discuss with the teacher the different methods of reporting on your child’s progress. Report cards should be designed to give appropriate and understandable feedback, as well as to provide an adequate permanent record of your child’s progress. Establish with the teacher opportunities for informal feedback — in person, by phone, or by written notes or communication booklets.
- Be Patient. Try to avoid being too forceful with your requests before you have attempted a more cooperative approach. Give the school time to learn and include your child. Give positive feedback when things work. The school needs a chance to respond to your requests and wishes in a way that fits with their programs, routines, and expectations. Be supportive.

SCHOOL PERSONNEL

The following are descriptions of the roles and responsibilities of some of the personnel at the school and district level that may be involved with your child.

Principal and Vice Principal

Principals and Vice Principals are charged with managing the school and ensuring that the actions of the teachers, students and support staff are consistent with the philosophy of the education system in a particular district. The principal plays a key role in modeling a supportive philosophy that is conducive to the inclusion of your child.

The Classroom Teacher

Your child’s teacher is often the primary link between you and the school. Responsibilities of a classroom teacher include assessing the student’s progress at the beginning of each year; evaluating progress throughout the year, assisting in the implementation of the Individual Education Plan, communicating with the parents regarding their child’s education, and of course implementing established curriculum.

**Special Education Aide/Assistant**

SEA's duties may include providing personal care for children with disabilities with regards to feeding, grooming, mobility and other tasks. They also help students with any special equipment or technical aids they may need in the classroom. Special Education Aides help students perform learning activities designed by the classroom teacher. They also facilitate social interactions among students.

Resource Teacher

Resource teachers are district based specialists who provide support for students with special education needs in the schools to which they are assigned. Resource teachers, work directly with families, and the school based team. They observe students in the classroom in order to assess and suggest suitable learning strategies. They may also arrange for assessment of your child, if appropriate. Resource teachers also oversee the implementation of your child's Independent Education Plan (IEP). They can assist parents in their understanding of how schools work as well as assist schools in understanding the unique needs of your child.

Speech and Language Pathologists

Provide support to children whose educational or social progress is affected by difficulty in communicating. Their responsibilities include identification and assessment of speech and language difficulties, direct instruction in speech therapy for students and consultation and collaboration with other educators.

Area Counsellor

Area Counsellors play an important role with children whose needs require social and emotional support, as they assist the School Based Resource Team in co-coordinating supports necessary to maximize a student's opportunity to be included in the school. They also provide individual and group counselling, consultation with families and other services.

School Psychologist

School psychologists provide school based educational services designed to support students parents and teachers. Typical duties may include school and district based consultation, formal and informal assessment and evaluation.

Physiotherapist

Physiotherapists provide services to children with orthopedic neurological, muscular, spinal or joint dysfunctions. Their services include: helping to maintain and improve muscle strength, balance, coordination and functional independence.



INDIVIDUAL EDUCATION PLAN

What exactly is an IEP?

- An education plan designed for your child based on their strengths and needs
- A report outlined in a 2 – 4 page format written in clear concise terms
- An assessment by teachers, parents, and related service personnel concerning the progress of a student’s academic, social and behavioral needs
- Is a plan developed by the School Based Team, in collaboration with the parents and the student (when appropriate)

It is important to remember that an IEP is a “living document” with both short and long term goals that during the course of a school term, can be changed or adjusted to best meet your child’s learning needs.

An IEP may include:

- A description of the learning outcomes for the student within an established period of time
- A description of the programs and services the student should receive
- A description of the strategies and teaching methods the student should receive
- A description of how the student’s progress will be measured and the materials used

IEP meetings are typically held at least once a year. The initial meeting is usually held after the classroom teacher has had a chance to get to know and evaluate your child (maybe six weeks into the school year). There may be follow up meetings occurring at designated times throughout the year such as the end of term.

(Adapted from the North Vancouver School District’s: Inclusive Education A Handbook for Children with Special Needs, 1995)

In addition, IEPs have goals which are reported on in the report cards. Often there will be a separate report on the progress of the student towards the IEP goals. If you do not receive this in your report card, you should request it.



SAMPLE LETTER: REQUESTING AN IEP MEETING

To: **[NAME, TITLE, ADDRESS]**

From: **[NAME, ADDRESS]**

Date: **[DATE]**

Re: IEP meeting request

Dear, **[PRINCIPAL/NAME]**

I am writing to request a meeting to review **[STUDENT'S NAME]** IEP in accordance with policy. I am available at the following times and dates **[LIST THEM]**

Also, in accordance to policy, I am requesting the presence of the following personnel **[LIST ONLY THOSE RELEVANT TO YOUR SITUATION]**

- Regular and/or special education teacher
- Professionals providing services for your child: speech pathologist, occupational therapist
- Members of the assessment team, if recently evaluated or to make recommendations
- The student (if appropriate)
- Special education assistant

I will bring:

- Advocates, family members, or other support persons
- If necessary, your child's private therapist, psychologist, etc.

This will be a short meeting please schedule one and a half hours. Please contact me in writing within ten working days to confirm the date, time and persons who will be in attendance. Thank you in advance for your efforts on my child's behalf.

Sincerely,

[NAME]



ADVOCATING FOR YOUR CHILD IN THE SCHOOL SYSTEM

During the course of your child's education there will most likely be a time when you feel your child's needs are not being met. Whether that be a lack of services, or a differing opinion with school personnel, being able to advocate for your child in an effective and positive manner will go a long way to ensuring your child receives the support and services they deserve.

Most issues parents encounter arise at the classroom or school level and are often a result of poor communication. Most issues can and should be resolved at the level at which they arise. It makes sense to address concerns and try to resolve them using the resources the school offers.

NOTE: There is a wealth of information on-line concerning effective advocacy and IEPs found by doing a simple search for "IEP".

