

A Transition Toolkit for Duchenne Muscular Dystrophy: Supplementary Materials

Duchenne Muscular Dystrophy Pediatric to Adult Care Transition Tools:

Supplementary Material 1 Transition Readiness Assessment for Young Adults with Duchenne Muscular Dystrophy

Please fill out this form to help us see what you already know about your health, how to use health care and the areas you need to learn more about. If you need help completing this form, please ask your parent/caregiver. Then we'll review the form together to develop a plan.

Date: _____	Participants in today's discussion:
Name: _____	_____
DOB: _____ Age: _____	_____

Transition Importance and Confidence										
On a scale of 0 to 10, circle the number that best describes how you feel right now										
How important is it to you to prepare for/change to an adult doctor before age 22?										
0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
How confident do you feel about your ability to prepare for/change to an adult doctor?										
0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

My Health and Using Healthcare	Please check the box that applies to you right now:		
	I need a plan	I need to learn	Yes, I know this
I know my medical needs and can tell others about my needs			
I know my symptoms, including ones that need medical care quickly			
I know what to do if I have a medical emergency			
I know my medications, what they are for, and take them without reminders			
I carry important health information with me every day (e.g., insurance card, emergency contact information, medications I need) or have a phone app			
I know my non-medication treatments (e.g., physical therapy, cough assist, BiPAP) and when I need to do them			
I know my assistive devices and can direct others in helping me to use them			
I know how to maintain my assistive devices (including directing others to assist)			
I know my doctors and how to reach them (e.g., phone, email, text, EMR)			
I know how to tell my doctor's office about the special assistance I need before my visit (e.g., I need help to get out of my chair)			
I make and keep track of my own doctor appointments			
Before a visit, I think about questions to ask about my health			
I have a way to get to my doctor's office and know how to arrive early to check in			
I know where to go to get medical care when the doctor office is closed			
I have a copy of my key medical records, a medical summary, and urgent care plan			
I know how to fill out medical forms			
I know how to ask to be seen by other doctors and therapists			
I know where my pharmacy is and what to do when I run out of my medication			
I know where to get blood tests or x-rays if my doctor orders them			
I understand how health care privacy changes once I turn 18			
I have a plan so I can keep my health insurance after age 18			
My family and I have discussed my ability to make my own health care decisions at age 18			

**Duchenne Muscular Dystrophy
Pediatric to Adult Care
Transition Tools:**

**Supplementary Material 2
Transition Checklist for Young Adults with
Duchenne Muscular Dystrophy**

Health Plans		Check the box that applies to your assessment of the young person with DMD at this time:		
		Need to plan/help*	Progress on this	Ready to transition
Transition Readiness Assessment has been completed				
Parents move to a supporting role; individual with DMD is engaged in discussion				
Appointments are conducted (entirely or partially) without parents in exam room*				
DMD-appropriate providers for age 18 or older are identified/known to individual (or discuss plan to maintain providers but with adult-approach):				
	Adult Primary Care			
	Adult Neuromuscular/PM&R			
	Adult Pulmonary			
	Adult Cardiology			
	Adult PT, OT, AT (therapists)			
	Adult Endocrine			
Determine who will assist in transition to adult health care services (i.e., role of social work, care coordinator, PCP and subspecialists)				
A care coordinator is available to answer questions about health, resources, funding, and medical supplies/equipment				
A medical social worker is available to identify healthcare resources and funding, and to help access medical supplies and equipment				
Medical records are sent or shared with all health care providers (e.g., copies of records to new providers in advance of appointments)				
Details of plans and needs for follow up are communicated to receiving providers (e.g., prepare a transition letter or call receiving providers)				
Individual with DMD has a file/folder/summary of medical information or access to medical records electronically (includes AVS at each appointment)				
A medical emergency plan specific to stage of disease progression and related likely presenting complications is offered (see DMD Care Considerations for examples)				
Precursors to adult healthcare practices to gain confidence are practiced (e.g., carry ID, insurance, and emergency card; maintain phone app with appointments, contacts, and records access)				
Changes in health care benefits that change at age 18+ are explored (ensure plan for insurance or public funding coverage after age 18)				
Health care findings and plan of care are reviewed and understood (e.g., clarify medical terms, diagnoses, medications, therapies)				
Anticipatory guidance about expected healthcare changes are provided (e.g., guidance to allow time/preparations for financial, emotional and caregiving changes associated with loss of walking, scoliosis, cardiopulmonary function)				
Legal changes in healthcare privacy, consent, access to information and decision-making at the age of maturity are conveyed (typically age 18)				
Determine level of decision-making supports needed for those with maturity or intellectual challenges (refer to legal resources if long-term support expected)				
Assess and clarify goals of care throughout transition and into adult life (document goals of care discussions even if a definitive plan is not established)				
As appropriate, consult palliative care, advance care planning specialists or hospice for documentation of advance directives				

* "Need to plan/help" can mean there is a need to develop a plan to provide information or develop a plan for help/support in that area (guardian, conservator, DPOA-HC or support person). Once help is in place, transition is ready.

