

## Questions & Answers from Early Diagnosis of Cerebral Palsy Online Workshops

February 29, 2024

Part I: Fundamentals

March 7, 2024

Part II: Diagnosis and Beyond

July 4, 2024

Diagnosing Cerebral Palsy: Your Questions Answered and Next Steps

### 1. What needs to be done for prevention of CP?

There has been a decrease in the incidence of CP in developed countries in the last two decades, mostly related to better perinatal care. Other than that, with better knowledge on the genetic factors in many cases of CP, there are options for family planning counselling.

### 2. Are the opportunities for DIGMA (Drop-In Group Medical Appointment) for support in the community?

We are not aware of any current opportunities of DIGMA in BC. This is definitely something to look at with future community services planning, potentially within the new Family Connection Centres.

### 3. Is there stem cell therapy post-natally?

Please see a list of fantastic FAQ videos from the Cerebral Palsy Alliance on how stem cells can be harnessed to prevent, protect and treat cerebral palsy, as well as other brain conditions:

<https://cerebralspalsy.org.au/news-stories/communication-research-series/>

### 4. Do you think it is better to diagnose on the first visit if suspected or a secondary visit?

This depends on the family. Generally speaking, I would usually give the diagnosis on the first visit if possible, unless I don't have "enough" information to make a diagnosis (then often I use "high risk/probability for CP"), or if the caregivers seem like they wouldn't be able to receive a diagnosis at the time and I feel that another appointment is preferable.

Often, I will make a diagnosis on the first visit and will explain a bit about CP, but will give more information on a follow-up visit, so the caregivers are not overwhelmed with too much information in one visit.

5. **Would you recommend MRI if you meet a child who is quite a bit older (like 5-6 years old), with history of gross motor delay but "eventually meeting all the milestones just later than expected" and slowly catching up but still "clumsy" compared to peers (for example: has difficulties learning how to ride a bike now), and on exam, you find mild increased tone in lower limbs with mildly brisky reflexes? The physiotherapist is also concerned about the increased tone.**

I think this may be enough to make a diagnosis. I would recommend MRI in such a child, to get more clarity also about possible etiology, but don't think I would delay the diagnosis until I have the MRI results.

6. **Do you find that families are happy with a clinical diagnosis only? My sense is we need to proceed with MRI to confirm to help rule out other things etc.**

Sedation is required so families may be hesitant. It depends on the family. In any case, I suggest not to delay giving the diagnosis (and if needed, use "high risk/probability for CP").

7. **How early would you consider medications for tone? Does that alter long term outcome (i.e., a 10-month-old with high tone, should we be considering tone management already)?**

I have started anti-tone meds in a few weeks-old infants. Usually, I would start baclofen as early as two months of age. It depends on goals – I would start meds for very young infants if I feel that the tone is causing pain or significant discomfort, or interferes with sleep. In a 10-month-old, I would definitely consider meds if needed – to help with tolerating being in a car seat or a stroller, ease of care (if tone is so high that it interferes with dressing and changing), or if I see that tone interferes with development (for example ability to sit or use hands because of dystonia).

Again, it all depends on functional goals – don't just treat the tone, but think about what you want to achieve by reducing the tone.

8. **What are the tone goals? How do you balance maintaining head tone, with peripheral tone?**

Comfort, pain, care giving, positioning (see also answer to the previous question).

Usually after adjusting to the meds, the children will not experience significant change in head or trunk control, but will see tone reduction in the hypertonic extremities.

9. **When I looked up HINE scoring recently, there seemed to be different ranges depending on how premature a baby was born. Please explain.**

Yes, the cut off changes based on age, but there are general cut off scores that apply for all ages. For the HINE in premature infants, we use their corrected age.

**10. Is there a minimum age for the parking pass?**

No. Please visit <https://www.sparc.bc.ca/parking-permits/#apply> for details.

**11. Do you think parents want both diagnoses of a genetic condition and CP?**

Yes. Discussion of etiology may be important to patients. In a study<sup>1</sup> which included 197 respondents: 108 adults with CP; 89 caregivers:

- 75% valued knowing the cause of their CP
- Helped anticipate symptom evolution (84%)
- Explain symptoms to others (86%)
- Access services (86%)
- Join support communities (78%)

**12. How many children with CP also have ASD and ID?**

From an evidence review<sup>2</sup> in 2014<sup>2</sup>, it is estimated 1 in 2 children with CP will have intellectual disabilities/cognitive challenges.

*Answers provided by Dr. Ram Mishaal, Developmental Pediatrician, Sunny Hill Health Centre, BC Children's Hospital.*

References

1. Aravamuthan BR, Shusterman M, Green Snyder L, Lemmon ME, Bain JM, Gross P; For Simons Searchlight; Cerebral Palsy Research Network. Diagnostic preferences include discussion of etiology for adults with cerebral palsy and their caregivers. Dev Med Child Neurol. 2022 Jun;64(6):723-733.
2. Novak I. Evidence-Based Diagnosis, Health Care, and Rehabilitation for Children With Cerebral Palsy. J Child Neurol. 2014 Aug;29(8):1141–56.