Standing, Walking and Mobility: Decision-making and Options
Standing, walking and options for wheeled mobility

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Disclosure

The authors have nothing to disclose.

(We’re in this out of love for our patients, not for the money 😊)
Plan for Today…

• Topics to discuss
• Standing
• Mobility
  — Bracing
  — Walking
  — Wheeled mobility
  — Other means of mobility
• Learn from everyone in the room
• Open dialog

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Getting upright, standing and walking
Upright weight bearing: what we know

General advantages

- Quality of life enhanced
- ↑’d self esteem
- Participation in group activities with ↑’d independence
- Positioning for upper extremity use
- ↑’d socialization
- May delay progression of scoliosis

Physiologic advantages

- Positioning and alignment
- Prevention of contractures
- Prevention of UTI’s
- ↑ cardiopulmonary tolerance
- ↑ head and trunk control
- Strengthening

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Upright weight bearing, standing and walking: What we are not really sure about

- Effect on bone density or osteoporosis
- How well devices allow for weight bearing
  - Ongoing Clinical Care study funded by Cure SMA may help us answer this question
- Optimal dosage or frequency
Standing and ambulation with bracing: what we know

- Timing: earlier is better and amount of practice may affect outcomes
- Success is variable
- When and how, what makes my child a good candidate?
  - Hands free sitting
  - Good head and torso control
  - Minimal contractures
  - Start between 2 and 6 years of age
  - Lightweight components
  - Experienced orthotist, frequent adjustments
  - Support only as needed
  - Allow for compensations once aligned
  - Function over alignment

(Granata et al 1987; Evans et al 1881, Granata et al 1993)
Preparation: Splinting, bracing and standers may be used to stretch and to complement manual stretching.
Standing vs walking: How to decide

Decision-making process

- Goals
- Physiological demands need to be prioritized over functional demands
- Clinical assessment
- Support for follow up
- Training and practice
  - Time commitment and support
- Effects of strength
- Types of bracing
  - Changes with TLSO use

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Bracing: How do we decide?
Standards and standing boxes
Standing Boxes and Standing Tables

Ikea

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Bracing for standing and walking
Orthotic Goals

- Preserve bony alignment
- Preserve or gain range of motion
- Improve mobility
- Conserve energy
- Preventing pain
Conserve energy for efficient mobility

- Light weight materials
- Avoid components
- Ounces are pounds in this population

e.g. the increase in weight between Dacron® backed or non-backed Velcro® straps will make a difference for some.
External posting to maintain alignment

Conserve energy for efficient mobility
A post is a bit of extra material that levels the external surface of the orthosis to provide a stable base.
Leg length assessment with orthoses and shoes on.

Equal lengths are important for balanced standing and walking.
Types of bracing for standing and walking

- SMO (above the ankle)
- AFO (ankle-foot-orthosis)
- KAFO (knee-ankle-foot-orthosis)
- Ischial weight bearing KAFO
- HKAFO (hip knee ankle orthosis)
- RGO (reciprocating-gait-orthosis)
- Standers/Parapodium
Supramalleolalar orthosis (SMO)

- Offers medial-lateral ankle control
- Sides extend above the ankle bones (malleoli) for greater leverage to stabilize the foot at the heel (subtalar joint)
- This brace may help with standing and walking, and decrease foot pain in those who are walkers.

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Ankle foot orthosis (AFO)

• AFOs
• Different types
  — Solid
  — Hinged
  — Flexible
• AFOs can be used to:
  — prevent contractures (at night or during the day) for all SMA types
  — help with standing or walking for those with weak muscles (type 3)
    - may assist weak leg muscles and stabilize the foot (and even the knee)
Ankle contractures and alignment
To hinge or not to hinge???

Can I wear my party shoes???

Daytime, nighttime or both??
Indications for hinged AFO

- Strength to use joint
- Flexibility to control joint
Knee ankle foot orthosis (KAFO)

- Support the foot, lower leg, and thigh for standing and walking.
  - AFO as the base
  - Extends above the knee, usually into the groin area
  - Aluminum uprights with knee joints to allow a user to sit down
  - *Light weight* bars and joints
  - Ischial weighbearing vs ‘standard’ KAFO

- design details
  - Keep Lightweight
  - Ventilate
Ischial weightbearing KAFO - a KAFO variant

• Two years old to about six.

• Good head and torso control, and be able to sit independently.

• Contractures of the hip, knee, and feet should be minimal.

Granata et al, Evans et al
What the child needs to be a strong candidate for KAFO

• good torso control
• minimal contractures
• body type
• hands free sitter
Good alignment makes it easier to balance, stand and walk with less energy.
KAFO for standing and walking

• Use for exercise
• Use at a play table
• Contracture control
Gait training in KAFOs

Practicing balance and fall strategies is critical

Granata et al, 1987
Practice with long leg braces (KAFOs)
Reciprocating Gait Orthoses - RGO

- May allow for standing and walking short distances when strength is limited.

