Holland Blcorview Kids Rehabilitation Hospital

On the path to possibility

A guide book for children, youth and families living with cerebral palsy Child Development Program

Table of Contents

client

Family

Introduction	3
What is cerebral palsy?	4
How is cerebral palsy diagnosed?	5
Are there different types of cerebral palsy?	6
Between the child's 6th and 12th birthday	7
What causes cerebral palsy?	8
Do children with cerebral palsy have more medical problems than other kids?	10
Can cerebral palsy be treated? How do we manage cerebral palsy?	12
What is Botulinum toxin A and how does it work?	14
What's new in research?	14
Do alternative therapies work?	15
What other services do you offer?	16
School and preschool issues	17
Where do I go from here?	17
Financial resources for families of children with disabilities	18
Glossary	20
About Holland Bloorview Kids Rehabilitation Hospital	23



Introduction

Many parents ask us, "What can I read to learn about cerebral palsy?" This booklet was written to answer that very question! We hope this booklet will help explain what cerebral palsy is and what supports we can offer. At the back of the booklet is a list of resources and a glossary of all the **bolded** words. Of course, your team at Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) is always here to answer any additional questions you may have.

Throughout the booklet you will find pictures of children with cerebral palsy who come to Holland Bloorview for care. These children and their parents wanted to share a part of themselves with you and the photos say it all – they are happy kids! There are also comments from parents about having a child with cerebral palsy. These heartfelt words were written for you: read them and know that you are not alone. We hope this booklet helps you discover some of the many possibilities for your child and how together we can help them achieve their best!

What is cerebral palsy?

Cerebral palsy (CP) is a condition that affects movement. Children and youth with CP may use wheelchairs, walkers or canes to get around. Others may be able to walk all by themselves. Even though children with CP have different abilities, the brain has trouble sending signals to the muscles making it difficult for a child to move. Although we don't have ways of fixing how the brain sends the signal to the muscles, we can try to help children and youth with CP learn new ways of moving to let them live full lives and be as independent as possible. Over time, most people with CP improve in their motor skills, but how much improvement and how long this takes depends on each individual and their abilities.

How is cerebral palsy diagnosed?

Parents are often the first to notice that their child is having difficulty with their movements. For example, your child may not sit up or walk when other children do. They may do things differently, such as "**commando crawling**" (crawling on their stomachs), walking on tiptoes, or only using one hand from a very early age. Sometimes it is a doctor or therapist who is the first to notice these differences. Signs of CP may be there as early as six months of age, but most times, CP is not diagnosed until the child is around one to two years old.

A doctor usually diagnoses cerebral palsy. The doctor will ask many questions about your pregnancy, your child's movements, and your child's development. They will check your child's muscles to look for physical signs such as tightness in the muscle (called **hypertonia**). They may use tests such as a head ultrasound or magnetic resonance imaging (MRI) of the brain to confirm a diagnosis of CP. Not all children and youth need these specialized tests to make a diagnosis of CP.





Are there different types of cerebral palsy?

There are many types of CP. The type of CP your child has will depend on which parts of the body are affected and the type of problem your child has with movement. Spastic CP is the most common type, which means the main problem is tightness in the muscles. It can involve the legs (**spastic diplegia**), one side of the body such as an arm and a leg (spastic **hemiplegia**), or the whole body (spastic quadriplegia). **Dyskinetic** CP is less common and is seen in about 10% of all children with CP. Children with **dyskinetic** CP have extra movements that are not under their control which we call **dystonia** or **choreoathetosis**. Some children have a combination of spastic and dyskinetic CP, which we call mixed CP. Another type of CP is ataxic CP. Children with **ataxic** CP have difficulties with their balance and motor co-ordination.

CP can also be described based on how the child's movement abilities affect their day-to-day life using the Gross Motor Function Classification Scale (GMFCS). The GMFCS measures the child's motor skills and divides CP into five levels. Children with Level I CP typically have milder motor difficulties and can participate in most activities such as walking and running. However, they have differences in the quality of their movement including the speed, accuracy, and smoothness of movements. Children with Level V have the most motor involvement. More information about the different levels in CP can be found on the next page. Please feel free to discuss your child's motor function or GMFCS level with your developmental pediatrician or physiotherapist.

