

## II. STRATEGIC FRAMEWORK

CDC and LAF collaborated in 2002 to comprehensively address cancer survivorship within the realm of public health. Through a series of subsequent meetings among key partners (Appendix A), areas within public health that could be enhanced to address cancer survivorship were identified.

To expand these efforts to additional partners, including numerous organizations, advocates, survivors, and researchers, the CDC and the LAF conducted a workshop in June 2003 entitled *Building Partnerships to Advance Cancer Survivorship and Public Health*. This 2-day workshop brought together nearly 100 experts from multiple disciplines to discuss how public health can be mobilized to address cancer survivorship in the identified public health areas. Using the core public health functions and services as a guide (see Section I.D.), participants were led through a process to identify priority needs in the following four identified topic areas within the realm of public health:

- Surveillance and applied research
- Communication, education, and training
- Programs, policies, and infrastructure
- Access to quality care and services

The culmination of these efforts is *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*. This National Action Plan provides a vision and a framework for addressing the problems faced by cancer survivors in our nation. It further proposes strategic initiatives that would constitute a coordinated, responsible approach within the entire public health structure, including at the national, state, and community levels. This National Action Plan is groundbreaking in that it outlines a comprehensive, systematic public health approach to acknowledging and addressing cancer survivorship.

### A. Purpose

The goal of this National Action Plan is to identify and prioritize cancer survivorship needs and identify strategies within public health to address those needs that will ultimately lead to improved quality of life for the millions of Americans who are living with, through, and beyond cancer. A first step in addressing these needs is to develop strong partnerships with health professionals, researchers, survivors, advocates, and other key stakeholders. These partnerships will serve to identify and prioritize the steps necessary to integrate cancer

survivorship issues into the public health domain. Outcomes of the National Action Plan's development include the following:

- Laying the foundation for public health activities in cancer survivorship.
- Identifying, discussing, and prioritizing strategies to expand and enhance the role of public health agencies and practitioners in cancer survivorship.
- Facilitating the development and enhancement of collaborations and partnerships that will assist with the expansion of public health's role in cancer survivorship.

## **B. Overarching Goals and Objectives**

The overarching goal of this National Action Plan is to establish a coordinated national effort for addressing cancer survivorship within the realm of public health. Specific objectives include the following:

- Achieve the cancer survivorship-related objectives in **Healthy People 2010** (Appendix B) that include benchmarks for success in measuring improvements for addressing ongoing survivor needs.
- Increase awareness among the general public, policy makers, survivors, and others of cancer survivorship and its impact.
- Establish a solid base of applied research and scientific knowledge on the ongoing physical, psychological, social, spiritual, and economic issues facing cancer survivors.
- Identify appropriate mechanisms and resources for ongoing surveillance of people living with, through, and beyond cancer.
- Establish or maintain training for health care professionals to improve delivery of services and increase awareness of issues faced by cancer survivors.
- Implement effective and proven programs and policies to address cancer survivorship more comprehensively.
- Ensure that all cancer survivors have adequate access to high-quality treatment and other post-treatment follow-up services.
- Implement an evaluation methodology that will monitor quality and effectiveness of the outcomes of this initiative.

## **C. Guidelines for the National Action Plan**

Addressing and achieving the National Action Plan's goals and objectives require a multifaceted approach that is both ambitious and feasible. The National Action Plan consists of prioritized needs and strategies in four major areas of public health work, which are defined below: surveillance and applied research; communication, education, and training; programs, policies, and infrastructure; and access to quality care and services.

### **C.1 Surveillance and Applied Research**

**Surveillance and applied research** are the scientific tools of public health and can be used to establish a solid, systematic knowledge base in cancer survivorship.

#### *Surveillance*

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Cancer surveillance is the systematic collection, analysis, and use of cancer data. Information obtained through surveillance measures is critical for directing effective cancer prevention and control programs (CDC, 2001). Primary surveillance measures include cancer registries and several national and regional/state surveys. Cancer registries (National Program of Cancer Registries [NPCR]; Surveillance, Epidemiology, and End Results [SEER] Program) implement and maintain information systems designed to collect and manage data on each newly diagnosed case of cancer. National surveys, such as the National Health Interview Survey (NHIS) and the Behavioral Risk Factor Surveillance System (BRFSS), provide information on health attitudes, beliefs, and behaviors that could be used to help understand issues related to all stages of cancer survivorship.