Education and Employment Plans	Check the box that applies to your assessment of the young person with DMD at this time:		
	Need to plan/help*	Progress on this	Ready to transition
Ensure a written plan at school outlining needs, plans, and goals for the future (e.g., 504 Plan or IEP in the US, EHC Plans in England)			
Recommend the youth with DMD attend school meetings to learn and practice self-advocacy skills, i.e., student to participate in planning			
Identify strengths and interests and how those apply to future plans (e.g., guide individual to education/vocation that uses their talents and abilities)			
Facilitate a health plan at school/work to ensure well-being and physical care are met (balancing medical needs, time for rest, and advancing academic progress or work)			
Identify resources and acquisition of necessary equipment and technology for educational (or vocational) purposes (e.g., consult AT, OT, PT)			
Refer to regional, state and federal services offering services to support education or vocational planning (e.g., Vocation Rehabilitation Services)			
Refer to advocacy groups offering planning strategies, peer-to-peer advice, moderated chats, blogs, discussion forums, support networks, etc.			
Communicate physical needs to college campus programs or employers (e.g., Office for Students with Disabilities, or Human Resources office for FMLA)			
<u>College Planning:</u> Begin planning for housing, attendant care, academic planning and accommodations (this must start 1-2 years before actual start date)			
<u>Post Education Planning:</u> Begin planning for housing, attendant care, meaningful daily activities and employment options (this takes 1-2 years to explore and arrange)			
Key questions to guide discussions and planning: What do you want to do each day? What personal skill sets (talents and interests) will be maximized? What financial resources will be needed? What community, state, federal resources are available? What educational/vocational planning resources are available? What equipment or technology might be needed? What caregiving might be needed?			

Housing and Transportation Plans	Please check the box that applied to you right now:		
	Need to plan/help*	Progress on this	Ready to transition
Discuss housing options (where to live) as an adult (e.g., family home, college, apartment, assisted living home, on own w/assistance)			
Assess family home accessibility (ramps, doors, commode, shower, living spaces)			
Assess housing away from home accessibility, e.g., dorms, apartments, group homes (ramp, doors, commode, shower, living spaces)			
Consult PT, OT, AT and vendors/builders for input on modifications and assistive technology options (e.g., roll-in showers, adaptive equipment, smart home options)			
Consult social work or public social services to learn about laws regarding renting and accessible housing for persons with disabilities			
Consult social work or public social services for guidance on local, state, and federal grants, loans, and financial incentives for homeowners with disabilities			
Discuss transportation in family vehicle (adapted for access and safety)			
Explore options for accessible public transportation			
Consider independent driving with vehicle modifications (explore funding options)			

Activities of Daily Living Plans		Please check the box that applied to you right now:		
		Need to plan/help*	Progress on this	Ready to transition
Provide guidance on hiring/training personal care assistants				
Provide guidance on finding funding for care (e.g., private and public funding)				
Provide guidance regarding changes in benefits that pay for caregiving. Often benefits vary based on age, employment, or educational status (Consider referral to estate planners, agencies providing disability advocacy, or attorney services specializing in legal aspects of eligibility criteria)				
Ensure respite is available for family caregivers				
Refer for assistive technology and OT/PT to maximize independence at home				
Consider need for guardianship, conservatorship or other support in various aspects of adult living experiences (e.g., finances, arranging daily care)				

Autonomy and Personal Life		Please check the box that applied to you right now:		
		Need to plan/help*	Progress on this	Ready to transition
Register to vote (as age appropriate)				
Register with military, or provide waiver if required (as age appropriate)				
Take steps to establish a line of credit or personal financial independence (e.g., a bank account, a credit or debit card in their name)				
Teach, mentor, and encourage individual to direct his own care				
Discuss social connections (assess risk for social isolation)				
Identify activities to remain socially connected to friends/peers (e.g., clubs, events, social groups) – troubleshoot barriers to participation				
Refer to psychologists for assistance with social skills when individual self-identifies difficulty with networking and confidence				
Discuss relationships, dating, sexuality, and intimacy				
Provide medical facts about ability to have sex, masturbation, producing children				
Offer referral to resources or professionals to learn more about topics of intimacy and sexual activity				
Review genetic counseling, including DMD inheritance risk, implications for family planning, and carrier testing for relatives				
Assess for mental health concerns related to risk factors associated with social isolation and changes in health status (e.g., anxiety, depression)				

