

A Guide to Cerebral Palsy

Acknowledgments

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

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

Cerebral Palsy - Facts and Figures
United Cerebral Palsy, 1993

Cerebral Palsy - Information kits for educators and parents
Cerebral Palsy Association of Manitoba, 1989

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

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Introduction

Every person who has cerebral palsy is unique. CP describes many different types of disability, ranging from mild to severe, with different 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. Having CP should be no barrier to leading an enjoyable and productive life but, realistically, it does present some additional challenges. Being well informed about the options and opportunities available is a first step in coping with these challenges.

This booklet is designed to be a general introduction for anyone interested in cerebral palsy, such as:

- parents whose child has recently been diagnosed as having CP, or who is suspected of having CP
- people with CP wanting basic information, or wishing to provide information to friends and assistants
- education, social service and health professionals
- friends, relatives and colleagues of people with CP

The Cerebral Palsy Associations that published this booklet will be pleased to supply further

information on areas of particular interest to you. A list of books for more detailed reading is also suggested [[at the end](#)].

To Use this Booklet Effectively

Because CP effects everyone uniquely, highlight sections that are appropriate to you or your child when passing this booklet along to interested people. They can focus on important points when highlighted.

Editorial Notes:

To make this text easier to read:

- The abbreviation "CP" is used throughout
- CP affects roughly equal numbers of men and women. Rather than use the clumsy "he/she", "he" and "she" are used in alternating sections

What is Cerebral Palsy?

Cerebral palsy (CP) is a term used to describe a group of disorders effecting body movement and muscle co-ordination. The medical definition of CP is "a non-progressive but not unchanging disorder of movement and/or posture, due to an insult or anomaly of the developing brain."

Development of the brain starts in early pregnancy and continues until about age three. Damage to the brain during this time may result in CP. This damage interferes with messages from the brain to the body, and from the body to the brain.

Cerebral = "of the brain"

Palsy = "lack of muscle control"

The affects of CP vary from individual to individual. At its mildest, CP may result in a slight awkwardness of movement of hand control. At its most severe, CP results in virtually no muscle control, profoundly affecting movement and speech.

Depending on which areas of the brain have been damaged, 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 such as writing and speaking

- abnormal perception and sensation

These effects may cause associated problems such as difficulties in feeding, poor bladder and bowel control, breathing problems, and pressure sores.

The brain damage which caused CP may also lead to other conditions such as :

- seizures
- learning disabilities
- hearing impairment
- vision problems

It is important to remember that limbs affected by CP are not paralyzed and can feel pain, heat, cold and pressure. It is also important to remember that, just because someone with CP may not be able to speak, it does not mean he has nothing to say. The degree of physical disability experienced by a person with CP is not an indication of his level of intelligence.

People with CP have a normal life-expectancy. Damage to the brain is a one-time event so the condition will not get worse 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. Others may get worse: tight muscles can cause problems in the hips and spines of growing children which require orthopaedic surgery; the aging process can be harder on bodies with abnormal posture or which have had little exercise.

Cerebral Palsy is:

NOT contagious
NOT hereditary
NOT life-threatening

How Many People have Cerebral Palsy?

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

It is estimated that one out of every 500 babies, and up to one in three premature babies is affected to some extent. There are over 50,000 Canadian with CP.

What Causes Cerebral Palsy?

Any damage to the developing brain, whether caused by genetic or developmental disorders, injury or disease, may produce CP.

During pregnancy:

Anything which tends to produce a low birth weight baby will increase the likelihood of CP. Factors during pregnancy which may cause CP include:

- multiple births (twins or triplets)
- a damaged placenta which may interfere with fetal growth
- infections
- poor nutrition
- exposure to toxic substance, including nicotine and alcohol
- maternal diabetes, hyperthyroidism or high blood pressure
- biochemical genetic disorders
- chance malformations of the developing brain

During labour:

- premature delivery
- abnormal positioning of the baby (such as breech or transverse lie) which makes delivery difficult
- rupture of the amniotic membranes leading to fetal infection

In early childhood:

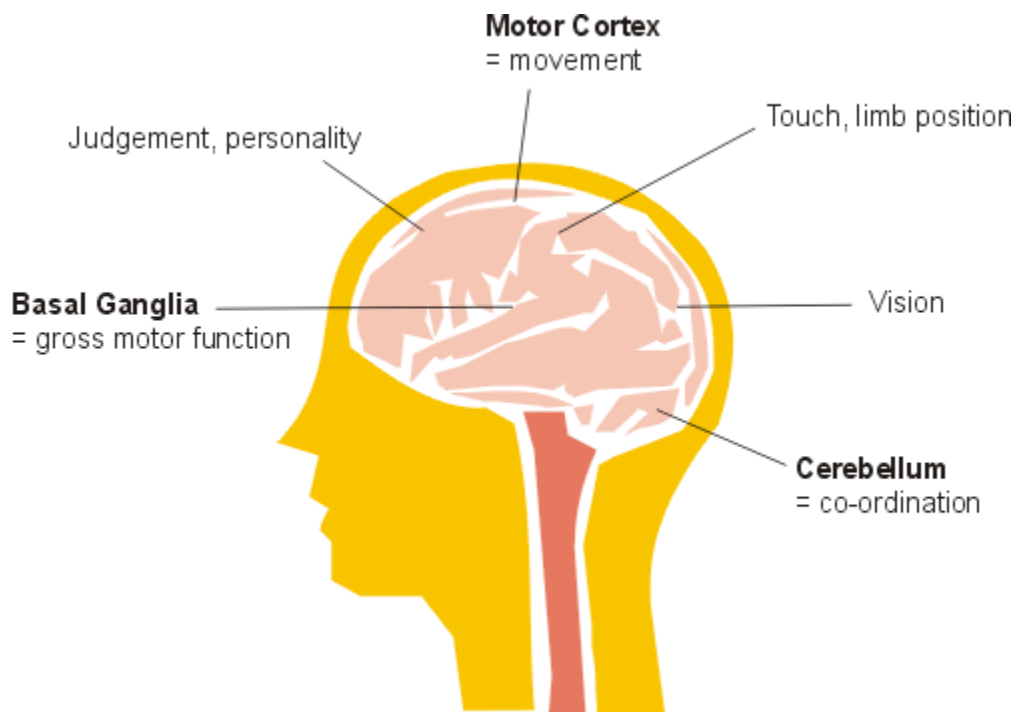
CP can occur if a young child suffers brain damage due to:

- infection such as meningitis
- brain haemorrhages
- head injury following falls, car accidents or abuse
- a lack of oxygen (asphyxia) due to accidents such as drowning
- seizures

Not many years ago, CP was usually described as being caused by "a lack of oxygen at birth". Researchers have come to realise that the causes are far more complex. In many cases, a difficult labour may be a symptom rather than a cause of CP. Many people with CP are born prematurely, but other families sail through a straight-forward pregnancy and delivery to by hit be CP "out of the blue".

