# Cerebral Palsy Diagnosis

TOOLKIT FOR COMMUNITY HEALTH-CARE PROVIDERS









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We'd like to thank the generous support from the BC Children's Hospital Foundation for this work

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Publication date: September 2024, Updated: December 2024

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This resource was created in collaboration with Creative Learning at Continuing Professional Development, Faculty of Medicine, University of British Columbia.

Download this resource from <u>ubccpd.ca</u>







The classic board game of Snakes and Ladders is used here to illustrate the stress, frustration, and fear that BC families experience waiting for a cerebral palsy (CP) diagnosis. The timeline here represents the common ups and downs during the long assessment process.

We dedicate this work to children with cerebral palsy, their parents and caregivers in BC. We hope this resource will provide physicians the tools to make an early diagnosis of CP, allowing for timely intervention and supports.

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# What is Cerebral Palsy (CP)?<sup>1</sup>

- A group of permanent disorders of the development of movement and posture
- Causes activity limitation
- Is attributed to non-progressive disturbances that occurred in the developing fetal or infant brain

Often accompanied by: disturbances of sensation, perception, cognition, communication, and behaviors, as well as epilepsy and secondary musculoskeletal problems.1

#### ■ Note:

It is the most common childhood physical disability in Canada

# Types of Cerebral Palsy

There are two ways to classify and describe CP:

#### 1. BY ASSOCIATED MOVEMENT DISORDER<sup>2-4</sup>

**Spastic** Affects 70–85% of children. Velocity dependent increased tone.

Dyskinetic

Affects 10-15% of children.

Dystonic: Sustained or intermittent muscle contractions, causing twisting and/or repetitive movements or abnormal posture.

Athetosis: Slow, continuous writhing movements. Most often in the arms, hands, feet, and around the mouth.

Chorea: brief, random, flitting movements, often involving multiple body parts.

Ataxic

The least common (<5%).

Movements are uncoordinated and children have trouble with balance.

Mixed

15%. Usually spastic and dystonic

#### 2. BY TOPOGRAPHY<sup>5</sup>



## 39% are affected by Unilateral/Hemiplegia

The leg and arm on one side of the body are affected.

GMFCS IV - V MFCS I - III

99%

## 38% are affected by Diplegia

Both legs are predominantly affected.

MFCS I - III

GMFCS IV - V

98%

2%



# 23% are affected by Quadriplegia

Both legs and both arms are affected. Usually in addition to the trunk.

ķ	GMFCS I - III	GMFCS IV - V
Spastic	24%	76%
Dyskinetic	25%	75%
Ataxic	23%	77%

Fig. 1. Proportion of cerebral palsy by topography and severity<sup>6</sup>

Types of Cerebral Palsy Updated: December 2024

# Describing Functional Ability: Functional Classification Systems Commonly Used for Children with CP

## 1. THE GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM (GMFCS)7

**GMFCS** Level I

Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.

#### **GMFCS** Level II



Youth walk in most setting but environmental factors and personal choice influence mobility choices. At school of work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.

#### **GMFCS** Level III



Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.

#### **GMFCS** Level IV



Youth used wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distanced with physicals assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.

#### **GMFCS** Level V



Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self mobility is severely limited, even with the use of assistive technology.

Fig. 2. Illustrations of GMFCS E & R between 6th and 12th birthday © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham GMFCS - Expanded & Revised © Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007 CanChild Centre for Childhood Disability Research, McMaster University

#### 2. THE MANUAL ABILITY CLASSIFICATION SYSTEM (MACS)8

MACS Level I	MACS Level II	MACS Level III	MACS Level IV	MACS Level V
Handles objects easily and successfully.	Handles most objects but with somewhat reduced quality and/or speed of achievement.	Handles objects with difficulty; needs help to prepare and/or modify activities.	Handles a limited selection of easily managed objects in adapted situations.	Does not handle objects and has severely limited ability to perform even simple actions.

More Information: MACS - Manual Ability Classification System

## 3. THE COMMUNICATION FUNCTION CLASSIFICATION SYSTEM (CFCS)9

CFCS Level I	CFCS Level II	CFCS Level III	CFCS Level IV	CFCS Level V
Effective Sender and Receiver with unfamiliar and familiar partners.	Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners.	Effective Sender and Receiver with familiar partners.	Inconsistent Sender and/or Receiver with familiar partners.	Seldom Effective Sender and Receiver even with familiar partners.

