

A Transition Toolkit for Duchenne Muscular Dystrophy

Christina J. Trout, MSN,^a Laura E. Case, PT, DPT, MS, PCS, C/NDT,^b Paula R. Clemens, MD,^c Alexandra McArthur, BA,^d Garey Noritz, MD,^{e,f} Marie Ritzo, MSW, LCSW,^g Kathryn R. Wagner, MD, PhD,^{h,i} Elizabeth Vroom, DDS,^j Annie Kennedy, BS^k

abstract The care of individuals with Duchenne muscular dystrophy (DMD) now extends into adulthood. Childhood to adulthood transition planning is an important aspect of care, affecting health outcomes as well as other important aspects of adult life. In this article, we address transition planning as it relates to DMD health care, education, steps toward vocations, personal care, accessing the home and community, and the importance of relationships with others. Because of the complex, disabling, and progressive nature of DMD, coordinated, well-timed planning is critical to ensure that all components of transition are accomplished. In this article, we introduce the DMD Transition Toolkit. The toolkit is designed to help assess readiness for transition, track progress toward transition goals, and provide a template for documenting key elements of medical care, medical equipment, and services. The transition readiness assessment for young adults with DMD is used to gauge readiness for adult health care and living practices. Consistent with the 2018 DMD Care Considerations, the transition checklist for young adults with DMD is a comprehensive list to be considered, discussed, and planned for during transition. The medical summary for young adults with DMD can be used by a provider or individuals with DMD to communicate details of their health plan, provider contacts, and medical equipment needs. It can be used in transition handoffs, when adding new providers, or when informing new nursing agencies or personal care attendants. It could also be useful in urgent care settings by providing baseline information about the individual with DMD.

Improvements in care and the emergence of disease-modifying treatments are prolonging the lives of individuals with Duchenne muscular dystrophy (DMD), resulting in an unprecedented need for strategies to help them accomplish a successful transition into adulthood. These individuals seek independence and want to achieve their adult life goals. However, they are at risk for experiencing difficulties in navigating the complex health care systems necessary to support them, if proper



^aDivision of Child Neurology, Department of Pediatrics, University of Iowa, Iowa City, Iowa; ^bDoctor of Physical Therapy Division, Department of Orthopedics, School of Medicine, Duke University, Durham, North Carolina; ^cDepartment of Neurology, University of Pittsburgh School of Medicine and Neurology Division, Department of Veterans Affairs Medical Center, Pittsburgh, Pennsylvania; ^dNorth Carolina Council on Developmental Disabilities, Raleigh, North Carolina; ^eDepartment of Pediatrics, Nationwide Children's Hospital, Columbus, Ohio; ^fDepartment of Pediatrics, The Ohio State University, Columbus, Ohio; ^gDepartment of Family Services/Clinical Social Work, Children's National Medical Center, Washington, District of Columbia; ^hKennedy Krieger Institute, Baltimore, Maryland; ⁱSchool of Medicine, Johns Hopkins University, Baltimore, Maryland; ^jDuchenne Parent Project Netherlands, Amsterdam, Netherlands; and ^kParent Project Muscular Dystrophy, Hackensack, New Jersey

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guidance is not provided. Challenges in transitioning to adult living also relate to their physical reliance on others for activities of daily living (ADLs), for which funding and other critical resources may be limited. In addition, individuals with DMD may experience psychosocial impediments or neurocognitive impairments that create barriers to full participation in future planning or hinder their personal potential. Despite these challenges, improved health management, effective support systems, and societal acceptance can allow young people with DMD to have high expectations and gain desired levels of independence and achievement.

Recommendations for the medical and psychosocial management of DMD were addressed by the Centers for Disease Control and Prevention Care Considerations in 2010.^{1,2} However, these recommendations did not provide specific guidance on the transition to adult living. Transition for individuals with DMD was added to the 2018 DMD Care Considerations, and the updated core recommendations outline the importance of addressing the common physical and psychosocial elements of planning for the future.³ This article is intended to describe those areas in greater detail and provide a DMD transitions toolkit for individuals with DMD and their providers, families, and educators.

This article and the accompanying DMD transitions toolkit (a 3-component toolkit that consists of a transition readiness assessment form, a transition checklist, and a medical summary form; see the Supplemental Materials) are based on a review of the published literature on transition strategies designed to guide and support youth with and without disabilities in establishing adult health care practices and on a review of DMD-related literature on gaps in services and the extent of unmet needs.^{4–12}

For a detailed overview of transitions topics, visit the Got Transitions Web site at <http://www.gottransition.org/resources/index.cfm>.

