


In-person
March 13-16, 2024

**45th National Conference
on Pediatric Health Care**




Virtual
May - July 31, 2024

**Finding a Place to Call Home:
The Importance of a Medical Home
for Children with Cerebral Palsy**

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NAPNAP's Children and Youth with Special Health Care Needs SIG is pleased to support this session.




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Experts in pediatrics, Advocates for children.

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Speaker Disclosure

- No disclosures




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Learning Objectives


- Review the diagnosis of cerebral palsy
- Describe recommended surveillance and targeted interventions for children with CP
- Identify common problems and co-morbidities in children with CP
- Discuss ways that pediatric providers can advocate for children with CP



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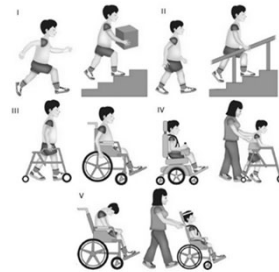
I am not broken,
I am beautiful.
I am different,
not less
I am challenged,
not challenging
I'm not a burden,
I am blessed
Cerebral Palsy is not a choice,
but Acceptance is.



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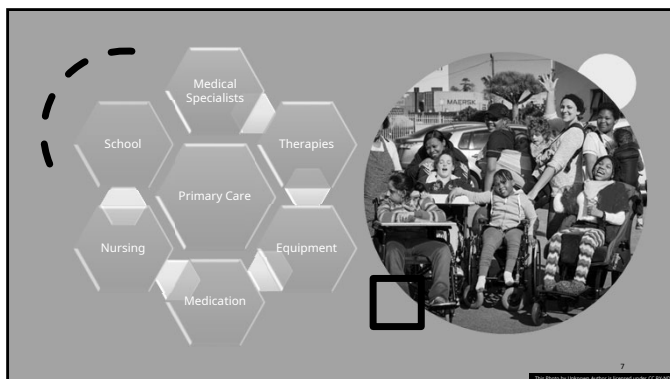
Cerebral Palsy (CP) /,serəbrəl 'pôlzē/

1. group of permanent disorders affecting movement and posture, non-progressive **2.** caused by abnormalities in the developing brain in the fetus or young infant **3.** can cause activity limitations and affect body movement, muscle control, muscle coordination, muscle tone, reflexes, posture, balance, fine motor skills, gross motor skills and oral motor functioning **4.** most common physical disability in childhood

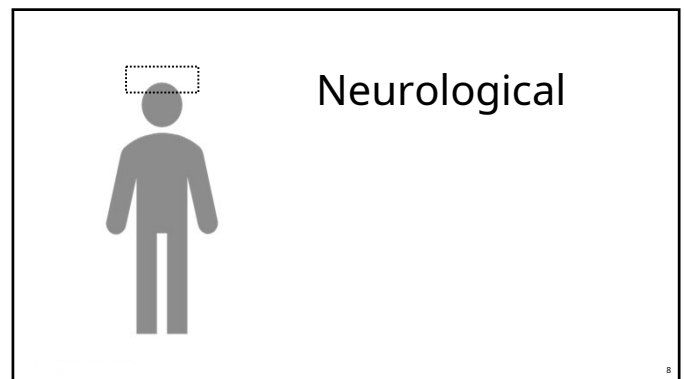


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Seizures


- Epilepsy affects approximately 40% of those diagnosed with Cerebral Palsy
- Common seizure types include focal, generalized, combined generalized and focal, or unknown
- Diagnosis is based on family history, semiology, and characteristics of clinical events
- Electroencephalogram (EEG) is the diagnostic gold standard



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Hearing, vision and oral health



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Oral health


- Sialorrhea
- Dental care

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Communication

- 60%-80% of children with CP will have communication difficulty
- 19%-32% are nonverbal
- Inability to speak at 2 yrs is associated with poorer speech and language ability at 4 years
- Higher rate of hearing loss



