

Delivering Effective & Meaningful Survivorship Care

by **Anita Chatigny, PhD, and
John S. Macdonald, MD, FACP**

As advances in early detection and more effective treatments dramatically increase survival rates for cancer patients, the rapid growth in the number of cancer survivors has become a catalyst for improving the transition from active treatment to post-treatment care, while also addressing the range of medical and psychosocial issues faced by survivors. This growing emphasis on cancer survivorship, defined by the Association of Community Cancer Centers (ACCC) as “the experience of living with, through, and beyond cancer for both patients and the peo-

ple in their lives who are impacted by the diagnosis,” underscores the necessity to develop and deliver comprehensive, effective, and meaningful survivorship care services.

Given the large and rapidly rising numbers of cancer survivors in the U.S. (currently more than 11.1 million people), as well as the remarkable 65 percent of newly diagnosed cancer patients who are expected to become at least five-year survivors, organized cancer survivorship services are increasingly becoming a key indicator in the provision of high-quality cancer care. As a result, we must recognize the



PHOTOGRAPH/BIGSTOCKPHOTO

...the optimal cancer survivorship program provides an integrated suite of both medical and supportive care services...

importance and uniqueness of the post-acute treatment and surveillance phase of the cancer patient—and apply chronic disease management models to cancer survivorship.

Meeting Survivors' Long-Term Needs

Survivorship care has received increased attention in the United States since the 2006 release of the Institute of Medicine (IOM) report, “From Cancer Patient to Cancer Survivor: Lost in Transition,” which alerted the oncology community that survivors’ follow-up care needs were not being met. The report describes four essential components of survivorship care for adults:

1. **Prevention** of recurrent and new cancers.
2. **Surveillance** for cancer spread, recurrence, or new cancers, and assessment of medical and psychosocial late effects.
3. **Intervention** for consequences of cancer and its treatment.
4. **Coordination** of care between specialists and primary care providers.

The report also included specific recommendations for a comprehensive care summary and follow-up plan written by the principal provider(s) of the oncology treatment. The IOM report notes that the plan should be clearly explained to the patient and should summarize essential patient information to inform all future healthcare providers.¹

Numerous organizations have since released national standards of care for both adult and pediatric cancer survivorship services, including those for specific cancers (e.g., breast and prostate cancers). However, patients all too often finish their primary cancer treatment without a specific course of action for managing the long-term challenges, lasting effects, and heightened risks associated with living beyond cancer.

Integrating Medical and Supportive Care Services

Ideally, the essential components of cancer survivorship services span patients’ continuing medical needs and care, including the coordination of care across provider systems, along with support that focuses on the broader educational, psychosocial, and rehabilitative needs of patients and their family members. Thus, the optimal cancer survivorship program provides an integrated suite of both medical and supportive care services; however, such fully developed programs remain rare.

To date, a range of survivorship care delivery models have been developed. These include:

- **One-time, consultative visit model.** Survivors attend a comprehensive program and receive a detailed follow-up plan that is implemented by their primary care physician.



- **Multi-visit model.** The oncologist and primary care provider share patient care. The role of each provider is clearly defined, with the primary care provider seeing the patient on an ongoing basis, while the oncologist typically sees the patient on an annual basis.
- **Ongoing model.** The survivor is followed through a specialized, academically based program—often nurse-led or provided by a multidisciplinary team.
- **Integrated model.** The patient’s primary oncology team provides survivorship care until it is deemed appropriate to transition the patient to the primary care provider.^{2,3}

Still other cancer survivorship services focus on subsets of the cancer patient population (e.g., by age range, primary disease, or disease stage). In the absence of formally structured survivorship services, some community cancer centers provide patients with some combination of educational materials, “graduation” ceremonies, and support groups and information about survivor-specific resources at the national and community levels.

