

## Caring for Persons with Cerebral Palsy – PCP Handout

Cerebral palsy is a nonprogressive disorder of movement due to early CNS insult during pre- and perinatal (80%) or postnatal (20%) period. Occurs in ~ 3 per 1000 live births. Symptoms and comorbidities vary across subsets as classified by:

- Type - spastic 70-80%, dyskinetic 2.5 -10%, ataxic 1-2.5% or mixed 15%
- Distribution - hemiplegia 25-40%, diplegia 35%, triplegia, quadriplegia 20%
- Severity - General Motor Functional Classification System I-V, least to most severe, 58% ambulatory

Comorbidity	Summary	Management
Intellectual disability	<ul style="list-style-type: none"> <li>• IQ &lt;70 in 19% GMFCS 1-2, 35% GMFCS 3-5</li> <li>• IQ &lt; 50 (7-55%) assoc. w/ GMFCS, spastic quadriplegia, hypotonia</li> </ul>	<ul style="list-style-type: none"> <li>• Dysarthria is not indicative of ID</li> <li>• Verify prior testing for adaptations and planning.</li> <li>• Access adaptive services</li> </ul>
Communication difficulties	<ul style="list-style-type: none"> <li>• 61% overall - hypotonia 95%, dyskinesia 94%, spastic quadriplegia 89%</li> </ul>	<ul style="list-style-type: none"> <li>• Verify ability to report pain and illness</li> <li>• Use augmentative communication – ipad, PECS, etc.</li> </ul>
Mental health	<ul style="list-style-type: none"> <li>• Depression 21%; anxiety 21%; mood disorders 23%, dementia 3.8%, w/ID 16%</li> <li>• Hyperactivity 31%, emotional difficulties 29%, conduct problems 17%</li> </ul>	<ul style="list-style-type: none"> <li>• w/o ID - PHQ9 &amp; GAD7, w/ ID adapted PHQ9 &amp; GAD7 or Glasgow scales. First line SSRI, consider GABA analogue.</li> <li>• Watch neuro sx, interaction of meds w/ spasticity.</li> <li>• Screen for aging changes eg. NTG-EDSD</li> </ul>
Hearing loss	<ul style="list-style-type: none"> <li>• 5% to 16% w/ increasing GMFCS, or hypotonia, higher in dyskinetic, ataxic</li> </ul>	<ul style="list-style-type: none"> <li>• Periodic hearing screen. Check cerumen impaction.</li> <li>• Adaptive services for impairment.</li> </ul>
Vision loss	<ul style="list-style-type: none"> <li>• 30 – 49% assoc w/inc. GMFCS, hypotonia, eg. strabismus, retinopathy of prematurity, cortical visual impairment, field defects, blindness 5.5% assoc w/ GMFCS V or tri/quadruplegia.</li> </ul>	<ul style="list-style-type: none"> <li>• Routine vision exam</li> <li>• Adaptive services for impairment.</li> </ul>
Seizures and other neuro issues	<ul style="list-style-type: none"> <li>• 23-28%, small subset resolve by age 5</li> <li>• GMFCS V 65%, tri/quadruplegia 53%</li> <li>• Pain 65% - back 47%, spasticity</li> <li>• Autonomic dysfunction 33% - flushing, tremors, acute HTN, bradycardia, stroke risk</li> </ul>	<ul style="list-style-type: none"> <li>• Surveillance for seizure-like activity</li> <li>• Address pain management</li> <li>• Spasticity Rx – meds esp. baclofen, botox, surgery</li> <li>• Urgent Rx - sit up, loosen clothes, relieve noxious trigger – bladder, constipation, Rx BP w/nitropaste</li> </ul>
GI issues	<ul style="list-style-type: none"> <li>• GERD 16%, fecal incontinence 14.6%</li> <li>• Constipation 17%, non-ambulatory 59%, ID 67%</li> <li>• Underweight 16.5%, non-amb 22.9%, ID 12-17%</li> <li>• Short stature (shortest quadriplegia vs di/hemi)</li> </ul>	<ul style="list-style-type: none"> <li>• Verify stooling frequency, consistency</li> <li>• Verify diet intake, BMI</li> <li>• Nutrition support, supplements, multivitamins.</li> <li>• Consider growth hormone deficiency</li> </ul>
MSK	<ul style="list-style-type: none"> <li>• Contractures, scoliosis 46% w. progression risk</li> <li>• Hip dislocation (esp. non-ambulatory)</li> <li>• Age 30-40 risk mobility loss, inc. w/ age, early osteoarthritis 16-19%</li> </ul>	<ul style="list-style-type: none"> <li>• Maintain surveillance of scoliosis curve</li> <li>• Shared decision making for surgery w/ curve &gt; 40-50 or hip relocation</li> <li>• PT for loss of function</li> </ul>
Fragility fractures	<ul style="list-style-type: none"> <li>• 5.5% overall up to 38%, risks - immobility, undernutrition, anticonvulsant use.</li> </ul>	<ul style="list-style-type: none"> <li>• Consider Vit D testing, DEXA</li> <li>• Encourage weight bearing as able</li> </ul>
Lung disease	<ul style="list-style-type: none"> <li>• Asthma 24%, COPD 11%, CLD from perinatal injury, fibrosis 2.4% from recurrent aspiration, restriction from severe scoliosis</li> </ul>	<ul style="list-style-type: none"> <li>• Verify swallowing concerns</li> <li>• Consider swallow study</li> <li>• Adapt diet and feeding positioning as needed</li> </ul>
Cardiovascular disease	<ul style="list-style-type: none"> <li>• Increased hypertension 26%, ischemic heart disease, stroke, cerebrovascular disease</li> </ul>	<ul style="list-style-type: none"> <li>• Regular BP testing, routine cholesterol screening</li> </ul>
Urinary incontinence	<ul style="list-style-type: none"> <li>• 32%, increase w/ worse motor or cognitive function, CKD 3.1%, UTIs, hydronephrosis</li> </ul>	<ul style="list-style-type: none"> <li>• Continence supplies prn</li> <li>• Low muscle mass, use cystatin C for GFR <a href="https://www.kidney.org/professionals/gfr_calculator">https://www.kidney.org/professionals/gfr_calculator</a></li> </ul>
Skin ulcers	<ul style="list-style-type: none"> <li>• 7.8- 9.2%, non-ambulatory 27.9%, ambulatory 1.8%, w/ ID 35.3%, w/o ID 1.7%</li> </ul>	<ul style="list-style-type: none"> <li>• Screen skin, teach home surveillance</li> <li>• Verify weight shifting, safe transfers, etc.</li> </ul>
Dental	<ul style="list-style-type: none"> <li>• High dental caries, due to hygiene, enamel hypoplasia, GERD, medication effects</li> <li>• Bruxism, malocclusion, hypersalivation</li> </ul>	<ul style="list-style-type: none"> <li>• Regular dental care, accommodations prn</li> <li>• Supportive care for drooling, meds, salivary surgery.</li> </ul>

### Center for Youth and Adults with Conditions of Childhood — CYACC

Ryan JM, et al (2023). Prevalence and incidence of chronic conditions among adults with cerebral palsy: a systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, 65(9), 1174-1189. Summary by CYACC In 4/25.