

Cerebral Palsy

FOR THE PRIMARY CARE PROVIDER

MED-PEDS NOON CONFERENCE

MARCH 14, 2022

ALEX SCHOENBERGER

Objectives

1

Identify historical risk factors and physical exam findings that should prompt a referral for cerebral palsy.

2

Synthesize clinical information into a comprehensive description of a patient's cerebral palsy.

3

Describe supports for and barriers to a successful transition to adult healthcare.

4

Describe how to report concerns for abuse/neglect of a person with a disability.

Cerebral Palsy

Phenotype

Permanent

Non-progressive

Formal Definition

Per the most recent consensus definition (2006), “cerebral palsy describes a **GROUP** of **PERMANENT** disorders of the development of movement and posture, causing activity limitation, that are attributed to **NONPROGRESSIVE*** disturbances that occurred in the developing fetal or infant brain.” (Noritz et al., 2022)

Diagnosis

Early diagnosis is important!

1. Optimize natural plasticity and improve motor and cognitive outcomes
2. Prevent the onset of hip dislocation, scoliosis and contracture
3. Happy families 😊

Role of the Pediatrician

1. Screen for risk factors
2. Perform comprehensive physical exams
3. Refer to therapy and *indicate concern for CP*

Identify Risk Factors

Newborn Risk Factors

- Preterm
- Encephalopathy
- History of neurologic risk factors
- Parental concern

*Put these in your patient's problem list or medical history so that future providers are aware!

Well Child Checks (birth – 12 months)

1. Assess developmental milestones
2. Comprehensive physical exams
3. Address parental concerns

TRIVIA QUESTION

Name at least 3 physical exam findings within the first 12 months that should raise your concern for cerebral palsy.

Physical Signs

After 4 months



Your baby makes tight fists with their hands (this continues past 4 months of age).



Your baby is unable to hold their head up without help (this continues past 4 months of age).

After 6 months



Your baby's legs feel stiff or tight. They may not be able to bring their toes to their mouth during nappy changes (this happens between 6-12 months of age).

After 9 months



Your baby is unable to sit up by themselves (this continues past 9 months of age).

Any time before 12 months



Your baby seems to prefer to use one side of their body or they lean to one side (this happens when they are moving and also when they are still).



Your baby seems to prefer using one hand more than the other (this happens before they are 12 months of age).

