



CEREBRAL PALSY NATIONAL GUIDELINES SRI LANKA 2022



World Health
Organization



Cerebral Palsy National Guidelines - Sri Lanka 2022

Sri Lanka College of Paediatricians in collaboration with the Family Health Bureau and the World Health Organization



Cerebral Palsy National Guidelines –Sri Lanka 2022

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Child Care, Development and Special Needs Unit
Family Health Bureau

Message from the Director General of Health Services

Cerebral palsy is a prevailing childhood disability in Sri Lanka. It is generally associated with issues in posture and movement, cognitive impairment, visual impairment, language and communication impairment, feeding difficulties and intellectual impairment. Though there is no permanent cure for this we can take steps to improve their quality of life.

In order to make functional outcomes of these children better, early interventions with an approach of a multi-disciplinary team are required. Early interventions should be conducted through an EI SMART approach, which includes addressing enhancement of environment, sensory development, learning motor tasks, responsive parenting and communication.

This guideline provides a comprehensive guidance for the management of cerebral palsy to all the health care workers. Therefore, I look forward to a positive outcome following the utilization of this manual. Furthermore, as this was brought out successfully by the immense effort of Sri Lanka College of Paediatricians, Family Health Bureau of Ministry of Health and the World Health Organization. I would like to take this as an opportunity to extend my heartfelt gratitude to all those contributors.

Dr. Asela Gunawardena

Director General of Health Services
Ministry of Health

Message from the President, Sri Lanka College of Paediatricians

Cerebral palsy (CP) is the commonest neuro-developmental disorder resulting in physical impairments with a prevalence of 2.5- 5 per 1000 live births in the low middle income countries. With the advancement of perinatal care, surviving infants with morbidities are rising, placing them at a higher risk for CP. The international guidelines on CP recommend evidence based practices in early detection and early intervention with the aim of positively impacting the activity and participation of children with CP in the society and to ensure better futures for them as productive adults.

In keeping with the Sustainable Goal 3 which includes Universal Health Coverage as a strategic priority, we hope that this guideline will enable Sri Lanka to plan and deliver services with equitable access for children with cerebral palsy as envisioned by the World Health Organization.

Therefore, by publishing this guideline the College of Paediatricians aims to collaborate with the Family Health Bureau, of the Ministry of Health to address the gaps and strengthen the processes of early detection, intervention and follow up of children at risk or with CP to optimize their developmental potential.

The editorial committee of this guideline has synthesized the most recent evidence on CP management and has presented this in a simple and user friendly format to be used by medical and allied health professionals. I thank the editorial committee, reviewers and the guideline committee of the SLCP for compiling this valuable guideline.

As the President of the SLCP I sincerely hope that, this guideline will be used by the relevant clinicians in Sri Lanka to uplift the quality of life of children in Sri Lanka.

Professor Shaman Rajindrajith

MBBS (Ruhuna), MD Paediatrics (Colombo), FRCPCH (UK), PhD (Amsterdam)
President Sri Lanka College of Paediatricians

Message from the Director Family Health Bureau

Cerebral palsy is the commonest childhood physical disability. Preterm births and perinatal asphyxia are known to be the most common causes of cerebral palsy. In present, an increase number of children are acquiring cerebral palsy due to many causes. It is a life-long permanent condition which is static and unchanging. With early identification and early intervention a comprehensive service can be provided to the affected children. This will help them to have a quality life by improving their movements and muscle coordination.

Early interventions for cerebral palsy is not beneficial only for the affected child but for the entire family as well. However, interventions have to be provided in a methodical manner under the supervision of a multi-disciplinary team. Therefore, all the standardized steps in management of cerebral palsy extending from screening to follow up were compiled and cerebral palsy national guidelines were prepared. I expect that it will bring out the maximum of our health care workers capabilities in the process of cerebral palsy management.

Here by with warm thanks I would like to appreciate all the hard work undertaken by the Paediatric team to make this product a success. Moreover, my gratitude goes to Ministry of Health, child care, development and special needs unit of Family Health Bureau and to the World Health Organization for their utmost support. My wish is to see this valuable creation being helpful to bring a smile to the faces of those budding flowers.

Dr. Chithramalee De Silva

Director Maternal and Child Health
Family Health Bureau

Message from the WHO country Representative

Cerebral palsy (CP) refers to a heterogeneous group of conditions involving permanent motor dysfunction that affects muscle tone, posture, and/or movement. Worldwide it is known to be the commonest motor disability among children. Population-based studies report that the prevalence estimates of CP range from 1.5 to more than 4 per 1,000 live births. As there is no cure, majority of them require the help of their family and society to carry out their daily routines.

Early stage identification is very important for better outcome of a child. Once cerebral palsy is diagnosed, initiation and continuum of rehabilitation is very important. Similar to other neurodevelopmental disorders, Cerebral palsy also warrants a multi-disciplinary approach.

Sri Lanka provides a free health care service to its citizens and has to depend on available scarce resources. It has been a long term challenge to deliver quality health services for children with disabilities including CP . With gradual expansion of subspecialty experts and allied health professionals, Ministry of Health attempts to upgrade the available services facilitating multidisciplinary approach.

The present National Guideline for Cerebral Palsy Management has been prepared, with the aim of streamlining the management of children with CP by the multidisciplinary team. I would like to take this opportunity to extend my gratitude for all the experts who contributed this important work.

Dr. Alaka Singh

WHO Country Representative for Sri Lanka

List of abbreviations

Abbreviation	Definition
AAC	Augmentative and Alternative Communication
AFO	Ankle Foot Orthosis
AIMS	Alberta Infant Motor Scale
CFCS	Communication Function Classification System
CIMT	Constraint-induced Movement Therapy
CNS	Central Nervous System
CP	Cerebral palsy
COPM	Canadian Occupational Performance Measure
CVI	Cortico Visual Impairment
CVS	Cardio Vascular System
DAYC	Development Assessment of Young Children
DBS	Deep Brain Stimulation
EDACS	Eating and Drinking Classification System
EI SMART	Early Intervention: Sensorimotor Development, Attention and Regulation, relationship and Therapist support
GAME	Goal-Active-Motor Enrichment
GAS	Goal Attainment Scale
GIT	Gastro-intestinal Tract
GMA	General Movement Assessment
GMFCS	Gross Motor Function Classification System
GOR	Gastro-oesophageal Reflux
HAT	Hypertonia Assessment Tool
HINE	Hammersmith Infant Neurological Examination
ICF-CY	International Classification of Functioning: Children and Youth
IQ	Intellectual Quotient
IUGR	Intra Uterine Growth Restriction
LL	Lower Limb
LMIC	Low and Middle Income Countries
LMN	Lower Motor Neuron
MACS	Manual Ability Classification System
MDT	Multi-Disciplinary Team
MRI	Magnetic Resonance Imaging
NA	Nutrition Assessment

NI	Nutrition Impairment
OT	Occupational Therapy
PLIC	Posterior Limb and Capsule
PVE	Periventricular Echogenicity
PVL	Periventricular leukomalacia
RBC	Red Blood Cells
ROM	Range Of Motion
SDR	Selective Dorsal Rhizotomy
SEMLS	Single Event Multiple Surgery
UL	Upper Limb
UMN	Upper Motor Neuron
USS	Ultra Sound Scan
VFCS	Visual Function Classification System
WHO	World Health Organization
WMI	White Matter Injury

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Cerebral palsy is the most common physical disability in childhood. Every 1.5 to 3 children born per 1000 live births are diagnosed with cerebral palsy (CP) ¹. Epidemiological studies conducted in Low and Middle Income Countries (LMIC), reports higher prevalence ranging from 4.4 to 10 per 1000 live births or children which depicts the increased risk of cerebral palsy². Preterm is the most important cause for cerebral palsy³, with the risk being 50 times more than that of full term birth, if babies are born before 28 weeks of gestation. Perinatal hypoxia is the other commonest cause but only $\leq 10\%$ children with CP experience major birth asphyxia³. With the availability of high-quality evidence through systematic reviews, “high risk of cerebral palsy” can be accurately predicted before 5 months of corrected age². Earliest possible diagnosis and interventions will result in better motor and cognitive outcomes improving activity and participation of children and caregiver well-being. It is therefore, imperative to identify children who are at substantial risk of cerebral palsy, as early as possible to offer appropriate early interventions with the view of investing on neural plasticity, aiming to minimise the costs of long term interventions.⁴ **Data from high income countries indicates that 2 in 3 individuals with cerebral palsy will mobilise, 3 in 4 will talk, and 1 in 2 will have normal intelligence⁴**

It is important to have an honest discussion with the family about outcome and interventions in light of non-availability of cure at the current era. **Offer evidence-based guidance to improve the functional outcomes of children at the earliest possible time through a multi-disciplinary approach.** It is essential to provide psychological support for parents and guidance to carry out home based activities because the outcomes of children will depend on the experience dependent motor learning that will take place at home⁵.

Outcomes following early and prompt detection and evidence based intervention strategies

Early and prompt implementation of clinical practice guidelines in higher-income countries have improved clinical outcomes in children with CP and latest evidence through CP registers suggest a decline in CP prevalence in such settings by 30%⁶.

BOX
01

Definition of cerebral palsy

Cerebral palsy describes 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.

The motor disorder of cerebral palsy is often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal disorder.^{1, 4}

BOX
02

02 Pathology of cerebral palsy

Cerebral palsy results from heterogeneous etiological and pathophysiological causes². Rather than abnormalities that take place during brain development, 90% of children develop cerebral palsy from destructive mechanisms which injure healthy brain tissue.⁷ Hypoxia and ischaemia are the main causes for brain injury which leads to a cascade of events of chemical and electrical activities in the brain tissue that will cause cell necrosis and apoptosis. Pathological and imaging studies demonstrate varying combinations of lesions in the cerebral cortex, the hemispheric white matter, the basal ganglia and the cerebellum. Some of the neuroprotective mechanisms described in perinatal medicine are targeted at preventing these events².

