Value of Physical Therapy

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PARENT PROJECT MUSCULAR DYSTROPHY ANNUAL CONFERENCE
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Disclosures

- **Scientific Advisory Board:**
  - Biogen, Cytokinetcs, Roche, Acceleron

- **Consultation:**
  - Roche, Audentes, ATOM International, Solid Bio, Seismic, Trinds, Pfizer, Audentes
Role of PTs

Encourage
Instruct
Educate
Consult
Advocate
PTs EXAMINE EACH INDIVIDUAL AND DEVELOP A PLAN, USING TREATMENT TECHNIQUES TO PROMOTE THE ABILITY TO MOVE, REDUCE PAIN, RESTORE FUNCTION, AND PREVENT DISABILITY.
Approach in Pediatric PT

- **Play Based Therapy**
- **Participation Based**
- **Family Involvement**
- **Collaboration and Coordination of Care with Other Disciplines**
  - Neurologists, Pulmonologists, Respiratory therapists, Occupational therapists, Speech Language Pathologist, Social Workers, Genetic Counselors, School therapists, PE Teachers, Community Therapists, etc.
- **Advocacy**
What do we do for boys with DMD

- **Work with families and individuals with DMD to reach maximum functional mobility**
- **Evaluate and support musculoskeletal health and mobility**
  - Strength and Range of Motion
    - Stretching/Bracing
  - Balance, Coordination
    - Gross motor skills
    - Overall Fitness: Do not over fatigue
- **Promote participation at home, school and the community**
  - Adapting/modifying environment
  - Assistive technologies
  - Equipment: Ordering, adapting, modifying
Purpose of your physical therapy exam

**WHAT AND WHY**

- Diagnostic
  - Extensive Muscle work up
- Follow-Up
  - Motor exam: Less extensive
  - Function based testing
  - Predictive Tests for Planning care
- Pre/Post Intervention
  - Motor Exam
  - Functional testing
Exam: Possible Outcomes to assess in clinic

FUNCTION BASED

- **Timed Performance Tests:**
  - 10 meter, supine to stand, stairs
- **Northstar Ambulatory Assessment (NSAA): Ambulatory**
- **6MWT**
- **Performance Upper Limb Scale (PUL): Both**
- **Pulmonary Function (Site Dependent): Both**
- **EK Scale: Non-Ambulatory**

IMPAIRMENT BASED

- **Strength Assessments**
  - Manual Muscle
  - Hand held myometry
  - Active Range of Motion?
- **Joint Integrity**
  - Passive range of motion
  - Active range of motion
Why Are Outcome Assessments So Important

- **PROVIDE EVIDENCE FOR STATUS AND CHANGE IN STATUS**
- **PROVIDE FEEDBACK FOR CHANGE IN MEDICATION OR TREATMENT**
- **DEMONSTRATE PATTERN OF WEAKNESS OR DECLINE**
- **PREDICT NEED FOR INTERVENTION**
  - Loss of ambulation: Equipment, braces, home access, transportation, transfer teaching, support
  - Help explain status to parents and others
| Stage 1:       | • Pre Symptomatic                  |
| Stage 2:      | • Early Ambulatory                |
| Stage 3:      | • Transitional                    |
| Stage 4:      | • Early Nonambulatory             |
| Stage 5:      | • Late Nonambulatory              |
Early Ambulatory Stage

Often just receiving diagnosis
Initiating steroids
Difficulty keeping up with peers
Elementary school

Goals for Therapy and Home Program

Maintain **Range of Motion**
Maintain postural symmetry
Improve balance
Improve coordination
Maintain **Fitness**

Recommendations for PE

- Adaptations/Modifications
Pre-symptomatic Stage – Early Ambulatory

**STRETCHING: MUSCLE TIGHTNESS**

- Hamstrings and heel cords
  - Manual stretching by parents/caregivers
  - Positioning
    - Long sitting
    - Incline standing board

Photo by Helen Posselt PT
Night Splints- Across all stages

- **INITIATE AT EARLY STAGE**
- **MAINTAIN PROLONGED STRETCH 6+HOURS/NIGHT**
- **SHOWN TO BE EFFECTIVE** (Scott et al 1981, Hyde et al 2000)
- **CUSTOMIZED**
  - Stretch should be up to the point of tightness
- **BEST WHEN FOREFOOT IS SUPPORTED**
- **NIGHT OR DAY USE FOR POSITIONING USE**
  - Not used for walking
Stretching Resources for Parents

PPMD WEBSITE
Stretches for Duchenne Muscular Dystrophy (CD)-View online
http://www.parentprojectmd.org/site/PageServer?pagename=Care_resources_materials

Instructional Photographs -View online

YOUTUBE
STRETCHES FOR DUCHENNE MUSCULAR DYSTROPHY-YOUTUBE VIDEO
HTTPS://WWW.YOUTUBE.COM/WATCH?v=6eHLt3KAOTG

CINRG WEBSITE
STRETCHOUT STRETCH INSTRUCTION AND WORKOUT
HTTP://WWW.CINRGRESEARCH.ORG/STRETCHVIDEO2/INDEX.CFM
Encourage Recreational Activities
Benefits of Exercise

