

# A GUIDE TO CEREBRAL PALSY



*“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”*



Thank you for coming to Sunny Hill and trusting your child under our care. You may feel overwhelmed with feelings of uncertainty, sadness or perhaps relief or comfort there are now answers to what is happening. These reactions are all very normal. Recognizing how you feel is an important step in coping and we encourage you to check in often with a trusted family member, friend, and doctor as you and your child continue the journey of living with cerebral palsy (commonly shortened as CP).

You are not alone. We hope this booklet offers a start to answering questions about CP and discovering the many possibilities for your child to achieve their best potential. Developing a strong support system can be helpful for both you and your child. Don’t try to do it all yourself. Who to involve in this support system is up to you, but the following can help the process:

- Involve your family early on (including grandparents)
- Seek out other parents of children with CP for guidance and support
- Build up a support network of family, friends, and neighbours.

With an early diagnosis, your child will be able to access therapy, receive the appropriate medical care to prevent health complications, and have the best chance to thrive in life. As a parent or caregiver, we also want to ensure you feel equipped with knowledge and resources to care for your child.

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# ABOUT CEREBRAL PALSY

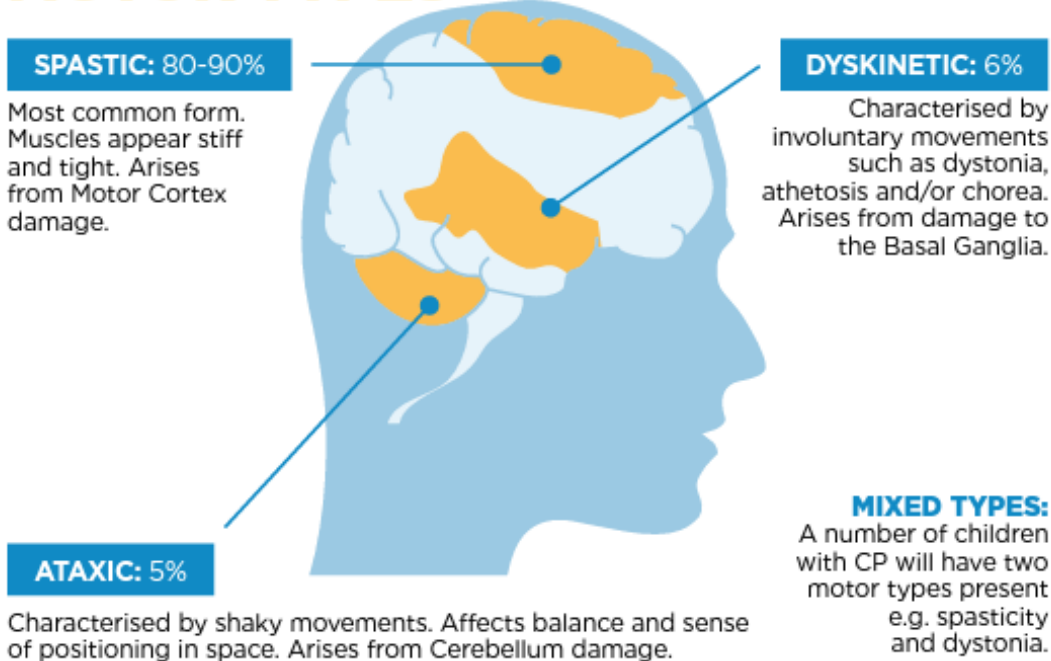
**Cerebral palsy** (CP) is a term used to describe a group of disorders which affect movement and posture. Different parts of the brain control the movement of every muscle of the body. In cerebral palsy, there is damage to, or lack of development in part of the brain (which occurs within the first two years of life). The impact can range from mild to severe, affecting everyday tasks and movements.

**Symptoms** of CP can be very different in every child. Children with cerebral palsy may have problems with gross and fine motor skills, muscle weakness or muscle tone (stiffness) and balance. It may affect other areas of development like learning and speech.

**Will it get worse?** It's important to know that CP does not get worse over time. The underlying brain disturbances do not progress although the exact symptoms can change over a person's lifetime.

There are several different **types of cerebral palsy**. One way of classifying cerebral palsy is according to the type of movement disorder.

