

*National Call to Action on  
Cancer Prevention and Survivorship*

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July 2008  
Washington, D.C.

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# Foreword

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As the U.S. Surgeons General, we have had the largest medical practice in the world. The American people have been our patients, and we and our predecessors have served as the doctors of the nation through four centuries. It has been our duty and honor to promote, protect, and advance the health, safety, and security of the nation and its people. During our individual terms of service, we have consistently addressed all health topics by relying on the best scientific information available and executing our duties and responsibilities with a focus on the health and well-being of the American people. Since the 1964 Surgeon General's Report on Smoking and Health, we have released numerous Surgeons General Reports, Calls to Action, and many other public health communications that have helped influence policy, encouraged legislation, promoted the adoption of healthy behaviors, and improved health outcomes for many Americans and others globally.

Now, with the *National Call to Action on Cancer Prevention and Survivorship*, we are uniting our voices, aided by multiple sources of collective knowledge, experience, and allegiance to the people of this great nation, so as to amplify the message that a transformation is needed to address cancer. For decades, countless resources have been allocated to research, prevention, detection, treatment, support, survivorship, and other individual aspects of the cancer continuum. Yet, in spite of all efforts, the toll of this disease continues to rise and is now at unbearable levels, including individual, economic, and societal.

In the face of this vast challenge, we are not without optimism because we have witnessed the far-reaching changes that have resulted under similar situations when resources have been fully coordinated under visionary leadership sharing common goals. Together, we stand before you, ready to lead an initiative that is unprecedented in scope and in promise.

Consistent with our beliefs and practices, this *National Call to Action on Cancer Prevention and Survivorship* is based on the best science available in the world. Yet, our effort does not end with data and research. This *National Call to Action* is a robust framework that encompasses all that we *know* and all that we *need* to confront the disease that is cancer. The blueprint for action begins and ends with the involvement of the American people. We must collaborate with all Americans and together affirm that hope is warranted and improvement is possible. That is why we are calling on every sector of society and every organization, research lab, government agency, community, health care system, policy-making body, school, and business to find the means and provide the stamina to elevate the war against cancer. We must unite in a common front, with common messages, to achieve optimal results. Together we will help build a secure bridge that will span the cancer continuum from prevention through survivorship so that the fight against cancer can be won. No American can or should ever again walk this bridge alone.

Antonia C. Novello, M.D., M.P.H., Dr.P.H.  
14th United States Surgeon General (1990-1993)

Joycelyn Elders, M.D., M.S.  
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16th United States Surgeon General (1998-2002)

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14th United States Surgeon General (1990-1993)

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# Introduction

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The human body is a marvelous system comprised of trillions of cells working together. Keeping these cells working in harmony is the foundation for a healthy life. This is our vision and this is our potential.

The reality we face today with cancer is in conflict with our vision. More than 1.4 million Americans are diagnosed with cancer each year, and cancer is now the leading cause of death for people under the age of 85 (American Cancer Society 2008; Jemal et al. 2006). On our current path, the United States will experience a dramatic increase in cancer, as well as other chronic diseases. The good news is that by improving prevention and survivorship, our nation could dramatically reduce the pain and suffering due to cancer and save more than \$410 billion in cancer costs alone by the year 2023 (DeVol and Bedroussian 2007).

Cancer is a very complex set of diseases that develops from a variety of genetic-environmental interactions as well as infectious agents that can occur throughout a person's life (American Cancer Society 2008). Some of the factors that cause cancer are well understood and a growing variety of tools to confront cancer exist, but research is needed to better understand some of the other factors. Fortunately, we have the ability to prevent many cancers from occurring, diagnose cancer as early as possible through recommended screenings, treat and monitor certain cancers as chronic and manageable diseases, and address quality of life for people with cancer.

We are issuing this *National Call to Action on Cancer Prevention and Survivorship* to end cancer as we know it. Our goal is to empower all Americans to achieve optimal health and wellness, and thereby reduce the burden that cancer and other chronic diseases place on our country.

If today we all start moving toward optimal health and wellness and adhering to the recommended cancer screenings, we will make great strides in improving cancer prevention and survivorship. After all, cancers that could have been prevented or detected earlier comprise at least half of all new cases (American Cancer Society 2008). This approach will also allow us to reallocate our resources to focus on tackling rare or currently untreatable cancers, including those that affect our nation's children.

