Welcome to
Allied Health Telehealth Virtual Education

Standing and powered wheelchair functions

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Presentation outline

• What makes a good candidate for standing?
• Standing wheelchair prescription process
• Alternate power functions
• Lessons through practice
• Clinical measures
• Case study / parent feedback
• Questions

Information in these slides is based on experience with children who have a neuromuscular condition only, and may not necessarily be applicable to other conditions.
Standing evidence

- No unequivocal evidence for standing in DMD – gap in research
- Supported Standing in Boys With Duchenne Muscular Dystrophy (Townsend et al 2016)
  - Study with 4 boys, age 12-14 years.
  - 2 of 4 had ankle surgery and AFO splints (3-4hrs a day)
  - Functional ability – 1 boy walking but not rise from floor; 3 boys wheelchair mobility
**Supported Standing in Boys With Duchenne Muscular Dystrophy. Townsend et al 2016**

**Lower Extremity Muscle Length for Ankle Plantar Flexor, Knee Flexor (Popliteal Angle), and Hip Flexor (Thomas Test Position). Muscles in Degrees.**

<table>
<thead>
<tr>
<th></th>
<th>Baseline (mean)</th>
<th>Mid Intervention</th>
<th>End Intervention</th>
<th>End Withdrawal</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>P1</strong> (stopped walking during trial)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Ankle PF-Knee extended</td>
<td>-6</td>
<td>-8</td>
<td>-14</td>
<td>-21</td>
</tr>
<tr>
<td>Knee Flexor</td>
<td>-20</td>
<td>-36</td>
<td>-35</td>
<td>-50</td>
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<tr>
<td>Hip Flexor</td>
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<td>-8</td>
<td>-26</td>
<td>-26</td>
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<tr>
<td><strong>P2</strong></td>
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<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Ankle PF-Knee extended</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Knee Flexor</td>
<td>-51</td>
<td>-46</td>
<td>-50</td>
<td>-50</td>
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<tr>
<td>Hip Flexor</td>
<td>-37</td>
<td>-28</td>
<td>-28</td>
<td>-28</td>
</tr>
<tr>
<td><strong>P3</strong></td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Ankle PF</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Knee Flexor</td>
<td>-55</td>
<td>-46</td>
<td>-45</td>
<td>-49</td>
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<tr>
<td>Hip Flexor</td>
<td>-37</td>
<td>-24</td>
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<td>-29</td>
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<tr>
<td><strong>P4</strong></td>
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<td>Ankle PF</td>
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<tr>
<td>Knee Flexor</td>
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<td>37</td>
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<td>-44</td>
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<tr>
<td>Hip Flexor</td>
<td>-45</td>
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</table>
Standing evidence (cont.)

• 2 Australian studies in current data collection.
• Protocol for Assisted Standing For DMD 2015 – Cochrane
• Paleg et al 2013-Systematic Review and Evidence Based Recommendations for dosing of Paediatric Supported Standing - Mostly CP children
• Strongest evidence for hamstring ROM - lost post standing
• Increased static and dynamic ROM plantar flexors
• BMD- requires 4-7 hours a week required. How much weight through tibia and femur?
DMD Standards of Care (Bushby, 2010)

• A passive standing device for patients with either no or mild hip, knee, or ankle contractures is necessary for late ambulatory and early non-ambulatory stages. Many advocate continued use of passive standing devices or a **power standing wheelchair** into the late non-ambulatory stage if **contractures are not too severe** to restrict positioning and if **devices are tolerable**.

Physical considerations for standing

- Motivation and current standing ability / frequency
- Medical clearance-BMD / surgery
- Anatomy – scoliosis / contractures
- Range of movement / flexibility – 2 joint muscles
- Trunk posture – additional support
- Pain- tolerance of weight bearing
- Size / weight
Functional considerations for standing

• Size / weight
• Medical clearance / surgery
• Anatomy / contractures
• Range of movement / flexibility
• Trunk posture
• Pain
Cognitive considerations for standing

- Cognitive demands on child are greater
- Resilience / perseverance
- Understanding of:
  - feeling stretch vs. pain
  - frequency & duration
  - standing purpose (‘stretchy’ vs. ‘doing stuff’)

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Psychosocial considerations for standing

- Grief and loss
- Parent vs. child expectations / perceptions
- Anxiety
- Motivation (intrinsic / extrinsic)
- Novelty
- Financial / trial
- Standing / sitting as part of identity
- Body image
How much standing?

9 hours and 10 minutes standing over 8 day period = 42 events
## Range of motion

<table>
<thead>
<tr>
<th></th>
<th>Knee Extension</th>
<th>Knee Extension</th>
<th>Hip Extension</th>
<th>Hip Extension</th>
<th>Elbow Extension</th>
<th>Elbow Extension</th>
<th>Ankle Dorsiflexion</th>
<th>Ankle Dorsiflexion</th>
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<th>Wrist Extension</th>
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<td>3</td>
<td>5</td>
<td>6</td>
<td>-10</td>
<td>-8</td>
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</table>
Degree of standing – Townsend (2016)

• 75% achieved maximum angle of −15 degrees from vertical
• Tolerated 20-60 minutes / day
• Mild-moderate hip, knee and/or ankle ROM
Standing wheelchair prescription process

• Evaluation of factors
• Trial and comparison
• Application & funding
  • 4 months (NDIS) vs 12 months (Enable)
  • Enable will not fund standing repairs/maintenance
  • Charities / NGOs / Family contribution
• Wait time (application processing)
Standing wheelchair prescription process (cont.)

