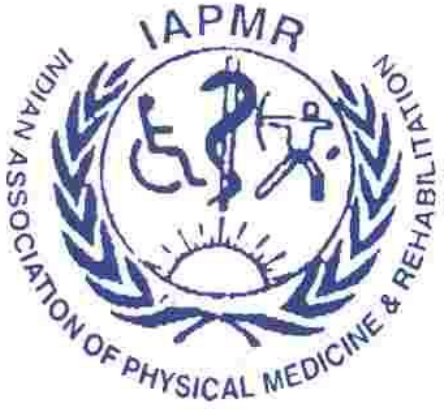
IAPMR GUIDELINES TO MANAGE A CHILD /ADULT WITH CEREBRAL PALSY 2017

Indian Association of Physical Medicine & Rehabilitation



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DISCLAIMER

The intent of the write up "**IAPMR GUIDELINES TO MANAGE A CHILD /ADULT WITH CEREBRAL PALSY, 2016**" is not an alternative to any books nor to replace the assessment and treatment procedures in the rehabilitation of children with CP in different institutions, advance research settings, private and government medical colleges.

This is an attempt to make standard guidelines about complete rehabilitation management of cerebral palsy in view of Indian scenario and to help the students, interns, senior residents, physiatrists and related medical specialities.

No financial help, gifts, sponsorships were received during development of the guidelines.

IAPMR Scientific Committee and Authors have no conflict of interest.

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IAPMR

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Introduction

AIM OF DEVEOPING GUIDELINES

Cerebral Palsy (CP) is one of the common paediatric conditions seen by physiatrists in India. Children with CP are seen by us during different developmental stages of the child. It is the job of the physiatrists to plan and execute comprehensive rehab management for infants and children with CP and long term care for adolescents and persons with CP. Keeping in mind the different environmental, social, economic, religious and cultural issues of India, these guidelines are prepared for Physiatrists practicing in India.

This is an initiative of Indian Association of Physical Medicine and Rehabilitation (IAPMR).

The Process was initiated by Academic Committee of IAPMR with voluntary participation by the IAPMR members by interchanging communication module.

Later on 19th till 21st November 2016, Guidelines finalization committee met with other members at Composite Rehabilitation Centre Bhopal, hosted by the excellent effort of Dr. Ganesh Arun Joshi, Dr. Harshanand Popalwar and their team. Around twenty four children's with different types of cerebral palsy were seen during the process of formulation along with their parents and the proposed guidelines were checked on them. The final guidelines are drafted and approved by Executive Committee of IAPMR.

The Following versions are prepared as follows.

1. Short version which will help the residents, junior post graduates, for quick assessment and management.
2. Detailed version to be used in comprehensive management and performing interventions.
3. The idea is to give the reader the principles of management. Once you understand the principles you will be able to devise different methods suitable to the environment of your work spot.

Dr. Feroz Khan,

Chairperson,

IAPMR Academic committee.

Definition of CP & Etiology

Dr. M. Feroz Khan

"Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation; those are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, by epilepsy and by secondary musculoskeletal problems". Modified after **Bax et al. 2005 and Rosenbaum (1)**

Dr. Gabriella Molner (2) well known paediatric physiatrist described Cerebral Palsy as a clinical syndrome which has three important criteria viz.

1. Motor dysfunction.
2. Non progressive brain damage.
3. Affecting an immature developing brain.

The involvement in other areas of brain in addition to motor function areas is possible leading to associated impairments of vision, communication, cognition, mental functions, seizures etc.
The damage might have occurred during prenatal, during the delivery or postnatal period.

AETIOLOGY

A. Congenital Causes:

- Encephalocele where a part of the brain is not developed resulting in severe neurological involvement with poor functional capacity.**(3)**
- In some children the proliferation of neurons may be reduced resulting in microcephaly or increased as in macrocepahly producing diffuse clinical pictures affecting global functional delay.
- The migration of cells from the core brain area near the ventricles to distant area of brain may get affected producing smooth brain with no gyri known as Lissencepahly, or many small gyri producing polymicrogyria. These children will have severe spastic CP with poor functional gain.
- The growth of the cerebral cortex may be affected leading to agenises of cortex and such children may have mild to severe involvement. Seizures are common.
- During brain growth the synaptic connections are very active and any seizure during this time can lead to interruption o synaptic formation and remodelling.

B. Neonatal Issues:

C. In premature babies there may be haemorrhage in the ventricle alone or in the surrounding areas of brain producing mild to severe forms of Intra ventricular Haemorrhage (IVH), which are graded depending on the severity.

D. These children will show neurological sign in relation to the site of affection. They do better functionally if there is only infarction than haemorrhage which will have severe involvement.

E. <u>Post Natal Issues:</u>

- These happen in full term infants during delivery resulting in hypoxia, asphyxia etc. In this situation the involvement may be diffuse with cyst formations in the cortex. Functionally there will be deficits like severe spasticity, cognitive, communication and mental abilities due to diffuse brain involvement.
- Vascular strokes in neonatal period happen mostly in middle cerebral artery leading to hemiplegic/ monoplegic types. There may be porencephalic cyst seen in the area of vascular injury in later stages. Functionally they will be able to walk and have independence in ADL but may have seizures, cognitive and behaviour problems.
- There are a group of children develop CP due to unknown aetiology.

The following risk factors would have contributed directly or indirectly in causing CP **(4)**

A. <u>Prenatal Period:</u>

Pre term (below 36 weeks), low birth weight (below 2000gms), TORCH infection, bleeding at third trimester, pre-eclamsic toxaemia, twins and multiple pregnancies.

B. <u>Neo natal Period:</u>

Prolonged labour pains, rupture of placental membrane outside and the time delay from rupture to delivery (if there is delay the child is exposed to infections), abnormal presentations like breech severe hypoxia, bradycardia etc.

C. <u>Post natal period:</u>

The causes during the post natal period include, Post encephalitis (both viral and bacterial), severe hypoxia, seizures, bleeding disorders, neonatal jaundice and traumatic brain injury etc. The exact time period to label a child with CP due to post natal involvement is variable in different countries and different set ups. In India we can propose up to the age of 5 years.

PRESENTING HISTORY

The majority of the parents bring the child with the following symptoms and point toward the following signs. A careful history will guide us to establish the site of lesion nature of the lesion and how bad is the lesion.

1. Motor milestones delay.
2. Unable maintain against gravity.
3. Poor hand functions.
4. Preference of one hand before the age of 2 years.
5. Global developmental delay
6. Unable to perform in the school in academic and sports activities.
7. Altered motor performance like bunny hopping, walking with equinus.
8. Poor participation of the child in daily activities like self care, eating etc.
9. Difficulty in handling the child during changing nappies.
10. Sensory issues like poor attention, perceptual disorders, mental impairment.

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Global HELP, 2318 Fairview Ave. E. #2, Seattle, WA 98102Page 8.

Diagnostic Tips

Dr. Asim Palit

- Early identification and labelling a child with CP should not be done in a hurry since the neurological signs which are apparent in the early stages may disappear with time due to maturation of the brain. Contrary to that a child labelled as normal may show signs of motor delay when more milestones develop.

- Some children who have developmental abnormalities of brain like Encephalocele etc, and with severe spasticity and or hypo tonicity persisting for more than six months, a definite diagnosis can be ascertained. Generally it is better to wait till the age of 2 years before definite diagnosis as CP is labelled.

- The Physiatrists should be able to convey the message in appropriate way considering the different environmental situations in our country. Many times the other professionals who have seen the child prior would have given a different picture or the parents are in denial mode.

- The development of child's brain goes through a fundamental principle which is related to the brain stem function.(1) The primitive infantile reflexes like Moro, TNR, TLR are essential for viability. They are present till 6 months and disappear and taken over by the postural reflexes and reactions which are due to higher level control and essential for rolling crawling, sitting, standing and walking.

Hence the signs and symptoms which help to identify Cerebral Palsy are

a) Inability to hold the head up against gravity.

b) Persistent neonatal reflexes (e.g. TNR ,Moro, Extensor thrust, Stepping reflex)

1. **ATNR:** Head turned to one side –limbs of same side extended and opposite side flexed
2. **STNR:** Head flexed in prone position – fore limbs will be flexed and hind limbs will be extended, Head extended in prone position –fore limbs will extend and hind limb will flex
3. **Moro:** a loud noise or a sudden jerk of the table causes the upper limbs to extend away from the side of the body and then to come together in an embracing pattern.
4. **Extensor thrust:** when the child is held upright by the armpits, the lower extremities stiffen out straight.
5. **Stepping:** When held upright, as soon as feet touch a surface, the child places a step forward

c. Altered Postural issues like fisted hand with thumb in palm, opisthotonus, scissoring of lower limbs, crouching gait and equines in the ankles

d. Delayed milestones of development e.g. if there is no Associated problems either alone or combination involving vision, hearing, speech, cognition, mental retardation, seizures and musculoskeletal involvement.

- Head control by 3 months
- Sitting by 6 months
- Rolling over by 6 months
- Walking by 18 months

References:

1. **Alfred L Scherzer.** Early Diagnosis and Interventional Therapy in Cerebral Palsy: An Interdisciplinary Age-Focused Approach (Pediatric Habilitation volume II) New York NY 2000:64-65.

➢ PHYSICAL EXAMINATION:

Keep in mind that CP is primarily a disorder of movement and posture. Motor dysfunction at different levels gives rise to the above problems. A step by step approach will help to direct towards diagnosis, classification, functional status and planning rehabilitation program and interventions. (*See annexure 1*)

➢ MOVEMENTS:

Passive Range of Motion: Examine and record in the joints where there is limitation

a. If there is limitation less than 20% of the anatomical range of motion then only therapeutic exercise will suffice

b. If there is limitation between 20% to 40 % then orthosis are required in addition to therapeutic exercise

c. If there is limitation of more than 40% then surgery shall be needed.

Some children with severe spasticity will show more limitation of passive range of movements. To differentiate a child who is predominantly in flexion put the child in prone wait for a minute and check for ROM- This is the anti spastic position. And for a child in flexion do the vice versa.

Active ROM (Strength): It is better to test with the child in floor and doing functional activities during cueing and playing and spontaneous movements. For grown up children active movement can be tested in relation to the amount of physiological range of motion is related to particular joint. It is important not to miss the antigravity muscles which are responsible for maintaining posture which are called core muscle (Abdominals and Para spinal muscles in particular).

Upper limb muscles have to be tested for gross movements of the proximal muscles which are needed for stability and distal movements in the hands for and fine activities including self care.

Postural Muscles and Movements:	**Right side**	**Left side**
Para spinals		
Neck		
Upper trunk		
Lower trunk and abdominals		
Hip abduction and extension		
Knee Extension and Flexion		
Ankle dorsi flexion and plantar flexion.		

Look for the types of movements in each segment of the body viz. Neck, Trunk, Upper and lower limbs.

1. Active (Spontaneous)
2. Voluntary.(Movements done on demand)
3. Volitional. (Movements done to complete a function)
4. Athetoid spontaneous increases with emotion, opposing action viz. When trying to open the hand few fingers will open and few will close simultaneously.
5. Dystonia (Too much effort is needed for small movements with postural abnormalities)
6. Ataxia (In co ordination during performance of a task)
7. Mixed (Any combination of two types)
8. Rigid.(No movements at all)

- **TONE:**

SPASTIC	FLACCID	VARIABLE	MIXED	NORMAL

Spasticity will be seen in diplegics, hemiplegics and quadriplegics

Flaccidity will be felt in hypotonic type, ataxic type and or initially hypotonic and then develop athetoid type.

Variable tone is seen in athetoid type. Mixed is combination of spasticity and athetoid.

- **POSTURE:**

(To be tested without aids splints etc)

1. LYING
2. SITTING
3. KNEELING
4. STANDING
5. WALKING.

- **CONTRACTURES AND DEFORMITIES:**

- **BALANCE**:

1. SITTING;
2. STANDING
3. WALKING.

- **GROSS MOTOR FUNCTIONAL ABILITY INDEPENDENT:**

1. LYING
2. SITTING
3. STANDING
4. WALKING

- **FINE MOTOR FUNCTIONS:**

HAND:

Thumb in palm, fisted hand, flexion in wrist point towards postural issues of the upper limbs.

Poor shoulder stability, elbow movements, and fine movements of the hand are needed in different combinations to achieve reach, grasp, place and release.

One of the earliest sign of motor dysfunction in the upper limb is child is unable to see his/her own palm.

There are many scales clinically useful to assess, plan and evaluate the body structure and functional aspects of CP child. They are useful as pre and post therapy, invasive and non invasive to know the positive effects on the child. (*See annexure 3*)

Clinical Classification

Dr. Tuffail Muzaffar

- **CLASSIFIACTION OF CEREBRAL PALSY:**

The following classification is based on tone changes.

1. Spastic (pyramidal) cerebral palsy :
2. Dyskinetic (extra pyramidal) cerebral palsy
3. Hypotonic cerebral palsy.
4. Ataxic cerebral palsy
5. Mixed types

- **SPASTIC TYPE** (75%)—manifest signs of upper motor neuron involvement Hyperreflexia , Clonus , Extensor Babinski response (abnormal at > 2 years), Persistent primitive reflexes, Overflow reflexes such as crossed adductor reflex.

- **DYSKINETIC TYPE**—Dyskinesias are characterized by extra pyramidal movement patterns secondary to abnormal regulation of tone, defects in postural control and coordination deficits

A. Athetoid or slow writhing involuntary movements, particularly in the distal extremities
B. Chorea—Abrupt, irregular jerky movements, usually occurring in the head, neck, and extremities
C. Choreoathetoid—Combination of athetosis and choreiform movements. Generally are large-amplitude involuntary movements. The dominating pattern is the athetoid movement
D. Dystonia—A slow rhythmic movement with tone changes generally found in the trunk and extremities, associated with abnormal posturing
E. Ataxia—Unsteadiness with uncoordinated movements, often associated with nystagmus, dysmetria, and a wide-based gait

- **HYPOTONIC TYPE**—Patients with flaccid type have a generalized decrease in muscle tone. Deep tendon reflexes are weak and patient is unable to maintain the posture and show hyper mobility sometimes.