General Tips:

- Have a long term vision for your child
- Be willing to compromise, to negotiate, and ask for advice, help and support
- Explain your concerns clearly and objectively
- Be flexible about expectations and allow time for progress and change

If a Concern Arises:

- Bring your concerns to the classroom teacher
- Ask the teacher if you can observe the child in the classroom
- Make a note of your concern in writing
- Keep a log of inquiries, meetings phone calls and any other correspondence concerning the issue
- Keep an open mind regarding the reasons and actions of others involved

When a Concern Becomes an Issue:

Step 1: Teacher

- At the meeting present your reasons as to why you have called this meeting and share your concerns
- Discuss the situation, try to resolve it together
- If you are unsatisfied with the outcome, tell the teacher so and request to have a third party meet with you both (Resource Teacher, Counsellor, Principal)



Step 2: Principal

- State your concerns, list the steps already taken
- State the goal you would like to see reached
- Discuss a variety of strategies
- Agree on a plan of action

If the issue is still not resolved, the Principal will assist you by reviewing the School district policy on conflict resolution and the Appeals Bylaw.

Step 3: Coordinator of Student Services

- Once you begin to meet with district personnel, you may experience a larger meeting involving people new to you
- Follow the same procedure as you would for other meetings but consider including a support person or service provider to help you
- If your concerns are still not resolved, the Coordinator of Student Services will help you in setting up a meeting with the Assistant Superintendent or the Superintendent

Step 4: Assistant Superintendent or Superintendent

- When meeting with the Assistant Superintendent or Superintendent follow the same steps as above
- If you are unable to reach an agreement, you have the right to appeal the superintendent's decision to the school board. Any administrative decision can be appealed.

Step 5: Appeal to the school Board

- The school act requires that each School District establish an appeal procedure for the elected school trustees to address decisions which significantly affect the education, health safety of a student.

Step 6: Appeals from Outside the School Board

It is possible to go in several directions in appealing a decision of the school board these include:

- Ombudsman's Office
- Human Rights Complaint
- Appeal to the Director of Student Support Services Branch of the Ministry of Education
- Your MLA



ADVOCACY: AN INTRODUCTION

In an ideal world you would receive all the best information regarding your child's Cerebral Palsy and the medical, therapeutic, and educational resources available to you. While the Canadian and Provincial governments do provide one of the most comprehensive support networks for disabled people in the world, the reality is that programs will be underfunded, services might not be available in your area, and the professionals providing them may not share your viewpoint. In this case you will likely have to speak on behalf of your child, yourself and others who share similar concerns in order to get the services programs and treatments you feel you deserve — this is advocacy.

DIFFERENT TYPES OF ADVOCACY

Peer Advocacy

Long-term relationship between two people who have a common connection like a similar disability. Often very similar to a mentoring relationship, generally undertaken by volunteers.

Citizen Advocate

This is a partnership between two people. One is typically called the advocacy partner, and one the citizen advocate. An advocacy partner is someone at risk of having choices, wishes and decisions ignored, and who needs help in making them known and making sure they are responded to. A citizen advocate is a person who volunteers to speak up for and support an advocacy partner and is not paid to do so.

FINANCIAL PLANNING

Financial planning is the process of reviewing your family's financial situation to plan the best way to meet your family's financial needs and goals. This becomes of particular importance if you have a son or daughter with a disability. People with disabilities may not experience the same employment opportunities as others, and with the potential for high medical expenses the need to plan for their financial future becomes even greater. Each family has different needs and resources so it is recommended to consult a financial adviser who can create a financial plan that best suits your needs. Please see our resource guide for more information for specific organizations.

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ADOLESCENCE: AN INTRODUCTION

Adolescence can be a particularly difficult time for all children, but for those with Cerebral Palsy this transition period can be even more difficult. Like most able-bodied teens, adolescents with CP will have to struggle with issues surrounding, body image, friendship, self-esteem and sexuality. All of these issues are of great importance as they all play a large role in the development of a healthy sense of self and identity. This section examines these issues with the hopes of shedding some light on this often overlooked aspect of living with Cerebral Palsy.

ADOLESCENTS AND SEXUALITY

It is a common myth that children and young people with disabilities have no sexual feelings and do not need to be educated about their sexuality. As does everyone, children with disabilities become adolescents with maturing bodies as well as social and sexual feelings and needs. As people with disabilities are becoming more independent and making their own choices, they need to have information about values, morals and friendship including relationships, love and intimacy. Sexuality is not just about physical relationships. It can't be separated from social development, beliefs, attitudes, values, self-awareness and self-esteem. It is about being accepted, liked, feeling worthwhile and attractive, sharing deep intimate friendships and giving and receiving affection.

Puberty, which usually starts between 9 and 13, brings physical changes, which are usually accompanied by a heightened sexual drive and emotional upheaval. Before these changes actually begin it is important that parents discuss what lies ahead with their children. Sexual education for young people with disabilities is important and challenging.

Because of the unique needs associated with CP, adolescents:

- Often have less opportunity to learn from their peers
- Have fewer chances to observe, develop and practice appropriate sexual behaviour
- May require resources that explain sexuality in ways that they understand

Sexual education should provide:

- Accurate information regarding human growth and development including human reproduction, anatomy, physiology, family life, pregnancy, sexual response, sexual orientation and issues surrounding safe sexual practices and contraception
- The opportunity to develop family, religious and cultural values, increase self esteem, develop insights into relationship building and an understanding of responsibilities to others



- The opportunity to develop interpersonal abilities; including, communication, decision making, assertiveness and refusal skills

As with their able-bodied peers, when given the opportunity to talk about the many aspects of sexuality, young people with disabilities will develop a greater understanding of the role sexuality will play in their life. They can also learn interpersonal skills and develop an awareness of the responsibilities for their bodies and actions.

BODY IMAGE AND SELF-ESTEEM

What is body Image?

