Evidence-based best practices for early intervention in natural environments for infants and toddlers with GMFCS Levels 4 and 5

Ginny Paleg, PT, DScPT and Elisabet Rodby-Bousquet, PT, PhD
Disclosures

• Elisabet Rodby-Bousquet has none
• Ginny Paleg is an educational consultant for Prime Engineering, a company that makes standers and gait trainers. Her travel expenses for this conference were provided by Prime.
Assessment Tools for EI

- Prechtl
- Bailey, Peabody, Mullen, Brigance, etc.
- GMFM can be done at age 1, it’s just not steady yet and we don’t have percentiles until age 2
Prechtl General Movement Assessment

- No more excuses
- Get certified
- Borrow the CD and learn to recognize “frigidity” movement
- When they are absent between 2-5 months corrected age, refer for early intervention
- This should automatically qualify infants
GMFCS Before Age 2

• Level III: Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

• Level IV: Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.

• Level V: Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.
GMFM before age 2

- At age 1, children who are Levels 4 and 5 have already different scores
- The child at Level 3 has a score around 25
- The child at Level IV has a score around 19
- The child at Level 5 has a score around 12
REFER EARLY

• Refer if child is approaching 9 months and is not sitting
• Other ideas?
Posture management
Consensus statement

• A postural management programme is a planned approach encompassing all activities and interventions which impact on an individual’s posture and function.

• Programmes are tailored specifically for each child and may include special seating, night-time support, standing supports, active exercise, orthotics, surgical interventions, and individual therapy sessions.

• Children in GMFCS groups IV-V should start 24-hour postural management programmes in lying as soon as appropriate after birth, in sitting from 6 months, and in standing from 12 months.

*Dev Med Child Neurol 2006, 48: 244–244*
Position as a Cause of Deformity in Children with Cerebral Palsy

G. E. Fulford  J. K. Brown
The pattern is established very early this gives us a very good reason for saying that early diagnosis and early intervention is important to overcome the immobility, so this has given rise to the idea of a 24 h positioning programme.

“If the child cannot move, move him, if he cannot change his own position, change it for him”

Start within a few weeks of birth if the child shows any delay in the development of normal postural skills!

*Physiother Pract 1985; 1, 37-41*
Contractures

Elbows
Hips
Knees
Ankle

GMFCS II
GMFCS III
GMFCS IV
GMFCS V

Contracture management

Systematic Review on ALL interventions for children with CP

Iona Novak
2013
The Chailey Levels of Ability

Posture and Postural Ability Scale

Clin Rehab 2014; 28(1) 82–90

Dev Med Child Neurol 1995; 37; 437-448
Hip surveillance

• GMFCS II
  Radiograph at 2 and 6 years, if RI <33 % and no deterioration

• GMFCS III-V
  Radiograph at earliest suspicion of CP, and yearly until 8 years, then individually

Contractures

Surgery

Windswept

Scoliosis

Gibson et al., 2009

- Participants: 5 non-ambulatory children with CP ages 6-9 years
- Activity progression:
  - Stood in a standing frame for 1 hour, 5 days/week, for 6 weeks
  - No standing frame for 6 weeks
  - Each phase repeated
- Data:
  - Popliteal angle measures at baseline and weekly throughout the study period
  - Feedback from caregivers about ease of performing ADLs at the end of each standing and non-standing phase
Gibson et al., 2009

- Hamstrings significantly elongated during standing phases:
  - Mean improvement of 18.1 degrees for first standing phase
  - Mean improvement of 12.1 degrees for second standing phase

- A trend for hamstrings to shorten during non-standing phases:
  - Mean change of -14.0 degrees for first non-standing phase
  - Mean change of -7.3 degrees for second non-standing phase

- Caregiver input: transfers and ADLs became easier after standing-frame usage phases
Martinsson & Himmelman, 2011

- Participant group: 205 non-ambulatory children with CP
- Control group: matched for age, motor ability, and surgery (from a national cerebral palsy follow-up study)
- Activity: 1 year of daily, straddled (abduction) weight bearing program
  - Positioning in maximally-tolerated hip abduction and hip and knee extension for 30, 60 and 90 minutes/day
- Results:
  - Participants using straddled weight-bearing after surgery had the largest decrease in migration percentage (MP) (n=20 controls; \( p=0.026 \))
  - Children using straddled weight-bearing at least 1 hour/day for prevention also improved (n=8, 63 controls; \( p=0.029 \))
  - Hip and knee contractures were found only in control group
Gericke, 2008

- Children in GMFCS groups IV-V should start 24-hour postural management programmes in lying as soon as appropriate after birth, in sitting from 6 months, and in standing from 12 months.
60 Degrees ("OUCH")

Superstand HLT abduction foot system

Martinsson & Himmelman,
0-2 years

STANDING

Use a supine, prone or upright standing frame.

