Physical Therapy Standards of Care
Portland, Maine
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Presented By:
Heather Salon, PT, DPT, NCS
Board Certified Specialist in Neurologic Physical Therapy
Massachusetts General Hospital
Partners: Physical Therapy and Families

• Provide education and resources to boys and families to allow them to participate:
  • At home
  • At school
  • At leisure activities
  • In the community
Physical Therapy

- Promote safe activity to prevent deconditioning and minimize muscle damage
- Recommend options for mobility that allow independence and access
- Promote muscle flexibility needed for
  - proper alignment in sitting and standing
  - Prevention of pain and decreased function
- Promote proper posture
Physical Activity: A balancing act

- Exercise maintains muscle strength but...
- Too little exercise = muscle atrophy
- Too much exercise = muscle breakdown
# Over Use: Signs & Management

## Signs
- Muscle cramping or pain, usually in the leg muscles
- Fatigue

## What to Do Now
- If you over-did it one day, it’s okay
  - Decrease duration or intensity the next time
- In the future: use energy conservation
  - Prioritize activities and use energy for high priority activities
Options for Exercise & Physical Activities:

- Engage in age-appropriate, fun activities!
  - Foster bonding as a family and with friends
- Choose activities/exercises that are non weight bearing or low load=
  SWIMMING!!
- Low friction tricycles or adaptive bicycles
Why Aquatic Exercise?

- Safe exercise for muscles – buoyancy minimizes the effects of gravity and increases freedom of movement for large muscle groups
- Great for the lungs – encourages deep breathing and keeps breathing muscles strong
- Great for the heart – the BEST way for boys with DMD to get the heart pumping and keep up endurance
- Swimming is fun, builds self-confidence, and can be enjoyed with peers, siblings, and other caregivers
- Swimming is a skill boys with DMD can enjoy for years to come
Flexibility: Why Does It Matter?

• “Your hip bone is connected to your back bone”
  • loss of flexibility at the ankle/foot can create pain and problems in the spine and other joints
• Proper flexibility = proper posture
  • At school desks
  • In wheelchairs
• Loss of flexibility can contribute to walking difficulties
• Proper joint alignment = prevents pain and improves comfort
Stretching Basics

- Be gentle
- Use a firm grip
- Be static (no bouncing)
- May use active or passive/assisted
- Intermittent or Prolonged

Leg muscles to stretch:
- Hip flexors (front of hip)
- Hip abductors (outside of hip)
- Hamstrings (behind thigh)
- Gastrocs (calves)
Very young children: parents help with passive stretching

- Activities while lying on your tummy stretch the front of the hip

Elementary age children: children can participate

- Activities on your tummy with wedge (hip flexors)
- Lying on back with leg on door frame (hamstrings)
- Standing on slant board for tabletop activities (calves)
- Self stretching for finger/wrist muscles

Older Children/Young Adults

- Can continue earlier examples if still tolerable and safe to get into/out of position
- Can include family/friends in passive stretching

How Do I Stretch?
Resources for Stretching:

- PPMD Video on you tube has a good review of techniques:
  - https://www.youtube.com/watch?v=6eHLt3KAOtg
Positioning for Stretching

Lying on a wedge

Standing on a slant board

Doorway hamstring stretch
Splinting

- Night splints = prolonged stretch to prevent loss of range of motion
  - used overnight when boys are ambulatory during the day
- Daytime splints
  - when boys using wheelchairs during the day
- Wrist/hand splints if upper extremity tightness develops
Standing Frames

- Provide supported standing
- Benefits of standing include:
  - Prolonged stretching
  - Bone density
  - GI function
  - Respiratory function
  - Pressure relief from sitting
- Recommendations: 60-90 minutes
  - Must be well aligned to prevent joint injury
Wheeled Mobility

• Boys can go longer distances without fatigue
• Boys can participate with peers and family
• Boys can participate in leisure activities, including adapted sports
• Prevents falls, especially when fatigued
<table>
<thead>
<tr>
<th>Scooter</th>
<th>Power Wheelchair</th>
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<tbody>
<tr>
<td>Good for long distance use, not classroom seating</td>
<td>Can be customized for all day comfort and proper posture</td>
</tr>
<tr>
<td>Lighter weight = can be lifted by family</td>
<td>Heavy= cannot be lifted by family</td>
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<tr>
<td>Can fit into trunk</td>
<td>Require appropriate van for transport</td>
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<tr>
<td>Do well on outdoor surfaces</td>
<td>Turn radius can vary on drive type</td>
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<tr>
<td>Large turn radius</td>
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<tr>
<td>Cannot be customized easily for height/back support</td>
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Thank you very much!