Therapy Needs throughout the Lifespan

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I have no disclosures.
Plan for this Hour:

• Stages of Presentation
• Physical Therapy Assessment
• Therapy Intervention
  • Stretching
  • Exercises
  • Aquatics
  • Equipment
• Participation
  • Home
  • School
  • Community
Signs and Symptoms

- Delayed motor skills
- Head lag with pull to sit
- Delayed walking skills
- Rising from the floor
  - Gower's Sign
- ↓ed Squat to stand
- ↓ed Walking up stairs
- ↓ed Jumping/Hopping
- Calf pseudohypertrophy
- ↓ed running speed
- ↑ed falling
- Language delays
- Cognitive delays
- Social Difficulties
- Hamstring tightness
- Heel cords tightness
- Diagnosis of Autism

[www.childmuscleweakness.org](http://www.childmuscleweakness.org)
Stage 1 • Pre-Symptomatic
Stage 2 • Early Ambulatory
Stage 3 • Late Ambulatory-Transitional
Stage 4 • Early Non-ambulatory
Stage 5 • Late Non-ambulatory
### Pre Symptomatic Observations Commonly Reported

#### Difficulty noted with:

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Climbing Stairs</td>
<td>Getting up from the Floor-Partial Gowers Sign</td>
</tr>
<tr>
<td>Jumping</td>
<td>Running: slow, no flight phase</td>
</tr>
<tr>
<td>Toe Walking</td>
<td>Frequent Falling</td>
</tr>
<tr>
<td>Weakness</td>
<td>Leg Cramps</td>
</tr>
<tr>
<td>Clumsiness</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Large Calf Muscles</td>
<td>Muscle Tightness-Hamstrings/HC</td>
</tr>
<tr>
<td>Head lag on pull to sit- difficulty lifting head from supine</td>
<td>Decreased score on BSID III Bayley Scale of Infant Development (Connolly et al, 2013)</td>
</tr>
<tr>
<td>Delayed Motor Skills</td>
<td>Delayed Speech</td>
</tr>
</tbody>
</table>
Early Ambulatory

- Often just receiving diagnosis
- Elementary School
- Initiating Steroids
- Difficulty keeping up with peers
- Increased falling
- Occasional leg pain or cramping
- ROM (tightness may begin to develop or worsen)
Late Ambulatory-Transitional
A Time of Change

- Limited community mobility
- Increased risk of falls
- Increased fatigue
- Consider power W/C purchase
- Needs change
- Provider(s), location of services change with needs, and frequency
- Continual assessment of status and needs
- Goals for this population are unique and challenging
Early Non-Ambulatory

- Family education!!!
- Encourage activity
  - Aquatic activities
  - Ergometers – active assist
- Assistance for Transfers
- Equipment needs changing

- Increased tightness
- Disuse atrophy
- Increased weight gain
- Loss of functional independence
- Changes in community participation
- Initiation of BiPAP/ Cough Assist
- May increase risk of scoliosis

Family education!!!
Late Non-Ambulatory

- Increase c/o Pain
- Maximal Assistance
- Limited UE Function
- Respiratory Support
- Reliance on Technology
- Decreased Participation
- Decreased Employment
- May need to employ caregivers
Why Are Therapy Assessments So Important

- Provide evidence for status and change in status
- Provide feedback for change in medication or treatment
- Demonstrate pattern of weakness and decline
- Predict need for intervention
  - Loss of ambulation: Equipment, home access, transportation, transfer teaching, support
  - Help explain status to parents and others
Postural and Gait Deviations

- Increased lordosis
- Steppage gait with reduced stride length
- Widening of base of support
- Increased lateral trunk lean
- Rising up on toes *not always seen
- Toeing in
- Pronation/Supination
Therapist’s Role
Encourage, Instruct,
Educate Families and Child,
Be available to Consult

