Rehabilitation Management of the Patient With Duchenne Muscular Dystrophy

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Steadily improving management of Duchenne muscular dystrophy (DMD) continues to lead to improved physical and functional status, allowing increasingly successful transitions to independence and self-actualization in adulthood. Rehabilitation principles remain key to overall management for individuals with DMD with increasing options for ever more successful management, reflecting a changing natural history based on the use of glucocorticoids, more consistent comprehensive care, and the emergence of disease-modifying treatments. Advances and expansion in assessment, cardiorespiratory management, preventive management of contracture and deformity, assistive technology, “smart” technology, and robotics with increased emphasis on function, participation, self-advocacy, and independence in decision-making should allow individuals with DMD to experience childhood and transition to adulthood with support that allows for increasing success in the achievement of individual goals and fulfillment across the life span.

The guidelines or recommendations in this article are not American Academy of Pediatrics policy, and publication herein does not imply endorsement.

Dr Case served as the chairperson of the Duchenne Muscular Dystrophy Care Considerations Rehabilitation Management Working Group as convened by the Centers for Disease Control and Prevention, drafted the initial manuscript, and reviewed and revised the manuscript; Drs Apkon, Eagle, and Matthews and Ms Gulyas, Ms Juel, Ms Newton, and Ms Posselt served in the Duchenne Muscular Dystrophy Care Considerations Rehabilitation Management Working Group as convened by the Centers for Disease Control and Prevention, contributed to the development of corresponding recommendations, and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Duchenne Muscular Dystrophy (DMD) Care Considerations, initially published in 2010,1–2 were recently updated.3–5 These considerations, supported by the Centers for Disease Control and Prevention, offer overall recommendations for management by the multidisciplinary team.3–5 In this specialty article, we offer in-depth descriptions of the current comprehensive, anticipatory, preventive rehabilitation management of DMD including an updated understanding of the pathokinesiology of disease progression, changing natural history, recommendations for assessment and intervention, and future directions. Respiratory rehabilitation management is covered in the article on respiratory management that is part of this supplement.6

DMD is characterized by well-known patterns of progressive muscle degeneration and weakness, postural compensations, risk of progressive contracture and deformity, and functional losses resulting from dystrophin deficiency (Tables 1 and 2).1,2,7–9 The natural history of DMD has changed over the years with more comprehensive medical and therapeutic management,1–3,6,9,15,16,20–37 the use of glucocorticoids,38–40 and the advent of emerging disease-modifying treatments.38–43 These advances have resulted in prolonged ambulation,28,43–54 decreases and/or delays in the development of severe contracture and deformity (including scoliosis),2–7,9,15,16,20–22,24–31,55,56 improved cardiorespiratory status,1–4,6,36,57 and prolonged function into adulthood. Patients have been supported by advancing adaptive equipment, assistive technology, and “smart” technology, all of which promise ever-increasing participation in adulthood.1–3,31

Figure 1 includes an overall summary of rehabilitative care during the various clinical stages of DMD.

**ASSESSMENT**

Multidisciplinary assessment across the International Classification of Functioning, Disability, and Health and care continuum remains important in guiding rehabilitation interventions. Assessment tools recommended in the original (2010) Care Considerations remain supported and expanded via newly developed tools (Tables 3 and 4). Impairment-level measures include passive ranges of motion (ROM) and the assessment of alignment and posture, which is critical in monitoring the success of musculoskeletal management and identifying needs for additional physical therapy (PT), occupational therapy (OT), orthotic intervention, serial casting, seating system modification, supported standing, and adaptive equipment. Standardized functional assessments for DMD have been expanded with the establishment of validity, reliability, predictive potential, and minimal clinically important differences, which are described in detail in the 2018 DMD Care Considerations.3–5 These assessments should be used across the life span (Table 3).32,41,58–66 Use of the same measures over time, including new assessments as appropriate, is recommended to monitor change and support anticipatory management. Measurement of pain,67–73 fatigue,74 disability,75 participation, quality of life,69,75–77 and patient-reported outcomes32,78–84 are important as is the increasing use of activity monitoring.59,60,63 Occupational therapist assessment of learning, attentional, and sensory processing differences, fine motor function, and activities of daily living (ADL) should begin early, guiding intervention and optimizing success. Multidisciplinary assessment across the International Classification of Functioning, Disability, and Health should occur at least every 6 months, with more frequent assessment being triggered by concern, change in status, or specific needs as supported by professional standards of care.85,86

**INTERVENTION**

Comprehensive, anticipatory, preventive rehabilitation management is focused on protecting fragile muscles; preserving and maintaining optimal strength; minimizing the progression of weakness when possible; preventing and minimizing progressive contracture and deformity; supporting optimal cardiorespiratory care and function; optimizing energy efficiency and energy conservation; providing adaptive equipment and assistive technology; maintaining skin integrity; preventing and minimizing pain; supporting function, functional independence, and participation at school, work, and in family and social life; and optimizing quality of life.1–3,6,9,20–31,108

A multidisciplinary rehabilitation team is required that includes physicians, physical therapists, occupational therapists, speech-language pathologists, orthotists, and providers of durable medical equipment who coordinate with those in pulmonary medicine, orthopedics, cardiology, neurology, genetics, social work, psychology, endocrinology, nutrition, and gastroenterology. Direct skilled PT, OT, and speech-language therapy, based on individual assessment, are provided in outpatient, home, and school settings and in inpatient settings during hospitalizations and should be continued throughout adulthood.