Each day in this nation, nearly 4,000 people are diagnosed with cancer (American Cancer Society 2008). Survivorship starts the day that a person receives a diagnosis of cancer and continues through and beyond treatment, and includes addressing the impact on caregivers, families, and friends. Survivorship involves ensuring that the pain and suffering from cancer are effectively addressed through pain and symptom management and facilitating a high quality of life beyond cancer.

In addition to making survivorship a standard component of comprehensive cancer care, we must also con-

tinue to conduct recommended cancer screenings for cancers that can be detected early and focus our efforts on research to develop new screening tools, detection technologies, and innovative treatment for those cancers that remain elusive. It is essential that information about screening, early detection, and treatment is available and accessible to all. Similarly, it should be developed at appropriate literacy levels, and should be linguistically and culturally appropriate.

It is known that with early detection and effective clinical, palliative, and psychosocial care, we can reduce pain and suffering and greatly improve the quality of life for cancer survivors, caregivers, and their families and friends. Cancer survivors need to be empowered to continue to be active partners in their care by following their evidence-based survivorship care plan, which summarizes long-term care and treatment; referrals for follow-up care and future screenings; ways to facilitate a healthy lifestyle and prevent recurrent or new cancers; guidance for employment, insurance, and financial matters; and availability of psychosocial services.

Since the passage of the National Cancer Act of 1971, which launched the War on Cancer, we have made tremendous progress against some forms of cancer, and we now have a variety of effective tools to fight this disease. Unfortunately, our battle against cancer has lost momentum and we are not using the tools as effectively as we can. We need to re-energize our fight against cancer and make comprehensive cancer control—cancer prevention, early detection, better treatment for all, and improved survivorship—a national priority and a national public health objective. We also need to transform our nation's culture from one that primarily emphasizes treatment to one that uses every tool we have to achieve optimal health and wellness for every American.

We know what it takes to save lives and live beyond the cancer experience. Over the past 20 years, numerous public health agencies and advisory groups, including the American Cancer Society, the Centers for Disease Control and Prevention (CDC), the Institute of Medicine (IOM) and its National Cancer Policy Board, the Lance Armstrong Foundation, the National Cancer Institute (NCI), the President's Cancer Panel, and many other public and private groups, have published recommendations to improve our approaches to combating cancer and its impact on our lives. This *National Call to Action* is our collective plan for cancer prevention, screening and early detection, treatment, and survivorship.

In developing this *National Call to Action*, we sought the input of a broad base of individuals and organizations. Our review of their recommendations allowed us to identify four major goals. These goals are based on the simple

principle that if we utilize and expand upon our scientific knowledge, our proven practices, and our convictions, we as a nation can begin to see immediate progress in combating this devastating disease and in achieving optimal health and wellness for all people. These approaches include identifying and mitigating risk factors, such as tobacco use, diet, sun exposure, environmental exposure, and genetics; promoting the use of recommended cancer screenings and early detection; and utilizing a patient-centered approach in cancer survivorship as a matter of integrative health and appropriate clinical practice.

The four goals in this *National Call to Action* and the proposed strategies to achieve each goal include attention to population health and individual health, and a focus on patient-centered, culturally competent, holistic care. The goals are modest in number but not in significance. They repeat what so many voices have stated before. Much progress has been made in some areas, but we still have much work to do.

This *National Call to Action* charges all Americans across all sectors of society, from our highest levels of government and the private sector to the individual person, to achieve the following four goals:

**GOAL 1:** Empower healthy lifestyles to prevent cancer.

**GOAL 2:** Apply what we know about cancer screening and early detection to all people.

**GOAL 3:** Ensure that all people can navigate through the health care system.

**GOAL 4:** Provide survivorship care plans and systems of support for all cancer survivors.

The lack of greater progress in cancer prevention and survivorship is more the result of failure to translate and implement proven strategies than it is the lack of knowledge. If we can achieve these four goals, we can help save hundreds of thousands of the approximate 560,000 lives our nation loses to cancer each year (American Cancer Society 2008). We can also enhance the quality of life of those individuals and families who have already been affected by cancer.