- Maximize Range of Motion and Gross Motor Skills
  - Safety First
- Families should be instructed in
  - STRETCHING-Keep building a routine
  - Safe activities for play, recreation
- Maximize Balance and Coordination
- Maintain Overall Fitness
- Consult with School: Adaptations/Modifications
- DON’T OVER FATIGUE-Rest periods are “OK”
Common Measures-
*You may see your therapist do the following
Clinic vs. Clinical Trial

- Manual Muscle test: (proximal weaker than distal; extensors < flexors; LE<UE)
  - Myometry
- Goniometry
- Postural and Gait assessment
- Timed Performance Tests
- North Star Ambulatory Assessment
- 6 minute walk test
- PUL
- Brooks Scale- UE
- Vignos Scale- LE
Pre-Symptomatic

Encourage Recreational Activities

Amazon.com

stjohn.ca
Begin A Regular Routine

Make it Enjoyable.....Make it Fun!!!!

<table>
<thead>
<tr>
<th>Concentration Areas</th>
<th>Stretching</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heel Cords</td>
<td>Incline Standing Board</td>
</tr>
<tr>
<td>Hamstrings</td>
<td>Long Sitting/Nada Chair</td>
</tr>
<tr>
<td>Hip Flexors</td>
<td>Stomach Lying</td>
</tr>
<tr>
<td>IT Band</td>
<td>Side Lying Stretch</td>
</tr>
<tr>
<td>Consider Initiation of Night Braces</td>
<td>Consider Behavior</td>
</tr>
</tbody>
</table>
Stretching
May Be Preventative-Start Before Tightness

- May maintain length of the muscle over time
  - Single and two joint muscles
- May maintain symmetrical postural alignment
- May prolong the ability to walk
- May improve positioning in wheelchair
- ROM assist with use of a standing frame/chair
- Improve comfort and positioning in bed
- Improve hygiene
- May improve fit of shoes
- May improve hand manipulation
- Improves Well Being
- Improves Circulation

Claudia Senesac
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
Start lying on his back. Allow one leg to fall where it is comfortable, making sure that your child’s back is flat against the surface. Bend the other leg so that the thigh is bent to 90 degrees. Use one hand to hold this position at the knee. Use the other hand to slowly straighten the knee until he feels a slight stretch in the back of his leg behind his thigh. Hold for 30 seconds. Repeat 2 times on each leg.
Myofascial Release for ITB

Have your child lie on his side with his legs straight. Using three or four fingers on his bare skin, place your hand near his hip. Gently but firmly allow your hand to glide down the side of his leg. Move with one continuous motion all the way down the leg and off the bottom of his toes. You should feel gentle traction between your fingers and his skin as your hand glides. Repeat this motion 5-6 times on each leg.
Elongation of the Hip Flexors

Encourage lying on his belly propped on bent elbows as shown to the left. This should be done on a firm surface where his feet can hang off the edge to help straighten his knees. Homework, watching TV, or playing games can be done in this position.

Start in sitting on the edge of a firm surface hugging one knee tight to his chest. Keeping the knee hugged to his chest, have him lay down. Let the opposite leg relax and hang over the edge. Be sure that his back stays flat on the mat and does not arch. Help keep his back flat by holding the bent knee close to his chest. Hold for 30 seconds. Repeat 2 times on each leg. Watch the leg hanging over the edge to make sure that it doesn’t go out to the side. If it does, gently bring it back towards the middle.

He should feel the stretch here in his hip
Elongation of the Pectoral Muscles

Lie on his back with his arms out like a goal post. His hands should face toward the ceiling and his arms should be flat on the surface. He should feel a gentle stretch on the front of his chest. Hold for 1 minute.

