

FACT SHEET

Transition to Adulthood: Guidelines for Patients with Neuromuscular Disorders

INTRODUCTION

Currently, many chronic congenital or genetic diseases previously considered exclusively childhood diseases are no longer associated only with children, as life expectancy has increased into adulthood. Thus, the lengthened lifespan has resulted in approximately 75,000 youth transitioning from pediatric to adult care each year.¹ The concept of medical/healthcare transition from pediatric to adult providers and the exposure of inadequate transitions has been at the forefront of conversations for almost 30 years, becoming a nationwide priority since 2011.^{2,3} However, according to the 2017-2018 National Survey of Children's Health by the Maternal and Child Health Bureau, 81.1% of youth with special healthcare needs did not receive services for transitioning to adulthood.⁴

The purpose of this fact sheet is to share evidence-based guidelines for supporting the transition from pediatric healthcare, including physical therapy, to adult services for young adults with neuromuscular disorders. Pediatric physical therapists (PTs) generally have long standing relationships with their patients with neuromuscular conditions and can be instrumental in supporting these individuals in their transition to adult healthcare providers.

WHAT IS HEALTHCARE TRANSITION?

Healthcare transition is commonly defined as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare providers, programs, and facilities.⁵⁻⁷ Healthcare transition is distinct from transfer of care. For example, the transition process is a dynamic, multi-faceted, multi-stage, active process that addresses the medical, psychosocial, and educational or vocational needs of adolescents as they move from pediatric to adult-centered care.^{1,8} Conversely, transfer of care refers to a single event or point in time where the responsibility of care shifts from one provider to another with the process of transition often taking much longer.¹

WHAT ARE NEUROMUSCULAR DISORDERS?

Neuromuscular disorders are largely genetic or acquired and include muscular dystrophy (MD), spinal muscular atrophy (SMA), Charcot-Marie Tooth (CMT), Friedreich's ataxia (FA), mitochondrial myopathies, metabolic myopathies, juvenile dermatomyositis (JDM), and cerebral palsy among other diagnoses. These childhood-onset diseases persist beyond childhood and require proper support, resources, and transition planning.

BARRIERS AND OBSTACLES TO TRANSITION

- Psychosocial resistance of adolescents and their families to letting go of their long-standing relationships and emotional attachments to their pediatric healthcare providers^{1, 5, 13-15}
- Young adult comfort in their pediatric environment and a perception that transition is challenging and scary causing negative feelings towards the transition of care^{2, 11}

- Possible resistance from the pediatric healthcare team as some pediatric practitioners still view their patients as having a short life span and perceive the transfer of care as unnecessary, leading to a paucity of referrals to adult healthcare providers and the development of an adult provider network^{2,5,15}
- Lack of available adult providers and/or adult providers who may have inadequate training in adolescent medicine nor have the knowledge about congenital and childhood-onset conditions such as neuromuscular disorders^{1,5, 14, 15}
- Differences between pediatric and adult models of care, as reported by adolescents^{2,5,8,16}:
 - Adult: less interdisciplinary, more fragmented, and more symptom/disease-focused
 - Pediatric: comprehensive and family-orientated view of their pediatric team
- Adult disengagement from healthcare at transition often due to the perceived low value of care as well as psychosocial, financial, and pragmatic barriers to navigating the healthcare system and disability services¹⁰
- Other barriers and obstacles ^{1,13,19}:
 - Starting the process too late
 - Poor communication between the pediatric and adult healthcare teams
 - Lack of insurance reimbursements for transition services
 - Difficulties accessing funding and equipment
 - Lack of time for the pediatric and adult healthcare providers

OVERVIEW OF SUCCESSFUL TRANSITION

- A successful transition should empower the patient, improve the transition, and optimize the patient experience. These tenets include ^{1,8,9,17-20}:
 - Attentiveness to the patient's needs
 - Clear communication
 - Collaboration among the healthcare team, patient, and family
 - Flexibility
 - Patient capacity building
 - Relationship building with adult providers to help patients embark on this important journey and reach autonomous participation in adult life
 - Psychosocial support for patients and families
 - Patient advocacy
- Transition should aim to achieve several goals such as^{1,13}:
 - (1) Prepare youth to understand their illness and take responsibility for self-management
 - (2) Empower patients to function as independently as possible in adult-oriented medicine and healthcare settings
 - (3) Identify appropriate adult healthcare providers available for transfer of care
 - (4) Communicate effectively and demonstrate self-advocacy with providers

SUMMARY

Transition planning for patients with neuromuscular disorders is vital to address the increasingly growing numbers of patients aging “out” of pediatric services and transferring to adult care. This “passing of the baton” for patients with neuromuscular disorders often occurs in the absence of research and with a lack of guidelines for a successful transition of care. Healthcare practitioners need to demonstrate strong, clear communication, remain flexible, and empower the patient to advocate for themselves during the transition process. This fact sheet provides tools and insights to guide this period of transition and spark additional research to further improve the transition experience and delivery of physical therapy and other healthcare services.

