AMERICAN PHYSICAL THERAPY ASSOCIATION ACADEMY OF PEDIATRICS

An Evidence-Informed Resource for School-Based Physical Therapists Working with Students with Duchenne Muscular Dystrophy

 Developed by expert contributors Rebecca A.A. Wilson, PT, MS, C/NDT, Board-Certified Pediatric Clinical Specialist; Lisa Iordanou, PT, DPT; Sandra M. Ribeiro, PT, DPT, MSEd, Board-Certified Pediatric Clinical Specialist; Jennifer Stephens, PT, DPT, Board-Certified Pediatric Clinical Specialist; Lisa Milkavich, PT, DPT, Board-Certified Pediatric Clinical Specialist.

TABLE OF CONTENTS

PURPOSE

The purpose of this evidence-informed document is to provide a resource for physical therapists (PTs) and physical therapist assistants (PTAs) providing school-based physical therapy (SBPT) for students with Duchenne Muscular Dystrophy (DMD). This resource includes information related to providing SBPT including etiology and diagnostic factors of DMD, relevant medical management factors, assessment strategies and evaluation tools, evidence-informed interventions and best practice strategies regarding accommodations and modifications to facilitate access and participation within the educational environment for students with DMD. Information presented is based upon the best available evidence. SBPT practice varies between regions of the United States. Therapists should follow state practice acts and local policies and guidelines when incorporating this information into practice.

I. ETIOLOGY, DIAGNOSIS, AND MEDICAL FACTORS

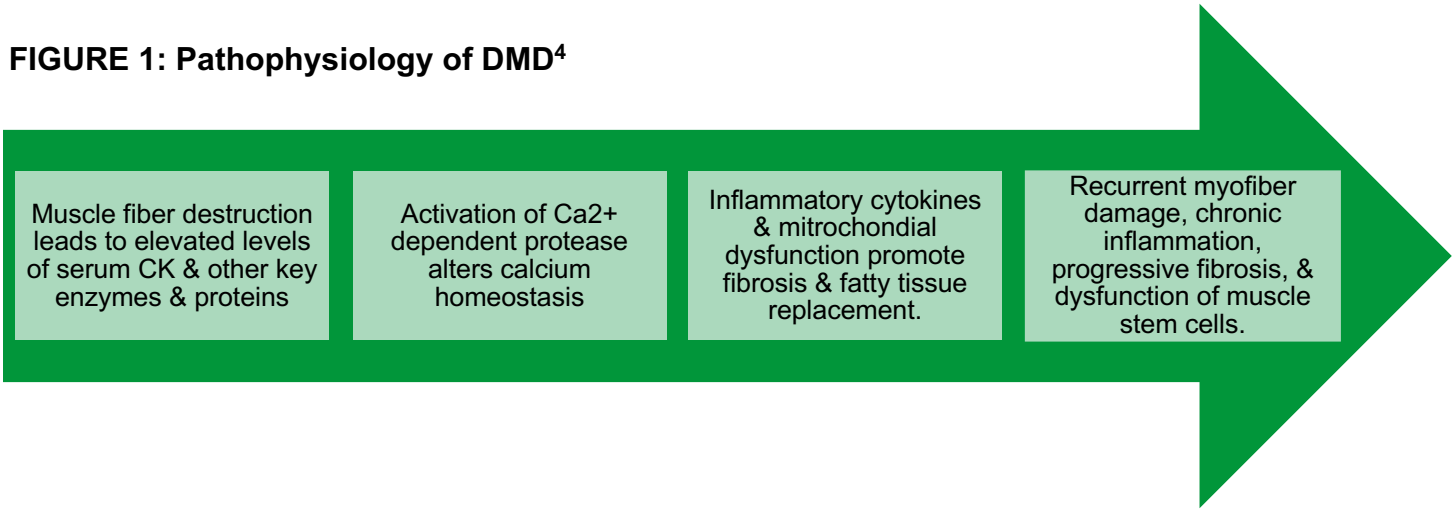
BASIC INFORMATION

- DMD is a recessive X-linked neuromuscular disease caused by deletions or mutations in DMD gene, which encodes the dystrophin protein[1].
- A lack of production of dystrophin protein results in steady, progressive skeletal and cardiac muscle degeneration leading to muscle weakness.
- The average age of diagnosis of DMD is 5 years[1] and takes an average of 2.2-years from the first signs and symptoms until diagnostic confirmation. DNA and muscle biopsy are used as confirmatory testing.[1]
- Compliance to therapy and environmental factors may play a role in disease progression.[2]
- Cardiorespiratory failure is the leading cause of death in DMD patients.[3]

PATHOPHYSIOLOGY OF DMD

The genetic mutations leading to DMD result in an absence of functional dystrophin, a cytoskeletal protein, and loss of the dystrophin-associated protein complex (also referred to as DAPC), which is responsible for the strength, stability, and function of myofibrils. Over time, muscle fibers increase in fragility during normal cycles of muscle degeneration and regeneration.[4] Due to muscle destruction, serum creatine kinase (CK) levels elevate, even before the presence of clinical signs and symptoms, peaking by the age of 2 years. There is deterioration of calcium homeostasis with the activation of Ca2+-dependent protease. Inflammatory cytokines and mitochondrial dysfunction promote fibrosis and fatty tissue replacement in muscles.[5] Levels of CK, aldolase, liver function test, and aspartate aminotransferase are elevated due to active muscle breakdown. Ultimately, the loss of dystrophin protein leads to recurrent myofiber damage, chronic inflammation, progressive fibrosis, and dysfunction of muscle stem cells.[4] Figure 1 outlines the pathophysiology progression of DMD.

FIGURE 1: Pathophysiology of DMD[4]



DIAGNOSIS

- Diagnostic testing includes analysis of CK level, electromyography, nerve conduction studies, and muscle biopsies. Results of diagnostic testing help to localize the pathology, guide the next steps in the diagnostic pathway, and inform the selection of appropriate genetic tests. [6]
- Dystrophin gene deletion and duplication testing are used for confirmatory testing. Preferred testing includes multiplex ligation-dependent probe amplification, which can identify boundaries of deletion, duplication mutation, or comparative genomic information. This allows determination of the type of mutation and reading frame or the portion of the DNA molecule that is preserved or deleted.[4]
- About 60-70% of individuals with DMD have mutations of one or more exons, and approximately 5% present with duplication in the dystrophin gene.[4] In about 25-30% of cases, a negative test for a deletion or duplication requires further analysis or next-generation genetic sequencing. This detects point mutations (nonsense or missense, small deletions, and small duplications or insertions) associated with DMD.[4]
- Precise genetic information is important for participation in gene therapy and mutation-specific clinical trials. There are now US Food and Drug Administration (FDA) approved medications for specific subgroups of DMD with mutations to exon 45, 51, or 53 skipping. [1]
- If DMD is not confirmed through genetic testing, a muscle biopsy sample is tested for the presence of dystrophin protein by either immunohistochemistry of tissue cryosections or western blot of a muscle protein extract.[1]

PHARMACOLOGICAL TREATMENTS

Pharmacologic treatment aims to manage symptoms and to slow disease progression and disability.