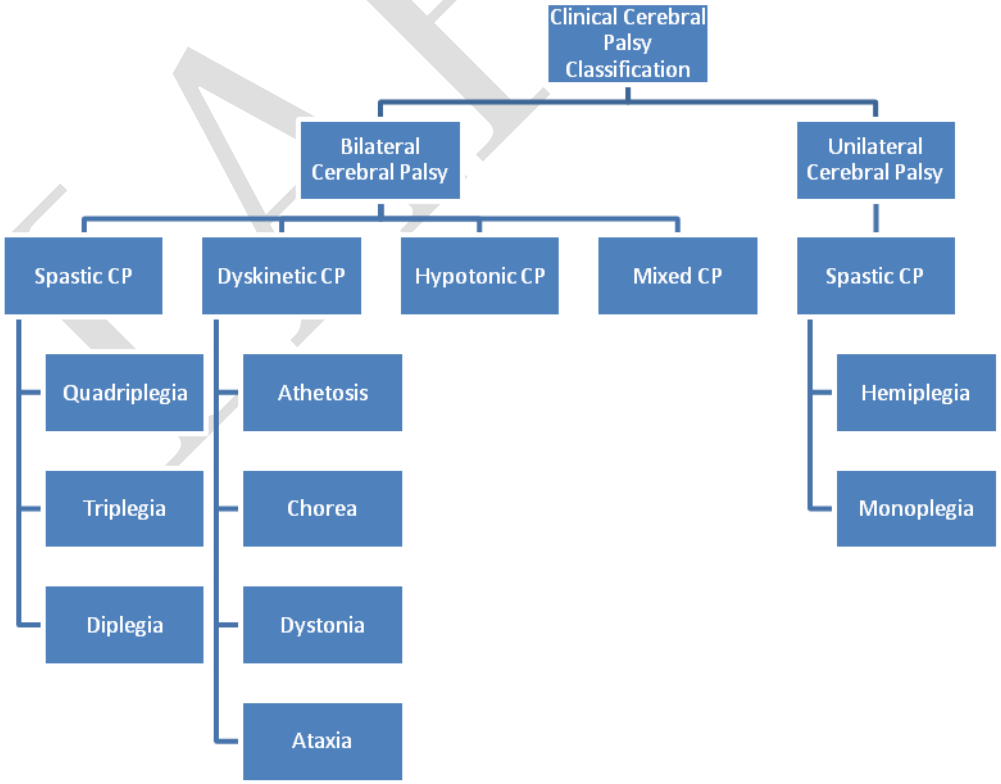
- **MIXED TYPE**: This includes descriptions from both spastic and dyskinetic classifications. e.g., spastic athetoid (predominant dyskinetic movement pattern with underlying component of spasticity)

This Classification of CP is according to the site of involvement.

It is also called **Topographical classification**. Only spastic Neurological type can be classified topographically as other types have generalized body involvement. In this type all four limbs are involved along with other functions of swallowing and speech.

A. **Spastic quadriplegia:** with severe form has only variable weakness of the all four limbs without any problem in speech and swallowing. It is also called tetraplegia.
B. **Spastic triplegia :** Involves 3 extremities, classically both lower extremities and one upper extremity. Spasticity results in the involved limbs with mild coordination deficits in the uninvolved limb. Upper motor neuron signs result with characteristic scissoring and toe walking
C. **Spastic diplegia:** Primarily lower extremity (LE) involvement, mild in coordination problems result in the upper extremities (UE) with upper motor neuron findings in the lower extremities
D. **Spastic monoplegia :** Rarely seen, however, has isolated upper or lower extremity involvement and usually a mild clinical presentation
E. **Spastic hemiplegia:** One side of the body is involved, usually the arm more than the leg.

The following algorithm will be helpful to identify types of Cerebral Palsy



Functional Assessment

Dr. Kousthub Chakraborthy

When a child with CP presents before a Physiatrist, the "General Survey" would include an observation of the following:

- Gross Motor
- Fine Motor
- Communication
- Cognitive Function
- Mobility

A. **GROSS MOTOR** -- Depending upon the highest achievable independent motor function, children with Cerebral Palsy can be graded as a:

1. Lying (means one who's confined to bed & cannot get up to sitting position)
2. Sit
3. Stand
4. Walk

There are many functional assessment scales available. But it is good if we develop our own functional assessment scales for Indian environment. The simple useful functional assessment for children with CP is given below.
The following scales have been agreed upon for the initial assessment for Rehabilitation, and subsequent follow-up for persons with Cerebral Palsy.

B. **FINE MOTOR** – Prehensile function being an important requisite of functional improvement, document whether the following are present or absent :

Reach	Present / Absent
Grasp	Present / Absent
Release	Present / Absent
Best Prehensile Function	Claw Grip / Spherical Grasp / Cylindrical Grasp / 3-jaw chuck (eg. holding a pen/chalk), Pinch Grip / Key Grip + Ulnar Grasp & Grasp with foot

C. **COMMUNICATION :** Whether the person with Cerebral Palsy can –

1. Verbalize making sense
2. Communicate with gestures (Speech being unintelligible or inadequate)
3. Communicate with AAC Devices or other gadgets
4. Use some jargon which only the caregivers can understand

5. Cannot communicate

D. MOBILITY: How is the patient moving around / being moved ?

1. Independently Ambulant
2. Ambulant with Orthoses / Mobility Aids
3. Ambulant with Manual Assistance
4. Transported by Manual Wheelchair
5. Transported by Power Wheelchair
6. Carried by Parent

FUNCTIONAL ASSESSMENT:

The documentation of function at baseline and at various intervals becomes an integral part of the Functional Assessment in a person with Cerebral Palsy.

For this purpose, use of the following scales has been decided:

A. General Mobility: The Gross Motor Function Classification System (GMFCS)

B. Overall Functional Assessment : The WeeFIM

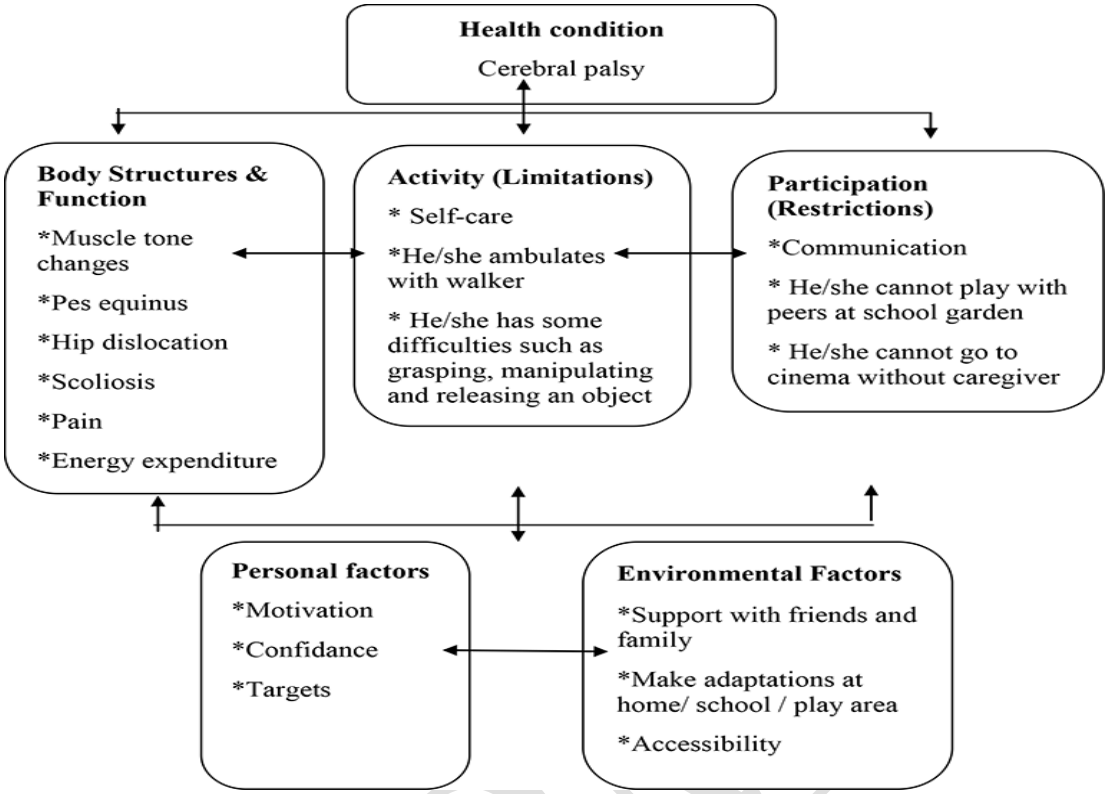
C. Hand Function Assessment: The Manual Ability Classification System (MACS)

D. Posture Assessment : The Postural Ability Assessment

E. Balance Assessment: The Balance Assessment & Grading Scale.

(For further details please see annexure 2)

Please note: **ICF (International classification of Function and Disability)** has a specific classification for children with cerebral palsy described below.



Many scales can be used to assess the child's function in relation to the domains of the ICF model. They are useful for evaluation and effectiveness of different interventions. Nowadays many journals look for ICF based assessments in articles / papers to accept for publication.

Few examples are:

Body structure and function: Ashworth, Tardieu for spasticity

Activity: FIM (FIM - Functional Independent Measure) in adults and Wee Fim in children

Participation: GMFC, MACS.

Investigation Guidelines for CP Children Coming To PMR Department:

A. Blood tests:

1. Peripheral smear to look for anaemic status.
2. Serum Vitamin D level in specific cases of malnutrition and risk of fractures before starting therapy.
3. Serum AED (Anti epileptic drugs) to find out for potential toxicity, non responding AED characterized by frequent interruption of rehab program.
4. Thyroid profile if there is family history.
5. Metabolic screening id suspected metabolic involvement if not already done.

B. Radiology:

1. X ray pelvis for a child who has severe scissoring, limitation of passive abduction less than thirty degrees, internal rotation and with spinal curvature to include spine also.
2. X ray chest for primary complex symptoms.
3. X ray of other joints if any severe deformities where serial casting, surgery is planned.
4. MRI.
   Most of the children come to rehab with MRI. New MRI is required
   1. To plan the rehab program in case which doesn't shows functional improvement after 10 years of age.
   2. If there is suspicion of deterioration of function to look for different demyelination diseases.
   3. Location of different MRI findings can tell us the time of insult and the plan for rehab potential
   4. To find out Congenital malformation point to insult in first half of pregnancy.
   5. Abnormality of cleavage (lobes, sulci and gyri) point towards 4 – 6 weeks of pregnancy.
   6. PVL (Periventricular Leukomalacia) indicate insult at 24 – 34 weeks of gestation.
   7. Diffuse cortical affection show haemorrhage after full term with asphyxias.
   8. Focal involvement shows a vascular lesion.
   9. As a precursor of metabolic and genetic screening test to be done in cases misdiagnosed as CP.
   10. In some instances for medico legal and disability certifications.
   11. Some lesions in brain can appear later as the brain matures which is not seen earlier MRI.

C. EEG

1. In hemiplegic children who have behavioural issues.
2. Recurrent seizures interfering with rehab program.
3. First time seizure is reported by parents during rehab care.

D. EMG

1. H reflex studies to confirm spastic patients from benign habitual toe walkers.
2. Hypotonia is seen in some children with DDH and congenital myopathies also.
3. To know the effect of Botulinum toxin A, therapy, medication for reducing spasticity.

E. GENETIC STUDIES:

1. When there is strong family history.
2. Dysmorphic features.
3. Associated conditions with cerebral palsy
4. When parents want to be clear about planning for another baby.
5. Medico legal issues and help in certification for disability in some cases.

F. BERA:

1. When communication is delayed
2. When hearing is impaired and interferes with rehab learning process audiogram followed by hearing aid selection.

G. VEP and Ophthalmic investigations:

1. For severe squints.
2. ROP (Retinopathy of prematurity)
3. Need for visual aids
4. Certify multiple disabilities.

Arriving at a Management Plan

Dr.Koustub Chkroborthy & Dr. Feroz Khan

Goals of Rehabilitation:

1. Improve mobility level of child
2. Prevent deformity and contractures
3. Educate parents regarding home management of child
4. To train child in activities of daily living (ADL)
5. To improve social participation of affected child.

Principles for quick decision making:

The age appropriate functional performance of CP child is influenced by the following factors:

1. Communication abilities:
2. Ability maintain the body against gravity – postural ability
3. Upper limb functions to help the child to crawl to come to standing position with the hands and prehensile functions for activities of daily living.
4. Ability to balance the body to maintain static functional positions.
5. Mobility functions using the lower limbs.
6. Sensory inputs from vision, hearing, superficial and deep poprioceptvie sensations.
7. Environmental aspects.
8. Cognitive abilities for learning.

Principles:

1. Identify the assets of the child (present abilities), which is to be improved with exercises and substitutes.
2. Identify the loss (pertaining to ambulation, self care, play activities and earning issues etc), which are to be improved with modification of ADL and aids.
3. Predict the functional abilities of the child for future capacities and plan schooling appropriately.
4. Identify the potential complications and tackle them with braces, and interventions like Botulinum toxin A injection, surgery etc.

Based on the findings of exhaustive history and careful clinical assessment we have to draft a rehabilitation plan. This is a quick assessment based on the Patient Evaluation Conference System (PECS).

This should be followed with respective detailed assessments when additional interventions are planned.

