

## I. BACKGROUND

The number of people affected by cancer, both individuals diagnosed with the disease and their families and friends, is staggering. Although all Americans are at **risk** of a cancer diagnosis in their lifetimes, there have been remarkable reductions in deaths associated with cancer. These reductions in deaths are largely due to the implementation of prevention and early detection efforts for certain cancers, increased screening of the general population and those at highest risk for developing these diseases, and advances in research and clinical care. As of January 2000, there were approximately 9.6 million persons living following a cancer diagnosis in the United States (NCI, 2003a) not including family members, friends, and caregivers. This number is expected to increase steadily over the coming years.

*A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* was developed through a partnership between the Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation (LAF). Through this partnership and with input from a variety of experts and advocates in public health and cancer survivorship, this National Action Plan charts a course for how the public health community can more effectively and comprehensively address cancer survivorship, including the following:

- Preventing secondary cancers and recurrence of cancer whenever possible.
- Promoting appropriate management following diagnosis and/or treatment to ensure the maximum number of years of healthy life for cancer survivors.
- Minimizing preventable pain, disability, and psychosocial distress for those living with, through, and beyond cancer.
- Supporting cancer survivors in accessing the resources and the family, peer, and community support they need to cope with their disease.

The goal of this National Action Plan is to advance public health efforts regarding cancer survivorship to actively address the needs of this growing population.

The following section describes elements important to understanding the issues cancer survivors face. Throughout this National Action Plan, the term “**cancer survivors**” refers to those people who have been diagnosed with cancer and the people in their lives who are affected by their diagnosis, including family members, friends, and caregivers.

## A. The Cancer Burden

Everyone is potentially at risk for developing some form of **cancer**. The American Cancer Society (ACS) predicts that as many as 1.3 million new cancer cases will be diagnosed in 2003 (ACS, 2003). Age is a primary **risk factor** for most cancers, with about 77% of all cancers diagnosed among individuals aged 55 or older. Cancer **incidence** varies by race and ethnicity, with some groups being more likely to be diagnosed with certain types of cancers than others. Cancer is the second leading cause of death in the United States, causing 1 of every 4 deaths each year (ACS, 2004). If current trends continue, one-third of Americans will be diagnosed with cancer in their lifetimes (NCI, 2003a). There is a great deal of misunderstanding about cancer, the effects it can have on those diagnosed with it, and the importance of addressing the ongoing needs of survivors as progress is made in finding treatments and prolonging life after diagnosis.

### **How many people are expected to survive cancer?**

As previously noted, there were approximately 9.6 million persons living following a cancer diagnosis in the United States as of January 2000 (NCI, 2003a) not including family members, friends, and caregivers. Survival rates from cancer depend a great deal on the site where the initial growth began (e.g., breast, colon) and the stage of progression at which the cancer was diagnosed (i.e., whether the growth has **metastasized**). The implementation of prevention (tobacco control and skin protective behavior) and early detection efforts for four cancer types (breast, cervical, colorectal, and prostate), which has increased screening of the general population and those at highest risk for developing these diseases, and advances in research and clinical care have led to remarkable reductions in cancer-related mortality.

Despite the optimistic outlook for most individuals diagnosed with cancer today, a closer examination of the literature and of statistical trends indicates that the benefits of current knowledge about state-of-the-art cancer care are not shared equally by all members of our society (Aziz & Rowland, 2003). When survival rates are broken down by race/ethnicity, it is clear that significant differences exist across racial/ethnic minority and medically underserved populations with respect to the risk of developing and dying from cancer. For all cancer sites combined, African Americans are more likely to develop and die from cancer than persons of any other racial or ethnic group. They are also at greater risk of dying of the four most

common types of cancer (lung, breast, colon, and prostate cancer) than any other minority group (ACS, 2004).

## **B. Redefining Cancer Survivorship**

When cancer was considered incurable, the term “survivor” was used to describe family members who survived the loss of a loved one to cancer (Leigh, 1996). As knowledge and success in understanding cancer increased, physicians began to use a 5-year time frame to define survivorship. If cancer did not recur in the 5 years following either diagnosis or treatment, patients were considered to have become “survivors” (Leigh, 1996).

As a result of strong advocacy efforts and coordination led by such organizations as the National Coalition for Cancer Survivorship (NCCS), the term “cancer survivor” has been redefined. The term is now commonly used to describe an individual from the time of diagnosis through the remaining years of life (NCCS, 2003; Leigh, 1996). The National Cancer Institute (NCI) has also expanded this definition to include caregivers and family members within its rubric (Aziz, 2002). This definition—cancer survivor as the person diagnosed with cancer, as well as family members, friends, and caregivers—is the one used in this National Action Plan. The next sections provide an overview of cancer survivorship and describe the issues many survivors face every day.