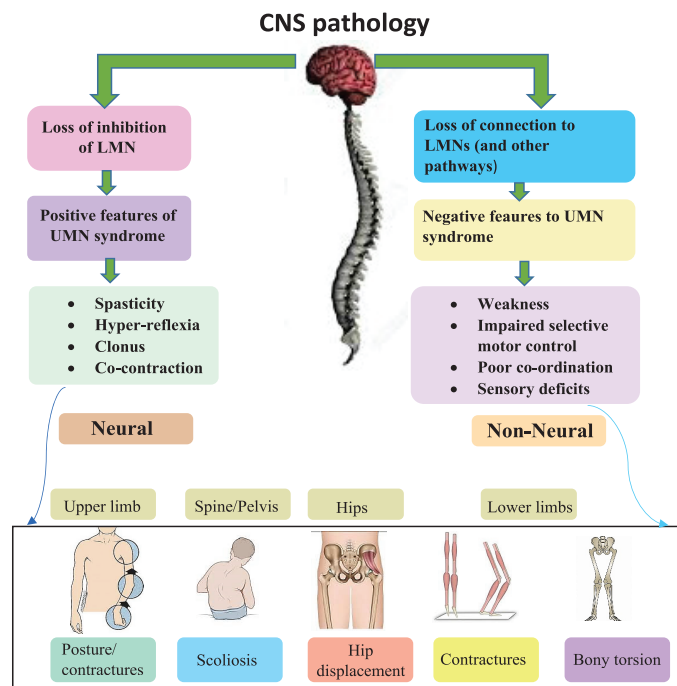


Figure 1: Upper motor neuron syndrome

Depending on the location of the brain lesion, cerebral palsy is associated with various motor deficits. Disruption of cortico–striatal–thalamic–cortical and cortico–cerebellar–cortical networks impairs motor planning, coordination, muscle strength regulation, motor learning and fine motor skills.² Primitive reflexes, abnormal posture and movement, abnormal muscle tone including spasticity and hyperactive reflexes retain with the damage that occurs to motor pathways projecting towards brain stem and spinal relays (figure 1).

The motor impairments, with poor motor repertoire, hypertonia, progressive muscle changes related to neuronal, nutritional and mechanical factors, lead to musculoskeletal deformities.²

03

Classification of cerebral palsy

a. Clinical classification according to motor type and topography (figure 2)³

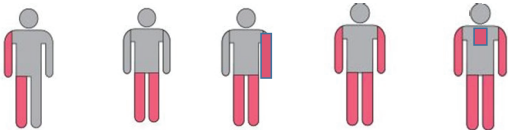
Confirmed diagnosis of cerebral palsy	
↑ TONE	↓ TONE
Persistent increased tone	Varying tone
Motor cortex damage  Spastic 85%-91%  Unilateral L/ Hemiplegia R/Hemiplegia Spastic Diplegia Spastic Triplegia Spastic Quadriplegia Spastic Pentaplegia	Basal ganglia damage  Dyskinetic 7%-4%  Dystonic CP Choreo-athetoid CP
	Cerebellum damage  Ataxia 4%-6%  Ataxic CP

Figure 2: Classification according to motor and topography

* Only in some countries hypotonic CP (2%) is described as a motor subtype³

b. Gross Motor Function Classification Systems (GMFCS) Levels

Gross Motor Function Classification system explains different levels of motor functions according to age groups describing ages from 0-18 years (figure 3). It describes abilities in movements such as sitting, walking and the use of mobility devices⁸. It is helpful because it provides families and clinicians with a clear description of a child's current motor function, and an idea of what equipment or mobility aids a child may need in the future. **The Cerebral Palsy Road map is a useful tool for clinicians because it will indicate how other functional requirements of children relates to the GMFCS Levels and functional abilities in other domains.**

https://www.gillettechildrens.org/assets/uploads/care-and-conditions/CP_Roadmap.pdf⁸

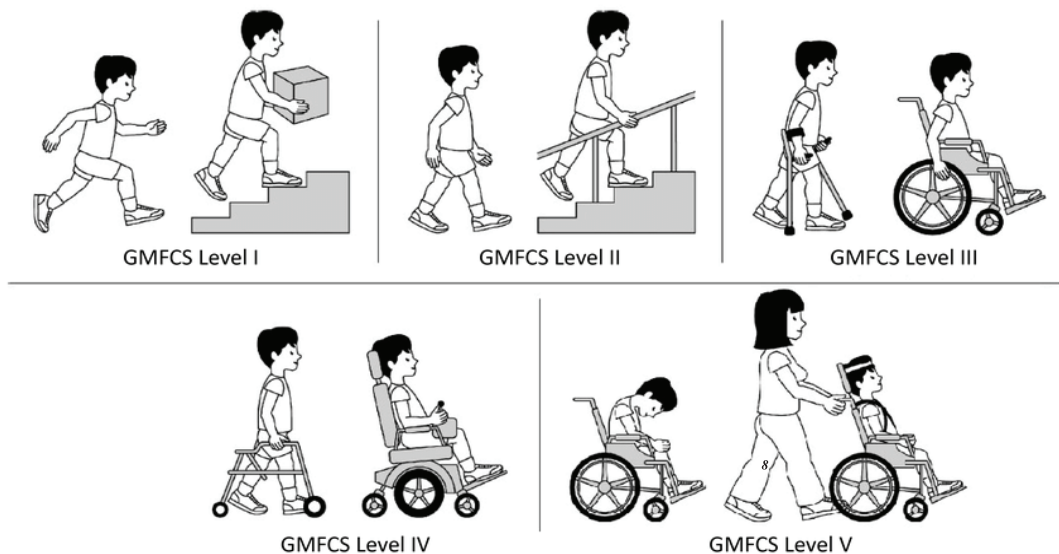


Figure 3: Gross Motor Function Classification GMFCS levels

c. International Classification of Functioning, Disability and Health (ICF-CY) framework

The World Health Organisation (WHO) brought in the ICF-CY to define the dynamic nature of a condition that results in body structure or functional impairment, based on the contextual factors (the environment and the personal factors) and to define the need for activity and participation of these children despite their difficulties (figure 4)⁹

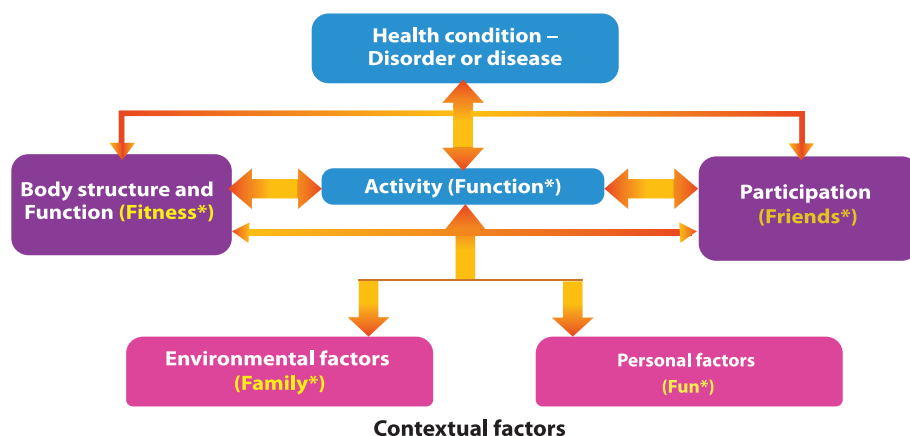


Figure 4 : International Classification of Functioning, Disability and Health (ICF-CY) framework 2021

Definitions of ICF-CY classification⁹

Body functions - The physiological functions of body systems (including psychological functions).

Body structures - Anatomical parts of the body such as organs, limbs and their components.

Impairments - Problems in body function and structure such as significant deviation or loss.

Activity - The execution of a task or action by an individual.

Participation - Involvement in a life situation.

Activity limitations - Difficulties an individual may have in executing activities.

Participation restrictions - Problems an individual may experience in involvement in life situations.

Environmental factors - The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning.

Functioning is an umbrella term for body function, body structures, activities and participation. It denotes the positive or neutral aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors).

Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors).

BOX
03

*“F-words” define a child-friendly version to the ICF-CY. This holistic approach encourages us to focus on factors that are important to all children's development - their participation, activities, and environment (annexure 1). <https://www.canchild.ca/en/research-in-practice/f-words-in-childhood>¹⁰

a. Arriving at a diagnosis before 5 months of age

This should mainly focus on the quality of movements rather than milestone acquisition.

There should be definitive essential criteria and one additional criterion to diagnose CP³.

1. Essential criteria

Motor dysfunction – assessed by specific tools according to the particular age groups

E.g.: -General Movement Assessment (GMA)¹¹ (**Annexure 2**), Hammersmith Infant Neurological Examination (HINE)¹² score. (**Annexure 3**).

2. Additional criteria

(At least one should be present)

1. Abnormal neuroimaging (Magnetic Resonance Imaging (MRI)/ Serial Ultra Sound Scanning (USS) findings).¹³
2. Clinical history indicating risk for cerebral palsy.

Up to 17% of people with cerebral palsy have normal MRI brain scans, a figure that rises to 50% for those with dyskinetic cerebral palsy.²

Cerebral palsy or “high risk of cerebral palsy” can be accurately predicted before age 6 months’ corrected age³

When the infant is perceived to be at risk of cerebral palsy, he or she should be referred for cerebral palsy-specific early intervention³.

b. Early prediction of motor severity

When an infant is detected as high risk for CP, the family will expect you to discuss the future of the child with them. Your team needs to undertake certain specific assessments. Refer annexures for assessments. This algorithm summarises the assessments that will guide you during the discussion with the families (figure 5)4.

