



## Family Matters

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# Transitioning from Pediatric to Adult Health Care: The Experience of Patients And Families

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Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care (McManus et al., 2013). As health care outcomes improve for children with complex medical conditions, the movement toward adult care is an expected and desired outcome (Davies, Rennick, & Majnemer, 2011). As early as 2002, a consensus statement of the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP)-American Society of Internal Medicine (ASIM) emphasized the importance of supporting and facilitating the transition of adolescents with special health care needs into young adulthood (AAP, AAFP, & ACP-ASIM, 2002; McManus et al., 2013). Recently, the same three organizations extended their statement in a clinical report, "Supporting the Health Care Transitions From Adolescence to Adulthood in the Medical Home" (AAP, AAFP, & ACP; Transitions Clinical Report Authoring Group, 2011). Further, the Maternal Child Health Bureau made preparation for adulthood one of six core outcomes defining a high-performing system of care for children with

Due to advances in medicine, many young adults with complex chronic conditions are now able to reach the age when they must transition from pediatric to adult care. But preparation for these transitions is often inadequate – for patients and their families, as well as for adult providers. As a result, many needs (clinical, psychosocial, and educational) may not be met, and patients and their families may feel uncertain about the quality of care. This article is the first in a series addressing this critical issue by providing insights from patients and families who have experienced transitions, as well as information about programs and available resources. In this article two parents and one young adult patient share their stories of transitioning, identify the numerous challenges they faced, and suggest strategies to improve the health care system for other patients and families.

special health care needs (Lotstein et al., 2009). This transition outcome states that these youth should receive the services necessary to make appropriate transitions to adult health care, as well as to both work opportunities and independence (Lotstein et al., 2009).

According to Tysbina, Kingnoth, Maxwell, Bayley, and Lindsey (2012), advances in health care have led to changes in the epidemiology of childhood chronic illness:

As many as 50-90% of children with congenital or acquired physical disabilities [are] now reach[ing] adolescence and liv[ing] into adulthood... Consequently, a new cohort of adults with childhood-onset disabilities and complex chronic conditions has emerged, requiring appropriate transitional care upon their "discharge" from pediatric facilities (p. 51).

Unfortunately, medical transition preparation is often minimal or lacking altogether for some 60% of youth with special health care needs (McManus et al., 2013). What lit-

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The **Family Matters** series focuses on issues, information, and strategies relevant to working with families of pediatric patients. To suggest topics, obtain author guidelines, or to submit queries or manuscripts, contact Elizabeth Ahmann, ScD, RN; Series Editor, or Deborah Dokken, MPA, Series Editor; *Pediatric Nursing*; East Holly Avenue/Box 56; Pitman, NJ 08071-0056; (856) 256-2300 or FAX (856) 589-7463.

tle does exist is often condition or sub-specialty contingent (Scal, 2002). Further, while many providers are encouraging transitioning teens “to assume responsibility for their own health, far fewer are discussing transfer to an adult provider and insurance continuity” (McManus et al., 2013, p. 1090).

Additionally, many adult providers and facilities are not well prepared to meet the needs of transitioning youth with special health care needs. In fact, in one study, internists identified a need for “better training in congenital and childhood-onset conditions... [and] training of more adult subspecialists” as well as a desire for “continued family involvement” and “concerns about patients’ psychosocial issues and maturity, as well as financial support to care for patients with complex conditions” (Peter, Forke, Ginsburg, & Schwartz, 2009, p. 417).

This lack of preparation is the case not only with doctors, but with nurses as well. As Brown (2014) describes, using the example of cystic fibrosis (CF):

Some...adult floor nurses have not been trained in CF because it has historically been a pediatric disease. So, when even healthier CF young adults arrive ready for transition [to adult care], they lose that trust and optimism when (for example) an adult floor nurse restricts their enzyme intake to three times a day or asks them why they would want double portions for their meals. One...transitioned patient...said, “They should be paying me for teaching these nurses about CF!” (p. 30).

Dr. W. Carl Cooley, Chief Medical Officer, Crotched Mountain Foundation, and Adjunct Professor of Pediatrics at the Geisel School of Medicine at Dartmouth, sums up the challenges well:

Unfortunately, most youth in the United States experience no preparation, minimal planning, and generally poor or absent coordination when their care is transferred from pediatric to adult providers. Pediatricians tend to postpone transition planning to age 18, offering little direct assistance with the transfer to a new adult care provider. While pediatricians experience difficulty finding adult providers for their patients, the adult providers find young adults poorly informed about their health conditions and medications, unready to ask questions, and unable to self-manage their care. The adult providers [also] worry about their limited training or experience in the management of conditions of childhood onset (Cooley, 2014, p. 10).