### **What are the stages of cancer survivorship?**

In “Seasons of Survival: Reflections of a Physician with Cancer,” Mullan (1985) was the first to discuss the experience of cancer in terms of a progression of events or stages. He proposed a model of survival that includes three stages: “acute,” “extended,” and “permanent.” The **acute stage** begins with diagnosis and spans the time of further diagnostic and treatment efforts. Mullan describes fear, anxiety, and pain resulting from both illness and treatment as “important and constant elements of this phase.” This stage is defined not only by the experience of the person diagnosed with cancer but also by those of the family members who are affected by the diagnosis.

The **extended stage** of survival begins when the survivor goes into remission or has completed treatment. Psychologically, this stage is a time of watchful waiting, with the individual wondering if symptoms may be signs of recurrence or just a part of everyday life. Cancer could return at the same site or in a new location. When treatment is complete, diminished contact with the health care team can also

cause great anxiety. Physically, it is a period of continued limitation resulting from having had both illness and treatment. During this stage, survivors may be learning to live with chronic side effects and accompanying anxieties.

The **permanent stage** is defined as a time when the “activity of the disease or likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested” (Mullan, 1985, p. 272). Mullan acknowledges, however, that this stage is more complex than simply the status of disease: a person in this stage may still face social and economic challenges, such as problems with employment and insurance, psychological challenges, the fear of recurrence, and secondary effects from previous cancer treatment.

End-of-life issues can occur during any of the three stages. **End-of-life care** affirms life and regards dying as a normal process, neither hastening nor postponing death while providing relief from distress and integrating psychological and spiritual aspects of survivor care. The goal of end-of-life care is to achieve the best possible quality of life for cancer survivors by controlling pain and other symptoms and addressing psychological and spiritual needs.

Following the work of Mullan (1985) and Leigh (1996), LAF defines the experience of cancer survivorship as living “with,” “through,” and “beyond” cancer. **Living “with” cancer** refers to the experience of receiving a cancer diagnosis and any treatment that may follow, **living “through” cancer** refers to the extended stage following treatment, and **living “beyond” cancer** refers to post-treatment and long-term survivorship. Although this definition is designed to signify the experience of survivorship as a progression, this process is unique for each patient, and movement from one phase to the next may not be clearly delineated.

### **C. Issues for Cancer Survivors**

#### **How does cancer affect individuals?**

Diagnosis of cancer is a threat to a person’s physical, psychological, social, spiritual, and economic well-being. During its various stages, cancer can deprive persons diagnosed with it of their independence and can disrupt the lives of family members and other caregivers.

**Physical** symptoms of cancer can be both acute and chronic and can occur during and after treatment. Physical symptoms may include pain, fatigue, nausea, hair loss, and others, depending on the cancer site and the types of treatments a patient receives. The symptoms experienced by some people with cancer can be debilitating and may result in bed rest. Adequate **palliative care** to

provide **pain and symptom management** through every stage of cancer and its treatment is a major concern for survivors. The late or long-term physical effects of cancer itself and/or its treatment can include decreased sexual functioning, loss of fertility, persistent edema, fatigue, chronic pain, and major disabilities. These effects can be devastating, resulting in a loss of mobility (e.g., loss of leg, spinal injury) and changes in bodily functions (e.g., colostomy, laryngectomy) and appearance (e.g., disfiguring surgery, amputation). Major physical issues that affect long-term survival include recurrence of the original disease, development of secondary cancers, premature aging, and organ/systems failure.

**Psychological** issues associated with cancer diagnosis and treatment includes fear, stress, depression, anger, and anxiety. However, the effects of cancer on an individual are not always negative. Cancer can also provide opportunities for people to find renewed meaning in their lives, build stronger connections with loved ones, and foster a commitment to “give back” to others who go through similar experiences. After cancer diagnosis and/or treatment, survivors can continue to live active, vital lives—but they may live with the uncertainty and the fear that cancer might return. People with cancer may also experience difficulties in coping with pain and disability caused by either their disease or the treatment they are undergoing. Emotional impacts on survivors can include feelings of helplessness, lack of self-control, changes to self-esteem and self-image for the survivor, and added stress and anxiety for their caregivers (NCI, 2002).

**Social** well-being can be affected by cancer diagnosis and treatment through the physical and psychological impacts discussed above. The physical difficulties of pain and disability may result in a decreased sense of social well-being by limiting the time survivors are able to spend with important people in their lives. Survivors also often experience increased difficulties in school or on the job, in terms of their ability to interact with friends and coworkers, because of the impact diagnosis and treatment can have on their self-image (NCI, 2003b).