### Connecting the Cancer Research Community

We live in an era of unprecedented scientific discoveries about the molecular underpinnings of cancer as a genetic disease of great complexity. Such new knowledge will enable a pre-emptive, preventive, and personalized approach to cancer.

In 2003, the National Cancer Institute (NCI) responded to researchers and administrators at NCI-designated Cancer Centers who needed both an information technology solution and a cultural transformation to address the major challenges of a disconnected cancer research enterprise characterized by redundancy of research efforts, long delays in translation of new discoveries to patients, and burdensome and continually rising costs.

The cancer Biomedical Informatics Grid, known as caBIG™, was developed to enable a new generation of patient-centric, personalized cancer medicine. The initial objectives, which have been accomplished, were to connect scientists and health care practitioners through a shareable, interoperable infrastructure; use standard rules, a unified architecture, and a common language to more easily share information; and build or adapt tools for collecting, analyzing, integrating, and disseminating information associated with cancer research and care.

The most important action of caBIG™ was to establish a community of participants to serve as advisors about cancer research information technology needs, as developers and adopters of the infrastructure and tools, and as disseminators of information about caBIG™ to their home institutions. More than 200 organizations and over 1,000 individuals participated in the first four years of the caBIG™ initiative. Today, caBIG™ is being implemented across the United States, including at 46 NCI-designated Cancer Centers and 16 Community Cancer Centers.

There is clear and growing evidence that caBIG™ has already accomplished dramatic shifts, both cultural and technical, including new collaborations among previously unconnected institutions and disciplines, greater willingness to share data, and facilitation of scientific studies, particularly in translational research.

One unintended result of the caBIG™ initiative has been the strong interest among scientists and administrators in other disease areas, who are enthusiastically embracing caBIG™ as a model for connectivity between research and care in diseases beyond cancer.

# The Who, What, and Where of Cancer

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This year, too many Americans will hear the words, “You have cancer,” launching them down an uncertain path that will exhaust them and their loved ones emotionally, physically, and, in many cases, financially. There are nearly 12 million Americans alive today who have been diagnosed with cancer at some point in their lives and millions more who have been impacted by the role of caregiving and the effects of cancer on the family (NCI 2008). Cancer patients and their families routinely report difficulty coping with a cancer diagnosis and short- and long-term side effects, compounded by the complex and confusing maze that comprises cancer care in many parts of the United States (Lance Armstrong Foundation and CDC 2004).

Cancer knows no boundaries. It affects people of all ages, races, ethnicities, socioeconomic status, faiths, and genders. Unfortunately, cancer strikes some population groups more than others. Cancer can also lead to long-term disabilities caused not only by the disease itself but also by the disease treatment.

## Cancer: By the Numbers

In 2008, it is estimated that there will be more than 1.4 million new diagnoses of cancer in our nation. This overall number also represents 65,000 to 70,000 cases among 20 to 30 year olds. Approximately 65 percent of the 1.4 million Americans who are diagnosed with cancer this year are expected to live at least five years after diagnosis (Ries et al. 2007). In contrast to that of pediatric and older adult cancer patients, the survival rates for young adults have not increased since 1975 (Bleyer et al. 2006).

## Cancer Deaths

Cancer is the second-leading cause of death in the United States (CDC 2008). It is the leading cause of death for people under the age of 85 and the leading disease-specific cause of death for young adults (Jemal et al. 2006; Bleyer 2007).

## Cancer Affects Some Groups of Americans More Than Others

Disparities in health and health care based on race and ethnicity have been documented for decades, and cancer is no different (*Unequal Treatment*, IOM 2003; Ries et al. 2007). For example, African Americans are 30 percent more likely to die of cancer than other population groups (HHS 2000). Other groups disproportionately affected by cancer include American Indians and Alaska

Natives, who have the lowest five-year survival rates of any other racial group from all cancer sites combined (*Unequal Burden of Cancer*, IOM 1999).

## There Are Geographic Differences in Cancer Incidence and Deaths

Cancer incidence and death rates can vary drastically by state (American Cancer Society 2008). These differences may be attributed to health literacy levels, socioeconomic status, differences between urban and rural areas, variations in population characteristics and practices, local differences in health policies and public health initiatives and funding, and geographic barriers to medical care.