Between the child's 6th and 12th birthday



Level 1

Children walk indoors and outdoors, and climb stairs without limitations. Children perform gross motor skills including running and jumping but speed, balance and coordination are reduced.



Level II

Children walk indoors and outdoors, and climb stairs holding onto a railing but experience limitations walking on uneven surfaces and inclines, and walking in crowds or confined spaces. Children have at best only minimal ability to perform gross motor skills such as running and jumping.





Children walk indoors or outdoors on a level surface with an assistive mobility device. Children may climb stairs holding onto a railing. Depending on upper limb function, children propel a wheelchair manually or are transported when travelling for long distances or outdoors on uneven terrain.



Level IV

Children may maintain levels of function achieved before age 6 or rely more on wheeled mobility at home, school and in the community. Children may achieve self-mobility using a power wheelchair.



Level V

Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At level V, children have no means of independent mobility and are transported. Some children achieve self-mobility using a power wheelchair with extensive adaptations.

What causes cerebral palsy?

There are many different causes of CP: some are known and some are unknown. We do know that CP is caused by a problem in the developing brain. Sometimes, this problem is an injury to the brain that occurs before, during or just after birth. The injury is in the part of the brain that controls movement. Even though CP affects the muscles, the problem is in the brain's control of the muscles, not the muscles themselves. A common risk factor for CP is **prematurity**. Infants who are born early (less than 32 weeks) might have a bleed in the brain or not enough oxygen to the areas of the brain that control motor function and can have CP.

When your child comes to the Holland Bloorview, you will meet a developmental pediatrician. This person has special knowledge and training in child development and neurology. The **developmental pediatrician** will make or confirm your child's diagnosis of CP and try to find a cause. Many people believe that CP is caused by a difficult birth, but this is not the case. Only a small fraction of CP is related to problems at birth and in almost all of these cases, even the best prenatal and obstetrical care could not have prevented the difficulties.

Because CP affects movement, it can affect many aspects of a child's life. Many parents who have children with CP are concerned about how to help their child walk or find ways to improve their movements. CP might affect big muscle movements such as walking and running (gross motor skills), as well as movements of the hand and arm, such as eating, dressing and printing (fine motor skills). As a result, children with CP may have difficulties with day-to-day activities. Sometimes, the muscles used for speech and language are also affected. Speech problems range from slowed speech, to difficulty making certain speech sounds, to not being able to speak at all. When a child is not able to speak, he or she may be able to use **augmentative communication** such as the Picture Exchange Communication System (PECS) – or a device or computer to help with communication.

My experience as the parent of a child with cerebral palsy has been so emotionally challenging and rewarding. The hardest part was not knowing what was in store for our child in the future. We still don't know for sure but we continue to be amazed at his growth and maturity as he enters his teenage years.

Parent of child with Cl

There is also a higher rate of developmental and learning problems in children with CP. Sometimes, the injury that occurred to the brain and caused the CP also affects thinking and learning. Some children are diagnosed with intellectual or learning disabilities. Others might have trouble paying attention or interacting and playing with other children. If you have any concerns about these areas of your child's development, please let your team know so that they can explore this with you. It is very important that we support all aspects of a child's development including their talking and understanding, social skills and learning abilities.

Do children with cerbral palsy have more medical problems than other kids?

Most Children with CP are quite healthy. However, there are some medical problems that are more common in kids with CP.

Seizures

Children with CP are more at risk of seizures (epilepsy) than the general population and some children need medications to help control seizures.

Drooling and dental care

Children with CP may have trouble managing their saliva. As in all children, dental care is important in children with CP.

Swallowing and chewing

Some children have trouble chewing and swallowing their food. They may choke on food or it may go into the lungs causing pneumonia. Some may need a special tube to help with feeding called a G-tube.

Nutrition and digestion

Some children may be underweight and need to have extra nutrition to maintain a healthy weight. Other children may be overweight or obese because they find it difficult to exercise. Other common issues in CP include gastro-esophogeal reflux (food that comes back up from the stomach into the swallowing tube) and constipation.