More Information: CFCS - Communication Function Classification System

## 4. EATING AND DRINKING ABILITY CLASSIFICATION SYSTEM (EDACS)<sup>10</sup>

EDACS Level I	EDACS Level II	EDACS Level III	EDACS Level IV	EDACS Level V
Eats and drinks safely and efficiently.	Eats and drinks safely but with some limitations to efficiency.	Eats and drinks with some limitations to safety; there may be limitations to efficiency.	Eats and drinks with significant limitations to safety.	Unable to eat or drink safely - tube feeding may be considered to provide nutrition.

More Information: EDACS - The Eating and Drinking Ability Classification System for Individuals with Cerebral Palsy

# Co-occurring Conditions<sup>6</sup>



#### **PAIN**

#### ♣ 3 in 4

✓ Treat to prevent sleep and behavioural disorders



#### INTELLECTUAL DISABILITY

♣ 1 in 2

■ Poorer prognosis for ambulation, continence, academics



#### **NON-AMBULANT**

🚣 1 in 3

■ Independent sitting at 2 years predicts ambulation



#### HIP DISPLACEMENT

♣ 1 in 3

 6-12 monthly surveillance using x-ray



#### **NON-VERBAL**

♣ 1 in 4

✓ Augment speech early



#### **EPILEPSY**

♣ 1 in 4

■ Seizures will resolve for 10–20%



#### **BEHAVIOUR DISORDER**

🚣 1 in 4

✓ Treat early and ensure pain is managed



#### **BLADDER INCONTINENCE**

👗 1 in 4

 Conduct investigations and allow more time



#### **SLEEP DISORDER**

♣ 1 in 5

✓ Conduct investigations and ensure pain is managed



#### **BLINDNESS**

👗 1 in 10

√ Assess early and accommodate



#### **NON-ORAL FEEDING**

**å** 1 in 15

 Assess swallow safety and monitor growth



#### **DEAFNESS**

👗 1 in 25

√ Assess early and accommodate

Fig. 2. The comorbidities of cerebral palsy and evidence-based management<sup>6</sup>

Co-occurring Conditions Updated: December 2024

# Importance of Early Diagnosis

Diagnoses have historically been made >2 years, after the optimal window for early interventions.<sup>11</sup> Evidence demonstrates that accurate diagnosis is possible earlier, even before 6 months of age in some cases.<sup>11-12</sup>

Timely diagnosis has been linked to 12,13:

- Access to early intervention and social supports
- Better long-term health and functional outcomes
- Increased family resilience
- Increased satisfaction with the healthcare system
- Better overall quality of life for the child and their family members



It was just exhausting constantly trying to fight with doctors and specialists just to get an answer. A diagnosis gave us a bit of peace to know that this is what we are dealing with now. And it wasn't just in our heads. When starting public school, he needed some sort of diagnosis to get him support. I needed to make sure that he had every bit of success he could right off the bat."

— Tabatha, mom to 8-year-old Beaudyn

Importance of Early Diagnosis

Updated: December 2024

# **Risk Factors for CP**

Risk factors for CP can be divided into two distinct groups: medical risk factors and clinical/developmental risk factors:

#### 1. MEDICAL RISK FACTORS

60-70% of children with CP will have one or more medical risk factor.<sup>14</sup>

#### **List of Medical Risk Factors**

- Prematurity <32 weeks</li>
- Low birth weight <1500 g</li>
- Cystic Periventricular Leukomalacia (PVL)
- Intraventricular Hemorrhage (IVH) Grade III–IV
- Moderate to severe neonatal encephalopathy (including, but not restricted to hypoxic-ischemic or infectious encephalopathy)
- Apgar score <7 at age 5 minutes</li>
- Congenital CNS defects
- Severe traumatic brain injury requiring hospitalization or rehab, or any history of hospitalization due to encephalitis or bacterial meningitis, before the age of two years
- Genetic abnormality associated with CP
- Placental abruption
- Neonatal meningitis
- Post-natal meningitis

These children often receive care in the neonatal intensive care unit (NICU). However, many of them may not be followed by a neonatal follow-up program (NFU).

