



Cancer Survivorship

SURVIVE CANCER AND LIVE



CENTERS FOR DISEASE
CONTROL AND PREVENTION

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Who Are Cancer Survivors?

Cancer survivors are people who have been diagnosed with cancer and those people in their lives who are affected by the diagnosis, including family members, friends, and caregivers.

The National Action Plan



The Centers for Disease Control and Prevention collaborated with the Lance Armstrong Foundation and key partners, including numerous not-for-profit organizations, advocates, survivors, and researchers, to identify and prioritize cancer survivorship needs within a public health context. Through this partnership, *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* was developed.

The *National Action Plan* can be used by governmental agencies, private and not-for-profit organizations, and individuals to select and develop activities that best suit their available resources and missions. The implementation of this *National Action Plan* will increase awareness and stimulate action to improve the overall experience and quality of life for the millions of Americans who are living with, through, and beyond cancer.

If you would like to order a copy of *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*, please visit our Web site at www.cdc.gov/cancer.



Redefining a Cancer Survivor and Public Health's Role in Cancer Survivorship



The term “cancer survivor” is now commonly used to describe a person from the time of cancer diagnosis through the remaining years of life. The *National Action Plan* supports expanding the definition of cancer survivor to include caregivers, family members, and friends.

Survivors face numerous physical, psychological, social, spiritual, and financial issues at diagnosis, during treatment, and throughout the remaining years of their lives. Cancer survivors could benefit tremendously from a coordinated public health effort to address their quality of life throughout the cancer experience.

The public health community could play an integral role in increasing the understanding of the physical, emotional, spiritual, and social effects of cancer, as well as applying existing knowledge about potential interventions for improving survivors’ quality of life. Creating and implementing successful strategies to help the millions of people who live with, through, and beyond cancer remain the overarching goals of survivorship efforts.

The Cancer Burden: Facts and Hope for the Future

Cancer is the second leading cause of death in the United States, causing 1 of every 4 deaths each year (ACS, 2004). Everyone is at risk of developing some form of cancer. Cancer incidence varies by race and ethnicity, with some groups being more susceptible to certain types of cancers than others. Age is also a primary risk factor for most cancers, with about 77% of all cancers diagnosed among people aged 55 or older. If current trends continue, one-third of Americans will be diagnosed with cancer in their lifetimes (NCI, 2003a).

Improvements in screening practices and rates, early detection, and cancer treatment and care are allowing more and more people to live “beyond” cancer each year. The number of people affected by cancer, both those diagnosed with the disease and their families and friends, is substantial. As of January 2000, approximately 9.6 million people with cancer were living in the United States (NCI, 2003a), and this number does not include others affected such as family members, caregivers, and friends of cancer patients. Scientists expect the number of survivors to increase steadily over the coming years.

References:

American Cancer Society (ACS). *Cancer Facts & Figures 2004*. Atlanta, GA: American Cancer Society; 2004.

National Cancer Institute (NCI). *Cancer Control and Population Sciences: Research Findings* [on-line]. Available at: <http://dccps.nci.nih.gov/ocs/prevalence/index.html>; 2003a.

“Together CDC and the LAF are charting a new course for the public health community to help cancer survivors enjoy all the wonderful things life has to offer.”

Julie Gerberding, MD, MPH
Director of the Centers for Disease Control
and Prevention

23 Recommended Needs



Using core public health functions and services as a guide, the *National Action Plan* identifies priority needs within four public health areas: surveillance and applied research; communication, education, and training; programs, policies and infrastructure; and access to quality care and services. The following list includes 5 cross-cutting and 18 priority needs that were identified through the development process. Strategies for addressing these needs are detailed in the *National Action Plan*.

Cross-cutting Needs:

1. Develop an infrastructure for a comprehensive database on cancer survivorship.
2. Develop, test, maintain, and promote patient navigation systems that can facilitate optimum care for cancer survivors.
3. Establish and/or disseminate clinical practice guidelines for each stage of cancer survivorship.
4. Develop and disseminate public education programs that empower cancer survivors to make informed decisions.
5. Conduct ongoing evaluation of activities to determine their impacts and outcomes and ensure continuous quality improvement of services.

Priority Needs:

6. Enhance the existing surveillance and applied research infrastructure.
7. Identify factors associated with ongoing health concerns of cancer survivors.
8. Determine programs and services that best address the needs of cancer survivors.

9. Conduct research on preventive interventions to evaluate their impact on issues related to cancer survivorship.
10. Translate applied research into practice.
11. Develop strategies to educate the public that cancer is a chronic disease people can and do survive.
12. Educate policy- and decision-makers about the role and value of providing long-term follow-up care, addressing quality-of-life issues and legal needs, and ensuring access to clinical trials and ancillary services for cancer survivors.
13. Empower survivors with advocacy skills.
14. Teach survivors how to access and evaluate available information.
15. Educate health care providers about cancer survivorship from diagnosis through long-term treatment and end-of-life care.
16. Identify and implement programs proven to be effective (i.e., best practices).
17. Implement evidence-based cancer plans that include goals and strategies for all stages of cancer survivorship.
18. Promote policy changes that support addressing cancer as a long-term, chronic disease.
19. Develop infrastructure to obtain quality data on all cancer management activities to support programmatic action.
20. Educate decision-makers about economic and insurance barriers related to health care for cancer survivors.
21. Establish and/or disseminate guidelines that support quality and timely service provision to cancer survivors.
22. Assess and enhance provision of palliative services to cancer survivors.
23. Establish integrated multidisciplinary teams of health care providers for cancer patients.

Survivorship in Action

The Centers for Disease Control and Prevention (CDC) addresses cancer survivorship issues in two of its national programs. First, the National Program of Cancer Registries (NPCR) collects data on the occurrences of cancer; the type, extent, and location of the cancer; and the type of treatment. With this information, scientists can explore possible data links that may suggest areas for improvements in quality of life for those living beyond their cancer experience.



In 2003, CDC supported the NPCR in 45 states, the District of Columbia, and 3 territories. Data collected from these registries enable public health professionals to better understand and address the cancer burden. Currently, CDC supports research in 10 states to estimate the proportion of patients who receive the recommended standard of care for prostate, breast, and colon cancers. In addition, patterns of care for these cancers will be described according to patient and disease characteristics, comorbid conditions, and insurance coverage.

The National Comprehensive Cancer Control Program (NCCCCP) is an integrated, coordinated approach to reducing the impact of cancer that includes monitoring, policy, research, education, programs, services, and evaluation. In 2003, CDC

supported comprehensive cancer control activities in 45 states, the District of Columbia, and 5 tribes and tribal organizations. Through these programs many states already are making a difference. For example, the Michigan Department of Community Health initiated the “Michigan Cancer Consortium” to provide newly diagnosed prostate cancer survivors with educational materials to assist them in making informed decisions about treatment options and maintaining personal control over their lives. North Carolina organized “The Care Subcommittee” that focuses on cancer survivorship issues such as financial needs, pain control, education and awareness, and access to care. This subcommittee has produced a video entitled “Living without Cancer Pain: A North Carolina Success Story.” The Care Subcommittee partnered with East Carolina University to link rural health care providers and urban cancer centers so that optimal care can be provided to cancer survivors in rural and remote locations across the state.

How to Order the National Action Plan

To learn how public health efforts can improve the lives of cancer survivors, you may order a copy of *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* by visiting our Web site at [www. cdc.gov/cancer](http://www.cdc.gov/cancer)





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