Bone health

Your child with CP may be at increased risk of having osteopenia (low bone mass) and fractures. Many children with CP take extra calcium and vitamin D to help keep their bones healthy.



Hip subluxation

Your doctor may order hip x-rays to look at the position of the hips because very tight muscles may cause the hips to slide (subluxate) out of their joints. Your doctor will monitor all of your child's joints carefully to determine if x-rays need to be done or whether they may need surgery to lengthen the muscles in the future.

Vision and hearing

Some children have difficulties with vision and hearing. For example, many children with CP have strabismus. This means that the muscles that control eye movements are affected. Children have one eye that turns in or out (cross-eyed). It is important that this is treated early to prevent further problems with vision.

Pain

Children with CP are at higher risk of having pain. There are many different causes for pain such as constipation (difficulty with bowel movements), muscle spasms or gastro-esophageal reflux. If your child has pain, please let your team know about this so that we can help.

Sleep problems

Problems with sleep can be particularly challenging for children with CP and their family. Our staff may be able to help if your child has trouble with sleep.



Can cerebral palsy be treated? How do we manage cerebral palsy?

There is no "cure" for CP. Our goal is to understand your child's unique abilities and strengths and support areas that need help. We believe that every child has a lot to offer the world. You will work with a team of people from Holland Bloorview and the community to help make that happen. Below are some of the team members that you may meet on your journey.

One of the first team members you will meet is the **developmental pediatrician.** Developmental pediatricians are pediatricians with special training in child development. They help make the diagnosis of CP and are often involved in connecting your child to other team members and community resources. **Nurses** also play an important role in your child's long term medical and developmental follow up and work together with the developmental pediatricians. Nurses teach families about common issues related to CP and help advocate for your child's needs.

Your child may benefit from therapy. The services your child receives will depend on their skills, abilities and needs. At Holland Bloorview, we offer treatment in therapy blocks and then reassess as needed.

Children may see a **physiotherapist** (**PT**) to help them develop motor skills such as rolling, crawling, sitting, standing and walking. PTs may use a variety of methods including a "hands-on" approach or designing a home exercise program. These programs may include stretches, exercises and participation in physical activities. Take time to talk to your partner or family, even though you may be reacting differently to this news, you are a team and you need each other's support. It will get easier. Love your child, enjoy your child and try to focus on the positive as much as possible. — Parent of child with CP

Physiotherapy will be based on specific goals discussed together with the therapist, child and family. The PT may suggest specialized equipment such as walkers, standers and orthotics.

An **occupational therapist (OT)** may assess your child's fine motor skills, strength and coordination. The OT will determine how your child's abilities are impacting on participation in daily activities such as dressing, feeding, bathing and play. The OT may also look at equipment needs for the home to increase safety, accessibility and independence.

Speech-language pathologists (SLP) help with communication skills and may also support feeding. They teach parents ways to help their children develop language, speech and other communication skills. SLPs help children improve their ability to speak and correctly make sounds. They will sometimes introduce other ways of communicating such as signs, pictures or electronic devices. Alternative and Augmentative Communication (AAC) is used when speaking is very difficult for the child or when speech is hard for others to understand.

Psychology is the science of how people think, feel and behave. Psychologists evaluate cognitive (thinking), learning, attention, academic and other skills depending on a child's needs. A child may be referred for a psychological assessment to help better understand the child's cognitive ability or patterns of learning strengths and needs. The assessment can also include evaluation of social, emotional, behavior or adaptive functioning. Results and recommendations can help families and teachers plan appropriate education programs and learning strategies. **Social workers** can help families with a number of topics such as parenting issues, sibling or peer relationships and problems at school. They also provide information about specialized community supports and resources and funding options for children with disabilities. Social workers offer individual, couple and family counselling as well as education and support groups.

You and your child may also receive care from a **nurse practitioner (NP)**. NPs work with children and families to manage complex chronic health issues. They ensure appropriate referral to many services at Holland Bloorview and in the community, and support families in navigating the health care system.

What is Botulinum toxin A and how does it work?