**Musculoskeletal Management (Prevention of Contracture and Deformity)**

Anticipatory preventive musculoskeletal management is focused on preserving muscle extensibility, joint mobility, and symmetry to prevent and minimize...
### TABLE 1 Pathokinesiology of Disease Progression

<table>
<thead>
<tr>
<th>Weakness</th>
<th>Compensations</th>
<th>Risk of Tightness (2-joint muscles get tight first)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Early stage</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Hip extensors (gluteus maximus)</td>
<td>• Posterior trunk lean and increased lumbar lordosis used to keep line of gravity behind hip joint (initially see less anterior pelvic tilt when hyperextension at hip joint in stance as long as quadriceps are strong enough to counteract movement into knee flexion)</td>
<td>• May see emerging tightness in the following:</td>
</tr>
<tr>
<td>• Ankle dorsiflexors (anterior tibialis)</td>
<td>• Lack of heel strike</td>
<td></td>
</tr>
<tr>
<td>• Hip abductors (gluteus medius)</td>
<td>• Increased hip flexion during swing to clear foot</td>
<td>• Plantar flexors</td>
</tr>
<tr>
<td>• Hip adductors</td>
<td>• May see “hip-waddling gait” due to inadequate forward weight shift</td>
<td>• Hip flexors</td>
</tr>
<tr>
<td>• Abdominals</td>
<td>• Increased UE abduction and lateral trunk sway</td>
<td>• Iliotibial bands</td>
</tr>
<tr>
<td>• Neck flexors (sternocleidomastoid)</td>
<td>• Neck and UE weakness not usually noticeable functionally but apparent with testing; may see slight head lag when pulled up to sit; may “slide through your hands” when lifted up under shoulders</td>
<td></td>
</tr>
<tr>
<td>• Shoulder depressors and extensors (lower trap and/or latissimus)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Shoulder abductors (deltoids)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Elbow extensors (triceps)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Transitional stage</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Weakness progresses in muscles listed above</td>
<td>• Must get line of gravity simultaneously in front of knee joint and behind and lateral to hip joint; see:</td>
<td>• Iliotibial band and tensor fascia lata</td>
</tr>
<tr>
<td>• Quadriceps weakness is key to gait deterioration</td>
<td>• Anterior pelvic tilt</td>
<td>• Hip flexors</td>
</tr>
<tr>
<td></td>
<td>• Increased posterior and lateral trunk lean during stance</td>
<td>• Hamstrings</td>
</tr>
<tr>
<td></td>
<td>• Increased lumbar lordosis</td>
<td>• Gastrocsoleus</td>
</tr>
<tr>
<td></td>
<td>• Diminished hip extension in stance</td>
<td>• Posterior tibialis</td>
</tr>
<tr>
<td></td>
<td>• Base of support widens</td>
<td>• Plantar fascia</td>
</tr>
<tr>
<td></td>
<td>• For balance</td>
<td></td>
</tr>
<tr>
<td>• Ankle evertors (peroneals)</td>
<td>• Secondary to tight iliotibial bands</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Increased ankle plantarfexion and equinus positioning to give torque that opposes knee flexion, begin to see increased falling; get inversion with posterior tibialis relatively stronger; leads to unstable subtalar joint and more falling due to “twisting of the ankle,” although most falling is due to weakness in quadriceps and “knee buckling”</td>
<td></td>
</tr>
<tr>
<td><strong>Later stages</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Weakness continues to progress in muscles listed above and becomes profound</td>
<td>• Before loss of ambulation, most compensations are used to maintain an upright posture and facilitate ambulation</td>
<td>• Accelerated development of LE contractures</td>
</tr>
<tr>
<td>• UE weakness becomes more significant functionally and is imbalanced</td>
<td>• After loss of ambulation, compensatory movements are primarily used to do the following:</td>
<td>• Beginning development of UE contractures</td>
</tr>
<tr>
<td>• Elbow extension weaker than flexion</td>
<td>• Achieve support and stability in sitting</td>
<td>• Tightness into elbow flexion and pronation</td>
</tr>
<tr>
<td>• Forearm supination weaker than pronation</td>
<td>• Assist UE function</td>
<td>• Tightness in wrist and finger flexors and/or extensors, lumbricals, other intrinsic hand musculature</td>
</tr>
<tr>
<td>• Wrist and finger extension weaker than flexion</td>
<td>• Compensatory movements include</td>
<td>• Increased potential for deformity, such as swan neck deformity</td>
</tr>
<tr>
<td></td>
<td>• Leaning for stability</td>
<td></td>
</tr>
</tbody>
</table>

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TABLE 1 Continued

<table>
<thead>
<tr>
<th>Weakness</th>
<th>Compensations</th>
<th>Risk of Tightness (2-joint muscles get tight first)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Distal hand function is relatively preserved at least in long flexors but may be functionally compromised by lack of proximal stability and/or scoliosis requiring use of hands for sitting stability</td>
<td>• Contralateral trunk leaning during UE function to substitute for shoulder girdle (deltoid) weakness in arm lifting</td>
<td>• Scoliosis: the development of scoliosis is a complication of the late or nonambulatory stage, with natural history changing (decreasing scoliosis) with steroids but still requiring conservative preventative management with optimal wheelchair seating system support</td>
</tr>
<tr>
<td>• Neck extensors, hamstrings, posterior tibialis are relatively spared until later in the disease</td>
<td>• Backward leaning and/or lurching to compensate for deltoid weakness in forward flexion and biceps weakness in elbow flexion</td>
<td>• Hypoextensibility in cervical (neck) spinal extensors and rotator</td>
</tr>
</tbody>
</table>