COMPONENTS OF SUCCESSFUL TRANSITION

Transition Planning

Successful transition to adult life requires careful and ongoing planning. Transition planning is a process, not a single event, and should begin when the individual with DMD is age 13 or 14 years old.⁷ However, the idea of planning for the future and forming personal expectations should begin even earlier, despite the presence of health concerns and other uncertainties. Children with DMD benefit from discussing such topics as their future careers and aspirations, the importance of personal relationships, the rewards of contributing to society, and the need to form and pursue a set of personal goals. In adolescence, these concepts become more tangible, and their realization requires planning and support just as for adolescents without disabilities. Health care providers and educators are among the best facilitators for discussions about health, education, employment, social development, and adult living. The youth with DMD should be a direct participant in these discussions.

The intention to provide transition services may be abandoned because of busy day-to-day schedules or when medical crises inevitably occur. However, addressing transition planning as a continual process throughout the adolescent years will help maintain a sense of forward momentum. One strategy for accomplishing this is to set aside a short period of time for transition planning at each clinic visit. This is also an opportunity to review larger goals and to celebrate any successes or achievements.

The DMD transition toolkit includes an assessment of readiness (Supplemental Material 1) modeled after the Got Transition Sample Transition Readiness Assessment for Youth tool.⁵ This form is designed to help determine the readiness of individuals with DMD to manage their own health care and consider the competencies needed for successful adult health care management.

Care Coordination

Adolescents with DMD will likely have a team of health care providers, as well as a team of educators and support staff while at school. Individuals within this team should be designated to lead discussions and ensure that all aspects of the transition process are explored and implemented. A care coordinator, along with a social worker, can provide anticipatory guidance for future planning and monitor the youth's progress toward transition goals. Coordinators can be a resource for a multitude of questions, facilitate communication between providers and across settings (including community settings), help families navigate funding to cover expenses (eg, insurance, governmental agencies, and private resources), identify agencies to provide physical care, advocate for the student in the school, and ensure that medical information is conveyed to those involved in care. Coordinated efforts by members of the team are essential to ensure that care is not disjointed, opportunities are identified, essentials of the plan are pursued, and interventions are appropriately timed.^{13,14}

The 2018 DMD Care Considerations provide general guidance on transitions in health care, education and employment planning, housing, assistance with ADLs, transportation, and relationships with others (Fig 1).³ These topics are organized into a worksheet format in the DMD

transition checklist (Supplemental Material 2). In each specific area of transition planning, the care coordination team can evaluate the individual's needs for information, document progress, and determine readiness to move toward adult approaches to health care, educational planning, and greater independence and autonomy.

Health Care

Transition plans should support the continuity of care during the transition to adulthood. Pediatric providers should continue care until the individual is firmly established with adult providers. Those overseeing the transition process should ensure that adult care providers are identified for primary care and each subspecialty.¹⁵ As part of the referral to new providers, consent to exchange information must be obtained and facilitated. On the basis of the types, expertise, or availability of some providers, the individual with DMD may not transition from one provider to another for certain aspects of care.

As the youth with DMD matures, interactions with the health care team, whether with new or continuing providers, should evolve from family centered to patient centered as developmentally appropriate. Questions should be asked of the youth, with parents encouraged to take a more passive but supportive role. It is essential for adolescents to have time alone with at least some of their providers. This not only allows for privacy in asking and answering sensitive questions, but it also encourages youth to talk about their health on their own behalf. Providers need to be sure that information is presented in terms youth can understand, clarifying medical terms, diagnoses, medications, and therapies as needed. The Muscular Dystrophy Association Roadmap to Independence for Young Adults¹⁶