A wealth of support resources exists to help community cancer centers develop cancer survivorship services. These tools and resources also help improve documentation of cancer treatments and facilitate improved communication among providers and their patients. For example, the American Society of Clinical Oncology (ASCO) has developed downloadable treatment plan and summary templates for chemotherapy, breast cancer, colon cancer, small cell lung cancer, and non-small cell lung cancer, which treating oncologists can use to tailor the treatment summary to meet their individual patients’ needs.⁴

'Seasons' of Survivorship

The concept of cancer survivorship as a progression of events was first described by Fitzhugh Mullan, MD, who shared his personal journey in "Seasons of Survival: Reflections of a Physician with Cancer," a 1985 article published in *The New England Journal of Medicine*. Dr. Mullan, co-founder of the National Coalition for Cancer Survivorship (NCCS), related three distinct "seasons" of survival:

- The **acute stage** when patients are in treatment and experience substantial fear, discomfort, and concerns about mortality
- The **extended stage** when, after therapy and during remission, uncertainties and physical limitations may persist, as well as changes in body image and issues of trust
- The **permanent stage** is described as the time in which cancer is not the first thought survivors have in the morning.¹

Twenty-five years later, Mullan's "seasons" were re-examined by Kenneth D. Miller, MD, director of the Lance Armstrong Foundation Adult Survivorship Program at Dana-Farber Cancer Institute and assistant professor, Harvard Medical School. Citing the many changes that have occurred with regard to diagnosis, treatment, and prognosis, Dr. Miller proposes following Mullan's acute stage with a transitional period, which can be defined as time when treatment ends and celebration blends with concern as the patient disengages from the treatment team. He also notes that while individuals in the long-term survivor stage may be cancer free, they may not be "free of cancer," because of chronic late and long-term health or psychosocial problems. Dr. Miller also suggests that survivorship care can be delivered within a multitude of care settings, meeting the needs of cancer survivors in each season of survivorship, thus improving each individual's long-term health.²

References

¹Mullan F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med*. 1985; 25;313(4):270-3.

²Miller K. *Medical and Psychosocial Care of the Cancer Survivor*. Sudbury, Massachusetts: Jones & Bartlett Publishers, Inc.; 2009: xviii-xix.

The Lance Armstrong Foundation (LAF), one of the most active private foundations in terms of cancer survivorship, provides a comprehensive online resource (www.LiveStrong.org), along with educational tools and brochures. LAF also promotes improved survivorship care through its LIVESTRONG Survivorship Centers of Excellence Network. This network facilitates the selection of cancer centers and community affiliates that then receive funding for development and implementation of survivorship programs.⁵

ACCC has an online resource on cancer survivorship (www.accc-cancer.org), which includes access to ACCC's publication, *Comprehensive Survivorship Services: A Practical Guide for Community Cancer Centers*; archived



Essential Elements for Developing Formal Cancer Survivorship Services

Los Angeles-based Aptium Oncology, a national leader in oncology consulting and management services, has integrated survivorship programs into the paradigm of cancer care. Aptium suggests six essential elements for developing formal cancer survivorship services at community cancer centers:

1. Significant support from senior leadership, including resource allocation to develop and maintain survivorship services.
2. Oncologist physician support from key physician leadership.
3. Nursing leadership support and the allocation of a nurse educator or, ideally, a FTE clinical specialist nurse coordinator position.
4. Significant participation of supportive care services staff resources (e.g., social worker, dietitian, psychologist or psychiatrist, rehabilitation or physical therapy services).
5. Collaboration with and referral patterns to all existing community cancer survivorship services providers.
6. Clear processes for ensuring that each primary care provider (PCP) who is following the cancer survivor has received an Active Treatment Summary and Cancer Survivorship Care Plan for that patient. Each PCP also needs to know how to easily refer the patient back to the cancer care provider, as appropriate, and should have access to phone consultation support related to the cancer survivorship care of the patient. Ideally, this support should be provided by the patient's oncologist and/or the clinical specialist nurse coordinator.

articles about model survivorship programs in community cancer centers across the country; and a comprehensive list of cancer survivorship resources.

Organizations such as ASCO, LAF, ACCC, and many other national and community-based cancer survivorship services, including the National Coalition for Cancer Survivorship (NCCS), The Wellness Community (TWC), and the National Cancer Institute (NCI), provide research and support resources, along with educational materials for both cancer survivors and healthcare professionals. Bottom line: in many medium-to-large metropolitan settings, no single provider organization needs to be the sole provider of cancer survivorship services.