With weakness and compensation, there is often no way to eliminate a compensatory position or pattern of movement without eliminating the function (ambulation and UE function), but intervention is used to prevent contractures that result from compensations, allowing compensations to be used to optimize function without leading to contracture that contributes to the self-perpetuating evolution of weakness, contracture, and/or functional loss that characterize DMD. Understanding the pathokinesiology below is required for optimal management.1

TABLE 2 Muscles and Structures Requiring Preventive Stretching

<table>
<thead>
<tr>
<th>LEs</th>
<th>UEs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stretching into isolated hip extension</td>
<td>Elbow flexors</td>
</tr>
<tr>
<td>Stretching into isolated knee extension</td>
<td>Forearm pronators</td>
</tr>
<tr>
<td>Hip flexors</td>
<td>Long wrist and finger flexors</td>
</tr>
<tr>
<td>Iliotibial bands</td>
<td>Finger extensors</td>
</tr>
<tr>
<td>Hamstrings</td>
<td>Lumbricals</td>
</tr>
<tr>
<td>Plantar flexors (with knee flexed and extended)</td>
<td>Thumb adductors</td>
</tr>
<tr>
<td>Posterior tibialis</td>
<td>Palm musculature</td>
</tr>
<tr>
<td>Plantar fascia</td>
<td>Shoulder musculature</td>
</tr>
<tr>
<td>Toe flexors</td>
<td>Other</td>
</tr>
<tr>
<td>Neck extensors</td>
<td>Rib cage mobility and expansion</td>
</tr>
<tr>
<td>Any other structures identified by assessment</td>
<td></td>
</tr>
</tbody>
</table>

contracture and deformity and should be a component of care at all stages.1-3,7,9,20-22,24-31 Joint contractures and diminished muscle extensibility in DMD result from interacting factors, including a lack of full active joint ROM, static positioning, and imbalanced muscle weakness across joints.2 Fibrotic changes in the muscle begin with early fibrosis in the newborn period, revealing the importance of early preventive management of muscle flexibility and extensibility.3,13-16,20-22,24-31,85,86,100,109 Effective maintenance of joint ROM, muscle extensibility, and prevention of contracture and deformity requires multiple coordinated interventions, including active and/or active-assisted elongation; daily passive stretching of joints, muscles, and soft tissues at risk for tightness and those identified via assessment; prolonged elongation; and support of optimal positioning throughout the day with splinting, orthotic intervention, standing devices, custom seating in mobility devices, and adaptive equipment.1-3,7-13,15,16,20-22,24-31,33,110-112

PT and OT Interventions for Musculoskeletal Management

Stretching to prevent and minimize contractures should be done a minimum of 4 to 6 days per week for joints and muscle groups known to be at risk for hypoextensibility and those identified via assessment (Tables 1 and 2).2 When stretching, providers should include manual therapy techniques, avoid the elicitation of pain, and establish a preventative stretching program before decreases in passive ROM occur, with direct PT and OT accompanied by support of optimal positioning and the use of splinting and orthotic intervention, custom seating systems, supported standing, and adaptive equipment. Preventive stretching of lower extremities (LEs) should be initiated early in the ambulatory phase and continued through adulthood. Preventive stretching of upper extremities (UEs) and the neck becomes increasingly important in nonambulatory stages and throughout adulthood. Increased risk areas for contracture and deformity in adults with DMD (Tables 1 and 2) necessitate detailed assessment and intervention over time. The maintenance of chest wall mobility is important in respiratory management and the prevention of scoliosis. Local care should be augmented by guidance from specialists every 4 to 6 months.1,3,7,8,11-13,15,16,20-22,24-31,33,110
Orthotic Intervention and Adaptive Equipment for Musculoskeletal Management

The prevention of contractures and deformity requires preventive splinting and orthotic intervention, positioning, supported standing programs, and the use of adaptive equipment and assistive technology in addition to manual stretching programs (see Supplemental Figs 2–11) (Tables 4 and 5). 1–3,7,8,13,15,16,20–22,24–31,108

Pain prevention and management
Pain prevention and comprehensive management, as needed, throughout life

Orthoses

Resting or stretching ankle-foot orthoses (AFOs) are necessary, with nighttime use having been shown to prevent and minimize progressive...
plantarflexion contractures, and are appropriate throughout life.2,3,7,11,13,18,24,28–31,109,113 AFOs should be custom molded, fabricated for comfort and optimum foot-ankle alignment. They are typically best tolerated if started preventively at young ages. Blanket lifter bars may ease bed mobility, increasing tolerance of nighttime AFO use. If nighttime tolerance cannot be achieved, the use of stretching AFOs during nonambulatory portions of the day is encouraged. Daytime AFO use can be appropriate for full-time wheelchair users, extending into adulthood. Lower-profile orthoses may be considered for full-time wheelchair users to control planar varus if adequate medial-lateral positioning is maintained and adequate dorsiflexion is supported by wheelchair footrests. Knee-ankle-foot orthoses (KAFOs) (eg, long leg braces or calipers) for supported standing, limited ambulation for therapeutic purposes, and the prevention of contracture and deformity in late-ambulatory and early nonambulatory stages11,13,20,21,27,28,44–56 are evolving and may not be tolerated at night.13 Adjustable knee extension splints can be considered for assistance in maintaining knee extension range in nonambulatory individuals. Comfortable support of neutral LE positioning in bed helps minimize contracture. The use of resting hand splints, stretching gloves, and oval-8 finger splints is appropriate, continuing into adulthood for stabilization, support, and musculoskeletal management. (Supplemental Fig 2).