- **Maintaining Mobility**
- **Improving Endurance, Function and Coordination**
- **Lowers Risk of Secondary Conditions**
  - Lowering risk of developing chronic diseases (i.e., Obesity, bone health)
- **Improves Sense of Well Being: Depression, Anxiety**
- **Improving the Ability of Weak Muscles to Utilize Energy**
  - Maintaining muscle mass
- **Improving Blood Flow/Oxygen Delivery to Muscles**
Benefits of Exercise

INDIVIDUALS WITH NMD

- Adaptations to exercise in NMD similar to sedentary population (McDonald et al, 2002, Fowler 2002)

GOALS:

- Improve/maximize function
- Fall prevention/balance
  - Weakness/sensory impairments
- Minimize Pain
- Improve sleep
- Management of range of motion

HEALTHY INDIVIDUALS

AEROBIC ENDURANCE

- 30 minutes VO2max 50-85%
- Improved circulation, oxygen usage, oxidative phosphorylation (Timmons et al, 2010)
- 30min of moderate exercise, 5/week decreased mortality rates (Whitehead et al, 1995)

STRENGTH TRAINING

- Increased muscle strength and power, increase lean body mass
Exercise Goals cont

- **AEROBIC EXERCISE: USE OF MOTORIZED DEVICES TO ASSIST IN ENDURANCE**
  - Walking (treadmill or over ground, body weight supported)
  - Stationary bicycle / Elliptical machines
  - Aquatics
  - Horseback riding

- **STRENGTH EXERCISE**
  - Isometric, Concentric vs. Eccentric (should avoid)
  - Trunk stabilization

- **ASSISTIVE TECHNOLOGY, DEVICES, ORTHOTICS, BRACES**
  - Use as needed to assist in exercise goals
    - Support joints: AFO (not for walking), SMO, shoe inserts
    - Active assisted devices to decrease force load to focus on aerobic exercise
Exercise/ Activity for Socialization

Engaging in enjoyable socialization (especially as the physical limitations progress) is critical to:

- mental health well-being
- improving quality of life

Places to explore socialization include:

- social skills group
- support groups
- special interest clubs
- adaptive sports programs

Participation in desired activities, social roles and habits correlate with strength and function (Bendixen et al 2014)
How do you measure Activity?

Rate of Perceived Exertion: How hard you feel your body is working

<table>
<thead>
<tr>
<th>COLOR</th>
<th>BORG</th>
<th>Explanation/ Perceived Exertion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Green</td>
<td>6</td>
<td>No exertion at all</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>Extremely light</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>(a, i, ia, is, ish)</td>
</tr>
<tr>
<td>Yellow</td>
<td>9</td>
<td>Very light - (easy walking slowly at a comfortable pace)</td>
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<tr>
<td></td>
<td>10</td>
<td>This is the effort level where you can't hear your breathing, you're able to easily talk and run for a very long time</td>
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<tr>
<td></td>
<td>11</td>
<td>Light. Here you are building aerobic endurance.</td>
</tr>
<tr>
<td>Orange</td>
<td>12</td>
<td>Somewhat hard (hand it quite an effort; you feel tired but can continue)</td>
</tr>
<tr>
<td></td>
<td>13</td>
<td>You start to hear your breathing, but not gasping for air</td>
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<td></td>
<td>14</td>
<td>You can talk, but more challenging, use one- or two-word answers</td>
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<tr>
<td>Red</td>
<td>15</td>
<td>Hard. This is considered your steady state.</td>
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<tr>
<td></td>
<td>16</td>
<td>Very hard (very strenuous, and you are very fatigued). Anaerobic Threshold</td>
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<tr>
<td></td>
<td>17</td>
<td>Breathing is vigorous. You can't talk, you're reaching for air</td>
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<td>18</td>
<td>Extremely hard (you're counting the minutes until it ends)</td>
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<tr>
<td></td>
<td>19</td>
<td>Maximal exertion</td>
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<td>20</td>
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Omni Scale
Common School Modifications

- Copies of PowerPoint or notes
- Extra set of books for home
- Use of laptop/tablet to take notes
- Modified homework to limit fatigue
- Extra time for standardized or timed tests
- Oral tests if writing difficult
- One-on-one aide
- Individualized and preferential seating or desk
- Modified PE
- Use of elevator
School Resources: PPMD

- **Education Matters: A Parent’s Guide**
- **Education Matters: A Teacher’s Guide**
  - For Duchenne Muscular Dystrophy
- **Education Matters: Adaptive Physical Education:**
  - A PE teacher’s guide to Duchenne Muscular Dystrophy
- **Education Matters: Learning and Behavior in DMD for Parents and Educators**
- **Support through Others: Network with families that have been through it!**
- **Get your rehabilitation team involved**
1. Stretch!

Stretching

Less Tightness

Optimal position for strengthening

Better Mobility

Stanford Medicine
2. Stay Active, Exercise!
3. Adapt Environment as Necessary

Enjoy LIFE... Don’t struggle when you may not have to
Thank you!

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