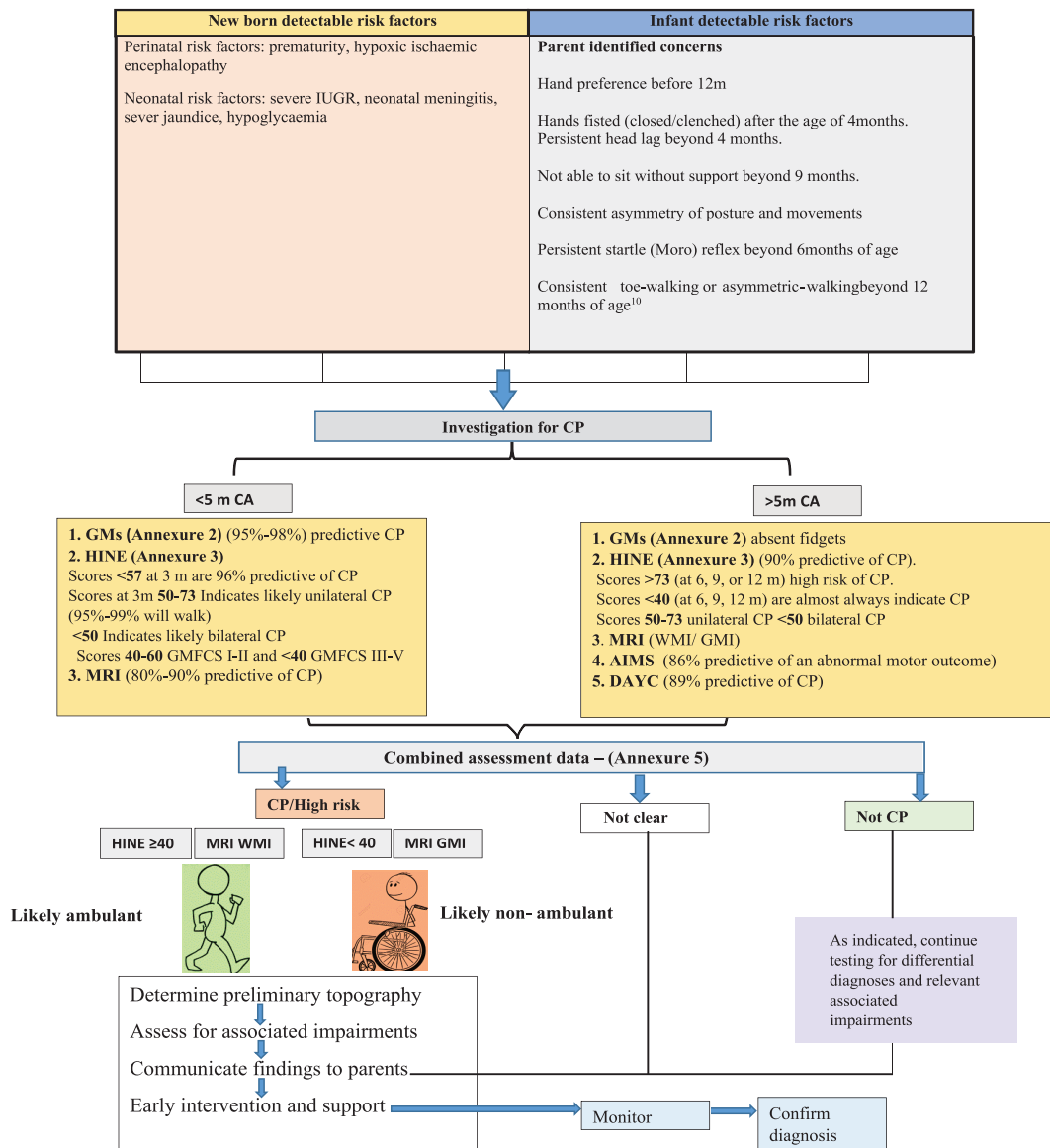


Figure 5: Early prediction of motor severity

IUGR : Intrauterine Growth Restriction
 CA : Corrected Age
 GMs : General Movements
 HINE : Hammersmith Infant Neurological Examination
 MRI : Magnetic Resonance Imaging
 AIMS : Alberta Infant Motor Scale
 DAYC : Developmental Assessment of Young Children
 WMI : White Matter Injury
 GMI : Grey Matter Injury

c. Early Intervention(EI)

Commence **cerebral palsy specific early interventions** for **high risk infants** as soon as they are identified, preferably within the first 12 months of life.

1. Key areas in early intervention

All high risk and confirmed infants should be referred for EI programmes following the EI SMART approach. (Early intervention, sensorimotor development, attention and regulation, relationships, and therapist support).^{14, 15} The following are the key principles of an early intervention programme.

Key principles of Early Intervention (EI)

1. Environment enrichment – An environment that facilitates enhanced motor, cognitive, language and sensory stimulation in comparison to standard housing conditions.

Eg: providing opportunities for tummy time, encourage the child to explore by having bright toys

2. Sensory development – Enhance the abilities of infants to use sensory information from the first month of life.

Eg: using different texture toys, adjusting the lighting in the room, gradual exposure to different environmental noises.

3. Motor learning: active ‘scaffolding’ - These infants need more task-specific practices than typically developing infants to **learn a motor task through active motor learning**. Invest in neural plasticity by repetitive activities with appropriate feedback to learn new motor skills.

Eg: encourage early hip movements through tummy time, early weight bearing while sitting on a bench and playing.

4. Responsive parenting: It is important to support parents to become sensitive to the infants’ signals of interests and distress from early days. This entails parents recognising and responding to the child’s emotional and cognitive needs by collaboratively engaging with them to overcome challenges during play and experiences to achieve their goals. These will also build attention control. And build a healthy relationship with the caregiver.

5. Communication - Highlights the importance of parent/ caregiver presence and input, from the neonatal period onwards to facilitate early language acquisition.

Eg: responsive cooing and babbling, exposure to early talking with the family members, introduction of early story telling.

d. Measure of outcomes

i Gross Motor Function Measure (GMFM)

Gross Motor Function and Measure (GMFM) is a motor specific assessment tool to assess the functional abilities of children with CP (Figure 6) and will direct the family and the therapists on the next goal to achieve.

(https://canchild.ca/system/tenon/assets/attachments/000/003/355/original/gmfm-88_and_66_scoresheet-V4.pdf)¹⁶

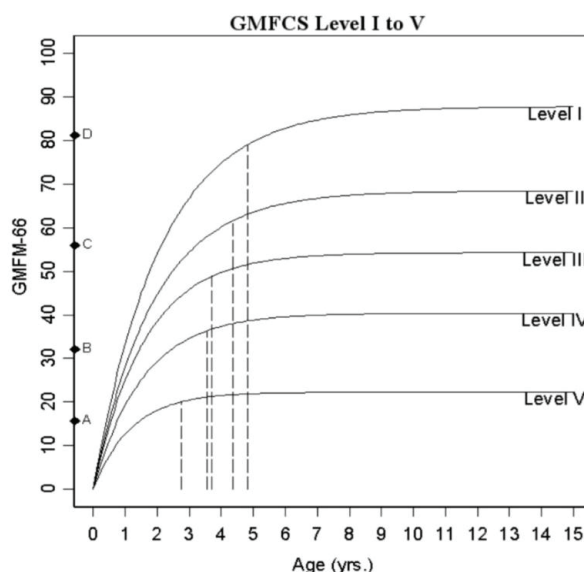


Figure 6: GMFCS Curves¹⁶

GMFCS curves describe the pattern of gross motor skills development of children with cerebral palsy over time.¹⁷

The Y axis of this graph denotes gross motor skills assessed by a specific assessment tool: Gross Motor Function Measure (GMFM) and the X axis indicates the age of the child. These curves show how children when detected early have a higher possibility to achieve better gross motor functions as the curves show a steep climb in the earlier ages and then plateaus.

Also these curves will be helpful to demonstrate to parents how the child's progression in motor functions can be tracked.¹⁷ Further GMFM skill scores can be interpreted by plotting on this graph and the child's progression will predict the final GMFCS level.

ii Other measures to monitor children

Hammersmith Infant Neurological Evaluation (HINE), Alberta infant motor assessment (AIMS)¹⁸ and Bayley scales of infant development are some of these.

Often in practice you will come across children diagnosed with CP. It is your responsibility to optimise the management of these children to ensure better activity and participation of these children.

Management will vary on the motor type of CP. Dystonia and spasticity have different pathological features, therefore different management strategies are required. (**Annexure 4**)