If not referred to the NFU, the presence of ANY ONE of these risk factors should prompt a referral by the NICU or nursery teams (or any other provider) to the Early Motor Screening Program (EMSP) before 4 months of age, where a General Movement Assessment will be done:

BC Early Motor Screening Program Referral Form

Risk Factors for CP Updated: December 2024

#### 2. CLINICAL/DEVELOPMENTAL RISK FACTORS – RED FLAGS

These children are detected by means of clinical findings related to abnormal or delays in development of motor milestones that appear after 4 months, known as clinical or developmental risk factors - red flags for CP.

These features have been agreed upon by international CP experts, 15 with additional features recommended by the BC CP Advisory Committee.<sup>14</sup>

30-40% have no known medical risk factors.

#### Clinical/Developmental Red Flags Infant (<1Y) Child (>1Y) • Child demonstrates a hand preference Child demonstrates consistent toebefore 12mo of age walking or asymmetric-walking beyond 12mo of age • Child is not able to sit without support • Unable to walk by 18 mo of age beyond 9mo of age • Child demonstrates stiffness or tightness • Child demonstrates stiffness or tightness in in the legs between 6 and 12 months the leas • Child keeps their hands fisted (closed/ clenched) after the age of 4mo • Child demonstrates consistent asymmetry of posture and movement after the age of 4mo • Child keeps their hands fisted (closed/ clenched) after the age of 4mo • Child demonstrates a persistent primitive reflexes, including startle (Moro) reflex beyond 6mo of age, or "Fencer" (ATNR) beyond 4mo of age



## Practice Tip

Parents will often be first to detect these warning signs and bring their concerns to their primary care provider. Physicians need to be proactive and assess for CP when ONE or more of these findings are present.

#### ■ Note:

These populations are sometimes referred to as having "newborn-detectable risks" (described here as having medical risk factors), and "infant detectable risks" (described here as having clinical/developmental risk factors - red flags) in the literature.12

Risk Factors for CP Updated: December 2024

# How is Cerebral Palsy Diagnosed?

The diagnosis of CP is a clinical one. Three criteria are required and sufficient to make this diagnosis. 15

#### **CRITERION 1**

History or previous investigations consistent with early non-progressive brain disturbance

#### Conduct a full history including:

- ✓ 1. Pregnancy and birth history
  - ✓ Asking specifically about risk factors (see <u>Risk Factors for CP</u> above) and complications such as prematurity, atypical intrauterine growth, NICU stay, seizures, or previous investigations and imaging.
- 2. Family history of CP or other neurological/developmental/genetic disorders
  - ✓ Ask about consanguinity of parents.

- 3. Motor history: developmental milestones, particularly gross motor skills and fine motor skills
  - ✓ Can use a standardized template such as the Rourke Baby Record.
  - ✓ Pay particular attention to red flags listed above (Risk Factors for CP).
  - ✓ Note any asymmetries e.g., early hand dominance.
  - ✓ If regression is present, suspect a progressive brain disorder.

## of Key elements of a motor history:

- Delayed or absent acquisition of skill: not meeting milestones.
- Involuntary movements or body stiffness.
- History of developmental regression suspect progressive brain disorder and NOT CP.

How is Cerebral Palsy Diagnosed?

Updated: December 2024

#### **CRITERION 2**

## Signs consistent with non-progressive brain disturbance

#### Conduct a full neurological exam:

#### ☑ 1. General observation, strength, tone, reflexes, gait

- ✓ Look for upper motor neuron signs.
- ✓ Assess motor skills and milestones.

#### of Key elements of general observation

- Decreased spontaneous movements.
- Movements may be cramped and synchronous, jerky, or tremulous.
- May display abnormal posturing (e.g., head or trunk bent markedly to one side, arms fixed in internal rotation, persistent fisting, no long leg sitting, tendency for limbs or back extension, scissoring of the legs).
- Muscle bulk may be decreased (note any asymmetries).

#### 2. Tone: Muscle resistance to passive stretch

- ✓ Excludes resistance due to joint, ligamentous, or skeletal properties.
- ✓ Different from strength (tone is assessed with passive movement versus strength is with active movement).
- ✓ Is tone increased with faster movement (i.e., spasticity)?
- Children with CP may present with hypotonia, often with hypotonia of the trunk and neck (and hypertonia of the limbs), or, more rarely, general hypotonia.
- ✓ If general hypotonia and weakness are present, consider neuromuscular disorders such as SMA and DMD.

