Preserving Function, Maximizing Independence: Skilled Therapy Across the Duchenne Muscular Dystrophy Journey

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Financial Disclosure

- I have no Financial Disclosures

Educational Need/Practice Gap

- Practice Gap:
  - Understanding the benefit of therapy and activities in patients with Duchenne's Muscular Dystrophy
- Educational Need:
  - The role of skilled therapists and PM&R team for patients with DMD

Learning Objectives

- By the end of this presentation, participants will be able to:
- **Recognize** the unique physical, functional, and communication challenges experienced by patients with Duchenne muscular dystrophy (DMD) across different stages of disease progression.
- **Describe** the roles of physical therapy, occupational therapy, and speech-language therapy in preserving function, promoting independence, and supporting quality of life in individuals with DMD.
- **Develop** a coordinated, individualized therapy plan for patients with DMD that incorporates disease stage, functional goals, and multidisciplinary care needs.

Expected Outcomes

- The hope of this presentation is to help with counseling around exercise, equipment, and therapy services for patients and families with DMD.

Duchenne Muscular Dystrophy

- X linked recessive neuromuscular disorder
- Mutation in Dystrophin gene
- Results in absent of insufficient functional dystrophin
- Dystrophin is a critical cytoskeletal protein that enables the strength, stability, and functionality of myofibers