- The standard of care includes the use of glucocorticoids or corticosteroids to delay loss of muscle and motor and cardiopulmonary function abilities.[6] Long-term side effects of steroids require monitoring for hyperglycemia, obesity, and decreased bone density.[6] Deflazacort is a corticosteroid with fewer reported side effects compared to other commonly available options.
- Dystrophin-targeted therapeutic strategies like gene-based, cell-based, and protein replacement interventions aim to restore the expression and/or function of dystrophin. Dystrophin-targeted therapies slow down the progression of DMD but do not restore the function of the abnormal muscle tissue. It is difficult to target all muscle tissues involved throughout the entire body.[7,8]
- Ongoing research is investigating synthetic steroids vamorolone and edasalonexent, which alter the nuclear factor NF-kB proinflammatory signaling pathway.[9] These medications aim to improve muscle function and quality by addressing inflammation, fibrosis, and muscle atrophy.

Research continues to examine new disease-modifying treatments and gene therapies to restore, replace, or remove mutations in reading frames of exons by addressing genetic material.[10]

MONITORING DISEASE PROGRESSION[11]

- Magnetic resonance imaging is an accurate, non-invasive technique used to monitor disease progression of DMD, particularly involving progressive skeletal muscle weakness and cardiac function.
- The 6-minute walk test, a measure of distance walked within 6-minutes, can provide prognostic information. However, lack of cooperation or motivation may limit interpretation in some patients.
- Serum levels of CK are used to monitor DMD muscle breakdown and related inflammation.
- Monitoring of serum and plasma microRNAs (miRNA), released during muscle damage, provide information on the severity of muscle deterioration.
- Other metabolic biomarkers may implicate cardiovascular complications and events:
    - Increased leptin levels is an indicator of altered fat metabolism or dyslipidemia.
    - Decreased L-carnitine levels reduces transport of fatty acids into the mitochondrial matrix.
    - Circulating phospholipids can lead to atherosclerosis.

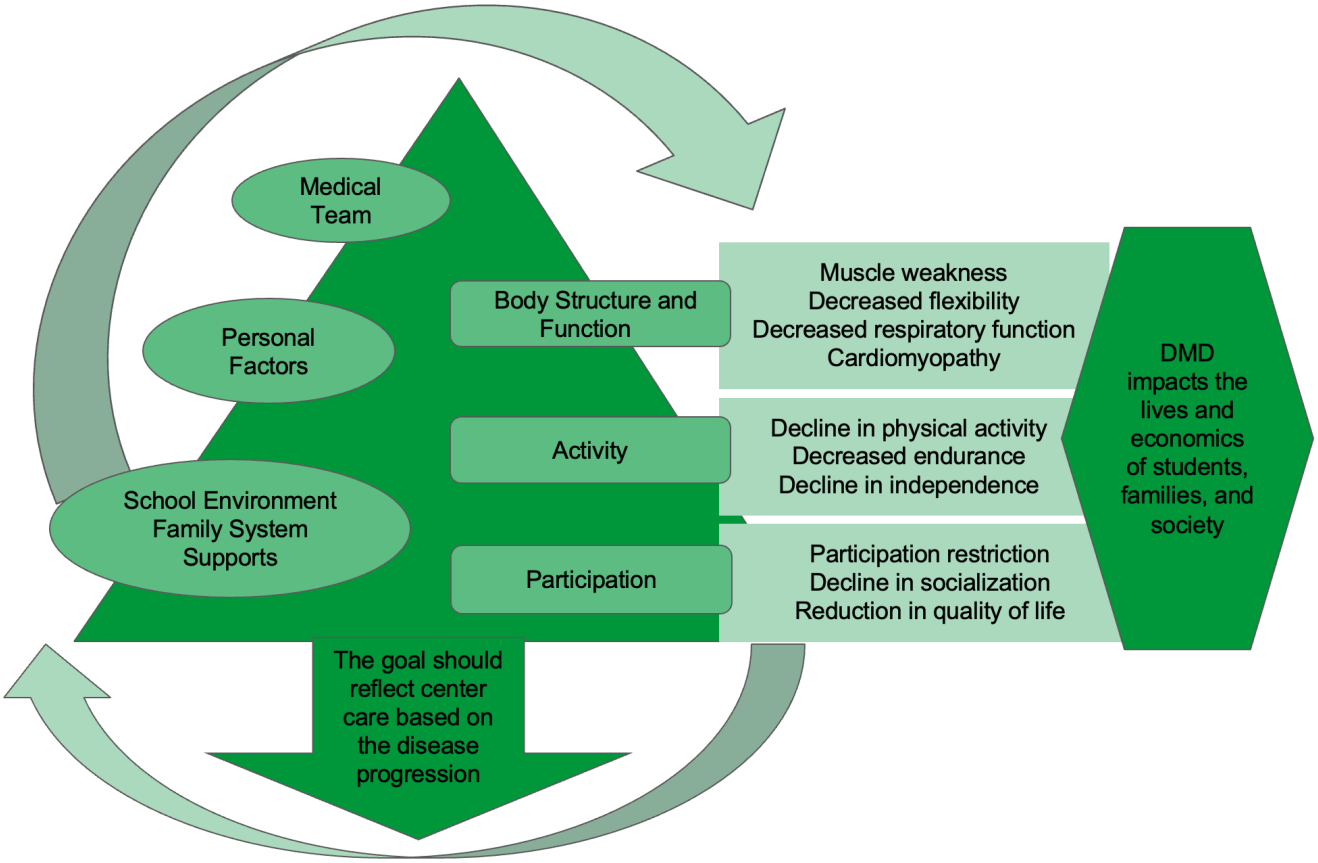
- Reduced levels of citrulline and nitric oxide metabolism may affect vasodilation, lowering blood pressure, which may load and damage the heart.
- Stress-responsive activation of xanthine oxidase affects effectiveness of glucocorticoids medication and has a role in the decline of cardiovascular function.
- Mitochondrial dysfunction of the muscles disrupts calcium gradients and membrane potentials with a buildup of intracellular calcium.

II. ASSESSMENT AND EVALUATION

THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

The International Classification of Functioning, Disability and Health (ICF) provides a framework and standard language for describing disease and health-related functioning. The major components of the ICF include body function and structure, activity, participation, and personal and environmental contextual factors. These core components contribute to the assessment of individuals with DMD as well as the development and monitoring of rehabilitation plans.[12,13] Figure 2 provides an overview of components of the ICF related to DMD.