a. Posture and movement

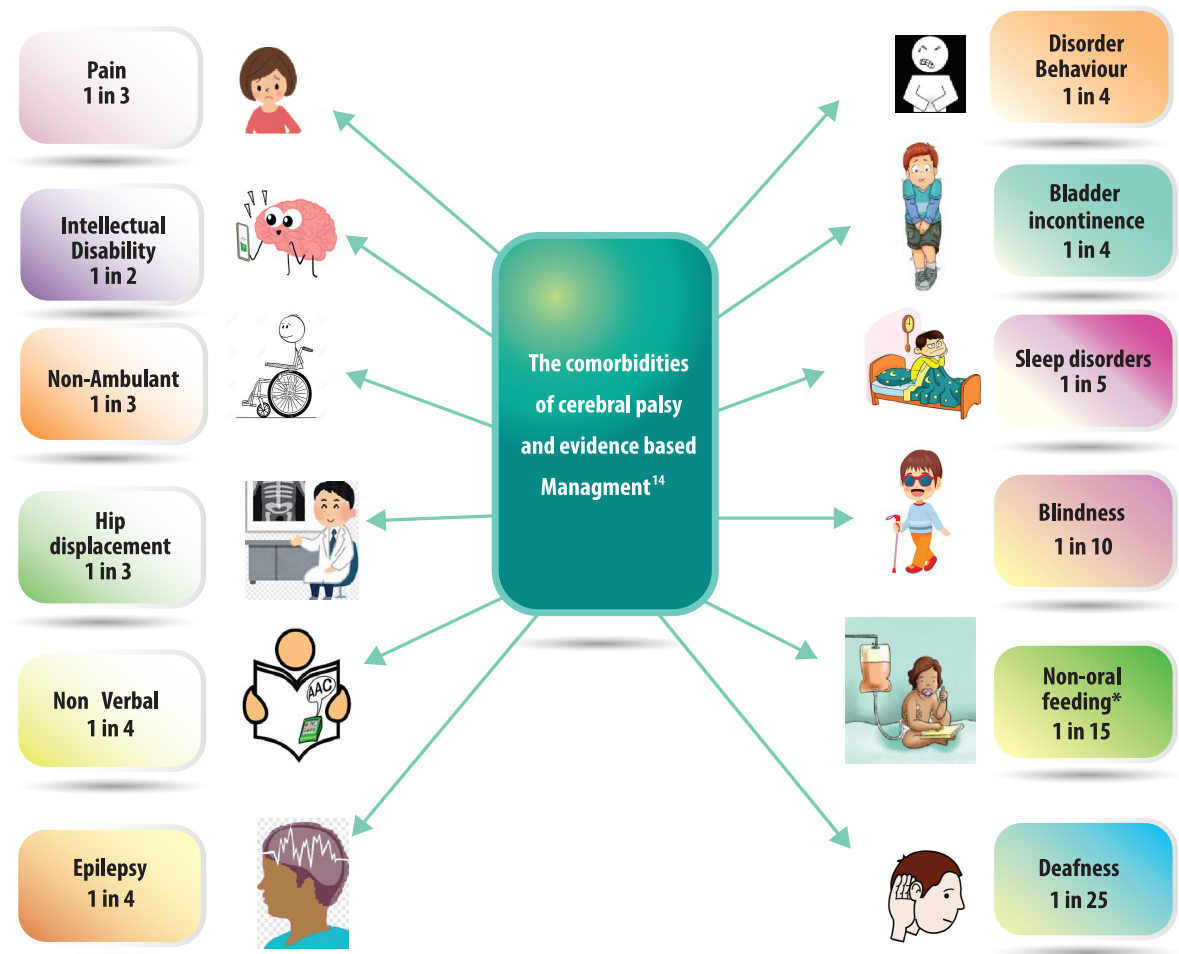
• Motor Assessments: functional mobility and GMFCS levels¹⁹ • Conduct Gait analysis: to alter the treatment options and find out the disability related to the function.¹⁹ • Hip Surveillance: all children should undergo antero-posterior pelvic radiographs according to hip surveillance guidelines (Annexure 6) commencing at age 12 months.²⁰ • Tone: Need to define the motor type		
HYPERTONIA – Abnormally increased resistance to externally imposed movement about a joint <i>Hypertonia Assessment Tool (HAT) 21</i>		
Spasticity	Dystonia	Rigidity
A velocity-dependent increase in stretch reflex activity. Resistance to externally imposed movement increased with increased speed of stretch of movement. <i>SPASTICITY IS FELT</i>	Increase in muscle activity at rest, tendency to return to a fixed posture, increases resistance with the movement of the contralateral limb, and changes with a change in behaviour or posture. Involuntary sustained or intermittent muscle contractions causing twisting and repetitive movement, abnormal posture, or both. <i>DYSTONIA IS SEEN</i>	Velocity independent bidirectional resistance.
Assess range of motion and joint contracture: Dynamic and static contracture evaluation. There is a steady decrease in the range of motion around joints from 2-14 years, because fixed contracture development takes place²². Assess for dynamic contracture and manage by medications, physical therapy, AFOs, casting and Botulinum toxin injections²³.		

Figure 7: Posture and movement management

b. Co-morbidities in CP

In children with a diagnosis of CP, team approach to management of comorbidities is vital.²⁴ It is essential to go through a check list to monitor the emergence or the presence of these and offer necessary interventions/ medications.

(Annexure 7): Recommended medication/ treatment for cerebral palsy complication management.



*GORD, Aspiration and recurrent pneumonia as complication may be seen in this group of children, however exact prevalence rates are not available.

Figure 8: The comorbidities of cerebral palsy

c. Cognitive impairment

Half of all children with cerebral palsy have co-occurring intellectual disability (46%) of varying severities.²²

All early intervention programmes should have cognitive stimulating activities included

d. Visual impairment

- Vision is essential for learning; connect information through all the senses, communication systems, access to the environment, reading and for autonomy and independence.
- Vision can be assessed in the first 48 hours of life using the early assessment of visual function in full-term new-borns.
- Any infant with abnormal vision at term-equivalent age should receive visual intervention and be reassessed at 3 months.
- Cortico- visual impairment (CVI) is an impairment of the vision due to injury to the visual pathways in the brain rather than ocular deficits. Needs detection before 12 months for best outcomes (**Annexure 8**).²⁵
- The Visual Function Classification System (VFCS), was developed to classify the visual abilities of children with CP. “Visual abilities”. It includes 5 Levels. Please refer further. <https://onlinelibrary.wiley.com/share/DEYDNVZAGMGF5M8K6RD2?target=10.1111/dmcn.14270> ²⁶

e. Language and communication impairment.

- Available evidence indicates that communication training and conversational partner training may be effective intervention strategies for children with cerebral palsy.²⁰
- Aided language stimulation (ALS) is a communication intervention strategy whereby the communication partner points to symbols on an AAC system while saying the corresponding word.
- Communication Functional Classification System (CFCS). Please refer following web links for further details:
http://cfcs.us/wp-content/uploads/2014/02/CFCS_universal_2012_06_06.pdf.²⁷

f. Feeding difficulties

- For non-oral feeding, swallowing safety should be comprehensively assessed because aspiration pneumonia is the leading cause of death in CP and is mitigated by tube feeding²⁸
- 30-80% of children with CP have feeding and swallowing problems (Depending on GMFCS Levels)²²

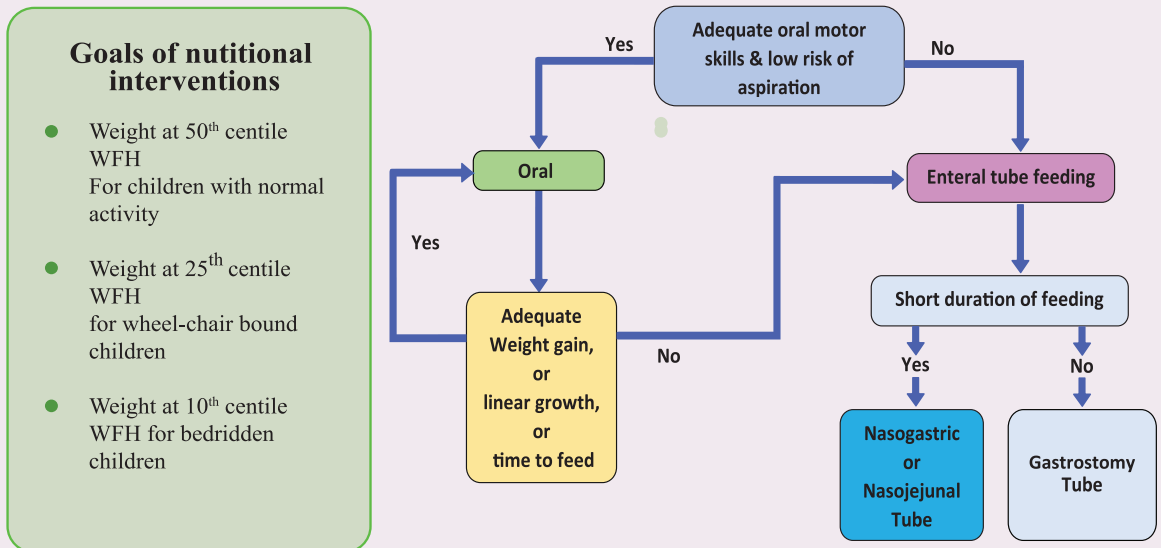


Figure 9: Route of feeding

Image courtesy: Claudio romano et al., 2017, European Society for Paediatric Gastroenterology and Nutrition Guidelines, ESPN congress The Hague 2017, Specific nutritional care in children, Maintaining good nutritional status in cerebral palsy., J Hulst

The Eating and Drinking Ability Classification System (EDACS), developed to determine the eating and drinking of individuals with CP in everyday life

- For further details please refer following web links:
<https://www.kidshealth.org.nz/sites/kidshealth/files/pdfs/edacs-algorithm-clinical.pdf?language=enhtml>²⁹

g. Education/ intellectual impairment

1. The educational convenience of students should be given priority over administrative inconvenience in service-system decisions.³⁰
2. Individual educational plans should be jointly developed by parents and educators to reflect the needs of students to function in a variety of current and subsequent integrated school or community environments.
3. All children should be offered mainstream education at possible instances with adequate accommodations for learning, play and examinations. The present Sri Lankan examination system provides multiple accommodations for all children with disabilities.
(<https://www.doenets.lk/>)³¹
4. When providing special educational opportunities teaching instructional content should be referenced against functional, age appropriate skills required for performance in integrated environments selected from at least the following domains: domestic living, vocational stores/services, transportation/mobility, and leisure.
5. Regardless of presumed physical, sensory, or cognitive deficits, students should be taught through skill adaptations when necessary, to participate at least partially in integrated environments.

There are several rare genetic and metabolic syndromes that mimic cerebral palsy³². In the absence of clear clinical criteria for the diagnosis of CP or when there are features which are not characteristic of CP, it is essential such differential diagnoses are considered by the team.²⁸