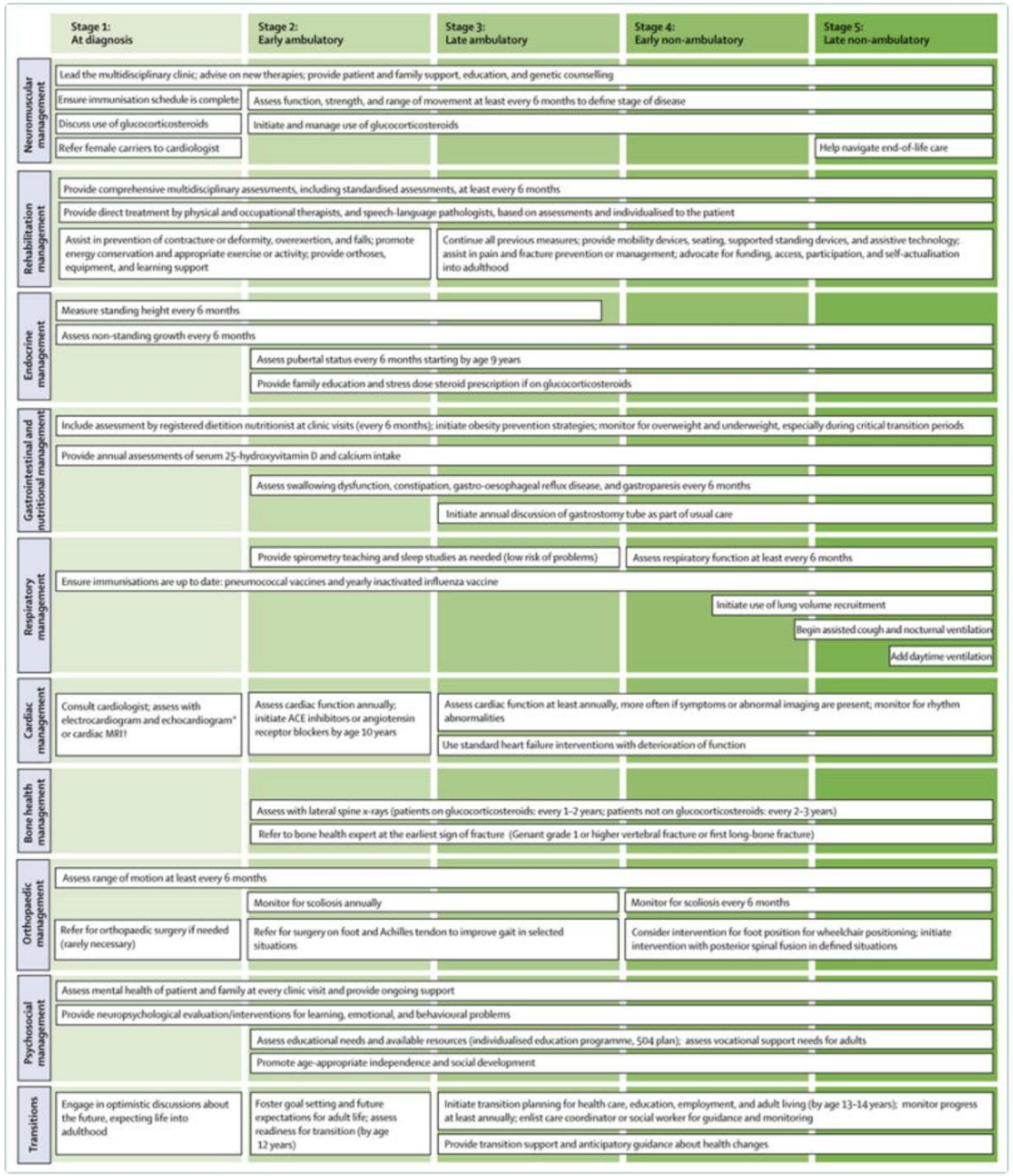
Dysfunctional Dystrophin

- Leads to progressive muscular damage and weakness
- Leads to loss of ambulation, respiratory compromise, and cardiomyopathy

Multidisciplinary Teams

- Multidisciplinary Clinics are critical for these patients and their survival and modifiable disease complications
- NEMO Clinic
  - Neurology Evaluation and Management Optimization
- Specialized DMD coordinated clinic days
  - Endocrinology
  - Pulmonology
  - Neurology
  - Cardiology
  - Physical Medicine and Rehabilitation
  - Skilled Therapies: Physical, Occupational, and Speech

Figure 1. Comprehensive care of individuals with Duchenne muscular dystrophy.



The DMD Timeline

- Stage 1: At Diagnosis
- Stage 2: Early Ambulatory
- Stage 3: Late Ambulatory
- Stage 4: Early Non Ambulatory
- Stage 5: Late Non Ambulatory

Stage 1: Diagnosis

Standardized Assessments at least every 6 months

Direct treatment and Observations with Physical and Occupational Therapists and Speech Language Pathologists

Prevention of contracture or deformity, overexertion, and falls

Promote energy conservation and appropriate exercise and activity

Consider Orthoses, equipment, and learning support

Standardized Assessments

- Range of motion
  - Passive
  - Active
- Posture and Alignment
- Strength
- Gait
  - North Star Ambulatory Assessment
  - 6 Minute Walk Test

North Star Ambulatory Assessment

16 Movements with standardized times

- Lift Head from floor
- Supine to Sitting on floor
- Supine to Rise from floor
  - Watching for Gower's
- Sit to Stand from chair (without using hands)
- Climb Step (Right and Left)
- Descend Step (Right and Left)
- Jump
- Walk 10 m
- Standing posture
- Standing on one leg (Right and Left)
- Run
- Hop on one leg (Right and Left)

