Providing Adult Medical Care for Childhood Cancer Survivors

Chad K. Brands, MD, and David E. DeLaet, MD, MPH

Dr. Brands is director of medical education and the Pediatric Residency Program at All Children’s Hospital Johns Hopkins Medicine in St. Petersburg, FL. Dr. DeLaet is an assistant professor of medicine and pediatrics at the Mount Sinai School of Medicine.

In the middle of the 20th century, pediatric hematologists and oncologists exercised scientific investigative genius when setting up their subspecialty field and academic medicine health care infrastructure to serve children with cancer. Large multicenter patient registries were established to study the effects of regimens of chemotherapy and radiotherapy being used to treat childhood cancer. These registries promoted the development of research in the new field, enabling physician investigators to conduct multicenter randomized controlled treatment trials for infants, children, and adolescents. Six decades later, thousands of lives have been saved, and the adverse effects of chemotherapy and radiotherapy are increasingly well known to clinicians treating pediatric or adolescent patients presenting with common and rare malignancies. In addition, the pediatric hematology-oncology specialty has also demonstrated great vision in establishing data registries to study the late effects of childhood cancer. The research from these long-term follow-up registries and studies continues to inform practices for those receiving initial treatment as well as those surviving well into adulthood.1

Nearly 12 million cancer survivors are alive in the United States, and nearly one third of a million patients were initially diagnosed under age 21.1 Seventy thousand adolescents and young adults between age 15 and 39 are diagnosed with cancer each year in the United States.2 Given these population demographics for childhood cancer survivors (CCS) and their adult medical care needs, today’s general internist must become familiar with the late effects of childhood cancer and its treatment. These effects continue to be studied and reported in the medical literature as investigators continue to follow cohorts of CCS. The discipline of survivor care will continue to mature as survivor clinics expand worldwide.

It is clear that the general internist of the future will be the quarterback of the medical home team.3 In this role, the generalist will need to ensure that CCS receive the evidence-based care that they require following treatment for childhood cancer by using an interdisciplinary approach. This leadership role within the medical home and medical neighborhood includes aspects of primary and secondary prevention, chronic disease management, risk assessment and modification, and interdisciplinary team management applied to the understanding of late effects of childhood cancer.

CCS are at risk for the development of secondary conditions resulting from the treatment of their childhood malignancies. These late effects can include essentially any organ-system depending not only on the extent of anatomic involvement of the initial disease but also the treatment modalities employed in effecting a cure, including but not limited to chemotherapy, radiation therapy, bone-marrow/stem-cell transplant, and surgical resection. Although a comprehensive review of these effects is well beyond the scope of this article, it is important to note that comprehensive resource guides are available that can help direct providers in the care of CCS and the long-term monitoring for these conditions.4

To facilitate optimal patient care in the context of a medical home that utilizes an interdisciplinary approach to wellness and illness, the general internist caring for CCS should follow several critical steps.

Review several key sources of important information on childhood cancer survivors. Although the care of CCS presents many challenges to the adult generalist, considerable resources are available to help guide the care of these individuals. The Childhood Cancer Survivor Study (CCSS) is a retrospective cohort study funded by the National Cancer Institute that includes children diagnosed between 1970 and 1986 and continues to illuminate the field.5 Similarly, the National Cancer Institute maintains online resources providing information on adolescents and young adults who have survived cancer.2 The Institute of Medicine has published a consensus report that focuses on improving the care and quality of life for CCS.6 Finally, the Children’s Oncology Group (COG) has prepared for health care providers the aforementioned specific guidelines for the long-term follow up of CCS.4

Reach out to the patient’s pediatric hematology-oncology team for a treatment summary. As recommended by expert panels, a portable medical summary should be established and updated annually by the pediatric medical home provider of all adolescents and young adults with special health care needs.6 For CCS, this document should summarize the patient’s course of medical treatment, including study protocols with chemotherapy and radiotherapy doses, surgeries and procedures, adverse acute effects of therapy, identification and risk of late effects, and health care professionals involved in the patient’s interdisciplinary care. The post-treatment roadmap will outline medical care continued on page 2
after the cancer treatment protocol has ended. A number of treatment summary formats have been proposed, implemented, and disseminated to facilitate transitions of care.

Consult the interdisciplinary team at your local/regional CCS clinic. Survivor clinics are more than transitional care clinics following treatment for cancer. These clinics follow protocols for care developed by organizations such as the COG that follow treatment on specific investigational protocols. The team monitors for symptoms or signs of late effects and prepares a summary useful to primary care providers. Many survivor clinics now combine the expertise of pediatric hematology-oncology, nursing, psychology, social work, and consultative subspecialty providers from pediatric and adult medicine.

Work with the patient on primary and secondary preventive strategies. Cancer survivors are not immune to the risks for obesity, heart disease, diabetes, and hypertension. In fact, some survivors will have higher risks for the development of these diseases acquired in young adulthood, mid-life, and beyond. If the internist identifies chronic diseases, CCS and their families will be very accustomed to working with an interdisciplinary team of health care professionals to improve their health, well-being, and quality of life. Providers should also remain vigilant for the previously described late effects of childhood cancer, particularly those most commonly associated with the individual patient’s primary malignancy and treatment modalities.

When symptoms are reported and/or signs are detected, seek subspecialty consultative expertise while tapping your own subspecialty knowledge as a general internist. You can commit to promoting the health of the patient within the medical home you lead with your interdisciplinary team. The growing population of CCS is depending on you to provide key components of their adult medical care.

References