INFANTS IN STANDING: Introduce standing after 8-10 mo of age.

SUPPORTS: Head, trunk, upper limb (via a tray), pelvic, knee (via straps above and below the knee), pommel and foot. Use tilt to provide support and encourage head control.

HIP POSITION: Aim for 15° + of hip abduction [4], more if tolerated by the infant.

DOSAGE: Used daily as per the infant’s tolerance.

2-6 years

STANDING

Continue with standing. Use a supine, prone or upright standing frame.

SUPPORTS: Head, trunk, upper limb (via a tray), pelvic, knee (via straps above and below the knee), pommel and foot. If needed use tilt to provide support and encourage head control.

HIP POSITION: Aim for hip abduction 15-30° [4, 8]. Avoid (0°) hip abduction [7].

DOSAGE: Aim for 60-90 minutes per day [3, 9].

And 10-15 degrees external rotation....
Who should stand in abduction (and who shouldn’t)

Yes - Abduct
• Hips at risk for subluxation
• Child is non ambulatory
• Tight adductors
• Child just had hip surgery

Nope – don’t need to abduct
• Child has reached skeletal maturity
• No issues with hip alignment (subluxation)
• No issues with tight adductors
• Pain with abduction
• Unable to get abduction
• You cannot access a device to accomplish abduction
Stability and attention

Interaction Between Executive Attention and Postural Control in Dual-Task Conditions

“Children with spastic CP are significantly more unstable compared with typically developing children, in the dual-task condition”

Reilly 2008
Instability

- 89% unstable in MWC
- 61% unstable in PWC
- 41% difficulty propelling

- Affects arm function
Independent mobility

• Vital for activity and participation, reducing dependence on caregivers
  

• Important to be “where it happens”
  
  Asbjörnslett 2008, Palisano 2009
Wheeled mobility

Manual wheelchair
- GMFCS IV Independent
- GMFCS V Independent
- GMFCS IV Assisted
- GMFCS V Assisted

Powered wheelchair

Rodby-Bousquet 2010
Handfunction MACS III-V

- 80% dyskinetic CP
- 41% ataxic CP
- 39% spastic bilateral CP
Best practice guidelines

- Use of power mobility enhances independence and overall development in young children who don’t walk.
- In children who have inefficient mobility or lose the ability to walk, power mobility enhances activity and participation.
- Without efficient, independent mobility, young children are at risk of developing passive, dependent behaviour and older children are at risk of decreased participation and isolation.

Livingstone, Paleg 2014
Parents placed high value on their children using the hands-free walker. This was not as much for the physiological benefits of walking or for the independence that walking fosters, but rather for their children’s ability to be in an upright position that enabled and improved their participation and inclusion in multiple aspects of daily life.

Parents stressed the importance of giving their children the opportunity to interact socially and physically in an upright position more than, or as much as, the ability to walk or move independently.
McKeever, 2012

- Recent studies have reported only modest measurable walking progress for severely disabled children using hands-free walkers.
- Despite these seemingly disappointing results, parents remained highly motivated to encourage their children to use these walking devices and appraised them very positively.
Seriously

- Children with GMFCS Level 4 and 5 make modest gains and you aren’t celebrating?
Several support walkers (gait trainers) were reported as used most often to improve gait, mobility, participation at school, and interaction with peers.

Use commonly included a month trial before purchase and 9 sessions of physical therapy to train a child for use in school.

Reasons given for the use of SWs were improving impairments, functional limitations, and participation with peers.