Many children with CP have stiffness in their muscles called **spasticity**. When spasticity is severe we sometimes use medications to decrease the stiffness. Some children may benefit from injections of Botolinum toxin A (also known as Botox). **Botulinum toxin A** works by blocking the signal causing the stiffness in the muscle and making it relax. Physiotherapy or occupational therapy after Botulinum toxin A injections is often needed to help strengthen weak muscles and to improve motor abilities. The decision to use Botulinum toxin A is made very carefully with input from you, your child and team members.

What's new in research?

At Holland Bloorview, we are always looking for new and better ways to help children with CP. Research is an important way to study whether or not a new treatment or therapy will truly benefit your child. Holland Bloorview has many exciting and important research projects that your child may be

a part of. The decision to participate is always yours and if you decide not to participate, it will not affect your child's care in any way. We work hard to put the things we have learned from research into practice so that all children can benefit.



Even though I knew the diagnosis was coming because my child had scans that showed damage and she was not meeting the milestones of sitting and crawling, I was still surprised. The term itself filled my mind with images and ideas of what I thought CP meant. — Parent of child with CP

Do alternative therapies work?

There are many alternative and complementary therapies that families may use for their children with CP. We understand that all families want to give their children the best chance of improving their health and abilities. There are some alternative therapies that have been shown to be helpful through research. For example, many families are involved with therapeutic horseback riding and hydrotherapy (therapeutic swim time) which have been shown to improve strength and balance in children with CP.

Some alternative and complementary therapies are not well studied and therefore we cannot recommend them to you. Other therapies may be harmful and have important side effects that you should be aware of. We encourage you to ask your team about these treatments so that we can provide you with what we know from studies and research. If I could give one piece of advice, it would be to let other people into your child's life. We didn't have family located close to us but we had a lot of help from caregivers who developed their own unique relationship with our child that enriched his life in ways we couldn't.

Parent of child with CF

What other services do you offer?

Holland Bloorview is a leader in providing recreation activities that are inclusive and that can be enjoyed by people of all abilities. We have many activities here at Holland Bloorview such as swimming, floor hockey, camps and even a **Snoezelen room**!

Some families with children with severe CP occasionally need a break from caring for a child with special needs. To meet these needs, we have an inpatient program that provides respite for families. Respite care is a family support service that provides short term relief from the physical and emotional demands involved in caring for a child with a disability. This allows parents to recharge and continue providing the best care possible for their child. Our social workers will help you determine which services are best for you, and whether your child would qualify for our respite service. They will also help you explore financial resources. Detailed information about financial resources is provided in the next section. Often families who have just learned their child has CP have a lot of questions as well as stressors such as multiple medical appointments. Our social work team is skilled at talking to families about their experience; connecting you with other families and helping you cope with all the new information you have received.

School and preschool issues

Holland Bloorview has several integrated nursery schools in Toronto. The philosophy of these integrated programs is that all children benefit from experiences with children of different abilities. Opportunities are available for children aged 2 to 5 who have neurological or physical disabilities. The City of Toronto sets the fees. Subsidy information can be obtained for those eligible by calling The City of Toronto at 416-392-5437 (Toronto Childcare Services).

Holland Bloorview has a small specialized school called the Bloorview School Authority. It runs the Integrated Education and Therapy (IET) program that is designed for children with physical disabilities who have active therapy needs. The IET program is for children in junior kindergarten (age 4 years) to grade 1 (age 6 years). Children accepted into this limited program typically have some school readiness skills as well as high physical needs or changing therapy needs.

Where do I go from here?

It can often be an overwhelming and stressful time when your child is diagnosed with CP. Many parents feel shock, disbelief, sadness and even anger. These are all normal reactions. Parents find themselves asking "How could this happen to me?" and "Why did this happen?"

This booklet provides you with accurate information about CP and the approach at Holland Bloorview. This booklet will not, however, answer all of your questions and it will likely create more questions about CP and how it affects your child. We have included a list of additional resources if you would like to do more reading. In our experience, even though there is sadness in the beginning, most parents go on to find parenting a child with CP one of the most rewarding and special challenges in their life. We welcome you to Holland Bloorview and hope to be an active partner with you and your child on the path to possibilities!

Financial resources for families of children with disabilities

Here are some of the financial resources available to families of children with disabilities. Many families need help to navigate "the system", so we invite you to talk to one of our social workers for assistance.