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

The Human Brain



Diagnosis of CP

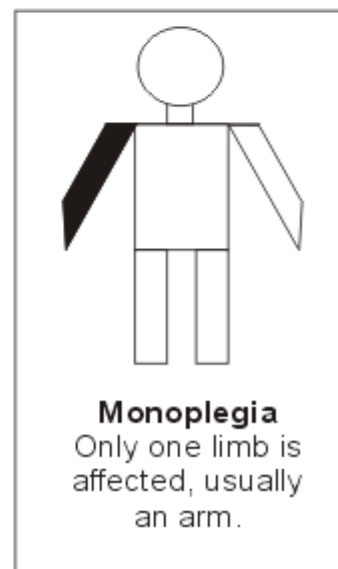
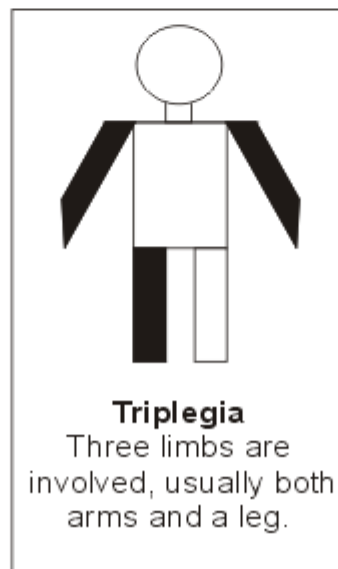
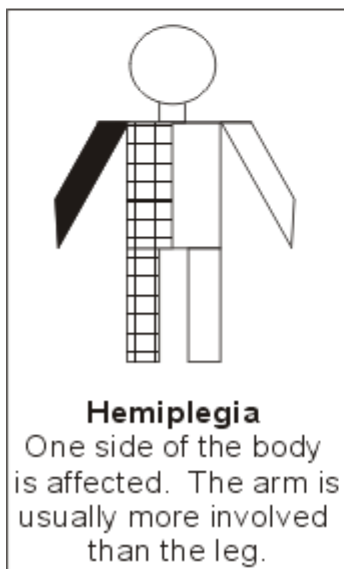
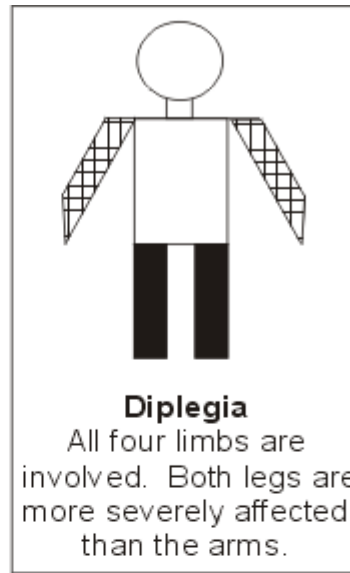
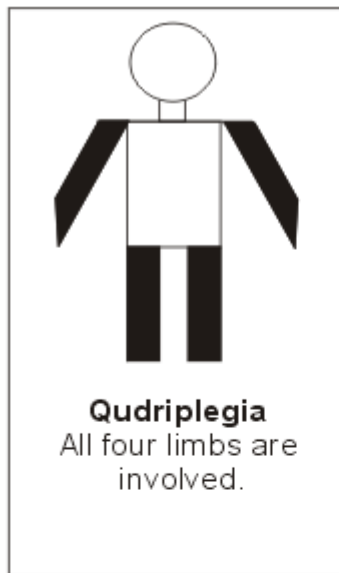
CAT scans (Computerized Axial Tomography) and MRI (Magnetic Resonance Imaging) can identify lesions in the brain. This technology enables some children, who are at risk of having CP, to be diagnosed very early. However, for the majority of people with CP it will be months and sometimes years, before a diagnosis is confirmed.

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, but they do not yet know why - is particularly stressful.

Types of CP

With so many different causes of CP, it is no surprise that it takes many forms. Every person with CP is a unique individual, but is likely to be classified as having a particular *type* of CP. Classification can be according 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 and is caused by damage 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 be very mild and affect only a few movements, or very severe and affect the whole body. The amount of spasticity usually changes over time.

Choreo-Athetoid cerebral palsy

Choreo-Athetoid CP results from damage to the basal ganglia or cerebellum and leads to difficulty in controlling and co-ordinating movement. Children may have involuntary movements (which frequently cease while they sleep), or have difficulty with skills that require coordinated movements such as speech or reaching and grasping objects smoothly. Some terms commonly used to describe these involuntary movements include:

- *Athetosis* - slow, writhing movements, particularly in the hands and face
- *Ataxia* - unsteady walking and balance problems. Ataxia results from damage to the cerebellum, the brain's major centre of balance.
- *Chorea* - jerky movements of the head, arms, or legs
- *Dystonia* - twisting movements and postures of the trunk or limbs

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 considered a curable condition and the word "management" is used more often than "treatment". However, there is much that can be done to lessen the effects of CP and to help people with CP to lead independent lives. This is a brief overview of some of the available options. "The Professional Team" on p.19 gives further information.

If you have a child with CP it is easy to be overwhelmed by the number of professionals involved with your child and the different management and therapy options. Not all interventions are appropriate for each individual and, as a parent, you are the person to decide what is right for you and your child. Some parents like to involve their child in every option that may be helpful; others decide that having family time is more important than spending hours each week on therapy or the stress involved in going through another bout of surgery. Some adults with CP consider the therapy and/or surgery they had as children very helpful; others quit therapy in adolescence and stay as far away from doctors and therapists as they can.

