

BEST PRACTICES

Caring for the Emerging Young Adult: The Role of the General Internist

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In daily clinical practice, general internists encounter an increasing number of young adults with chronic conditions originating in childhood. This population includes patients with a wide range of diagnoses—from cerebral palsy to congenital heart disease—who may have both physical and mental challenges. General internists are increasingly faced with trying to meet the unique health care needs of this diverse group of young adult patients. To do so, physicians and other health care professionals must develop the knowledge and skills required to provide high quality, developmentally appropriate health care to this population.

Each year, nearly half a million children with chronic conditions enter adulthood, and it is estimated that 20 percent of young adults in the United States have a chronic condition.¹ As children, these patients are often referred to as children or youth with special health care needs (CYSHCN). The U.S. Health Resources and Services Administration Maternal and Child Health Bureau (MCHB) defines CYSHCN as “children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require more than routine health and related services.”²

As these patients with childhood-onset conditions “age out” from pediatric practice, increasing attention has been paid to the importance of transition from pediatric to adult care. In 2002, the American Acad-

emy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and the American College of Physicians-American Society of Internal Medicine (ACP-ASIM) released a consensus statement recognizing the need for improved transition services.³ In 2011, the AAP, AAFP, and ACP published guidelines on implementation of a successful medical home transition.¹ The Maternal and Child Health Bureau (MCHB)-funded Center for Health Care Transition Improvement (Got Transition) is a valuable resource for both pediatric and adult providers.

General internists play a critical role in the life trajectory of young adults with special health care needs by providing both primary and secondary preventive care as well as chronic disease management. Only recently has there been an increasing awareness of young adults with chronic conditions of childhood onset within the general internal medicine community. In March and April 2013, two special theme issues of the *SGIM Forum* focused on the transition and care of young adults with special health care needs.^{4,5} In September 2013, the Adults with Complex Conditions Originating in Childhood (ACCOC) Task Force was formed.

The goal of this task force is to improve the care of all adults with disabilities and complex conditions originating in childhood, with the following specifically stated objectives:

1. Increasing awareness and education of SGIM membership

regarding issues related to the care of this high-risk population, which faces well-established health care disparities;

2. Collaborating within SGIM to ensure issues related to this patient population are incorporated into ongoing SGIM initiatives in practice redesign, education, health care payment reform, and health policy;
3. Promoting needed research and scholarship in this area; and
4. Partnering with other organizations to increase SGIM’s role in national efforts to improve care and draw attention to the needs of these patients during their adult lives.⁶

With the support of members of Council and the SGIM staff, the task force has been actively involved in achieving these objectives through a range of endeavors. For example, members of the task force serve on the Got Transition Advisory Committee and the Health Care Transition Research Consortium. The task force has also partnered with the Kaiser Foundation and Physician Parent Caregivers in an effort to develop and promote a policy agenda that will positively impact this vulnerable patient population. Education on issues relevant to this diverse group of patients has been disseminated by the task force members to other members of SGIM through workshops, symposia, and poster presentations at both regional and national society meetings. These sessions

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and projects have focused on a broad scope of issues including, but not limited to, the clinical care of specific conditions, sexual and reproductive health of young adults with chronic health conditions, social and psychological considerations, resources available to assist the adult provider in caring for this patient population, and research identifying potential gaps in educational curricula among trainees in internal medicine programs. Additionally, a Speaker's Bureau has been created to promote (both internally and externally) SGIM members as expert speakers on the topic of the emerging adult and caring for adults with complex conditions originating in childhood. Similarly, the task force website is being modified to serve as a resource for adult medical providers. Finally, two significant collaborations highlight the work being done by the task force to inform and educate adult providers about the importance of being able to provide comprehensive, developmentally appropriate care to this rapidly growing patient population.

First, the ACCOC task force has collaborated with the ACP Council of Subspecialties, Got Transition, and the Society of Adolescent Health and Medicine (SAHM) to lead a project involving more than 25 medical societies and organizations (including most of the internal medicine subspecialty organizations that are members of the ACP's Council of Subspecialties, the AAP, the AAFP, and other interested groups) to expand the ACP's High Value

Care Initiative in order to include tools to improve the care of Young Adults with Chronic Conditions. The goals of the project were as follows:

1. Adopt and utilize a tested standardized approach to transitions for all youth moving from pediatric to adult care in both primary care and subspecialty practices;
2. Customize the tools from Got Transition's Six Core Elements to facilitate the implementation of an improved transition experience for young adults with specific chronic conditions; and
3. Create a process to effectively disseminate the use of this approach among clinical practices.

The tools and results of this collaboration are available for all to use online.⁷

In December 2016, *Care of Adults with Chronic Childhood Conditions: A Practical Guide* was published.⁸ This book was the result of a joint effort between the SGIM ACCOC Task Force and Springer Publishing. It is the *first* published guide on the care of this population intended for adult health care providers, both the generalist and the specialist. The book serves as a timely reference that provides a new framework for thinking about the approach to caring for these young adults and identifying opportunities for positively impacting their health outcomes. The book is divided into five parts:

1. A detailed overview of the health care transition from pediatric to adult medicine;
2. An approach to emerging adulthood and how to provide comprehensive care for this population;
3. Condition-specific chapters for 16 commonly encountered childhood conditions including a case discussion and a chronic condition fact sheet for quick reference;
4. Additional clinical considerations including enteral feeding, respiratory support, and palliative care; and
5. A discussion of important socio-legal issues that arise when caring for adults with childhood conditions.

It is the hope of the ACCOC Task Force that these on-going efforts will enable adult providers to accept and embrace these young adults with chronic conditions originating in childhood and other special health care needs into their care.

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