

The Survivorship Center Year 03 Executive Summary

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The Survivorship Center Update

The National Cancer Survivorship Resource Center (The Survivorship Center) just wrapped up Year 03 of the five year cooperative agreement and is making great strides in addressing the immediate need for services and resources for the 13.7 million cancer survivors living today. The Survivorship Center's three major aims are; 1) improve the quality of life of cancer survivors and caregivers, 2) reduce death and disabilities due to cancer by focusing on the importance of improving functioning and helping survivors achieve optimal health and well-being, and 3) advance survivorship as a distinct phase of cancer care, promote healthy behaviors to reduce late and long-term effects of cancer and its treatment, and improve surveillance and screening practices to detect the return of cancer. The Survivorship Center's activities are based around three levels of the socio economic model: survivors, health care systems and policy. Patient and provider tools and resources have been developed to address the issues and gaps of post-treatment care in these areas.

Survivor-Focused Resources

The Survivorship Center has developed resources to assist survivors. These resources provide evidence-based information and seek to empower survivors to make informed decisions and manage their post-treatment care.

- **The Survivorship Center website**

The website provides access to resources, white papers and updates on the latest deliverables and activities. Please visit The Survivorship Center website at: www.cancer.org/survivorshipcenter.

- **The Survivorship Center email**

Please send any questions or comments to us at survivorship@cancer.org.

- **Life After Treatment Guide**

A concise booklet for post-treatment survivors that provides information about common survivorship late effects, defines a treatment summary and a survivorship care plan, lists online resources for information, and provides tips for how survivors can use the information they find online to communicate with their health care team. The booklet is available for free download at: www.cancer.org/survivorshipguide. (Free copies available in the distribution center #.004598).

- **“Cancer: Thriving and Surviving” Chronic Disease Self-Management Pilot**

Chronic disease self-management (CDSM) is a widely used concept to help adults advocate for themselves during their health care and manage multiple chronic conditions. Building upon the success with other disease-specific self-management programs, Stanford University developed a program for post-treatment cancer survivors called “Cancer: Thriving and Surviving.” The program is

a six-week, asynchronous online workshop that is facilitated by two trained cancer survivors. The workshop features self-management content, bulletin board discussion groups, and interactive self-management tools.

The Society is conducting a program pilot of the “Cancer: Thriving and Surviving” workshop to identify the most effective strategies for recruiting workshop participants and to determine the feasibility of delivering the workshop within the Society’s volunteer structure. Key health outcomes are being evaluated to determine the impact of the workshop on common survivorship issues. Potential workshop facilitators were recruited through ACS Divisions in the summer of 2012. Twenty-six (26) volunteers were invited to participate in the nine-week facilitator training. Eighteen (18) volunteers accepted the invitation and eight successfully completed the training. The Society exceeded the original recruitment goal of 600 and enrolled a total of 857 post-treatment cancer survivors between October 2012 and July 2013. Twelve workshops were delivered between November 2012 and September 2013.

To evaluate the pilot, participants will complete baseline, 6-month, and 12-month surveys capturing information on self-efficacy, health behaviors, disease control, health outcomes, health care utilization and workplace productivity. Collection of 6-month follow-up data began in June 2013 and will continue through April 2014. 12-month data collection will begin in December 2013 and continue through approximately October 2014. Additional satisfaction survey data is also being collected, as well as qualitative exploration of discussion board content. The Society will utilize the program evaluation to assess the potential of offering a CDSM program as a resource to post-treatment survivors nationwide.

Health Care Systems-Focused Resources

The Survivorship Center has developed resources to impact the delivery of survivorship care. These resources make it easier for health care systems to implement survivorship care within their facilities.

- **Prescription for Cancer Information**

Similar to a prescription pad, this is a communication resource for healthcare professionals to easily refer survivors to resources available in their office or clinic, in their community, via the telephone and online. The prescription pad is available for free download at www.cancer.org/survivorshipprescription. *(Free copies available in the distribution center # .004599).*

- **Moving Beyond Patient Satisfaction: Tips to Measure Program Impact Guide**

This Guide provides tips to measure program impact. Suggested measures include program satisfaction, program attrition and past participant referrals. The Guide also provides a list of validated tools to help programs evaluate impact on key quality of life outcomes. The Guide is available for free download at: www.cancer.org/survivorshipprogramevaluation.