**Standing Devices**

Supported standing devices for individuals with no or mild LE contractures are necessary for late-ambulatory and early nonambulatory stages, including standers and stand-and-drive motorized wheelchairs, extending...
Supported standing for prolonged passive elongation of LE musculature should be considered when standing and walking in good alignment become difficult. The importance of initiating the preventive use of supported standing before the development of contractures should be emphasized. Many advocate for the continued use of supported standing devices and a powered stand-and-drive motorized wheelchair into late-nonambulatory stages and throughout adulthood if contractures do not limit positioning and if devices are tolerated. Motorized stand-and-drive wheelchairs obviate the need for transfers to use supported standing, decreasing the risk of falls and increasing the number of hours per day of functional, comfortable, supported standing (Supplemental Fig 5).

**Serial Casting**

Serial casting can be considered when stretching and orthotic use have not maintained adequate ROM and/or when surgery is not preferred or chosen. Serial casting for ambulatory individuals is used only if ambulation remains possible while casted with sufficient quadriiceps strength to avoid compromising ambulation and losing function. In nonambulatory individuals, the risk of functional loss is less, but cast weight may compromise transfers, necessitating lift use, and may be contraindicated with severe contractures. Skin integrity and osteoporosis must also be considered. An experienced team is required for the successful use of serial casting.

**KAFOS**

The prolongation of ambulation for 2 to 4 years has historically been reported with KAFOS, with or without accompanying LE surgery, and associated with decreases in scoliosis and LE contracture, although with contextual qualifications, including individual, family, and team preferences, and greater success with experienced teams and in the absence of obesity. Individuals with DMD, who are now walking longer with glucocorticoids even without KAFOS, have differing height and body configurations at ambulation loss (decreased height, increased BMI, and increased relative hip abduction and/or external rotation versus spinal extension). These differences present challenges in wearing KAFOS, including an increased risk of fracture as a result of a higher risk of falls. Moreover, technological options, including increasingly routine use of stand-and-drive motorized wheelchairs, may be more common than KAFOS to maintain supported standing mobility. However, reports of KAFO use with glucocorticoids prolonging ambulation to even older ages, family satisfaction in spite of challenges, and situations in which KAFOS are the only means of supported standing suggest that KAFOS continue to be an appropriate option in some contexts. Rapidly advancing technology in robotics offers potentially improved future options. KAFO use should be viewed as therapeutic rather than functional, with care taken to support safety to minimize the risk of falls, and not used exclusive of motorized mobility, which is typically provided simultaneously or earlier for safe, optimal, functional independence; mobility; and participation in all settings.

**Falls and Fracture Prevention and Management**

Physical therapist collaboration with those in orthopedics to prevent falls and fractures and maintain or regain ambulation after a long bone fracture is increasingly emphasized. Extended ambulatory capacity, coupled with the risk of low-trauma fractures, increases the importance of fall prevention, including fall risk assessment across settings, pool shoes for fall prevention when walking on slippery surfaces, and the early use of lift and/or transfer equipment, especially in bathrooms, where transfer challenges compromise safety. Rapid appropriate team management of long bone fractures with associated rehabilitation is essential and may include the temporary use of assistive devices and other types of

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**TABLE 4** Orthotic Intervention, Splints, and/or Adaptive Equipment for Stretching

<table>
<thead>
<tr>
<th><strong>AFOs for stretching</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Modified leaf-spring AFOs (lighter weight, less cumbersome, allow for some movement) for use at night or during daytime periods when not walking</td>
</tr>
<tr>
<td>• Articulating AFOs may offer more movement for increased tolerance at night, but can be bulkier</td>
</tr>
<tr>
<td>• Adjustable-angle AFOs to try to gain increased range (a little bulkier) for use at night or during daytime periods when not walking</td>
</tr>
<tr>
<td>• Modular (3-piece) AFOs for use in combinations of night use and/or daytime use in nonambulatory stages</td>
</tr>
</tbody>
</table>

- **Ankle height (supramalleolar during the day to maintain medial-lateral alignment if 90° maintained by footrest)**
- **Taller AFO component to prevent plantar flexor tightness; may be rigid, flexible, or articulating (hinged) depending on need, tolerance, and preference**
- **Inner liner for comfort (can be important in any AFO)**
- **Knee extension splints**
- **KAFOS (or “long leg braces”)**
- **Stander and/or stand-and-drive motorized wheelchair**
- **Hand and/or wrist splints to maintain length in long wrist and finger flexors**
- **Stretching gloves to maintain length in finger extensors**
- **Oval-8 finger splints to prevent hyperextension at proximal interphalangeal joint**

See also Supplemental Figs 2–11.
TABLE 5 Seating System, Power-Positioning Components, and Functional Components for Motorized Wheelchairs