- Re-measure
- Wait time (wheelchair production)
- Delivery
- Training and education (ongoing)
  - Home
  - School (OHS, opportunities for standing, peer education)
Standing wheelchair prescription process (cont.)

• Ongoing support
  • Frequency (PIEL survey app, inclinometer)
  • Monitor range of motion
  • Growth and adjustments (complex)
  • Repairs, maintenance and ongoing funding
  • Education with school and family
Participation ↔ Standing

• Appropriate challenges and being able to do more things (goal setting)

• Feeling good about self and equipment (psychosocial impact)

• Choice and control over posture and position (comfort and stretching)
Participation ↔ Standing (cont.)

• For clinicians
  • Feasibility of methods and sampling of daily life activities using actigraph and PIEL survey app
  • Training for boy, parents and school
  • Monitoring and adjustments for growth
  • 2 year data collection – stabilising effect over time
  • Potentially positive effect on the clinical course
Implications (for child and family)

- Waiting time – loss of suitability
- Maintenance of standing ability from trial to delivery
  - Parent ‘buy in’ (standing as part of ADL vs. ‘therapy’)
  - Disease progression
  - Secondary effects of immobility
- Maintenance of equipment
- Family responsibilities vs. that of health professional
Implications (for therapist)

• Introduction of equipment to family vs. family’s request
• Time (trials & applications)
• Access to equipment and trials
• Functional changes from trial to delivery (suitability)
• Compromised use of funds
• Multi-disciplinary input required
Alternate power functions to standing

- Tilt
- Recline
- Power elevating legs
- Seat elevate
- Seat to floor
Issues and questions from practice

• Multi-disciplinary input required
  (family/child, school, orthotics, SW, OT, PT, doctor)
• Partial / asymmetric stand
• Time taken to achieve stand – functional?
• Postural / standing supports
• Does elevate function meet the same needs?
• Goal setting with family and school
Clinical measures

- Goal setting (COPM)
- Quality of life measures (PedsQL DMD module)
- Psychosocial impact (PIADS)
- Functional changes (EK Scale)
- Time spent in standing (Inclinometer/Actigraph)
- Activities in standing and perceptions about standing
- Physiological measures (myometry, ROM, FEV1)
- Chart review
PedsQL Summary Score vs Time (Parent and Child)

- MEAN SCORE CHILD
- MEAN SCORE PARENT
PIEL survey app

• 32 recorded survey events over 7 days
• Relieving physical discomfort/stretching simultaneous with doing
• Self directed activities
Case study

Bruce is an 8yo boy with a rare form of Muscular Dystrophy. He is cognitively unaffected by his condition and attends a mainstream school. Physically he has been reliant on a wheelchair full time for one year and is rapidly outgrowing his current power drive wheelchair. He has no anti-gravity movement in his shoulders. He has an extreme lordosis which is starting to become fixed and which prevents him using a urinary bottle. He and his parents are very keen to trial a standing PWC, in particular to assist with toileting.

What would be your considerations when planning intervention with Bruce?

Which of the standing PWC’s would you consider to be the most appropriate based on the information above?
“Just loving it!! We have been out every day, which is something he never wanted to do. He stands up in the shops and moves along slowly. It has been hard with the new AFO, as he has been complaining of some hamstring pain, today would be the best as he has had his AFO on since 8am and when he is uncomfortable he has been standing to stretch it out. He played in stand mode with his little mate on the Play station for a couple of hours, so today he has probably stood more than not. It is an adjustment for him getting used to the AFO, knee pads, chest straps but we are getting there.”
Case study: E-mail feedback

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Bruce: Standing functions
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Case study

Jane is a 10 year old girl with Spinal Muscular Atrophy 2. She was prescribed with her first power wheelchair at the age of 3. Her current powered wheelchair includes lateral supports, pommel and thigh guides. Jane has recently undergone successful spinal rod lengthening and she has adequate upper limb anti-gravity movements for reaching tasks. Jane has tight ankle and knee range and experiences mild pain when initially placed in standing. She also experiences anxiety when trialling new pieces of equipment.

- What are the benefits and barriers to Jane using a standing powered wheelchair? What alternatives would you consider?

- The wait-time for powered wheelchair funding is 6 months. What agreements/responsibilities should be discussed with the family to ensure a standing powered wheelchair remains a viable option when funding becomes available?
Jane standing
Levo standing mechanism
Permobil standing mechanism
Foot deformities
‘Offset standing’
Future directions

• Justification of equipment
• Use and results of outcome measures
• ‘Contract’ with families
• Longevity of equipment
• Participation/psychosocial vs. physiological effects
• NDIS environment – is it ‘reasonable and necessary’?
References

• DMD Standards of Care (Bushby 2010) (Guglieri and Bushby 2015)
• Systematic review about dosage of standing in children (Paleg 2013)
• Cochrane review on Assisted standing in DMD (protocol Pedlow 2015)
• Participation and boys with DMD (Bendixen 2012 and 2014)
• Meaning of Standing (McKeever 2013 and Nordstrom 2013)
• Supported standing in DMD (Townsend 2016)
Contacts

• Helena Young (Occupational Therapist)
  • Children’s Hospital at Westmead
  • helena.young@health.nsw.gov.au

• Karen Herbert (Physiotherapist)
  • Sydney Children’s Hospital (Randwick)
  • karen.herbert@health.nsw.gov.au

• Sarah-Grace Paguinto (Occupational Therapist)
  • Sydney Children’s Hospital (Randwick)
  • sarahgrace.paguinto@health.nsw.gov.au
Questions