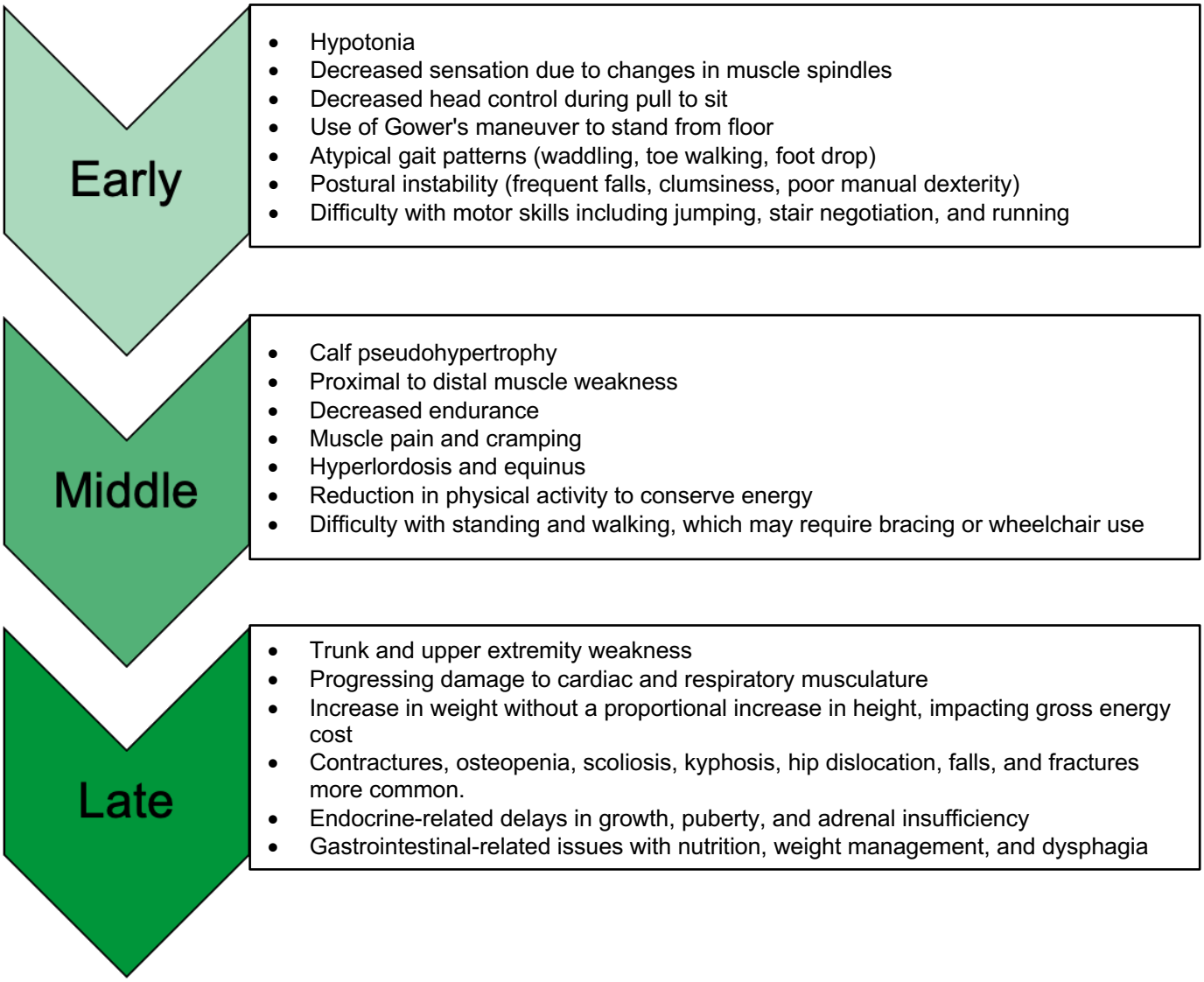
FIGURE 2: Overview of DMD within the ICF Framework[14-16]



COMMON SIGNS AND SYMPTOMS OF DMD

PTs working with students with DMD aim to develop individualized care plans that evaluate the body function and structure, activities, participation, and personal and environmental factors to support the greatest level of functioning at various stages of disease progression in students with DMD.[12] Figure 3 highlights the progressive weakness and commons signs across early, middle, and late phases of DMD.

FIGURE 3: Progressive Weakness and Common Signs of DMD[17-20]



ASSESSMENT

For children with DMD, physical assessment across ICF domains should occur at least every 6 months to monitor for change in function and effectiveness of interventions and to guide anticipatory changes in the plan of care.[1,2] Physical assessment should include the use of appropriate assessment tools to provide objective information to monitor change over time. Table 1 summarizes assessment tools appropriate for use with students with DMD by ICF domain.

TABLE 1: Tests and Measures[21]

TESTS AND MEASURES APPROPRIATE FOR STUDENTS WITH DMD		
ASSESSMENT TOOL	**ICF DOMAIN**	**BRIEF DESCRIPTION**
Goniometry	Body Structure/ Function	Assessment of range of motion of specific joints
Postural Assessment	Body Structure/ Function	Visual assessment of posture
Muscle Strength	Body Structure/ Function	Assessment of individual muscle strength or functional strength of muscle groups

Pediatric Quality of Life Inventory: Neuromuscular module[22]	Participation	Quality of life questionnaire
Pediatric Quality of Life Inventory: Multidimensional Fatigue Scale[23]	Body Structure/ Function, Participation	Fatigue level questionnaire
Children's Assessment of Participation and Enjoyment and Preferences for Activities of Children[24]	Participation	Quality of life questionnaire
North Star Ambulatory Assessment[25]	Activity	Rating scale of functional motor abilities in ambulatory children with DMD: used to monitor progression of DMD and treatment effects
6-Minute Walk Test[26]	Activity, Body Structure/ Function	Sub-maximal exercise test used to assess aerobic capacity and endurance
2-Minute Walk Test[27]	Activity, Body Structure/ Function	Sub-maximal exercise test used to assess aerobic capacity and endurance, particularly for those who cannot manage the longer 6-Minute Walk Test
School Function Assessment[28]	Participation, Activity	Assessment of student performance of functional tasks affecting academic and social aspects of elementary school (K-6)
Functional Independence Measure (WeeFIM)[29]	Participation, Activity	Assessment of a child's consistent performance in essential daily functional skills including self-care, mobility, and cognition
Brooke Upper Extremity Scale[30]	Activity, Body Structure/ Function	Assessment of upper extremity function
Vignos Lower Extremity Scale/ Modified Vignos Lower Extremity Scale[30]	Activity, Body Structure/ Function	Assessment of lower extremity function
Egen Klassifikation Scale[31]	Participation, Activity, Body Structure/ Function	Assessment of wheelchair mobility, upper extremity function, bed mobility, pulmonary function, and physical well-being of non-ambulatory individuals with DMD and other degenerative diagnoses
Gait, Stair, Gower, and Chair Assessment[32]	Activity, Body Structure/ Function	Timed assessment of gait, 4 stairs, sit to stand, and floor to stand
DMD Upper Limb Patient-Reported Outcome Measure[33]	Participation, Activity, Body Structure/ Function	Patient-reported measure of upper limb function in ADLs, specifically for individuals with DMD
Comprehensive Functional Scale for DMD (CFSD)[34]	Participation, Activity, Body Structure/ Function	Functional scale and classification system to evaluate functional abilities of individuals with DMD.
Segmental Assessment of Trunk Control (SATCo)[35]	Activity, Body Structure/ Function	Assessment of level of trunk control (static, active, and reactive)

III.INTERVENTIONS, ACCOMMODATIONS, AND MODIFICATIONS

TYPES OF SBPT SERVICES AND INTERVENTIONS

SBPT services for a student with DMD can include a combination of services to and on behalf of the student. Services to the student may include the PT working directly with the student on skills-based interventions and/or demonstrating strategies for classroom staff to incorporate into daily school routines when assisting a student. Services on behalf of the student may include consulting with the student or school staff on meeting the student's unique positioning and mobility needs, making recommendations about adaptive equipment and school accessibility, collaborating to identifying academic accommodations and/or modifications, providing resources to members of the school and family team related to DMD, or coordinating with community

healthcare providers to facilitate continuity of care. Evidence-supported interventions provided by PT described across ambulatory phases associated with DMD are described in Table 2.