A. Posture/Stability Assessment

Scoring System

1 2 3 4 5 6

Use red colour to mark	**X for present status/position**
Use green colour to mark	**X for proposed goal status/position**
Use blue colour to mark	**X for review after six weeks of therapy status/position**

Keys

1. Unable to be placed, if placed unable to maintain the position.
2. Able to maintain when placed.
3. Able to maintain but unable to move
4. Able to maintain and move within the base
5. Able to maintain and move outside the base
6. Able to maintain, move outside the base and come back to original position.

B. Ambulation/Mobility Assessment:

To be checked with and without aids, appliances about t he present achievable positions:

1X 2 3X 4X 5 6

Use red colour to mark	**X for present status/position**
Use green colour to mark	**X for proposed goal status/position**
Use blue colour to mark	**X for review after six weeks of therapy status/position**

Keys:

1. Immobile /moves by pivoting
2. Rolling
3. Creeping
4. Crawling, bottom shuffling
5. Kneel walking
6. Bipedal ambulation

1-3 trunk parallel to ground (require wheel chair ambulation)
4-6 trunk vertical to ground (can walk alone or with aids)

Example: If a child is a total body involved cerebral palsy and at present she/he is in stage 1 (immobile) marked red x and your aim is to make the child to crawl. you have to mark in stage 4 (crawl) marked green x , and after six to 8 weeks of therapy/ intervention is over to assess the effectiveness and if the child is able to creep in this case you have to mark the stage 3 (creep) with blue x .
This method will be useful for deciding the management plan quickly.

C. <u>Functional Status Assessment</u>

To be checked with and without aids about the present achievable positions:

Scoring System

1 2 3 4 5 6

Use red color to mark	**X for present status/position**
Use green color to mark	**X for proposed goal status/position**
Use blue color to mark	**X for review after six weeks of therapy status/position**

Keys

1. Bedridden
2. Totally Dependent
3. Partially Dependent (depends for more than 50% of the activities).
4. Partially Independent (independent for more than 50% of the activities).
5. Independent
6. Full restoration

In this manner we arrive at the current patient status

Then we work on the target to be achieved and evaluate the progress after 6 weeks and work towards the final aim. This may need changing treatment strategies, interventions to be done and so on.

Communication Issues with person with CP, Parents/ Caregivers and Rehabilitation Team Members

Dr. V.S. Gogia

➢ Considerations!

A. Intellect (child and parents/family members).

- Vocabulary
- Language skills

B. Cognition.
This will have a bearing on comprehension on part of PwCP(person with Cerebral Palsy), his/her parents/caregivers and will give an insight to the Physiatrist to phrase/rephrase the information delivery. Also how much time and repetitions are required to convey the information.

C. Speech, Language and Hearing.

Preservation of receptive language skills is a better indicator of good cognitive function than expressive language. Hearing loss should be ruled out prior to making judgments regarding receptive skills.

D. Concurrent Pharmacotherapy.
Antiepileptic/anti spasticity medication may make the child drowsy and hence communication may be affected.

E. Parents' education and awareness status.

F. Family's Socio economic status.

- Social norms and value system

G. Guard undesirable prognosis communication from PwCP.
While communicating any negative diagnostic or prognostic information the PwCP should not be present with parents to avoid any depression or negativity with him/her.

H. Make parents accountable for follow-up.

I. Menstrual hygiene and Marriage/Sexuality issues to be included in communication if applicable at PwCP's age.

➢ Assessment:

a) Family Members' Feedback regarding current situation.

b) Clinical assessment and progress.

c) Speech Intelligibility Test (AYJNIHH, 1989).

d) Receptive Expressive Emergent Language Scale (REELS) – Age standardized Receptive & Expressive Language Scale (not standardized for Indian Population).

➢ Needs:

a) Individualized approach/ Talk to PwCP wherever possible. usual practice of talking to parents *ONLY* should be avoided.

b) Sensitivity (during fist follow up – talk to PwCP & Parents separately).
Especially negative prognostic issues/menstrual hygiene issues (may be mother around)/marriage and sexuality issues.

c) Listening (not hearing).
Listen without judging/analysing or influenced by your own thoughts/perceptions/previous experience as each and every PwCP is different.

d) Patience on part of everyone, involved.
Especially with associated intellectual disabilities on part of PwCP as well as with parents who may have low socio-economic-educational status.

e) Language (& preferably dialect) of the person and his/her family. As far as possible speak the customer's language/dialect.

f) Coordination among Team Members.

Treatment/Rehabilitation Goal planning should involve all the members defining each one's roles and responsibilities. None of the members should change/modify/omit any of the tasks as originally planned on his/her own, instead there should be frequent follow-up meetings and such issues be discussed there and modified with consensus. Physiatrist, being team lead and legally responsible for the outcome may have to use veto albeit with proper evidence based justification**.**

g) Single point Info dissemination about Progress and Prognosis related queries (that's no conflicting information).

Physiatrist, being team leader, should be authorized to convey such info to the PwCP and/or his/her family members. Members may communicate information/concerns/issues to the physiatrist that they receive from PwCP and/or his/her family members during the course of treatment for him/her to take final call in the team meetings.

➢ Means!

a) Direct speech.

b) Gestures.

c) Eye Contact.

d) Shapes & Pictures.

e) Augmentative and Alternative Communication (AAC) devices.
Mostly not standardized for Indian conditions and languages.

f) Infotech Gadgetry.
Again mostly not standardized for Indian conditions and languages.

g) PwCP to be encouraged to express through any of the above means.

Acknowledgements!

- Dr Ravi Gaur, Assistant Professor, Dept of PMR, Dr Ram Manohar Lohia Institute of Medical Sciences, Lucknow.
- Mr Mayank Awasthi, Speech Therapist, Dept of PMR, Dr Ram Manohar Lohia Institute of Medical Sciences, Lucknow.
- Ms Sudhi Kulshreshtha, Clinical Psychologist, Dept of PMR, Dr Ram Manohar Lohia Institute of Medical Sciences, Lucknow.

Principles of Therapy prescription

- As a leader of the team Physiatrist should have a clear understanding of the therapies to be prescribed. Therapy should be aimed to have a positive direction and individualised to each child.

- Occasionally group therapy can be given if there are many non cooperative children and to teach all mother basic exercises at one sitting.
- The major issue in CP is motor dysfunction. To improve motor dysfunction for functional gains the following principles should be considered.

- The brain and spinal cord generate motor functions.

- The spinal motor functions are protective and reflexive in nature for survival.

- Brain stem initiates motor response for the environmental stimulation and tonic reflexes which are also protective for the child. As part of next developmental level the mid brain initiates motor functions to keep the body against gravity (postural positions). The cerebral cortex receives and learns/ analyses react immediately or store for an appropriate time for functional activities.

The exercises should be planned and prescribed by the physiatrist will and should influence all the different levels.

a. The exercise activities should be aimed to increase sensory input from skin, deep structures lie muscles, joints, vision, hearing and cognitive input in order for the brain to receive multimodal sensations.
b. Functional activities to help the brain analyse the sensation to initiate the response by cognitive stimulation and play therapy.
c. Repetition of activities for the cortex to learn and store the responses required.
d. To execute the movements by providing external environment and demand for the motor function to take place.

A. Basic exercises:

1. Isotonic to improve strength given by play activities, suspension pulley neuromuscular electrical stimulation.
2. Isometric exercises for stability of the antigravity posture and joints by assistive devices, poprioceptvie input with supported standing.
3. Eccentric exercises for increased neuronal activities by cognitive play therapy etc.

B. Postural abilities:

Postural abilities are improved by increases the sensory input through poprioceptvie means, vestibular inputs by suspension therapy, multimodal sensory input with video games and biofeedback VR (virtual reality) procedures.etc.

C. Primary Reflexes issues:

The spinal reflexes and tonic neck reflexes are executed below midbrain level (when the trunk is unable to attain antigravity positions,) the righting reflexes and cortical equilibrium reflexes are in and above midbrain level execution to maintain anti gravity positions.

This sequence is altered in CP child and he/she may get stuck at one level for a long time depends on the site of brain involvement. In such situations, place the child with support in the next level of maturation and start on functional activities without waiting for reflex maturation. By doing so we will be improving cognitive function of the brain at a higher level and it will start controlling the lower level in which the child is stuck.

(Example: If a CP child is stuck in tonic neck reflexes, therapist can make her sit with support and improve motor and cognitive functions which in due course will control tonic neck reflexes.) (1)

Therapy should be intensive in infancy up to six years when the maximum functional potential for ambulation and self care are achieved. Later the therapy can be modified as per school, family requirements and designed to concentrate on more functional activities for strength and endurance (2).

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Exercise Interventions

Dr. Sanjeev Sharma

- **General principles:**

1. In Infants, activities should be done on mother's lap (close to body & face) so that her touch, stroking & talking to baby will help in movement enjoyment by baby and development of body image and motor milestones.
2. Weaning of child to a PT/OT (Therapist) should be carefully done after mother-child bonding has established.
3. Introducing more than one therapist or developmental worker may be disconcerting to child & even parents.
4. Not to overload child with exercises, but rather allow child to do activities and use corrective movements & postures.
5. Use of equipments that facilitates function when impairment is preventing development e.g. sitting on adapted chair.
6. Try to maintain upright position of child during activities.
7. Allow child to explore environment as much as possible. Let him/her reach & find out about himself/herself whenever possible.
8. Always give child time to experience and understand tactile & auditory stimuli. Do not give too many stimuli at once

- **Range of motion (ROM) exercises:**

  Range of motion exercises helps in maintaining muscle fiber length and prevents joint contractures in upper and lower limbs (1). Dose: 10 repetitions, 1 set, twice-a-day through available range of motion should be performed for all upper and limb joints.

- **Stretching exercises:** Stretching of major group of muscles maintains range of motion of joints, decrease spasticity (short term) and helps prevent muscle contractures. However, recent studies show that there is limited evidence that manual stretching can increase range of movements, reduce spasticity, or improve walking efficiency in children with spasticity (2).

  Dose: Must be done regularly, usually once or twice a day. Sustained stretching of longer duration (20-30 sec), 5 repetitions, 1 set, twice-a-day is found to be better.

  In Upper limb, stretching of muscle that are spastic or are at-risk of contractures e.g shoulder adductors & internal rotators, elbow flexors, wrist flexors, long flexors of PIP/DIP joints are usually required in case of spastic hemiplegics and spastic diplegic cerebral palsy. Similarly in lower limbs, muscles which require stretching are Hip Flexors, adductors & internal rotators, knee flexors, knee extensors, gastrocnemius and soleus muscles.

- **Strengthening exercises:** Strength training in children with cerebral palsy results in improvement of function and participation in activities (3–5). Studies have found that there is no increase in spasticity and no loss of range of motion

following a progressive resistance training (Muscle strengthening) program, as was thought previously. Muscle strengthening by use of electrical stimulation (over quadriceps, Tibialis anterior) or by strengthening within synergistic movement patterns can be used. Also, feed-back & feed-forward response should be considered while training. The *Universal Exercise Unit (UEU)* is used to assist children in functional activities along with strengthening exercises within long intensive therapy sessions.

In pre-school age (age<5 years), activities used for muscle strengthening should be:

- Playful / motivating
- Challenging & meaningful
- Goal oriented & interesting to maintain motivation
- Incorporate both concentric & eccentric work e.g. Movements against gravity, playing/kicking soccer ball, etc.

To participate in a strength-training program, child must be able to comprehend & consistently produce maximal or near-maximal effort *(selective motor control)* i.e. **children with cerebral palsy GMFCS I-III**. Some strengthening (or functional exercises) that can be prescribed are : *sit to stand, heel raises, squats, step ups, lateral step ups, stairs, cycling, half knee rises, isotonic exercises with cuff weights, weight lifting machines, and leg press*. Dosing: Frequency 2-3 times/week for maximum 12 weeks (Age > 4 years).

For severely affected kids who are significantly weak or deconditioned, who may have poor selective motor control, or who are unaccustomed to exercise (**GMFCS IV-V)** need to start with functional activities with a *lower initial intensity* and *increase slowly* to optimize safety.

- **Aerobic or cardio-vascular training**: Recent studies have shown that greater gains in cardiorespiratory endurance and mobility capacity can be achieved with longer interventions (>2months) and for children with cerebral palsy who have greater mobility **(GMFCS I-III).**
  Dosing:'High intensity' training sessions, 45 minutes in duration, four times a week during the first session and twice a week in the second session for 9 months can be prescribed. Activities included are: *Cycling, wheelchair skills, running, swimming, and mat exercises*.
  For affected child with **GMFCS III-V level**, activities like over ground cycling with an adapted tricycle can be prescribed.

- **Exercise interventions to improve postural control in Cerebral Palsy children**:(6)
  There is ***moderate evidence*** to support the use of following interventions: Hippotherapy, treadmill training with no-BWS, trunk-targeted training, reactive balance training, and gross motor task training.
  There is ***only weak or conflicting evidence*** to support the use of these postural control interventions: Hippotherapy simulators, treadmill training with P-BWS

or F-BWS (including robotic assistance), NDT, virtual reality, visual biofeedback, and FES.

It was noted that *all of the effective interventions were reported by studies involving ambulant children with CP (GMFCS I–III) except NDT.*

- **Hippotherapy**: Hippotherapy is a therapy method that utilizes the natural gait and movement of a horse to provide motor and sensory input to the patient with cerebral palsy. Sixteen hours of therapy (two 1 hour sessions/week for 8weeks) can improve sitting balance and standing balance for ambulant, school-aged children (GMFCS I–II). Hippotherapy is more effective for ambulant children (age > 5 years) with CP (GMFCS I–II) than for children with Age < 5 years and more severe CP (GMFCS III-V) (7,8).

- **Treadmill training with no-BWS (Body weight support)**: Treadmill training with no-BWS, for children with CP GMFCS I–II, can improve standing balance and trunk balance during activity. Training duration: 7 hours (two 30min sessions/week for 7weeks). The use of a *specific protocol with gradual increase in treadmill speed* for children who are walking independently (GMFCS I–II), appears to be necessary for the success of this approach (9).