Forearm Stretch

Sit with his hands in the prayer position with palms pressed together and fingers as straight as possible. His wrists should be bent as close to 90 degrees as possible. Hold for at least 1 minute. He should feel a gentle stretch in his forearm and hand.
How To Fit Stretching into Daily Routines

- Make stretching part of the daily routine
  - Brushing teeth
  - During homework position for success
  - Active assistive stretching- get child involved

- Equipment to improve/maintain ROM
  - Night splints
  - Nada chair
  - Standing wedge
Night Splints- Across All Stages
*Consider Goals

- Maintains prolonged stretch (6+ hours/night)
  - Shown to be effective (Scott et al 1981, Hyde et al 2000)

- Medial trim lines-support forefoot
  - Shoes vs no shoes-
    - consider as they get older

- Night vs Day use
- Increased padding
Serial Casting

- Ambulatory Boys to regain ankle ROM
- Dorsiflexion less than neutral *no clear cut off
- Ability to stand up from the floor-pre cast
- Antigravity knee extension
- Ability to safely stand and walk with casts before leaving facility
- Cast change every 7-10 days- variable across facilities
- **No standard of care:** variable use and protocol, no common assessment used pre/post, varied criteria for selection

(Glanzman et al, 2011; Main et al 2007)
Exercise
Historically

- Exercise recommendations have been based on rodent studies that induced injury
- Resultant recommendations were: exercise may cause damage - exercise with caution
- Current studies suggest
  - Exercise may be beneficial - BUT questions remain
    - Age?
    - How much?
    - What type?
Exercise
What do we know…..

- *No exercise* leads to muscle atrophy
  - Important for bone health
  - Important for self-esteem

- Too much exercise increases *muscle breakdown*
  - *Rhabdomyolysis*

- Younger boys benefit from exercise more than older boys
* However most of the research is with this group

- Boys with DMD are 40% less active than age matched peers (McDonald, 2000) **Supported by other studies**
Exercise

- Staying active is **KEY**
- Stretch may maintain ROM allowing activity and participation
- Age appropriate recreational activities as opposed to “resistive” strengthening regimes
- Concentric low load or isometric versus eccentric high load - **stay submaximal**-add power if needed/energy conservation
- **Don’t overdo!!** Build in **Rest Periods**
  - Self modulation
  - Structured breaks
- **Fatigue** is **REAL**, Differences in endurance
- Incorporate balance and coordination skills
Assisted bicycle training delays functional deterioration in boys with Duchenne muscular dystrophy: the randomized controlled trial "no use is disuse".

Jansen M, van Alfen N, Geurts AC, de Groot U

Arm and Leg Ergometer Ex-n-Flex (active assist)
- 24 boys age 8-12 years (amb and non-amb)
- Training at 50% max, 40 minutes, 3 day/week
- 24 weeks

Assisted bicycle training
- Delays functional deterioration in boys with DMD
  - MFM and Assisted 6min cycling test- remained stable
  - No serious adverse events
- Safe and feasible
- May decline the deterioration due to disuse

Different types of upper extremity exercise training in Duchenne muscular dystrophy: effects on functional performance, strength, endurance, and ambulation.

Alemdaroglu I., Karaduman A, Yılmaz ÖT, Topaloğlu H

- **Subjects** = 24 boys ages 8-12 y/o, ambulatory

- **Study group** n=12 * assistive UE ex/PT-Arm Ergometer
  - 40 minutes per session, 3x/week x 8 weeks
  - positive effects on subjects’ muscular endurance, performance of ADL’s arm function, ambulation status- NO significant change in muscular strength

- **Control group** n=12 *strengthening ROM ex/Family
  - 40 minutes per session, 5x/week x 8 weeks
  - Improved grip strength and endurance only
  - Improved NSAA score

- **Summary-Both groups improved to varying levels**

Exercise- Looks promising!

• More studies are underway
• Prime emphasis is on Safety
• Appears to benefit younger boys more
• Low load, low resistance
• Active assist
• Stay tuned
Aquatic Exercise

Aquatic Therapy or Just Family Fun

Water is Fun!!!