North Star Ambulatory Assessment

	ACTIVITY	2	1	0
1	**Stand**	Stands upright, still and symmetrically, without compensation (with heels flat and legs in neutral) for minimum count of 3 secs	Stands still but with some degree of compensation (e.g. on toes or with legs abducted or with bottom stuck out) for minimum count of 3 secs	Cannot stand still or independently, needs support (even minimal)
2	**Walk**	Walks with heel-toe or flat-footed gait pattern	Persistent or habitual toe walker, unable to heel-toe consistently	Loss of independent ambulation—may use KAFOs or walk short distances with assistance
3	**Stand up from chair**	Keeping arms folded. Starting position 90o hips and knees, feet on floor/supported on a box step.	With help from thighs or push on chair or prone turn	Unable
6	**Climb box step-Right**	Faces step—no support needed	Goes up sideways or needs support	Unable
7	**Climb box step- Left**	Faces step—no support needed	Goes up sideways or needs support	Unable
10	**Gets to sitting**	Starts in supine—may use one hand to assist	Self assistance e.g.–pulls on legs or uses head-on- hands or head flexed to floor	Unable
14	**Jump**	Both feet at the same time, clear the ground simultaneously	One foot after the other (skip)	Unable
17	**Run**	Both feet off the ground (no double stance phase during running)	'Duchenne jog'	Unable
			TOTAL 3 years (max score 16)	
4	**Stand on one leg—Right**	Able to stand in a relaxed manner (no fixation) for count of 3 seconds	Stands but either momentarily or needs a lot of fixation e.g. by knees tightly adducted or other trick	Unable
5	**Stand on one leg—Left**	Able to stand in a relaxed manner (no fixation) for count of 3 seconds	Stands but either momentarily or needs a lot of fixation e.g. by knees tightly adducted or other trick	Unable
8	**Descend box—Right**	Faces forward, climbs down controlling weight bearing leg. No support needed	Sideways, skips down or needs support	Unable
9	**Descend box—Left**	Faces forward, climbs down controlling weight bearing leg. No support needed	Sideways, skips down or needs support	Unable
13	**Stands on heels**	Both feet at the same time, clearly standing on heels only (acceptable to move a few steps to keep balance) for count of 3	Flexes hip and only raises forefoot	Unable
			TOTAL 3.5years (max score 26)	
11	**Rise from floor**	From supine—no evidence of Gowers' manoeuvre*	Gowers' evident	(a) NEEDS to use external support object e.g. chair OR (b) Unable
12	**Lifts head**	In supine, head must be lifted in mid-line. Chin moves towards chest	Head is lifted but through side flexion or with no neck flexion	
15	**Hop—Right**	Clears forefoot and heel off floor	Clears forefoot and heel off floor	Unable
16	**Hop—Left**	Clears forefoot and heel off floor	Clears forefoot and heel off floor	Unable
			TOTAL 4 years and above (max score 34)	