- **Trunk-targeted training:** Trunk-targeted training involves exercises aimed at improving trunk muscle strength and control. Trunk-strengthening exercises are performed while patient with CP is positioned on a vibrating platform for 1.5-2.5 hours over 4 weeks (two 5–10 min sessions/week for 2weeks, followed by four or five 5–10min sessions/ week for next 2 weeks). This protocol can improve postural alignment, increase resting abdominal muscle thickness and functional muscle strength (10).

- **Vibration Therapy:** Vibration therapy activates weak and dormant muscles, and reduces need to use weights or high repetitions to strengthen abdominal muscles for postural control. A review of vibration therapy states that it perturbs the gravitational field to activate and strengthen muscles, stimulate peripheral sensory receptors, and evoke postural responses. In children with CP, vibration alone can improve gross motor function and bone density (11).

- **Reactive Balance Training:** Reactive balance training involves repeated practice of balance recovery, when standing on a support surface that is perturbed without warning in a forward, backward, or lateral direction. Training using a *laboratory-based force platform* for approximately 2 hours (one 20–25min session/day for 5 day [100 perturbations/session]) improves standing balance in ambulant children with CP (GMFCS I–II). Training using the *Biodex™ balance system*, for a higher dose of 18 hours (three 30min sessions/week for 12weeks), can improve limits of stability and standing balance and reduced fall risk, in children with spastic diplegic CP (GMFCS I–II) (12).

- **Gross motor task training** involves repetition of simple functional gross motor exercises (e.g. sit-to-stand exercises, step-ups, walking and standing

activities, and reaching to limits of stability). Thirty hours (five 1 hour sessions/ week for 6 weeks) of sit-to-stand and step-up exercises improves standing balance and dynamic postural stability during gait in children with CP aged between 5 and 12 years (GMFCS I-II) (13,14).

- **Hippotherapy simulators:** Hippotherapy simulator training in dose of 8 hours (two 40 min sessions/week for 6 weeks) can improve sitting balance, trunk control and pelvis asymmetry in children with CP (GMFCS II–IV) (15,16).

- **Treadmill training with P-BWS (Partial-Body weight support) or F-BWS(Full-Body weight support)** *(including robotic assistance)***:** Training with P-BWS or F-BWS and robotic assistance (Lokomat™) for 15 hours (five 45 min sessions/week for 4 weeks), by ambulant and semi-ambulant children with spastic diplegia (GMFCS II–III), improves standing balance, gait symmetry, foot loading symmetry (with eyes open) and self-selected gait speed (17).

- **NDT/ Bobath Approach:** Neurodevelopmental therapy (NDT) alone or NDT ('based on the Bobath technique') combined with 'conventional rehabilitation' treatments (i.e. joint mobility, muscle strengthening, and mobility activities) improves postural alignment over 6 weeks in children with spastic diplegia, aged between **8 months and 10 years (GMFCS I-V)** (18)**.** Eight hours (two 40min sessions/week for 6weeks) of NDT focusing on trunk control can improve postural control in sitting in children with spastic diplegia **(GMFCS II–V), aged 3 to 10 years.** NDT (composed of stretching, strengthening exercises, standing exercises, postural reactions exercises, reflex-inhibiting patterns, and gait training exercises) for 72 hours (three 120min sessions/wk for 12wks) improves limits of stability, standing balance and reduced fall risk, in children with **spastic diplegic CP (GMFCS I–II).**

- **Virtual reality:** Virtual reality involves balance training whilst playing computer games, that create a virtual environment using artificial sensory information to simulate real-life experiences or activities. It is proposed to influence anticipatory and sensory components through practice of voluntary movement, in conjunction with feedback through visual (screen) and/or tactile (hand control) modalities. It is suggested to fulfil three important requisites for motor learning: (1) movement repetition (2) active participation and (3) performance feedback.

One Study involving the Nintendo Wii Fit™ - Five hours (four 25 min sessions/week for 3 weeks) of supervised Wii Fit training, playing games aimed at improving standing balance and weight shift, resulted in improved standing balance for children with spastic hemiplegia (GMFCS I–II) (19).

- **Visual biofeedback:** It involves standing on a balance platform in a laboratory and keeping the centre of pressure, represented as a red dot on a computer screen, static, or shifting it to a target. Training for 9 hours (three 30min sessions/ week for 6weeks) improved static standing balance and dynamic standing balance in ambulant children with CP (GMFCS I) (20).

- **Functional Electrical Stimulation (FES)**: FES to abdominal and lumbar muscles simultaneously, with FES parameters (On:off time=10 seconds/12 seconds; Intensity=20-30mA; pulse width=250ms; and frequency=25-35Hz) used in the dosage of 10 to 18 hours (five or six 30 min sessions/week for 4–6 weeks), together with rehabilitation (stretching, strengthening, and mobility activities, and Bobath treatments of inpatients in rehabilitation hospitals) improve trunk balance and dynamic trunk stability during functional activities for children aged between 1 and 10 years with spastic diplegia (21,22).

- **Progressive resistance exercise** involves resisted motion or lifting tasks, with progressive increase in training loads, to improve muscle strength. Performing resisted ankle and knee exercises for a total of 6 hours (two 15 min sessions/week for 12weeks), combined with rehabilitation (12 hours), can improve standing balance or gait kinematics in ambulant children with CP (GMFCS I), aged 5 to 14 years (23).

Interventions for Upper limb dysfunction:

- **Constraint-induced movement therapy** (CIMT) or force use therapy. Two types:
  1. ***Classic CIMT (cCIMT),*** involved placing a full arm cast on the unimpaired upper limb for 21 consecutive days, accompanied by intensive training of impaired hand for 6 hours each day.
  2. ***Modified CIMT (mCIMT)*** protocols similarly involve restraint of the unimpaired UL, with variations in the type of restraint applied (eg, glove, mitt, sling), and are accompanied by repetitive uni-manual task practice. mCIMT is different from cCIMT in terms of the therapy delivery (more intensive, short duration and dose of intervention).

- Moderate to strong effects favoring **intramuscular injections of botulinum toxin A and occupational therapy (OT)** to improve upper limb functional outcomes compared with occupational therapy alone were identified.
- There is strong evidence that **goal-directed Occupational Therapy (OT) home programs** are effective and could supplement hands-on direct therapy to achieve increased dose of intervention.

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Orthotics & Mobility Aids Prescription

Dr. T. J. Renganathan

Orthotics (splints) are integral part of treatment for Cerebral Palsy. For practical Purposes they can be classified as per the use in extremities and spine

1. Upper limbs:

Thumb in palm is early condition in hemiplegic, diplegia and total body involved children. A simple thumb spica is mandatory even in early childhood since the extensive sensory receptors present in the palm help in sending different sensations to the brain. It is not advisable to obscure the palm with wide splints when the child is awake.

If there is impending contracture of the wrist and fingers in flexion cock up splints are useful to be applied while the child is resting. When the child is awake mother is advised to encourage more activities on the hand.
Elbow flexion contracture will interfere with crawling activities. Gaiter splints or the elbows can be used.

2. Spine:

A common condition in spine is functional kyphosis in some children due to hypotonia. A simple spinal support to help the child to maintain erect posture will be useful. For scoliosis of the spine which is normally C cure (which has no secondary compensatory curve) semi rigid spinal brace with front opening is preferable not to restrict breathing and feeding.

3. Lower Limbs:

A. **Child is unable to stand and walk** (with or without support): Above knee posterior plastic splint to prevent flexion adduction contracture in hips, flexion contracture in knees plantar flexion in the ankles.

B. **Child who is able to stand and walk** (with or without support)

The requirement and evaluation of a CP child who is waking are as follows:

- Stability In Stance Phase
- Clearance Of Foot In Swing
- Preposition Of The Foot Before Heel Strike
- Cadence
- Energy Expenditure.
- The orthosis recommended should be based on the above criteria.

a. If there is fair control in ankle but has valgus feet SMO (moulded supra malleolar orthosis) is enough.
b. If the child has poor ankle control with spasticity rigid short AFO (ankle foot orthosis) with sole extend up to tip of toes.
c. If there is active plantar flexion and minimal dorsi flexion AFO with ankle joint will be useful.
d. If there is recurvatum secondary to gastro soleus spasticity AFO with 5 degree dorsiflexion is suitable and reverse if there is over activity of dorsiflexors as seen in some children with crouch gait.
e. If the child has a crouching gait with ankle in plantar flexion; AFO with supracondylar extension should be given.
f. I there is dorsiflexion of the ankle instead of plantar flexion the FRO (floor reaction orthosis) to be given.
g. If the crouch is severe; KAFO (knee ankle foot orthosis) to be given to prevent flexion deformities in the knees.
h. If there are fixed flexion deformities of knee surgery is the option.
i. SWASH (sit walk and stand hip) orthosis is helpful in mild cases before 4 years of age. In established deformities of hips HKAFO are useful in post operative period to be worn for a period of one year.

➢ Postural control aids:

Good positioning is hallmark of treatment in from early childhood when the child in different positions.

A. On ground:

Side lying: This is a comfortable position for a child who has tonic neck reflexes interfering with rolling. Sideling helps the child to be in relaxed position, use both hands in midline and develop eye hand and mouth co ordination. A L shaped board with foam on top dimension of 5'x12''x3/4"x1" is ideal to keep the child in side lying. Child who has scoliosis has to lie on the concave side of curve for better alignment.(1)

B. Prone lying:

Wedges made up of wood with foam top with the elbows flexed at 90 degrees position will help the child to develop extension in child who has flexion pattern. If there is rectus femoris spasticity or flexion contracture of the hips the length of the board should extend beyond the knees.

For child who is severely affected and needs full support from the neck bean bags are ideal.

➢ WHEEL CHAIR (WC) & SEATING SYSTEM (SS) REQUIREMENTS:

In Indian conditions wheelchairs are not used frequently due to many issues. So the following factors should be kept in mind viz. safety, cost, convenience, parental concern, environmental situations.

A. Age of the child:

- **Below 5 years**

1. Some children will not have trunk control and balance and are unable to take a step in erect with maximal physical assistance wheel chairs are required. In many situations in India the child is forced to sit in WC due to environmental reasons and parental hurry even he/she has control of trunk

2. In children who have fair upper limb motor control self propelled wheel chair will be useful.

- **Above 5 years.**

1. Parents find it difficult to carry children after 5 years of age due to increased weight and height so seek WC for passive and active use.

If the child has active control in upper limbs and good cognition manual propelled wheel chair is useful. In children with athetoid with clumsy hand and poor trunk control with good cognition powered wheel chair will be useful. In poor cognitive function then passive WC mobility will be ideal.

For children who have to be propelled in crowded areas ideal will be stroller. It is advisable to make the child to sit in car seat when being transported in cars or buses since the position of seating will influence the tone and posture.

Few points to be noted by Physiatrist while advising the parents for wheel chair.

B. Seating systems:

- **Back rest.**
  1. If the child has predominantly trunk flexion due to hypotonia stiff back with vertical paraspinal supports to keep the trunk in neutral is ideal. In addition chest straps H type will help to restrain the trunk movement
  2. If the child shows extensor thrust backrest should be a soft sling type, and seat strap at the pelvic level will help to keep the pelvis tilted anteriorly.
  3. If there is adduction in the hips sponge wedges to be kept in between the thighs extending from knee level to mid thighs and the height of the wedge should be higher than the thigh level to prevent over riding of thighs.
  4. If there is severe scissoring additional reinforcement from hand rest can be applied as leather straps.

- **Foot rests**
  should be at 90 degrees and the difference in heights should be compensated with sponge blocks.

The standard measurements are
1. Seat depth from posterior gluteal region till bend of knee minus one inch.
2. Seat width the distance from both greater trochanter and add one inch each side.
3. Back rest from sacral tip up to inferior angle of scapula if there is good trunk control and can be extended up to vertex depending on the support required.

- **Walkers:**

1. If the child show tendency for crouching; posterior postural walkers are useful where the wheels are behind the heels and the back frame hitting at the sacroiliac level. This will encourage the child to gain upright position.
2. For a child who had trunk balance issues anterior walker which will increase the base of support will be useful.
3. In CP the flexion posture always inhibits extension and not vice versa.

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Principles of Drug Prescription

Dr. Geeta Handa

Important guidelines regarding drug prescription in Cerebral Palsy

A. Drug treatment of spasticity may should not be based on tone assessment only, functional gains or goals are important determinant for starting anti spasticity treatment

B. Some patients may experience a decline in function with spasticity reduction if started on anti spasticity medications without due considerations to functional status advantage gained with spasticity

C. Do not stop any drugs patient is taking abruptly , always take prior drug intake history and accordingly wean off the drugs if needed

D. Drugs take 3-4 weeks to have an effect and hence any titration should be done after 1 month. If the patients are stabilized on a dose then 6 monthly follow-up is adequate.

E. Refer to standard information for drug dosage and mechanism of action, Complications, its prevention and management and do monitoring of blood biochemistry (liver and kidney function tests) 6 monthly.

Important Drugs to consider

1. **Baclofen** – start with 5-10 mg TDS and titrate after monthly interval for best results. Monitor liver and kidney function. Not to be used in child with seizure disorder
2. **Tizanidine –** Start with 2 mg TDS and titrate to the desired dose
3. **Diazepam –** start with low doses and at night, useful for patients with seizure disorders and hyperactivity .It is effective for the short-term treatment of spasticity in children with CP. Ataxia and drowsiness are important side-effect affecting rehabilitation.
4. **Sodium valproate, carbamazepine and gabapentin** – drug of choice in CP associated with seizures or dyskinetic CP
5. **Trihexyphenydyl (anticholinergics)** – Useful to some extent for drooling and dystonia. Conflicting evidence. Side effects are usually reversible (dry mouth, constipation, urinary retention)
6. **L Dopa and Carbidopa** – conflicting evidence, very useful in Dopa responsive dystonic Cerebral palsy (In absence of specific tests a test trial may be considered.
7. **Glycopyrrolate** – Can be used for severe drooling, short term management
8. **Scopolamine patch** - may be used for drooling for short term.