Conquering the Challenges

A multitude of challenges must be addressed when implementing individualized active treatment summaries and plans for cancer survivors, including:

- **Access to required information.** Often, all pertinent data, such as treatment records, pathology reports, and information about other relevant events that occurred during treatment are not stored electronically. In many



Anatomy of a Treatment Summary and Survivorship Care Plan

Many long-term treatments, such as hormonal treatment for breast cancer, as well as chemotherapy or radiation, can have significant long-term effects on cognitive and endocrine function. Other late-onset effects may not present until six months or more following treatment. In addition, many patients have an increased risk of their cancer recurring and of developing secondary cancers, resulting either from treatment and/or the same risk factors that contributed to their first cancer. Therefore, one of the most important activities that must occur immediately following the initial active cancer treatment is to provide patients with a summary of their diagnosis and treatment, along with a specific care plan for ongoing follow-up. These two important tools will help reduce risks to the patient and ensure that recurrence is recognized as early as possible. We suggest a two-part treatment summary and survivorship care plan that provides a comprehensive record of a patient's cancer history, as well as recommendations for follow-up care.

Part I: Treatment Summary

- Date and details of the cancer diagnosis
- Type of cancer, location, stage, and histology
- Each treatment administered (e.g., date range, treatment type, chemotherapy or biotherapy regimen, drugs/dosages, radiation/site treated, surgical procedures, bone marrow transplants, clinical trials, etc.)
- Provider names and contact information
- Treatment facilities.

Part II: Follow-up Plan

- Disease-specific plan, including appointment scheduling and detailed recommendations for follow-up care (based on published guidelines, when available) and surveillance testing
- Preventive health and risk-reduction strategies
- Identification of late treatment effects (e.g., fatigue, depression, pain, impaired organ function, infertility, etc.)
- Education to facilitate identification and coping with survivorship needs
- Clear definitions of the responsibilities of cancer care providers and non-oncology-related providers, as well as psychosocial providers.

cases, a single provider is unlikely to have access to all requisite information.

- **Reimbursement for preparation time.** Preparing treatment summaries and plans requires significant time for clinicians and, to date, there remains a lack of third-party reimbursement. (Legislation is pending in Congress that would require Medicare to pay for cancer-survivorship plans.)
- **Research on impact of survivorship care plans.** There remains an absence of research with regard to care plans and patient outcomes that may call necessity into question. Still, a growing consensus among oncology physicians and nurses finds that treatment summaries and follow-up plans are essential to quality survivorship care.⁶

Nurses will likely play a key role in meeting the growing needs of cancer survivors and improving survivorship care. Oncology nurses routinely provide patients with guidance and support to ensure the best possible treatment outcomes and thus can naturally extend their role by preparing patients to transition from active cancer care to survivorship.⁷ In fact, the overall conclusion of a Cancer Survivorship Nursing Stakeholder Meeting held at the National Academy of Sciences was that nurses can assume a stronger role in helping cancer patients deal with survivor issues, ranging from late treatment effects and anxiety about body image, to fears of recurrence and transitioning to surveillance care.⁸

At the same time, multidisciplinary collaboration on development of surveillance guidelines and screening schedules is essential, as is support for the nurses' time in order to prepare the plan and review the plan with patients.

Ultimately, while barriers remain in the development,

funding, and management of a nationwide standard of cancer survivor care, survivorship care is emerging as a distinct component of the oncology continuum of care. Equally certain is that the growing number of cancer survivors demands innovative strategies and ongoing commitment to improving the quality and coordination of effective and meaningful post-cancer patient care. 📖

Anita Chatigny, PhD, is director of oncology supportive care services at the Comprehensive Cancer Center at Desert Regional Medical Center in Palm Springs, Calif., and John S. Macdonald, MD, FACP, is chief medical officer, Aptium Oncology, Inc.

References

- ¹Hewitt M, Greenfield S, Stovall E. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: National Academies Press; 2006.
- ²Landier W. Survivorship care: essential components and models of delivery. *Oncology*. 2009 Apr;23(4 Suppl Nurse Ed):46-53.
- ³Grant M. The evolving paradigm of adult cancer survivor care. *Oncology*. 2008 Apr;22(4 Suppl Nurse Ed):28.
- ⁴American Society of Clinical Oncology. ASCO Cancer Treatment Summaries. Available online at: <http://www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries>. Last accessed March 4, 2010.
- ⁵Lance Armstrong Foundation. The LIVESTRONG Survivorship Center of Excellence Network. Available online at: <http://www.livestrong.org>. Last accessed March 4, 2010.
- ⁶Houlihan NG. Transitioning to cancer survivorship: plans of care. *Oncology*. 2009 Jul;23(8 Suppl):49.
- ⁷Eastman P. Nurses urged to take strong leadership role in helping cancer patients become empowered cancer survivors. *Oncology Times*. 2006. December 10, 2006: 16-17.
- ⁸Cure Search: Children's Oncology Group. Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. Available online at: www.survivorshipguidelines.org. Last accessed April 20, 2010.