<table>
<thead>
<tr>
<th>Components</th>
<th>Purpose and Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seating System Components</td>
<td>To prevent pelvic asymmetry and obliquity; support a midline-level pelvic position to provide a level base of support in sitting for support of spinal symmetry, maintain symmetry of weight-bearing through ischial tuberosities for maintenance of skin integrity, and prevent pain</td>
</tr>
<tr>
<td>• Solid seat with hip guides</td>
<td>For pressure relief, maintenance of skin integrity, prevention of pain, and to maximize sitting endurance over time while maintaining a level pelvis</td>
</tr>
<tr>
<td>• Pressure-relief cushion with adequate stability</td>
<td>To maintain support at midline and maintain a midline, symmetrical, extended spinal alignment to prevent or minimize the development of scoliosis</td>
</tr>
<tr>
<td>• Solid planar back with rigid lateral trunk supports</td>
<td>To support knees at midline and prevent positioning in excessive hip abduction and external rotation that leads to iliobibial band tightness; swing away, removable, and/or flip down to allow easier urinal use</td>
</tr>
<tr>
<td>• Adductors</td>
<td>To maintain hand on joystick when driving, especially during power tilt and recline</td>
</tr>
<tr>
<td>• Elbow supports</td>
<td>For safety and support of hand control</td>
</tr>
<tr>
<td>• Headrest</td>
<td>To maintain midline head position and safety in the presence of decreased neck strength, decrease neck fatigue, and prevent neck pain</td>
</tr>
<tr>
<td>• Facial components on headrest (swing away)</td>
<td>Can be added to hip guides, trunk supports, adductors, arm rests, elbow supports, and headrest for pressure relief, maintenance of skin integrity, and tolerance of support</td>
</tr>
<tr>
<td>• Gel overlays</td>
<td>Access to support smartphone and tablets</td>
</tr>
<tr>
<td>• Mounts for smartphones and tablets</td>
<td>For safety and support of pelvic alignment</td>
</tr>
<tr>
<td>• Padded seatbelt</td>
<td>For functional access to the environment and to increase safety in transfers between surfaces</td>
</tr>
<tr>
<td>Power-positioning components</td>
<td>To provide weight shift for the redistribution of pressure for pressure relief to maintain skin integrity (especially important if unable to shift weight independently); to allow resting intermittently to maximize functional endurance throughout the day</td>
</tr>
<tr>
<td>• Power tilt</td>
<td>To provide weight shift for the redistribution of pressure for pressure relief to maintain skin integrity, provide elongation of hip flexors for prevention and/or minimization of progressive hip flexor contractures, and allow resting intermittently to maximize functional endurance throughout the day</td>
</tr>
<tr>
<td>• Power recline</td>
<td>To maintain optimal positioning of seating system components, especially trunk supports, during position change with power-positioning components</td>
</tr>
<tr>
<td>• Power sliding (antishear) back</td>
<td>For functional access to the environment and to increase safety in transfers between surfaces</td>
</tr>
<tr>
<td>• Power-adjustable seat height</td>
<td>For elongation of hamstrings and assistance in preventing and/or minimizing progression of knee flexion contractures</td>
</tr>
<tr>
<td>• Separately elevating power-elevating leg rests</td>
<td>To provide independent, supported standing intermittently throughout the day in optimal LE alignment with greater duration of standing than a separate stander can provide; minimize LE contracture and deformity; promote bone density, strength, and integrity and minimize the development of osteoporosis; provide support of function and/or ADL that are not possible in sitting; minimize risk of falls during supported standing by obviating the need for transfers to provide supported standing; and provide vibration during weight-bearing while driving in supported standing for increased bone density</td>
</tr>
<tr>
<td>• Power stand and drive</td>
<td>To provide elongation of hamstrings and assistance in preventing and/or minimizing progression of knee flexion contractures</td>
</tr>
<tr>
<td>Functional components</td>
<td>To provide weight shift for the redistribution of pressure for pressure relief to maintain skin integrity, provide elongation of hip flexors for prevention and/or minimization of progressive hip flexor contractures, and allow resting intermittently to maximize functional endurance throughout the day</td>
</tr>
<tr>
<td>• Tray</td>
<td>For UE support and function</td>
</tr>
<tr>
<td>• Swing-away and/or retractable joystick</td>
<td>Access</td>
</tr>
<tr>
<td>• USB charger</td>
<td>For phone access for safety</td>
</tr>
<tr>
<td>• Lights and blinkers</td>
<td>For safety in community mobility for participation</td>
</tr>
<tr>
<td>• Group 4 base with high-speed package</td>
<td>Needed for safety on all terrain and crossing streets safely in community mobility</td>
</tr>
<tr>
<td>• Bluetooth and infrared capabilities</td>
<td>For access and safety in environmental control and communication</td>
</tr>
<tr>
<td>• Separate flip-up or swing-away footrests</td>
<td>Can be needed for safety in transfers</td>
</tr>
<tr>
<td>• Aggressive tread-on tires</td>
<td>For safety and function on all terrains</td>
</tr>
</tbody>
</table>

See also Supplemental Figs 2–11. USB, Universal Serial Bus.

Exercise and Activity Levels

Physical therapists prescribe, monitor, and guide exercise in DMD on the basis of understanding potential effects of activity and exercise on dystrophin-deficient muscle. Concern about exercise hardening the progression of weakness in DMD is longstanding based on pathophysiology, including the risks of contraction-induced muscle injury and exercise-induced structural damage related to strength, the duration of contraction, and the load imposed. Other concerns include nitric oxide synthase dysfunction leading to increased ischemia during exercise and cardiac concerns, including a lack of correlation between skeletal and cardiac muscle involvement.

