

# The Young Adult Follow-Up Multidisciplinary Clinic

*at the Helen F. Graham Cancer Center*

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**Y**oung adult cancer survivors require ongoing education, lifetime surveillance for late effects from treatment, and long-term risk factor management. Historically, the primary goal for young adults with cancer was survival of the primary disease process. But as early as 1975, the National Cancer Institute (NCI) held the first large-scale meeting to deal with toxicity-related issues in this patient population.<sup>1</sup> As time progressed, clinicians gained a better understanding of the relationship of treatment dosing to late effects, and pediatric oncologists initiated efforts to track and educate childhood cancer survivors. As a result, significant strides have been made toward studying and reducing the late effects of anti-cancer treatment. And by the early 2000's, the cancer community began to see a need for young adults to be followed up by "transitional" centers.

## **Establishing Our Young Adult Follow-Up Multidisciplinary Clinic**

In New Castle County, Del., a partnership developed between the Alfred I. DuPont Hospital for Children and the Helen F. Graham Cancer Center at the Christiana Care Health System. The two programs wanted to initiate a process to transition patients from the pediatric oncology program to an adult oncology program with timely access, support, and guidance. So in 2003, the Helen F. Graham Cancer Center established its Young Adult Follow-Up Multidisciplinary Clinic.<sup>2</sup> When the children's hospital refers cancer patients to the multidisciplinary team, patients arrive with a copy of their medical records and an individualized clinical summary (see Table 1, page 30), which outlines surveillance needs according to the Children's Oncology Group's Long-Term Follow-Up Guidelines.<sup>3</sup> Our Young Adult Follow-Up Multidisciplinary Clinic also sees childhood cancer survivors who have come from

other institutions, such as those who have recently moved from other states to our immediate area. Generally, patients at our Young Adult Follow-Up MDC are 19 years of age and older.

A medical oncologist performs the initial evaluation, assisted by an oncology-certified nurse navigator. Within the clinic, social workers, health psychologists, genetic counselors, and registered dietitians are also available for immediate consultation. Patients are evaluated by organ system, treatment type, and disease process. Based on anticipated late effects and chronic conditions, patients are counseled and referred as necessary to other subspecialists that have been established as contacts (see Table 2, page 31). The medical oncologist will monitor any necessary follow-up evaluations, such as pulmonary function testing, laboratory testing, and ophthalmological referrals. Many of these patients also require help establishing a relationship with an adult primary care provider. Our Young Adult Follow-Up Multidisciplinary Clinic continues its ongoing efforts to transition these individuals to providers who are adept at dealing with both their medical and psychosocial issues. Even when patients are transitioned to primary care physicians, the medical oncologist sees all patients at least on a yearly basis, and more frequently when needed.

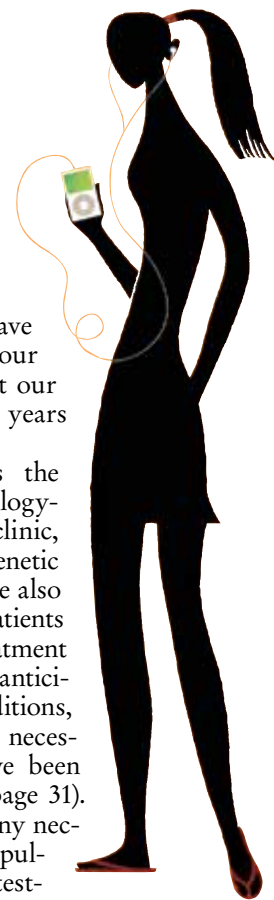
## **Long-Term Management**

Successfully transitioning patients from pediatric to adult cancer programs involves overcoming a number of potential barriers. Some key factors that we focus on at our Young Adult Follow-Up Multidisciplinary Clinic include:

- Educational issues in the form of knowledge deficits
- Empowerment and advocacy issues
- Social and financial challenges
- Obstacles put into place by the patient, family members, and providers (see box on page 31).