Comparison of Two Support Walkers on the Gait Parameters of Children with Cerebral Palsy

- This was a limited study as it only compared two of the Gait Trainers available.
- In the gait lab, she found that subjects did better in the Mulholland Walkabout.
- For ease of use, she found that parents/caregivers liked the Rifton Pacer better.
Eisenberg, 2009

- N=22 children with severe cerebral palsy, 11 underwent treatment using a Hart Walker (HW) device, and the other 11 underwent a passive standing program.
- Constipation prevalence and adverse events were recorded.
- Bone quantitative ultrasound was performed for the tibia.
- The Pediatric Evaluation of Disability Inventory was used to assess activities of daily life.
- Children exposed to the HW improved bowel function, but no added quantitative benefit to bone was observed when compared with passive standing.
- Children using the HW were able to take steps independently in the device, but did not reach a functional walking level.
- Gait Trainer use makes you poop!
Wright, 2006 – David Hart Walker

- N= 20 children who used a gait trainer (DHW)
- Children over 12 had outgrown it
- Of those who used DHW for 3 years, no change in GMFM or timed walk
- Steering ability improved
3 studies that looked at gait trainer use as part of the whole MOVE Program (Mobility Opportunities via Education)

www.move-international.org
19 subjects mean age of 6 years (range 2-14), primary diagnoses of cerebral palsy and were not yet able to independently sit, stand and walk.

MOVE Top-Down Motor Milestone Test on day one (beginning) and day five (conclusion) of a one week intensive (40 hrs therapy) in-patient stay.

95% of the children learned to walk, 58% learned to sit and
39 kids age 3.5-13 yrs
Progress over 1 year w/ MOVE & no direct PT
79% gained FM
28% improved developmental level (Gesell)
Majority made gains w/o PT

44 kids Level IV and V taught to walk using MOVE. The level of independence of the experimental group increased significantly in performing movement skills; the control group did not increase significantly. At an individual level, 20 children (63%) of the experimental group improved in comparison with the control group, in which four children (33%) improved.
<table>
<thead>
<tr>
<th>PHASE</th>
<th>Activity &amp; Movement</th>
<th>Understanding of tool use</th>
<th>Expressions &amp; Emotions</th>
<th>Interaction &amp; Communication</th>
<th>STAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 Expert</td>
<td>Occupation, composed of two or more activities</td>
<td>Integrated tool use</td>
<td>Dependent on the doing of ‘other’ activities</td>
<td>Multi-level integrated interaction</td>
<td>EXTROVERT STAGE explore performance</td>
</tr>
<tr>
<td>7 Proficient</td>
<td>Occupation for its own sake</td>
<td>Fluent precise use of tool</td>
<td>Happiness Satisfaction</td>
<td>Concurrent interactions</td>
<td></td>
</tr>
<tr>
<td>6 Competent</td>
<td>Activity</td>
<td>Competent use of tool</td>
<td>Serious Content Laugh Excited</td>
<td>Consecutive interactions</td>
<td></td>
</tr>
<tr>
<td>5 Sophisticated beginner</td>
<td>Sequences of acts</td>
<td>Idea of competent use is born</td>
<td>Eager Smile Serious Frustration</td>
<td>Reciprocated interaction Triadic interaction</td>
<td>Difficult transition explore sequencing</td>
</tr>
<tr>
<td>4 Advanced beginner</td>
<td>Chains of acts</td>
<td>Exploration of extended use</td>
<td>Serious Smile Sometimes laugh</td>
<td>Mutual interaction</td>
<td></td>
</tr>
<tr>
<td>3 Beginner</td>
<td>Act</td>
<td>Basic use</td>
<td>Serious Contented Smile</td>
<td>Initiates interaction</td>
<td>INTROVERT STAGE explore function</td>
</tr>
<tr>
<td>2 Curious novice</td>
<td>Pre-act</td>
<td>Idea of basic use is born</td>
<td>Contented Curious Anxious angry</td>
<td>Responds to interaction</td>
<td></td>
</tr>
<tr>
<td>1 Novice</td>
<td>Excited Non-act Rejection</td>
<td>No or vague idea of use</td>
<td>Open Neutral Anxious</td>
<td>No response Avoidance</td>
<td></td>
</tr>
</tbody>
</table>

Durkin & Nilsson (2010) ICPM, Glasgow, Scotland

- Infant with L4/5 meningomyelocele
- 7 months - 12 months of age
- Power mobility training 2-3 times a week
- Bayley III - all scores at 5-6 month level
- Weekly physiotherapy
Conclusions

• Mobility deprivation contributes to cognitive impairment
• Mobility deprivation may even cause the cognitive impairment
• DME folks are uniquely positioned to facilitate these trials
• We can have a huge impact
• The sooner we introduce therapeutic mobility, the better