TABLE 2: Evidence-Supported Interventions within Scope of SBPT

Key: KAFO = Knee, Ankle, Foot Orthoses; LE = Lower Extremity; UE = Upper Extremity	**EARLY AMBULATORY PHASE**	**LATE AMBULATORY PHASE**	**EARLY NON-AMBULATORY PHASE**	**LATE NON-AMBULATORY PHASE**
	Early	**Middle**		**Late**
All Phases	Monitor for musculoskeletal changes (including scoliosis).[4,36]			
	Be proactive to preserve flexibility and strength, prolong walking phases, provide adaptive equipment, and support functional independence.[4,36]			
	Build student, staff, and family competence and capacity in addressing current and anticipated future needs.[36]			
	Coach student & staff in planning strategies to address changing needs (next steps, changes to look for, responsive programming).[36]			
	Avoid high-intensity exercise, frequent activity, and/or eccentric muscle activity. Encourage low-intensity (sub-maximal) exercise and sufficient rest between activities.[4,36,37]			
Mobility[4,36]	Consider stroller or lightweight manual wheelchair, if needed for longer distances.	Consider walker or gait trainer with or without KAFOs. Consider manual ultralight wheelchair or power wheelchair, if indicated. Advocate for stand/ sit to stand option.[38]	Encourage KAFOs and walker/gait trainer for use therapeutically (not for mobility).[39] Emphasize fall prevention. Consider power wheelchair (if not already using).	Consider power wheelchair with features that optimize independence.
Positioning[4,36]	Provide supportive seating for symmetry and LE alignment.	Provide supportive seating (may need to add UE and/or trunk supports).	Provide custom postural support system in wheelchair. Conduct staff training on transfers and positioning.	Add programming for regular position changes. Use lifting/transfer equipment, as needed.
		Incorporate supported standing when difficult to maintain standing and/or walk with good alignment.[40]		
Activity Recommendations[4,36,37,38]	Educate that pain reported within a day after activity is sign of overexertion. Provide activity accommodations & modifications.	Encourage activity participation at self-selected pace. Emphasize energy efficiency and conservation. Review mobility & environmental accessibility.	Emphasize supporting participation in targeted & meaningful activities.	Continue to support meaningful participation. Find alternative activities whenever necessary.

Range of Motion [4,36,40,41]	Do not stretch to pain Encourage use of positional stretch focusing on: ankles, hips, knees.	Focus additional manual stretching of wrists, elbows, neck.	Encourage use of positional stretch for LE. Increase emphasis on UE for manual stretching.	Include programming for regular position changes. Address chest wall mobility.

ORTHOTIC & POSITIONING MANAGEMENT

For PTs contributing to the management of orthotic and positioning interventions for students with DMD, evidence-informed suggestions by ambulatory phase are identified below:

Early Ambulatory Phase

- Use ankle foot orthoses (AFO)/splints at night to preserve ankle dorsiflexion.[4,36,43,44]
- Generally, avoid orthotics for ambulation, but consider minimal-design corrective orthotics (eg., heel lift), if the resulting improved gait pattern prolongs independent ambulation without an increased risk of falling or significant energy cost.[36,40,44,45]

Late Ambulatory Phase

- Continue use of night splints.
- Consider knee ankle foot orthoses (KAFO) for added support in standing and/or to prolong assisted ambulation.[35,36,40]

Early Non-ambulatory Phase

- Use daytime AFOs for positioning while seated and/or during supported standing to preserve ankle range of motion.[36,40,41]
- Initiate supported standing programs when difficult for student to maintain standing and/or walking with good alignment: protocols vary, but best evidence suggests a total of 60 minutes per day for 5-7 days per week has significant effect on preserving ROM.[41]
- Collaborate with occupational therapy to determine upper extremity splinting needs.[35,36]

Late Non-ambulatory Phase

- Continue use of orthotics/splints to preserve range of motion and/or support joints in positions of maximum function.[35,36]

ACCOMMODATIONS, MODIFICAITONS, AND SUPPORTS

PTs consult on accommodations, modifications, and support that allow students with DMD to access the various activities that occur during the school day. Figure 4 provides evidence-informed accommodations, modifications, and supports related to access during recess and physical education/adaptive physical education, and Figure 5 provides suggestions related to mobility, mealtimes, and toileting.

FIGURE 4: Evidence-Supported Accommodations, Modifications, and Supports for Recess and Physical Education[18,20,22,23,49,50,54]