- Incorporates a KAFO or AFO on each leg connected to a plastic back section with heavy duty hip joints.
  - The hip joints are connected by cables or a rocker bar that “connects” one leg to the other.

- Pushing back on one leg or pushing back at the trunk can move the opposite leg forward to step.

- A well fit RGO may allow a child to walk with a walker and stand hands free.

- Cost vs benefit ratio and alternative approaches
RGO- requirements for use

- Requires head and some torso control
- Fair + hip flexors (often less)
- Good cognition
- Motivation
- Some arm strength to control the walker
- Use with reverse heavier walker
  - for exercise ambulation, standing and stretching
- Use KAFO clinical assessment to determine need for torso support
Walkers: variability of movement

Pros and Cons of bracing

Posture
Alignment
Balance
Fatigue
Frequency
Quick word about TLSOs

Keep in mind - non sitters often have multiple caregivers

encompass trochanters for stability
TLSOs
Walkers, gait trainers and body weight support systems
<table>
<thead>
<tr>
<th>Parallel bars</th>
<th>Walkers</th>
<th>Gait trainers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make be of value in early standing and walking practice</td>
<td>Provide additional support for standing and/or walking</td>
<td>Provide more support than a walker</td>
</tr>
</tbody>
</table>
| Provide stability, allowing for initial balance and weight shifts | Individual considerations:  
• Anterior vs posterior  
• Wheels vs no wheels  
• Heavier vs lighter weight  
• Should try different types before making a final decision | Include trunk support and arm rests  
Heavier and may be difficult for the child to move |

**Commercial vs Homemade**

**Commercial vs Push toys**
The landscape of SMA may be changing…

The fundamentals of how we approach caring for and supporting our children should not.
Wheeled Mobility

- Consider for anyone with a need for household, community, or long-distance mobility.
General Considerations and Options for Wheeled Mobility
General Considerations

- Seat: Seating/positioning/stability
- Base (stroller, manual, power)
- Means of propulsion: manual vs power
- Transport and home access
- Funding
- Vendor access
Seating/Positioning Goals

• Comfort and Stability

• Adaptability for growth and status changes

• Maximize function
  — Upright head control if respiratory status is stable
  — Self propel if possible
  — Energy conservation
Stability/Posture

• Provide maximum stability to allow optimal function
  — Support should not compromise function

• Seating should be comfortable and support position changes
  — Accommodate joint contractures
  — Tilt and recline
  — Elevating seat
  — Elevating leg rests

• Wait until after planned orthopedic surgery for better fit
Options for Seating

- Fully reclined position for respiratory support
- Linear seating system
  - Options: hip guides, lateral supports, head rest, arm troughs, multiple cushion options
More Options for Seating

• Custom molded seat

• Tilt in space

• Recline
Mobility Bases
Mobility Base Options

- Stroller
- Light weight or ultra-light manual wheelchair
- Standard manual wheelchair
- Power wheelchair
# Strollers

<table>
<thead>
<tr>
<th>Mobility base</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strollers</td>
<td>• Light weight</td>
<td>• Not as supportive</td>
</tr>
<tr>
<td></td>
<td>• Fold for transport</td>
<td>• Minimal custom adaptations</td>
</tr>
<tr>
<td></td>
<td>• Some fully recline</td>
<td>• Can’t self propel</td>
</tr>
<tr>
<td></td>
<td>• Some with equipment storage beneath</td>
<td>• Funding may be limited</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Social impact</td>
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</table>
# Lightweight Manual Wheelchairs

<table>
<thead>
<tr>
<th>Mobility base</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
</table>
| Lightweight manual wheelchair | • Light weight, easy to transport  
• Easy to self-propel | • May tip easily  
• Hard to move on uneven surface  
• Minimal ability for custom seating and this adds weight to chair  
• Insurance may not fund both manual and power |
# Standard Manual Wheelchair

<table>
<thead>
<tr>
<th>Mobility base</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
</table>
| Standard manual wheelchair         | • Sturdy rigid frame  
• Allows for growth  
• Less likely to tip  
• Allows for custom adaptations  
• Can support respiratory equipment  
• Allows for tilt/recline          | • Heavier  
• More challenging to transport  
• May not fold or fit in care  
• Insurance may not fund both manual and power                                               |
# Power Wheelchairs

<table>
<thead>
<tr>
<th>Mobility base</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
</table>
| Power wheelchair | - Independent function  
- Speed options  
- Multiple posture, seating and drive options  
- Allows community and peer interaction  
- Supported by research (promotes development) | - Heavy/hard to transport ($$$)  
- Repairs: time consuming and inconvenient  
- Home access challenging ($$$)  
- Funding challenges ($$$) |
Power Wheelchairs
In-depth View
Why?