Wavetherapies.com
Seattle, WA
Aquatic Activities

- Safest form of exercise
  - Non weight bearing low load activity
  - Able to move through full range of motion
  - Improve aerobic function
- Develops independence and confidence
- Fosters a life long recreational activity
- Freedom of movement in later years
Fracture? Now what?
Fractures

- Most often in the lower extremities
- Generally in boys older than 9 years
  - Falls while ambulating
  - Falls from wheelchair (seat belts!!)
- May result in loss of ambulation
- Boys need to avoid immobilization
- Families need to contact their specialists
- Follow NEW Care Guidelines published Jan. 2018…
  www.parentprojectMD.org

James et al, 2015; Subasi et al, 2016 Abstract MDA Clinical Conference
Consult “NEW” Care Guidelines www.thelancet.com or www.parentprojectmd.org
Remobilization After Fracture

- Mat Exercise
- Aquatic Therapy
- Alter-G Treadmill
- Body Weight Supported TM
- Up and Free walker- May be an option
- Introduce weight bearing ASAP

http://www.alterg.com/

www.litegait.com

Up & Free walker
Why Predicting Loss of Ambulation is Important

• The impact on families is huge and life changing
• Discussion: start early and repeat often
• Equipment often takes 6 months to receive
• Home modifications are costly and stressful
• Transportation becomes challenging
• Transfers are challenging
• School needs time to prepare (hoyer, classroom location, evacuation plan, etc).
Daily Routines Changing

- Transfers - more dependent
- Continue LE stretching
- Include UE stretching
- Sustained positioning
  - ¼ - ¾ Prone lying if tolerated
  - Side Lying
  - Standing frames
  - Elevating leg rests
  - Reclining in WC

www.easystandevlov.com
Transfers

• Stand pivot with maximum assist
• **Sliding board** (Supervised → Max Assist)
• Maximum lift of caretaker
• Use of mechanical transfer lift
  – Hoyer lift
  – Ceiling lift
• Minimize transfers with rolling bath chair
Equipment

- Therapist
- Medical Vendor
- Insurance Funding

Family
Early Mobility Devices

• Consider for recreation and outdoor play
  • Requires a helmet for safety outdoors
  • Child needs appropriate safety judgement
• When child unable to keep up with peers
• Independence for long distance community events
• Can be transported in most vehicles
Scooters and alternative motorized systems

GO-GO scooter
- more portable than w/c
- negatives:
  - large turning radius
  - poor/no seating support
  **poor posture in scooter can contribute to contractures if used too much**
- UE’s may get tired from reaching for handles

http://www.pridemobility.com/gogo/
E-Z Lite Cruiser

http://www.ezlitecruiser.com/
Scooters and alternative motorized systems

Zappy
- more portable than w/c
- can stand or sit
- ~13 mph

EV Stand/Ride

http://www.zapworld.com/vehicles/zappy-pro-flex-500
Portable power assist wheelchairs

Efix

E motion power assist
or twion power assist

http://www.alber-usa.com

Smart Drive
Power Wheelchair purchase

• Drive Mechanism
  • Front wheel
  • Mid-wheel
  • Rear wheel

• Power Options
  • Power standing feature
  • Power tilt and/or recline
  • Power seat elevation
  • Separately elevating power elevating leg rest
Seating for young men

- Emphasis on comfort
- Pressure relieving cushion
- Larger head rest
- Wider arm rests
- Elbow blocks
- Padded footrests
- Joystick modifications
- Attendant controls
Supported Standing

Permobil F5 stand & drive
www.permobilus.com/f5vs.php

Stand & Drive chairs
Bath Chairs and Toileting Systems:
Stair Solutions:
Other Ideas for Adaptations:

• Feeding: dycem, adaptive feeding utensils, straws
• Bathroom: Electric tooth brush, suction hand rails, urinals
• Dressing: Nike velcro shoes, Adrienne adaptations
• Home environment: Hoyer lift, positioning chair

http://www.homemobilitysolutions.com/
Summary
Assisted cycling and cycling without excessive resistance can be beneficial
Avoid excessive resistance
Avoid hills or give assistance
Add power when needed
Assistive Technology
Exciting and Changing all the Time

- Blue tooth devices
- Siri/Dragon Speak
- Environmental control systems
  - Google home & Amazon Echo
- Computers / tablets / smart phones
  - Alternative keyboards/ touch pad screens
  - Electronic pointing devices
- Voice assist (amplifiers)
- Glassouse
- TouchTapSwipe guide (dmdpathfinders.org.uk)
MedTrade Expo
Largest Medical Equipment Tradeshow and Conference