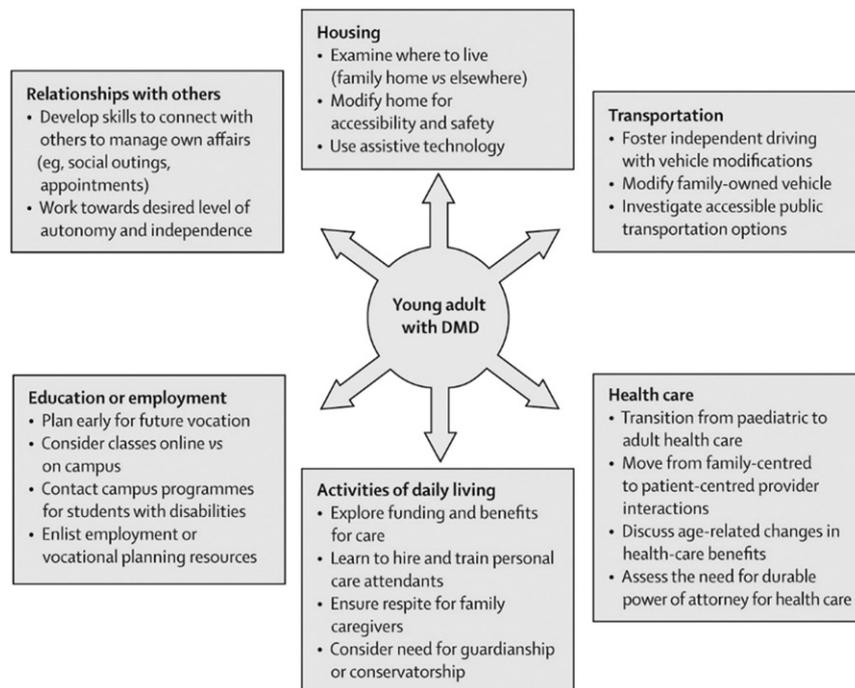


FIGURE 1

Components of young adulthood to be addressed during transition planning. This figure illustrates the 6 major issues of young adulthood to be addressed in transition planning. (Reprinted with permission from Birnkrant DJ, Bushby K, Bann CM, et al; DMD Care Considerations Working Group. Diagnosis and management of Duchenne muscular dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across the lifespan. *Lancet Neurol.* 2018;17[5]:7.)

is a tool designed to guide such discussions. By opening the door to discussion, anticipatory guidance can be shared about expected health care developments, allowing the youth and the family to prepare for financial, emotional, and caregiving changes.

Although adolescents with DMD can begin to assume more responsibility and independence for their health care, some transitioning youth may need parental support for an extended period of time. Asking parents for guidance and involvement is not a sign transition is failing; rather, it can be an insightful observation that family and close friends can provide helpful feedback and dialogue before a health care decision is made. Discussion about maturity and transition readiness can shed light on which areas of transition are revealing progress toward independence and which

areas need more practice. The DMD transition checklist (Supplemental Material 2) provides examples of activities that are geared toward helping youth become comfortable with adult health care practices, such as carrying identification, insurance, and urgent care information¹⁷ or maintaining appointments using smart phone applications.¹⁸

The commonly accepted age of maturity for adult decision-making is age 18 years old. However, many youth, particularly those with an intellectual disability, may need decision-making support, which might include having a health care power of attorney or a guardian or conservator. Neurocognitive testing done earlier in educational settings may not be sufficient to determine the level of support needed, and updated testing may be warranted. The medical social worker can assist in describing various levels

of support, making referrals to legal resources if needed, and explaining health care benefits that may change with age, including health insurance and access to government-funded programs, which, in the United States, include Medicaid, Medicaid Waiver programs, Medicare, independent living, and vocational rehabilitation. If care coordinators and social workers in the clinic are not able to address all aspects of benefits and estate planning, referrals should be made to help families identify and structure assisted living services in the least restrictive manner possible. These services include applying for social security disability, establishing an ABLÉ National Resource Center account¹⁹ or a special needs trust, protecting resources, and income planning. Got Transitions provides materials for clinicians and social workers to use in working with families on topics such as guardianship and decision-making.²⁰

In the 2018 DMD Care Considerations, providers are encouraged to engage in open discussion about prognosis and changes in health, both short- and long-term. Individuals and families often feel uncomfortable discussing goals of care or advanced planning because of the emotional strain of acknowledging life with DMD, or they may feel they do not have sufficient or correct information. Asking individuals with DMD to articulate what is important and how they view their quality of life can allow for medical plans to be developed consistent with the youth's own value system.

Not all adolescents and young adults with DMD will have the same health care needs at the same age, but all will need the same information about the expected course of DMD, including the loss of ambulation, risk of developing scoliosis, need for respiratory support, and changes in heart function. These developments, which can occur rather abruptly or

worsen gradually over time, pose threats to personal independence and good health. Anticipatory guidance allows families time to consider what may be needed for adaptation to changes in physical abilities or health. Additional assessment, support, or intervention services, such as palliative care, also can be considered.²¹

As young adults are introduced to new adult providers and services, a summary that compiles a diagnosis or problem list, recommended treatments from each subspecialist, medication and equipment lists, and a contact list in one global document may be useful. The DMD transition toolkit includes a medical summary for young adults with DMD used to communicate common clinical findings and guidance on the basis of the 2018 DMD Care Considerations (Supplemental Material 3). This tool may be helpful to other users as well (eg, to home care agencies arranging attendant or nursing services, to a student disability office at a college, or to emergency departments in which an urgent complication is evaluated).³ Incorporating this summary into electronic records with self-populating fields or creating a modifiable PDF form can ensure that the document is always up to date. A DMD care coordinator or medical social worker can help fill in pertinent details and ensure that the patient, family, and new providers or caregivers have the summary.