- How you perceive your physical appearance
- How you feel about your appearance
- How you feel about your body
- How you think other people perceive your appearance

BODY IMAGE CONCERNS

Being young, especially if one has CP can be a difficult time of change and self discovery. As socializing and dating begin to play a larger role in the lives of most teenagers, with or without disabilities, issues surrounding body-image and self esteem become ever more important. Western Culture has firm and idealized notions of how men and women should look. Turn on the television or flip through a popular magazine and images of tall slender women and large muscled men are everywhere. If you somehow look different then you may think of yourself as somehow less attractive and desirable. This poor body image can be hard on one's self-esteem. It is important to maintain a positive self-image; while this may seem difficult, especially if you have a visible disability, the truth is that most people, with or with out disabilities, have concerns about how they look. People often stare simply because they are curious.

WISDOM FOR YOUR TEEN

Explaining your condition to peers and classmates will go a long way to helping people to see the whole you; including the person you are inside. If you are comfortable with the way you look chances are others will be as well.



POST SECONDARY EDUCATION

THE IMPORTANCE OF PARTICIPATION IN POST SECONDARY EDUCATION

It is important for those with disabilities to be able attend post secondary institutions if they so choose. It is not only beneficial for the student to receive high level academic or vocational training, but it is beneficial for the institutions themselves. The presence and participation of people with disabilities in campus life enriches the experience for everyone involved. Disability is part of the human experience that sooner or later will directly or indirectly affect us all. The presence of people with disabilities will lead to greater understanding on the part of students, teachers, and society as a whole, helping to break down the many social barriers that prevent people with disabilities from realizing their full potential.

People with disabilities are present and visible at universities and post secondary institutions as never before. This reflects changes in societal attitudes, law, public policy and government programs; perhaps most importantly, the expectations many people with disabilities now have of themselves.

Whether it be a vocational school, local college or university, choosing an academic program requires some planning and research. For those with CP it is important to find out what accommodations and services are offered for those with disabilities. Most post secondary schools in Canada have a Disabled Students Service Centre (DSS) which can arrange for adaptive equipment and course and classroom modification suited to each person's needs.

These accommodations are intended to allow those with disabilities to compete equally with their non-disabled peers and help facilitate a student's participation in chosen extracurricular activity. It is important to contact your prospective school well in advance, usually 4 – 6 weeks before the start of term, so that the proper arrangements can be made. Our resource guide provides the contact information for the Disabled Student Services Centres for most major post secondary institutions in the province.



Listed below are some examples of Auxiliary Aids and services that may be offered to students with disabilities:

- Taped texts
- Note takers
- Interpreters
- Video text displays
- Electronic readers
- Braille calculators
- Voice synthesizers
- Library assistance
- Classroom modification

Students with disabilities succeed in the post secondary environment by demonstrating the following characteristics of any successful student:

- Are academically prepared
- Demonstrate self advocacy skills
- Demonstrate organization skills
- Demonstrate time management skills

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AGING AND CP

Most treatment and research programs concern children with CP and so far, little research has been done on aging with a disability. CP affects individuals in different ways and it is hard to generalize about the effects of aging. Although people with CP are considered to have a normal life expectancy, the physical challenges of CP may intensify with age. Some may experience increased spasticity and fatigue, loss of strength and declining mobility. Researchers indicate that adults with CP tend to lose some of the mobility they gained as children. They consider that this to be due to weight gain, lack of therapy and exercise, and the development of secondary conditions associated with aging such as arthritis.

While it is true that loss of strength and decreased mobility is a natural part of the aging process for everyone, for a person with CP, these changes may begin to take place sooner than typically expected — presumably thanks to the life-long impact on their disability upon their bones and muscles. These physical challenges can in turn lead to increased stress and anxiety.

It can be frustrating for adults to deal with a health care system that appears to have little knowledge or interest regarding the changing needs of aging with a disability. A positive attitude makes a big difference, and developing relaxation techniques and coping skills can have a beneficial effect on mental and physical health.

MAINTAINING PHYSICAL AND MENTAL HEALTH

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 an already busy schedule. But a good general fitness level will help with range of motion and flexibility. Exercise to improve cardiovascular fitness can improve endurance and help offset age related changes that lead to lower energy levels.

Having CP does not mean a person is immune to other conditions. People with CP are as likely as anyone else to contract heart disease, cancer or diabetes.

In recent years we have seen a shift to a wellness concept of health care with emphasis on self-directed care that requires the individual to take responsibility for decisions and actions that affect their overall health. Individuals need appropriate knowledge, attitudes and skills to make these decisions. Learning strategies to increase independence and develop coping skills



is a lifelong process. Parents can foster attitudes that promote self-sufficiency and build self-esteem. Adults with disabilities need to learn to take an active role in their personal health management.

The importance of learning skills to increase independence and self-confidence throughout an individual's lifetime cannot be overemphasized. The stresses associated with aging will be lessened if a person is able to maintain a positive personal attitude, is involved in meaningful activities, and has developed a supportive environment. One needs confidence to seek information, to plan for age related changes, and to be an active participant in one's health care and lifestyle choices.



This person now uses a manual wheelchair or scooter to enhance her mobility. A lifetime of crutch walking has contributed to an overuse injury to her shoulder.

CONCLUSION

Cerebral Palsy describes a number of movement disorders ranging from mild to very severe and affects each person in a unique way. Many people with CP also experience secondary or associated disabilities. The vast amount of information that surrounds Cerebral Palsy may seem overwhelming at times. However, Canadians are fortunate to be part of a large support network that provides a wide range of informational, and medical and educational services for those with disabilities. Cerebral Palsy does pose unique challenges and opportunities to those living with the condition, their families and ultimately to the community as a whole. While having Cerebral Palsy may be difficult at times, with the proper information, support, and planning, people with Cerebral Palsy can, and do lead productive fulfilling lives.

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RESOURCE AND SERVICE GUIDE

The final section of the Manual is a resource guide with descriptions and contact information for many of the organizations that provide services and information for those with disabilities.