#### Examples of Increased tone you may detect on exam:

**Spasticity:** velocity-dependent increased tone. May vary dependent on state of alertness, activity, or posture.

✓ Look for: spastic catch on exam.

**Dystonia:** involuntary sustained or intermittent muscle contractions causing twisting and/or repetitive movements and/or abnormal postures. May fluctuate in presence and severity; commonly triggered by discomfort, attempted voluntary movement, tactile stimulation of another body part, or emotional reaction; resolves during sleep.

**Rigidity:** constant stiffness/increased tone throughout movement, velocity independent; rarely seen in children; if present, consider other diagnosis.

#### ✓ 3. Deep tendon Reflexes

- ✓ Brisk, or may observe clonus (beats or sustained).
- ✓ If absent- consider neuromuscular disorders such as SMA.

#### 4. Persistent Primitive Reflexes

√ Moro, asymmetric tonic neck reflex (fencer).

#### ▼ 5. Abnormal or Asymmetric Gait

- May observe internal rotation at the ankles, hyperextension of the knees, scissoring.
- ✓ Look for: tendency to stand on tiptoes.

How is Cerebral Palsy Diagnosed?

#### **CRITERION 3**

## Observation or report of activity limitation due to motor impairment

- ✓ 1. May be observed and/or reported on history
- 2. Consider the child's corrected age
  - ✓ Consider the information you have gathered, do you believe the child is limited in the activities they should be able to perform at their developmental stage, or performing at a lower level than their peers?

Our best practice recommendations for early diagnosis of CP are summarized in a comprehensive diagnostic pathway made for BC community pediatricians.



## Practice Tip

The initial appointment, including the full history and neurological exam, can take some time. Consider using the 00511 billing code for a complex consultation, which includes time to review assessment results. Pediatricians can also use the Medical Services Commission billing code for additional follow-up appointments, to consult the Physician-to-Physician service, or discuss the diagnosis with the family.

How is Cerebral Palsy Diagnosed? Updated: December 2024

# BC Cerebral Palsy Community Diagnostic Care Pathway

#### **CRITERIA FOR CP**

All of the following must be true

- Sign(s) consistent with a nonprogressive brain disturbance (such as, but not exclusive to, upper motor neuron signs etc.)
- History or previous investigations consistent with early nonprogressive brain disturbance
- Observation or report of activity limitation due to motor impairment (including delay in or not achieving milestones)

Legend: A Pathways direct link

Request a Pathways BC account to access full functionality and other resources mentioned

If medical risk factor(s) is present, and no early motor screening has been done before, consider using this pathway.

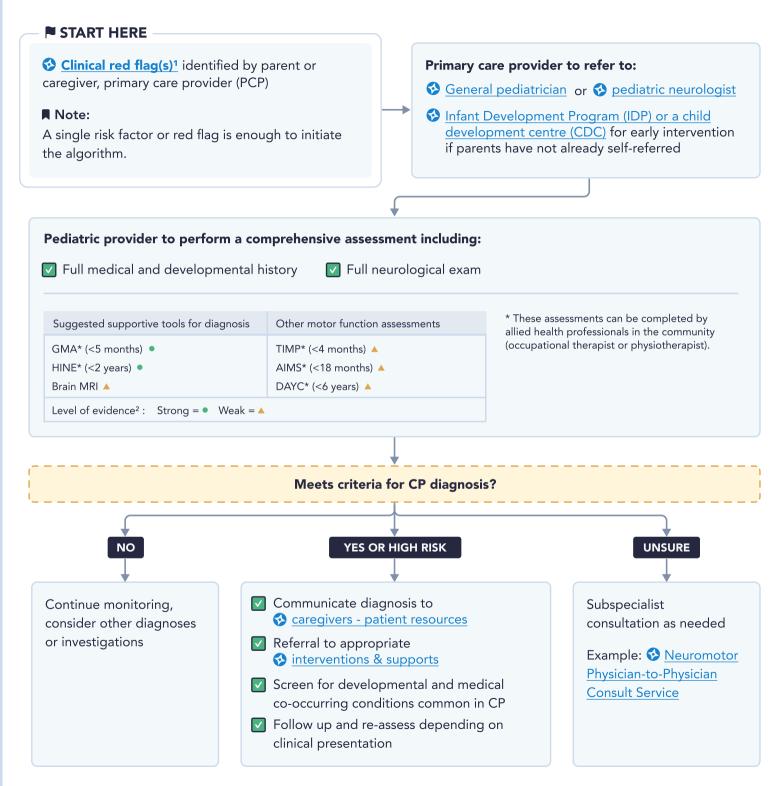




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#### **Cerebral Palsy**

Cerebral palsy is a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.<sup>3</sup>