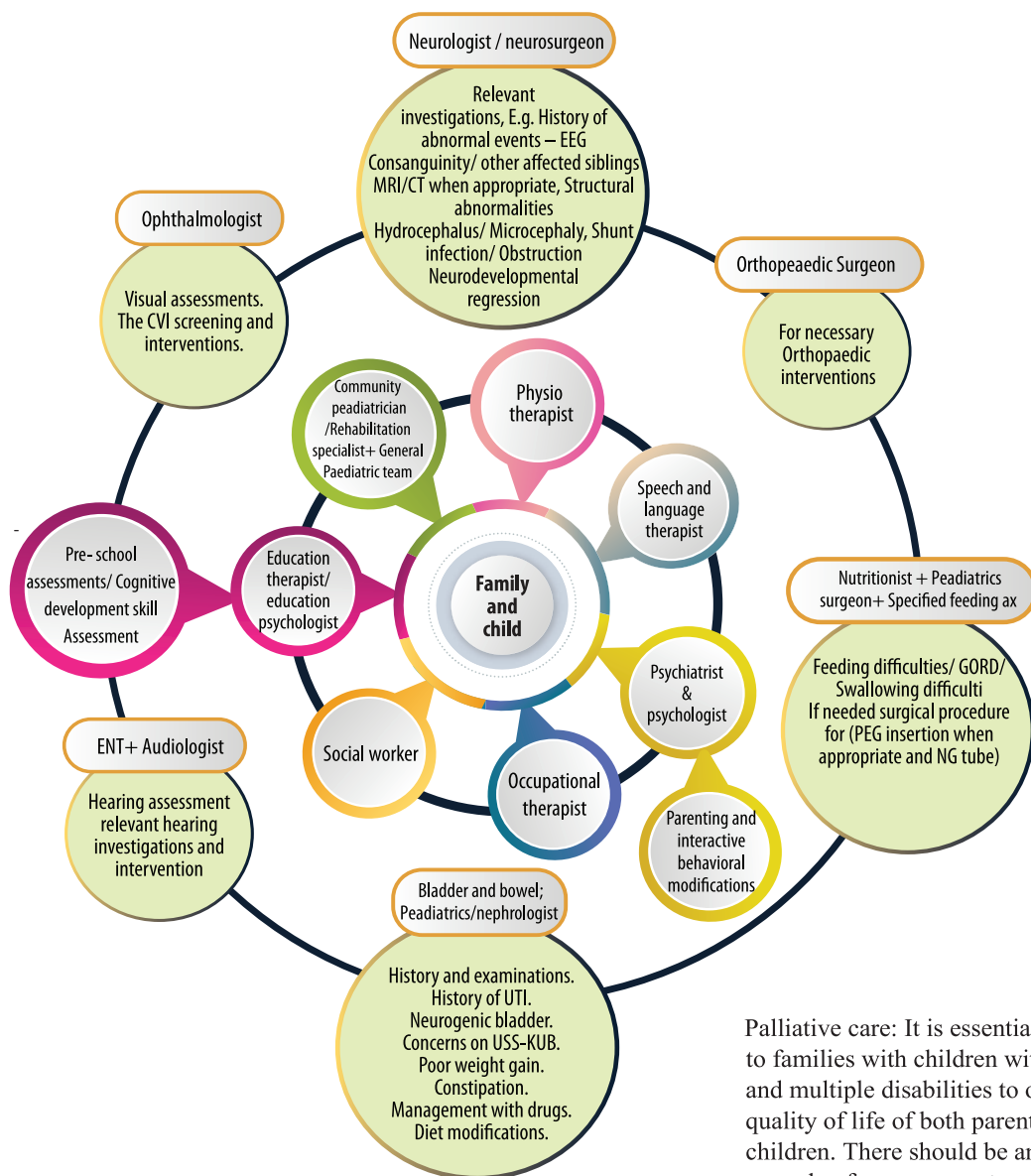
If a child presents with following features referral to a tertiary center with adequate resources for further investigations and management should be considered.

Clinical features that should make you suspect conditions other than CP

- No history suggestive of a perinatal insult
- Normal findings on imaging (MRI/CT brain)
- Fluctuating or paroxysmal symptoms (motor, eye or systemic)
- Developmental regression or lack of expected improvement from therapy
- Family history of consanguinity, neurological disorders/ early deaths, miscarriages
- Systemic features (vomiting, episodic drowsiness, protein aversion, dysmorphism, organomegaly, neurocutaneous stigmata, large head)
- Features of peripheral nervous system involvement (eg: absent reflexes, fasciculation's, sensory signs)
- Unexplained new onset neurological symptoms or signs

BOX
05

All interventions should be goal directed and family centred at all times. Working with a multi-disciplinary team (MDT) in an interdisciplinary approach is important when managing a child with cerebral palsy and assessing the progress and will influence the child's activity and participation will impact the future.



Palliative care: It is essential to speak to families with children with severe and multiple disabilities to optimize quality of life of both parent and children. There should be an advance care plan for assessment and treatment of physical, psychosocial and spiritual issues.

Figure 10: Roles of clinicians in multi-disiplinary team

a. Setting goals: How to set measurable goals:

Goals should be made according to the Goal Attainment Scale (GAS)

- Goals can be written for all levels of functional difficulty identified by the International Classification of Functioning, Disability, and Health.^{33, 34}
- Basic requirements for goal setting should be relevant, understandable, measurable, behavioural, attainable and within a time frame.
- Set one or two goals at a time for better outcomes.

Example of Goal setting:

For a child of four years GMFCS II level with spastic diplegic CP, who can stand alone and walk with difficulty.

Therapy discipline: Physical therapy

Sub category: Functional voluntary movement control.

Target area: Functional play to throw a ball

Functional level: Functional engagement in play.

The goal set for this child's age and GMFCS level and skills level are relevant and is understandable by the family and the child. The goal is measurable and attainable within the time frame. It is a behaviour related skill

Time Line: 3 months.

Goal Attainment Rating Scale:

-2 The child should be able to grab the ball with both hands and lift to initiate throw to any target with support within 10 minutes.

-1 The child should be able to grab the ball with both hands and lift the ball to throw to any target with support within 8 minutes.

0 The child should be able to lift the ball from both hands and throw to any target within 8 minutes without support.

+1 The child should be able to lift the ball from both hands and throw to any target within 5 minutes without support.

+2 The child should be able to lift the ball and throw to a specific target within 2 minutes without support.

BOX
06

b. Outcome measurements:

Using Canadian Occupational Performance Measure (COPM)

This tool is a standardized evidence-based outcome measure that focuses on self-care, productivity and leisure from the client's perception to be measured and addressed by the multi-disciplinary team (MDT). This measure should be conducted in the following steps:

1. The MDT members should conduct a detailed assessment of the child.
2. Then they should discuss with the family about the most important concerns which they want to address. It will be helpful to encourage the family to think about a typical day or their expectations of the child in the near future *eg: the child needs to attend the preschool in six months.*
3. Then the family is requested to score the present performance of the child in a scale from 0-10 and their level of satisfaction (0-10) in each skill they identified.
4. Following the intervention programme the child will return to the same group of MDT members after a defined time period. Then the COPM should be carried out to re-assess the progress.

<http://blogs.elon.edu/ptkids/files/2012/03/COPM.pdf> ³⁵

<https://www.thecopm.ca/learn/#wp-video-lightbox/0/> ³⁶

Initial assessment			Reassessment	
Occupational performance problems	Performance 1	Satisfaction 1	Performance 1	Satisfaction 2
1.Able to remove the pants when using the toilet	4	3		
2. Walk from the door to the gate 2m) using the walking aids by himself	3	3		
3. Able to use the pencil in the class room for 50% of the writing activities	5	4		
4.Able to bat with friends when playing while sitting on wheelchair	2	0		
5. Answer question in the classroom, orally during lessons	5	1		
Scoring Total score = total performance/ #of problems	Performance score 1 14/4	Satisfaction score 1 10/4	Performance score 2	Satisfaction score 2

Example: Master X: 4 year-old boy in GMFCS Level III

c. Practising Evidence-based interventions and recommendations

In the landmark systematic review on interventions for children with cerebral palsy in 2020, Novak²³ introduced “traffic light action” system for managing CP. The below table identifies the green light interventions which are of proven benefit to children according to level 1 evidence.

Table 1: Evidence based interventions and recommendations

Area of intervention		
Early intervention	Constraint-Induced Movement Therapy CIMT & Bimanual Goal active motor enrichment General stimulation	Improve bimanual hand function and active motor learning
Cognition	Literacy Play therapy Early stimulation	Improve cognitive development
Communication	Augmentative and Alternative Communication (AAC) Speech and language therapy	Improve functional communication Social inclusive
Posture and movement/ Motor	Task specific training Mobility training Botulinum toxin + Physiotherapy+ Casting Intrathecal baclofen Ankle Foot Orthoses (AFO)	Improve functional mobility Improve motor function
Tone	Intramuscular Botulinum toxin Botulinum toxin +OT Oral baclofen Diazepam	Reduce spasticity, dystonia Improve gait kinematics Goal achievement
Contractures & alignment	Botulinum toxin + Casting UL and LL casting	Improve passive (Range of Motion) ROM Prevent hip displacement and spinal deformities
Drooling and oral health Meal time	Botulinum toxin Electrical stimulation +oral sensory motor treatments Glycopyrrolate Trihexyphenidyl	Improve oral function Reduce sialorrhea Improve dental health
Parent outcomes	Acceptance and commitment therapy Stepping stones triple p	To reduce stress Improve quality of life Improve child behaviour
Self-care/ function	Goal directed training Home program	To improve self-care

Hypertonia lowering medications and Botulinum toxin

- 1. Hypertonia lowering medications (baclofen, trihexyphenidyl, carbidopa/ levodopa) are beneficial during early stages of CP to enable motor learning but should be prescribed after careful team evaluation and discussion with the Consultant.**
- 2. Decision to inject Botulinum toxin is decided by careful assessment of motor type, range of motion of muscles, muscle mass and gait analysis. There should be discussion with Developmental Paediatrician/ Paediatric Neurologist/ Rehabilitation specialist with the physiotherapist and prosthetic and orthotic clinician in an ideal setting.**
- 3. Botulinum toxin is recommended for functional improvement for the upper limb from later infancy and for lower limbs when children start weight bearing³⁷**