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Communication-Interventions

- Hearing test
- Face to face talking, singing
- Speech therapy- Augmentative devices/Alternative communication
- Mother Infant Transaction Program Morgan
- Premie Start
- It Takes Two to Talk
- School Program



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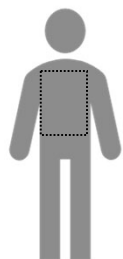
Vision



- 50%-90% of children with CP will have vision impairment or other ophthalmologic condition
- >50% of children with CP have cerebral vision impairment
- Strabismus (esotropia/exotropia)
- Amblyopia

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Pulmonary



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Lung Health

Pulmonary problems are the leading cause of death and hospitalization for children with CP

- Breathing treatments
- Airway clearance devices
- Suction
- Tracheostomies
- Aspiration
- Immunizations



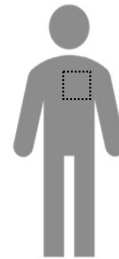
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Sleep

- 20%-40% of children with CP will have sleep difficulties
- Insomnia
- Difficulty with sleep cycle
- Pain or discomfort in bed
- Non-ambulatory CP may have higher prevalence of sleep disturbance
- Sleep disordered breathing
- Hypoventilation

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Cardiac

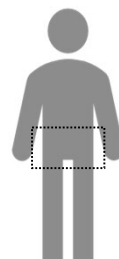
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Does CP result in heart problems?

- Individuals with CP are more likely to develop heart conditions in adulthood than those without
- Heart problems and CP are not directly related
- Limitations in physical activity increase the risk of developing heart conditions as individuals reach adulthood

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Urological

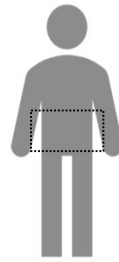
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Urinary Incontinence

- Predictive factors
- Prevalence
- Types
- Managing incontinence

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Gastroenterology



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Gastrointestinal Complications

- Growth
- GERD
- Dysphagia
- Gastrostomy tubes
- Constipation

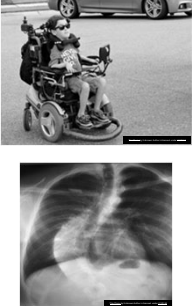


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Musculoskeletal



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Musculature and Bone abnormalities

- Bone Health
- Tone
- Scoliosis, kyphosis, lordosis
- Contractures
- Hip dysplasia
- Fractures
- Pain

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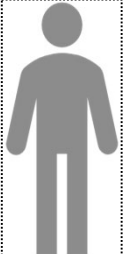


Equipment

- Orthotics (AFO, SMO,WHO, TLSO)
- Custom car seats
- Medical beds
- Stenders
- Gait trainers
- Home modifications
- Lift systems
- Bath equipment
- Toileting equipment
- Wheelchairs

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Integumentary

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Skin Concerns

- Pressure injuries
- Intertrigo

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Development

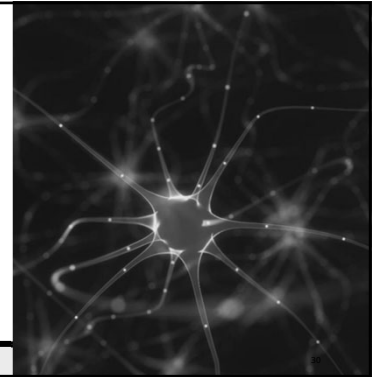
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Developmental Considerations

- Developmental delay
- Cognitive Function
- Impact on mental health
- Early intervention
- Complimentary therapies

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Adolescence

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Adolescence

- Puberty
- Menses Suppression
- Sexual Health
- Risk for Abuse
- Vaccination

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Support Services

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Supportive Services

- Palliative Care
- Family support groups
- Care coordination
- Dayhabs

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Disparities among children with Cerebral Palsy

- Racial, ethnic, and socioeconomic disparities
- Lack of access to care
- Uninsured/Underinsured
- Burden of disease
- Life expectancy