ADVOCACY AND SERVICE ORGANIZATIONS

Associate Family Care

Supports, educates, and advocates for unpaid caregivers in BC. Coordinates and maintains a network of volunteer regional representatives, and provides information and referrals regarding services support groups.

Contact Information:

Phone: 604.734.4812 or 1.800.833.1733

Fax: 604.730.1015

Website: <http://www.caregiverbc.ca>

Address: 306 – 1212 West Broadway Vancouver, BC, V6H 3V1

BC Aboriginal Network on Disability Society

Advocates on behalf of Aboriginal people with disabilities.

Contact information:

Phone: 250.381.7303 or 1.888.815.5511

Fax: 250.381.7312

Website: <http://www.bcands.bc.ca>

Address: 1179 Kosapsum Crescent, Victoria, BC, V9A 7K7

BC Association for Community Living

Provincial association which advocates for people in BC who have a developmental disability. Acts as a provincial resource for the federation of local associations throughout the province. Publishes a list of local associations and affiliated members.

Contact information:

Phone: 604.875.1119

Fax: 604.875.6744

Website: <http://www.bcacl.org>

Address: #300 – 30 East 6th Avenue, Vancouver, BC. V5T 4P4



BC Civil Liberties Association

Defends classical civil liberties (including freedom of speech and association, privacy and access to information, and due process) through public education, meetings with government officials, and (infrequent) court action. Accepts written complaints about civil liberty violations where such complaints are outside the jurisdiction of federal or provincial human rights bodies or the Ombudsman's office. Provides information and referrals pertaining to human rights and civil liberties.

Contact Information:

Phone: 604.687.2919

Fax: 604.687.3045

Website: <http://www.bccla.org>

BC Coalition of People With Disabilities

Self-help, province wide group that represents all people with disabilities.

Contact information:

Phone: 604.875.0188

Fax: 604.875-9227

Website: <http://www.bccpd.bc.ca>

Address: 204 – 456 West Broadway, Vancouver, BC, V5Y 1R3

BC Council for the Family

A non-profit organization concerned with the well-being of the family. They act as a clearing house for information about family programs and resources and produce program material, brochures and manuals on family related matters. Offers a resource library for use by both members and non-members.

Contact information:

Phone: 604.660.0675 or 1.800.663.5638

Fax: 604.732.4813

Address: #204 – 2590 Granville Street Vancouver, BC, V6H 3H1



BC Epilepsy Society

Provides information and referral services to people with epilepsy and to their families/care-givers. Has a resource library and produces information sheets. They also run support groups and offer public education about seizures and first aid.

Contact Information:

Phone: 604.875.6704

Fax: 604.875.0617

Website: <http://www.bcepilepsy.com>

Address: 510 – 999 West Broadway, Vancouver, BC, V5Z 1K5

BC Paraplegic Association

Offers a wide range of programs and services to both those with spinal cord injuries and other mobility disabilities.

Contact Information:

Phone: 604.324.3611

Fax: 604.326.1229

Website: <http://www.bcpara.org>

Address: 780 sw Marine Drive, Vancouver, BC, V6P 5Y7

BC Rehab Society

Fundraises and allocates money to organizations that support people living with physical disabilities in BC, in the areas of education, research, arts, recreation, and wellness programs.

Contact Information:

Phone: 604.737.6383

Fax: 604.737.6494

Website: <http://www.bcrehab.com>

Address: 4255 Laurel Street, Vancouver, BC, V5Z 2G9

BC Self Advocacy Foundation

Supports people with developmental disabilities in speaking for themselves. Delivers workshops to people with developmental disabilities, informing them about their rights. Produces plain language information packages about issues affecting this population.

Contact Information:

Phone: 604.875.1119

Fax: 604.875.6744

Website: <http://www.bcacl.org>

Address: 300 – 30 East 6th Avenue, Vancouver, BC, V5T 4P4



Canadian Council of the Blind

Seeks to encourage people whose lives have been disrupted by blindness or severe vision impairment, and to build and restore their confidence, self-reliance, and independence. Provides information and referrals, individual and group peer support, advocacy, and a newsletter.

Contact Information:

Phone: 604.669-2201 or 1.800.874.4666

Fax: 604.669.2214

Email: Blindcouncil@telus.net

Address: 818 – 602 West Hastings Street, Vancouver, BC, V6B 1P2

Canadian National Institute for the Blind

Provides a number of services to people with visual impairment, such as: counseling, optical aids, rehabilitation services, career counseling services and others. Many of the CNIB services are available to people whose vision is impaired to the extent that it interferes with or restricts normal activities.

Contact Information:

Phone: 604.431.2121

Fax: 604.431.2199

Website: <http://www.cnib.ca>

Address: 100 – 5055 Joyce Street, Vancouver, BC, V5R 6B2

Community Legal Assistance Program

Litigates test cases and seeks to reform laws relating to people who are economically, socially, physically, and mentally disadvantaged. Processes EI appeals, WCB appeals, and judicial reviews of welfare tribunal appeals and charitable tax law. Trains lay advocates and offers legal education to the public.

Contact Information:

Phone: 604.685.3425 or 1.888.685.6222

Fax: 604.685.7611

Address: 300 – 1140 West Pender Street, Vancouver, BC, V6E 4G1



Deaf Children's Society of BC

Offers a family centered approach to support deaf and hard of hearing children and their families by improving the ability of the family to develop and advocate for opportunities to maximize their child's development. The following services are offered:

- Family Support
- Speech & Language
- Sign Language Instruction
- Preschool
- Outreach
- Summer Family Program

Contact Information:

Phone: 604.525.6056

Fax: 604.525.7307

Website: <http://deafchildren.bc.ca>

Address: 7355 Canada Way, Burnaby, BC, V3N 4Z6

Family Support Institute

Aims to strengthen and support families of people with disabilities. Provides information, referrals, training, and networking opportunities. Offers workshops for professionals, and training for parents who wish to act as resource parents in their communities. The resource parents connect with parents requiring support and offer their guidance by utilizing their own experiences.