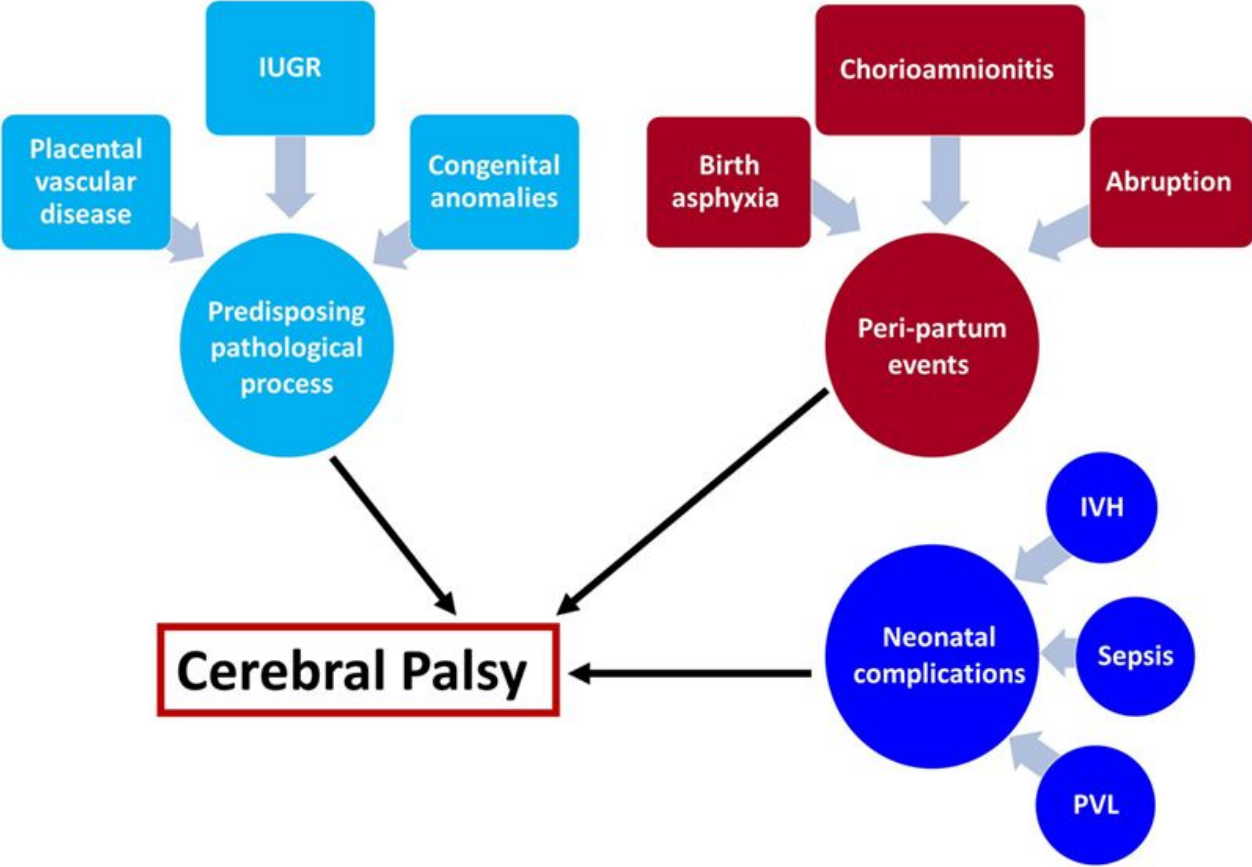
12 Year Well Child Check

Jane is back in town, and her family can't wait to see their favorite pediatrician! Her family states that she was diagnosed with "low-functioning CP" – what a useless description!