Therapy

Physical Therapy (PT) aims to help people achieve their potential for physical independence and mobility. PT includes exercises, correct positioning, and teaching alternate ways of movement such as walkers, bracing or handling a wheelchair.

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 Therapy aims at improving communication. A child may only need help to overcome a slight articulation problem, or she may not be able to communicate verbally and may require a non-verbal communication system. Alternative communication systems include eye-gaze systems, blissymbol boards, and electronic voice synthesizers.

Music Therapy uses music for the treatment of neurological mental or behavioural disorders.

New therapies are being developed all the time. Contact your local Cerebral Palsy Association for information on alternative treatments.

Orthotics, Casts and 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 and help to provide stability, keep joints in position, and help stretch muscles.

Medications

Your child may take medication for conditions associated with her CP, such as seizures. Drugs may sometimes be prescribed for severe spasticity or painful spasms. Spasticity can be temporarily reduced by nerve blocking injections. A recent development is the injection of botulinum toxin ("Botox") into a spastic muscle group. This can reduce tone for several months.

Surgery

Orthopaedic 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 reposition and stabilize bones.

Neurosurgery involves surgery on the nerve roots which control muscle tone. Selective posterior rhizotomy aims to reduce spasticity by severing some of the nerve roots in the spine.

Adaptive Equipment

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

Mobility Devices include:

- wheelchairs (manual, power and sports)
- scooters
- specially made bicycles and tricycles
- walkers and crutches

Communication Devices include:

- symbol boards
- voice synthesizers
- head sticks and keyguards for computers

Daily Living Aids include:

- electronic door openers
- large-handled eating utensils
- grab sticks
- environmental control systems

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

Educational Supports

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

Canada has some of the world's best "early intervention" programs. Children with CP will often start their education early to help improve their mobility and communication skills before starting school.

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

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

"The ultimate long-term goal is realistic independence. To get there we have to have some

short-term goals, those being a working communication system, education to his potential, computer skills and, above all, friends." - Parent of a boy with CP

*"The ultimate long-term goal is realistic independence. To get there we have to have some short-term goals, those being a working communication system, education to his potential, computer skills and, above all, friends." - **Parent of a boy with CP***

Independent Living

The effects of CP are lessened considerably by an environment which enables people with disabilities to play a full part in their communities. It is never too early to start working toward future independence.

Barriers against people with disabilities - both physical and attitudinal - have fallen due to the efforts of social policy-makers. There is still much to do, but Canada can take pride in being one of the world's most progressive countries on disability issues.

Living with CP

A person with CP has to cope both with disabilities and handicaps. A disability is a physical loss of function such as being unable to walk, having difficulty with hand control or speech. A handicap is the degree to which that disability puts you at a disadvantage in daily life. For instance, someone who is very short-sighted may be considered to have a disability, but she is unlikely to consider this a handicap if she has corrective lenses. A disability may prevent someone with CP from climbing stairs, but this will only be a handicap if the building she wants to enter is not wheelchair-accessible. CP is not a life-threatening condition and, in itself, is no barrier to leading a long and productive life. People with CP enjoy satisfying careers, university education, social life, and become parents. Some limitations are unavoidable, but very few people manage to achieve their dreams of becoming Olympic athletes, concert pianists or brain surgeons.

Disability = a loss of function

Handicap = the effect of that disability on daily life

The key elements to minimizing the handicapping effects of CP are:

Management and Treatment

Therapy, surgery and the use of adaptive equipment help many people with CP to use their minds and bodies to their full potential.

Access

You cannot lead an independent life if public buildings, washrooms and transportation are not accessible. To have a good career you need educational opportunities. To have a satisfying social life you need access to recreational facilities and opportunities to develop friendships.

Attitudes

It is very hurtful to have someone pat you on the head if you are sitting in a wheelchair, or to walk away because they cannot understand what you are trying to say to them. Prejudice and teasing can be very damaging. A good sense of self-esteem is required to cope with these negative attitudes. Children can also be handicapped if they are over-protected and allowed to become too dependent. People with disabilities are **people** first and should never be described by such negative labels as "wheelchair-bound", "spastic", or "afflicted with cerebral palsy". All people share similar needs, desires, drives and responsibilities.