**GMA:** General Movement Assessment

HINE: Hammersmith Infant Neurological Exam

**TIMP:** Test of Infant Motor Performance

AIMS: Alberta Infant Motor Scale

**DAYC:** Developmental Assessment of Young Children

#### Medical Risk Factors<sup>1</sup>

- Prematurity <32 weeks
- Low birth weight <1500 g</li>
- Cystic Periventricular Leukomalacia (PVL)
- Intraventricular Hemorrhage (IVH) Grade III-IV
- Moderate to severe neonatal encephalopathy (including, but not restricted to hypoxic-ischemic or infectious encephalopathy)
- Neonatal meningitis
- Congenital CNS defects
- Severe traumatic brain injury requiring hospitalization or rehab, or any history of hospitalization due to encephalitis or bacterial meningitis, before the age of two years
- Post-natal meningitis
- Genetic abnormality associated with CP
- Placental abruption
- Apgar score <7 at age 5 minutes</li>
- History of stroke in child

## Clinical/Developmental Red Flags<sup>1</sup>

- Child demonstrates a hand preference before 12mo of age
- Child is not able to sit without support beyond 9mo of age
- Child demonstrates stiffness or tightness in the legs
- Child keeps their hands fisted (closed/clenched) after the age of 4mo
- Child demonstrates a persistent head lag beyond 4mo of age
- Child demonstrates consistent asymmetry of posture and movement after the age of 4mo
- Child demonstrates persistent primitive reflexes, including startle (Moro) reflex beyond 6mo of age, or "Fencer" (ATNR) beyond 4mo of age
- Child demonstrates consistent toe-walking or asymmetric-walking beyond 12mo of age
- Unable to walk by 18mo of age

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For more clinician resources on early diagnosis of CP, visit https://ubccpd.ca/cp-resources

#### OTHER SUPPORTIVE ASSESSMENTS:

- Standardized clinical assessments such as the Hammersmith Infant Neurological Exam (HINE), and General Movements Assessment (GMA) are recommended in the diagnosis of CP.12
- However, they have not been studied in children with no medical risk factors, and therefore recommendations for their use in this population with clinical/ developmental risk factors is conditional.<sup>12</sup>
- For further information on HINE training, see Resources section below



#### Practice Tip

In the presence of motor delay and low peripheral tone, always consider treatable neuromuscular disorders, such as SMA and DMD.



#### Practice Tip

If desired, patient can be referred to a local Child Development Centre (CDC) or Infant Development Program (IDP) to have these assessments completed by a trained occupational therapist or physiotherapist.

#### **BRAIN IMAGING**

- As part of the assessment of a child with CP, brain MRI is recommended to help consolidate an etiology and rule out other conditions.
- However, the diagnosis of CP is a clinical one and MRI it is not required to make a diagnosis. In the presence of sufficient clinical information, waiting for an MRI should not delay the diagnosis and referral to CP-specific interventions.
- Majority of infants and young children require sedation with general anesthesia, which may have effects on the developing brain.<sup>17</sup>
- MRI may not feasibly be done in a timely manner, particularly if travel from remote communities is required; which leads to diagnostic delays.

Strongly consider MRI in the following cases<sup>11</sup>:

- History does not match clinical findings (e.g., prematurity with ataxia)
- Atypical CP (e.g., hypotonic, ataxia)
- History of developmental regression or other history suggestive of progressive brain disturbance



## Practice Tip

Engage in shared decision making with the family regarding whether to order an MRI, exploring the pros and cons. MRI is recommended but should not delay diagnosis or referral to early intervention.

How is Cerebral Palsy Diagnosed? Updated: December 2024

#### HIGH RISK OF CP: A DESIGNATION

- The interim clinical diagnosis of "high risk/high probability of CP" should be given when a diagnosis of CP is suspected but cannot be made with certainty.<sup>12</sup>
- Providers may choose to assign this diagnosis until they have additional information (e.g., achieving additional milestones, MRI results, etc.)
- Large-scale population data has shown that less than 5% of suspected cases are confirmed as not CP by the age of 5 years.<sup>19</sup>
- This interim diagnosis should be communicated to families and other providers
- Reassess when new developmental milestones are expected (e.g., from seating to standing, from standing to walking) or a new concern is present.