- **Cancer Survivor Program Resource Inventory**

The Cancer Survivor Resource Inventory Survey collected information about post-treatment resources and support services offered through Commission on Cancer (CoC)- accredited facilities. The information captured will be incorporated into the cancer resource connection and help inform a gap analysis and manuscript identifying programmatic priorities to address post-treatment issues. Initial data collection began in April 2012 with Florida and New England Divisions as pilot sites.

Division staff engagement resulted in impressive response rates of 60% and 56% respectively. In early 2013, the survey was administered via email across the remaining Divisions over a 6-month period, resulting in a response rate of approximately 33%. Data analysis and compilation is currently underway.

Health Care Provider-Focused Resources

The Survivorship Center has developed resources to educate health care providers on survivors' needs and provide guidance to improve post-treatment clinical follow-up care.

- **Survivorship Clinical Care Guidelines**

The Survivorship Center is coordinating the work of experts in oncology, primary care, and other health care professions to develop follow-up care guidelines for 10 priority cancer sites. The guidelines are aimed at primary care providers to better equip them to deliver comprehensive patient-centered care following treatment for cancer. The guidelines include components addressing healthy behaviors, physical/sexual/psychosocial long-term and late effects, screening for new cancers, surveillance for recurrent cancers, genetic counseling and coordination of care among specialists and primary care providers.

A recently published article shares the formative work for the development of the survivorship clinical care guidelines. **CA: A Cancer Journal for Clinicians**, "Advancing Survivorship Care through the National Cancer Survivorship Resource Center: Developing American Cancer Society Guidelines for Primary Care Providers," May/June 2013, Volume 63, Number 3, pages 147-150. To learn more, read the article at: <http://onlinelibrary.wiley.com/doi/10.3322/caac.21183/pdf>.

On May 23, 2013, the National Board of Directors (NBOD) approved post-treatment clinical care follow-up guidelines for breast, prostate and colorectal cancers. Manuscript development is underway with an anticipated submission to CA for publication in early 2014. Draft post-treatment clinical follow-up guidelines for head and neck cancer are being developed and will likely be submitted for approval by the NBOD in spring 2014 with publication in CA following shortly after. The Survivorship Center also plans to develop guidelines to address post-treatment clinical follow-up care for gynecologic cancers, lung cancer and melanoma.

- **Primary Care Provider (PCPs) Education**

The growing number of cancer survivors combined with a looming shortage of oncology specialists will require greater coordination of post-treatment care responsibilities between oncologists and PCPs. 70% of all cancer survivors have at least one comorbid condition and are likely to be regularly seen by a PCP to address these and other issues. Training of health care provider teams on delivering survivorship care is imperative for quality care.

The George Washington Cancer Institute, in collaboration with The Society as part of The Survivorship Center's work, developed the *Cancer Survivorship E-Learning Series for Primary Care Providers*. This online resource features content on the role of clinical generalists and specialists in providing follow-up care to cancer survivors, how to manage late and long-term medical and psychosocial effects of cancer and its treatments, and the importance of survivorship care planning. Free continuing education credits for physicians, physician assistants, nurse practitioners and nurses are available. The e-learning series supports the dissemination of post-treatment survivorship

education and the clinical follow-up care guidelines to primary care providers. To learn more, please visit: <https://cancersurvivorshipcentereducation.org>.

Policy & Advocacy Focused Resources

Survivorship is a critical stage in the cancer journey. The focus of the Survivorship Center's policy advocacy efforts is to increase awareness of survivorship among U.S. policy and decision-makers, as well as, to further the development and implementation of policies to promote the delivery of high-quality services to cancer survivors. Resources are available on our website and others are underway.

- **Landscape Analysis**

The paper provides an overview of the current policies related to survivorship care, reimbursement for services and research funding. Available for free download at: www.cancer.org/survivorshippolicypapers.

- **Survivorship as a Public Health Priority**

A manuscript is in development to highlight the relevance of survivorship as a public health priority and frame survivorship within the context of chronic disease. It is anticipated that the manuscript will be submitted for publication in fall 2013.

If you would like to know more about The Survivorship Center, please feel free to contact Patrice Bowles (404-329-7764, Patrice.bowles@cancer.org) with questions.

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