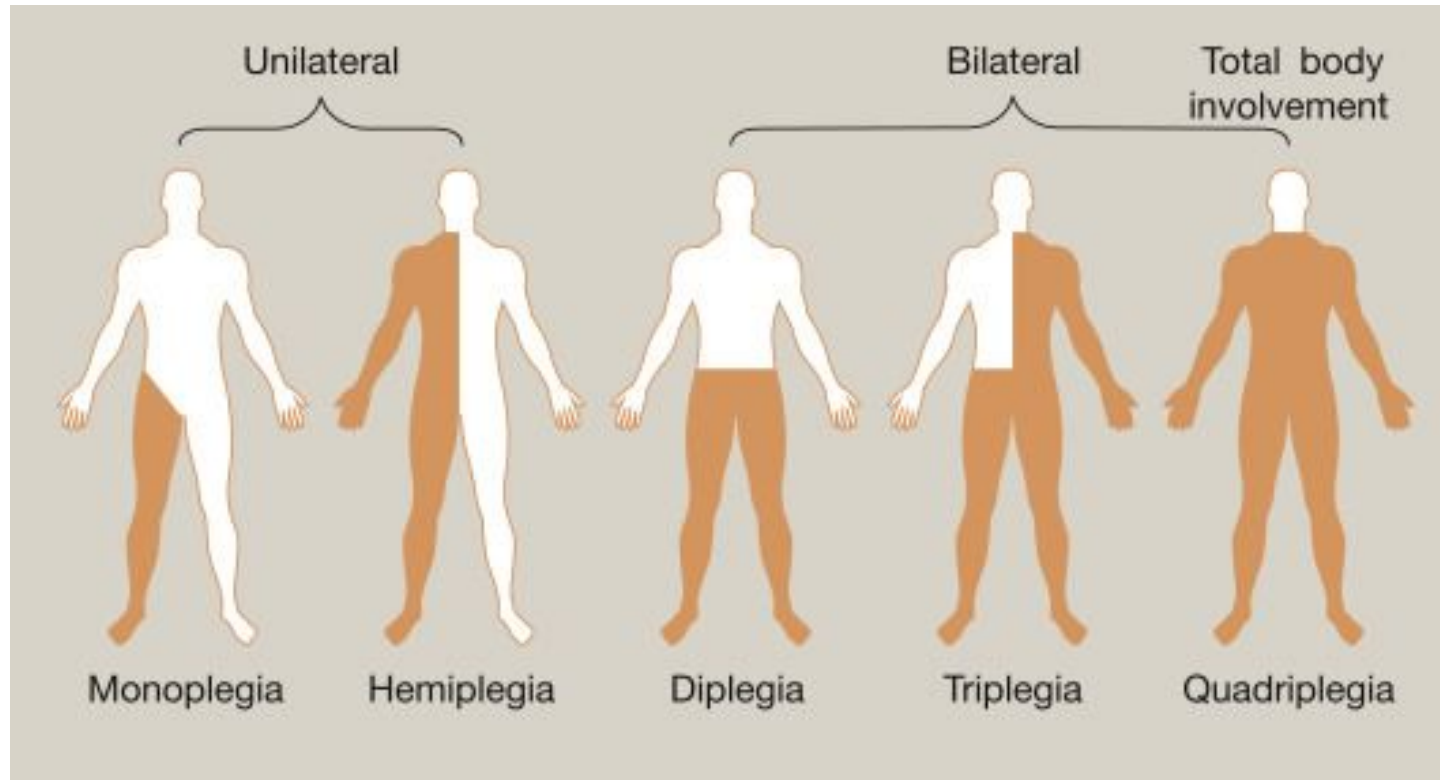
TRIVIA QUESTION

What are 3 ways in which we can characterize the cerebral palsy phenotype?