In many cases, these challenges—rather than medical issues—are at the forefront of the day-to-day problems in these patients' lives.

When evaluating young adult cancer patients for long-term management, consideration of multiple facets of care are critical to success. Our Young Adult Follow-Up Multidisciplinary Clinic implements its plan of care for the patient by subdividing potential late effects into disease type, treatment type, and organ system.





Tina Scherer, RN, nurse navigator (left) and Pamela Simpson, MD, medical oncologist, at the Helen F. Graham Cancer Center, Newark, Del.

**Table 1. The Children's Oncology Group's Long-Term Follow-Up Guidelines<sup>3</sup>**

Comprehensive treatment summaries should include:

- Diagnosis, including site and stage, date, and date of relapse, if any
- Pertinent secondary diagnoses
- All chemotherapy agents received, including route of administration; cumulative doses for alkylators, bleomycin, and anthracyclines; and designation of standard vs. high dose for methotrexate and cytarabine
- Radiation therapy summary for all fields, including type, site and volume, dates, total dose (in cGy), dose per fraction, and number of fractions
- Hematopoietic cell transplant(s), including type(s), date(s), conditioning regimen, and GVHD prophylaxis and/or treatment
- Significant complications, including treatment required
- Adverse drug reactions/allergies.

**Disease type.** Examples of disease type that affect aspects of care include:

- Brain tumor survivors may require management of potential educational and/or neurocognitive, endocrine (due to effects on the pituitary gland), and audiologic effects
- Bone tumor survivors may require orthopedic follow-up, as well as considerations according to the chemotherapeutic agents they received
- Wilm's tumor patients require special considerations due to prior nephrectomy
- Leukemia and lymphoma patients require follow up for bone marrow insufficiency, gonadal insufficiency, and potential for GVHD management if receiving a bone marrow transplant.<sup>1</sup>

**Treatment type.** Certainly, multiple effects of chemotherapeutic agents are well documented in the literature, such as anthracyclines causing cardiomyopathy and bleomycin causing pulmonary fibrosis. Many more social issues, including decreased fertility, growth retardation, obesity, and educational delays are also attributable to chemotherapeutic agents. Our Young Adult Follow-Up Multidisciplinary Clinic helps patients cope with and manage these issues to the best of their ability. A different set of issues are associated with radiation therapy. Both chemotherapy and radiation therapy may also increase the risk of secondary malignancies.

**Organ System.** While at times this category overlaps with disease type, an alternative way of capturing late-effect risk to the patient is to look at the organ systems that have been affected by care. For example, a patient who has survived Hodgkin's disease may be at risk for the following late effects, subdivided into the organ systems involved:<sup>1</sup>

- Cardiac—anthracycline exposure brings a risk of cardiomyopathy and radiation exposure carries a risk of pericarditis and valvulitis
- Immunologic—considerations if splenectomized, immunosuppression after treatment
- Musculoskeletal—premature osteoporosis and AVN (avascular necrosis) from steroids
- Endocrine—premature gonadal failure
- Genitourinary—hematuria from cyclophosphamide and nephrotoxicity from platinum agents
- Secondary malignancies.

### Education and Advocacy are Key

Research has shown that childhood cancer survivors often have knowledge deficits. One study showed that most of these patients could recall general treatment information—72 percent could recall the name of their disease, 94 percent knew that they had received chemotherapy, and 89 percent remembered receiving radiation. However, only 30 percent and 52 percent could recall if they had received the drugs daunorubicin or doxorubicin respectively—even when prompted with the names. And the study revealed that only 15 percent had written treatment summaries.<sup>4</sup> One of the goals at our Young Adult Follow-Up Multidisciplinary Clinic is to empower these survivors to become knowledgeable about their cancer history and encourage self advocacy. A major challenge during this transitional time is how to convert surveillance responsibilities from the parents to the young adult patient.