6 Minute Walk

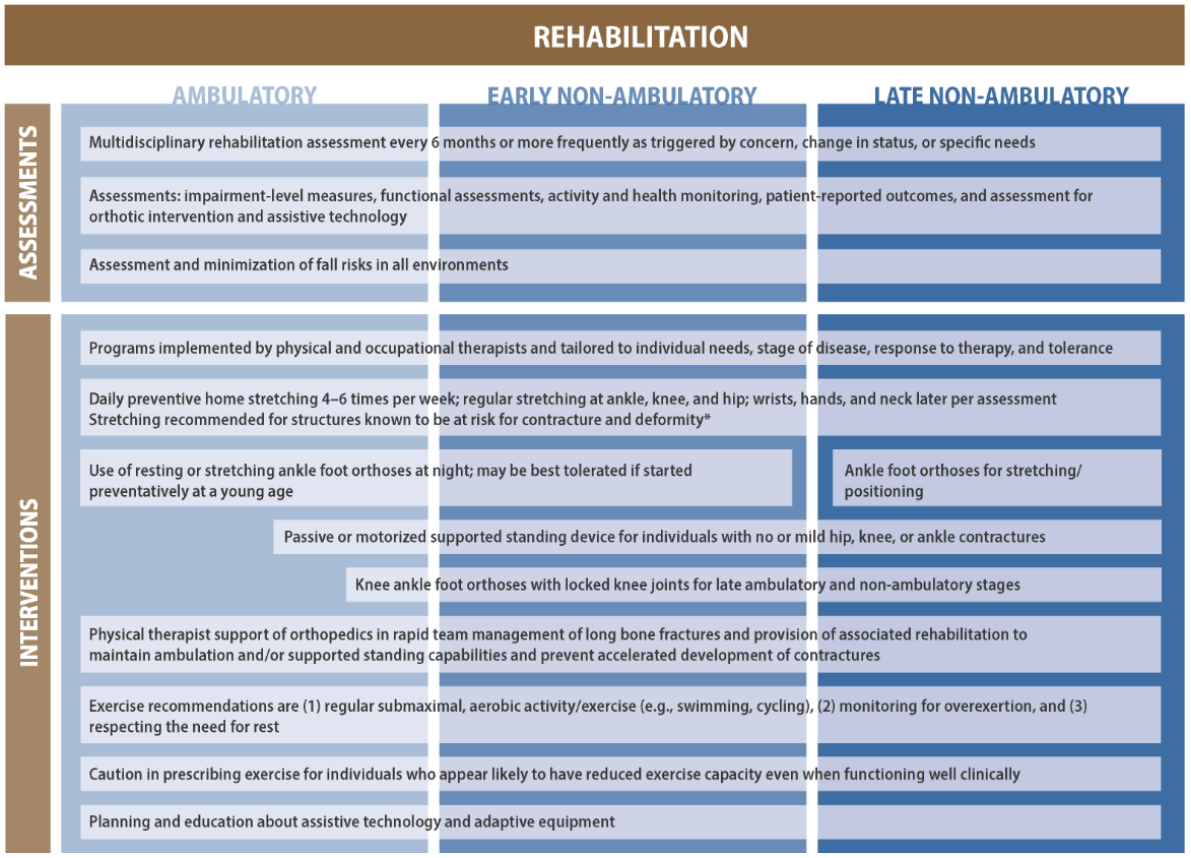
Assessment Trends

Can be used to guide proactive care

Greater Functional Decline with potential loss in Ambulation over the next 12 months when:

- 6 min walk test of < 325 m
- Time to stand > 30 sec
- Time to climb 4 stairs > 8 sec
- 10 m walk or run> 10-12 sec

Rehabilitation Management



Stage 2: Early Ambulatory

- Encouraging Physical, Occupational, and Speech Therapy as needed to promote independence and functional skills
- Focusing on Flexibility and Joint Mobility to prevent/minimize contracture and deformity
  - Early Initiation of these can help with compliance
- Recommend continued physical exercise and participation
  - Submaximal Aerobic Activity Exercise
    - Swimming and Cycling are preferred
  - Monitor for Overexertion
  - Regular Rest Breaks
  - Strongly discourage Trampolines and Bounce Houses

Isometric Activity

- Isometric Activity is preferred and shown to be safe for DMD patients
- Isometric: muscles contract and generate force without changing length or joint movement
- Exercise needs to be personalized for each patient regarding:
  - Frequency
  - Intensity
  - Time
  - Type

RED FLAGS FOR EXERCISE

These are also key signs that may indicate you have overdone your exercise(s), or you need tc and potentially change the exercises you are doing. A Physical Therapist can assist in modify exercise program to better fit your needs.

- Increased fatigue
- Increased muscle, joint, or back pain
- Muscle soreness that lasts greater than 24 hours
- Red, brownish red, or dark urine
- Difficulty sleeping
- Shortness of breath that continues longer tha a couple of minutes after ending the exercise
- Tachycardia (rapid heartbeat) that does not resolve a few minutes after exercise is over
- Low or high blood pressure out of the ordinar for the individual with muscular dystrophy

Stretching Programs

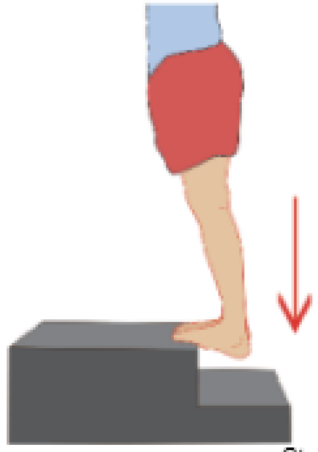
- Developing Home and School based stretching programs

Recommend doing long leg sitting to help with hamstring stretching



- Sit with butt up against wall or couch with feet out in front of you
- You can wear AFOs while doing this to help with ankle stretching as well
- Starting off would recommend holding the stretch for 30 seconds and then increas