## Cancer Costs Lives and Money

Cancer can exact a tremendous human toll on the individual, the caregivers, families and friends, the work-site, and the community. This toll starts at diagnosis and continues through treatment and survivorship. The loss of a family member or friend affects people of all ages and can become a tragedy of epic proportions.

Cancer can be an economic burden for anyone diagnosed with the disease, and uninsured and underinsured Americans are increasingly challenged financially due to a cancer diagnosis. Underinsured Americans quickly reach the catastrophic limits of their insurance plan in just a few months of covering the cost of cancer treatment. Large corporations and small businesses experience a loss of income from employees who either need cancer treatment themselves or who are serving as caregivers for family members diagnosed with cancer. The absenteeism, loss of productivity, and cost of replacing employees either temporarily or permanently can represent a significant financial burden on employers. Cancer survivors and caregivers can experience financial strain caused by additional medical costs and new living expenses—such as transportation costs, parking fees, co-pays at treatment centers, costs of child care, or even temporary or permanent relocation costs.

## What the Facts Tell Us

We know the burden of cancer can be reduced. Our public health strategies in survivorship, however, have not focused effectively on the patient as a whole to address the physical, psychosocial, and financial challenges that come with the disease, including those of caregivers and family members. Disparities in cancer incidence and death exist

by race, ethnicity, socioeconomic status, education level, and geography. Lack of health insurance, as well as inadequate health insurance, may be responsible for the underuse of recommended cancer screenings, causing many Americans to put off seeing a health care professional until after their disease has progressed beyond the point where treatment is most effective.

We need to incorporate wellness strategies into our individual lives, community activities, health policies and practices, and national culture. In addition, by continuing to support research to develop innovative new tools—such as diagnostics, prevention tools, and treatments—and empowering leaders to use the evidence from this research to develop and implement effective public health strategies, we can greatly improve comprehensive cancer control.

This *National Call to Action on Cancer Prevention and Survivorship* incorporates previous knowledge and outlines four goals with proposed practical strategies to meet the goals. It is our hope that through collective actions toward achieving these goals, we will help to eliminate cancer from the lives of millions of people and as a result improve the quality of life for millions more for generations to come. We know what is needed for action. Now, let us go and do it.

## **Reducing Transportation Barriers Can Improve Treatment and Survivorship**

The Ride With Emilio Patient Transportation program addresses basic, practical transportation barriers that affect low-income, Hispanic children and families receiving cancer treatment at Rady Children’s Hospital in San Diego County, California. Transportation barriers can prevent patients from making medical appointments and can have serious consequences in their treatment and survivorship. Before the Ride With Emilio program was introduced, Rady Children’s Hospital reported that because of transportation barriers, up to four patients each day missed their treatment appointments.

The Ride With Emilio Patient Transportation program helps ensure that low-income pediatric cancer patients access cancer treatment in a timely manner, providing them with the best chance possible for surviving cancer and having a healthy life. The program provides bi-lingual drivers and transportation services for patients and their families for their medical appointments. An estimated 2,500 patients and 52,000 family members (caregivers and siblings) have been transported since the program started in 2005.

Since the introduction of the Ride With Emilio program, Rady Children’s Hospital has reported zero missed appointments because of transportation barriers. Children now receive their cancer treatments on time, and families connect with other families and staff and learn about other services available to them.

Eighty-five percent of families served by this program report annual incomes of \$15,000 to \$18,000. Ten percent report incomes of \$10,000. Vans average 36 miles per patient. The longest trip was 126 miles, which indicates the remoteness of some of the patients.

This program has provided services for a greater-than-anticipated number of children needing transportation and has received requests from neighboring counties for similar services. The Rady Children’s Hospital is developing a family resource center around survivorship issues and is receiving overwhelming support from the local community. This program removed a basic, but previously unrecognized, transportation barrier for pediatric cancer survivors and their families and has seen tremendous growth and support for this service.

# GOAL 1: Empower Healthy Lifestyles to Prevent Cancer

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The war on cancer begins with prevention. Today, we have cancer prevention tools that include adopting healthy behaviors, clinical interventions, and policy approaches that are working to prevent cancer cases and recurrences in cancer survivors. As a nation, we must do better at applying these prevention strategies and tools, as well as developing new prevention strategies. Such efforts will help to alleviate not only the overall burden of cancer in our nation, but in particular the disproportionate burden that is borne by members of racial and ethnic minority groups (*Fulfilling the Potential*, IOM 2003).