Contact Information:

Phone: 604.875.1119

Fax: 604.875.6744 or 1.800.441.5403

Website: <http://www.familysupportbc.com>

Address: 300 – 30 East 6th Avenue, Vancouver, BC, V5T 4P4

Learning Disabilities Association of BC

Offers a continuum of services on the basis that learning disabilities are a life-long influence. Programs and services focus on the development of coping strategies and building self-advocacy skills. Operates Resource centers where materials may be borrowed.

Contact Information:

Phone: 604.873.8139

Fax: 604.873.8140

Website: <http://www.ldav.ca>



North Shore Disability Resource Centre

Provides disability-specific information and referral services, resource materials, personal advocacy, education, and other programs for people with disabilities and for the community.

Contact Information:

Phone: 604.985.5371

Fax: 604.985.7594

Website: <http://www.nsdrc.org>

Address: 3158 Mountain Highway, North Vancouver, BC, V7K 2H5

Pacific Assistance Dogs (PADS)

Provides specially trained assistive animals to aid personal independence — opening doors or retrieving fallen objects etc.

Contact Information:

Phone: 604.527.0556

Fax: 604.527.0558 (TDD/TTY)

Website: www.padsdogs.org

Address: 9048 Stormont Ave, Burnaby, BC, V3N 4G6

Pacific Disabled Women's Network

Pacific DAWN is an emerging group of feminists who live with disabilities. The group is committed to addressing issues of concern such as mothering, employment, health, violence and self-image. The group is open to women who have all kinds of disabilities.

Contact Information:

email: admin@dawnCanada.net

Address: 776 East Georgia Street, Vancouver, BC. V6A 2A3

Planned Lifetime Advocacy Network

Serves people with disabilities. Provides advocacy services and up-to-date legal information on wills and estates, trustees, and financial planning. Works with families in developing personal support networks for their relative with a disability.

Contact Information:

Phone: 604.439.9566

Fax: 604.439.7001

Website: <http://www.plan.ca>

Address: 260 – 3665 Kingsway, Vancouver, BC, V5R 5W2



Public Interest Advocacy Centre

Aims to advocate for and advance the interests of groups that are generally unrepresented/under-represented in issues of major public concern, with an emphasis on utilities regulation and anti-poverty work. Represents these groups before courts, administrative tribunals, and regulatory bodies. Also works with other service providers to ensure the most effective allocation of resources, and operates as a community resource for advocacy, analysis, public education, and information.

Contact Information:

Phone: 604.687.3063

Fax: 604.682.7896

Website: <http://www.bcpiac.com>

Address: 208 – 1090 West Pender Street, Vancouver, BC, V6E 2N7

Special Needs Adoptive Parents Family

Assists adoptive parents of children with special needs, and all parents and professionals who care for children with special needs. Provides mutual support, information sharing, and advocacy. Mandate is to establish support groups and resource parents throughout BC, and provide public workshops and conferences concerning special needs adoption.

Contact Information:

Phone: 604.687.3114 or 1.800.663.7627

Fax: 604.687.3364

Website: <http://www.snap.bc.ca>

Address: 101 – 2780 East Broadway, Vancouver, BC, V5M 1Y8

Vancouver Resource Society

Provides information and referral services for people who have physical disabilities. Promotes community independent living. Operates group homes for children and adults.

Contact Information:

Phone: 604.731.1020

Fax: 604.731.4003

Website: <http://www.vrs.org>

Address: 310 – 2006 West 10th Ave., Vancouver, BC, V6J 4P5



Voice of Cerebral Palsied of Greater Vancouver

Non-profit society operated by adults with Cerebral Palsy. Offers peer counselling, life skills training, advocacy, and information sharing, as well as a consultative group for parents and professionals. Has a resource guide on how to set up a trust, and on attendant care.

Contact Information:

Phone: 604.874.1741

Fax: 604.874.1746

Website: <http://www.vcpvgv.org>

Address: 103 – 577 East 8th Ave., Vancouver, BC, V5T 1S9

Western Institute for the Deaf and Hard of Hearing

Promotes the well-being of all people who are deaf or hard-of-hearing. Provides audiology services, communication aids, counseling services, employment/vocational services, and interpretation services.

Contact Information:

Phone: 604.736.7391 or 1.888.736.7391

Fax 604.736.4381

Website: <http://www.widhh.com>

Address: 2125 West 7th Ave., Vancouver, BC, V6K 1X9

MEDICAL SERVICES AND EQUIPMENT

BC Children's Hospital

Offers highly specialized medical, dental, and surgical services on an inpatient outpatient basis. Physician's referral is necessary.

Contact information:

Phone: 604.875.2000

Fax: 604.875.2292

Website: <http://www.cw.bc.ca>

Address: 4500 Oak Street, Vancouver, BC, V6H 3N1



Canadian Red Cross Society BC Region

Provides a 90-day equipment loan service for people who need equipment to help them recuperate from operations, injuries, and illness in the comfort of their home. Equipment loan depots are located in communities throughout BC.

Contact Information:

Phone: 604.709.6600

Fax: 604.709.6688

Website: <http://www.redcross.ca/lowermainland>

Address: 3400 Lake City Way, Burnaby, BC, V5A 4Y2

Dial- A Dietitian

Operates a free and confidential nutrition hotline for BC. The public can talk directly to a Registered Dietitian/Nutritionist (RDN), who can answer nutrition questions and explain special diets recommended by physicians for medical conditions.

Contact information:

Phone: Vancouver 604.732.9191 or 1.800.667.3438

Website: <http://www.dialadietitian.org>

Medical Services Plan of BC

Provides medical coverage to all BC residents. Covers medically-required services by physicians and specialists (when referred by a physician), and diagnostic x-ray and laboratory services when ordered by a physician, podiatrist, or dental/oral surgeon. Covers dental and oral surgery when medically required to be performed in a hospital. For beneficiaries who qualify for premium assistance, offers limited coverage for the services of other qualified health care practitioners such as chiropractors and massage therapists. Enrollment under the plan is mandatory.