Resources for Transition and Young Adults in the United States (Some topics may apply to those living outside the United States)	
Got Transitions: Links for providers and families, e.g., guidance on insurance, guardianship, and support for decision-making, parents “letting go of control,” mental health tips for teens graduating high school, think college website	www.gottransition.org
Centers for Independent Living and Statewide Independent Living Councils Example topics: assistance to develop plan that outlines independent living goals and skills, assistance with self-advocacy skills, transition to employment or supported employment opportunities	www.ilru.org/projects/cil-net/cil-center-and-association-directory
Social Security Administration, Disability: FAQs about disability benefits and eligibility; Includes link to Ticket to Work Program	https://faq.ssa.gov (click on disability)
Muscular Dystrophy Association: Articles, links and resources for transitioning teens and adults covering education, employment, and independent living; personalized coaching sessions for teens and young adults	https://strongly.mda.org/tag/transitions/ https://www.mda.org/young-adults
Parent Project Muscular Dystrophy: Community blogs, chats, Q&A for teens and adults (age 18+ Living with Duchenne); links to webinars/presentations, Adult Advisory Committee for teens/adults with DMD	Parentprojectmd.org (click on Connect, Join the community)

This document should be shared with and carried by youth and families/caregivers		
Date completed:	Date revised:	
Form completed by:		
Contact Information		
Name:	Nickname:	
DOB:	Preferred language:	
Parent (Caregiver):	Relationship:	
Address:		
Cell#:	Home#:	Best time to reach:
Email:	Best way to reach: <input type="radio"/> Text <input type="radio"/> Phone <input type="radio"/> Email	
Emergency Contact:	Relationship:	Phone:
Preferred Emergency Care Location:		
Advanced Directive: <input type="radio"/> Yes <input type="radio"/> No		Conservator, guardian, durable power of attorney for HC: <input type="radio"/> Yes <input type="radio"/> No Specify details below.
Health Insurance Coverage: (keep cards available or attach copies)		
Provide special information or instruction the youth or family wants health care professionals to know below: <i>Examples: Assistance with decision-making, details of advanced directives, communication preferences</i>		
Provider's rating of youth's understanding of the diagnosis and the long-term health implications: <input type="radio"/> very good <input type="radio"/> good <input type="radio"/> fair <input type="radio"/> poor		
Diagnosis/Problem List:		
	ICD10	Details and Recommendations:
Primary Diagnosis: Duchenne muscular dystrophy	G71.0	
Secondary diagnoses (check all that apply):		
<input type="radio"/> Corticosteroid use, chronic		<input type="radio"/> Stress dose coverage Plan:
<input type="radio"/> Respiratory <input type="radio"/> restrictive lung disease <input type="radio"/> chronic respiratory failure <input type="radio"/> BiPAP dependent <input type="radio"/> ventilator dependent via tracheostomy <input type="radio"/> obstructive sleep apnea <input type="radio"/> Ineffective airway clearance	J98.4 J96.10 Z99.89 Z93.0 G47.33 R06.89	<input type="radio"/> <u>Caution:</u> Oxygenation should be accompanied by adequate ventilation <input type="radio"/> Airway clearance requires cough-assist device followed by suctioning due to muscle weakness
<input type="radio"/> Cardiac <input type="radio"/> cardiomyopathy <input type="radio"/> tachycardia, sinus <input type="radio"/> heart failure	I42.9 R00.0 I50.9	
<input type="radio"/> Orthopedic/Musculoskeletal <input type="radio"/> Scoliosis: surgically fused: Yes / No <input type="radio"/> Contractures, multiple joints <input type="radio"/> Osteoporosis <input type="radio"/> Vertebral/compression fractures <input type="radio"/> Immobility, loss of ambulation	M41.50 M24.50 M81.8 M48.5 M62.3	

Secondary diagnoses continued...	ICD10	Details and Recommendations:
<ul style="list-style-type: none"> ○ Gastrointestinal and Genitourinary <ul style="list-style-type: none"> ○ constipation* (○ gastroparesis) ○ GERD ○ Nutritional concerns: _____ <ul style="list-style-type: none"> ○ G-tube: Yes* / No ○ Assistance to eat or drink: Yes / No ○ Urinary frequency, urgency, hesitation ○ Kidney stones, recurrent 	K59.0* K21.9 variable Z93.1* variable N20.0	
<ul style="list-style-type: none"> ○ Neurology/Psychiatry <ul style="list-style-type: none"> ○ Learning Disability: Yes / No ○ OCD ○ Anxiety disorder ○ Other: 	F42 F41.9	
○ Delayed Puberty	E30.0	
○ Cataract: right / left	H26.9	
○ Other:		
○ Other:		

Emergency Care Considerations for Duchenne Muscular Dystrophy are published: Search CDC Care Considerations. See CDC Care Considerations for detailed expected course of action for common urgent care situations.