FIGURE 1: PROPOSED TRANSITION GUIDELINES

Phase 1: Early Awareness of Transition Planning (prior to 13-years old)

- Begin transition discussion
- Develop transition plan
- Use a transition toolkit
- Set expectations for future transition
- Understand evolving roles
- Identify a nurse, care coordinator, or social worker for the inter-team liaison
- Provide psychosocial support & patient education

Phase 2: Annual Review and Identification of an Adult Provider (between 14- and 18-years old)

- Create a formal written transition plan (prior to 14 years old)
- Review transition checklist and readiness assessment annually
- Identify adult provider
- Acknowledge the differences between adult and pediatric models of care
- Provide psychosocial support & patient education

Phase 3: Transfer Completion and Orientation into Adult Care (between 18- and 21-years old)

- Send medical records via transfer packet from pediatric to adult provider
- Ensure a longer follow up with pediatric provider
- Continued psychosocial support
- Provide additional and individualized support to the patient throughout the first months following transfer of care

Transfer To Adult Care Complete (between 18- and 23-years old)

REFERENCES

1. Tilton AH, de Gusmao CM. Transition from pediatric to adult neurologic care. *Continuum (Minneapolis)*. 2018; 24(1):276-287. doi:10.1212/CON.0000000000000570
2. Varty M, Speller-Brown B, Phillips L, Kelly KP. Youths' experiences of transition from pediatric to adult care: an updated qualitative metasynthesis. *J Pediatr Nurs*. 2020;55:201-210. doi:10.1016/j.pedn.2020.08.021
3. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110(6 Pt 2):1304-1306.
4. Child and Adolescent Health Measurement Initiative. 2017-2018 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). 2017-2018 National Survey of Children's Health (NSCH) data query. <https://www.childhealthdata.org/>. Accessed April 4, 2021.
5. Lanzkron S, Sawicki GS, Hassell KL, Konstan MW, Liem RI, McColley SA. Transition to adulthood and adult health care for patients with sickle cell disease or cystic fibrosis: current practices and research priorities. *J Clin Transl Sci*. 2018;2(5):334-342. doi:10.1017/cts.2018.338
6. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult healthcare systems for adolescents with chronic conditions. *J Adolesc Health*. 1993;14(7):570-576. doi:10.1016/1054-139x(93)90143-d
7. Got Transition. Six core elements of health care transition. 2014.

<https://www.gottransition.org/six-core-elements/>. Accessed January 1, 2021.

8. McDonagh JE. Growing up and moving on: transition from pediatric to adult care. *Pediatr Transplant*. 2005;9(3):364-372. doi:10.1111/j.1399-3046.2004.00287.x
9. Birnkrant DJ, Bushby K, Bann CM, et al. 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):445-455. doi:10.1016/S1474-4422(18)30026-7.
10. Wan HWY, Carey KA, D'Silva A, et al. "Getting ready for the adult world": how adults with spinal muscular atrophy perceive and experience healthcare, transition, and well-being. *Orphanet J Rare Dis*. 2019;14(1):74. doi:10.1186/s13023-019-1052-2
11. Wan HWY, Carey KA, D'Silva A, et al. Health, wellbeing, and lived experiences of adults with SMA: a scoping review. *Orphanet J Rare Dis*. 2020;15(1). doi:10.1186/s13023-020-1339-3
12. Treat NMD: Neuromuscular Network. The Guide to the 2017 International Standards of Care for SMA. 2017. http://treat-nmd.org/wp-content/uploads/2019/06/uncategorized-A-Guide-to-the-2017-International-Standards-of-Care-for-SMA_UKEnglish_Digital-v2L.pdf. Accessed May 2, 2022.
13. Coyne I, Sheehan A, Heery E, While AE. Healthcare transition for adolescents and young adults with long-term conditions: qualitative study of patients, parents, and healthcare professionals' experiences. *J Clin Nurs*. 2019;28(21-22):4062-4076. doi:10.1111/jocn.15006
14. Lemly DC, Weitzman ER, O'Hare K. Advancing healthcare transitions in the medical home: tools for providers, families, and adolescents with special healthcare needs. *Curr Opin Pediatr*. 2013;24(4):439-446. doi:10.1097/MOP.0b013e3283623d2f
15. Schidlow DV, Fiel SB. Life beyond pediatrics: transition of chronically ill adolescents from pediatric to adult health care systems. *Med Clin North Am*. 1990;74(5):1113-1120. doi:10.1016/s0025-7125(16)30505-3
16. Trout CJ, Case LE, Clemens PR, et al. A Transition Toolkit for Duchenne muscular dystrophy. *Pediatrics*. 2018;142(2):S110-S117. doi:10.1542/peds.2018-0333M
17. Stewart D. Transition to adult services for young people with disabilities: current evidence to guide future research. *Dev Med Child Neurol*. 2009;51:169-173. doi:10.1111/j.1469-8749.2009.03419.x
18. Schwartz LA, Daniel LC, Brumley LD, et al. Measures of readiness to transition to adult health care for youth with chronic physical health conditions: a systematic review and recommendations for measurement testing and development. *J Pediatr Psychol*. 2014;39(6):588-601. doi:10.1093/jpepsy/jsu028.
19. Stewart D, Freeman M, Law M, et al. An evidence-based model and best practice guidelines for the transition to adulthood for youth with disabilities. *The Best Journey to Adult Life for Youth with Disabilities*. Canadian Association of Paediatric Health Centres. 2009. <https://canchild.ca/system/tenon/assets/attachments/000/000/688/original/BJAmodelandbestpracticeguidelinEspdf2009.pdf>. Accessed May 2, 2022
20. Carroll EM. Health care transition experiences of young adults with cerebral palsy. *J Pediatr Nurs*. 2015;30(5):e157-e164. doi:10.1016/j.pedn.2015.05.018

©2022 by the APTA Academy of Pediatric Physical Therapy, 1020 N Fairfax St, Suite 400, Alexandria, VA 22314-1488, www.pediatricapta.org

Developed by expert contributors Nicole Crippen Schremp, PT, DPT; Mary Jane Rapport, PT, DPT, PhD, FAPTA; Lisa Dannemiller PT, DSc, Board-Certified Pediatric Clinical Specialist Emeritus. Supported by the Fact Sheet Committee of APTA Pediatrics.

The APTA Academy of Pediatric Physical Therapy provides access to these member-produced fact sheets and resources for informational purposes only. They are not intended to represent the position of APTA Pediatrics or of the American Physical Therapy Association.