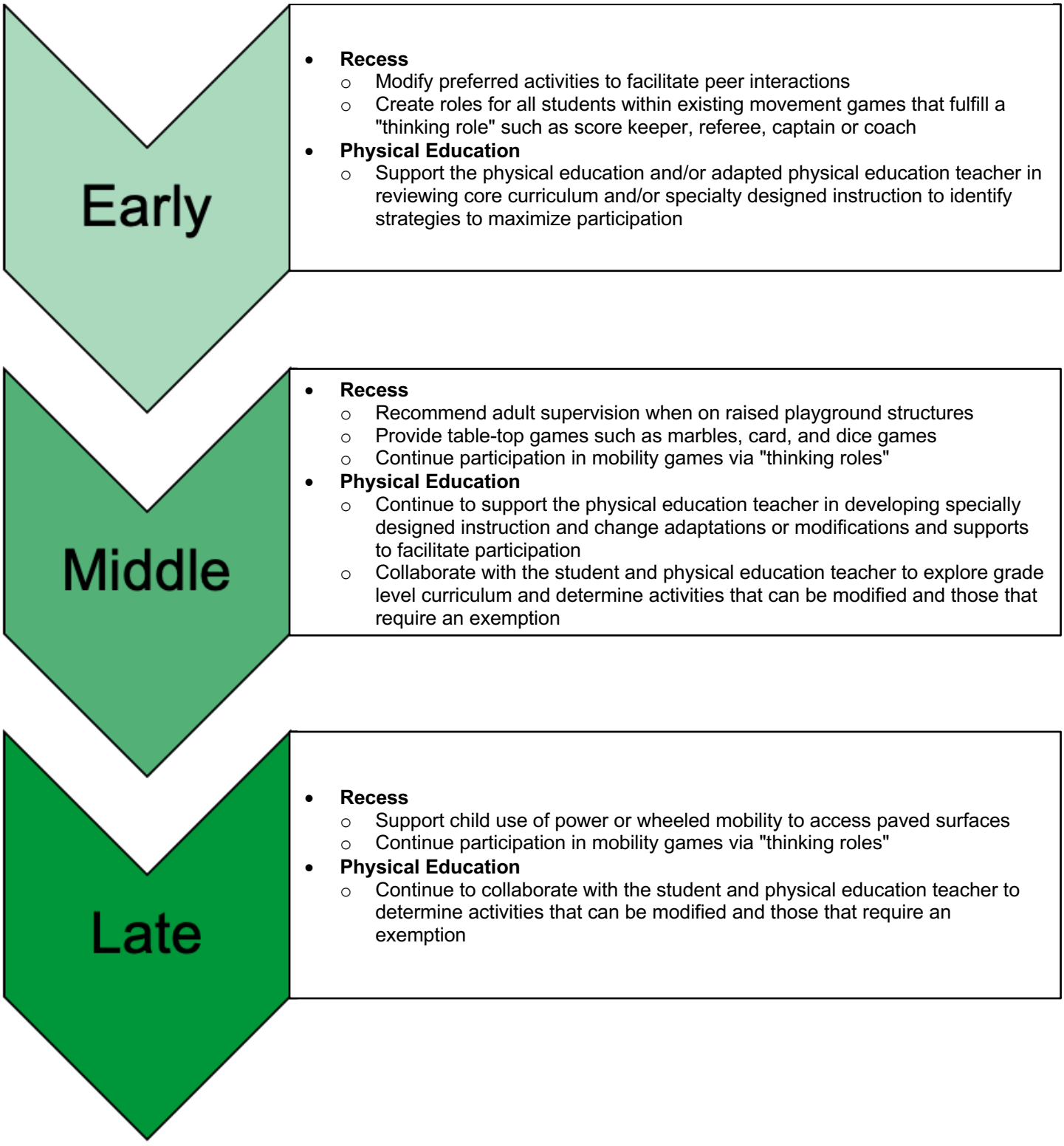
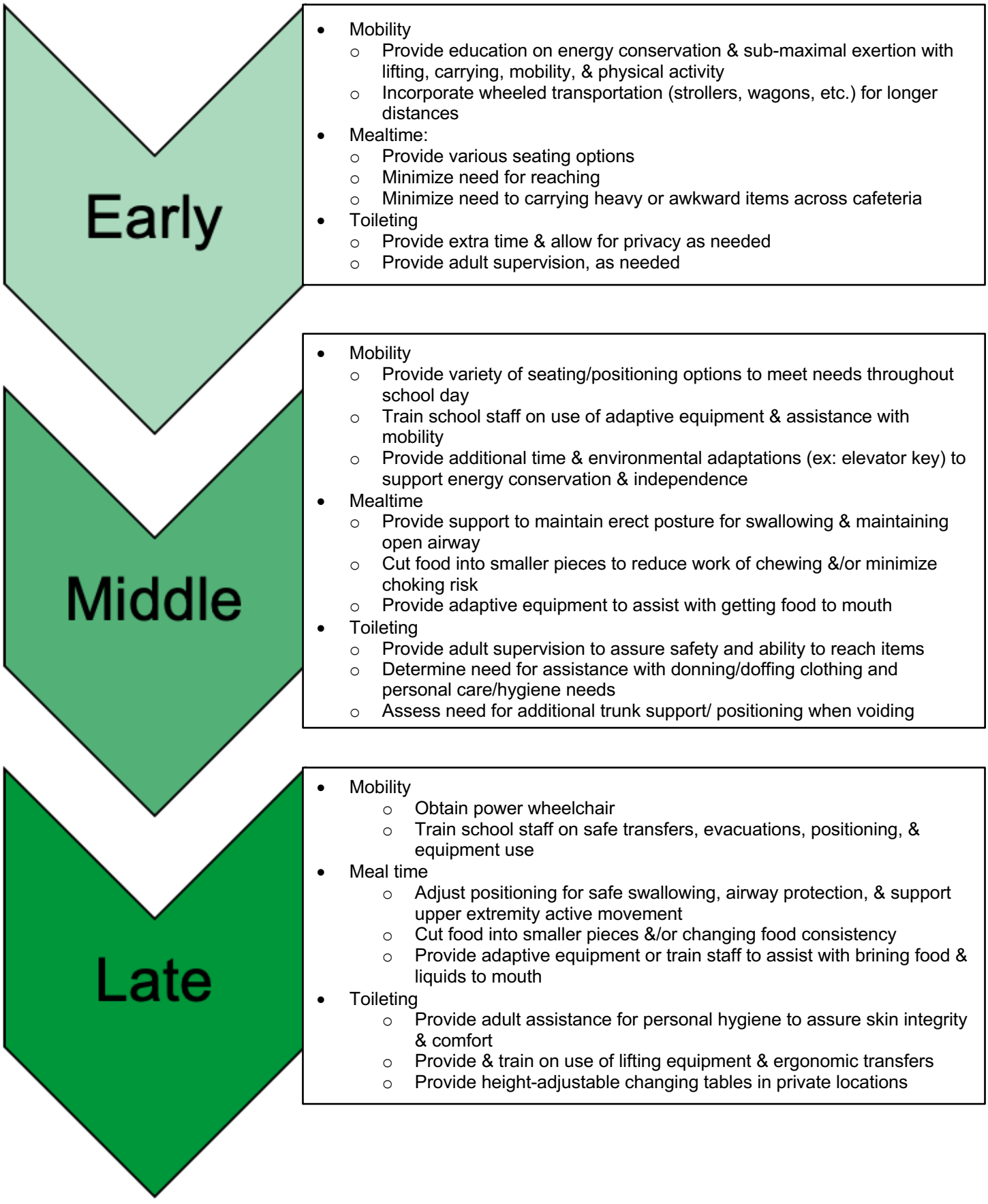


FIGURE 5: Evidence-Supported Accommodations, Modifications, and Supports for Mobility, Mealtimes, and Toileting[18,23,35,49,50,52,53,54]



COLLABORATION

SBPT services are not designed to meet all the physical needs of students with DMD. When working with families or community-based healthcare providers to support continuity of care, the following list offers some suggestions for evidence-based interventions with potential for collaboration:

- Orthotics management
- Assisted mobility device prescription and management[35,36,39,41]
- Positioning equipment (postural support in wheelchair(s), standers, transfer equipment, etc.)[35,36,41]
- Serial casting to preserve or gain ankle dorsiflexion to prolong walking phases[36,46]
- Respiratory (cough assistance and airway clearance) techniques[47,48]

IV.CLINICAL PEARLS FROM SBPTS

Clinical expertise is a critical component of evidence-based practice. This section lists additional considerations that are valuable in meeting student needs and supporting student success.

- The rate of disease progression in DMD can vary greatly. Interventions need to address present needs; always plan for probable needs in the next phase (use anticipatory guidance for future needs).
- Interactions in the natural environment allow the PT to observe early and/or minute changes in the child's function. Changes may include a decline in functional ankle range of motion signaling the need for daily stretches, nighttime splints, or AFOs. Difficulty in walking longer distances may signal the need for consideration for an assistive device.
- Work with the school team to encourage students with DMD to build the capacity for self-advocacy and the ability to self-direct those providing help/assistance.
- Work with school nurse regarding current medical interventions and necessary staff education.
- Use coaching strategies with classroom staff to ensure they are educated on the student's unique positioning and mobility needs and the importance of accommodations, modifications, and other supportive programming.
- Address emergency evacuation procedures for the student, making specific plans (ex: staff assignments). Plan for evacuation from every learning location in student's schedule, assist district with purchasing necessary equipment, and assist with training staff on how to use equipment when appropriate).
- Monitor environmental access to all school areas regularly to ensure functional accessibility.
- Collaborate with assistive technology providers to ensure effective positioning and accessibility throughout the day for students with DMD. Many wheelchair manufacturers have resources to aid in writing letters of medical necessity. Although classrooms are ideally fitted with universally designed environmental controls, augmentative devices such as typing instead of writing, voice to text, ramps, power doors, automatic faucets, motion-initiated lights, etc., may be required.