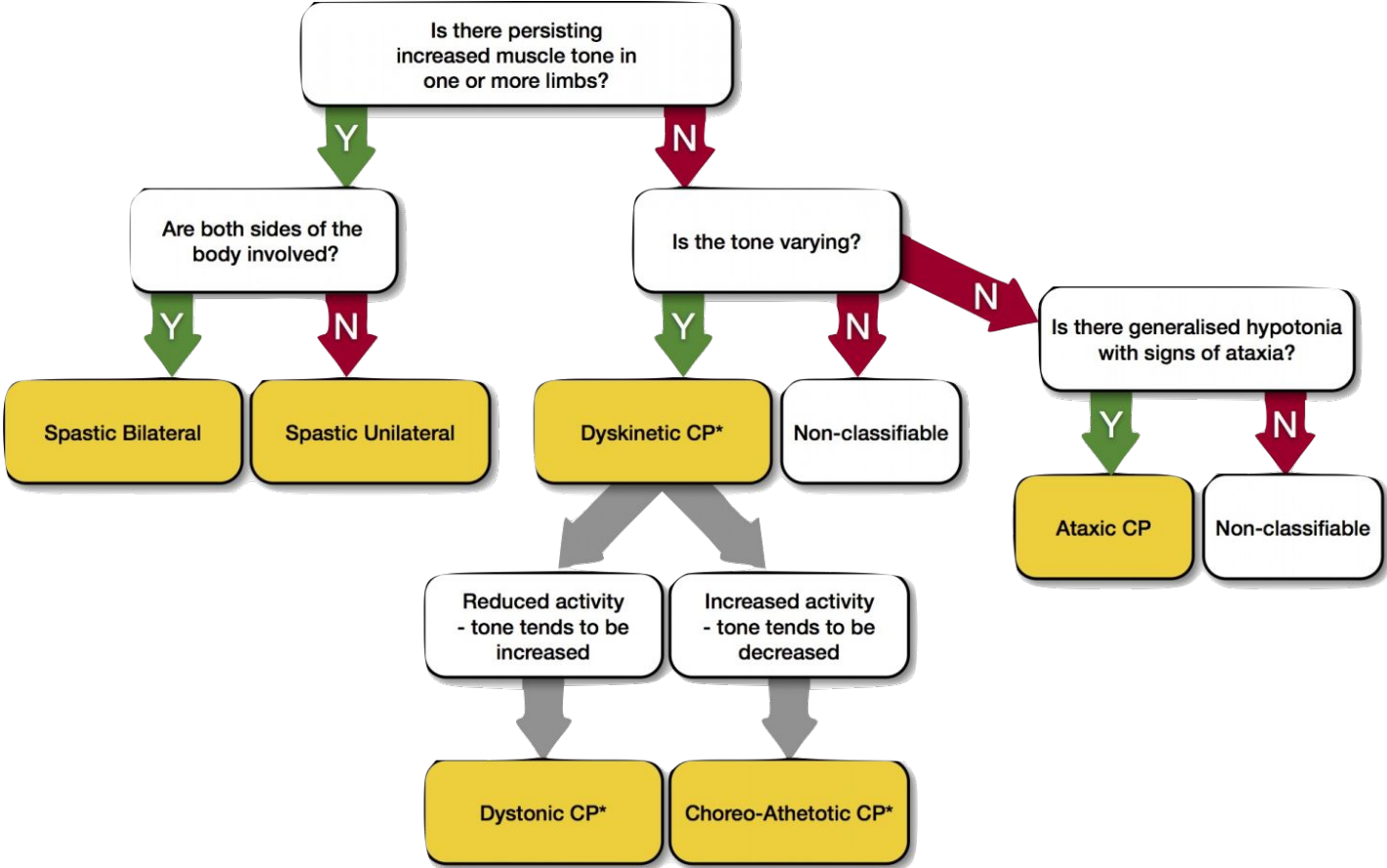
Etiology



Topography



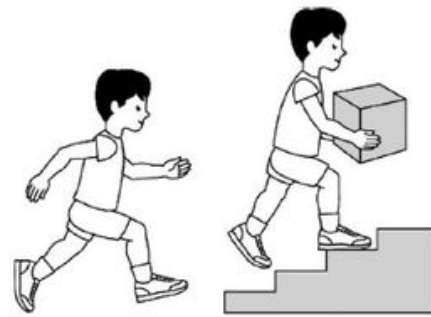
Movement



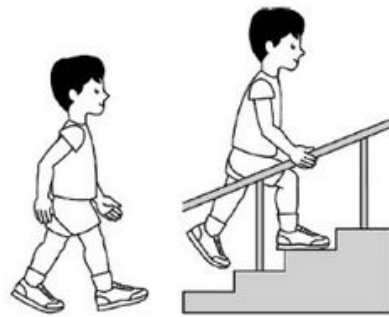
TRIVIA QUESTION

What are 4 different ways in which we can characterize the baseline abilities of someone with cerebral palsy?

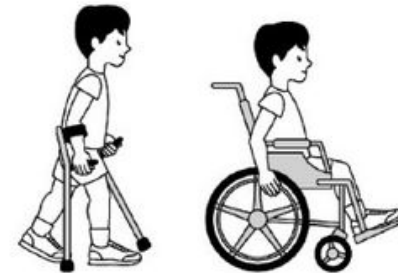
Gross Motor Function Classification System (GMFCS)