Access2Entertainment

Access2Entertainment is for people who have a permanent disability who require a support person or attendant when attending an entertainment, cultural, recreation or sporting event. There is a fee for the card. For more information visit the website.

www.access2card.ca

Assistance for Children with Severe Disabilities (ACSD)

ACSD is a monthly allowance for children with disabilities to assist with expenses related to the disability. It is geared to income. If you qualify, your child may receive a drug and dental card.

416 325-0623 www.children.gov.on.ca

Assistive Devices Program (ADP)

ADP covers approximately 75% of the cost of certain equipment (i.e. wheelchair, feeding pump, ankle foot orthotics). Your child's therapist or dietician will help you apply for ADP.

416 327-8804 / 1-800-268-6021 www.health.gov.on.ca

Diaper Grant (Incontinence Grant Supplies) Program

Available from The Easter Seal Society for children over age 3 who use diapers. A physician must sign the incontinence grant application.

1-888-377-5437 www.easterseals.org

Disability Tax Credit

This is a tax credit that may reduce the amount of tax you have to pay. A T2201, Disability Tax Credit Certificate, signed by a doctor, needs to be sent in with your taxes.

1-800-959-8281 www.ccra-adrc.gc.ca

Easter Seals Society

Easter Seals may help with costs of some equipment such as wheelchairs, orthotics and ramps. They also run summer camps and may provide financial assistance toward local camping programs.

416 421-8377 / 1-800-668-6252 www.easterseals.org

Jennifer Ashleigh Foundation

Jennifer Ashleigh provides financial assistance for children with disabilities, such as cost sharing of equipment and certain drug costs, such as Botulinum Toxin.

905 852-1799 www.jenniferashleighfoundation.ca

Ontario Federation for Cerebral Palsy (OFCP)

The OFCP provides some financial support for equipment. OFCP also offers a variety of programs including educational services and individualized planning.

416 244-9868 www.ofcp.on.ca

President's Choice Children's Charity

Provides funding support for expensive mobility equipment, environmental modifications and other expenses related to a child's disability for families who have a household income of \$70,000 or less per year.

www.presidentschoice.ca/childrenscharity

Respiteservices.com

This service helps families with in and out of home respite needs. Families can register you for the Community Helpers for Active Participation (CHAP) Program. This program helps families find people interested in working with children with disabilities. SSAH funding can be used to pay a CHAP worker.

416 322-6317 www.respiteservices.com

Special Services at Home (SSAH)

SSAH funds workers that you hire for skill development and/or respite. It is not income dependent.

416 325-0623 www.cfcs.gov.on.ca

Trillium Drug Plan (TDP)

TDP is available to families who spend a large portion of their income on prescription drugs.

416 326-1558 / 1-800-575-5386 www.moh.gov.on.ca

Glossary

Alternative therapy

Therapy that is outside of the scope of traditional medical and health professional practice.

Ambulatory care nurse

The nurse who you will meet when you first come to the centre. They are professionals with a variety of skills and will be your primary contact. The nurses take a family centered approach to support you within the centre and the community.

Ankle-Foot-Orthotic (AFO)

A plastic brace that is molded to the shape of your child's foot. It helps stretch tight leg muscles and helps keep the foot in a good position.

Ataxia

A movement disorder causing difficulties with balance and co-ordination.

Audiologist

A professional who checks hearing.

Botox

Brand name for Botulinum toxin A. It is a toxin that comes from bacteria. We use it to relax tight muscles in CP and to improve motor abilities.

Choreoathetosis

A movement disorder causing quick movements of the body that are not under the control of the child.

Commando crawl

Refers to moving on one's stomach by pulling along with the arms, without much movement in the legs, like an army commando crawling under a wire.

Complementary therapy

Complementary therapy is used together with traditional medical therapy. It may include things like therapeutic horseback riding or sensory integration therapy.

Constipation

This means that children are not having regular, soft bowel movements (stools). Most children should have one soft stool each day that is easily passed.

Developmental pediatrician

A developmental pediatrician is a pediatrician who has completed specialized training in child development. They will collect detailed information and do a physical examination to make a diagnosis. Sometimes they will complete additional tests to assess specific aspects of development.

