

Cancer Survivorship

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The good news is that more patients than ever are surviving cancer. The challenge that this brings, however, is in providing resources, services, information, support, and education to meet the needs of cancer survivors, their families, and caregivers.

It is estimated there are approximately 12 million cancer survivors in the United States today.¹ According to groups including the National Cancer Institute, the National Coalition for Cancer Survivorship, and the Lance Armstrong Foundation, an individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition. The population of cancer survivors will continue to grow rapidly as our population ages and as advances in early detection and treatment allow more and more pediatric and adult cancer patients to live through and beyond cancer. Currently, more than 65% of adult and 78% of childhood cancer patients survive for at least 5 years beyond initial diagnosis²—but not without a cost. Rather than being seen as a death sentence as in previous generations, cancer is becoming conceptualized more as a chronic disease, especially for cancers such as prostate, breast, and colon where survival rates are quite high for patients when diagnosed in early stages. This chronic disease model of cancer argues for a greater focus on quality of life and health promotion to optimize functioning and prevent additional cancers as well as other chronic diseases for which cancer survivors may be at greater risk, such as diabetes and cardiovascular disease.³

Whereas most of the focus of cancer therapy is, importantly,

on eradicating or controlling the disease and saving lives, many survivors experience an array of enduring physical symptoms which may develop or persist for years after the completion of active cancer treatment.⁴ Not only can the disease itself cause lasting damage, but the side effects of treatment approaches—primarily chemotherapy, radiation therapy, surgery, and hormone therapy—can permanently damage various organ systems and can cause long-term functional impairment.^{5,6} Although there

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is substantial variation according to factors such as type and stage of cancer, type of treatment, and demographics such as age, survivors commonly experience problems such as fatigue, pain, neuropathies, and lymphedema. In addition, a growing body of evidence underscores the psychosocial impact of cancer on patients during both active treatment and subsequent survivorship. Psychosocial issues related to cancer include anxiety, depression, and fear of recurrence, which can lead to clinically significant problems in many cancer survivors and their families.⁷ The recent Institute of Medicine of the National Academies report, *Cancer Care for the Whole Patient: Meeting Psychosocial*

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Health Needs, has drawn widespread public and professional attention to this critical aspect of cancer care, but as yet the psychosocial needs of most cancer survivors are inadequately addressed.⁸

In 2006, the Institute of Medicine and National Research Council (IOM/NRC) issued the report *From Cancer Patient to Cancer Survivor: Lost in Transition*.⁵ This landmark report highlighted many of the problems that cancer patients face once initial treatment is completed. In particular, the report documented a problem with a lack of continuity of care and follow-up between the hospital/specialists that have provided the initial cancer treatment and the patient's subsequent return to the community health care provider. In the report, patients described the experience as feeling they were "dropped off a cliff" and that rather than a time of celebration, the end of active treatment can be the most frightening time since the initial diagnosis. Many patients report that once active treatment is over they feel they are no longer combating the illness, and they may experience a loss of support from the treatment team combined with ever-present uncertainty about cancer recurrence. In addition, survivors may face issues such as economic and employment problems, difficulties with medical expenses and health insurance, and adjusting to the "new normal" of living with and beyond cancer.

One of the key recommendations of the 2006 IOM/NRC report was to provide each patient with a treatment summary and a survivor care plan that includes recommendations for follow-up care and surveillance as well as for preventive behaviors such as smoking cessation, physical activity, and weight management. The treatment summary document serves as information and education for the patient as well as a way to transmit this information and recommendations to the primary care provider or whomever will be following up with the patient for primary health care. Currently several groups including the American Society of Clinical Oncology, the American Cancer Society, and the Lance Armstrong Foundation are actively developing templates and software to produce treatment summaries. It is anticipated that this will become a standard of care for all cancer survivors in the near future. In addition, patients and clinicians can utilize resources such as Oncolink/Oncolife from the University of Pennsylvania's Abramson Cancer Center (www.oncolink.org/oncolife) to generate survivorship care plans. Given the unique health information and support needs and interests of each patient, however, such care plans should be further tailored to the individual by the health care team. The National Cancer Institute also has a 'Facing Forward' series addressing some of these issues for patients and caregivers that is helpful during the transition from treatment to extended survival.

In North Carolina, cancer survivorship has emerged in recent years as a major focus of attention. The North Carolina Advisory Committee on Cancer Coordination and Control (A4C) has included survivorship in the State Cancer Plan and recently established a Survivorship Workgroup composed of key state officials, community advocates, cancer survivors, and researchers. The A4C, led by Walter L. Shepherd and supported

"Unstoppable is the best word to describe me. I was just 28 years old when diagnosed with stage I cervical cancer. After the surprise, crying and getting mad, I realized that I had to be strong not only for me but for my mother. Cancer gave me an opportunity to share my story with others. To realize what was truly important in life, family. So, 11 years later I am still unstoppable, doing volunteer work, raising awareness, and keeping active. Life does go on. I always say, surviving is the first step—living is what matters."