Contact Information:

Enrollment: 604.683.7151 or 1.800.465.4911

Claims: 250.952.2654

Fax: 250.952.3427

Website: <http://www.gov.bc.ca/health/cont/>

Address: PO Box 9035 Stn Prov Govt, Victoria, BC, V8W 9E6



Ministry of Health and Seniors' Information Line (formerly The Health Information Line)

Is a toll free BC telephone line that provides information on health programs within BC, and federal and provincial senior specific programs. Staff are able to answer questions about a broad range of government services for seniors, as well as help people fill out forms, and provide direct contact information for other agencies. The line also provides copies of the *Information for Seniors Guide*.

Contact information:

Toll free: 1.800.465.4911

Hours of Operation: 8:30 AM – 4:30 PM, Monday to Friday excluding Statutory Holidays.

Ministry for Children and Families (MCFD)

This ministry works to ensure that the province's children and families have the best chance possible to succeed and thrive. The Ministry's general responsibilities include:

- Child Protection and Family Development
- Adoption
- Foster Care
- Early Childhood Development and Child Care
- Child and Youth Mental Health
- Youth Justice and Youth Services
- Special Needs Children & Youth
- Adult Community Living Services

Contact Information:

Phone: In Victoria, call Client Relations: 250.387.7027

If you are outside Greater Victoria, please call Enquiry BC (toll-free): 1.800.663.7867, or 604.660.2421 in the Greater Vancouver area.

Ask to be transferred to the Ministry of Children and Family Development in Victoria at 250.387.7027

Website: <http://www.gov.bc.ca/mcf>

Email: MCF.CorrespondenceManagement@gov.bc.ca

Mailing Address: P.O. Box 9770 Stn Prov Govt, Victoria, BC, V8W 9S5

**Neil Squire Society**

National non-profit organization that identifies and responds to the needs of adults with severe physical disabilities. Specializes in the development of products and programs that assist these individuals to be more independent. Main service includes Creative Employment Option, an employment training project that assists adults with severe physical disabilities obtain meaningful employment in an area of their choice.

Contact Information:

Phone: 604.473.9363

Fax: 604.473.9364

Website: <http://www.neilsquire.ca/>

Address: Suite 220 – 2250 Boundary Road, Burnaby, BC, V5M 3Z3

Queen Alexandra Centre For Children's Health Victoria

The Queen Alexandra Centre for Children's Health (QA or QACCH), provides specialized health care services to children and youth with physical, developmental and or emotional/behavioural challenges. These services are delivered by a multidisciplinary team of health care professionals.

Contact Information:

Phone: 250.477.1826

Fax: 250.721.6715

Website: <http://www.viha.ca/children/>

Address: 2400 Arbutus Road, Victoria BC, V8N 1V7

Sunny Hill Health Centre for Children

A tertiary care, teaching, and research facility, operating as a provincial rehabilitation and assessment centre. Offers a wide range of services for children birth to 19 years who have complex disabilities. Services are offered on an inpatient, outpatient, or outreach basis, and include consultation, assessment, treatment, and follow-up. Areas of specialization include multiple developmental and physical disabilities, acquired brain injury, hearing and vision, fetal alcohol syndrome, pervasive developmental disorders (autism), feeding and swallowing, augmentative communication, and position and mobility. Physician referral required for assessment. An agency of PHSA.

Contact Information:

Phone: 604.453.8300

Fax: 604.453.8301

Website: <http://www.bcchildrens.ca>

Address: 3644 Slocan Street, Vancouver, BC, V5M 3E8



Special Education Technology BC

Assists BC school districts in meeting the technology needs of students with physical disabilities, visual impairments, or autism. Lends assistive technologies (reading, writing, and communication tools) where required to ensure students' access to educational programs, and assists school districts by providing training for students and educators in the use of these technologies.

Contact Information:

Phone: 604.261.9450

Fax: 604.261.2256

Website: <http://www.setbc.org>

Address: 105 – 1750 West 75th Avenue, Vancouver, BC, V6P 6G2

Technology for Independent Living

TIL installs and maintains electromechanical assistive devices for individuals with severe physical disabilities, for the purpose of independent living.

Contact Information:

Phone: 604.326.0175

Fax: 604.326.0176

Address: 6 Shaughnessy Street, Vancouver, BC, V6P 6R9

Tetra Society of North America

Recruits skilled volunteer engineers, health professionals, and technicians to work one-on-one with people who have physical disabilities to create customized assistive devices that help achieve greater independence and integration into the community.

Contact Information:

Phone: 604.688.6464

Fax: 604.688.6463

Website: <http://www.tetrasociety.org>

Address: A304 – 770 Pacific Boulevard, Box 27, Plaza of Nations, Vancouver, BC, V6B 5E7



RECREATION

BC Disability Sports

Works to encourage those with disabilities to participate in sport, recreation, and fitness activities and to increase these opportunities for people with disabilities. Provides a forum for the coordination of groups with an interest in these issues.

Contact Information:

Phone: 604.598.7890 or 1.877.456.4673

Fax: 604.737.3035

Website <http://www.disabilitysport.org>

Address: #217 – 12837 – 76th, Surrey, BC, V3W 2V3

BC Mobility Opportunities Society

Provides wilderness experiences and recreation programs for people with significant disabilities.

Contact Information:

Phone: 604.688.6464

Fax: 604.604.688.6463

Website: <http://www.disabilityfoundation.org>

Address: A304-770 Pacific Boulevard, Box 27, Plaza of Nations, Vancouver, BC, V6B 5E7

BC Special Olympics

Provides opportunities for individuals with an intellectual disability to enhance their lives and celebrate personal achievements through positive sport experiences.