Nutrition, Feeding & Drooling In Cerebral Palsy

Dr. Ritu Mujumdar

➢ Nutrition:

When to do Nutrition intervention?

1. **Plateaus in weight gain** or **growth** resulting in deviation from an established 'pattern'.

2. **Evidence of low body-fat stores** in combination with low weight in respect to height or length.

3 Prolonged **or stressful** oral feeding

4. Signs of **pulmonary aspiration** or **dehydration**.

5. Evidence of **micronutrient deficiencies**.

➢ Clinical Examination:

Appearance:

a) **Wasted (too thin)**
b) **Normal** (rounded contours, no noticeable excess fat)
c) **Overweight** (noticeable fat)
d) Anaemic,
e) Vit.D deficiency/Rickets
f) Multivitamin deficiency

➢ Anthropometric assessment

1. **Weight of child:** Weighing scale
2. **Height/ Length**: Stadiometers/Infantometers
3. **(Height-Child who can stand/ Length**:**Recumbant child)**
4. **Mid arm circumference(Triceps skin fold thickness) -**Tape
5. **Head circumference-** Tape

   a) For **infants** : **assess** growth every 1–3 months

   b) For older children may **vary** depending on their nutritional and heath

6. The **95th centile values of weights and heights for given age/gender** can be taken to be representative of **well- nourished normal population** and considered as standard reference values for India

➢ Feeding Skills

A. Check for Oral and pharyngeal problems: reduced lip closure, poor tongue function, tongue thrust, exaggerated bite reflex, tactile hypersensitivity, delayed swallow initiation, reduced pharyngeal motility and drooling

B. Check for constipation.

➢ Key Questions to ask Parents

Questions	Red Flags
How long does it take to feed your child?	More than 30 min, on any regular basis
Are meal times stressful to child or parent?	Yes, if one or other, or both
Is your child gaining weight adequately?	Lack of weight gain over 2–3 months in young child, not just weight loss
Are there signs of respiratory problems?	Increased congestion at meal times, 'gurgly' voice, respiratory illnesses .

➢ Feeding route

❖ **Oral:**

a) Most children able to feed orally
b) No improvement in nutritional status after 1–3 months ,supplementation with oral nutritional supplements

❖ **Enteral:**

a) Dysphagia , prolonged coughing, Gurgling sound, Gastroesophageal reflux, danger of aspiration, extended feeding times , Undernutriton
b) Caregivers should be gradually introduced to the topic of alternative feeding methods with sensitivity
c) Input of entire team (Physiatrist,Speech therapist,Clinical psychologist,ENT Specialist,Gastrosurgeon)

❖ **Aim:**

a) Assess, reassess and sometimes intervene to help each child maintain optimal growth over time.
b) Frequent follow-up at least every 3–6 months
c) Broad knowledge and an individualized approach that takes into account the specific needs of each child within his/her family.

d) The child and family should enjoy a safe eating experience

❖ **Management**

a) Textures of food and thickness of fluids may need to be modified to obtain: airway safety, maximise eating efficiency and reduce fatigue during meal times.
b) The bolus size can be manipulated for safety in some children.
c) Include Diet with Fibre, Vegetables, and Fruits. In-between drinking of water to help swallowing
d) Modified feeding devices according to need of the child
e) Proper positioning while feeding
f) Regular and thorough oral care is also vital for all children.
g) Feeding should not be stressful for caregiver or child
h) Consider Enteral feeding after proper counselling & sensitizing the parent or caregiver

- **<u>Drooling</u>**

a) Drooling beyond the age of 4 is abnormal
b) Drooling is a multi factorial problem
c) Impaired oral sensory motor function can result in drooling that in turn results in impaired hydration

❖ **Assessment**

a) ENT Specialist, Speech & language therapist, Clinical psychologist
b) History and patient's goal for treatment
c) Posture and mobility
d) Oro facial examination and oral hygiene
e) Oral sensory motor functions and abilities
f) Communication and speech possibilities
g) Eating and drinking observation
h) Specific swallow and drooling measures
i) Self management strategies

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A. Anterior drooling

Saliva spilled from the mouth that is clearly visible Oro-motor, oro-sensory therapy

Management

a) Behavioural therapy
b) Speech & Language therapy
c) Pharmacologic treatment(Anti cholinergic)
d) if no improvement than
e) Surgery (Refer to ENT Surgeon)

B. Posterior drooling

Saliva spilled into the pharynx possibly creating a risk of aspiration

Management

a) Physical and dysphagia treatment
b) Pharmacologic treatments
c) Surgery
d) Radiotherapy

It is critical that all decisions for the management of feeding and swallowing problems are made in consideration of the primary needs of the child that is, a stable airway with adequate nutrition and hydration. In addition, any feeding/ swallowing intervention should be pleasurable and non-stressful for patients and care givers

a) visual assessment is very important, consider what is "typical" for the diagnosis

b) Consider all possible contributors to energy needs: mobility status, respiratory status, and muscle tone.

c) Screen for dysphagia to determine a safe feeding route.

d) Screen for motility issues, including GERD and constipation/diarrhea—"what goes in must come out".

e) Assess drug/nutrient interactions, such as the effect of seizure medications and birth control medications on bone health.

f) Ensure adequate protein and micronutrient intake, especially in hypometabolic or hypocalorically-fed individuals.

Cognition in Cerebral Palsy

Dr. Ganesh Arun Joshi

- Often Mental Retardation is tagged as accompaniment of Cerebral Palsy. It is not always so. About one third of persons with cerebral palsy have mental retardation. However few Indian studies mention that the prevalence of mental retardation is very high, upto seventy five percent, in Indian persons with Cerebral Palsy.

- Mental Retardation is renamed as Intellectual Deficiency Disorder (IDD) as there is no "retardation" of cognition. Simply having low marks on standard Intelligence Quotient (IQ) scales is not sufficient to define IDD. It must be accompanied by deficiency in at least two adaptive living skills and must start during the developmental age viz. before the age of 18 years. Classically IQ grades define mild (50-70), moderate (35-49), severe (20-34) and profound (<20) mental retardation and it continues to be used in disability certification. However, it is more practical to classify persons with IDD as educable (mild to moderate), trainable (moderate to severe) and custodial (severe to profound). These levels bring forth the learning abilities (strengths) and indicate the required supports (deficiencies) that can be used to prepare lesson plans.

- The cerebral palsy patient has issues with motor functions and also associated problems with perception that affect the performance on standard IQ test batteries. The clinical/rehabilitation psychologist (RCI registered professional qualified to do IQ tests) must use appropriate tests and provide sufficient flexibility on the scores to arrive at appropriate evaluation of IQ. The persons with Athetoid Cerebral Palsy are usually having normal intelligence but are at risk of labelling of Mental Retardation due to performance issues on the IQ tests.

- The topography and dynamics of the physical and social environment cannot be learnt if the child with cerebral palsy is confined to his room and does not get to know other members of society. It is essential to provide appropriate learning environment to the children with cerebral palsy during early age when the learning skills are sharp. Special Educator (Cerebral Palsy) is RCI registered personnel who provides teaching to children with cerebral palsy. Special Educator (Mental Retardation) is other RCI registered personnel skilled to teach the children with mental retardation. The teaching includes self care, play, vocationally useful skills in addition to academics as suitable for the child and is customised to his/her requirement. These professionals can be found in the "registered with us" tab in RCI website rehabcouncil.nic.in

- According to the intellectual level, skills and interest of the person with cerebral palsy, appropriate vocational training shall be instituted at an early age viz. 15

years because mastering of the earning skill will take more time than non-disabled peer. Government of India has initiated a dedicated skill training scheme that certifies them with appropriate training and also targets placement in sheltered workshop/employment/self-employment as suitable. The details are available in website disabilityaffairs.gov.in

- Intellectual Deficiency Disorder is considered to be unable to decide his own future suitably. Hence the Government of India has established The National Trust through an Act in 1999. The National Trust is given the responsibility to certify persons with Cerebral Palsy, Mental Retardation, Autism and Multiple Disabilities and appoint a legal guardian for such persons to take appropriate decisions on their behalf once they attain the age of 18 years. The National Trust operates through Collector of each district and is supposed to ensure wellbeing of persons such certified throughout their lifecycle even after the death of the parents. The National Trust runs various schemes to provide home, activity, health insurance, recreation etc.

- Autism is a possible association with Cerebral Palsy, but is less often seen. Psychiatric complications do occur in persons with Cerebral Palsy usually in teenage or later age. Appropriate Psychiatric referral is required to manage these issues.

Principles of Managing associated Disabilities

Dr. Feroz Khan

1. Vision:

Ocular Motor disorders:

- Many CP children get visual problems and different studies show different percentage of affection. Spastic CP children have more visual problems than athetoid. Basically the function of the extra ocular muscles is to coordinate to bring the image within the retina.
- The motor dysfunction in CP affects the movements of extra ocular muscles interfering with (1) visual acuity , (2) squint (strabismus) (3) binocular vision (which completes at the age of 8 years).

These impairments interfere with learning process in the therapy sessions and in classrooms.

Simple evaluations:

- Visual acuity in each eye separately.
- Squint is tested by focussing torch light on the child's eye and look for light reflex which should be identical. In squinted eye there will be deviation.
- Test for binocular vision.

Management:

- *Glasses:* When needed should be started from the age of 24 to 30 months. They should be started early if the squint is severe.
- *Occlusion:* Normal eye is to be occluded till the age of 18 months after that the child will remove the patch. The idea is to stimulate the squinted eye to develop vision. In mild cases the normal eye will develop squint indicating improvement. Parents should be informed about the reason for closing the normal eye. The occlusion should be for two hours a day and gradually decreased.
- *Surgery*: The surgical interference is recommended after one year of age depending on the goal for surgery. If there is fair visual acuity, hope for binocular vision and vision is required for non verbal communication surgery is done earlier. For cosmetic reasons the surgery is to decided with the consent of the patient.

Visual Perceptual disorders:

These disorders are due to brain damage. The oscillating eye movement with poor neck positioning leads to improper fixing of the images in the retina and for shorter period of time. This interferes with perceptual and conceptual performance. (Perception is when sensations are given a meaning and mapping is created in the brain and concept is the action performed by the individual in the mind) There will be difficulty in figure ground and depth perception, seen more in spastics. Surgeons should have a clear idea about that before planning for surgery in such children, as this can be one of the reasons some children despite good surgical interference are afraid to walk.

Management: Visual therapy by Orthopticians who train the children on perceptual training like improving eye movements, different level of tracking objects with eyes, awareness of body, teaching directions, size and shape identification etc.

2. Hearing:

A. Peripheral involvement:

- Hearing is important for developing speech. The ears in CP can be affected by outer and middle ear and inner ear disorders.
- The outer and inner ear disorders produce conducting defects may need surgical treatment and hearing aids behind the ears to improve hearing.
- Inner ear disorders produce sensory neuronal loss cannot hear low sounds but hypersensitive to high sounds. CP children may not follow the instruction of the therapists and parents leading non co operation. Hearing aids may help in some children.

B. Central involvement:

- When brain stem is affected children can hear only at a higher level of sound and the parent and therapist should modulate their tone during therapy.
- When reticular formation affected children will have poor arousal sometimes and increased for simple stimuli. In cortical affection child will be confused and unable to understand the speech and command.
- Normal hearing aids are prescribed as per the audiogram results. In CP children specialized techniques should be used which includes detailed behavioural aspect of the child to different sounds.

Hearing acuity and hearing aids:
15 – 25 dB occasional hearing aid.
25 – 40 dB mild gain hearing aid.
40 – 60 dB Normal hearing aid.
60dB and above hearing aids are not beneficial.

3. Sensory issues

- Sensations play an important role in postural and movement control production and performance. There may be some automatic reaction from the motor unit without much sensory feedback but a smooth well co ordinate movement needs the proper sensory input for planning, execution, maintain and audit the movement for betterment next time. Physiatrist should look for sensory issues and use them to plan ideal program to improve the motor function.(1)

➢ **Cutaneuos Exterocepticve input:**

1. Spino thalamic sensation which are protective in nature for pain, crude touch and temperature. They are reflexive and linked to autonomic and reticular formation function producing a flight and fight response. This is exaggerated in children with Cerebral Palsy making them uncomfortable during change in therapy procedures or therapy personal.
2. Laminiscal system which are well represented and areas in parietal region of the cortex to analyze and recommend suitable response. The sensations from poprioceptvie impulses also pass through them and are dealing with touch, pressure, localization, quality etc. This system controls the spino thalamic system as well to prevent exaggeration of responses of it. In CP this control may be lost .
3. The therapy procedures can be used to stimulate the spino thalamic input to elicit a specific motor response at times and laminscal system by sustained pressure, stroking, to relax the muscle on the skin over the muscle. This should be taught to mothers who can deal with the spastic muscle while applying splints in the night.

➢ **Poprioceptvie input:**

The muscle spindles which play a vital role in maintaining the tone of the muscles can be manipulated with positioning, gentle stretching, and relaxation techniques, to reduce the firing muscle spindles in hypertonic conditions. In hypotonic conditions vibration, electrical stimulation, passive and active motion to encourage the muscle spindle firing to increase tone.

