

Lifelong Occupational Therapy Needs

Heather Simpson, OTD, MOT, OTR/L
January 26, 2018

Parent JOIN THE FIGHT.
Project END DUCHENNE.
**Muscular
Dystrophy**

Disclosures

- None

Images utilized from commercial products from the Performance Health company (www.performancehealth.com) unless noted otherwise

What is Occupational Therapy

- “Therapeutic use of everyday life activities which enhance or enable participation in roles, habits and routines.” (AOTA, 2014, S1)
- Occupational Therapists (OT) enable participation in activities that children, adolescents and adults desire such as:
 - Activities of Daily Living
 - Leisure & Play
 - School & Work
 - Sleep
 - Socialization



Why is this important?

- Studies show that the more children with MD participate in desired activities (such as roles, habits and routines), that it correlates to strength and function. (Bendixen et al., 2014)

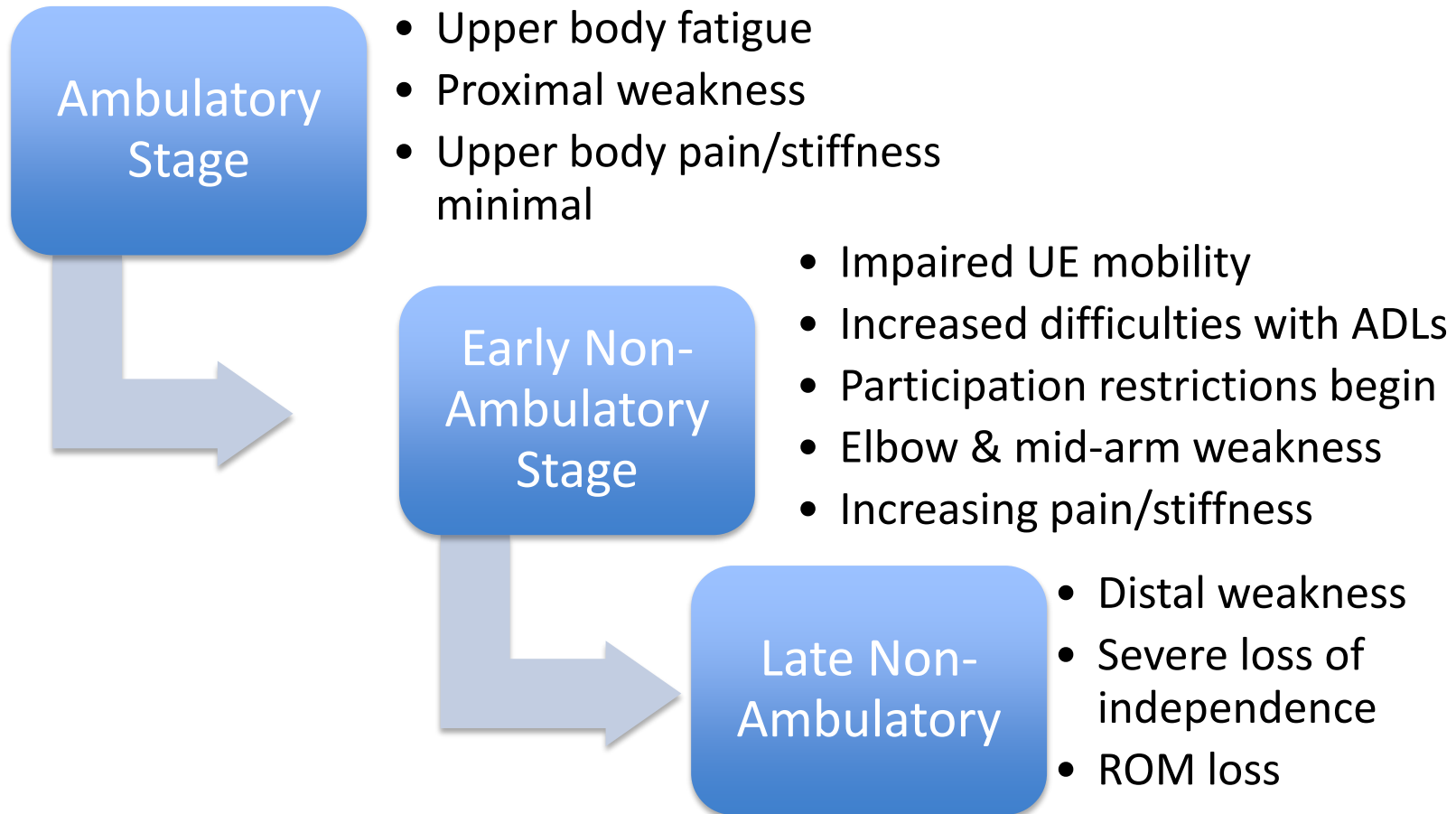
How is the goal of independence achieved?