BOX
07

a. Antenatal and perinatal care

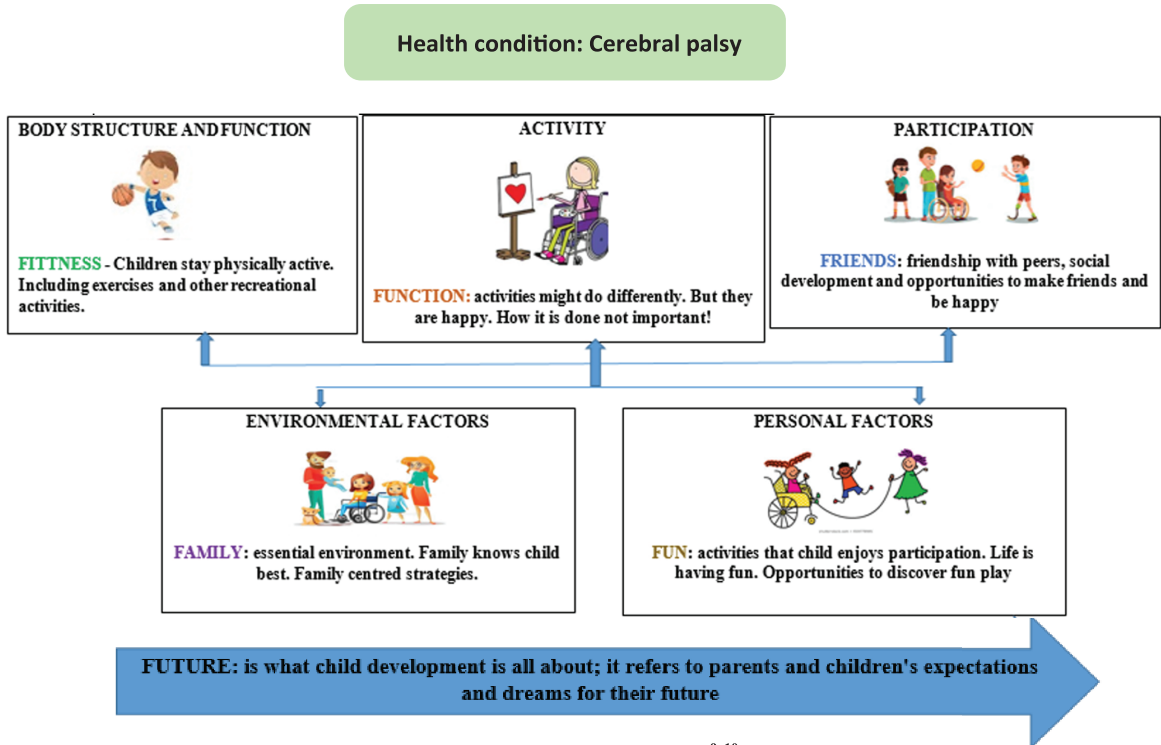
- Antenatal magnesium sulphate before delivery of an infant less than 30 weeks' gestation prevents 30% of cerebral palsy²³.
- Antenatal corticosteroids decrease intracranial haemorrhage and thereby also act as an effective Neuroprotectant (green light) and have become the standard of care
- Prophylactic caffeine (methylxanthines) before extubation contributes to preventing cerebral palsy
- For babies born at term with neonatal encephalopathy or asphyxia, therapeutic hypothermia commenced within 6-h of delivery is neuroprotective and prevents 15% of cerebral palsy associated with intrapartum hypoxia according to evidence published in high income countries. However recent data from low middle income countries including Sri Lanka shows therapeutic hypothermia for HIE did not reduce the combined outcome of death or disability at 18 months of age³⁸.

Things not to do!!!!

- **Handling child passively or manipulating using hands of therapists/caregivers or rote practices, will only result in adversities of the musculoskeletal system**
- **Orthopaedic surgery for contractures should not be performed before 6 years of age.**
- **There is no place for steroids in management of cerebral palsy.**
- **Surgeries for squint should not be performed without complete assessment for CVI and discussion with the ophthalmologist and the child development care team.**

	0-20 weeks			5m-1Y	1-18 Y			
	0-8wk	9-12wk	12-20wk	5m-12m	1-3Y	3-5Y	5-12Y	12-18 Y
Neurology								
General movements assessment								
Writhing age								
Normal								
Cramp synchronized								
Chaotic								
Poor Repertoire								
Fidgety age								
Normal								
Abnormal								
Absent								
Neuroimaging								
Tone and reflexes								
Motor Functions								
HINE/AIMS								
GMFM								
GMFCS Levels								
Fine motor/ Communication/Visual/etc.								
CVI Screening & Assessment								
MACS Level								
CFCS Level								
Communication assessments and alternative devices /AAC								
Hearing assessment								
Sensory profile								
Cognitive development								
Development assessment								
Feeding & swallowing assessment								
Musculoskeletal Assessment								
Gait assessment & abnormalities								
Hip surveillance and migration percentage (MP %)								
Musculoskeletal deformities/ structural abnormalities								
AFO								
Botox								
Serial casting								
Ambulatory/mobility devices								
Orthopaedic referrals								
Education								
Preschool assessment								
School accommodation, IEP/ School visits/ school readiness program								
IQ Assessment								
General Assessment								
Growth (weight and height)								
Sleep disorders								
GORD assessment								
Bone profile								
Constipation								
Toilet training								
Activities of Daily Living								
Associated syndromes								
Epilepsy / seizures								
Dental hygiene								
Pain assessment and management								
Parental counselling								
Social								
Social support and family wellbeing								
Supported employment								
Other associated complications								
Transitional care and puberty								
Mental health								

Annexure 1: The “F words” in childhood disability



'F words' adaptation of WHO (2001) Framework^{9,10}

Annexure 2: General Movements Assessment (GMA) summary⁹

This is an observational, non-invasive analysis by trained professionals.⁹

Without being triggered, the fetal and neonatal nervous system generates a variety of motor patterns that involve the whole body.

Wax and wane intensity, force and speed Gradual beginning and end.

This was introduced by Prechtl 1990.

How to take a GM video:

Infant should be in supine on a plane colour mat, mattress wearing only Small and nonrestrictive nappy. Using a video camera placing high above the infant, should obtain the video. {Writhing period (20- 30 min) fidgety (5 min)}. External stimulations should not be present and child should not cry during the recording. Infant should stay awake and alert on his/her normal behavioral state.



Writhing age (0-8 weeks – *consistent and predominant cramp synchronized GMs possibly followed with absent fidgets possibly at risk for cerebral palsy*⁴⁾

Normal writhing GMs	Abnormal writhing GMs		
Normal writhing movements	Poor repertoire	Cramp synchronized (CS)	Chaotic
Small to moderate amplitude and speed. Fast and large extension movements may occasionally breakthrough, particularly in the arms.	Sequence of movement. Components is monotonous and the intensity, speed, and range of motion lack the normal variability.	Appear rigid Lack of smooth fluent character. All limb and trunk muscles contract and relax almost simultaneously. If Persistent over a few weeks highly predictive of CP.	Movements of all limbs are of large amplitude. Occur in a chaotic order with no fluency nor smoothness. Consistently appear to be abrupt. Transient. Often develop CS few weeks later.

Fidget age (12-20 weeks – *absent fidgety at the age of 3 months - 95% - 98% predictive of CP*⁴⁾

Normal	Abnormal	
Normal Fidgety	Absent fidgets	Abnormal fidgety
Circular movements. Small amplitude. Moderate speed. Variable acceleration of neck trunk and limbs in all directions. They are continual in awaked infant, except during focused attention. They may be concurrent with other gross movements such as kicking, wiggling, oscillating and swiping of the arms.	No fidgety, other movements can be observed. Absence of movements. Severe neurological deficits and early predictor of CP.	Looks like normal fidgety except that their amplitude, speed and jerkiness are moderately or greatly exaggerated.

Annexure 3: Hammersmith Infant Neurological Assessment Scoring Sheet (HINE)¹⁰

HAMMERSMITH INFANT NEUROLOGICAL EXAMINATION (v 07.07.17)

Name

Date of birth

Gestational age

Date of examination

Chronological age / Corrected age

Head circumference

SUMMARY OF EXAMINATION	
Global score (max 78)	
Number of asymmetries	
Behavioural score (not part of the optimality score)	
Cranial nerve function score	(max 15)
Posture score	(max 18)
Movements score	(max 6)
Tone score	(max 24)
Reflexes and reactions score	(max 15)
COMMENTS	

(Throughout the exam, if a response is not optimal but not poor enough to score 1, give a score of 2)

NEUROLOGICAL EXAMINATION

ASSESSMENT OF CRANIAL NERVE FUNCTION

	score 3	2	score 1	score 0	score	Asymmetry / Comments
Facial appearance (at rest and when crying or stimulated)	Smiles or reacts to stimuli by closing eyes and grimacing		Closes eyes but not tightly, poor facial expression	Expressionless, does not react to stimuli		
Eye movements	Normal conjugate eye movements		Intermittent Deviation of eyes or abnormal movements	Continuous Deviation of eyes or abnormal movements		
Visual response Test ability to follow a black/white target	Follows the target in a complete arc		Follows target in an incomplete or asymmetrical arc	Does not follow the target		
Auditory response Test the response to a rattle	Reacts to stimuli from both sides		Doubtful reaction to stimuli or asymmetry of response	No response		
Sucking/swallowing Watch infant suck on breast or bottle. If older, ask about feeding, assoc. cough, excessive dribbling	Good suck and swallowing		Poor suck and/or swallow	No sucking reflex, no swallowing		

Source: Hammersmith Neurological Examinations: HOME, <http://hammersmith-neuro-exam.com/recording-scoring-proformas/>¹⁰