➢ **Vestibular system:**

This is a highly interconnected system with many sensory and motor areas. The static posture which is influenced by gravity is controlled with vestibules, and dynamic control in up down, forward and backward and lateral displacement of the body by the semi circular canals. These are impaired in CP interfering with maintain posture against gravity, develop milestones and required motor functions; develop eye hand mouth and midline co ordination and activities. Special techniques should be used to facilitate the

vestibular function (eg. Use of suspension systems like bungee cords, swings to decrease the hyperactive responses and high speed to facilitate low tone.(2)

- **Auditory system:**

It is a well known practise used in households to control and facilitate the motor functions through music and voice modulation in children. The reticular system activation helps to increase learning, memory and motor responses. Children having athetoid movement like fast music and those with heprtonicity relax with soft music.

- **Olfactory system:**

The peripheral receptors in the roof of the nose are directly linked to olfactory cortex without interruption. So children may respond favourably with some smell and react harshly by crying for unpleasant smell in therapy room and hospitals. (Disinfectants used to clean floors)

- **Visual:**

Vision is the gift for learning, highly skilled complex sensory system. Alteration of colours, scenarios is used to pacify the hyperactive child and facilitate learning. Many children with CP like blue colour mats!!
The position of the eyes, the background behind the therapist during speech therapy and dysphagia program is very important to get favourable responses.
The position of the eye balls can influence the tone in the trunk used in relaxation exercises.

- **Gustatory:**

  Colour, smell and texture of the food will alter the response to swallowing. Mother/ caretaker should be asked to look out for the suitable type and texture of the food to prevent exacerbated motor responses.

4. Speech Issues:

- Speech and language are complex process involving many motor, sensory functions. This is highly skilled motor functional activity. Communication in any form is the most important require for a purposeful living.
- In children with CP speech is affected either directly due to a cortical lesion or indirectly in other areas which interfere with speech production and reception.
- The requirement for speech production are intact speech apparatus (lips, tongue, pharyngeal and laryngeal components, chest wall, diaphragm, trachea and lungs)
- The air required to create and transit the sound in supplied by the respiratory system. Normal respiration is controlled in brain stem. The cortical centres modify the respiratory pattern to produce phonation, resonance and prosody. This function of cerebral cortex is affected in CP.
- Physiatrist should understand that and plan program to improve the motor, cognitive and sensory function of the cerebral cortex to improve the respiratory control.

- The points to be insisted by Physiatrist is that for speech production good hearing, proper stimulation and ideal environment and the necessity to speak (like schools, social situation etc.)

The details of speech production and management are beyond the scope of this write up the reader can refer standard text books in speech therapy. One such book suggested is "Treating Cerebral Palsy For Clinicians by Clinicians" Edited by Eugene T.McDonald 1987 edition pro –ed, Austin, Texas.

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Miscellaneous issues in cerebral Palsy:

(DR. Gita Handa)

- **Adolescent and adult issues in Persons with Cerebral Palsy** – Educational , Vocational and skill development, Socialization and community support, Sexual Concerns- Menstruation hygiene in Females , Sex education, Marriage counselling and family planning issues.
- **Growing up and ageing with Cerebral Palsy** – Management of old age issues (eg Bisphosphonates for osteoporosis etc)
- Many children with CP have sleep disturbed due to pain, regurgitation of food , not given much attention by clinicians and parents. Suitable doses of Ranitidine will help to control regurgitation of food.
- Pain is mainly due to contractures and spasm they develop occasionally and can be managed with proper positioning and simple medications.

Principles of Conservative Intervention for Spasticity Management

Dr. Harshanand Popalwar

A. Botulinum Toxin A

1. Introduction:

Botulinum toxin A (BoNT-A) is considered a safe and effective therapy for children with cerebral palsy. It is neurotoxin which prevents acetylcholine release from nerve terminals at neuromuscular junction

2. Indications:

a. Spastic cerebral palsy.
b. Focal dystonia
Botulinum toxin can be injected as early as 18 months of age. There is no upper age limit, however.(1)

Localization	Unilateral CP	Bilateral ambulant CP	Bilateral non-ambulant CP
Upper limb	Improved function and aesthetics/appearance	N/A	Pain management, Easier caring and positioning, Functional and/or cosmetic improvement of hand position
Lower limb	Improved gait	Improved gait	Pain management, Easier caring and positioning, Improvement of weight bearing, Prevention of hip dislocation.
Spine	N/A	N/A	Postural management Care, Pain management

Table 1: The most common indications for botulinum toxin A treatment in unilateral, bilateral ambulant and bilateral non-ambulant children with cerebral palsy (2)

3. Contraindications

a. Athetoid CP
b. Dyskinetic CP
c. Hypotonic CP
d. Ataxic CP

4. Clinical Examination, Assessment, Evaluation and Documentation

a) Active and passive range of motion.

b) **Specified muscle testing** e.g., Thomas-test, popliteal angle, Silverskiöld, Duncan-Ely etc

c) **Muscle strength** according to Janda, MRC, Oxford-scale.

d) **Observational gait analysis** supported by video documentation (3)

e) Goal attainment scale (GAS) (4)(5)

f) **Modified Ashworth Scale (MAS)** is simple and reproducible in the assessment of muscle spasticity, but is probably of limited validity (6)(7)

g) **Modified Tardieu Rating Scale** is more reliable, and is focused on most clinically relevant parts of the Tardieu Scale (8)

h) **Gross Motor Function Measure (GMFM**) is a validated tool for the measurement of motor function in children with CP (9). It may, however, not be sensitive enough to detect the minimal changes that occur following relatively minor interventions.

i) Upper limb assessment tools e.g., SHUEE and AHA scores or PEDI (10)

j) **Three-dimensional instrumented gait analysis** (3DGA) has been invaluable in order to document function before and after BoNT-A injection, which may be used as an objective parameter to assess gait (in cases where gait improvement is the aim). It is also extremely useful in planning surgical management and as an outcome measure in clinical studies (11)

5. Assessment of gross motor function, activities and activity limitation

a) The gold standard measure of gross motor function in children with CP is the **Gross Motor Function Measure** (GMFM-66) (12)(13)

b) The Functional Independence Measure for Children **(WeeFIM)**(14) and the **Paediatric Evaluation of Disability Inventory (PEDI)**(15) are also well established and useful in the research context for children with more severe involvement (GMFCS levels IV and V)

6. Goal setting:

The goals of treatment should be agreed between the child and family and the health professionals involved in his/her care.

Goals should always be patient-specific and realistic. It is often useful to define short-term (for each injection cycle) and long-term goals.

Selection of Key Muscles: Key muscles are those muscles that, due to spasticity, prevent attainment of the next motor milestone.

Spastic muscles do not have to be injected if the pathologic tone does not impair function.

7. Doses:

Product	Range in literature	Recommendation	Maximum total dose
Botox	6–24 U/Kg (up to 30 U/Kg used in occasional multilevel injections)	GMFCS I–IV without risk factors: 16–20 U/Kg GMFCS V with risk factors*: 12–16 U/Kg	<300 U (16)(17) <400–600 U
Dysport	10–30 U/Kg	20 U/Kg (18) (level B recommendation)	200–500 U (19)(level U Recommendation) <900 U

Table 2: Product and doses

8. Method of administration:

To maximize the clinical effectiveness of BTX-A, the toxin must be injected inside the fascia compartment of the muscle in a dose suitable of neutralizing the neuromuscular junction activity and in an adequate volume such that diffusion to the junctions at the end-plate area occurs while unwanted spread is minimized.

Several sites of injection at the mid-muscle belly are needed for optimal treatment.

9. Techniques to Guide Injection

Several techniques are available to guide injection, including palpation, ultrasound, electromyography (EMG) or electrical stimulation.

a. By using palpation and anatomical landmarks, target muscles can be identified. The technique described by Cosgrove, to observe needle move while passive motion of body segment, may be easily used for localisation of the needle in the target muscle. **Correct needle placement guided by palpation has shown no difference in clinical outcome compared with other techniques.** (16)(17)
b. **Ultrasound** is a real-time, dynamic imaging method that does not involve ionising radiation, and has excellent spatial resolution. It is, therefore, well suited to interventional guidance. Being a low-cost examination, ultrasound guidance provides rapid and reliable identification of target muscles, even deep-seated

ones such as the iliopsoas.(18) There is good acceptance of the technique in young children and it may also be useful in sedated patients. (19)

c. For EMG-guided injection, a standard or portable EMG machine may be used, and a Teflon®-coated EMG needle is recommended. Target muscles can be identified by recording the motor unit potentials. Identification by EMG is well adapted for focal dystonia. However, spastic muscle groups in CP do not allow the differentiation of single target muscles.
d. Electrical stimulation uses an EMG machine or portable stimulator together with a Teflon®-coated EMG needle, and elicits contraction of the target muscle.

10. Post injection treatment:

a. The antispastic effect appears within 24 h to 3 days after injection and becomes maximum at 10 days to a month. It lasts for 3– 6 months.

b. Some patients are golden responders in whom the antispastic effect lasts for over a year.

c. Proper exercises, splinting and casting may increase the number of golden responders. Casting for 2–3 weeks after injections may improve the results (20)

11. Side effects post injection:

a. Side-effects are rare when the dosing and technique protocols are correctly followed.
b. Adverse events can be located into the site of injection or can be distant from the site of injection.
c. Pain at the site of the injection is unlikely a clinical problem.
d. The most common side-effect is weakness in adjacent muscles caused by diffusion of BTX across the muscle boundaries.
e. Side-effects distant from the site of injection are unusual and consist of generalized weakness, flu-like syndrome, urinary incontinence, constipation and dysphagia.
f. The most serious side-effect is aspiration pneumonia. This is critical in CP patients with general involvement and pre-existing pseudobulbar palsy because in these patients.

12. Reasons for failure of Botulinum toxin A therapy:

Factors contributing to an inadequate clinical response include

a. Inadequate dosage,
b. Inappropriate goal setting,
c. Excessive weakness in the affected muscles.
d. Wrong injection technique
e. Neutralizing antibodies have also been reported to cause an inadequate response (25)

13. The Importance of an Integrated Approach

An essential component of any BoNT-A treatment concept is the multimodal treatment approach, which may include exercises, orthoses, etc. When relevant, patient-centred goals have been set and BoNT-A treatment is potentially indicated based on severity and age, the place of BoNT-A within the integrated treatment should be assessed.

1. exercise therapy (especially stretching and strengthening) and occupational therapy (in the upper limb) combined with BoNT-A therapy is more beneficial than occupational and physiotherapy alone, (21) and is recommended in patients receiving BoNT-A therapy (22)(23)
2. **There are limited data on the benefits of combining BoNT-A therapy with orthoses** (24)**, and one study has suggested that orthoses may not be as beneficial as casting when used as part of multimodal treatment involving BoNT-A therapy** (25)**.**
3. There are also conflicting data on the benefits **of combined casting and BoNT-A therapy** versus either treatment alone,(26)(27)(28) but recent reports suggest the **combination is beneficial.** (29)(30)
4. Selective dorsal rizotomy (SDR) may reduce spasticity in selected individuals. There is a role for BoNT-A therapy in the long-term follow-up of SDR in many children (31)
5. In cases of severe generalised spasticity, the combination of oral tone-reducing medications or intrathecal Baclofen treatment and BoNT-A may have a therapeutic effect.

Others

Other physical modalities that have been reported to ameliorate spasticity include application of tendon pressure, (33) cold, warmth, vibration, splinting, bandaging, massage, low power laser, and acupuncture. (34, 35)

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Principles of Surgical Interventions

Dr. S.Y. Kothari

General Principles:

- Surgery is just one of the interventions in the management of CP. Should be done after thorough considerations of all relevant aspects.

- Surgery should have Functional and not exact anatomical correction, as its objective. Overall Rehabilitation is the aim.

- General and operation specific indications and contraindications should be observed. (Cognitive function, extra-pyramidal/ cerebellar dysfunction, ability to co-operate in exercises and follow-up etc.)

- The indications may vary from functional improvement to improvement of posture, sitting in wheel chair to improvement in hygiene. Surgery may be needed to avoid impending dislocation of a joint (hip), but should be performed with caution in cases of long standing dislocation only if some functional improvement is expected.

- You shall defer the surgery if you have other management modalities at hand.

- If in doubt about indication of surgery, always try some reversible technique first (BoNT(Botulinum Neuro toxin)/Phenol inj.) and if satisfied then only operate.

- Primary aim should be “No harm if No improvement”

- Patient/Relatives should be counselled very well before surgery and all doubts be cleared. Goals should be discussed and set with them.

- Learn/ develop proper clinical examination techniques before deciding any surgery.

- One should perform surgery according to his capabilities and training.

- Surgery usually gives good result in lower limb. One should be very clear if the surgery in upper limb in a particular case is going to give tangible benefits.

- Proper selection of cases and post-operative exercises, orthosis, counselling, etc is equally important.

- Surgery should be started from distal to proximal end of extremity, as a general guideline.

- Shifting of spasticity from one muscle to another one/synergistic group, imbalance of agonist-antagonist should be taken into consideration.

- Repeat surgery is needed in some cases, who do not follow post-operative management after first operation or due to sudden skeletal growth. It is more difficult than first surgery and hence the first operation should be deferred as much as possible commensurate with response from other therapies.

- One should also take full responsibility of supervising the post operative rehabilitation to achieve possible functional improvement without passing / blaming the reasons to paramedical personal for any functional decline.

Discussions--

Dr Harshanand opined that on-table assessment after anaesthesia is important, to which Dr Kothari disagreed, as under anaesthesia spasticity disappears for dynamic functional assessment.

During discussions, Dr Kothari opined that reduction of a long standing hip dislocation may be difficult, damage abductors and may not be stable as the acetabulum may be shallow. It may give a painful, unstable and non-functional joint to the patient. On the contrary the dislocated head femur may give adequate pelvic support and stability and in turn a better function.