Assistance With ADLs

Providing health care and assistance with ADLs are intertwined and typically involve complex equipment for optimal care and independence. Just as health care benefits can change during the transitional period, funding for caregiving assistance and equipment also may change. Eligibility for benefits can vary on the basis of state, regional, or country policies; waiting lists can be long, and funding streams (whether public or

private) may be limited and variable. It is never too early for families to establish connections with services, supports, and resource navigators.

Individuals with DMD will need to learn to instruct others on how to provide help with ADLs. This activity begins with parents gradually empowering their children to make choices, direct their own care and assistance, and have control in their lives. At school and at home, the individual should be encouraged to direct school personnel and home caregivers in how to provide care and how to assist with preferred methods for transfers and ADLs. This will lead to confidence when it is time to hire and manage a personal care attendant independently as an adult.

Although family time together is important, it is also important that parents and other family members have time away from caregiving and that the young person with DMD experiences independence at home and in the community. This is often achieved through respite programs or agencies that provide attendant care or nursing care. Social workers and care coordinators can help families identify community agencies that provide these services and provide guidance on hiring and training independent personal care attendants. Most types of care can be provided by unlicensed but trained attendants, whereas other aspects of care, such as tracheostomy and ventilator care, meet the criteria of skilled nursing and require a licensed nurse.

Education and Employment Planning

As young people with DMD mature, they should be encouraged to identify their interests, talents, and the ways they would like to contribute to their community, with the expectation of a transition to successful adulthood. This sense of meaning and responsibility can begin in early childhood by including the child in household chores and self-care

activities and by asking the child, “What change do you want to make in the world?” Later, involvement in scouting, adaptive sports, volunteer opportunities within school and the community, and involvement in other organizations can cultivate leadership skills, provide work experience, and foster a sense of purpose. The DMD transition toolkit’s transition checklist (Supplemental Material 2) includes questions that youth can be asked about what they want to do and what supports they might need to accomplish their educational and vocational goals.

In typically developing children, their world expands and opportunities for growth emerge throughout adolescence, but the progressive nature of DMD often causes their world to shrink. Navigating poorly designed or inaccessible buildings and environments can hinder participation in social events and the community. The educational setting is the ideal environment for students with DMD to learn to use mobility supports and assistive technology (AT), which can help them overcome physical barriers and expand their access to the world.

Beginning at age 13 years, youth with DMD should be encouraged to participate in educational planning meetings. As students move through middle and high school, their annual educational plans should progressively involve occupational therapists, physical therapists, and AT professionals, who can recommend devices to support success in the academic and posteducational settings. Referrals should be facilitated to vocational rehabilitation centers for guidance and possible financial assistance if goals are work related.

Housing

Young people with DMD should be supported in pursuing their desired level of autonomy and independence

as they mature into adulthood. As decisions about college, vocational training, or employment are being made, housing becomes an important consideration, requiring substantial planning. Appropriate housing should be based on finances or funding, dependable personal care attendants, physical accessibility, and proximity to school, work, public transportation, and family and friends. In the United States, federal and state agencies, such as departments of human services, disability law or rights centers, the US Access Board, and civil or human rights commissions, have laws to support and protect the rights of people with disabilities to access appropriate housing. They also provide guidance for identifying and establishing independent living options and support efforts to protect and maximize the integration of persons with disabilities into the community.^{22–25} Centers for Independent Living, for example, are national networks of nonprofit agencies intended to direct individuals with disabilities to community-based independent living resources.²³ Some states also have AT loan programs, which can provide financing for home modifications.

For adults with DMD, one of the most critical components of independent living is the existence of a reliable caregiving network. Traditionally, young people with DMD receive the majority of their personal care from family caregivers. However, just as individuals with DMD grow older, so do their family caregivers (often beyond their ability to provide physical care). As the desire for independent living is met, the care paradigm shifts to caregivers, housing, and personal care models outside of the family. Some individuals with DMD marry and have families, whereas others opt for housing in apartments with roommates, on campus during college, or in community settings,

such as organized facilities or homes shared with others with DMD or similar conditions. Still, others choose to remain in their family home, but with caregiver support from outside of the family.