- **Maintaining Body Functions** (as much as possible)
 - Physical, Neuromuscular & Cardiovascular
 - Mental
 - Sensory
- **Addressing the performance patterns and context of the occupation**
 - Environmental modification
 - Social Modifications
 - Habit, Routine, Ritual and Role Analysis

EVALUATION

Reminder:

Expected UE Functional Stages (Janssen et al., 2014)



Performance of the Upper Limb (PUL) (Mayhew et al., 2013)

- Designed for & developed by those affected with DMD
- Addresses all levels of ability
 1. High level
 2. Mid level
 3. Distal level
- Client-centered, reflecting meaningful ADLs
- Used primarily in research
- Excellent inter- & intrarater reliability (Pane et al., 2014)

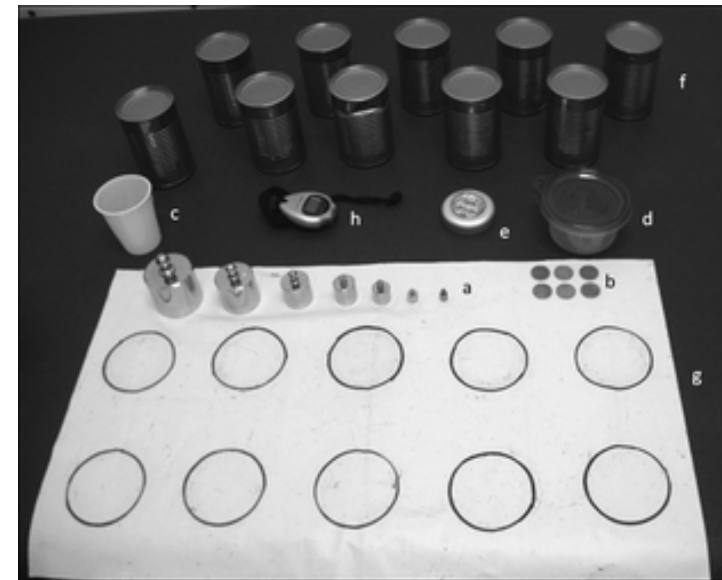


Figure 1: PUL Kit Mayhew et al., 2013

Patient-Reported Outcome Measure (PROM) (Klingels et al., 2016)

- Developed in parallel to PUL
- Client-centered measure for DMD; 7 years - adults
- Focused on upper-limb function impacting QoL in four domains:
 - Food
 - Self-care
 - Household & environment
 - Leisure & communication
- Self-completed measure
- Internal consistency and test-retest reliability

Other Assessments

(Escolar et al., 2001) (Mayhew et al., 2007)

- Manual Muscle Testing
 - Reliable when trained consistently and with small number of clinicians
- Quantitative Muscle Measures
 - Hand-held dynamometer (MVIC) is reliable
 - Reliable with larger number of clinicians



SUPPORTIVE AIDS

Splinting

Addressing Body Function

Purpose:

- Prevent contractures
- Prevent pain
- Maintain function and mobility of a joint
- Allow increased function by placing joint in ideal position
 - Particularly thumb
- **NOTE:** should be combined with stretching

Elbow Flexion
Contracture Block
Splint



Thumb support



Night resting hand splint



Figure 2: Weichbrodt et al.

Splint Recommendation Guidelines (Weichbrodt et al., 2017)

Begin passive stretching at:

- Wrist extension with finger extension $< 70^\circ$

Begin splinting:

- Wrist extension with finger extension $< 50^\circ$

- Alternate sides each night
- Functional position



Mobile Arm Supports (MAS)

Addressing Body Function



Figure 3: Neater MAS (n.d.)



MAS Purpose:

- Increase function
- Upper limb training (Jansen et al., 2015)
- Fixed height at horizontal plane **vs.** horizontal & vertical plane
- Powered **vs.** non-powered (spring-balanced)
- Free standing **vs.** wheelchair mount

Upper Extremity Function

(Jansen et al., 2016)

Promotes

- Cortico-steroids
- Healthy BMI
- Functional Activities



Figure 4: Wheelchair (Huntstock , n.d.)

Hinders

- Contractures
- Spinal deformities
 - Position
- Pain and stiffness

Adaptive Equipment

Addressing Occupations

Purpose

- Enable independence
- Improve quality of life
- Increase accessibility

Note:

- Insurance coverage varies
- Options are endless

Easy open scissors



Sliding Tub Transfer Bench

Figure 5: Wheelchair Pants (2018)



Flexible Arms



Sip-Tip Cut (easy sipping long straw)



Assistive Technology

Possibilities are Endless

- Ranges from simple to complex
- Smart Home Technology
- Benefits:
 - Increase independence
 - Ease of use
 - Increasing availability
- Limitations:
 - Cost
 - Trained providers

PARTICIPATION

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



Figure 6: (Kaneff Productions, 2014)



Figure 7: Camp ASCCA, n.d.)