#### *Applied Research*

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Cancer survivorship research in a public health context would focus efforts on applying our knowledge of cancer and issues survivors face to the development of appropriate interventions. Understanding specific structural, policy, or behavioral barriers to desired outcomes and evaluating programmatic efforts are other examples of applied research. Applied research investigates the extent to which these efforts effectively address survivor needs and provides findings that can guide further development of initiatives.

### **C.2 Communication, Education, and Training**

**Communication, education, and training** include efforts to communicate with the general public and policy and decision makers, educate survivors and their families, and train **health care providers**

to meet informational needs of all those affected by cancer survivorship.

#### *Communication with the Public*

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Communication with the general public and policy or decision makers about the issues surrounding cancer survivorship aims to create a societal understanding and acceptance of the growing population of cancer survivors and the issues they face.

#### *Survivor Education*

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Education of cancer survivors includes provision of information tailored to the particular stage of survivorship. Such educational interventions may be most appropriate during the first 5 years after diagnosis as this is the time when many of the challenges associated with the adjustment to survivorship occur (Mullan, 1984).

#### *Provider Training*

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Health care provider training aims to ensure that providers are aware of the medical and other special needs of cancer survivors so they can offer the spectrum of services available to enhance quality of life throughout survivorship and refer survivors to these services as appropriate.

### **C.3 Programs, Policies, and Infrastructure**

**Programs, policies, and infrastructure** are the means by which change can be made in public health.

#### *Programs*

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Programs are the actual implementation of specific interventions at the national, state, and community levels to address a public health problem (NAAP, 1999). Medical, psychosocial, legal, and financial issues could be addressed by programs that are comprehensive in scope and encompass care for each stage of cancer survivorship.

#### *Policies*

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Policies include legislation, regulations, ordinances, guidelines, and norms that establish an environment conducive to program implementation and other changes specific to survivorship (NAAP, 1999). These policies may be implemented at the national, state, organizational, and community levels in an effort to advance public health.

## *Infrastructure*

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Infrastructure is comprised of the basic resources and facilities in place to address survivorship and includes components of the health care and public health systems, such as state and local health departments, and the services and programs they provide. Effective infrastructure is required to operate and manage effective programs. As our health care system continues to evolve, delivery of quality care becomes more complex. Relationships among the public and private sectors, individual practitioners and managed care organizations, and voluntary health organizations directly influence access to care and provision of clinical and community services (NAAP, 1999).

### **C.4 Access to Quality Care and Services**

**Access to quality care and services** means ensuring that survivors have access to evidence-based and appropriate treatment and services delivered in a timely and technically competent manner, with good communication, shared decision making between the cancer survivor and health care providers, and cultural sensitivity across the continuum of care and throughout the remainder of life (IOM, 1999). Public health can play a role in identifying and disseminating proven programs in the following areas to groups of cancer survivors.

#### *Access to Quality Treatment*

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Cancer treatment is complex and differs for each individual based on his or her specific situation and needs. All cancer patients should have timely access to the latest and most effective treatments available. This would include **clinical trials**, if appropriate.

#### *Pain and Symptom Management*

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An important part of cancer treatment is the management of pain and other symptoms associated with both disease and treatment. The goal of pain and symptom management is to provide relief so that survivors can tolerate the diagnostic and therapeutic procedures needed to treat their cancer and live comfortably throughout each stage of cancer survivorship.

#### *End-of-Life Care*

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Issues facing survivors and their families during end-of-life are complex and serious. Appropriate end-of-life care affirms life and regards dying as a normal process, neither hastening nor postponing death. The goal of end-of-life care is to achieve the best possible quality of life for cancer survivors. Although many survivors live many years beyond their diagnosis, the needs and desires of those who are in the process of dying must be addressed.

Lindy, Cancer Survivor



*“Survivorship means I get to watch my grandchildren growing up.”*