V.RECOMMENDED COMMUNITY, FAMILY, AND EDUCATOR RESOURCES

- Cure Duchenne
- Muscular Dystrophy Association
- Parent Project Muscular Dystrophy
- Imperatives for Duchenne MD (an NIH parent and staff-friendly resource)
- National Task Force for the Early Identification of Childhood Neuromuscular Disorders
- Links to priority literature with free access:
    - Diagnosis and management of DMD, Part 1 (Bimkrant et al., 2018)
    - Diagnosis and management of DMD, Part 2 (Bimkrant et al., 2018)
    - Rehabilitation management of the patient with DMD (Case et al., 2018)

VI. SUMMARY

In summary, school-based PTs play a critical role in the care of students with DMD. It is important for PTs to understand the pathophysiology, disease progression, methods for measuring outcomes, precautions, and appropriate intervention strategies, for students with DMD in order to promote participation and engagement in the educational environment. Physical therapists should prioritize collaboration with families, school educational and medical staff, and community resources to support students with DMD in meeting their educational and personal goals.

REFERENCES

1. Thomas S, Conway KM, Fapo O, et al. Time to diagnosis of Duchenne muscular dystrophy remains unchanged: findings from the muscular dystrophy surveillance, tracking, and Research Network, 2000-2015. *Muscle Nerve*. 2022. doi:10.1002/mus.27532
2. Narayan S, Pietrusz A, Allen J, et al. Adult North Star Network (ANSN): Consensus document for therapists working with adults with Duchenne muscular dystrophy (DMD) – therapy guidelines. *J Neuromuscul Dis*. 2022;9(3):365-381. doi:10.3233/jnd-210707
3. Meyers TA, Townsend DW. Cardiac pathophysiology and the future of cardiac therapies in Duchenne muscular dystrophy. *Int J Mol Sci.* 2019;20(17):4098. doi:10.3390/ijms20174098
4. Birnkrant DJ, Bushby K, Bann CM, et al. Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. *Lancet Neurol*. 2018;17(3):251-267. doi:10.1016/s1474-4422(18)30024-3
5. Klingler W, Jurkat-Rott K, Lehmann-Horn F, Schleip R. The role of fibrosis in Duchenne muscular dystrophy. *Acta Myol*. 2012;31(3):184-195.
6. Chikkannaiah M, Reyes I. New diagnostic and therapeutic modalities in neuromuscular disorders in children. *Curr Prob Pediatr Adolesc Health Care*. 2021;51(7):101033. doi:10.1016/j.cppeds.2021.101033
7. Chung Liang L, Sulaiman N, Yazid MD. A Decade of Progress in gene targeted therapeutic strategies in Duchenne Muscular Dystrophy: A systematic review. *Frontiers*. https://www.frontiersin.org/articles/10.3389/fbioe.2022.833833/full. Published January 31, 2022. Accessed May 1, 2023.
8. Yao S, Chen Z, Yu Y, et al. Current pharmacological strategies for Duchenne muscular dystrophy. *Frontiers*. https://www.frontiersin.org/articles/10.3389/fcell.2021.689533/full. Published July 23, 2021. Accessed May 1, 2023.
9. Mendell JR, Sahenk Z, Lehman K, et al. Assessment of systemic delivery of Raavrh74.mhck7.micro-dystrophin in children with Duchenne muscular dystrophy: a nonrandomized controlled trial. *JAMA Neurol.* https://pubmed.ncbi.nlm.nih.gov/32539076/. Accessed May 1, 2023.
10. Fix GM, VanDeusen LC, Bolton RE, et al. Patient-centred care is a way of doing things: How healthcare employees conceptualize patient-centred care. *Health Expect*. 2017;21(1):300-307. doi:10.1111/hex.12615
11. Lee-Gannon T, Jiang X, Tassin TC, Mammen PP. Biomarkers in Duchenne muscular dystrophy. *Curr Heart Fail Rep*. 2022;19(2):52-62. doi:10.1007/s11897-022-00541-6
12. Martinuzzi A, Salghetti A, Betto S, et al. The International Classification of Functioning Disability and Health, version for Children and Youth as a roadmap for projecting and programming rehabilitation in a Neuropaediatric Hospital Unit. *J Rehabil Med*. https://pubmed.ncbi.nlm.nih.gov/20111844/. Accessed May 1, 2023.
13. Conway KM, Ciafaloni E, Matthews D, et al. Application of the International Classification of Functioning, Disability and Health system to symptoms of the Duchenne and Becker muscular dystrophies. *Disabil Rehabil*. 2018;40(15):1773-1780. doi:10.1080/09638288.2017.1312567
14. Uttley L, Carlton J, Woods HB, Brazier J. A review of quality of life themes in Duchenne muscular dystrophy for patients and carers. *Health Qual Life Outcomes*. 2018;16(1). doi:10.1186/s12955-018-1062-0
15. Quinlivan R, Messer B, Murphy P, et al. Adult North Star Network (ANSN): Consensus guideline for the standard of care of adults with Duchenne muscular dystrophy. *J Neuromuscul Dis*. 2021;8(6):899-926. doi:10.3233/jnd-200609
16. Ryder S, Leadley RM, Armstrong N, et al. The burden, epidemiology, costs and treatment for Duchenne muscular dystrophy: an evidence review. *Orphanet J Rare Dis*. 2017;12(1). doi:10.1186/s13023-017-0631-3