Dystonia

A movement disorder that causes slow, twisting movements and postures of parts of the body such as the arms or legs.

Epilepsy

A condition where an individual has seizures regularly.

Dyskinetic cerebral palsy

A type of CP in which children have a movement disorder with slow, twisting posture (dystonia), quick movements that are not under the control of the child (choreoathetosis), or a mixture of both.

Fine motor skills

Refers to movements of the hand and arm, such as eating, dressing and printing.

Gastro-esophageal Reflux Disease (GERD)

This refers to liquid or food in the stomach moving back up to into the esophagus (swallowing tube). Many young children experience this, but when a child has CP and their muscles don't function normally, reflux can be severe. Symptoms can include pain, irritability and vomiting.

GMFCS

Gross Motor Function Classification System is used to describe the motor abilities of a child with CP.

Gross motor skills

Refers to large movements such as rolling, sitting, crawling, standing and walking.

Gastrostomy tube (G-tube)

A g-tube is a gastrostomy tube. This tube is inserted by a surgeon or radiologist by placing a tube from outside the skin of the tummy into the stomach. It is used for children who have difficulty swallowing or cannot take in enough food by mouth.

Motor cortex

The motor cortex refers to the area in the brain that is responsible for movement.

Magnetic Resonance Imaging (MRI)

MRI stands for Magnetic Resonance Imaging. An MRI machine is a large magnetic tube. The patient goes inside that tube and the magnetic forces in their brain are measured and turned into a picture.

Nurse practitioner

A nurse practitioner is a registered nurse with additional education and training. NPs can make diagnoses, order tests and prescribe medications. They work closely with other members of your child's care team to ensure seamless, coordinated care.

Occupational therapist

An occupational therapist is a professional trained in helping clients achieve maximal functional independence, and often focuses on hand function as well as the equipment needs of your child.

PECS

This is a short form for Picture Exchange Communication System. It refers to a series of cards that can be used in place of spoken language to request items and activities.

Physiotherapist

A professional trained in helping clients achieve maximal mobility.

Pneumonia

A lung infection that can require hospitalization.

Prematurity

Refers to infants who are born before 37 weeks gestational age.

Psychologist

A professional trained in assessing children's thinking or cognitive skills.

Seizure

A seizure is caused by uncontrolled electrical activity in the brain. This can result in blacking out and shaking of the arms and legs. Sometimes seizures are less obvious and result in the loss of control of only certain muscles, staring spells or changes in heart rate.

Snoezelen Room

The Snoezelen room is a room that provides stimulation through lights, sounds, smells, music and textures.

Social Worker

A professional with a broad range of skills who can help you and your family cope with the challenges of having a child with a disability and provide links to financial and community programs.

Spasticity

Spasticity refers to tightness in the muscles. This can make movement difficult.

Speech language pathologist

A professional who is trained to help with talking and language skills. This may be verbal or nonverbal (pictures, computers, signs).

Subluxation

Subluxation of the hip refers to a sliding or slipping of the hipbone out of its joint. When children have very tight muscles and are not weight bearing, this can change the forces at work on the hip and cause the hip to gradually move out of the socket.



About Holland Bloorview Kids Rehabilitation Hospital

Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) is Canada's largest children's rehabilitation hospital focused on improving the lives of kids with disabilities. We are a global leader in applied research, teaching and learning, and client and family centred care. Our vision is to create a world of possibility for kids with disability.

We are dedicated to knowledge generation and sharing innovative treatments, therapies, and technologies that give children with disabilities the tools to participate fully in life. Located onsite, the Bloorview Research Institute conducts transformational research in pediatric rehabilitation.

Holland Bloorview is an internationally recognized teaching hospital fully affiliated with the University of Toronto. Our Teaching and Learning Institute embraces best practice models to train and develop the next generation of experts in childhood disability.

We are a provincial resource transforming care for children with cerebral palsy, acquired brain injury including concussion, muscular dystrophy, amputation, epilepsy, spina bifida, arthritis, cleft-lip and palate, autism and other physical and developmental disabilities.

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A teaching hospital fully affiliated with the University of Toronto

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