Meeting the Unique Needs of Pediatric Cancer Survivors

Prior to 1970, most children and young adults who were diagnosed with cancer had little hope of a cure. Since then, the cure rate—measured in five-year survival increments—has grown to more than 80 percent. However, in contrast to adult cancer survivors, pediatric patients are treated while their brains and bodies are still developing. Powerful anti-cancer treatments, such as chemotherapy and radiation, can have considerable long-term consequences that impact cognitive functioning, mobility, and fertility, along with an abundance of other physical and emotional issues. As a result, while the dramatic improvement in childhood cancer treatment is remarkable, that success comes at a price that more than two-thirds of pediatric cancer survivors pay in the years that follow.

The pediatric cancer program within The Cancer Institute at NYU Langone Medical Center, The Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders, has long taken an interdisciplinary and family-centered approach to children's cancer. This approach combines the most advanced medical treatments with psychosocial and emotional support services. Recently, the center has integrated a pediatric survivorship program to help ensure the type of long-term follow up that will adequately address the potential late effects of childhood cancer.

Drawing on the strengths of NYU Langone's pediatric oncology, neuro-oncology, and hematology programs, the Pediatric Survivorship Program was launched in early 2009, based on the Children's Oncology Group's (COG) long-term follow-up guidelines, which include tools to adequately screen and manage late effects of treatment.¹ Led by a pediatric nurse practitioner (PNP) certified in pediatric hematology and oncology, the launch followed extensive planning and preparation for this successful pilot with neuro-oncology patients.

According to the Children's Oncology Group, approximately two-thirds of childhood cancer survivors experience one or more late effect(s), while about one-third will experience a late effect that is severe or life-threatening. Equally significant is that the potential for developing long-term complications apparently does not decrease with time. As a result, NYU Langone's interdisciplinary team—consisting of the PNPs, along with a dietitian, psychologist, social worker, physician, recreational specialist, physical therapist, research coordinator and medical librarian—follows its young survivorship patients for the long term.

"The program's enrollment process is extensive," reports survivorship program coordinator Erin Hartnett, CPNP. "Patients may enroll in the program once

they have been off-treatment for two years. Each patient entering the survivorship program receives a complete physical examination, including screening for psychosocial, educational, and nutritional issues." She notes that late effects may include learning difficulties, endocrine problems, cardiovascular disease, hearing loss, low bone density, restrictive lung disease, high lipids, cataracts, and musculoskeletal difficulties, which may develop at any time. Survivors need to be monitored for late effects throughout their lifetime.

Additionally, the survivorship team meets with each family to educate them about the disease and recommended follow-up care. Families receive a binder that includes a comprehensive summary of the patient's course of treatment for personal reference, as well as for use by other clinicians. A flow sheet is included detailing the recommended follow-up care. Each patient is also given contact information for the program coordinators to address any questions or concerns.

A primary goal of the program is to accurately identify existing and potential late effects, so that the team can initiate appropriate monitoring and intervention. Significantly, this process resulted in the identification of a young cancer survivor who was struggling at school and subsequently received support from the center's psychology team to assist in resolving classroom issues. In another instance, a young teen cancer survivor was experiencing chronic anxiety related to his diagnosis and treatment during early childhood. The teen was appropriately screened and referred for more comprehensive counseling and additional support offered through the program.

To date, the Pediatric Survivorship Program at NYU Langone has several dozen patients enrolled and the numbers continue to grow. The Survivorship program is held monthly and has thus far received an overwhelmingly positive response from the families involved. While it was not that long ago that many pediatric patients did not live to adulthood, an overwhelming majority are now cured of their primary cancer. However, many of these young patients now face additional challenges directly related to the treatment that was administered during their developmental years. Survivorship programs are an essential part of comprehensive pediatric oncology care, and allow oncologists and primary care providers to be in a better position to help their pediatric patients maximize their future potential—and lead long, productive lives. ☺

References

¹Children's Oncology Group's Cure Search. Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. Available online at: <http://www.survivorshipguidelines.org/>. Last accessed March 4, 2010.