Learning, Attentional, and Sensory Processing Issues

OT is important for early assessment and intervention for learning, attentional, and sensory processing issues, which are increasingly understood as being important in DMD (Table 6).
overexertion and overwork. Rests, and the avoidance of activity, support of self-initiated moderation, lower-duration is higher, with an emphasis on the disease, when residual strength some, especially early in the course of based activity, is recommended by aquatics, cycling, and safe recreation-aerobic functional activity, such as Participation in regular, gentle defiently known.7, regarding the optimal type, frequency, effects of muscle activity are not fully understood. Certain amounts of muscle activity are assumed to be beneficial in preventing disuse atrophy, maintaining residual strength, providing or maintaining potential trophic influences of active movement, and maintaining functional status and flexibility.2,3,128,129,132,134 but eccentric muscle activity and maximal- or high-resistance exercise are believed to be detrimental2,3,123–126,128,132–134 and inappropriate across the life span because of potential contraction-induced muscle-fiber injury. Specifics regarding the optimal type, frequency, and intensity of exercise in DMD are not definitively known.7,22,33,74,116–136,139 Participation in regular, gentle aerobic functional activity, such as aquatics, cycling, and safe recreation-based activity, is recommended by some, especially early in the course of the disease, when residual strength is higher, with an emphasis on moderation, lower-duration activity, support of self-initiated rests, and the avoidance of overexertion and overwork weakness.2,3,7,4,116–136,139 Aquatics, with potential benefits for aerobic-conditioning respiratory exercise and support of gravity-minimized movement, is highly recommended for the early ambulatory through nonambulatory stages and into adulthood as long as it is medically safe.2,3,128,132,134 Cycling is recommended as a submaximal aerobic form of activity, with benefits of assisted cycling recently reported (Supplemental Fig 3).141 Fibrosis (beginning in the newborn period, before extensive cell necrosis),109 the proliferation of connective tissue, and increased stiffness, increases loads (resistance) against which muscles must work, further taxing contractile units and potentially contributing to ischemia and vascular and structural impediments to regeneration. The role of active movement, positive or negative, on the fibrotic process and vascularity is not clear.

Individualized assessment and monitoring of activity levels is important. Significant muscle pain or myoglobinuria in the 24-hour period after a specific activity is a sign of overexertion and contraction-induced injury, and if it occurs, the activity should be modified.2 Cardiac concerns regarding exercise include cardiomyopathy and/or arrhythmias,2,4,34–36,139,142 abnormalities of calcium regulation,34 and cardiac wall movement34; fibrosis34; fatty infiltration34; and conduction abnormalities.138 These typically progress to dilated cardiomyopathy with arrhythmias, including ventricular tachycardia.24 Early cardiac involvement can be present even before overt clinical manifestations.139 Symptoms may not present until cardiac involvement is more advanced because of limited physical activity and a lack of correlation between cardiac and skeletal muscle involvement.3,132,134,139 supporting caution in prescribing exercise for individuals with dystrophinopathies, who appear likely to have a reduced exercise capacity even when functioning well. Individuals with DMD should have early referral to cardiology for the identification and preventive management of cardiomyopathy.2,4,34–36,57,142

### Assistive and/or Adaptive Devices for Function

AFOs are not typically indicated for use during ambulation because they tend to limit the compensatory movements needed for efficient ambulation, add weight that can compromise ambulation, and make it difficult to rise from the floor and climb stairs.2,143 During the late-ambulatory stage, KAFOs with locked knees can prolong ambulation but with use decreased, as described.

During the early ambulatory stage, lightweight manual mobility devices are appropriate for pushing the child on occasions when long-distance mobility demands exceed endurance. In the late-ambulatory stage and/or early nonambulatory stages, an ultralightweight manual wheelchair with custom seating (Table 5) to support spinal symmetry and LE alignment and swing-away footrests is necessary and may be used in situations without access or transport for motorized mobility. A variety of motorized mobility devices, including standing mobility devices, may be used intermittently for energy conservation and independent long-distance mobility by individuals who continue to walk (Supplemental Figs 2–11).

As functional community ambulation becomes more difficult, a motorized wheelchair is advocated. Custom seating and power-positioning components for the initial motorized wheelchair are important standards of care (Table 5), with power stand-and-drive having been shown to be used more successfully if initiated before the development of contracture and deformity.112 Custom seating for safety, support of

**TABLE 6 Areas for Specialized OT Assessment and Intervention**

<table>
<thead>
<tr>
<th>Area</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning differences (specific differences in DMD are increasingly identified, including differences between verbal and performance IQ and differences in verbal memory, dyslexia, dyscalculia, and dysgraphia)</td>
<td></td>
</tr>
<tr>
<td>Attentional issues</td>
<td></td>
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<tr>
<td>Sensory processing issues</td>
<td></td>
</tr>
<tr>
<td>Fine motor</td>
<td></td>
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<tr>
<td>ADL</td>
<td></td>
</tr>
<tr>
<td>Computer access</td>
<td></td>
</tr>
<tr>
<td>Assistive technology</td>
<td></td>
</tr>
<tr>
<td>Swallowing and oral motor dysfunction</td>
<td></td>
</tr>
<tr>
<td>Planning for academics and vocation in transition to adulthood</td>
<td></td>
</tr>
</tbody>
</table>