"Imparable, es la palabra que mejor describe a Marie. Solo tenía 28 años de edad cuando fui diagnosticada con etapa I de cáncer cervical. Luego de la sorpresa, los llantos y de darme coraje llegue a la realización que tenía que ser fuerte, no solo por mí sino por mi madre también. El haber tenido cáncer me dio la oportunidad de compartir mi historia con otros y ayudarlos. Me ayudo a reconocer lo que realmente era importante en esta vida, la familia. Así que, 11 años después sigo imparabile, realizando trabajo voluntario, llevando el mensaje que es cáncer a nuestra comunidad y manteniéndome activa. La vida continúa. Siempre digo, sobrevivir es el primer paso—vivir es lo que importa."

**— Marie
Cervical Cancer**

by legislative funding, has convened 2 highly successful statewide Survivorship Summits in June 2007 (Research Triangle Park) and June 2008 (Winston-Salem) that have focused on identifying and addressing the needs of cancer survivors.

North Carolina is fortunate to have 3 National Cancer Institute-designated Comprehensive Cancer Centers at Duke University, the University of North Carolina at Chapel Hill,

and Wake Forest University. Each Cancer Center is addressing survivorship needs with innovative programs and services. In January 2008, the University of North Carolina at Chapel Hill's Lineberger Comprehensive Cancer Center was awarded a prestigious Lance Armstrong Foundation (LAF) Center of Excellence in Cancer Survivorship. This Center, also supported by funds from the V Foundation, is 1 of 8 in the United States—and the only Center in the southeast—to have this designation. The mission of the UNC Lineberger Survivorship Center is to promote optimal health and well-being for cancer survivors by promoting outstanding clinical services, education, community outreach, and research. The approach is for every cancer patient to receive a Treatment Summary and Survivorship Care Plan at the end of active treatment, with appropriate follow-up and surveillance for their primary cancer and other risk factors, effective management of symptoms such as fatigue and pain, psychosocial support for the patient and family/caregivers, and health promotion advice and resources in order to ensure the best possible long-term quality of life.

Programs at Duke University Medical Center also reflect current practices with respect to survivorship care. The Duke Center for Cancer Survivorship (DCCS) was founded to broaden awareness of the diverse needs of patients, family members, and caregivers as they navigate the cancer journey, while providing an array of resources designed to help patients live fuller lives throughout treatment and survivorship. A multidisciplinary team of health care providers collaborates to provide family and individual counseling, support groups, self-image resources, multimedia patient education materials, physical and occupational therapy, and pharmaceutical and nutritional counseling. Recently the DCCS opened Duke's first long-term survivorship clinic for breast cancer survivors. The primary goal of this clinic is to empower patients to make healthy lifestyle choices that contribute to improved quality of life and to minimize the risks of secondary cancers and other illnesses.

Wake Forest University's Comprehensive Cancer Center addresses survivorship issues through their psychosocial oncology service, the Cancer Patient Support Program (CPSP). This program provides psychosocial support and counseling services that are integrated into the medical care of patients and extend

into survivorship. The program strives to enhance the quality of life of patients and family members during diagnosis, treatment, and survivorship. In addition to individual counseling, the program offers educational and appearance resources as well as referrals to community support and advocacy groups.

Recognizing the priority of cancer survivorship issues, Wake Forest is currently developing a survivorship program which will address long-term survivor issues including careful evaluation and check-ups, assessment for treatment-related problems, health promotion and health maintenance, and the psychosocial aspects of cancer survivorship.

In 2007, funds from the NC General Assembly established the University Cancer Research Fund (UCRF), a \$50 million annual appropriation to support cancer care and research. A major priority of this UCRF funding is to promote cancer survivorship research and the reduction of cancer health disparities across our state. The UNC Lineberger Comprehensive Cancer Center has spearheaded the establishment of a North Carolina Cancer Outreach Network with the goal of collaborating with communities, oncology centers, and hospitals in order to provide survivorship clinical care and education. In addition, the UCRF funds will support a landmark research cohort study that will follow cancer patients from initial diagnosis and treatment through long-term survivorship in order to better understand how to promote the health and well-being of this important population.

We are in the midst of an exciting time for cancer survivorship in North Carolina. Across the state there is evidence of growing interest, momentum, and commitment of resources to provide appropriate programs and services for cancer survivors and those who care for them. However we still have a way to go in terms of finding and disseminating optimum models for survivorship care and education as well as reaching survivors in all communities, especially those in rural areas, minorities, and the medically underserved. Research is urgently needed to better understand the needs of cancer survivors and to design and evaluate effective programs and interventions to meet these needs.⁹ Progress will require ongoing dedication and support from researchers, practitioners, patients, agencies, advocacy groups, legislators, and others working together to achieve these goals. **NCMJ**

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