

FAST FACTS AND CONCEPTS #346
SERIOUSLY ILL PEDIATRIC PATIENTS WHO TRANSITION TO ADULTHOOD
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Background: Although illnesses such as cystic fibrosis, leukemia, Duchenne muscular dystrophy and congenital heart defects used to be fatal in childhood, recent medical advancements have allowed many with a pediatric illness to live beyond their second decade (1). The goal of this *Fast Fact* is to identify challenges a young adult (ages 18-25) with a life-limiting illness may encounter when transitioning from a pediatric to an adult health care system and offer strategies to facilitate this transition.

Effect of Illness on Young Adults: Adolescence and young adulthood is a period of great developmental upheaval. Growing up with a life-limiting illness adds physical, psychological, and social consequences that make this developmental transition even more complex. Frequent hospitalizations and other health-related issues disrupt maturation, education, and vocational training, leading to lower rates of educational attainment, employment, and health insurance (2,3). Approximately 20% of young adults with a life limiting illness report significant psychological distress (4). Many more describe themselves as “tired of being sick”. This reflects the challenges in coping with a chronic illness at a young age when many may not have developed the independence necessary to coordinate their own care (5,6).

Effect of Illness on Families: Serious illness has an undeniable impact not just for the young adult patient, but the entire family unit. Interruptions in plans and prognostic uncertainty add to a myriad of financial and social stressors from having a chronically ill child (7). Some studies describe these stressors as having a significantly negative impact on the parents; other studies describe the opposite, with parents reporting better cohesion and communication (8-10). Sibling relationships can be significantly strained as the healthy child may feel “forgotten” by their parents, contributing to an increased risk of depression and anxiety (11). Interestingly, divorce rates do not significantly differ from the general population (9). Given these complexities, an interdisciplinary team involving social workers, chaplains, case managers, and psychologists is typically needed for this patient population.

System-Based Practice Barriers: The transition between pediatric and adult care can be fraught with many challenges which fragment patient care.

- Only a minority transition to adult care with complete medical records (12).
- Most young adults and parents feel unprepared for the transition from a family-oriented model of pediatric medicine, which often has a defined medical home that strives to anticipate medical needs, to an adult-oriented care model which offers less community aid and psycho-social resources, while expecting greater patient responsibility (13,14).
- Clinicians, due to their unfamiliarity with certain childhood-onset conditions, may be reluctant to assume the care of these patients (15).
- These and other factors contribute to an increased prevalence of a “poor” clinician-patient relationship with adult vs pediatric clinicians (16,17).

Strategies to Facilitate this Transition:

- Pediatric teams should develop strategic partnerships with adult clinicians and begin the transition to adult care-system well before a point of acute medical crisis.
- On first visits, adult clinicians should dedicate extra time “getting to know” these patients, establishing trust, and coaching patients and families on how to navigate the adult healthcare system (18).
- Adult clinicians should reach out to pediatric teams when major health care decisions are necessary. Patients may be more comfortable having important discussions with the clinicians they have come to know through childhood who can offer clinical acumen on childhood illnesses with which adult clinicians may not be very familiar (19).
- Often, a long-standing interdependence exists between parents and the patient regarding health care decision-making. As many children age out of the pediatric environment, they are more likely to seek independence in medical decision making, even though parents may have difficulty ceding control (20,21). Clinicians should clarify what role young adult patients want their family to play in their health care before involving family members into end-of-life discussions. If appropriate, clinicians should ask parents to leave the room when doing this.

- The process of taking more responsibility for medical decision-making evolves over time. Therefore, discussions about this process need to be ongoing. Clearly communicate and document the degree of independence the patient wishes to maintain with medical decision-making.
- Young adults may be more receptive to various social media platforms that bring together similar patients with similar disorders than older adult patients (22). They may also prefer text messaging and smart phone applications designed for tracking symptoms, medications, and doctor's appointments (23). Clinicians should familiarize with these digital platforms and resources.
- Many EMRs now have care coordination templates for pediatric patients transitioning to adult health care systems which should be used to standardize the transition process.
- See the www.gottransition.org website for examples of digital platforms and EMR templates (24).

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