To save more people from a diagnosis of cancer or other chronic disease, educators, employers, government agencies, health care professionals, insurers, policymakers, researchers, faith-based organizations, and individual people should focus on efforts to create and coordinate a national culture of prevention. We must begin by stimulating and sustaining efforts to create tobacco-free environments and lifestyles, increasing availability of healthy foods and opportunities for physical activity, keeping alcohol consumption at low to moderate levels, and ensuring that recommended cancer screenings and preventive measures such as vaccines and tobacco cessation tools are accessible and available for all people. These efforts are especially important for cancer survivors, as they are meant to minimize the likelihood of recurrences and secondary cancers, and, where possible, manage the long-term or late effects of cancer treatment.

Many of the behaviors that place people at risk for cancer are well recognized, and calls should be heeded for adopting healthy behaviors. What has been lacking is a sustained and appropriately resourced multi-sector commitment designed to help facilitate and support the adoption of healthy behaviors among all Americans.

To begin, prevention interventions to modify risk should be implemented at multiple levels and throughout the course of a person's life. It is never too late to start new strategies at all levels. Such strategies can be individual (e.g., tobacco cessation programs, healthy eating, physical activity), interpersonal (e.g., advice and support from a health care professional for tobacco cessation, developing and following a survivorship care plan), organizational (e.g., health care benefit policies that support tobacco cessation and recommended screenings, access to healthy foods at worksites, mass media programs that encourage physical activity), and societal (e.g., tobacco control legislation, improved standards for school nutrition programs). These levels are not mutually exclusive and reflect an evolution in prevention research from a primary focus on determinants of behavior within

the individual to broader perspectives that focus on societal determinants of health.

There are numerous known actionable steps across the cancer continuum—from prevention to survivorship—that every American can take to reduce his or her risk of developing cancer. The prevention and early detection health messages should go beyond simply telling people what to do. We must start by effectively translating the science into culturally competent messages and programs. By doing so, Americans can become empowered and encouraged to take action. Lack of education and lack of health knowledge are two important health literacy barriers that must be overcome if prevention is to succeed. Thus, it is important to expand existing health literacy programs and create educational materials and public health strategies that are appropriate for all languages, ages, genders, cultures, and communities, regardless of socioeconomic or educational barriers. The American people need consumer-tested, uniform, accurate, and consistent prevention and early detection messages that can be individualized to offer immediate and long-term benefits. Similarly, survivorship education should be a critical component of all cancer treatment. Cancer patients, inclusive of caregivers, families, and friends, often need information and tools that promote behaviors that can enhance their quality of life and prevent recurrences or secondary cancers as a part of their overall approach to health and wellness.

Three lifestyle factors may prevent a significant percentage of cancers: elimination of tobacco use and exposure to tobacco smoke, healthy eating, and increased physical activity. Smoking and exposure to tobacco smoke accounts for nearly one-third of all cancer deaths in America. In addition, up to one-third of all cancers may be related to being overweight, unhealthy eating, and physical inactivity (President's Cancer Panel 2007). This evidence clearly demonstrates that we know the facts, and we need to put the information into action to improve cancer prevention and survivorship. The time to act is now.

Research is ongoing to better understand cancer and how to prevent, detect, diagnose, and treat primary and advanced metastatic cancers as well as cancer recurrences. Recommended cancer screening and early detection programs are proven to be effective at diagnosing certain cancers at their earliest stages when they are most treatable, sometimes before the cells have turned cancerous. Promising new research into areas of chemoprevention has shown that pharmaceuticals can be developed and used to prevent cells from turning cancerous, enabling the onset of certain cancers to be prevented and managed—

just as heart disease is prevented and managed for millions of people (Meyskens et al. 2008; Redman et al. 2008).

### **Tobacco Use and Exposure to Tobacco Smoke Increase Cancer Risk**

Tobacco use is the single-most preventable cause of death and disease in the United States. All tobacco products, including smokeless tobacco and cigars, can cause cancer. Despite the knowledge that tobacco use can have hazardous, potentially lethal effects, on both oneself and others, more than 23 percent of men and 18 percent of women ages 18 years and older smoke cigarettes. Smoking prevalence is higher among lower socioeconomic groups and varies widely among racial and ethnic groups. Overall, smoking prevalence decreases as education level increases (*Cigarette Smoking*, CDC 2007).