Although some teens/young adults manage the transition to adult services with relative ease (Scal, 2002), for others, this lack of preparation and readiness on all sides can have serious consequences for care. Documented concerns include poor treatment adherence, lack of adequate care, in some cases no care at all, an increased risk of secondary complications, an increase in emergency department use and hospitalization, and even diminishment of productive participation in society (Pai & Ostendorf, 2011; Scal, 2002; Tysbina et al., 2012). Poorer transition outcomes have been documented especially for youth with more severe conditions, absence of a medical home, and those of Hispanic or African-American ethnicity, lower income, or public insurance (Lotstein et al., 2009; McManus et al., 2013).

Further, as the parents in this article describe in their stories, inadequately orchestrated transitions contribute to

a significant burden on both young people and families. They are often forced not only to find appropriate care but also to coordinate it themselves. As a result, parents feel abandoned, frustrated, fearful, and uncertain when leaving behind the familiar world of pediatrics and transitioning to adult medicine (Davies et al., 2011; Tysbina et al., 2012). One study directly addressed the issue of support for parents, citing numerous benefits of a parent-led peer support group related to transitions (Kingsnorth, Gall, Beayni, & Rigby, 2011).

Addressing the important topic of transitions, *Family Matters* will publish a three-part series, identifying the needs and challenges of patients and families who are transitioning from pediatric to adult health care, and also highlighting several programs and resources that have been developed to address those needs. By incorporating “voices” of families drawing from the latest, though limited, research on this issue, and highlighting innovative programs, this series will provide a context and impetus for nurses and institutions to team with young people and parents in improving the transition process for teens and young adults to adult care.

## John’s Story

John is a 25-year-old young man with a rare genetic disorder called MECP2 duplication syndrome, which is a severe neuro-developmental disorder characterized by profound mental retardation, with poor speech development, hypertonnia, recurrent respiratory infections, and seizures (Van Esch, 2012). The condition primarily affects males, and 50% die before the age of 20 years. John and his mother Helen have



John

been intimately involved in the world of pediatric health care since John was an infant. Since that time, he and Helen have seen pediatric specialists from over a dozen services, including neurology, cardiology, surgery, urology, and gastroenterology. He has had countless stays in the hospital for surgeries as well as for pneumonia or seizures. When John was 21 years old, his pediatric health team told his mother that he had to transition to the adult health care system. John was referred to a primary care doctor dually certified in adults and pediatrics, but finding sub-specialists was very difficult. In an interview with co-author Amy Hopper, John’s mother Helen identified a number of challenges they faced in the transition process, accompanied by strategies that might help patients and families.

## Challenges

- “You feel pushed out. Your whole life you go to the same group of doctors, and then you have to find new ones who understand how to care for your child. Adult doctors do not know how to care for kids like my son.”
- “I felt comfortable at the children’s hospital that anything that needed to be done to help my son would be available... He has complex medical problems, and I feel the care in the adult setting is scattered. I feel like it is unsafe for John.”

- “We are in this four years, and we still have not completed the transition process.”

### Strategies

- Acknowledge the likelihood of ambivalence, fear, and feelings of abandonment.
- Assure availability of more dual-certified physicians.
- Prepare adult care providers to meet the needs of transitioning teens and young adults.
- Identify appropriate sub-specialists before the transition.
- Provide advance, perhaps gradual, preparation for the transition process before it happens.
- Educate families in the differences to be expected between pediatric and adult care.
- Determine the timing and length of the transition process by the patient’s needs as opposed to a set age or time frame.
- Develop transition clinics where pediatric and adult providers work together as a team.
- Encourage transition “forums” and peer support groups where patients and families can learn from one another.

### Kathleen’s Story

Kathleen is a 23-year-old young woman with microcephaly, severe physical and cognitive impairment, and a significant medical history for cerebral palsy and intractable seizures. Kathleen has had multiple hospitalizations for seizures, pneumonia, and pancreatitis throughout her childhood, and she has been followed by multiple specialties, including neurology, pulmonology, and gastroenterology. Kathleen’s family did not have any formal medical transition preparation. When she reached 21 years of age, she was referred to a dual-certified internist who specializes in the care of young adults with special medical needs. Because Kathleen’s mother, Jeanne, had been a nurse for over 30 years, she was able to navigate many aspects of Kathleen’s transition. In an interview with co-author Amy Hopper, Jeanne also identified both challenges and strategies.