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Advocacy

- Individual
- State
- Federal

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Take Aways

- Children with CP do best in a medical home
- PCPs are in an ideal situation to identify, monitor and treat symptoms and co-morbidities of CP
- Further advocacy is needed to ensure children with CP have adequate resources to ensure best outcomes



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References

- Deramone Denver, B., Froude, E., Rosenbaum, P., & Inms, C. (2022). Measure of Early Vision Use: initial validation with parents of children with cerebral palsy. *Disability and Rehabilitation*, 44(15), 4066-4074. <https://doi.org/10.1080/09638237.2022.2088888>
- Pavone, P., Gulizia, C., Le Pira, A., Greco F.P., Di Cara, G., Falcaferla, R., Lubrano, R., Minardi, C., Spalice, A., & Ruggieri, M. (2020). Cerebral palsy and epilepsy in children: clinical perspectives on a common comorbidity. *Children (Basel)*, 31(8), 16. doi: 10.3390/children3010016
- Garne, E., Goldsmith, S., Barisic, I., Braz, P., Dekovic, I., Gibson, C., Hansen, M., Hoei-Hansen, C.E., Hollung, S.J., Klumpner, K., Smithers-Sheedy, H., Virella, D., Badawi, N., Watson, L., & McGroarty, S. (2023). Severe Congenital Heart Defects and Cerebral Palsy. *The Journal of Pediatrics*, 262(1), 15-17.
- Marciniak, C., O'Shea, S.A., Lee, J., Jesselson, M., Dudas-Sheehan, D., Beltran, E., Gabeler-Spira, D. (2014). Urinary incontinence in adults with cerebral palsy: prevalence, type, and effects on participation. *Physical Medicine and Rehab*, 6(2), 110-120. doi: <https://doi.org/10.1016/j.pmrj.2013.07.012>
- Mcghee P.G., Claridge, E.A., Noordlyn, S.G., Gorter, J.W. (2019). Cardiovascular disease and related risk factors in adults with cerebral palsy: a systematic review. *Developmental Medicine and Child Neurology*, 61(8), 915-923. doi: 10.1111/dmcn.14028
- Morgan, C., Fetter, L., Addie, L., Badawi, N., Bancal, A., Boyd, R., N., Choma, O., Cioni, G., Damiano, D. L., Darrah, J., de Vries, L. S., Dusing, S., Einspieler, C., Eliasson, A. C., Ferriero, D., Fehlings, D., Forsberg, H., Gordon, A. M., Greenes, S., Guzzetta, A., Novak, I. (2021). Early Intervention for Children Aged 0 to 2 Years With or at High Risk of Cerebral Palsy. International Clinical Practice Guideline Based on Systematic Reviews. *JAMA pediatrics*, 175(8), 846-858. <https://doi.org/10.1001/jamapediatrics.2021.0878>
- Noritz, G., Davidson, L., Steingass, K., Council on Children with Disabilities, THE AMERICAN ACADEMY FOR CEREBRAL PALSY AND DEVELOPMENTAL MEDICINE, & Council on Children with Disabilities, THE AMERICAN ACADEMY FOR CEREBRAL PALSY AND DEVELOPMENTAL MEDICINE. (2022). Providing a Primary Care Medical Home for Children and Youth With Cerebral Palsy. *Pediatrics*, e2022060055. Advance online publication. <https://doi.org/10.1542/peds.2022-060055>
- Sedowska, M., Sarecka-Hujar, B., & Kopyta, I. (2020). Cerebral Palsy: Current Opinions on Definition, Epidemiology, Risk Factors, Classification and Treatment Options. *Neuropsychiatric disease and treatment*, 16, 1509-1518. <https://doi.org/10.2147/NDT.S233162>
- Samijn, B., Van den Broeck, C., Deschepper, E., Renson, C., Hoebeke, P., Plazzaert, F., Vande Walle, J., Van Laecke, E. (2017). Risk factors for daytime or combined incontinence in children with cerebral palsy. *The Journal of Urology*, 198(4), 937-943. doi: <https://doi.org/10.1016/j.juro.2017.05.067>

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Questions?

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