Regardless of where individuals with DMD choose to reside, their home should be assessed for accessibility and safety. Home physical therapy, occupational therapy, and assistive technology evaluations should begin when function begins to be difficult and should be emphasized during middle and high school to identify devices that will make daily life more efficient or easy and that are also safe for bathing, toileting, transfers, and sleeping. In the transition plan, AT for school is often addressed, but many devices and relatively inexpensive smart-home technology applications can be considered for home or work to control lights, open doors, send messages, respond to falls and emergencies, schedule appointments, and keep a calendar.

Transportation

Navigating the community can either be one of the greatest keys to employment and social connectedness or one of the most significant barriers to independence. For young adults with DMD, community mobility is essential to staying connected with friends, getting to school or work, going shopping, or going out to dinner. Discussions in high school should include how adolescents with DMD plan to navigate their community. If public transportation is an option, assistance with acquiring a rider card and practice using the transport system or paratransit services should be provided. Individuals with DMD with good arm and hand function may be interested in learning how to drive a vehicle. Modifications to a vehicle can take many months, and lessons may be available at only a few locations, so advanced planning and financial supports are needed. For

those who plan to use a family-owned vehicle, discussion about whether nonfamily caregivers or friends will be permitted to drive the vehicle should occur.

Financial Aptitude

Being an adult with DMD is more complex and more expensive than being an adult without DMD. The systems that provide resources and supports to individuals with disabilities are fragmented and complex to navigate, often requiring a financial aptitude above and beyond that held by most young adults. Adults with DMD must firmly grasp disability benefit eligibility, be aware of funding streams that support them and what waiting lists they may be on, and learn how to prepare complex benefit justifications. For this reason, it is recommended that families and a designated provider (eg, social worker or case manager) begin to formally and gradually involve the adolescent with DMD in discussions related to benefits during the high school years. Familiarity with the application processes involved, any relevant income thresholds, the utility of a special needs trust, the acquisition of an ABLÉ National Resource Center¹⁹ account and the disbursement process, and use of Medicaid, Medicaid Waiver programs, Medicare, independent living communities, and vocational rehabilitation will empower young adults with DMD to be better equipped to advocate for themselves and gain financial stability.

Relationships With Others

As adolescents with DMD graduate from daily interactions with peers

within the school setting and childhood friendships become more distant, social connectedness may become less natural. For those who enroll in college, friendships form through engaging with classmates and joining clubs and activities. However, for those who may not have daily contact through school or employment, socialization can shift to a virtual paradigm through gaming and social media. To counter this social withdrawal, adolescents with DMD should be encouraged to connect with peers and the community. Involvement in volunteer groups, church or community activities, and policy efforts related to personal causes, social groups, and other activities, including non-disability-oriented initiatives, should be fostered.

Dating, intimacy, sexuality, and privacy are topics that too often are not raised or are evaded by health care providers of adolescents and adults with DMD, but are among the highest priority for people in this age group. A desire for intimacy and companionship, questions about family planning, and questions about the mechanics of sex in light of a complex disability are all topics that can be meaningfully addressed by trusted providers. Reassurance that individuals with DMD can be sexually active and that they have the ability to become wonderful spouses and parents is an important message to convey to young people and can be critically important in their developing self-esteem. Within a multidisciplinary team, genetic counseling should be provided to address questions about DMD inheritance when appropriate.

CONCLUSIONS

Barriers to a successful transition from youth to adulthood often come from not knowing what is possible. The DMD transition toolkit (see the Supplemental Materials) is a way for individuals with DMD and their family and care team to assess their readiness for this process, outline specific plans for transitioning, document progress toward adult care and living, and provide a summary of expected health care needs. It is essential that all have a sense of what the future holds for the individual with DMD and that realistic excitement and high expectations for that individual be communicated. Anticipatory guidance and careful planning for health care, education, employment, or other meaningful activities after high school are critical in helping the youth with DMD achieve independence and a successful adulthood. Care coordinators, social workers, providers, educators, parents, and the individual with DMD all play a role in preparing for the future.

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ABBREVIATIONS

ADL: activity of daily living
AT: assistive technology
DMD: Duchenne muscular dystrophy

Address correspondence to Christina J. Trout, MSN, RN, Department of Pediatrics, Neuromuscular Program, University of Iowa Hospitals and Clinics, 1300-15 BT, 200 Hawkins Dr, Iowa City, IA 52242. E-mail: christina-trout@uiowa.edu

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