Spring: Las Vegas March 2018
Fall: Atlanta October 2018

https://www.medtrade.com/
Participation
Participation at Home, School and Community

- Ideas for Home

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**Chores Checklist**

*Participating in Chores at Home: A Facilitator of Employment*

Written by Connie Johnson, PT, DScPT

Created by SeekFreaks

<table>
<thead>
<tr>
<th>Easiest</th>
<th>Moderate Difficulty</th>
<th>Most Difficult</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ pick up toys</td>
<td>□ make own bed</td>
<td>□ load dishwasher</td>
</tr>
<tr>
<td>□ put books on a shelf</td>
<td>□ fold clothes</td>
<td>□ change light bulbs</td>
</tr>
<tr>
<td>□ feed pets</td>
<td>□ match socks</td>
<td>□ hang clean clothes</td>
</tr>
<tr>
<td>□ carry light items from the car to house</td>
<td>□ carry heavy items from car to house</td>
<td>□ move trash can from house to curb &amp; back</td>
</tr>
<tr>
<td>□ put clothes in hamper</td>
<td>□ use handheld vacuum</td>
<td>□ clean most home areas</td>
</tr>
<tr>
<td>□ wash clothes</td>
<td>□ clear table after meal</td>
<td>□ dust furniture</td>
</tr>
<tr>
<td>□ set the table</td>
<td>□ empty dishwasher</td>
<td>□ clean/wipe off table</td>
</tr>
<tr>
<td>□ throw trash away</td>
<td>□ mop/sweep floors</td>
<td>□ handwash dishes</td>
</tr>
<tr>
<td>□ sort recycling</td>
<td>□ water house plants</td>
<td>□ put groceries away</td>
</tr>
<tr>
<td>□ wipe up spills</td>
<td>□ pull out weeds</td>
<td>□ wash car</td>
</tr>
</tbody>
</table>

For more info on this and other pediatric topics, visit www.seekfreaks.com
Common Classroom Modifications

- Copies of PowerPoints or notes
- Extra set of books for home
- Use of laptop/tablet or scribe
- 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

Seekfreaks.com
School Resources: PPMD

- *Education Matters: A Parent’s Guide*
  - For Duchenne Muscular Dystrophy
- *Education Matters: A Teacher’s Guide*
- *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**
Common Campus Modifications

• ADVOCATE and ASK QUESTIONS!
• Extra time to get to class
  • Classes close together if possible
• Individualized PE modifications
  • With extended breaks as needed
  • Adaptive sports (involve the whole class for socialization)
• Use of accessible bathroom
• Key for elevator (for those still ambulating)
• Staff trained in transfers (using a lift)
• Assistance for lunch set up
• Safety evacuation plan
Transition to Higher Education

Resources
• State Vocational Rehabilitation Department STAR program

• Scholarships & Financial Aids
  • https://www.mda.org/young-adults/resources

• College or University Office of Student Disability Services

• Center for Independent Living (dependent on location)

• For Michigan go to: http://www.michigan.gov/mdhhs/
  Michigan Rehabilitation Services
What is Vocational Rehabilitation?

**What is it?**
Federal program designed to:
• Enhance independence of people with disabilities by helping them find and maintain employment

Located throughout the state by county and city

**Services**
• Can vary at each location
• Ranges from:
  o Career Counseling
  o Job Training & Placement
  o Supported Employment
  o Assistive Tech training & support
  o Medical & Psychological Assessment
• STAR Program
  • Ages 15-21 for students
Community:

• Adaptive Recreation
  • Mary Free Bed YMCA:
    sports@maryfreebed.com
    616.840.8356
  • Park District
  • Kentwood Park and Rec

• Church
  • https://pathways.org/tools-resources/inclusion-worship/
THANK YOU!

Laurey Brown: laubrown@luriechildrens.org
PPMD: www.parentprojectmd.org