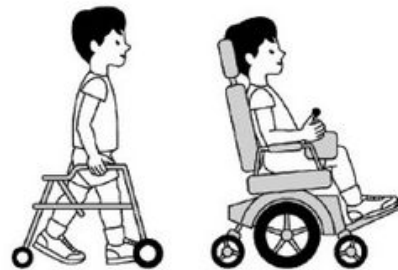
GMFCS Level I



GMFCS Level II



GMFCS Level III



GMFCS Level IV

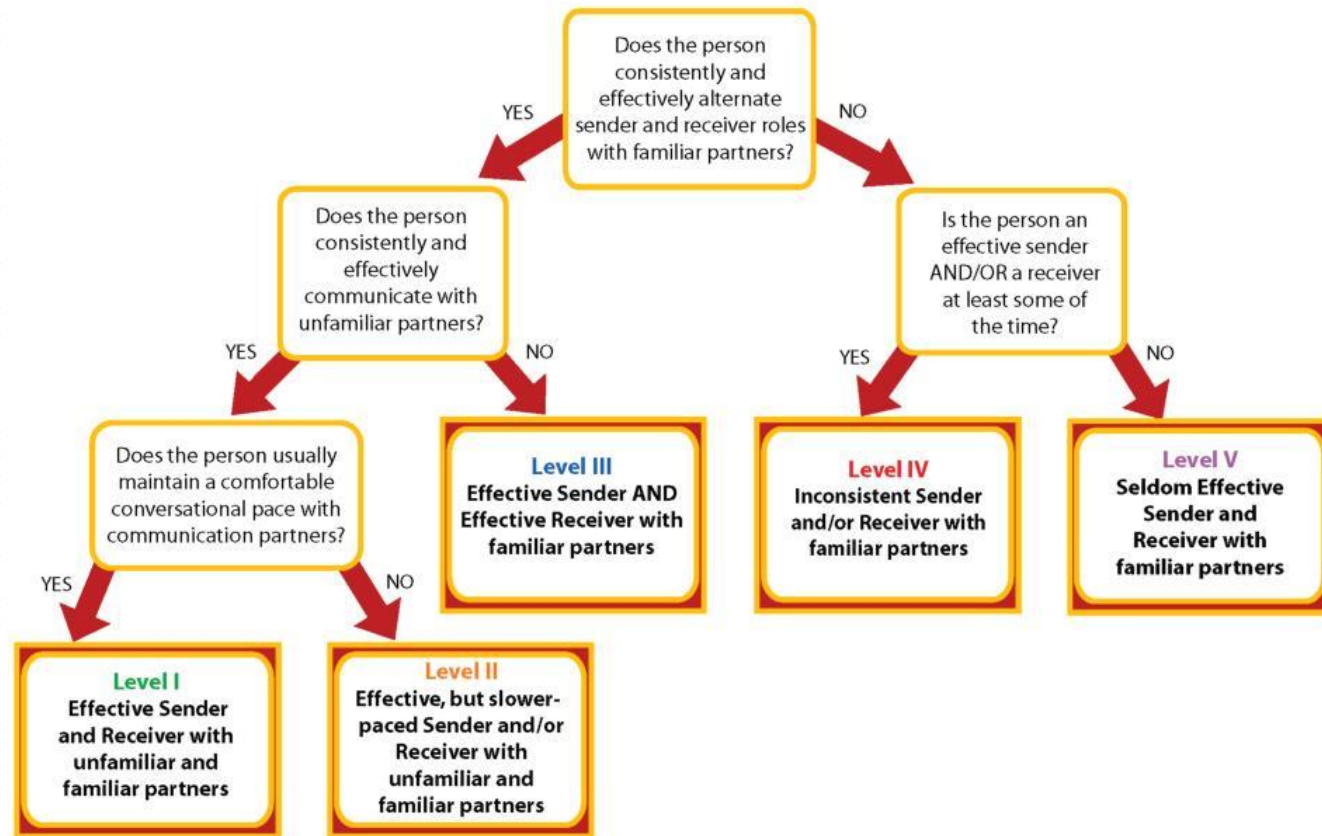


GMFCS Level V

Manual Ability Classification System (MACS)



Communication Functioning Classification System (CFCS)



Hidecker et al.

Please do not use without permission

Communication Functioning Classification System (CFCS)

Eating and Drinking Ability Classification System (EDACS)



A note about “functioning” scales...

