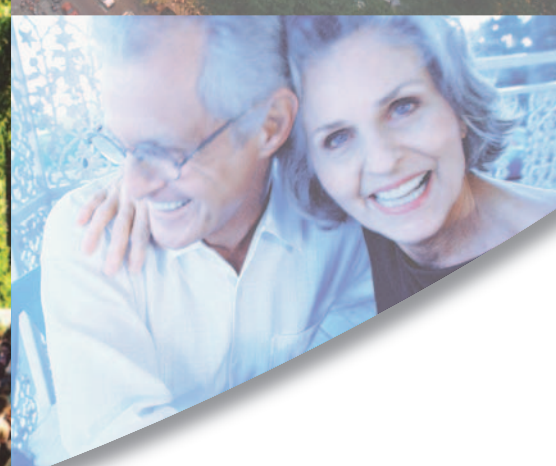


Section II: Connecticut Cancer Plan 2009 – 2013

B. The Continuum of Cancer Control

4. Survivorship

The Power of Unity.



SURVIVORSHIP COMMITTEE

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Hartford Hospital
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4. SURVIVORSHIP

Finding meaning in the cancer experience and learning to appreciate everyday life in a new way is commonly reported among cancer survivors. Yet, the experience of the diagnosis and treatment can produce long-lasting physical and psychological effects for patients and their families.¹ Although they are relieved to have completed treatment, anxiety and uncertainty often increase as they leave the health care team and the supportive treatment environment.² They may not know what to expect or how to begin to return to life after treatment.

In 2004, the Centers for Disease Control and Prevention, in partnership with the Lance Armstrong Foundation, produced a national action Plan for the public health community to address cancer survivorship.³ Some of its key objectives are: to increase awareness of cancer survivorship and its impact; train health care professionals to improve delivery of services and increase awareness of issues faced by cancer survivors; and ensure that all cancer survivors have adequate access to post-treatment follow-up services. In 2006, The Institute of Medicine published, *From Cancer Patient to Cancer Survivor: Lost in Transition*,⁴ which identifies unmet needs of and gaps in health care delivery for, cancer survivors. Also published by the Institute of Medicine, *Childhood Cancer Survivorship: Improving Care and Quality of Life*,⁵ notes “the intense effort to care for and cure a child with cancer does not end with survival. Continued surveillance and a variety of interventions may, in many cases, be needed to identify and care for consequences of treatment that can appear early or only after several decades and impair survivors’ health and quality of life.... A comprehensive policy agenda links improved health care delivery and follow-up, investments in education and training for health care providers, and expanded research to improve the long-term outlook for this growing population.”

Why this goal is important...

1. Rising Number of Survivors

- The number of cancer survivors in the U.S. today is approaching 11 million and is growing at a rate of about 3% per year.⁽¹⁾
- Although the majority of survivors successfully adapt to gradual physical and psychological recovery during the first year after treatment ends, about 20-25% report depressive symptoms.⁽²⁾

2. Changes in Connecticut’s Population

- Resources for supportive interventions may be limited in ambulatory care settings, where most survivors receive their treatment and care.

3. National Guidelines

The few national guidelines for follow-up that do exist are not well known or used by the average practitioner.

- There is often a lack of continuity of care for survivors across and within specialty care practices.

(1) Espey DK, Wu XC, Swan J, et. al. Annual report to the nation on the status of cancer, 1975-2004. *Cancer* 2007; 110(10):2119-2152.

(2) Redeker NS, Lev EL, Ruggiero J. Insomnia, Fatigue, Anxiety, Depression, and Quality of Life of Cancer Patients Undergoing Chemotherapy. *Research and Theory for Nursing Practice*. 2000; 14(4):275-290.

Goal: *To ensure a high quality of life and care for all Connecticut residents living with cancer and for their families*

Cancer patients and their families need to be empowered to make effective choices after treatment has been completed. With the passage of time, the needs of people who have had cancer change, with some requiring few services, while others need many resources to help them.

1. Rising number of survivors

Improvements in early detection and treatment, together with successful prevention efforts, have ensured that more Americans live with cancer than die from the disease (see Section II-A *The Burden of Cancer in Connecticut*). Persistent side effects from treatment can negatively affect the quality of life of many cancer survivors. Cancer survivors also are at risk for physical and psychological long-term or late effects of treatment, including second cancers, cardiovascular disease, diabetes, osteoporosis, and functional limitations. They also may experience problems with employment or insurance.⁶ Post-treatment, survivors often receive little direction and guidance about their return to work and expectations for productivity.⁷

Despite their higher prevalence of comorbidities, cancer survivors are less likely than people without cancer to engage in all types of preventive activities.⁸ A tremendous need thus exists for behavioral health interventions. There is considerable evidence that lifestyle interventions may decrease the risk of many post-treatment health problems among cancer survivors. These interventions include weight management, nutrition and diet (balancing fat, protein, and carbohydrate intake and increased consumption of fruits and vegetables), physical exercise, smoking cessation, limiting alcohol consumption and sun exposure, and getting appropriate screenings for new cancers.⁹

The growing number of persons living with cancer presents challenges to public health practitioners—to understand and address the needs of cancer survivors and to develop programs that promote their health and well-being. As noted in the National Action Plan for Cancer Survivorship¹⁰ four components are essential to survivorship care: *prevention* of recurrent and new cancers; *surveillance* for new or recurrent cancer and late effects; *intervention* for treatment effects and their impact on life; and *coordination* between oncology specialists and primary care providers to make sure needs are met.