Common Urgent Presenting Problems	Typical course of action for this problem:
Respiratory distress related to: pneumonia, mucous plugging, chronic hypoventilation	<ul style="list-style-type: none"> ○ assess O2 saturation, consider blood gas <u>Caution:</u> Oxygenation should be accompanied by adequate ventilation ○ provide assisted ventilation via BiPAP (ventilator, if trach'ed) ○ provide aggressive airway clearance (ideally with cough-assist device) ○ consult pulmonary and RT ○ consider fat embolism syndrome, especially after fracture
Cardiac dysfunction: dyspnea, tachycardia, arrhythmias, abdominal pain, edema	<ul style="list-style-type: none"> ○ check troponin-I, B-type natriuretic peptide ○ monitor for ECG changes (compare to previous ECG) ○ consult cardiology
While not part of DMD, illness and injury may be less tolerated than for those without DMD. CDC Care Considerations provide details to several of these concerns: GI distress, vomiting, abdominal pain, flu-like symptoms, injury due to falls or transfers, back or musculoskeletal pain, etc.	<ul style="list-style-type: none"> ○ determine etiology DMD is a complex disorder; Often s/s can be caused by multiple risk factors ○ consult neuromuscular specialist ○ consider stress dose coverage for significant injury or illness, if on chronic corticosteroids (Protocol available in CDC Care Considerations) ○ consult orthopedics for most fractures (goal: return to baseline function if ambulatory, consider surgical fixation) ○ consult endocrine for compression fractures ○ consult GI for constipation, gastroparesis

Other Precautions and Special Considerations:		Comments and Recommendations:			
Allergies: (list or attach list)					
Sedation Risk: Yes / No		○ Avoid analgesics or sedatives that may reduce respiratory drive, unless breathing is supported (w/BiPAP or other support); avoid inhaled anesthesia, which can cause adverse effects in DMD.			
Fall or transfer precautions:					
Clinical Trial Participation:					
Medications	Dose	Frequency	Medications	Dose	Frequency
Medication notes:					

Health Care Providers, Agencies and Vendors				
Provider/Contact	Specialty	Clinic/Hospital/Location	Phone	Fax
	Primary Care			
	Neuromuscular			
	Pulmonary			
	Cardiology			
	Physical Therapy			
	Occupational Therapy			
	Orthotics			
	DME			
	Home Health Care Agency			
	DHS/Caseworker			

Include ALL providers involved in prescribing, ordering or assisting with equipment, care coordinators and social workers

Equipment, Orthotics, Assistive Technology, Supplies (record type, brand, size and weight if applicable)		
○ Wheelchair or other power mobility Type: Year purchased:	○ Stander Type: Used _____ hrs/day	○ Orthotic devices Type: Year Purchased: Used _____ hrs/day; used day vs night
○ BiPAP or CPAP (circle one) Type: Interface (e.g., mask): Used _____ hrs day/night Frequency of tubing changes: _____ Settings:	○ Sip/Puff (mouthpiece) ventilation Used _____ hrs/day Frequency of tubing changes: _____ Settings:	○ Tracheostomy with ventilation Trach Type: Vent Type: Used _____ hrs/day and night Frequency of tubing changes: _____ Settings:
○ Suction machine and catheters, cough assist device _____ Settings:	○ Nebulizer	○ Oxygen and tubing
○ Gastrostomy	○ Oximeter parameters:	○ Communication Device:
○ Supplemental nutrition Formula:	○ Lift/transfer technique/equipment	

Baseline Vital Signs and Measures				
HT:	WT:	HR:	RR:	BP:

Past Medical History (Surgeries, Procedures and Hospitalizations)		
Date:		
Date:		
Date:		
Date:		
	Test	Result
Date:	ECG	
Date:	Echocardiogram	
Date:	Cardiac MRI	
Date:	Spine X-ray	
Date:	DEXA scan	
Date:	PFTs	
Date:	Peak cough flow	
Date:	Blood gas	
Date:	Vitamin D	
Date:		
Date:		

School and Work Information			
School:	Contact Person:	Phone:	Fax:
Work:	Contact Person:	Phone:	Fax:

Other Important Contacts			
	Contact Person:	Phone:	Fax:

Add insurance case manager, education consultants, benefits coordinators, advocacy organizations (e.g. MDA, PPMD)

Attach Immunization record and recent clinic notes to this form for future reference.