with moderately to severely reduced exercise capacity, as measured by cardiopulmonary exercise testing, even in the presence of normal or mildly impaired gross motor function and capacity.139,140 The balance between beneficial versus harmful effects of muscle activity are not fully understood. Certain amounts of muscle activity are assumed to be beneficial in preventing disuse atrophy, maintaining residual strength, providing or maintaining potential trophic influences of active movement, and maintaining functional status and flexibility.2,3,128,129,132,134 but eccentric muscle activity and maximal- or high-resistance exercise are believed to be detrimental2,3,123–126,128,132–134 and inappropriate across the life span because of potential contraction-induced muscle-fiber injury. Specifics regarding the optimal type, frequency, and intensity of exercise in DMD are not definitively known.7,22,33,74,116–136,139 Participation in regular, gentle aerobic functional activity, such as aquatics, cycling, and safe recreation-based activity, is recommended by some, especially early in the course of the disease, when residual strength is higher, with an emphasis on moderation, lower-duration activity, support of self-initiated rests, and the avoidance of overexertion and overwork weakness.2,3,7,4,116–136,139 Aquatics, with potential benefits for aerobic-conditioning respiratory exercise and support of gravity-minimized movement, is highly recommended for the early ambulatory through nonambulatory stages and into adulthood as long as it is medically safe.2,3,128,132,134 Cycling is recommended as a submaximal aerobic form of activity, with benefits of assisted cycling recently reported (Supplemental Fig 3).141 Fibrosis (beginning in the newborn period, before extensive cell necrosis),109 the proliferation of connective tissue, and increased stiffness, increases loads (resistance) against which muscles must work, further taxing contractile units and potentially contributing to ischemia and vascular and structural impediments to regeneration. The role of active movement, positive or negative, on the fibrotic process and vascularity is not clear.

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optimal posture, and the prevention of contracture and deformity includes a solid seat with hip guides and a pressure relief cushion; a solid planar back with rigid lateral trunk supports; flip-down, swing-away, or removable knee adductors; and a headrest. Facial components on headrests may be needed in older individuals for adequate head support and symmetry. Swing-away or flip-up footrests facilitate transfers. Power-positioning components include power tilt and recline, power stand-and-drive, power-adjustable seat height, and separately elevating power-elevating leg rests. Elbow supports may be needed for UE support that keeps the hand on the joystick during position changes and on rough terrain. Retractable, swing-away joystick hardware and trays may be needed for access. Lights and blinkers are required for safety in evening community mobility. Ventilator holders are needed for those using ventilatory support (Supplemental Figs 2–11).

**Assistive Technology**

Referral to assistive technology (AT) specialists should be considered whenever function, independence, and participation are compromised, and is necessary when UE weakness affects reach, fine motor skills, and ADL. AT is helpful in optimizing fine motor skills, enhancing strategies for independence in ADL, and improving access to alternative computer, mobility, or environmental control (Table 7). Simple adaptations supporting UE function include elevated lap trays and/or desks, adaptive straws, a hands-free water pouch, and/or turntables if the hand cannot be brought to the mouth or if biceps strength is ≤3 in 5. More advanced AT options include motorized and nonmotorized mobile arm supports (considered at Brooke Upper Extremity Scale score ≥2), robotics, miniature-proportional joysticks, microswitches, Bluetooth capabilities, software and applications for computers, fall detection systems with built-in Global Positioning System detection, voice activation and texting systems on smartphones and tablets, and “smart home systems” that are able to interface with motorized wheelchairs. Key pinch, microswitches, mouth call buttons, and monitoring systems are considered if hand or voice weakness precludes the use of standard call buttons. Adaptive equipment for the support of ADL, safety, and the maintenance of skin integrity include power-adjustable beds with pressure-relieving mattresses; bathing and toileting equipment; lift and/or transfer devices, including hydraulic and motorized patient lifts; ceiling lifts (hoists); slide sheets; and environmental control options (Supplemental Figs 2–11).

AT assessment and intervention are focused on optimizing function and participation across the life span, which are particularly important during transitions between functional levels and transitioning into adulthood.

Extended ambulation, the importance of energy conservation for muscle preservation and function, and increased independence into adulthood require expanded technology for mobility, a greater variety of choices for different situations, and increased AT options for mobility, driving, and community access that are instrumental in participation, employment, and avoidance of social isolation. Vehicle adaptations increase options for community access, and adapted controls may allow for independent vehicle driving. Skill development via accessible public transportation, OT driving evaluation, and future driverless cars promise ongoing increases in independence.

The early development of independent decision-making and respectful and responsible delegation skills in children with DMD, supported by the use of AT, self-advocacy skills, the hiring and directing of aides, the use of service animals, and social participation foster transitions to independent adult function.

Funding for the support of AT and support services is critical, as is the education of families about funding opportunities, including private insurance, Medicaid, Medicaid Waiver programs, Medicare, Independent Living, Vocational Rehabilitation, Supplemental Security Income, Achieving a Better Life Experience accounts, and other funding sources, which vary depending on the country, state, and local environment.

**Pain Management**

Pain, which is considered the fifth vital sign, is important to assess in all individuals with DMD across the life span.72–73 A more uniform assessment of pain, however, does not always lead to successful management of pain, which is an important priority in transitions to adulthood and the management of DMD in adulthood.72 Pain of varying types and intensities may occur in DMD. Effective pain management requires an accurate determination of the cause and may require comprehensive team management. Postural correction, orthotic intervention, PT, adaptive equipment, assistive technology, and pharmacological interventions may all be required. Adaptive equipment and assistive technology should be used to emphasize the prevention and management of pain and optimize comfortable function and movement with transfer, bathing,
and toileting equipment. Power-positioning components offering positional support and change, weight shift, and pressure relief on motorized wheelchairs and beds can be used as needed to maintain skin integrity and pain prevention or relief. Providers of pharmacological interventions must consider possible interactions with other medications (eg, steroids and nonsteroidal anti-inflammatory drugs) and side effects, particularly those that might negatively affect cardiac or respiratory function. Rarely, orthopedic intervention might be indicated for intractable pain that is amenable to surgery. Back pain, especially if the patient is receiving glucocorticoids, is an indication for careful assessment for vertebral fractures.1–4,144,145

KEY ANTICIPATORY DISCUSSIONS FOR REHABILITATION

Key anticipatory discussions should occur before a time of crisis in each of the following areas. Care team members can reassure the patient and family that rather than being evidence of disease progression, these issues provide opportunities to discuss options for optimizing management:

- plans for when stairclimbing becomes difficult;
- continuum of options for energy conservation and safe, functional, independent mobility and participation in all settings;
- fall risk assessment and prevention;
- fracture management;
- initiating supported standing;
- transfers and/or access at home, at school, at work, and in the community;
- consideration of KAFO use;
- spine surgery;

### TABLE 7 Adaptive Equipment and Assistive Technology

<table>
<thead>
<tr>
<th>Equipment and Technology</th>
<th>Purpose and Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Adapted and/or assisted cycling; adapted tricycles (with stand for indoor use in inclement weather); power-assisted bicycles and/or tricycles; free-standing (stationary) power-assisted cycling</td>
<td>To provide supported submaximal activity and movement in UE and LE cycling.</td>
</tr>
<tr>
<td>• Lifts</td>
<td>For safe functional transfers in all settings, may need &gt;1 piece of equipment for different settings.</td>
</tr>
<tr>
<td>• Stand-and-raise lifts: manual or motorized</td>
<td>Require reasonably good ankle ROM and tolerance of supported weight-bearing. Allow easier clean-up and clothing adjustment after toileting.</td>
</tr>
<tr>
<td>• Free-standing lift: motorized versus hydraulic with crank; can be portable</td>
<td>Portable and motorized offer most options for safe functional transfers in numerous settings, free standing lifts do not provide transfer into tub or to surface if cannot get legs of lift under object to which being transferred.</td>
</tr>
<tr>
<td>• Ceiling lifts</td>
<td>Do not take up any floor space, can be used throughout house and between rooms; can transfer down into tub and out.</td>
</tr>
<tr>
<td>• Wall-mounted lifts</td>
<td>Do not take up floor space; may be used if cannot use ceiling mount.</td>
</tr>
<tr>
<td>• Bath, shower, and/or commode chairs</td>
<td>If ceiling does not accommodate ceiling-mounted lift.</td>
</tr>
<tr>
<td>• Tub benches padded with back support</td>
<td>For safe support during bathing, tub and/or shower transfers, hygiene; typically used with handheld shower.</td>
</tr>
<tr>
<td>• Hydraulic bath seats that descend into water</td>
<td>Can go in tub.</td>
</tr>
<tr>
<td>• Slide bath chairs</td>
<td>Can go in tub; descend into water for soaking, may be useful before stretching.</td>
</tr>
<tr>
<td>• Roll-in shower chairs with tilt and seating system support</td>
<td>Can go in tub; provides mechanical sliding transfer.</td>
</tr>
<tr>
<td>• Modified toilets: height, armrests, lift, and bidet</td>
<td>Roll-in shower required.</td>
</tr>
<tr>
<td>• Modified motorized beds, pressure-relieving mattresses, lateral rotation mattresses and/or beds for position change and weight shift throughout the night</td>
<td>Safety, hygiene.</td>
</tr>
<tr>
<td>• Ceilings</td>
<td>Pressure relief, maintenance of skin integrity, function, prevention and/or minimization of pain.</td>
</tr>
<tr>
<td>• Stair lifts</td>
<td>Access, safety, energy conservation, protection of muscle.</td>
</tr>
<tr>
<td>• Platform and/or porch lifts</td>
<td>Access, safety, energy conservation, protection of muscles.</td>
</tr>
<tr>
<td>• Ramps: fixed, modular, portable, foldable, and threshold</td>
<td>Access, safety, energy conservation, protection of muscles.</td>
</tr>
<tr>
<td>• Modified vehicles with lifts, adapted controls</td>
<td>Access, safe transport, participation, independent driving.</td>
</tr>
<tr>
<td>• Adapted sports equipment</td>
<td>Safety, activity, participation.</td>
</tr>
<tr>
<td>• Smart home systems, Bluetooth, infrared</td>
<td>Environmental control, safety, independence.</td>
</tr>
<tr>
<td>• Evacuation chairs for school and/or work fire evacuation</td>
<td>Safety, access.</td>
</tr>
<tr>
<td>• Fine motor and communication: pencil grips, ergonomic pens and pencils; “smart” pens, phones, tablets; computer adaptations, access; voice activation systems, call buttons; eye gaze systems</td>
<td>Continuum of support in the presence of weakness, to decrease fatigue, increase efficiency of function and support independence.</td>
</tr>
<tr>
<td>• Mobile arm supports</td>
<td>Continuum of support in the presence of weakness, to decrease fatigue, increase efficiency of function and support independence.</td>
</tr>
<tr>
<td>• Robotics</td>
<td>Continuum of support in the presence of weakness, to decrease fatigue, increase efficiency of function and support independence.</td>
</tr>
</tbody>
</table>

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- initiating supported standing;
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- consideration of KAFO use;
- spine surgery;
CONCLUSIONS
As disease-modifying treatments become available, questions will emerge regarding potential increases in exercise capacity and muscle recovery, optimizing potential benefit versus damage from specific types, durations, and frequency of exercise. Robotics and AT advances are anticipated to provide ever increasing functional independence, capacity for participation, and successful musculoskeletal management, and it will be important to explore ways that these developments can be used to benefit individuals with DMD.

ABBREVIATIONS
ADL: activities of daily living
AFO: ankle-foot orthosis
AT: assistive technology
DMD: Duchenne muscular dystrophy
KAFO: knee-ankle-foot orthosis
LE: lower extremity
OT: occupational therapy
PT: physical therapy
ROM: ranges of motion
UE: upper extremity

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