1. Strengths based

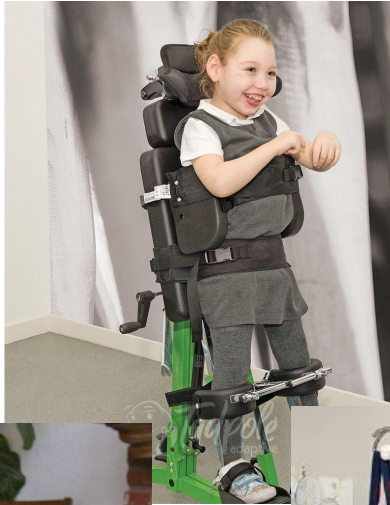
2. Helpful for baselines, but...

*Diagnosed functional ability is not always “functional”
functional ability*

TRIVIA QUESTION

What are some physical supports utilized by patients with CP?

Physical Supports



AAC Devices



BigMack



GoTalk 4+/20+



Talkables



PECS



TouchChat



Proloquo2go



Tobii

Physical Supports

Movement: Braces (AFOs, SMOs), splints, wheelchairs

Home: Shower chairs, lifts, bed height adjustments

Eating: Adaptive silverware

Communication: Augmentative and Alternative Communication (AAC) devices

And so much more!

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TRIVIA QUESTION

What are 5 comorbidities that can be associated with CP?

COMORBIDITIES

Cognition and learning (~50%)

Communication difficulties (60-80%)

Behavioral and mental health

Epilepsy (35-60%)

Sensory impairments

Pulmonary problems

Sleep disturbances

Nutrition/growth/GI concerns

Bone health

Ortho complications

Pain (75%)

Associated Medications

Sialorrhea anti-cholinergics

Spasticity Botox, baclofen

Epilepsy anti-epileptics

Pulmonary concerns airway clearance

Nutrition enteral feeds, supplements

Bone health Vit D, calcium

Pain pain medication*

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TRIVIA QUESTION

When should we begin discussing transition with families of patients with CP?

Transition Age

Between the ages of 12 and 14!

TRIVIA QUESTION

But wait...how do we know
when they're ready?!

Transition Readiness Assessment Questionnaire (TRAQ)

No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
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Managing medications
Keeping appointments
Tracking health issues
Talking with providers
Managing daily activities

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TRIVIA QUESTION

Dad heard that transitioning providers will jeopardize their ability to be admitted at CCHMC. Is this true, fake news, or somewhere in between?

CCHMC Adult Admissions

Can be expedited *only* if one of the following:

1. In one of the adult care programs
2. Complex Care patient
3. Meets criteria to be Complex Care patient

TRIVIA QUESTION

What are 3 options for supporting a patient with CP in the healthcare system?

Support Options

Informal support

Supported decision-making

Healthcare POA

Guardian

Guardianship

Can be pursued once someone turns 18

Does not require person's consent

Last resort restrictive and difficult to terminate

FINAL TRIVIA QUESTION

How do you report concern for abuse/neglect for a patient with an IDD?



Mandated Reporting

MUI (Major Unusual Incident)

Police vs. APS (241-KIDS) *[and then police]*

**Resource will soon be in Silver Fridge!*

Resources for Providers & Families

Cerebral Palsy Alliance Treatment Guides

AAP Executive Summary : Providing a Primary Care Medical Home for Children and Youth with Cerebral Palsy

American Academy for Cerebral Palsy and Developmental Medicine Early Detection of Cerebral Palsy

References

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Peterson N, Walton R. Ambulant Cerebral Palsy. *Orthopaedics and Trauma*. 2016;30(6):525-538. doi:10.1016/j.mporth.2016.08.005

Stavsky M, Mor O, Mastrolia SA, Greenbaum S, Than NG, Erez O. Cerebral palsy—trends in epidemiology and recent development in prenatal mechanisms of disease, treatment, and prevention. *Frontiers in Pediatrics*. 2017;5. doi:10.3389/fped.2017.00021