17. Kröger S, Watkins B. Muscle spindle function in healthy and diseased muscle. *Skelet Muscle*. 2021;11(1). doi:10.1186/s13395-020-00258-x
18. Sienko S, Buckon CE, Bagley A, et al. Longitudinal changes in energy cost during walking in boys with Duchenne muscular dystrophy (DMD). *Gait Posture*. 2021;90:301-306. doi:10.1016/j.gaitpost.2021.09.173
19. Filiz MB, Toraman NF, Kutluk MG, et al. Effects of lumbar lordosis increment on gait deteriorations in Ambulant Boys with Duchenne Muscular Dystrophy: A cross-sectional study. *Braz J Phys Ther*. 2021;25(6):749-755. doi:10.1016/j.bjpt.2021.05.001
20. Kennedy RA, Carroll K, McGinley JL, Paterson KL. Walking and weakness in children: a narrative review of gait and functional ambulation in paediatric neuromuscular disease. *J Foot Ankle Res*. 2020;13(10).
21. Johnson A, Kiefer M, Townsend E. FACT SHEET: Duchenne Muscular Dystrophy. APTA Academy of Pediatric Physical Therapy; 2023. Available at: https://pediatricapta.org/fact-sheets/
22. Davis SE, Hynan LS, Limbers CA, et al. The PedsQL in pediatric patients with Duchenne muscular dystrophy: feasibility, reliability, and validity of the Pediatric Quality of Life Inventory Neuromuscular Module and Generic Core Scales. *J Clin Neuromuscul Dis*. 2010;11(3):97–109.
23. Alemdaroglu-Gurbuz I, Bulut N, Bozgeyik S, et al. Reliability and validity of the turkish translation of pedsql™ multidimensional Fatigue scale in Duchenne muscular dystrophy. *Neurosciences* (Riyadh). 2019;24(4):302-310. doi:10.17712/nsj.2019.4.20190035
24. Bendixen RM, Lott DJ, Senesac C, Mathur S, Vandenborne K. Participation in daily life activities and its relationship to strength and functional measures in boys with Duchenne muscular dystrophy. *Disabil Rehabil*. 2014;36(22):1918–1923.
25. Mayhew AG, Cano SJ, Scott E, et al; North Star Clinical Network for Neuromuscular Disease. Detecting meaningful change using the North Star Ambulatory Assessment in Duchenne muscular dystrophy. *Dev Med Child Neurol*. 2013;55(11):1046–1052.
26. McDonald CM, Henricson EK, Abresch RT, et al; PTC124-GD-007-DMD Study Group. The 6-minute walk test and other clinical endpoints in Duchenne muscular dystrophy: reliability, concurrent validity, and minimal clinically important differences from a multicenter study. *Muscle Nerve*. 2013;48(3):357–368.
27. Witherspoon JW, Vasavada R, Logaraj RH, et al. Two-minute versus 6-minute walk distances during 6-minute walk test in neuromuscular disease: Is the 2-minute walk test an effective alternative to a 6-minute walk test? *Eur J Paediatr Neurol*. 2019;23(1):165-170. doi:10.1016/j.ejpn.2018.10.001
28. Davies PL, Soon PL, Young M, Clausen-Yamaki A. Validity and reliability of the school function assessment in elementary school students with disabilities. *Phys Occup Ther Pediatr*. 2004;24(3):23–43.
29. Wong V, Wong S, Chan K, Wong W. Functional Independence Measure (WeeFIM) for Chinese children: Hong Kong Cohort. *Pediatrics*. 2002;109(2):E36. doi:10.1542/peds.109.2.e36
30. Lu YM, Lue YJ. Strength and functional measurement for patients with muscular dystrophy. In: Hegde M, Ankala A, eds. *Muscular Dystrophy*. Intech; 2012:671–688. doi: 10.5772/31970
31. Steffensen B, Hyde S, Lyager S, Mattsson E. Validity of the EK scale: a functional assessment of non-ambulatory individuals with Duchenne muscular dystrophy or spinal muscular atrophy. *Physiother Res Int*. 2001;6(3), 119-134.
32. Angelini C. The role of corticosteroids in muscular dystrophy: a critical appraisal. *Muscle Nerve*. 2007;36(4):424–435.
33. Klingels K, Mayhew AG, Mazzone ES, et al. Development of a patient-reported outcome measure for upper limb function in Duchenne muscular dystrophy: DMD upper limb PROM. *Dev Med Child Neurol*. 2017;59(2):224-231. doi:10.1111/dmcn.13277
34. Kim J, Jung IY, Kim SJ, et al. A new functional scale and ambulatory functional classification of Duchenne muscular dystrophy: scale development and preliminary analyses of reliability and validity. *Ann Rehabil Med*. 2018;42(5):690-701. doi:10.5535/arm.2018.42.5.690
35. Butler PB, Saavedra S, Sofranac M, Jarvis SE, Woollacott MH. Refinement, reliability, and validity of the segmental assessment of trunk control. *Pediatr Phys Ther*. 2010;22(3):246-257. doi:10.1097/PEP.0b013e3181e69490
36. Case LE, Apkon SD, Eagle M, et al. Rehabilitation management of the patient with Duchenne muscular dystrophy. *Pediatrics*. 2018;142(Supplement 2):S17-S33. https://doi.org/10.1542/peds.2018-0333d.
37. Jansen M, de Groot IJ, van Alfen N, Geurts AC. Physical training in boys with Duchenne muscular dystrophy: the protocol of the No Use is Disuse study. *BMC Pediatr.* 2010;10(1). https://doi.org/10.1186/1471-2431-10-55

38. Kostek MC, Gordon B. Exercise Is an adjuvant to contemporary dystrophy treatments. *Exerc Sport Sci Rev*. 2018;46(1):34-41. https://doi.org/10.1249/jes.0000000000000131
39. Bayley K, Parkinson S, Jacoby P, et al. Benefits of powered standing wheelchair devices for adolescents with Duchenne muscular dystrophy in the first year of use. *J Paediatr Child Health*. 2020;56(9):1419-1425. https://doi.org/10.1111/jpc.14963
40. Stevens, P. Lower limb orthotic management of Duchenne muscular dystrophy: a literature review. *J Prosthet Orthot.* 2006;18:111–119.
41. Townsend EL, Bibeau C, Holmes TM. Supported standing in boys with Duchenne muscular dystrophy. *Pediatr Phys Ther.* 2016;28(3):320-329. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5603175/
42. Craig J, Hilderman C, Wilson G, Misovic R. Effectiveness of stretch interventions for children with neuromuscular disabilities. *Pediatr Phys Ther*. 2016;28(3):262-275. https://doi.org/10.1097/pep.0000000000000269
43. Hyde SA, FlŁytrup I, Glent S, et al. A randomized comparative study of two methods for controlling Tendo Achilles contracture in Duchenne muscular dystrophy. *Neuromuscul Disord*. 2000;10(4-5):257-263. https://doi.org/10.1016/s0960-8966(99)00135-2
44. Aprile I, Bordieri C, Gilardi A, et al. Balance and walking involvement in facioscapulohumeral dystrophy: a pilot study on the effects of custom lower limb orthoses. *Eur J Phys Rehabil Med*. 2013;49:169-178.
45. Mercer V, Gross M, Shelton T, et al. *Immediate effects of foot orthoses on gait and balance in boys with Duchenne muscular dystropy: a pilot study.* DPT Capstone report. The University of North Carolina; 2017.
46. Glanzman AM, Flickinger JM, Dholakia KH, Bönnemann CG, Finkel RS. Serial casting for the management of ankle contracture in Duchenne muscular dystrophy. *Pediatr Phys Ther*. 2011;23(3):275-279. https://doi.org/10.1097/PEP.0b013e318227c4e3
47. Birnkrant DJ, Bushby K, Bann CM, et al. Diagnosis and management of Duchenne muscular dystrophy, part 2: respiratory, cardiac, bone health, and orthopaedic management. *Lancet Neurol.* 2018;17(4):347-361. https://doi.org/10.1016/s1474-4422(18)30025-5
48. Camela F, Gallucci M, Ricci G. Cough and airway clearance in Duchenne muscular dystrophy. *Paediatr Respir Rev.* 2019;31:35-39. https://doi.org/10.1016/j.prrv.2018.11.001
49. Arora H, Willcocks RJ, Lott DJ, et al. Longitudinal timed function tests in Duchenne muscular dystrophy: Imaging DMD cohort natural history. *Muscle Nerve*. 2018;58(5):631-638.
50. Goudriaan M, Van den Hauwe M, Dekeerle J, et al. Gait deviations in Duchenne muscular dystrophy – part 1. A systematic review. *Gait Posture*. 2018;62:247-261.
51. Migliorelli C, Gómez-Martinez M, Subías-Beltrán P, et al. Multidimensional biomechanics-based score to assess disease progression in Duchenne muscular dystrophy. *Sensors (Basel)*. 2023;23(2):831.
52. Yildiz S, Sahin S, Bulut N, Tunca Yilmaz O, Karaduman AA, Akel BS. Comparison of motor proficiency and functional ambulation in Duchenne muscular dystrophy with healthy peers. *Somatosens Mot Res*. 2020;37(4):252-256.
53. Kennedy RA, de Valle K, Adams J, Ryan MM, Fitzgerald AK, Carroll K. Characterising gait in paediatric neuromuscular disorders: an observational study of spatio-temporal gait in a clinical cohort. *Disabil Rehabil*. 2022;44(23):7023-7029.
54. Maciel FKL, Santos ALYDS, Sá CDSC. Responsiveness of upper limb scales and trunk control for the evolution of patients with Duchenne muscular dystrophy. *Rev Paul Pediatr.* 2021;24(39):e2020045.