Aging and CP

Most treatment and research programs concern children with CP and little research has so far 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 (such as increased spasticity, fatigue, loss of strength and declining mobility), and these physical challenges can in turn lead to increased stress and anxiety.

Research indicates that adults with CP tend to lose some of the mobility they gained as children. They consider that this is due to weight gain, lack of therapy and exercise, and the development of other conditions such as arthritis.

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 & Mental Health

A lifestyle that involves regular exercise and proper nutrition is important to everyone, including those with disabilities. Exercise may just seem like one more thing to fit into a schedule already overwhelmed by the additional demands of therapy and medical appointments. But a good general fitness level will help with range of motion and flexibility, and exercise to improve cardiovascular fitness can improve endurance and help offset age-related changes that lead to fatigue. A nutritious, high-fibre, low-fat diet will help avoid problems with constipation and weight gain and will increase energy levels.

Having CP does not make you immune to other conditions. People with CP are as likely as anyone else to contract heart disease, cancer or diabetes. Sometimes a change in the body can be put down to an effect of CP when it is actually a different condition.

The 1990s 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 life-long 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 over-emphasized. The stresses associated with aging will be lessened if a person is able to maintain a positive personal attitude, if he is involved in meaningful activities, and if he has developed a supportive environment. He needs confidence to seek information, to plan for age-related changes, and to be an active participant in his health care and lifestyle choices.

"Time and gravity are enemies of very aging body, especially mine." - **Adult with CP**

A Parent's Perspective

by Cal Lambeth

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

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

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

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

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

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

Although I presented a bold front to those around me, the truth of the matter was that I was depressed and frightened. I was fortunate to have a family which offered physical help and a listening ear. Not everyone is so lucky. Furthermore, 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, 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. But 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.

Preventing CP

Some measures of prevention are possible today. 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. Newborns with jaundice can be treated effectively with phototherapy. Other preventive programs are directed towards preventing premature delivery, reducing exposure to infections, X-rays, drugs and medications. Diabetes and anemia can be kept under control during pregnancy.

Education programs stress the importance of optimal well-being prior to conception and adequate prenatal care. Safety campaigns give advice on protecting children from accidents and injuries.

These measures have undoubtedly prevented many children from developing CP. However, other developments - such as neonatal intensive care - have enabled very low birth weight babies to survive. These babies are at high risk of developing CP.

Research

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

- What are the factors that predispose the developing brain to injury? Can these factors be eliminated?
- Can CP be diagnosed before birth and better diagnosed shortly after birth?
- Could brain cells be re-grown to repair the damage which results in CP?
- Which treatments are most effective for specific disabilities of people with CP?
- What are the effects of aging on the person with CP?
- Based on new developments in surgical techniques, computer technology, and bioengineering sciences, what improvements can be made in the quality of life of people with CP?
- What are the social and emotional effects on a child growing up with CP? How can she be helped to develop a positive self-image?

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

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

Ear, Nose & Throat (ENT) Surgeon: Can diagnose and treat problems in hearing, feeding, swallowing and drooling. ENT surgeons may be consulted about problems with severe or

repeated ear infections, enlarged tonsils or adenoids.

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

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

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

Neurologist: Specializes in the diagnosis and treatments of problems of the nervous system

Neurosurgeon: Performs operations on the spinal cord and brain

Nutritionist or Dietician: Specializes in feeding and nutritional needs. Children who have difficulty feeding may need special nutritional supplements. The 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. 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 physician specializing in disorders of the eyes and vision.

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

Orthopaedic Surgeon: Specializes in disease and abnormalities of the locomotor system (bones, muscles, joints and tendons). In addition to performing surgery, the orthopaedic surgeon can recommend special footwear or braces.

Orthotist: Designs braces and shoe supports

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 behavioural disorders.

Physiatrist: A doctor specializing in physical medicine and habilitation.

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

Podiatrist: Diagnoses and treats disorders of the foot.

