



Meeting the Increasing Need for Navigating the Transition from Pediatric to Adult Healthcare

Children with neuromuscular diseases (NMDs) are living longer than ever before. Groundbreaking therapies, particularly for conditions like [spinal muscular atrophy \(SMA\)](#) and [Duchenne muscular dystrophy \(DMD\)](#), have led to significant improvements in life expectancy and quality. Because of these advancements, many patients with NMDs are living well into adulthood and, simultaneously, reshaping the conversation around the transition from pediatric to adult care.

“When I first arrived at our clinic four years ago, the treatments for SMA were just emerging from clinical trials,” says Kelly Sichmeller, RN, BSN, a nurse in the Pediatric Neuromuscular Clinic at the University of Minnesota. “Since then, those treatments have become the standard of care, which has been a huge shift for families and providers.”

Disease-modifying therapies, such as gene therapy for SMA and exon skipping for DMD, are changing not only the prognosis but also the goals and expectations of patients and their families. For other NMDs, improved disease management leads to greater life expectancy and quality of life. As life expectancy increases, so does the need for these patients to move to adult care.

“As patients live longer, their needs are going to change,” Sichmeller says. “Providers who are accustomed to working with children must expand their knowledge and adapt to the growing healthcare needs of adult patients.”

This is where the shift from pediatric to adult care becomes more critical and where the healthcare system must evolve to meet the needs of these patients.

Growing Need

Several studies and reviews have documented an increase in the transition from pediatric to adult care for patients with NMDs.

A [2022 fact sheet](#) from the American Physical Therapy Association (APTA) highlights that many chronic congenital or genetic diseases, previously considered exclusive to childhood, now see patients living into adulthood. This extended lifespan has led to approximately 75,000 youths transitioning from pediatric to adult care each year. However, the same report notes that, according to the 2017-2018 National Survey of Children’s Health, 81% of youth with special healthcare needs did not receive services for transitioning to adulthood.

Additionally, a [2022 article](#) in Neurological Research and Practice introduces the “Essen Transition Model,” which was developed in response to the increasing life expectancy of patients with NMDs. This model aims to structure the transition process from pediatric to adult care, ensuring efficient integration of various disciplines into the complex treatment and care process.

These sources recognize the need for structured transition processes to accommodate the growing population of adults with NMDs.

Transition Challenges and Best Practices

The move to adult care requires careful consideration of patients' evolving medical, physical, and social needs, which vary depending on the individual's condition.

For example, patients with DMD who once may not have lived beyond their 20s are now reaching their [30s and beyond](#). This longevity requires ongoing care not just for physical health but also for mental and emotional well-being.

According to Sichmeller, the transition process is not a one-size-fits-all model. It varies depending on the patient's condition and life goals.

"In our clinic, we start by setting achievable goals with patients," she says. "For some, it's as simple as being able to independently order their medications. For others, it's about making decisions regarding living arrangements, such as whether they want to live with family or move out on their own."

Open communication between care teams, patients, and families is critical to making the shift successfully. While many patients are used to relying on their families for day-to-day care, empowering patients to take more responsibility is a major step in the transition process.

"It's about helping patients gradually take on more responsibility for their care, whether that means using MyChart to communicate directly with their providers or making independent decisions about their healthcare," she says.

Sichmeller suggests that families start planning early and recognize that transitioning to adult care involves more than just moving from one clinic to another.

"Patients and families must be ready to accept that adult care looks different from pediatric care," she says. For example, pediatric specialty care is family-centered, including parents and patients equally in discussions and decisions. Adult care is patient-centered, relying on the patient to make decisions or invite others into healthcare discussions. In addition, adult patients are expected to take the lead on

scheduling appointments, requesting medication refills, navigating billing issues, etc. “The transition must be managed gradually, not suddenly,” Sichmeller says.

A Holistic Approach

Another essential part of this process is ensuring that patients are connected to the right resources within the healthcare system and their communities. For example, in Minnesota, high school vocational rehabilitation counselors can help patients navigate life after high school. “These resources are crucial in preparing for independent living, and most people don’t know they’re there,” Sichmeller says. Connecting patients to these services early can provide the support they need to make the transition to adulthood more manageable.

Families and care teams must also consider the patient’s goals beyond health, such as education, employment, and independent living. The transition to adulthood often involves exploring different living situations, mobility options, and work opportunities. Each of these elements requires careful planning.

“Transitioning is about preparing the whole person, not just their healthcare needs,” Sichmeller says. “It’s about helping patients and families navigate the larger world — where they live, how they get around, and what they want to achieve in life.”

Resources

Connect patients to these resources:

- Call the [MDA Resource Center](#) at 833-ASK-MDA1 (833-275-6321) or email ResourceCenter@mdausa.org
- To download the [MDA Transition Guide: Pediatric to Adult Care](#), go to mda.org/education and click “K-12 Education Resources.”
- Find more resources through [Parent Project Muscular Dystrophy](#) at parentprojectmd.org.