Information to parents on usefulness and complications of surgery for cerebral palsy children

Dr. Akoijam Joy Singh

- ***Who needs surgery*?**

a) Fixed deformities of the limb that interfere with function like cleaning of perianal area, reaching, sitting, standing or walking
b) Inability to control a spastic (stiffness of muscles) deformity by conservative measures such as medications, splinting and exercises
c) Secondary complications such as bony deformities or dislocation of a joint (commonly of hip joint)
d) Instability of joint which increases the risk for the joints to become displaced

- ***Who should not be operated?***

a) Generalised involvement of whole body
b) Lack of trunk control (inability to hold the body upright while sitting or standing)
c) Child with abnormal involuntary movement of the limbs (dystonic or athetoid patients)

- ***Usefulness of surgery***

a) Correct deformities
b) Free permanently tighten muscles (contracture)
c) Easier nursing care of the peri-anal area
d) Decrease pain by reducing stiff muscles (spasticity)

e) Improve body balance
f) Improve posture
g) Improvement of the walking pattern
h) Prevent complication like hip dislocation

- ***Possible complications after surgery:***

1. Surgery for flexion (bending) deformity of hip

a. Increase in difficulty in climbing stairs due to diminish in hip flexion pull
b. Pelvic rotation while walking

2. Surgery for crossing over of the legs (scissoring)

a. Wide opening of the leg while lying or standing leading to asymmetrical abduction deformity at hip

3. Surgery for flexion(bending) deformity of knee

a. Backward bending of the knee (genu recurvatum) and high placement of the knee cap bone (patella alta)

4. Surgery for downward bending deformity of foot: (equines deformity)

a. Decrease step length (short steps), difficulty in push up on toes while walkingand progressive crouch gait (walking in excessive hip, knee flexion, both knee coming closer and raising of the heel)

Problems of surgery in Cerebral Palsy

Dr. Sanjay Keshkar

- **Introduction:**

A surgical procedure in cerebral palsy is something that people do not agree to lightly. However, there are some cases where a surgical procedure can bring comfort, relief from pain, and improved function. When considering surgery, though, there are some factors that people should weigh carefully.

Surgery intervention is used only if benefit outweighs risk. Since surgical procedures have the limitations and the potential for serious complications, less invasive and alternative options are usually considered before surgery is recommended. The accumulated experience has now shown that results considered satisfactory in short term follow-up tend to deteriorate in time. The relapse rate is found to be about 25-35% after such procedures, as hamstring & achelis tendon lengthening. High recurrence rate is because of certain issues / problems related to surgery and such issues relevant to physiatrist will be discussed in this topic.

- **When to operate is a big question.** The ideal age of operation is 5-7 years though the range is 3-10 years depending on individual. Amongst them the most suitable candidates are ambulatory child with GMFCS 1-3. As a physiatrist we should stick to the said the age & GMFCS to get positive results. Beyond this may land up into some problem unless done by some experienced orthopaedic surgeon.

- **Where to put knife is another issue.** The location of surgery can vary from the upper extremities (wrists, arms, shoulders, spine, and back) to the lower extremities (feet, ankles, legs and hips). Orthopedic surgeries performed on those with Cerebral Palsy are more often performed on lower extremities, versus upper extremities, due primarily to the possible risk of sensory damage and loss of functional abilities. As a physiatrist one can safely do soft tissue release (faciotomy, aponeurectomy, tenotomy, myotomy & tendon lengthening) in lower limb. For Upper limb surgery, bony surgery and tendon transfer etc. may require further skills and training.

- Next issue is knowledge of **musculoskeletal changes with growth**: The major problem is related to the poor understanding of the changing relationship between growth and muscle imbalance. Another problem is the tendency to **misinterpret spasticity as strength** which contributes to place surgical procedures, in many cases, on the borderline of experimentations leading to high incidence of unexpected results.

- **Other issues related to individual:** Each individual's condition is unique, therefore treatment and surgery on Cerebral Palsy doesn't follow a set protocol or certain time parameters. The extent, location and severity of the impairment vary among individuals. Their abilities, home environment, support structure, educational situation, compensation factors, and associated conditions all contribute to decisions on quality of life and surgery issues.

- **Surgical complications are the main problems** and should be explained clearly beforehand particularly about the expected results. Risks of surgery may include bleeding, infection, and loss of functioning, as well as the possibility that repeated or additional surgeries may become necessary.

The most common surgical procedures, which are still of value in the ambulatory child and can be done by physiatrists are presented with their possible problems / complications.

A. Hip Surgery:

SN	Procedure	Indication	Expected results	Possible complications
1.	Z-lengthening of Psoas tendon	Flexion deformity of the hip over 20 degree, shifting the centre of gravity forwards if	Improvement of balance at gait shifting the centre of gravity backwards	i.Decrease in hip flexion pull (causing increased difficulty in climbing stair) ii Compensatory

		primarily due to Psoas		caliper gait with increased pelvic rotation at swing phase inducing more energy consumption
2.	Adductor tenotomy	Scissoring gait causing instability (mild to moderate)	Improvement of balance	Asymmetrical abduction deformity with pelvic tilt
3.	Adductor tenotomy with Obturator neurectomy	---- do ---- (severe)	---- do ----	---- do ----

B. Knee surgery

SN	Procedure	Indication	Expected results	Possible complications
1.	Medial hamstring lengthenig	Flexion deformity of the hip over 30 degree during the gait	Increased step length & preventing patellofemoral pain	Patella alta, Knee recurvatum and Secondary rotation of tibia
2.	Lateral hamstring lengthening (Biceps)	Popliteal angle showing insufficient correction after medial release (over 30 degree)	Increased step length & preventing patellofemoral pain	Patella alta & Knee recurvatum
3.	Distal rectus release	Caliper gait (lack of flexion at swing phase)	Prevention of Patella alta & Knee recurvatum	Decrease of extension pull inducing relapse of flexion at stance phase

C. Ankle & Foot Surgery

SN	Procedure	Indication	Expected results	Possible complications
1.	Tendo Achilles	Equinus deformity	Improvement of gait by	Insufficient take off with decreased step

	lengthening		increased step length & decreased abnormal cadence	length in early stages. Progressive crouch gait in late stage.

The type of orthopedic surgery that would be best for given child depends mostly on whether they are considered to be ambulatory or not. The purpose of surgery for ambulatory children is to improve their ability to walk, which is essential to improving self-reliance. For example, a child who "toe-walks" may have their stride corrected with a tenotomy or tendon lengthening procedure. Orthopaedic surgery can also correct issues caused by poor alignment of the hips or knees.

In non-ambulatory children surgery is used to stop certain complications from getting worse. Surgeries correcting spinal curvature, hip dislocations and contractures alleviate pain and promote a comfortable, well-aligned sitting position.

Final recommendation: To avoid problems the recommendation is to do soft tissue release (faciotomy, aponeurectomy, tenotomy, myotomy & tendon lengthening) in lower limb of ambulatory child with proper explanation of risks.

Follow Up Assessment

An idea of the lifespan changes and requirement of the children with CP and persons with CP will help a quick review and decision making in planning a rehabilitation program(1)

1. Birth to 3 years:

New neurological signs will appear and old one may disappear. The parents will show maximum concern in the care of the child. They will be able to attend therapy sessions and learn with interest. This attitude should be encouraged. Due to rapid bone growth intervention should be avoided and importance to be given to therapy methods and follow up home exercises.

2. Preschool age:

The diagnosis and classifications are established now. Associated issues like speech, cognition, hearing, sensory, contractures become apparent and the treatment spectrum will widen with more interventions. Etc. This is the time the parents may exhaust the resources and in a confused state. Proper counselling and interest shown by the rehab team will help the parents to stick to rehab and not going astray.

3. School Age:

Priorities should be given to learning and the follow up should be on strategies to minimize the effect of contractures, maintain the functions gained and the therapy to improve strength and endurance within his/her physical abilities. Enhanced motor activities should be made to groom the child with CP to be special athlete.

4. Adolescent age:

Hormonal changes, body image and self identity issues associated with this age will interfere with the regular therapy visits. With the help of the peer group activities will yield good result. Specific interventions, short time therapy sessions will help solve local problems like pain and improve cosmetic appearance.

5. Adult :

Maximum independence in self care should be stressed and vocational, recreational, sheltered homes necessities have to be looked for. There will be decrease in motor functions and therapeutic interventions are required to keep the maximal function attained. The occurrence of other diseases like hypertension, diabetes, infections, constipations etc need to be addressed without delay.

Reference: (1) **Alfred L Scherzer.** Early Diagnosis and Interventional Therapy in Cerebral Palsy: An Interdisciplinary Age-Focused Approach (Pediatric Habilitation volume II) New York NY 2000:18-20.

Cerebral Palsy- Research Status and Possibilities in India

Dr. Sanjay Wadhwa

- The current status of research in Cerebral Palsy in India is poor, though it has improved in the past two decades. There are several reasons for the relatively poor status of research in Cerebral Palsy, especially in PMR in India. Only a small number of Medical Colleges and Institutions in India have a department of PMR. The total number of Physiatrists in India is still very small. Almost all the Physiatrists in the country are trained to be General Physiatrists. There are a very small number of Physiatrists who have received training in specialized areas, and among them, a miniscule are trained in Cerebral Palsy Rehabilitation. Accordingly, out of whatever little research is done in India, a very small proportion is related to Cerebral Palsy.

- In most of the PMR departments in India, there is very limited research infrastructure, whether Physical, Financial, or Manpower. This also hinders good quality research. It is also observed by experts that there is deficiency in training of PG students in various areas related to Research Methodology. There are hardly any regular structured training programs on research methodology in India.

- There are a few critical issues concerning Publication of Research work done in India. The number of journals is very small. The quality of papers published needs to be improved significantly. The official journal of IAPMR which is IJPMR is not yet indexed. As per MCI guidelines, publications in non-indexed journals are not to be given weight-age in selections and promotions.

- There are a few other challenges also as regards research in PMR in India. The major focus of Physiatrists is on provision of services to persons with disabilities and research is a low priority.

- However, the possibilities for research in Cerebral Palsy in India are enormous if concerted efforts are made at various levels. At the individual level, every Physiatrist in India should develop interest in CP, update his/ her knowledge, acquire skills related to management of CP in India etc.

- At the department of PMR level, the resident doctors need to be trained better in evaluation and management of Cerebral Palsy. There should be a separate multi-disciplinary Cerebral Palsy Clinic once a week. Seminars and Journal Clubs on CP are important.

- At the association (IAPMR) level, period workshops on Cerebral Palsy should be organized in different parts of the country. Mid-term CMEs and dedicated sessions during annual conferences of IAPMR will also be useful. IAPMR's official journal i.e. IJPMR should have a separate section devoted to research in CP.

- At the National level, questions on Cerebral Palsy should be included regularly in the theory and Cerebral Palsy cases for discussion included in the practical examinations such as for award of MD (PMR) or DNB (PMR). A Fellowship on Cerebral Palsy may be started in association with NBE. Existing and new AIIMS as well as National Institutes should take interest and play leadership role in conducting, training and guiding research in CP. Collaborative research in CP with department of Pediatrics should also be seriously explored.

- At the international level, efforts should be made to develop multi-centric collaborative research in cerebral palsy, international faculty exchange programs should be explored, and conferences organized.

Conclusion

- The focus of the physiatrist should to assess, improve and maintain FUNCTION of every individual child and person with Cerebral Palsy.
- In India, Children with CP are seen by many medical professionals, para medicals, alternative medicine practitioners and quacks. We hope the guidelines will be useful when physiatrist examines and gives an opinion of the child / adult with CP and, it should impress the parents to feel *"here is a doctor who will take care of my child with CP, better than others*".

We the Physiatrists should make the difference!

Annexure 1

CLINICAL ASSESSMENT
(Sample assessment sheet)

(Tick the appropriate)

Name of Child:	**Age (in months):**	**Sex:**
Name of mother:	**Age of mother:**	**Tel No:**

Presenting complaints:

1. Motor 2.Sensory. 3. Delay in milestones. 4. Combined

Period of gestation: (in weeks):

Maternal issues:

HTN	DM	Malnutrition	Others.

Nature of delivery:

Normal	Caesarean section	prolonged labour	Premature rupture of membranes	twin or multiples

Birth weight (in grams)

Days in incubator: **Ventilator:**

Events in Ventilator/ Incubator:

Seizures	Jaundice Septicaemia	Hypoglycaemias

PRESENT MILESTONE ACHIEVED:

rolling	creeping	sitting	crawling	cruising	walking

HEIGHT		WEIGHT		HEAD CIRCUMFERENCE	

(Add percentile)

Medications presently taking:

PREVIOUS INTERVENTIONAL PROCEDURES:

Splints	Phenol	Botox	Surgery (soft tissue/ bone)

VISION:

Eye contact	Squint	Poor visual acuity	Visual perceptual	others

HEARNG:

Normal	Impaired	Recognise parental voices

MENTAL FUNCTIONS:

Normal	Educable	Trainable	Custodial

SPEECH:

Nil	Monosyllables	Bi syllables	Understandable	Normal	Others

SOCIAL INTERACTION:

Normal	Affected

SWALLOWING

Normal	Solid	Liquid	Chewing	Choking	Others

DROOLING:

Yes	No

Annexure 2

ASSESSMENT SCALES FOR CEREBRAL PALSY

Dr.Kousthub Chakraborthy

The following scales have been agreed upon for the initial assessment for Rehabilitation, and subsequent follow-up for persons with Cerebral Palsy.