## MOTOR TYPES

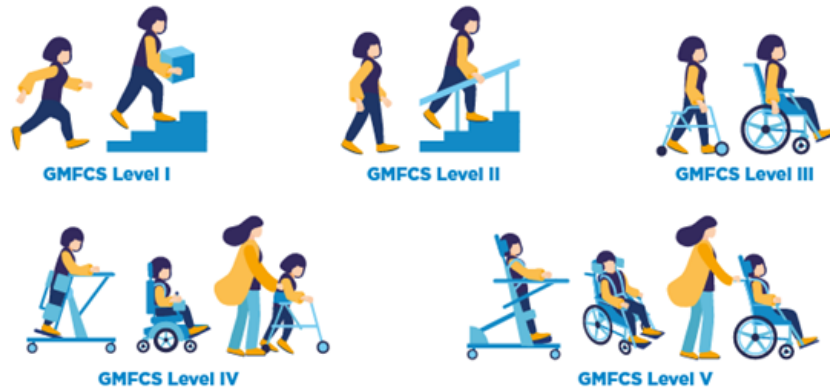


## HOW WE DESCRIBE FUNCTION

The **Gross Motor Function Classification System (GMFCS)** is used to describe the range of abilities in gross motor function seen in children with cerebral palsy. It can be accurately assessed from the time a child is two years of age. Knowing this can help your doctors and therapists to predict the likelihood of experiencing certain problems with bones, muscles, and joints as they grow .

### GROSS MOTOR SKILLS

The gross motor skills (e.g. sitting and walking) of children and young people with cerebral palsy can be categorised into 5 different levels using a tool called the Gross Motor Function Classification System (GMFCS) developed by CanChild in Canada.



Authors: CP 360 Cerebral Palsy's Global Network, Cerebral Palsy Alliance, CanChild Centre for Childhood Disability Research

## WHAT TO EXPECT?

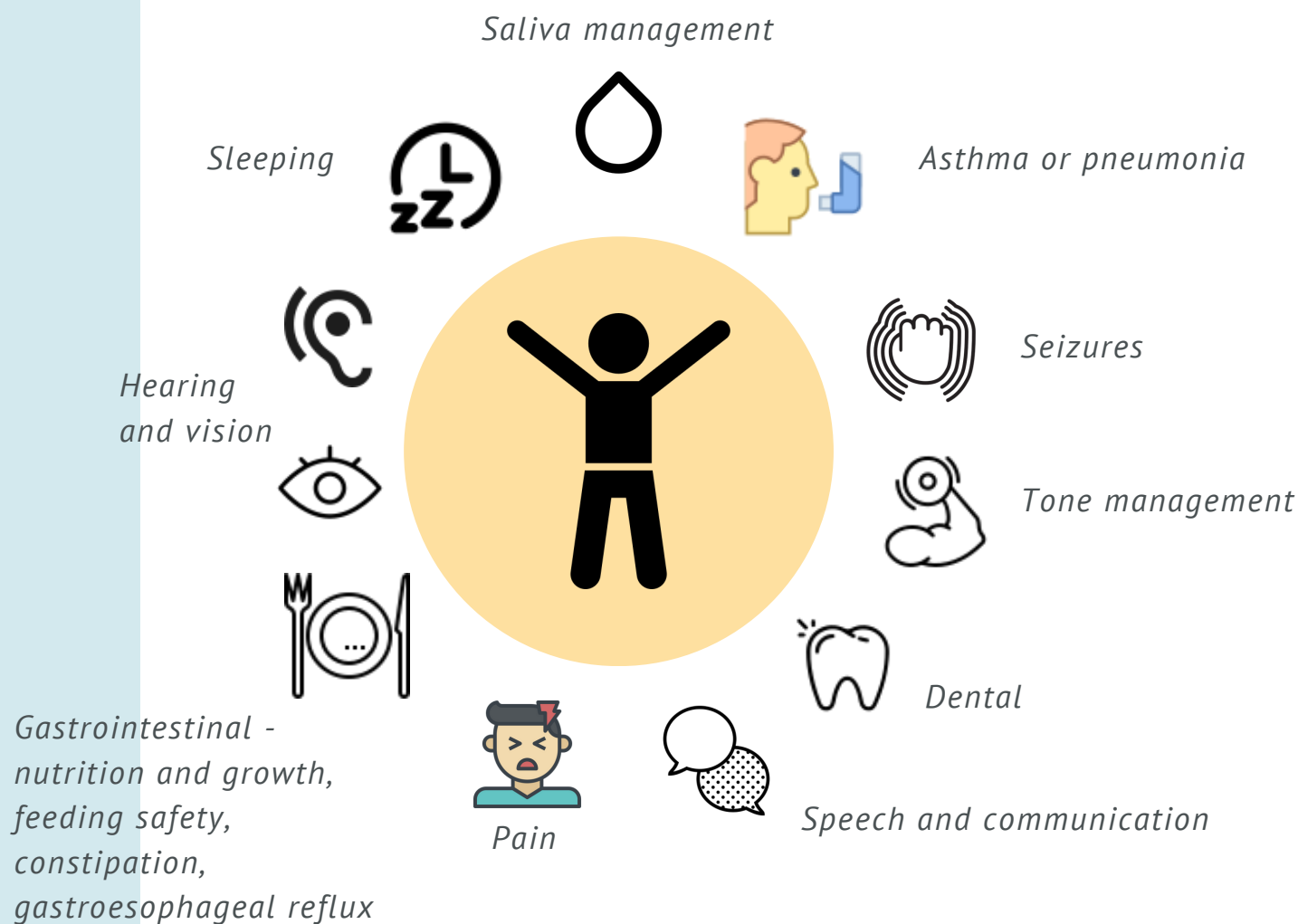
At this time, there is no cure for CP as we know. However, a tailored management plan will be created in order to maximize your child's potential growth and development. Services and therapies will change over the years, depending on your child's age, type of CP, and changes to their medical needs and preferences