## Practice Tip

If you have questions regarding a case, consider booking a 20-minute appointment with the Sunny Hill Neuromotor Program Physician-to-Physician consult service.

How is Cerebral Palsy Diagnosed? Updated: December 2024

# How to Communicate the Diagnosis to the Family/Caregivers

Disclosing a new diagnosis of CP can be daunting for physicians but it is important. It requires a compassionate and well-planned conversation. To support acceptance in the transition period after diagnosis, conversations should include essential information parents and caregivers need about the following<sup>20</sup>:

- Diagnosis and potential etiology
- Need for additional investigations?
- Possible interventions
- Daily caregiving
- Equipment
- Support

- What to expect: Prognosis & future function
- How to explain the disability to others
- Healthcare/service plan
- The effects on the family



The biggest thing we would have found helpful when we received the official diagnosis is to have an inclusive and easy roadmap for us: What therapies is he going to require, different specialists he is likely going to see, resources in the community that were available to us. It was so many months of just collecting all of these pieces of data from resources and specialists."

— Charlene, mom to 9-year-old Liam



## Practice Tip

A diagnosis of CP connects the family with vital resources and supports. At a time of loss, grief, and uncertainty, clinicians can reassure that a child with CP will have a good quality of life. With the support of the family, community, and medical partners, the child and their family can enjoy happy and fulfilling lives.

#### **FAMILY CENTERED LANGUAGE**

The following are examples of language used by providers at Sunny Hill Health Centre when communicating the diagnosis to a family:

"What do you know about cerebral palsy? What have you read/heard?"

"What do you want to know or have answered during today's appointment?"

"This is the same child you came in with this morning. Now we have a name for what you were seeing. This will help your child's healthcare team understand and support them."

"This is no-one's fault. There is nothing you could have done to prevent this."

"You are doing all the right things to help your child fulfill their potential. Your ongoing support and love is the best therapy."

"What are your thoughts about what I have shared with you today?" This is to avoid only asking if parents have questions.

"This is a lot for you to take in. Please reach out if you have guestions or if something was unclear."

"We are here for you and your family."

Avoid saying: "I'm sorry". Use neutral language, for example: "your child has cerebral palsy, and this is neither good nor bad. It is just a description of what's going on, and helps us determine what they need to stay healthy and reach their full potential."

Emphasize the non-progressive brain disturbance: "something happened to the brain early in life, and we are seeing the effect on your child's motor function. There is no progressive, ongoing disease in your child's brain."

#### OTHER TIPS TO SUPPORT PARENTS AND CAREGIVERS:

- Review the criteria for CP and help family/caregiver understand how their child meets criteria
- Talk about prognosis, if known. Parents want to know if their child will walk, talk, etc. You can use the GMFCS for this. Note that the brain is developing, and we don't always know what the future may hold for their child. Be realistic, but optimistic.
- If you anticipate the child will use a mobility aid, such as wheelchair, explain that many adults who use these aids live and function independently and live well.
- Focus on the function. What the child CAN do, not on what they cannot do.
- Give parents time to think and process what was shared... Don't be afraid of periods of silence.
- Invite questions.
- Provide resources to take away and review. Schedule a follow-up appointment to discuss questions and next steps.



## Practice Tip

A Guide to Cerebral Palsy is a resource created by the Sunny Hill Health Centre CP Early Diagnosis Team. We recommend giving this to families who receive a new diagnosis of CP.

# Next Steps: Early Intervention & Support for Child and Family

After a diagnosis is made, the most important step is providing intervention as early as possible. If the child is not already connected, refer immediately to their local IDP, CDC or closest therapy service provider.

- It is helpful to classify the type of CP, and functional ability of the child, when possible, as this facilitates communication between providers and has potential implications for prognosis, treatment, and medical benefits.
- There are a variety of early interventions and treatments available for children with CP. The evidence behind their levels of effectiveness has been summarized in a recent landmark systematic review.<sup>21</sup> See EDIT-CP, a quick summary of the review.
- Regions vary in what services are available, the types of therapy staff, and wait times. We suggest becoming familiar with what services and supports are available in your region and community.