Recommend heel drops on edge of stair to help with ankle range of motion



- Start by doing 10 drops and then take a break
- Try to do 3 sets

Bracing when needed

- Consider Nighttime Stretching AFO (Ankle Foot Orthotics) to prevent plantarflexion contractures



Stage 3: Late Ambulatory

- Introducing the need for Mobility Equipment to help with energy conservation and maximizing independence
- Preventing falls and brainstorming ideas for mobility in the community and home settings



Duchenne Jog



Stage 4: Early Non Ambulatory

- Discussing Power Assist options to Mobility equipment to maximize independence
- Focusing on adaptations for upper extremities to maintain range of motion and ability to care for themselves
- Introduction of more specialized equipment to assist with transfers











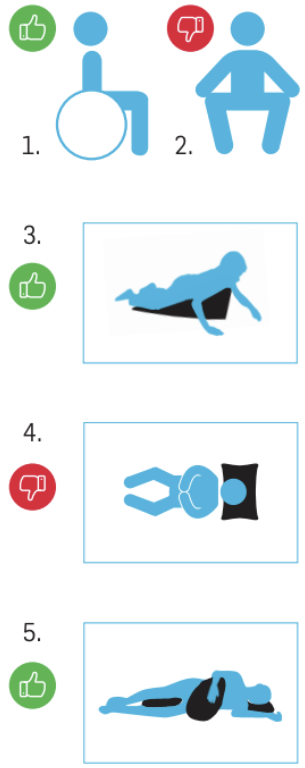
Stage 5: Late Non Ambulatory

- Transition to Full Power Mobility and necessary wheelchair modifications
- Consider including standing option to help with more weight bearing



Contracture Prevention

- Without routine stretching and bracing, contractures will begin to form
- Positioning is crucial in mobility equipment and in bed



Fingers and wrists tend to get tight over time as seen in this photo:



A typical wrist and finger splint used when wrist and fingers are tight:



Occupational Therapy

- Monitor need for wrist bracing to prevent wrist flexion and finger flexion contractures
- Monitor Upper Extremity Strength and function with the Performance of the Upper Limb 2.0
- Typically start to show decline in shoulder strength around the loss of ambulation mark

Performance of the Upper Limb

- 22 item scale graded per task over 3 different levels
  - High Level (shoulder)
  - Mid Level (elbow)
  - Distal Level (wrist/finger)
- The scores range from 0 to 2
  - 2: completed without compensation
  - 1: completed independently but with modifications or compensation
  - 0: unable to perform the task

High level shoulder dimension	Item A	Entry item
	Item B	Shoulder abduction to shoulder height
	Item C	Shoulder abduction above shoulder height
	Item D	Shoulder flexion to shoulder height
	Item E	Shoulder flexion above shoulder height
Mid level elbow dimension	Item F	Hand(s) to mouth
	Item G	Hand(s) to table from lap
	Item H	Move weight on table
	Item I	Lifting light cans
	Item J	Lifting heavy cans
	Item K	Stacking light cans
	Item L	Stacking heavy cans
	Item M	Remove lid from container
Distal wrist and hand dimension	Item O	Tracing path
	Item P	Push on the light
	Item Q	Turning light
	Item S	Placing finger on number diagram
	Item T	Lifting with finger pinch grip
	Item U	Lifting with 3 point grip
	Item V	Lifting with Thumb (key) grip

Speech Language Pathologists

- Helpful with feeding and communication challenges that can present later in the disease course.
- Voice to text modifications for school assignments
- Assistive Feeding Technology
- Swallow Studies to evaluate potential dysphagia/aspiration

Assistive Feeding

- Can be simple like an elevated table to help prop arm to eliminate gravity
- They do make assistive feeding robots



Teamwork and Creative Thinking

- The major goal of PM&R and Skilled Therapies with our DMD patients is to help maintain and optimize independence with patients and families
- Community and Connection with these families is critical to have an ongoing relationship over the course of this disease
- With new treatment advances, we are optimistic that we will be able to slow functional decline.
- Like my dad always says "The best offense is a good defense"

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Thank you

- Thank you so much for your time and attention and I'm happy to answer any questions.