2. Changes in Connecticut's Population

Not only are greater proportions of people surviving cancer, but also the number of elderly people in Connecticut is growing. As noted in Section II-A, *The Burden of Cancer in Connecticut*, the greatest risk factor for cancer is advanced age. For many older people, cancer and other health problems combine with the aging process to make the tasks of daily living more difficult. As the Connecticut population ages, increased efforts will be needed to Plan for the optimal health of older persons, many of whom will become cancer survivors.

Connecticut is also becoming more racially and ethnically diverse (see Section II-A, *The Burden of Cancer in Connecticut*). Overcoming the long-term residual side effects of treatment and post-treatment needs may be more challenging for minority and low-income population groups and those with cultural and/or language differences as a result of system barriers that affect both quality of life and treatment outcomes.

3. National Guidelines

Few guidelines exist for post-treatment surveillance of adult cancer survivors for persistent and late effects of treatment.¹¹ The American Society of Clinical Oncology (ASCO) has developed cancer treatment summaries for adjuvant treatment of breast and colorectal cancer, and a survivorship care Plan for those diagnosed and treated for breast and colon cancer.¹² In addition, ASCO published information on late effects,¹³ and the National Comprehensive Cancer Network produced Supportive Care Guidelines, some of which are relevant for survivors.¹⁴ The Childhood Oncology Group has developed clinical guidelines to address the needs laid out by the Institute of Medicine.¹⁵ It is important to monitor guideline development and make them available to both providers and patients.

Convincing data exist that obesity is associated with breast cancer recurrence and survival, and evidence on obesity and prognosis is also accumulating for other cancers.¹⁶

The Survivorship Committee formulated goals and objectives for Connecticut that interface with the aforementioned national goals and plans. Note to Reader: Measures, Targets, and Data sources may be found in the Appendix D. with a preface in the Implementation section: Tracking Plan Progress. All targets in the objectives are 2013 targets.

Survivorship Objectives

OBJECTIVE 1. Increase the proportion of provider referrals and cancer survivors who access and use survivor support services.

Strategies:

1. Develop a system of monitoring utilization of survivor services over time.
2. Develop mechanisms to identify and address deficiencies and gaps in services for populations of interest, including but not limited to, survivors with less common forms of cancer.
3. Maintain and update resource inventory and accessible centralized clearinghouse; market availability to providers and patients.
4. Educate community members, groups, and organizations about survivor issues and the value of support services (during and post-treatment) and how to access services, with special focus on reaching underserved population groups.
5. Coordinate with Patient Navigators and similar service coordinators to assure survivor services are provided and included in referral options.

OBJECTIVE 2. Increase the number of health care providers who are knowledgeable about survivorship care.

Strategies:

1. Monitor the release of survivorship care guidelines and information, and make the guidelines and information available on the Partnership web site.
2. Partner with academic institutions and professional organizations to develop and offer educational opportunities for health care providers on topics such as survivorship issues and care guidelines.
3. Use the Partnership web calendar to provide timely notification of educational opportunities, conferences, and continuing education on survivorship.

OBJECTIVE 3. Increase the number of providers, families, and caregivers who are knowledgeable about the needs of children surviving cancer.

Strategies:

1. Support efforts of pediatric cancer programs in state to follow guidelines on follow-up care for survivors of childhood cancers.
2. Partner with community and professional organizations, faith-based groups, and academic institutions to develop and offer educational opportunities on the needs of childhood cancer survivors.

OBJECTIVE 4. Increase the proportion of cancer survivors who practice positive health behaviors regarding weight, diet, physical activity, tobacco and alcohol use, sun exposure, and cancer screenings, using culturally appropriate methods.

Strategies:

1. Partner with insurance companies and/or academic institutions to monitor and report on survivor health status and health risk behaviors.
2. Engage providers, key stakeholders, and other initiatives to disseminate, promote, and use national recommendations for routine physical activity and healthy food choices, such as the *American Cancer Society guide for Informed Choices on Nutrition and Physical Activity during and after Cancer Treatment*.¹⁷
3. Disseminate information on the importance of psychological screenings to address depression and other factors that may affect quality of life.
4. Advocate for insurance coverage of screening and wellness programs.
5. Develop culturally appropriate activities and methods of improving health literacy for providing information to low literacy and non-English speaking cancer survivors.

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