#### Practice Tip

If hand preference is seen before age 1, consider BabyCIMT for 30 minutes daily - it's an evidence-based intervention that can be done at home by a parent. For details see the practical guide for parents and handbook.

#### Next, it is crucial to screen for associated conditions:

- ✓ Other areas of development and cognitive/academic function:
  - √ Delays in communication
  - ✓ Specific Learning Impairments, Global Developmental Delay, cognitive/academic function, Intellectual Developmental Disorder, ASD, and ADHD
- Hearing and visions concerns

- Feeding difficulties
- Pain
- ✓ Sleep Challenges
- Seizures
- ✓ Increased tone
- Constipation and GE reflux
- Musculoskeletal conditions: Scoliosis or other spine deformities, hip concerns



#### Practice Tip

Physicians may choose to refer for further assessment (e.g., SLP for language delay, OT for swallowing assessment) as deemed appropriate.

Physicians may also consider further investigations to determine etiology of CP if not yet established. The appropriateness of these investigations should be discussed with the parents, exploring the benefits and drawbacks. Investigations may include:

- Neuroimaging (MRI)
- Genetic testing
- Metabolic work-up: particularly if history or clinical findings suggestive of metabolic disturbance (e.g., there is a history of regression)
- Coagulation work-up: particularly if there is clinical suspicion or imaging findings suggestive of infarction

#### **OTHER BEST PRACTICES**

- Every child with CP should have a primary care provider who will regularly see them and address any medical concerns, including issues regarding sleep, nutrition, and pain management.
- Children with CP should be referred to the <u>Child Health BC Hip Surveillance</u> <u>Program for Children with Cerebral Palsy.</u>
- Children who are not walking should be advised to have daily intake of vitamin D.

# **Resources for Clinicians**

#### 1. DIAGNOSTIC SUPPORT

#### The Sunny Hill Health Centre Neuromotor Physician to Physician Consult Service

- Physician-to-physician Consult Service Referral PDF
- This service provides community physicians with guidance and resources for making a diagnosis of cerebral palsy, and to assist with tone management as needed. Referring physicians will be booked for a 20-minute phone or teleconference appointment to discuss their patient with a neuromotor developmental pediatrician.

#### **UBC CPD Cerebral Palsy Diagnosis in Community Pediatrics**

 <u>UBC CPD</u> hosts resources from the Cerebral Palsy Diagnosis in Community Pediatrics program, run in partnership with BC Children's Hospital. This includes presentation slides and webinar recordings from workshops run by local CP experts on early diagnosis.

#### **Pathways**

Pathways is an online resource that provides BC physicians and their office staff/ teams quick access to current and accurate referral information, including wait times and areas of expertise of specialists and specialty clinics. Pathways can also provide access to hundreds of patient and clinician resources, as well community service and allied health information that is categorized and searchable. Type 'Cerebral Palsy' in the search bar.

#### Hammersmith Infant Neurological Exam (HINE)

- Learn to administer the Hammersmith Infant Neurological Exam
- Watch an introductory webinar about administering and scoring the HINE

#### **EDIT-CP toolkit for early detection (McGill)**

- A visual summary of clinical red flags for community physicians to detect CP in infants as part of their well-baby care visits.
- A poster format is also available

#### Information and referrals for BC Children's Hospital

- CP Early Diagnosis Program [7]
- Early Motor Screening Program

#### Child Development and Rehabilitation InfoSource

 BCCH and Sunny Hill Development and Rehabilitation houses a collection of clinical resources on a variety of topics related to child development. Type 'Cerebral Palsy' into the search bar.

# American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) Early Detection of Cerebral Palsy

• <u>Comprehensive summary and algorithm</u> outlining a logical path from assessment to treatment, published evidence, and practical tools.

Resources for Clinicians Updated: December 2024

#### 2. EARLY INTERVENTION & MANAGEMENT

#### **EDIT-CP** tookit for early intervention

Useful evidence summary on different early interventions for cerebral palsy. The site includes a list of outcomes examined in the selected studies for a particular type and severity of CP, whether the intervention was more or not more effective than the comparison intervention (e.g., usual care), and the level of evidence.