We will be making the appropriate referrals to your local Child Development Centre or Infant Development Program. Depending on where you live, each region varies in what services are available, the types of therapy staff and wait times.



# COMMON HEALTH ISSUES

Every child with cerebral palsy should have a pediatrician who will regularly see them and address any medical issues they are experiencing. **The pediatrician often is your first point of contact** (If your child does not currently have a pediatrician, please let us know and we can refer you to one in your local community or closest to you).



## HEALTH CHECKLIST

There will be important routine check ups at different points of your child's life to ensure their healthy development. We suggest working with your pediatrician to plan ahead and create a schedule for these:

- Clinical exams**  
*When will this take place?*  
How often your child requires clinical exams and x-rays depends on their ability to move according to GMFCS level.  
*By who?* [The Hip Surveillance Program Team](#)
  
- Spine and hip x-rays**  
*When will this take place?*  
How often your child requires clinical exams and x-rays depends on their ability to move according to GMFCS level.  
*By who?* The BC Children's Orthopedics Team will follow up according to findings
  
- Vitamin D**  
For children who are not walking, we recommend a daily intake of Vitamin D. Ask your pediatrician or dietitian about specific dosages.
  
- Dental**  
At least once a year, your child should visit a pediatric dental clinic
  
- Weight & growth**  
A pediatrician or dietitian should follow up twice a year to discuss any concerns about nutrition, feeding safety, and growth.

## FINDING YOUR WAY



Many families need help to navigate “the system” of the many different disability and special needs programs. The process of applying for these supports is often complex and not easy. We can connect you to a clinical social worker at Sunny Hill or refer you to community organizations who have dedicated navigators to help.



PEER-LED  
SUPPORT

Below is a list of major services, benefits, peer resources, and funding options. This is not a complete list by any means but a start of what is available to find the support that is right for your child. Our hope is that through time, you find the supports and services needed to unlock your child's potential.



A great place to start is connecting with the [Cerebral Palsy Association of BC](#). It offers a variety of services and resources specific for children and adults living with CP including adapted recreational activities, financial assistance, and family and individual support.

The support hotline is **604-408-9484** or toll-free **1-800-663-0004**.

They also host a peer-to-peer support group called “CP Connections” every week. This group aims to connect people with CP across the province. <https://www.bccerebralpalsy.com/programs/cp-connections/>

Parent Support Groups also run monthly by Zoom and parents, caregivers are invited to join for an informal, frank conversations.

**CPABC's Parent Support Group**


You are invited to meet with parents of children of all ages who live with cp for informal, frank conversation sharing our joys and challenges.

**Meetings are held once a month via Zoom and topics are chosen by participants.**

There is also a **Parent Support Group Facebook group** that supports our families and enables them to connect as well as continue on with the conversation(s) that were developed within the zoom meeting. Please find below a link to register for **Parent Support Group**: [Programs@bccerebralpalsy.com](mailto:Programs@bccerebralpalsy.com)

Please find below a link to our Parent Support Group Facebook group: [Facebook Group](#)

**We hope to meet you soon!**

  
Cerebral Palsy Association  
of British Columbia

*“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 CP*

PEER-LED  
SUPPORT

The [Family Support Institute of BC](#) offers confidential support and ongoing guidance by its staff and volunteers **who are all parents or family members** of someone living with special needs. It is a great place to get support and connect with other parents:

- [Find Support BC](#) is a database to search for services and supports <https://findsupportbc.com/>
- [MyBooklet BC](#) is a customizable profile you can make about your child and keep everything important about them in one place. It makes it very easy to share with others and help them learn about your child. <https://mybookletbc.com/>

FINANCIAL  
SUPPORT**Medical Benefits**

Do you or a family member have extended health benefits through an employer? If so, we encourage you to reach out to the provider and find out what is eligible under your specific plan. You may also wish to explore private therapy services that charge a fee. Typically, this means paying out of pocket or through your employer's extended health benefits coverage.