Contact Information:

Phone: 604.737.3078 or 1.888.854-2276

Fax: 604.737.3080

Website: <http://www.specialolympics.bc.ca>

Address: 210 – 3701 East Hastings Street, Burnaby, BC, V5C 2H6



BC Therapeutic Riding Association

Promotes therapeutic rehabilitation of person with disabilities through the use of horse back riding.

Contact Information:

Phone: 604.462.7786

Fax: 604.462.9597

Website: <http://www.vcn.bc.ca/bctra/index.html>

Address: 25768 128th Avenue, Maple Ridge, BC, V4R 1C4

Canadian Cerebral Palsy Sports Association

The Canadian Cerebral Palsy Sports Association (CCPSA) is an athlete focused national organization administering and governing sport opportunities targeted to athletes with CP and related disabilities. CCPSA and its provincial partners cooperate as a proactive force to facilitate the development of equitable and fair sporting opportunities for our athletes.

Contact Information:

Phone: 1.866.247.9934

Fax: 613.748.1355

Website: <http://www.ccpsa.ca/>

Address 305 – 1376 Bank Street, Ottawa, ON, K1H 7Y3

Cerebral Palsy Sports Association of British Columbia

Provides sports and Recreation opportunities for people with Cerebral Palsy or other physical disabilities.

Contact Information:

Phone: 604.599.5240

Fax: 604.599.5241

Website: <http://www.cpsports.com>

Address: 6235A 136th Street, Surrey, BC, V3X 1H3

Disabled Sailing Association of BC

Provides sailing instruction, and recreational and competitive sailing opportunities, for people with significant disabilities.

Contact Information:

Phone: 604.222.3003

Fax: 604.222.3004

Website: <http://www.reachdisability.org/dsa>

Address: Jericho Sailing Centre 1300 Discovery Street, Vancouver, BC, V6R 4L9



Disabled Skiers' Association of BC

Offers alpine, cross-country skiing, and snowboard programs for people with disabilities. Also sponsors competitive skiing and other recreational activities for people with disabilities.

Contact Information:

Phone: 604.737.3038

Fax: 604.737.6043

Website: <http://www.disabledskiingbc.com>

Address: 226 – 1367 West Broadway, Vancouver, BC, V6H 4A9

Lions Society of BC

Provides services for children and youth with physical and or developmental disabilities, including patient care, and help with education and personal development. Operates Easter Seal Houses in Vancouver, Victoria, and Prince George. Also operates Easter Seal Camps at Squamish, Winfield, and Shawnigan year-round.

Contact Information:

Phone: 604.873.1865

Fax: 604.873.0166

Website: <http://www.lionsbc.ca>

Address: 3981 Oak Street, Vancouver, BC, V6H 4H5

Theatre Terrific Society

Theatre company for artists with disabilities. Provides classes at locations such as community centers; teachers also provide outreach to different societies. Activities include theatre games, theatre readings, dramaturgical services, and professional productions.

Contact Information:

Phone: 604.222.4020

Fax: 604.222.4020

Website: <http://www.theatreterrific.ca>

Address: Office: 4397 West 2nd Avenue, Vancouver, BC, V6R 1K4



Vancouver Adapted Music Society

Assists and encourages people with disabilities to compose music and play musical instruments. Provides agent services for musicians with disabilities, and develops assistive devices that make music production possible for people with disabilities.

Contact Information:

Phone: 604.688.6464

Fax: 604.688.6463

Website: <http://www.disabilityfoundation.org/vams>

Address: A304 – 770 Pacific Boulevard, Box 27, Plaza of Nations, Vancouver, BC, V6B 5E7

EDUCATIONAL RESOURCES AND POST SECONDARY INSTITUTIONS

BC Confederation of Parent Advisory Councils

Provincial organization of public school parent advisory councils encourages parents to share information about education issues, participate in educational activities and decision-making, and to serve on parent committees, which provide advice to educational decision-makers, and strengthen the role of families in education and schooling.

Contact Information:

Phone: 604.687.4433

Fax: 604.687.4488

Website: <http://www.bccpac.bc.ca>

Address: 202 – 1545 West 8th Avenue, Vancouver, BC, V6J 1T5

UNIVERSITIES

SFU Centre for Students with Disabilities

Provides assistance with note taking, tutor support, access to adaptive technology, course material in alternative formats, support for exam modification, advocacy and coordination of sign language interpreters.

Contact Information:

Phone: 604.291.3112

Fax: 604.291.4384

Website: <http://www.sfu.ca/csd/>

Address: 1250 Maggie Benston Centre, Simon Fraser University, Burnaby, BC, V5A 1S6



Trinity Western University

Contact Information:

Phone: 604.888.7511

Website: <http://www.twu.ca/>

Address: 7600 Glover Road, Langley, B.C. V2Y 1Y1

UBC Access and Diversity Centre

The Disability Resource Centre works with the University to eliminate structural and attitudinal barriers to those with disabilities. We provide disability-related services to the students, staff and faculty of UBC. The DRC is also active in research, teaching, and program initiatives associated with disability.

Contact Information:

Phone: 604.822.5844

Fax: 604.822.6655

Website: <http://students.ubc.ca/access/drc.cfm>

Address: The University of British Columbia Brock Hall, 1203 – 1874 East Mall, Vancouver, BC, V6T 1Z1

UNBC Disability Services

Committed to the goal of creating and maintaining physical and social access to the University for persons with disabilities by reducing the physical and attitudinal and systematic barriers faced by students with disabilities.

Contact Information:

Phone: 250.960.6355

Fax: 250.960.5775

Website: <http://www.unbc.ca/disabilities/index.html>

Address: University of Northern BC, room 7 – 103



UVIC Resource Centre for Students with a Disability

Provides assistance with note taking, tutor support, access to adaptive technology, course material in alternative formats, support for exam modification, advocacy and coordination of sign language interpreters.

Contact Information:

Phone: 250.472.4947

Fax: 250.472.4443

Website: <http://rcsd.uvic.ca/>

Address: Campus Services Building, Rm 150, P.O. Box 3015 Victoria, BC, V8W 3P1

COLLEGES

Camosun College Disability Resource Centre

Support services are provided to students with a broad range of disabilities who access regular college programs to ensure equitable access to post secondary opportunities.