**Kathleen and Her Mother, Jeanne**

### Challenges

- “The medical transition occurs at the same time as a lot of other transitions (for example, funding changes for educational services that meant changes in transportation, day programs, teachers, and aides). It’s a lot of changes at one time and a lot of uncertainty.”
- “At the children’s hospital, there were other kids like my daughter, and the staff were comfortable caring for them. The adult providers seem afraid of her seizures and refer to her ‘condition.’”
- “When my daughter was admitted to an adult hospital, I had to sleep in a chair by her bedside because there were no accommodations for family members.”
- “I have to do a lot more explaining in the adult environment.”

- “Since the adult setting is different, I obtained legal guardianship so I would not have any issues with continuing to give consent and talking on the phone to physicians about her.”

### Strategies

- Allow for a period of overlap in services.
- Consider staggering medical, educational, and vocational transitions.
- Provide transition plans, referrals, and summaries from each specialist in advance.
- Assess in advance whether the adult providers and facility(s) have the equipment and medications needed for the individual patient, and make arrangements as needed.
- Prepare portable transition summaries for patients and families with information about condition(s), medications, treatments, hospitalizations, and surgeries
- Inform families about resources within the community.
- Develop opportunities for information sharing among families.
- Consider the need for medical power of attorney or guardianship on a case-by-case basis for young adults who cannot make decisions for themselves.

### Desirae’s Story

Desirae is a 27-year-old woman with sickle cell disease and severe asthma. When she was younger, her pediatric providers had been a major source of support, assisting in keeping her compliant with her care. Her pediatric hematology team worked with her for two years towards the transition to adult care. A social worker explained insurance issues, and Desirae attended a transition clinic with an adult hematology provider who now provides her care. The hematologist insisted she have a primary care provider as well to address potential co-morbid conditions. If she needs to be admitted to the hospital, Desirae goes to the large health care center where her hematologist admits patients, although she has had to try several emergency rooms (ERs) to discover doctors who really know how to care for sickle cell, and she is not able to use the ER closest to home. The first few years of the transition were hard on her health, and she had many ER visits. However, Desirae has finally begun to manage her disease with more independence, and she has become stable enough to start taking college classes and consider a career direction. In an interview with co-author Amy Hopper, Desirae identified challenges of the transition and some helpful strategies.



**Desirae**

### Challenges

- “I was not prepared for how the adult health care system works; it took almost three years to understand what was expected of me as a patient.”
- “My health was not good when I had to transition. That made it hard.”
- “The adult providers wanted my mom to step back, but transition was a very hard time for me, and I needed my mom to help out.”

- “Because I was young, the doctors thought I didn’t know about my own disease. One adult doctor even told me that he didn’t think sickle cell patients had as much pain as they say.”
- “Until last year, I was in and out of the hospital so much that I could not start college classes.”
- “Once I left the children’s hospital, not all emergency rooms understood my needs.”
- “The adult doctors did not coordinate with each other well.”

### Strategies

- Provide advance, perhaps gradual, preparation for all aspects of the transition process well before it happens.
- Time the transition process based on the patient’s health status, if possible.
- Educate adult care providers about the important and evolving role of young adult patients in their own health care.
- Assure understanding and acceptance by adult care providers of the role parents continue to play in the health care of young adults with special medical needs.
- Make the effort to develop true partnerships between pediatric and adult providers as well as between them and young adult patients, and their families.
- Offer transition planning that addresses not only medical but also psychosocial and educational needs of young adult patients.
- Educate adult providers about the importance of provider collaboration and coordination of care.
- Teach patients and their families about case management as part of transition planning.

### Closing

Because of significant advances in medicine, a large population of young adults with special health care needs is transitioning from pediatric to adult care. However, as the stories of John, Kathleen, and Desirae illustrate, this transition is often difficult. As a result, patients and families feel abandoned and uncertain about care, and many important needs (clinical, psychosocial, educational) are not addressed or met. Preparation for the transition is lacking for all parties involved. Adult providers are not comfortable addressing medical and other needs of these patients. Young adults and their families are neither sure of their roles in the new, adult, system – nor of how to work in partnership with adult providers. Little research has been done on what constitutes an effective transition (Huang et al., 2011; Tysbina et al., 2012). Although several potentially useful models exist, many nurses and other providers lack awareness of them and their importance.

Two future articles in this series will fill in some of these gaps for nurses. In the next article, Juliette Schlucter, a leader in patient- and family-centered care and the mother of a son and daughter with cystic fibrosis, will share insights about her children’s transitions and why the principles of patient- and family-centered care must be at the foundation of transitioning. In the final article in the series, a number of programs and resources for transitioning young adults will be highlighted. ■

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