Additional funding is available through the [At Home Program](#), designed to help parents with some of the costs of caring for a child with severe functional limitations. The funding is for respite (a short-term break or period of rest for primary caregivers) and basic, medically necessary equipment and supplies. Either your pediatrician or someone from our team can help you complete the application.

If you currently receive income assistance from the Ministry of Social Development and Poverty Reduction (MSDPR), you may be eligible for additional supplement to help with some of your child's medical costs.

**Disability Tax Credit**

The disability tax credit (DTC) is a non-refundable tax credit that helps persons with disabilities or their supporting persons reduce the amount of income tax they may have to pay. Being eligible for the DTC can open the door to other federal, provincial, or territorial programs such as the registered disability savings plan, the Canada workers benefit, and the child disability benefit.



FINANCIAL  
SUPPORT

A portion of the DTC application must be filled out by a physician. Either your pediatrician, family doctor, or someone from our team can help with this.

A plain language overview about the DTC is available through [Disability Alliance BC](#).

**Other Tax Claims and Refunds**

A number of other medical or disability related costs can be claimed on yearly income taxes. The complete guide to disability-related tax information can be found on the [Government of Canada's website](#)

The BC [Fuel Tax Refund for Persons with Disabilities](#) may also help reduce your transportation costs.

**Charity Funding**

These are privately-run foundations that offer various financial assistance of supporting children living with disabilities

[The Jason and Rand Equipment Subsidy](#)

[The JGL Foundation](#)

[Variety Club – The Children's Charity](#)

[BC Rehabilitation Foundation Fund](#)

[CKNW Kid's Fund](#)

[Shriners of BC](#)

[BC Cerebral Palsy Association](#)

MORE  
RESOURCES

BC Children's Hospital Family Support and Resource Centre

<https://bcch.andornot.com/en> (type in search 'cerebral palsy')

<http://www.bcchildrens.ca/health-info/coping-support/cerebral-palsy>

Holland Bloorview Hospital in Toronto also has a comprehensive guide to CP written together with families.

<https://hollandbloorview.ca/services/programs-services/cp-booklet>

CanChild is a research centre dedicated to generating knowledge & transforming lives of children and youth with developmental conditions and their families.

<https://www.canchild.ca/en/diagnoses/cerebral-palsy>

US-based Cerebral Palsy Foundation has a fantastic video series called "Insights from Experts"

<https://www.yourcpf.org/expert-videos-cp/>

## REFERENCES

Anne Kawamura, Amber Makino, Scott McLeod. Comprehensive care of the ambulatory child with cerebral palsy (GMFCS I and II): A Canadian perspective; Canadian Paediatric Society, Developmental Paediatrics Section. Paediatr Child Health 2020 25(6):397. (Abstract).

CanChild Centre for Childhood Disability Research. "What is cerebral palsy?" <https://worldcpday.org/wp-content/uploads/2021/08/CPA-Poster-2.pdf>

CanChild/McMaster University, University of Western Ontario  
Allison Reid BSc, MPT, Emily Brouwer BAKin, MPT, Shannon Clutton BKin, MPT, Heather Imrie BKin, MPT, Jan Evans PT, MSc Thames Valley Children's Centre, London Ontario, Dianne Russell PhD, Investigator, CanChild Centre for Childhood Disability Research, McMaster University, Hamilton Ontario, and Doreen Bartlett PT, PhD, Associate Professor, School of Physical Therapy, University of Western Ontario, London Ontario. (2009, December) "If I knew then what I knew now." <http://cpnet.canchild.ca/en/resources/98-if-i-knew-then-what-i-know-now-parents-reflections-on-raising-a-child-with-cerebral-palsy>

Centers for Disease Control and Prevention. (2020, December 31). Dalila's story: "how my cerebral palsy gives me strength". Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/cp/features/dalila.html>.

Holland Bloorview Kids Rehabilitation Hospital. "On the path to possibility". <https://hollandbloorview.ca/services/programs-services/cp-booklet>

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BC Children's Hospital  
4500 Oak Street  
Vancouver BC V6H 3N1

Email: [CPEDC@cw.bc.ca](mailto:CPEDC@cw.bc.ca)  
Phone: 604-875-2345  
Toll-free 1-888-300-3088  
[bcchildrens.ca](http://bcchildrens.ca)

Authors:  
Carolyn Chowne, Mor Cohen-Eilig,  
Carol Lai, Ram Mishaal, and Vivian  
Wong