

Transitioning youths with chronic medical conditions from adolescence to adulthood



A generation ago, many children with serious or complex medical problems died before reaching maturity. Today, improved medical care has increased the odds that children with chronic conditions will become adults. As many as 60 percent of these patients, however, experience gaps in medical care, health insurance coverage or both as they move from adolescence to adulthood. Through consultation, referrals, education and research, the UCLA Medicine-Pediatrics Transition Care Program (Med-Peds TCP) is helping chronically ill patients successfully transition from pediatric to adult care.

Preventing high-risk patients from falling through the cracks

Children with chronic or complex medical conditions — such as congenital heart disease, cystic fibrosis, diabetes, renal failure or sickle cell disease, as well as those with mental illnesses or developmental delay — require intensive medical care involving both primary care and care from several medical specialists on a long-term basis. UCLA Med-Peds TCP targets a wide range of adolescents and young adults (primarily ages 15 to 25 years) through outpatient consultation services.

Preventing gaps in coverage and care

Planning and organizing resources for patients with complex and chronic medical conditions who need to transition from pediatric to adult medical care can be complicated and time-consuming, which is one reason their continuity of care sometimes suffers. “It’s very common that these patients experience some gaps in their care,” says Debra Lotstein, M.D., M.P.H., director of UCLA Medicine-Pediatrics Transition Care Program (Med-Ped TCP). “It’s also quite dangerous for them because they tend to be a high-risk population medically.”

The Med-Peds TCP is designed to give patients access to a continuum of care that includes comprehensive medical assessments, referrals to adult-centered primary and specialty care physicians, assistance in obtaining appropriate health insurance coverage, effective patient self-care competencies and connections to educational and vocational training resources in the community.

“We believe preparation and planning is important to maximizing lifelong health for our patients, particularly among those with limited financial resources or education,” Dr. Lotstein adds.

The program facilitates seamless transitions from pediatric to adult medical care by focusing on four key areas:

Providing referrals to adult-centered primary and specialty care. Some children and parents are reluctant to shift to adult healthcare because they fear losing access to known providers and support systems sensitive to their needs. Others require help identifying appropriate resources for complex healthcare needs. UCLA Med-Peds TCP is developing a comprehensive network of resources — both within UCLA Health and in the community — through which these patients may be referred for medical and psychosocial needs as they become adults.

Maintaining health insurance coverage. Most health-insurance programs include age limits that affect how long children are covered by the plan. When children lose health-insurance coverage, they lose access to necessary healthcare resources and medications. UCLA Med-Peds TCP works with families to assess medical needs and refer patients to potential sources of coverage, including Medicaid and other public programs, to support those needs.

Developing effective self-care skills. During childhood, most parents act as primary caregivers in the home, handling tasks such as administering medications, scheduling medical appointments and monitoring diet and exercise. Transitioning these tasks from parents to children is often difficult for chronically ill children and those with cognitive or developmental problems. Med-Peds TCP staff provide patient self-care education and also referrals to community-based organizations offering disease-specific self-care classes.

Connecting to educational and vocational training resources. An important aspect of patients' well-being is their willingness and ability to engage in school and work. In addition, many patients rely on their jobs for health insurance coverage. To assist in this area, the program offers school advocacy, referrals to educational and vocational programs and connections to job resources.

Training the next generation of physicians in both pediatric and adult medicine

A goal of UCLA Med-Peds TCP is to advance medical education and resources for physicians serving this complex patient population. The program is unique because of the key role played by residents under the supervision of faculty members who are board-certified in both internal medicine and pediatrics. Working closely with faculty, a program coordinator and social workers from other pediatric services within UCLA Health, the residents receive comprehensive medical training and experience dealing with financial and psychosocial issues important to patients. Residents from the Combined Internal Medicine and Pediatrics program staff the outpatient TCP clinic. Other residents also have the opportunity to do elective rotations with the TCP.

Participating Physicians

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