**Spirituality** can take many different forms in the lives of cancer survivors; it can come from organized religion or from personal beliefs and faith. Some survivors struggle with spirituality as part of their cancer experience and say that their faith has been tested. Others gain support from their faith and allow it to guide them through their experience (NCI, 2002). Surviving cancer is a complicated journey that takes its toll on the spirit as well as the body. Some survivors wrestle with “why me” questions about having a cancer

diagnosis or experience survivors' guilt because they lived through their diagnosis while others have died. Spiritually, survivors may deal with unresolved grief, reevaluate their lives, reprioritize their goals and ambitions, and redefine "normal" for themselves. Cancer survivors are often looking for guidance and strength to help them through the spiritual journey. In many cases, survivors' spirituality helps them to understand the meaning of their cancer experience and embrace life with a renewed vigor and sense of purpose. Survivors often gain strength through their faith; this strength allows survivors and their loved ones to answer tough questions and to face each day with love and confidence (NCI, 2002).

**Economic** costs incurred by survivors and their families are another important consideration. Cost implications of cancer include inability to access quality care, financial burdens resulting from health care costs, and income loss resulting from work limitations. Often, survivors have to cope with losing a job because of their employers' preconceived notions about the impact cancer will have on their work capabilities. With job changes, survivors may be unable to qualify for health insurance and often find it difficult to obtain life insurance after diagnosis. Family members of cancer patients may experience significant financial burdens while serving in the role of caretaker, especially during the end-of-life phase. Similarities or differences in the survivorship experience among different racial or ethnic groups or among medically underserved people are virtually unexplored.

## What are the common myths about cancer and cancer survivorship?

There are many myths and misunderstandings about cancer and the effects it can have on survivors. The following table summarizes some selected myths and the facts to counteract these misconceptions.

| Common Myth   | Facts to Counter Myth   |
|---|---|
| Cancer is a disease that only affects older people.             | Although approximately 77% of all cancer cases are diagnosed at age 55 or older, everyone is at risk of developing some form of cancer (ACS, 2003).   |
| Cancer only affects the person diagnosed with the disease.      | For many years, the focus of cancer diagnosis and treatment was on the person diagnosed with the disease. However, recent advances in our understanding of survivorship have led to the expanded definition of "survivor" to include others touched by this disease, such as families, friends, and caregivers.   |
| Cancer is the same for everyone.                                | Because cancer can occur anywhere within the body, survivors can experience different symptoms depending on the site of their diagnosis. Depending on the site of the initial cancer growth and the stage at diagnosis, the available treatments and resources will vary greatly, such that more services and resources are available to survivors of certain cancers (e.g., breast or leukemia) than for other rarer forms of cancer (e.g., myeloma or laryngeal).   |
| The need for care of survivors ends once treatment is complete. | Cancer can be a <b>chronic disease</b> that often has long-term effects on a survivor's life. Although many cancers can now be cured or the growth greatly slowed, the impacts of diagnosis will remain with a survivor for years. Because more survivors are living longer, especially those diagnosed with cancer as a child or young adult, there is a need to address long-term issues of survivorship. These can include ongoing physical, psychological, and other types of issues (see Section I.C.) |
| Diagnosis of cancer means certain death.                        | The risk of dying of cancer following diagnosis has steadily decreased over the past several decades. Fewer than half the people diagnosed with cancer today will die of the disease; in fact, some are completely cured, and many more survive for years because of early diagnosis or treatments that control many types of cancer (ACS, 2004).   |

Although many dedicated individuals and organizations have contributed to reductions in the number of cancer diagnoses and an increase in the likelihood of survival following diagnosis, much remains to be done. An ever-growing population of cancer survivors is in need of medical care, public health services, and support. All of these factors need to be taken into account when assessing the experience of cancer survivorship.

#### **D. Public Health and Cancer Survivorship**

A primary purpose of this National Action Plan is to identify areas within the realm of **public health** that can be mobilized to address the needs of cancer survivors. Although the role of biomedical research is to increase our understanding of the causes and physical effects of cancer, responsibility for applying knowledge about potential interventions that can be implemented to eradicate disease and/or improve the quality of life rests within both the medical care and public health communities. Because cancer survivorship imposes a tremendous individual and societal burden and proven interventions are available to address survivor needs, a coordinated public health effort is warranted. The focus of that effort should be broad and encompass entire population groups, in contrast with the medical model, which generally focuses on individual patients. The following provides an overview of public health and existing infrastructure that can be used to initiate efforts for cancer survivors.