Accommodations



"Live Life to Its Fullest"



Figure 8: FOTA

- School
 - Involvement in 504/IEP
 - Assistive technology
- Work/vocation
 - ADA
 - Vocational Rehabilitation
 - Transition Skills
- Relationships
 - Bullying prevention
 - Caregiving roles
 - Sexual relationships

Pain Management

Through Passive Range of Motion

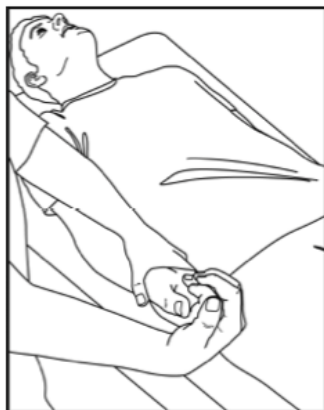
http://www.parentprojectmd.org/site/DocServer/Sep_11_DMD_Book_Stretches1.pdf?docID=11703

□ Hands and Fingers

1. With the patient's palm facing up towards the ceiling, use your hand to curl the fingers toward the palm of the hand. Return fingers to a straightened position.
2. With the patient's palm facing upwards grasp the patient's thumb and move it outwards away from the hand. Return thumb back to the palm and across towards the little finger.

Repeat ____ times.

Do ____ sessions per day.



LONG FINGER FLEXORS

Position

- With elbow as straight as possible
- Support the child's palm, maintaining straight fingers
- Keep thumb out to the side
- Support the wrist

Stretch

- Slowly bend the wrist and hand back until a stretch is felt in the forearm

Figure 9: ROM

Questions?



References

Adaptations by Adrian. (2018). *Part #812-Side zippers open to mid calf*. Retrieved from <http://adaptationsbyadrian.com/denim-custom-sitter-wheelchair-pants/>.

Bendixen, R. M., Lott, D. J., Senesac, C., Mathur, S., & Vandeborne, K. (2014). Participation in daily life activities and its relationship to strength and functional measures in boys with Duchenne muscular dystrophy. *Disability and Rehabilitation*, 36(22), 1918–1923. <http://doi.org/10.3109/09638288.2014.883444>

Camp ASCCA (n.d.). *Aquatic Therapy* [Video]. Retrieved from <https://www.flickr.com/photos/campasca/95592644>.

Escolar, D., Henricson, E., Mayhew, J., Florence, J., Leshner, R., Patel, K. & Clemens, P. (2001). Clinical evaluator reliability for quantitative and manual muscle testing measures of strength in children. *Muscle Nerve*, 24(6), 787-793.

Florida Occupational Therapy Association [FOTA]. (n.d.). *I love OT*. Retrieved from <https://goo.gl/images/nBuQ2d>

Huntstock (n.d.) *Man with Duchenne muscular dystrophy in motorized wheelchair*. Retrieved from <https://www.gettyimages.com/detail/photo/man-with-duchenne-muscular-dystrophy-in-a-motorized-royalty-free-image/107697973>

Jansen, M., Burgers, J., Jannink, M., van Alfen, N. & de Groot, I. (2016)). Upper limb training with dynamic arm support in boys with Duchenne muscular dystrophy: A feasibility study. *International Journal of Physical Medicine & Rehabilitation*, 3(256), 1-8. doi:10.4172/2329-9096.1000256

Janssen, M., Bergsma, A., Geurts, A. & de Groot, I. (2014). Patterns of decline in upper limb function in boys and men with DMD: an international survey. *Journal of Neurology*, 261(7), 1269-1288. doi: 10.1007/s00415-014-7316-9.

References

Kaneff Productions (2014). *Muscular Dystrophy Documentary 2014* [Video]. Retrieved from <https://vimeo.com/123444563>

Klingels, K., Mayhew, A., Mazzone, E., Duong, T., Decostre, V., Werlauff, U...Upper Limb Clinical Outcome Group. (2016). Development of a patient-reported outcome measure for upper limb function in Duchenne muscular dystrophy: DMD Upper Limb PROM. *Developmental Med Child Neurology*, 59(2), 224-231. doi: 10.1111/dmcn.13277.

Mayhew, J., Florence, J., Mayhew, T., Henricson, E., Leshner, R., McCarter, R. & Escolar, D. (2007). Reliable surrogate outcome measures in multicenter clinical trials of Duchenne muscular dystrophy. *Muscle Nerve*, 35(1), 36-42. DOI: [10.1002/mus.20654](https://doi.org/10.1002/mus.20654)

Mayhew, A., Mazzone, E., Eagle, M., Duong, T., Ash, M., Decostre, V....Perofrmace of the Upper Limber Working Group. (2013) Development of the Performance of the Upper Limb module for Duchenne muscular dystrophy. *Developmental Med Child Neurology*, 55(11), 1038-1045. doi: 10.1111/dmcn.12213.

Neater (n.d.). *Neater Arm Support* [Image]. Retrieved from <https://goo.gl/images/nv6tts>.

Performance Health (2017). *Products*. Retrieved from <https://www.performancehealth.com>

Weichbrdot, J., Eriksson, B. & Kroksmark, A., (2017) Evaluation of hand orthoses in Duchenne muscular dystrophy. *Disability and Rehabilitation*, 0(0), 1-9. <https://doi.org/10.1080/09638288.2017.1347721>