Young adults who survive cancer have other educational needs, including knowledge of 1) their risk factors for chronic conditions, 2) secondary malignancies, and 3) warning signs that should prompt immediate medical re-evaluation. Our Young Adult Follow-Up Multidisciplinary Clinic offers patients counseling about cancer and secondary prevention. For example, we counsel patients at risk for cataracts due to radiation, and we educate patients about early initiation of breast cancer screening when appropriate. These issues are extremely important. In fact, one childhood cancer study showed that these survivors are at higher risk for chronic health conditions, and at an earlier age than their siblings.<sup>5</sup> In this study, the cumula-

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**Table 2. Common Referrals Made from the Young Adult Multidisciplinary Center**

- Established contacts for secondary referrals include:
- The Congenital Heart Clinic at the Heart and Vascular Center has two pediatric cardiologists and an adult heart failure specialist
  - An orthopedic oncologist who has training in both pediatric and adult orthopedic care
  - An endocrinologist who also participates in the separate Endocrine Multidisciplinary Clinic at the Helen F. Graham Cancer Center
  - High-risk obstetrics and gynecology
  - Cancer patients with fertility issues are referred to Reproductive Associates
  - A behavioral health psychologist who assists patients with learning difficulties, provides recommendations for school, and performs neuropsychiatric testing
  - Primary care providers.

## Obstacles from the Patient, Family, and Providers

Patients can exhibit:

- Dependent behavior
- Immaturity
- Lack of trust
- Lack of adherence and compliance
- Psychological issues.

Family members can exhibit:

- A perceived need to maintain control
- A tendency toward over-protectiveness
- A heightened sense of continued disability.

Providers can exhibit:

- A lack of awareness of all potential problems
- A lack of anticipation about late effects and chronic conditions, leading to delays in diagnosis.

tive incidence of a chronic health condition reached 73.4 percent by 30 years after the diagnosis, with a cumulative incidence for severe disabling or life-threatening conditions of 42 percent.<sup>5</sup>


## Social and Financial Issues

The young adult cancer survivor and young adult active cancer patient have several social and financial issues in common. In fact, some of these factors are thought to potentially explain why young adult active cancer patients do not live as long as their younger and older counterparts. These factors include:<sup>6</sup>

- Lack of health insurance
- Employment issues
- Educational delay
- Severe disability
- Inadequate community resources
- Lack of awareness of special needs by employers, school personnel, and the community at large.

Our Young Adult Follow-Up Multidisciplinary Clinic has social workers, psychologists, and financial experts immediately available if an issue is discovered at the time of the patient's initial assessment.

Our efforts at the Helen F. Graham Cancer Center focus on maximizing our multidisciplinary resources to optimize our patients' outcomes and to help our patients lead the most productive adult lives possible. Future goals

at our Young Adult Follow-Up Multidisciplinary Clinic include continued expansion of trained referral bases, long-term data collection, tracking compliance of surveillance, and determining the impact of a proactive, ongoing approach to early detection of late effects of childhood cancer treatment. 

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## References

- <sup>1</sup>Schwartz C, Hobbie W, et al. *Survivors of Childhood and Adolescent Cancer: A Multidisciplinary Approach*. 2<sup>nd</sup> ed. Heidelberg: Springer, 2005. Pp. VII, 6-16.
- <sup>2</sup>Berkowitz I, Griffin G, et al. Young adult follow-up center: a collaborative program between the Helen F. Graham Cancer Center at Christiana Care and the Alfred I. DuPont Hospital for Children. *Del Med J*. 2004; 77(8):299-302.
- <sup>3</sup>Children's Oncology Group. *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers*. Version 1.2 March 2004.
- <sup>4</sup>Kadan-Lottick NS, Robison LL, et al. Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. *JAMA*. 2002;287:1832-1839.
- <sup>5</sup>Oeffinger K, Mertens A, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006; 355(15):1572-1582.
- <sup>6</sup>Bleyer A. Young adult oncology: the patients and their survival challenges. *CA A Cancer J for Clin*. 2007;57(4): 242-255.