Psychiatrist: A doctor who treats mental, emotional and behavioural disorders.

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

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 to cope with the additional challenges of raising a child with a disability.

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

Urologist: A specialist in diseases of the urinary tract.

Cerebral Palsy Associations

Cerebral Palsy Associations are independent, non-profit organizations directed by volunteers in each Canadian province.

The associations offer a wide range of support and information services. These may include:

- Information through newsletter and library services
- Public education
- Advocacy in areas such as education, accessibility and human rights
- Equipment loans
- Support groups
- Recreational programs
- Funding for equipment, education and research

Contact your local Cerebral Palsy Association for more information or to offer your support.

Bibliography

Your provincial Cerebral Palsy Association has a resource library of books and videos you may find helpful. The following are frequently recommended:

For Parents

Children with Cerebral Palsy - A Parent's Guide

Elaine Geralis & Tom Ritter

Woodbine House, 5616 Fishers Lane, Rockville MD 20852

An informative book about CP for parents of young children. Chapters alternate between factual information and parents' experiences.

Caring for Children with Cerebral Palsy - A Team Approach

John P. Dormans & Louis Pellegrino

Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, Maryland 21285-0624

This interdisciplinary text is the definitive reference for team-based care of children with CP.

For Children

Can't You Be Still/ Nobody Knows/ Here's What I Mean to Say

Sarah Yates

Gemma B Publishing Inc, Box 740, 776 Corydon Ave, Winnipeg, MB R3M 0Y1

Three books about Ann, who finds out that having CP causes her all sort of difficulties. She resolves her problems by utilizing her real strengths.

For Adolescents

Taking Charge - Teenagers Talk about Life and Physical Disabilities

Kriegsman, Zaslow & D'Zumura-Richsteiner

Woodbine House, 5615 Fishers Lane, Rockville MD 20852

Written for teenagers with CP, spina bifida, and muscular dystrophy. It delivers a positive message to help them work through difficulties, recognize their abilities, and reach for their dreams.

Sex for Young People with Spina Bifida or Cerebral Palsy

Association for Spina Bifida & Hydrocephalus, Tavistock House North, Tavistock Square, London WC1H 9HJ, England.

An outline for young people and their parents, of sex and sexual relationships, with clear drawings. Contraception and parenthood are discussed.

For Adults

Aging with a Disability

R. Trieschmann

Demos Publication, 156 Fifth Avenue, New York, NY 10010

Examines the aging disabled population with information from people with disabilities.

Enabling Romance

Kroll & Klein

A frank and insightful guide to love, sex and relationships for people with disabilities.

Individuals and couples with a wide range of disabilities share their insights and experiences.

For Educators

Changing Canadian Schools: Perspectives on Disability and Inclusion

Gordon Porter and Diane Richler

Roehrer Institute, Kinsmen Building, York University, 4700 Keele Street, North York, ON M3J 1P3

An exploration of legal and policy issues, the roles of parents and advocacy organizations, and innovative inclusive practices.

Putting the Puzzle Together - a handbook of ideas for including all kids in regular classrooms

Cerebral Palsy Association of B.C., 1996

Videos

Cerebral Palsy - A Video Guide for Families (17 minutes)

The Cerebral Palsy Association of B.C. produced this award-winning video which provides an orientation to CP for parents, health care professionals, support staff and volunteers.

Never Say NEVER(11 minutes)

Cerebral Palsy Association in Alberta

This short video aims to raise awareness about CP and the Alberta Association. Hosted by Joe Coughlin, a former CBC anchor who has CP.

Cerebral Palsy - A Lifelong Journey (88 minutes)

Ontario Federation for Cerebral Palsy

Four-part video: Understanding CP; Infancy & Early Childhood; The Adolescent & Young Adult; The Middle Years and Beyond.

My Left Foot (103 minutes)

The Oscar-winning movie of Irish author Christy Brown's struggles and triumphs growing up with CP.

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.cerebralpalsycanada.com

A web site with information about Cerebral Palsy Associations across Canada

www.ofcp.on.ca

Web site of the Ontario Federation for Cerebral Palsy

www.ucpa.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 Spastic 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.

[Cerebral Palsy Associations in Canada](#)