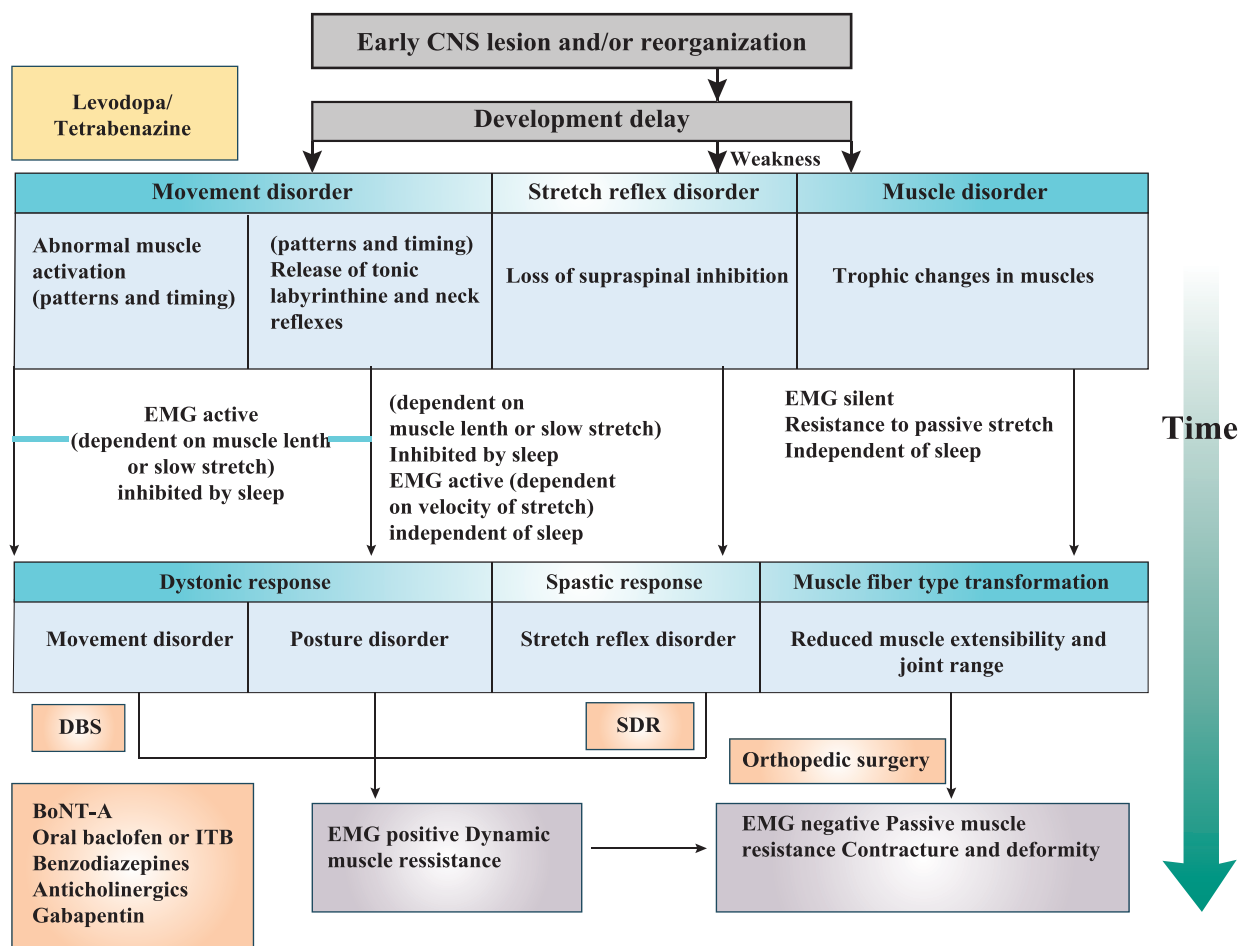
Annexure 4: Clinical signs indicating Motor Type and Topography of Infants

Unilateral Spastic Hemiplegia	Bilateral Spastic Diplegia	Bilateral Spastic Quadriplegia	Dyskinesia	Ataxia
GMs				
Poor repertoire or cramped synchronized GMs, followed by absent fidgety movements plus an asymmetry in segmental movements (eg, wrist or hand). Note that some cases of hemiplegic CP may be missed by GMs	Cramped synchronized GMs, followed by absent fidgety movements	Early onset and long duration of cramped synchronized GMs, followed by absent fidgety movements	Poor repertoire GMs, followed by absent fidgety movements with circular arm movements and finger spreading	Unknown
MRI				
- Focal vascular insults (24%) - Malformations (13%) Unilateral - haemorrhage (grade IV) with porencephaly Lesions in the parietal white matter involving the trigone - Middle cerebral artery stroke with asymmetry of myelination of the PLIC	- Bilateral white matter injury (31%-60%) - Cystic PVL (grade II-III) with sparse or absent myelination of the PLIC - Moderate to severe white matter injury (also known as PVE)	- Gray matter injury (34%) - Malformations (16%) - Cystic PVL (grade III) with absent myelination of the PLIC - Severe white matter injury with or without deep nuclear grey matter	Gray matter injury (21%) with thalamic and lentiform nuclear injury	- Malformations (18%) •Normal imaging(24%-57%) •Cerebellar injury
HINE Scores				
50-73	<50	<50 <40 GMFCS level IV-V	<50	Unknown
Unilateral Spastic Hemiplegia	Bilateral Spastic Diplegia	Bilateral Spastic Quadriplegia	Dyskinesia	Ataxia
Motor Tests				

● Asymmetrical hand preference ● Stuck in floor sitting (ie, unable to transition out of sitting) ● Cruises or steps consistently in one direction with the same leg always leading ● Reduced variation in motor behaviour	● Good hand function compared with lower limb function ● Dislike or avoidance of floor sitting ● Weight bears on toes ● Reduced variation in motor behaviour	● Head lag ● Persistent rounded back in supported sitting ● Bilateral fisted hands ● Slow to reach and grasp with either hand ● Reduced variation in motor behaviour	● Twisting arm or neck postures on voluntary movement (maybe painful) ● Finds midline play difficult, prefers toys positioned at shoulder width ● Switches hands during reaching task ● Requires a lot of extra time to initiate movement ● Voluntary movement and emotion worsens postures ● Reduced variation in motor behaviour	● Nonspecific
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Abbreviations: CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; GMs, Prechtl Qualitative Assessment of General Movements; HINE, Hammersmith Infant Neurological Examination; MRI, magnetic Resonance imaging; PLIC, posterior limb internal capsule; PVE, periventricular echogenicity; PVL, periventricular leukomalacia.

Annexure 5: Movement disorders in cerebral palsy²



Central nervous system (CNS) lesions and/or reorganization can lead to movement disorders, which can be electromyographically (EMG) active or lead to EMG-silent trophic muscle changes and contracture

When the movement disorders are independent of sleep, loss of supraspinal (central) neuronal inhibition should be suspected, leading to a spastic response characterized by a disorder of velocity-dependent stretch reflexes. Dystonic disorders are inhibited by sleep and either present as a movement disorder (abnormal proximal-to-distal muscle sequencing with co-contraction) and/or a postural disorder (abnormal tonic labyrinthine reflexes, with scissoring or fisting). In dystonia, sustained EMG discharges are present 'at rest' and are length dependent (worsened by slow stretch) and arousal dependent. The majority of management strategies that have emerged over the past 70 years are depicted in the orange boxes. Management depends on the patient characteristics. All management plans aim to support innate adaptive motor development, but the anatomy and physiology of the muscles in cerebral palsy inexorably tends towards fixed, irreversible deformity and muscle contracture over time. Management strategies include seating systems, communication aids, neurosurgical interventions (Deep Brain Stimulation (DBS), Intrathecal Baclofen (ITB) and Selective Dorsal Rhizotomy (SDR)), pharmacological approaches and orthopaedic surgery: all within a multidisciplinary team and according to the WHO International Classification of Function Children and Youth version 2007 (WHO-ICF-C-Y 2007). BoNT-A, botulinum neurotoxin A.²

Image courtesy: H. Kerr Graham et al., 2016, www.nature.com/nrdp, The Royal Children's Hospital, Parkville, Victoria, Australia, 2016 Macmillan Publishers Limited.

Annexure 6: Hip surveillance protocol for children with cerebral palsy²⁰

GMFCS level	I	II		III		Type IV hemiplegia		IV		V		
1-2 y or @ Dx	C X	C X		C X				C X		C X		
After 6 m				C X				C X		C X		
				Stable	MP abnormal or unstable			Stable	MP abnormal or unstable	6m till 7y or MP stable		
After 1 year		C X		Annual	6m till stable			Annual	6 m till stable			
		Stable	MP abnormal or unstable									
3 yrs		C	R/v @ 5y			Annual till stable						
5 yrs		C	C X			C X						
		Discharge if normal	Stable	MP abnormal or unstable	Stable	MP abnormal or unstable						
7 yrs			R/v @8-10y	Annual till stable	C X		R/v 10y	Annual till stable	C X		C X	
					Stable or MP <30% + stable gross motor function	MP abnormal or unstable			Stable or MP <30% + stable gross motor function	MP abnormal, unstable or if evidence of pelvic obliquity or scoliosis	Stable or MP <30% + stable gross motor function	MP abnormal, unstable or if evidence of pelvic obliquity or scoliosis
					R/v @ 8-10y	6m till stable			R/v 8-10y	6m		
	C X				C X				C X			
	Stable				MP abnormal or unstable	C X			C X			
8 – 10 yrs (prepuberty)		Discharge	Annual till stable or skeletal maturity	C X Annually	C X Annually till skeletal maturity	C X		Annual till skeletal maturity	6m till skeletal maturity			
						Stable or MP <30% + stable GMF	MP abnormal, unstable or if evidence of pelvic obliquity or scoliosis					
					Annual till skeletal maturity	6m till skeletal maturity						
Skeletal maturity		Annual surveillance must continue if pelvic obliquity, leg length discrepancy or deteriorating gait present						Annual if MP abnormal &progressive scoliosis or significant pelvic obliquity				

C- Clinical examination

X- AP pelvic radiograph

MP- Migration percentage

Annexure 7: Recommended medication treatments for CP complication management

Indication	Drug	Route	Details on administration	Specific concerns
Dystonia and Spasticity	Trihexyphenidyl hydrochloride / Benzhexol Hydrochloride	By mouth	Initially, 1-2 mg daily in 1-2 divided doses then increased in steps of 1mg every 3-7 days according to the response and the side effects. Maximum dose 2mg/kg/day	
	Co-careldopa	By mouth	Initially, 250micrograms/kg 2-3 times a day, increased according to the response every 2-3 days up to 1mg/kg 3 times a day.	Preparation containing 1:4 ratio of carbidopa:levodopa is to be used.
	Baclofen	By mouth	Initially, 300 micrograms/kg daily in 4 divided doses, increased gradually at weekly intervals until satisfactory response. Maintenance 0.75-2mg/kg daily in divided doses maximum dose 1month -7 years 40mg/day 8-17 years 60mg/day	Review treatment if no benefit within 6 weeks of achieving maximum dose
	Diazepam	By mouth	1-11 months 250µg/kg bd 1-4 years 2.5 mg bd 5-11 years 5mg bd 12-18 years 10 mg bd	
Delayed sleep initiation	Melatonin	By mouth	Initially, 2-3mg daily for one to two weeks, if a necessary increase to 4-6 mg daily Maximum dose 10mg/day	The need to continue Melatonin therapy should be reviewed every 6 months.