When a patient of Cerebral Palsy presents before a Physiatrist, the "General Survey" would include an observation of the following:

(A) Gross Motor

(B) Fine Motor

(C) Communication

(D) Mobility

A. GROSS MOTOR -- Depending upon the highest achievable motor function, children with Cerebral Palsy can be graded as a:

a. Lier (note the spelling → means one who's confined to bed & cannot get up to sitting position)

b. Sitter

c. Stander

d. Walker

B. FINE MOTOR – Prehensile function being an important requisite of functional improvement, document whether the following are present or absent:

Reach	Present / Absent
Grasp	Present / Absent
Release	Present / Absent
Best Prehensile Function	Claw Grip / Spherical Grasp / Cylindrical Grasp / 3-jaw chuck (eg. holding a pen/chalk), Pinch Grip / Key Grip + Ulnar Grasp & Grasp with foot

C. COMMUNICATION: Whether the person with Cerebral Palsy can –

a. Verbalize making sense

b. Communicate with gestures (Speech being unintelligible or inadequate)

c. Communicate with AAC Devices or other gadgets

d. Use some jargon which only the caregivers can understand

e. Cannot communicate

D. MOBILITY: How is the patient moving around / being moved?

a. Independently Ambulant

b. Ambulant with Orthosis / Mobility Aids

c. Ambulant with Manual Assistance

d. Transported by Manual Wheelchair

e. Transported by Power Wheelchair

f. Carried by Parent

FUNCTIONAL ASSESSMENT:

The documentation of function at baseline and at various intervals becomes an integral part of the Functional Assessment in a person with Cerebral Palsy.

For this purpose, use of the following scales has been decided:

F. General Mobility: The Gross Motor Function Classification System (GMFCS)

G. Overall Functional Assessment : The WeeFIM

H. Hand Function Assessment: The Manual Ability Classification System (MACS)

I. Posture Assessment : The Postural Ability Assessment

J. Balance Assessment: The Balance Assessment & Grading Scale.

A. The Gross Motor Function Classification System (GMFCS)

LEVEL 1	Walks without restrictions, limitations in more advanced gross motor skills
LEVEL 2	Walks without assistive devise limitation walking outdoors and in the community
LEVEL 3	Walks with assisted mobility devices limitations with walking outdoors and in the community
LEVEL 4	Self mobility with limitations, transported or use power mobility outdoors and in the community
LEVEL 5	Self mobility severely limited even with the use of assistive technology

The Gross Motor Function Classification System (GMFCS) Scale is helpful because in a very short-interval of time, it will give an idea of both the child's current functional status, as well as what equipment or mobility aids (eg. crutches, walker, wheelchair) the child would need in the future, since a child aged more than 5 years is very unlikely to improve his GMFCS status henceforth.

B. The WeeFIM Scale can be administered in the age group of 3 – 8 years. It consists of 6 Domains (Self-Care, Sphincter Control, Transfers, Locomotion, Communication & Social Cognition), each containing some specific items (a total of 18 across the 6 Domains) that are rated from 1 – 7, 1 being complete dependence (needing total assistance) & 7 being complete independence. Thus, the maximum score achievable is 126, and the minimum is 18.

It is obvious that a 3-year old child would not have the same capacity for independent function as an 8-year old child. For this purpose, there is a detailed chart accompanying the table that divides this 3 – 8 year age-group into 3-monthly intervals, and sets an achievable score against each age.

C. The Manual Ability Classification System (MACS) Scale Assesses the ability of the child to handle objects in important activities of daily living, like play, leisure, eating & dressing. It gives an overall picture of the child's ability to use his / her hands in daily life, including the influence of cognitive problems upon hand function.

It has 5 levels, ranging from I (best) to V (worst).

LEVEL I	Handles objects easily and successfully.
LEVEL II	Handles most objects but with somewhat reduced quality and/or speed of achievement.
LEVEL III	Handles objects with difficulty; needs help to prepare and/or modify activities
LEVEL IV	Handles a limited selection of easily managed objects in adapted situations.
LEVEL V	Does not handle objects and has severely limited ability to perform even simple actions.

D. **The Postural Ability Assessment** measures the control of the Trunk in lying, sitting & standing.

LEVEL 1:	Unplaceable
LEVEL 2 :	Placeable but unable to maintain.
LEVEL 3 :	Able to maintain but no to move
LEVEL 4 :	Able to maintain and move within the base
LEVEL 5 :	Able to maintain and move outside the base
LEVEL 6 :	Able to move out of position
LEVEL 7 :	Able to attain the original position

The assessment may be documented as:

Position :	POSTURAL ABILITY ASSESSMENT SCORE :		
	1ST VISIT	2ND VISIT	3RD VISIT
LYING			
SITTING			
STANDING			

E. The Balance Assessment & Grading Scale is a simple way to document the balance of the person with Cerebral Palsy at initial assessment and at subsequent follow-up visits.

0	ZERO	Maximal assistance required for balance
1	POOR	Needs support to maintain balance
2	FAIR	Able to maintain balance without support, cannot tolerate challenge, can maintain balance while shifting weight
3	GOOD	Able to maintain balance without support, accepts moderate challenge and can shift weight with limitations
4	NORMAL	Able to maintain balance without support, accepts maximal challenge and can shift weight in all directions

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Annexure 3

Body structure and Function Scales

1.MODIFIED ASHWORTH SCAL E FOR SPATICITY

(Useful to quantify spasticity to know the effectiveness of different interventions for spasticity management)

0 No increase in muscle tone

1 Slight increase in muscle tone, manifested by a catch and release or by minimal resistance at the end of the ROM when the affected part(s) is moved in flexion or in extension

1+ Slight increase in muscle tone, manifested by a catch, followed by minimal resistance throughout t the reminder (less than half) of the ROM

2 More marked increase in muscle tone throughout most of the ROM, but affected part(s) easily moved

3 Considerable increase in muscle tone, passive movement is difficult

4 Affected part(s) rigid in flexion or extension

2.MODIFIED TARDUE SCALE

0. Slight increase in resistance through passive ROM but no catch
1. Passive movement is interrupted at a specific angle y a clear catch followed by release.
2. Fatigable clonus <10sec when maintaining pressure at the given angle
3. Indefatigable clonus >10 sec when maintaining pressure appearing at a specific angle
4. Joint is rigid.

3.ADDUCTOR RATING SCALE

0. No increase in tone
1. Increase in tone but easy abduction up to 45 degrees.
2. Abduction 45 degrees with mild effort
3. Abduction 45 degrees with moderate effort
4. Abduction 45 degrees with 2 persons

4.FUNCTIONAL TONE:

(Useful to assess the tone during active movements)

(0) Normal Tone:	Quick and immediate postural adjustments during movement ability to use muscles in synergic and reciprocal pattern for stability and mobility during task and movement.
(+ 1) Mild Hypertonia:	Increase in one delay in postural adjustments and slow co ordination may be affected.
(+ 2) Moderate Hypertonia:	Increase tone limits speed, co ordination, variety of movement pattern and active R.O.M in the joint
(+ 3) Severe Hypertonia:	Severe stiffness of muscles in stereotypic fashion, limited active R.O.M little or no ability against gravity, great effort needed to overcome stiffness during movement.

5. <u>SELECTIVE CONTROL OF FEET .(useful for pre surgical interference in foot)</u>

0. No active movement
1. Predominant activity of EHL and Ext Dig
2. Activity of EHL with co activity of Tibialis Anterior
3. Dorsiflexion of the foot (Tibialis Anterior) with concomitant knee and hip flexion.
4. Selective dorsiflexion of foot.

<u>Functional Scale for active R.O.M (Strength measurement)</u>

0-25 %(of the physiological range of joint)	grade 1
25 – 50%	grade 2
50 – 75%	grade 3
75 - -100%	grade 4

Acknowledgement

I have great pleasure in affirming that the idea which was in my mind for a long time to make IAPMR as a premier organization in drafting national guidelines for rehabilitation of person affected with disabilities. I was offered the post of Academic Committee Chairman in IAPMR CON 2015 in Thiruvanathapuram, for which I am very thankful to the Executive Committee and General Body for approving the same.

I had great support from our previous Academic Committee Chairman, Dr.Prof U. Singh and all members of IAPMR. The first thing I wanted to do was to develop simple guidelines for Physiatrists for common condition which we meet as soon as we come out of training. Since we are considered as different kind of specially I thought we should give suitable guidelines than the conventional ones practised abroad for Simple reason being patients and their problems are entirely different.

I thought I will start with Cerebral palsy which is very close to my heart. When I suggested to Dr. Shivlal Yadav, President; Dr. Thirunavukkarasu, Secretary; and all members of Executive Committee, of IAMPR at that time; immediate approval and all support was extended to me and I thank them for their excellent support.

A guidelines committee was formed with the following members who voluntarily came forward and involved fully with me in developing guidelines. In addition I got opinions from other senior members and the response was very useful.

Dr. Prof. Sanjay Wadhwa	Professor, Dept. of Physical Medicine and Rehabilitation, AIIMS, New Delhi- 110029.
Dr. T. J. Renganathan	Consultant Physiatrist, Jambulingam Neuro Rehabilitation Centre. Coimbatore
Dr. Prof. Gita Handa	Professor, Dept. of Physical Medicine and Rehabilitation, AIIMS, New Delhi- 110029.
Dr. Anand Varma	Assistant Professor (PMR),Hubbaalli , (Karnataka) 580023
Dr. Ritu Mujumdar	Associate Professor, Dept. of Physical Medicine & Rehabilitation, Lady Hardinge Medical College & Associated Hospitals, New Delhi
Dr. Tuffail Muzaffar	Senior Resident Dept of PMR SKIMS Srinagar J&K
Dr. Sanjeev Kumar Sharma	Assistant Professor Department of PMR, RUHS-CMS, Jaipur
Dr. A K Palit	Professor & HOD, PM&R,DR B C Roy PGIPS,Kolkata 700054
Dr. Nonica Laisram	Professor, Consultant and Head, Dept of Physical

	Medicine and Rehabilitation, VMMC and Safdarjang Hospital, New Delhi.
Dr. Kunjabasi Wangjam	Consultant in PMR Imphal, Manipur.
Dr. Anil Gaur	Deputy Director, All India Institute of Physical Medicine and Rehabilitation, Mumbai
Gr. George Zakariah	Professor, PMR, Medical college. Thirvanathapuram.
Dr Krishnaprasad	Consultant in Rehabilitation Medicine, Aster MIMS, Kozhikode
Dr. Soumya Visawnath	Consultant Physiatrist, NIARC Paediatric Rehabilitation Centre Kozhikode, Kerala.
Dr. Ganesh Arun Joshi	Assistant Professor Physical Medicine & Rehabilitation/ Medical Education CRC BHOPAL
Dr. Koustubh Chakraborty	Consultant Physical Medicine and Rehabilitation PEERLESS HOSPITAL, KOLKATTA
Dr. Harshanand Popalwar	Specialist, Department of PMR, VMMC & Safadarjung Hospital, New Delhi
Dr. Harleen Uppal	Physiatrist, New Delhi.
Dr. Nitu Devassy	PMR Department, St.Johns Medical College, Bangalore

Once the skeletal guidelines were prepared, we planned for guidelines drafting and finalization procedure to be held at CRC Bhopal. we were fortunate to get excellent efforts of Dr. G.A. Joshi and Dr. Harshanand Popalwar in conducting a three day meeting in end of November 2016. We had brain storming sessions on the first day from early morning till late night.

On the second day to check whether the guidelines which we proposed are practically applicable, we tested them on twenty four different kinds of Cerebral Palsy children at CRC Bhopal. All the parents were happy that specialists from different part of the country saw and advised management. They were thankful to IAPMR for doing so. I feel such small camps should be part of future CME / Conference events of IAPMR to impress on the community and other specialists.

On day three all the experts wrote their contributions for the guidelines which are edited and presented in the document.

I have no words to express my gratitude to all those who participated in developing the guidelines, those who came all the way to Bhopal, despite their busy schedules, in short notice to pen down the final guidelines and seniors who edited them.

Dr. Sanjay Keshkar , Dr.Joy Akhijam and Dr.Anil Gaur gave their inputs via email. I sincerely thank them and appreciate their efforts.

Dr. S. Wadhwa with his vast academic experience guided the team whenever we drifted from main issues.

DR S. Y. Kothari was very kind enough to participate in all the discussions and despite his recent surgery he was enthusiastic to guide and check the guidelines along with us sitting on the floor and examine the children and give his inputs. And he took us to excellent local food outlets and dropping us back in the airport. We thank him for his kind gesture.

Dr. Ganesh Arun Joshi with his pleasant smile made our work and stay pleasant and his organizational skill and his family's contribution in tolerating his absence and the great food we had in house.

Dr. Harshanand Popalwar was great with timing schedules, his effort on pre and post meeting arrangements and making us feel at home. I felt our speciality has great future with people like Dr. Joshi and Dr. Harshanand around.

Special thanks to Dr. Ritu Mazumdar and Dr. Tufail Muzaffar for their inputs with their personal association with CP. It made a lot of difference in our thoughts when we wrote the final document.

We want to thank Director of CRC Bhopal for permitting us to have meeting and able to see the patients.

Our sincere thanks to Dr. Haldar and Dr. Ajay Gupta present President and Secretary of IAPMR and all members executive committee past and present for accepting the guidelines.

My sincere thanks to my co chairman, Dr. T. J. Renganathan who always encouraged me and supported me whenever I felt low and sometimes hyper!

And our sincere thanks to the children and persons with CP and their parents who had faith in us to come to the camp and helping us to learn from them and test the guidelines.

Thanks to entire IAPMR family and all those who helped me corrected me, answered the questionnaire I circulated and much more.

Unlike protocols guidelines are subject to editing, make changes according to the local situation whether we are working in primary care centres, district rehab centres, and private practise in rural or urban centres, general hospitals, and medical institutions or advanced research settings. We hope these guidelines will be able to help our physiatrists to understand the principles and deliver better care for children affected with Cerebral Palsy.

The guidelines are subject to corrections, opinions, criticism and we are ready to amend them whenever and wherever needed which will improve the care of children with CP.

The full credit for the success of this effort will go to those who helped in developing this and I submit the guidelines to President and Secretary of IAPMR and the executive committee and they can present it in any forum they decide.

Dr. M. Feroz Khan

Coordinator for Developing IAPMR guidelines to manage a child /adult with cerebral palsy,

Chairman,

Academic Committee of IAPMR.