Contact Information:

Phone: 250.370.3000

Website: <http://www.camosun.bc.ca/> (Click on student services)

Address 3100 Foul Bay Rd, Victoria BC, V8P 5J2

Capilano College Disability Services

Provides individualized educational planning, registration assistance, educational and technical equipment, classroom accommodations, sign language interpreters and various other services for students with a disability.

Contact Information:

Phone: 604.983.7526

Website: <http://www.capcollege.bc.ca/services/advice/disabilities.html>

Address: Birch Building Rm.284, 2055 Purcell Way, North Vancouver, BC, V7J 3H5



Douglas College for Students with Disabilities

Provides assistance with note taking, tutor support access to adaptive technology, course material in alternative formats, support for exam modification, advocacy and coordination of sign language interpreters.

Contact Information:

Phone: 604.527.5486

Website: <http://www.douglas.bc.ca/csd>

Address: Rm: 4600, 700 Royal Avenue, PO Box 2503, New Westminster, BC, V3L 5B2

Emily Carr College of Art & Design Student Disabilities Centre

Provides assistance with note taking, tutor support, access to adaptive technology, course material in alternative formats, support for exam modification, advocacy and coordination of sign language interpreters.

Contact Information:

Phone: 604.844.3823

Fax: 604.844.3801

Website: <http://www.eciad.ca/www/services/disability.html>

Address: 1399 Johnson Street, Granville Island, Vancouver, BC, V6H 3R9

Kwantlen College

We promote full and equal opportunity for students with disabilities to achieve their potential for success as self-directed independent learners.

Contact Information:

Phone: 604.599.2003

Fax: 604.599.2409

Website: <http://www.kwantlen.ca/ssd/>

Address: 12666 –72nd Avenue, Surrey, BC, V3W 2M8



Langara College

Disability Services at Langara College is committed to promoting an educational environment which is accessible to students with disabilities, to co-ordinating services and programs for these students, to providing information regarding the educational implications of disabilities and enhancing the awareness of disability issues. Disability Services celebrates diversity by fostering the personal and intellectual growth of academically qualified students with disabilities.

Contact Information:

Phone: 604.323.5635

Website: <http://www.langara.bc.ca/disability/>

Address: 100 West 49th Avenue, Vancouver, BC, V5Y 2Z6

Malaspina College

Provides individualized educational planning, registration assistance, educational and technical equipment, classroom accommodations, sign language interpreters, and various other services for students with a disability.

Contact Information:

Phone: 250.740.6416

Website: <http://www.mala.ca/services/studentssupport/disabilityservices.htm>

Address: 900 Fifth Street, Nanaimo, BC, V9R 5S5

EMPLOYMENT RESOURCES

Employment Program for Persons with Disabilities (EPPD)

Is a provincially funded program that provides persons with disabilities (18 and older) access to a full range of services, tools and supports that address the distinct needs of persons with disabilities.

This program recognizes that individuals experience disabilities in varying degrees, at different stages of their lives and that their needs may also change over time. The Employment Program for Persons with Disabilities provides flexibility to individuals with disabilities who want to volunteer or work either full-time, part-time, or be self-employed.

Contact Information:

Your Ministry of Human Resources office can advise you of which agencies in your area are offering this program.



Employment Outreach

A federally funded employment program operated by the BC Paraplegic Association. Assists people with physical disabilities to seek employment, by providing the opportunity to develop job searching skills. Also, promotes the hiring of people with disabilities, to employers.

Contact Information:

Phone: 604.324-3611

Fax: 604.326.1229

Website: <http://www.bcpara.org>

Address: 780 sw Marine Drive Vancouver, BC, V6P 5Y7

Iam Cares

Promotes the employment of people with all types of disabilities and/or chronic health conditions, and offers a full range of employment assistance and placement services.

Contact Information:

Phone: 604.436.2921

Fax: 604.436.9100

Website: <http://www.iamcares.com>

Address: 102 – 5623 Imperial Street, Burnaby, BC, V5J 1G1

Also runs:

North Shore Employment Assitance Program

Assists people with a disability and/or chronic health condition prepare for, obtain, and keep employment, or become self-employed. Services include: needs assessment, case management, career planning, help accessing educational funding, job search skill training, access to the internet, direct employer contacts, and referrals to job leads. Also coordinates wage subsidies for employers who choose to hire a person with a disability and/or chronic health condition.

Contact Information:

Phone: 604.903.3355

Fax: 604.903.3345

Address: 303 – 935 Marine Drive, North Vancouver, BC, V7P 1S3



Neil Squire Foundation-National

Non-profit organization that identifies and responds to the needs of adults with severe physical disabilities. Specializes in the development of products and programs that assist these individuals to be more independent. Main services include Creative Employment Option, an employment training project that assists adults with severe physical disabilities obtain meaningful employment in an area of their choice.

Contact Information:

Phone: 604.473.9363

Fax: 604.473.9364

Website: <http://www.neilsquire.ca/>

Address: Suite 220 – 2250 Boundary Road, Burnaby, BC, V5M 3Z3

Youth Bridges to the Future

Assists those with disabilities (15 – 24 years of age) to achieve community integration and participation and attain realistic educational, employment and life skills training.

Contact Information:

Phone: 604.788.7124

Fax: 604.731.6127

Website: <http://www.bridgestothefuture.ca>

Address: 303 – 1338 West Broadway, Vancouver, BC, V6H 1H2



WEB SITES

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

www.vcpvgv.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 with people with disabilities in the U.K.

www.aacpdm.org

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.



YOUR KNOWLEDGE CENTRE

- Knowledgeable BC Cerebral Palsy staff are available to answer your questions about CP, CPABC 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 work 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 both 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 community.
- 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.



Volunteer Board of Directors — 2006

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