• Weakness limits function

• Early power enhances development
  — (Butler 1983; Dunway, Montes 2013)

• Simulates typical motor, cognitive and visual/spatial development

• Does not limit other mobility skills
Drive Requirements

• Upright head control to see
• Endurance to sit and operate controls
• Access to controls
• Cognitively appropriate
• Adequate respiratory support
  — Can use ventilatory support or non-invasive ventilation
  — Frequent suctioning?
When to Order

• Research reports ready by 18 months (start earlier)  Butler 1983; Dunaway, Montes 2013

• Documented safe driving skills with PT

• Documented home access (helps with funding approval)

• Transportation availability
  — Can be left at school
Don’t Give Up

• School and public transportation options
• Keep wheelchair at school
  — Bring home for weekends and breaks
• Use loaner for training and trial
• Work on fund raising
• Seek out “loaner closets” in your community
Tips on Obtaining Insurance Approval

• Start early with PT/OT; work on stop/go
• Work on upright head control
• Try different drive options
• Loaner for training from vendor
• Video successful driving and submit to insurance
• Prepare for denial and appeal
Power Mobility: Seating, controller/access, and transport options
# Power Seating

<table>
<thead>
<tr>
<th>Seating options</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Power tilt</td>
<td><img src="image1.png" alt="Power tilt" /></td>
</tr>
<tr>
<td>Power recline</td>
<td><img src="image2.png" alt="Power recline" /></td>
</tr>
<tr>
<td>Seat elevator</td>
<td><img src="image3.png" alt="Seat elevator" /></td>
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</tbody>
</table>
# Power Seating

<table>
<thead>
<tr>
<th>Seating options</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Standup option</td>
<td></td>
</tr>
<tr>
<td>Elevating leg rests</td>
<td><img src="image1" alt="Image" /></td>
</tr>
<tr>
<td>Lower to floor</td>
<td><img src="image2" alt="Image" /></td>
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</tbody>
</table>
## Drive Control Options

<table>
<thead>
<tr>
<th>Controller options</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Standard joystick</td>
<td></td>
</tr>
<tr>
<td>Mini-joystick</td>
<td></td>
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</tbody>
</table>
# Drive Control Options

<table>
<thead>
<tr>
<th>Controller option</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Fiber optics</td>
<td><img src="image1.jpg" alt="Image" /></td>
</tr>
<tr>
<td>Eyegaze</td>
<td><img src="image2.jpg" alt="Image" /></td>
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</tbody>
</table>

*Picture used with permission*
## Drive Control Options

<table>
<thead>
<tr>
<th>Controller options</th>
<th>iPad, robotics, Bluetooth, etc.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head array</td>
<td><img src="image1.png" alt="Image" /></td>
</tr>
<tr>
<td>Multiple hand switches</td>
<td><img src="image2.png" alt="Image" /></td>
</tr>
<tr>
<td>Other options evolving daily</td>
<td></td>
</tr>
</tbody>
</table>
Overcoming the Challenges: How to transport your power wheelchair
## Vehicle Adaptations

<table>
<thead>
<tr>
<th>Transport options</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Portable ramp</td>
<td><img src="image1.png" alt="Portable ramp" /></td>
</tr>
<tr>
<td>Power lift</td>
<td><img src="image2.png" alt="Power lift" /></td>
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</tbody>
</table>
## Vehicle Adaptations

<table>
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<tr>
<th>Transport options</th>
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<tbody>
<tr>
<td>Trailer hitch</td>
</tr>
<tr>
<td>Trunk lift</td>
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</tbody>
</table>
## Other Transportation Options

<table>
<thead>
<tr>
<th>Transport options</th>
<th><img src="image.jpg" alt="School bus" /></th>
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</thead>
<tbody>
<tr>
<td>Public transportation</td>
<td></td>
</tr>
<tr>
<td>School bus</td>
<td>(must have tie-downs)</td>
</tr>
</tbody>
</table>
Other Mobility Options
Other Mobility Options

- Manual chair with power assist wheels
- Mobile standers

Shown w/ Mobility Kit
Other Power Mobility Options

- Power scooters
- Adaptive bikes
Other Power Mobility Options

Manual chair with power add-on option

Lightweight folding power wheelchair
Adaptive Toys

- Go-Baby Go
- Get creative
Summary
Guidelines for Choosing a Wheelchair

• Use seating specialist if available
• Consider orthopedic needs
  — Planned surgeries (scoliosis, contracture releases)
  — Brace recommendations
• Use vendor that knows SMA
• Trial when possible
• Support with documentation for funding