##### **What is public health?**

Public health practice is the science and art of preventing disease, prolonging life, and promoting health and well-being (Winslow, 1923). More recently, the Institute of Medicine (IOM) (1998) has defined the mission of public health as assuring conditions in which people can be healthy. Public health's mission is achieved through the application of health promotion and disease prevention technologies and interventions designed to improve and enhance quality of life (PHFSC, 1994). Health promotion and disease prevention technologies encompass a broad array of functions and expertise, including the 3 core public health functions and 10 essential public health services presented in the following table.



### Three Core Public Health Functions

- Assess and monitor the health of communities and populations at risk to identify health problems and priorities.
- Formulate public policies, in collaboration with community and government leaders, designed to solve identified local and national health problems and priorities.
- Assure that all populations have access to appropriate and cost-effective care, including health promotion and disease prevention services, and evaluation of the effectiveness of that care.

### Ten Essential Public Health Services

- Monitor health status to identify community health problems.
- Diagnose and investigate health problems and health hazards in the community.
- Inform, educate, and empower people about health issues.
- Mobilize community partnerships to identify and solve health problems.
- Develop policies and plans that support individual and community health efforts.
- Enforce laws and regulations that protect health and ensure safety.
- Link people to needed personal health services and assure the provision of health care when otherwise unavailable.
- Assure a competent public health and personal health care workforce.
- Evaluate effectiveness, accessibility, and quality of personal and population-based health services.
- Research for new insights and innovative solutions to health problems.

Source: Public Health Functions Steering Committee (PHFSC), 1994.

### What is the relevant public health infrastructure for addressing cancer survivorship?

Two agencies within the U.S. Department of Health and Human Services—the National Institutes of Health (NIH) and CDC—have been established to conduct research and implement public health strategies to address cancer. Within NIH, NCI works to reduce the burden of cancer **morbidity** and mortality among Americans. NCI's goal is to stimulate and support scientific discovery and its application to achieve a future when all cancers are uncommon and easily treated. Through basic and clinical biomedical research and training, NCI conducts and supports research programs to understand the causes of cancer; prevent, detect, diagnose, treat, and control cancer; and disseminate information to the practitioner, patient, and public (NIH, 2003). NCI works to “enhance the quality and length of survival of all persons diagnosed with cancer and to minimize or

stabilize adverse effects experienced during cancer survivorship” (NIH, 2003). Through its conduct and support of research, NCI works to effectively address all issues facing cancer survivors (see Section I.C.).

Within the CDC, the National Center for Chronic Disease Prevention and Health Promotion works to prevent cancer and to increase early detection of cancer. CDC works with partners in the government, private, and nonprofit sectors to develop, implement, and promote effective cancer early detection, prevention, and control practices nationwide (CDC, 2003a). Within the CDC, the **National Comprehensive Cancer Control (CCC) Program** provides a mechanism for addressing cancer survivorship within the realm of public health.

### **Background on the CDC’s Comprehensive Cancer Control Program**

CDC began implementing the CCC Program through state health departments and other entities in the mid-1990s and defines this Program as “an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation” (CDC, 2002, p. 1). This strategy aims to engage and build a coordinated public health response and provide a way to assess and then address the cancer burden within a state, territory, or tribal organization. Not only do state-level CCC Programs build on the achievements of cancer programs, they enhance the infrastructure created for them—many of which focus on individual cancer sites or risk factors. Partnerships between public and private **stakeholders** whose common mission is to reduce the overall burden of cancer provide the foundation for these statewide programs:

**“These stakeholders review epidemiologic data and research evidence (including program evaluation data) and then jointly set priorities for action. The partnership then mobilizes support for implementing these priorities and puts in place a systematic plan to institutionalize the comprehensive approach as a means to coordinate activities, monitor progress over time, and reassess priorities periodically in light of emerging developments in cancer and related fields” (CDC, 2002, p. 2).**

Public health agencies are using this support to establish broad-based cancer coalitions, assess the burden of cancer, determine priorities for cancer prevention and control, and develop and

implement comprehensive plans, most of which include addressing the needs of cancer survivors.

## **E. Summary**

*A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* was developed to identify and prioritize cancer survivorship needs and strategies within the context of public health that will ultimately improve the overall experience and quality of life of the millions of Americans who are living with, through, and beyond cancer. It can be used by state agencies, organizations, and individuals in selecting and developing activities to comprehensively address cancer survivorship. The primary outcomes of this National Action Plan are to increase awareness among the general public, policy makers, researchers, advocates, survivors, and others of the role public health can play in advancing cancer survivorship issues and to stimulate organizations to take action to meet the identified needs in surveillance and applied research; communication, education, and training; programs, policies, and infrastructure; and access to quality care and services.

Theodore, Cancer Survivor



*“Survivorship means more time and responsibility —  
time for family, friends, work and life.”*