Control of upper airway secretion and hyper salivation	Glycopyrrolate/ Glycopyrronium bromide	By mouth SC/ IM/ IV injection	40-100 µg /kg 3-4 times a day Maximum dose of 2mg per dose adjusted according to the response 1 month -11 years 4-10 µg /kg 4 times a day Maximum dose of 200 µg / dose 12-17 years 200 µg every 4 hours as required	For administration by mouth injection solution may be given crushed or tablets suspended in water
Constipation Disimpaction Maintenance therapy	Polyethylene glycol PEG 3350 Lactulose PEG 3350-4000 Bisacodyl Liquid Paraffin	By mouth By mouth By mouth By mouth Rectal By mouth	1-1.5g/kg/day (3-4 days) 1-5 year 5ml bd 6-10 year 10ml bd 11-18 year 15ml bd 0.26-0.84g/day 4-10 year 5mg at night 11-18 year 5-10 mg at night 2-10 years 5 mg in the morning 11-18 years 10 mg in the morning 3-12 year 0.5-1ml/kg bd (maximum 30ml bd) 13-18 year 10- 30 ml daily	Failing oral route can use rectal enemas to relieve fecal loading After achieving disimpaction it is vital to start daily oral laxatives to soften the stool and prevent the re-impaction

GORD	PPI Omeprazole	By mouth	1month -1 year 700 µg/kg daily Increase if necessary 3mg/kg/daily maximum per dose 20mg 2-17 year (10-19kg) 10mg daily Increase if necessary to 20mg daily (20kg or above) 20mg daily Increase if necessary, to 40 mg/daily In severe cases maximum 12 weeks at higher doses	PPIs are superior to Histamine-2- receptor blockers for both healing of erosive esophagitis and relief of GORD symptoms Thickening of liquid enteral formulas in addition to therapeutic options also helpful.
	Histamine-2- receptor blockers			Not routinely recommended. May be considered in uncontrolled GORD
	Prokinetic agents			

Annexure 8: CVI Range²⁵

0.00	Not resolved, usually or always a factor affecting visual functioning					
0.25	Resolving					
0.50	Resolving, sometimes a factor affecting visual functioning					
0.75	Resolving					
1.00	Resolved, not a factor affecting visual functioning					
	Not Resolved		Resolving		Resolved	
1. Color Comments:	0	.25	.5	.75	1	
2. Movement Comments:	0	.25	.5	.75	1	
3. Latency Comments:	0	.25	.5	.75	1	
4. Visual Fields Comments:	0	.25	.5	.75	1	
5. Complexity Comments:	0	.25	.5	.75	1	
6. Light Gazing Comments:	0	.25	.5	.75	1	
7. Distance Viewing Comments:	0	.25	.5	.75	1	
8. Visual Reflexive Responses Comments:	0	.25	.5	.75	1	
9. Visual Novelty Comments:	0	.25	.5	.75	1	
10. Visual Motor Comments:	0	.25	.5	.75	1	
Total						

Scores:

Phase I: 0-3

Phase II: 3.25-7

Phase III: 7.25-10

References

1. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl* 2007; 109:8-14.
2. Graham H, Rosenbaum P, Paneth N, Dan B, Lin J, Damiano D et al. Cerebral palsy. *Nature Reviews Disease Primers*. 2016; 2(1).
3. Khandaker G, Muhit M, Karim T, Smithers-Sheedy H, Novak I, Jones C et al. Epidemiology of cerebral palsy in Bangladesh: a population-based surveillance study. *Developmental Medicine & Child Neurology*. 2018; 61(5):601-609
4. Novak I, Morgan C, Adde L, Blackman J, Boyd R, Brunstrom-Hernandez J et al. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy. *JAMA Pediatrics*. 2017; 171(9):897.
5. Novak I. Evidence-Based Diagnosis, Health Care, and Rehabilitation for Children With Cerebral Palsy. *Journal of Child Neurology*. 2014;29(8):1141-1156.
6. Galea C, McIntyre S, Smithers-Sheedy H, Reid S, Gibson C, Delacy M et al. Cerebral palsy trends in Australia (1995-2009): a population-based observational study. *Developmental Medicine & Child Neurology*. 2018; 61(2):186-193.
7. Bax M, Tydeman C, Flodmark O. Clinical and MRI Correlates of Cerebral Palsy. *JAMA*. 2006;296(13):1602.
8. [Internet]. Gillettechildrens.org. Available from: https://www.gillettechildrens.org/assets/uploads/care-and-conditions/CP_Roadmap.pdf
9. World Health Organization. International Classification of Functioning, Disability, and Health (Ic. World Health Organization; 2001.
10. F-Words in Childhood Disability | Can Child [Internet]. Canchild.ca. 2020. Available from: <https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability>
11. Cerebralpalsy.org.au. 2020]. Available from: <https://www.cerebralpalsy.org.au/wp-content/uploads/2018/03/Parental-Fact-Sheets.pdf>

12. pna.org.uk. 2020 Available from: https://bpna.org.uk/userfiles/HINE%20proforma_07_07_17.pdf
13. Bellman M, Byrne O, Sege R. Developmental assessment of children. *BMJ*. 2013; 346(jan15 2):e8687-e8687.
14. Novak I. Evidence-Based Diagnosis, Health Care, and Rehabilitation for Children with Cerebral Palsy. *Journal of Child Neurology*. 2014; 29(8):1141-1156.
15. Hutchon B, Gibbs D, Harniess P, Jary S, Crossley S, Moffat J et al. Early intervention programmes for infants at high risk of a typical neurodevelopmental outcome. *Developmental Medicine & Child Neurology*. 2019; 61(12):1362-1367
16. https://canchild.ca/system/tenon/assets/attachments/000/003/355/original/gmfm-88_and_66_scoresheet-V4.pdf
17. Rosenbaum P, Palisano R, Russell D, Raina P. Prognosis for Gross Motor Function in Cerebral Palsy: Creation of Motor Development Curves. *Journal of American Medical Association*. 2002; 2002:288:1357-1363.
18. Piper M, Darrah J. Alberta Infant Motor Scale (AIMS). Ottawa: École des Sciences de la réadaptation, Sciences de la santé, Université d'Ottawa; 2004.
19. Novacheck T, Trost J, Sohrweide S. Examination of the Child with Cerebral Palsy. *Orthopedic Clinics of North America*. 2010; 41(4):469-488.
20. Australian Hip Surveillance Guidelines - AusACPDM [Internet]. AusACPDM. 2020 [. Available from: <https://www.ausacpdm.org.au/resources/australian-hip-surveillance-guidelines/>
21. K nights S, Dattoo N, Kawamura A, Switzer L, Fehlings D. Further evaluation of the scoring, reliability, and validity of the Hypertonia Assessment Tool (HAT). *J Child Neurol*. 2014;29(4):500-4
22. Hägglund G, Wagner P. Development of spasticity with age in a total population of children with cerebral palsy. *BMC Musculoskeletal Disorders*. 2008;9(1).

23. Novak I. Evidence-Based Diagnosis, Health Care, and Rehabilitation for Children with Cerebral Palsy. *Journal of Child Neurology*. 2014; 29(8):1141-1156.
24. Novak I, Morgan C, Edmondson M, Galea C, Hines A, Langdon K. State of the Evidence Traffic Lights 2019: Systematic Review of Interventions for Preventing and Treating Children with Cerebral Palsy. *PEDIATRIC NEUROLOGY*. 2020;(2020) 20:3
25. Roman -Lantzy C. Cortico Visual Impairment: An Approach to Assessment and Intervention. American Foundation for the Blind; 2007.
26. Baranello G, Signorini S, Tinelli F, Guzzetta A, Pagliano E, Rossi A et al. Visual Function Classification System for children with cerebral palsy: development and validation. *Developmental Medicine & Child Neurology*. 2019; 62(1):104-110.
27. [Internet]. Cfcs.us.. Available from: http://cfcs.us/wp-content/uploads/2014/02/CFCS_universal_2012_06_06.pdf
28. romano C, van Wynckel M, Hulst J, Broekaert I, Bronsky J, Dall'Oglio L et al. European Society for Paediatric Gastroenterology, Hepatology and Nutrition Guidelines for the Evaluation and Treatment of Gastrointestinal and Nutritional Complications in Children With Neurological Impairment. *Journal of Pediatric Gastroenterology & Nutrition*. 2017;65(2):242-264.
29. Eating and Drinking Ability Classification System (EDACS) [Internet]. Kidshealth.org.nz. 2022 [cited 27 February 2022]. Available from: <https://www.kidshealth.org.nz/sites/kidshealth/files/pdfs/edacs-algorithm-clinical.pdf?language=en>
30. Rye H, Skjorten M. Children with severe cerebral palsy. [Paris]: Unesco; 1989.
31. Department of Examinations - Sri Lanka [Internet]. Doenets.lk. 2021 [cited 9 April 2021]. Available from: <https://doenets.lk/>
32. Pearson T, Pons R, Ghaoui R, Sue C. Genetic mimics of cerebral palsy. *Movement Disorders*. 2019; 34(5):625-636.

33. Elearningcanchild.ca. 2020. Available from:
http://elearningcanchild.ca/dcd_pt_workshop/assets/planning-interventions-goals/goal-attainment-scaling.pdf
34. Turner-Stokes L. Goal attainment scaling (GAS) in rehabilitation: a practical guide. *Clinical Rehabilitation*. 2009; 23(4):362-370.
35. Blogs.elon.edu. Available from: <http://blogs.elon.edu/ptkids/files/2012/03/COPM.pdf>
36. Learn to Use the COPM. COPM. Available from: <https://www.thecopm.ca/learn/#wp-video-lightbox/0/>
37. Ilhan E, Johnston L. Appraisal of Clinical Practice Guideline: 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. *Journal of Physiotherapy*. 2021;67(4):314.
38. Thayyil S, Pant S, Montaldo P, Shukla D, Oliveira V, Ivain P et al. Hypothermia for moderate or severe neonatal encephalopathy in low-income and middle-income countries (HELIX): a randomised controlled trial in India, Sri Lanka, and Bangladesh. *The Lancet Global Health*. 2021;9(9):e1273-e1285.



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