#### Functional classification systems for children with cerebral palsy:

- GMFCS Gross Motor Function Classification System [7]
- MACS Manual Ability Classification System
- CFCS Communication Function Classification System
- EDACS The Eating and Drinking Ability Classification System for Individuals with Cerebral Palsy

#### **Canadian Pediatric Society**

■ General care considerations for patients with CP, GMFCS levels I & II

#### CanChild

 General information on CP as well as measures for monitoring growth and function in children with CP.

#### **BC Hip Surveillance Program**

- General information about hip surveillance required for patients with CP 「
- Schedule for hip surveillance by GMFCS level ☐

#### **AACPDM Care Pathways**

- Current care pathways [7]
- For management of medical comorbidities associated with CP (e.g., dystonia, sialorrhea, respiratory health).

#### **CP Growth Charts**

■ New growth charts 🔀

#### 3. FAMILY RESOURCES & SUPPORTS

#### Physician's Guide to the Disability Tax Credit

- PDF Download
- A non-refundable tax credit for people with disabilities or their caregivers. There is a portion of the application that must be filled out by a physician, which may be a GP or a pediatrician. The diagnosis of CP is sufficient to meet the criteria.

#### At Home Program

- <u>Program Information</u>
- The program funds equipment, medications, and other needs (such as diapers), as well as additional funding for therapy. Eligibility depends on the child's function and level of dependence for ADLs.

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# **Resources for Families**

#### 1. GENERAL INFORMATION & EDUCATION

#### BC Children's Hospital

- General Information about CP 🖸
- A Guide to Cerebral Palsy: Created by Sunny Hill Health Centre Early CP Diagnosis team. A handbook for parents and caregivers who have recently received a new diagnosis.
- BC Children's Hospital Family Library: Houses a collection of books and resources related to CP curated by a clinical librarian. Type 'Cerebral Palsy' in the search bar to display the collection. The Family Library can mail any physical items for free to any location in BC or the Yukon. The collection also includes eBooks.

#### Child Development and Rehabilitation InfoSource

 BCCH and Sunny Hill Development and Rehabilitation houses a collection of clinical resources on a variety of topics related to child development. Type 'Cerebral Palsy' into the search bar.

#### HealthLink BC

• General Information about CP for parents/caregivers.

#### CanChild

- CP Resources 「
- The F-Words in Childhood Disability 🔀

#### **Cerebral Palsy Alliance**

 A global center of expertise for cerebral palsy services and support, research, technology, innovation, and advocacy.

#### Holland Bloorview Hospital CP Booklet

Guide to CP written together with families.

#### Unique

 <u>A UK-based charity</u> that links families whose children share similar genetic profiles.

#### **Cerebral Palsy Foundation**

- <u>Information</u> about diagnosis, therapies, assistive devices, new research.
- Insights from Experts: video series by US-based Cerebral Palsy foundation.

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#### 2. COMMUNITY PROGRAMS & SERVICES

#### Cerebral Palsy Association of British Columbia

- General Information
- Offers a variety of programs and services for children and their families including adapted recreational activities, peer-to-peer support groups, financial assistance, and parent support groups.
- The support hotline is 604-408-9484 or toll-free 1-800-663-0004.
- <u>CP Connections</u> is a peer-to-peer support group hosted every week, which aims to connect people with CP across the province. Parent support groups also run monthly.

#### Family Support Institute of BC

- A resource for families to connect and support one another.
- Find Support BC is a database to search for services and supports.
- My Booklet BC is a customizable profile you can make about your child and keep everything important about them in one place. This can be shared with care providers to help them learn about your child

#### Parent Guide for Hip Surveillance

Hip Surveillance Program Family Booklet 2018 PDF

#### The Disability Tax Credit

- General information
- Application Form [⁻¹]
- A helpful guide for applicants by Disability Alliance BC

#### At Home Program

- Medical Benefits [7]
- Provides funding for respite care and medical equipment for children and teens
  with a severe disability or complex health care needs find out about the
  application and eligibility requirements. Families may require assistance with the
  application.
- Application Form ☐

#### Fuel Tax Refund for Person with Disabilities

- Registration information
- May help reduce transportation costs

#### **SPARC BC Parking Permit**

- Application and general information
- Allows people with mobility limitations to park in designated parking spots throughout BC.

#### Variety Adaptive Mobility & Equipment Fund

- Application and eligibility requirements
- Grants for mobility and adaptive equipment such as manual & power wheelchairs, hearing aids, standing walkers, custom orthotics and van conversions.

Resources for Families Updated: December 2024

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