Developed by expert contributors Rebecca A.A. Wilson, PT, MS, C/NDT, Board-Certified Pediatric Clinical Specialist; Lisa Iordanou, PT, DPT; Sandra M. Ribeiro, PT, DPT, MSEd, Board-Certified Pediatric Clinical Specialist; Jennifer Stephens, PT, DPT, Board-Certified Pediatric Clinical Specialist; Lisa Milkavich, PT, DPT, Board-Certified Pediatric Clinical Specialist. Supported by the Fact Sheet Committee of APTA Pediatrics.

APPENDIX A: Example Classroom Staff "Traffic Light" Resource Page

	CLASSROOM ACTIVITY RECOMMENDATIONS			
	LEVEL 1	**LEVEL 2**		**LEVEL 3**
	NO RESTRICTIONS	**WITH RESTRICTION**		**AVOID**
Activity		**Activity**	**Modifications**	
Arrival	Walking to classroom; Doffing coat/jacket; Unpacking backpack			Bus steps (use lift if possible)
Classroom Mobility	Seated learning (monitor for slouching or other signs of poor posture/positioning)		Keep materials within reach, when possible	Floor transfers/ transitions, whenever possible
School Mobility	Walking in line with peers	Weighted walking	Provide assistance in carrying heavy objects/ backpack; Provide duplicate materials	Unnecessary walking between classes
Outdoor Mobility	Walking in line with peers		Seek out even/paved surfaces	
Recess	Walking at self-selected pace	Encourage seated rest breaks; Schedule 1-2 breaks with a peer		Recess on physical education days (provide alternative activities)
	Throwing/catching/kicking (monitor for fatigue)	Gaga ball	No jumping; Limit game time	Climbing ladders
		Stairs	Limit stair repetitions; Use slide for descent instead of stairs	Tag/chasing games
	Participating in less physically active games with peers			Overhead equipment (ex: monkey bars)
				Jumping or jump rope
Departure	Donning jacket/coat; Packing back pack		Limit materials sent home to keep backpack light	Bus steps (use lift if possible)
General	Walking at self-selected pace	Limit total daily walking distance		Running or jumping
	Transferring in/out of chair; Sitting whenever appropriate/ necessary	Schedule low-energy tasks between high-energy tasks to allow recovery time		Avoid walking long distances (offer wagon or stroller for field trips)
	Gathering/carrying light-weight materials	Provide preferential locker or desk placement for ease of access		
	Assuring seat/desk setup supports good posture			

NOTE: If student is not self-limiting activity, staff needs to provide limits and help with recognition of overworking.

APPENDIX B: Example Physical Education "Traffic Light" Resource Page

	PHYSICAL EDUCATION ACTIVITY RECOMMENDATIONS			
	LEVEL 1	**LEVEL 2**		**LEVEL 3**
	NO RESTRICTIONS	**WITH RESTRICTION**		**UNABLE TO PARTICIPATE**
Unit		**Activity**	**Notes/Suggestions**	
Warm ups	Most standing or seated flexibility/stretching warm-up exercises	Warm up exercises	Participate in standing or seated position; Limit to 1-2 laps at walking speed	Floor warm-up exercises (push-ups, planks, sit-ups); Strenuous exercises (pull ups, squats, lunges, racing)
Fitness testing	Height/weight testing	Sit & reach	Sit on stack of mats to avoid floor transfer	Mile run, pacer run, buddy run, curl ups, flex arm hang
Bowling	Bowling/rolling balls at targets		Use light weight ball; Set pins only when can be reached while seated in a chair	
Soccer	Basic skill development (foot drills, etc.)	Practice	Limit chasing/retrieving ball; Substitute walking for running	Extended play time
Tennis (and other racquet sports)	Basic skill development (racquet skills) in place	Practice	Volley only or play 2-on-2 to limit area of play; Have peer retrieve ball; Play in short matches only	Play for full set/match
Gymnastics	Balance elements	Floor skills	Limit participation; Avoid transitioning between floor and standing frequently	Parallel bars, rings, climbing, vaulting or jumping
Football	Punting	Throwing & catching	Watch for arm fatigue; No running to catch/retrieve ball	Scrimmage/game participation
Volleyball	Skill development (bumping, setting, serving)	During game	Monitor for fatigue and rotate out as necessary	Retrieving/chasing ball
Scooters			Very limited participation; Have peer tow student or participate as 1 leg of relay	Not recommended (because must complete floor transfer)
Baseball	Batting with light weight bat	Throwing, catching, & fielding	Limit total throw/pitch count; No running to retrieve balls; Limit fielding (avoid repetitive bending down to get ball)	Base running (have another child run in place after batting OR allow to walk); Out-fielding
Basketball	Basic skill development (dribbling, bounce pass) while stationary; free throws		Allow walking vs. running	Extended play time during games
Floor hockey	Basic skill development (use of stick, targeted passing/shooting) while stationary		Stay in place; walk instead of run; Consider turn as goalie	Participation in game generally not recommended
Golf or disc golf	Basic skill development (types of swings, putting) while stationary	Practice & game	Limit ball retrieval and number of holes to minimize total walking distance	

Tag/chase games		Substitute walking for running	Not recommended
Jumping rope		Limited twirling for others; Stepping instead of jumping for limited repetitions	Repetitive jumping
Parachute		Limited participation when stationary or at a walking speed	
Speed stacks	Full participation	Limit bending over to pick up cups; Allow participation while sitting in chair	
General accommodations should always include the following: avoiding transitioning to the floor by having a chair (or stack of mats) available, allowing participation at a self-selected pace, and allowing for frequent rest breaks. AVOID PARTCIPATION TO THE POINT OF FATIGUE. Whenever possible, keep student engaged by assigning him/her alternate jobs (managing equipment; 'coaching' or cheering peers, score keeping, etc.). If student is not currently self-limiting activity, staff needs to provide limits and help student learn to recognize overworking.			