The lethal effects of cigarette smoke extend beyond the smoker. Cigarette smoke contains more than 4,000 chemicals (e.g., cyanide, formaldehyde, benzene, arsenic, DDT, acetylene, ammonia), including more than 50 known carcinogens and poisonous gases. Each year, 3,000 non-smokers die from lung cancer caused by exposure to secondhand smoke (HHS 2006).

The one sure way to reduce tobacco-related death and disease is to stop using tobacco. This single behavior change would eliminate one-third of cancer deaths. The risk for developing cancer declines with the number of years of smoking cessation (HHS 2004).

Today, more than 45 million Americans smoke tobacco (*Cigarette Smoking*, CDC 2007). Among current U.S. adult smokers, 70 percent report that they want to quit using tobacco completely (CDC 2002). Tobacco cessation counseling has proven to be highly effective and cost-saving, yet it is delivered to fewer than half of smokers (National Commission on Prevention Priorities 2007). By increasing access to and use of tobacco cessation programs, many tobacco-related deaths could be avoided.

Investments in tobacco control, including a variety of health policy initiatives and public education campaigns, have resulted in a reduction in the prevalence of smoking and other tobacco use in the United States. There is some variability in smoking prevalence among the states. States that have made larger investments in comprehensive tobacco control programs have seen cigarette sales drop more than twice as much as in the United States as a whole, and smoking prevalence among adults and youth

### **New York City's Public Health Approach to Addressing Cancer**

New York City has implemented an aggressive program to address the burden of cancer in the city. Relying on national and local data, the city's health department developed a plan focused on tobacco and obesity control as primary prevention measures, and recommended cancer screenings as a secondary prevention measure.

Smoking is the leading cause of preventable death in New York City—at 8,000 deaths per year—and contributes to numerous diseases caused by secondhand smoke. In 2002, city and state tax increases on tobacco products resulted in a gradual decrease of adult smokers at a rate of about 5 percent per year—a package of cigarettes in New York City now costs approximately \$8.15. Subsequent legislation created smoke-free worksites, which further reduced the number of smokers. An aggressive anti-tobacco media campaign is currently underway, and bans are enforced on tobacco advertising, promotion, and sponsorship. These three tobacco use and prevention policies are estimated to have yielded more than 240,000 fewer smokers, which will result in as many as 80,000 fewer tobacco-related deaths in future years.

The city is also tackling obesity and its medical complications, one of which is cancer. New York City

gained 10 million pounds from 2002 to 2004, with the number of obese adults increasing from 18.2 percent to 21.7 percent. The city changed the context for addressing obesity by relying less on moral persuasion and more on enforced policy. It enforced calorie labeling in restaurants and healthy food standards in schools, and promoted physical activity in childcare centers and schools. Outcomes from these efforts are being carefully tracked.

As the lowest-screened and most preventable cancer, New York City has focused on colon cancer, and particularly on promoting colonoscopies for all eligible people 50 and over. A multi-pronged effort has included media campaigns, the creation of a broad group of stakeholders called C5 (Citywide Colon Cancer Control Coalition), and a colonoscopy-screening patient navigator program that is now active in 16 hospitals to ensure that referred patients are successfully screened. Since 2003, the number of eligible New Yorkers screened over the past 10 years has increased 50 percent. In addition, race and ethnic disparities in colon cancer screening rates have been eliminated in white, African American, and Hispanics New Yorkers, with important increases in the Asian community.

have declined faster as spending for tobacco control increases (*Best Practices*, CDC 2007).

For the past 40 years, public health campaigns have educated Americans about the dangers of tobacco use and have shaped social norms related to tobacco use. These campaigns, combined with other interventions and strategies, are effective for decreasing the likelihood of tobacco initiation and also promote tobacco cessation (Zaza et al. 2005). There is a need to develop public health campaigns that are effective with health-disparate populations and to make sure that the American people are aware of the variety of social and pharmaceutical interventions that are available to help people eliminate tobacco use.

There is no risk-free level of exposure to secondhand smoke. Eliminating smoking in indoor spaces is the only way to fully protect nonsmokers from secondhand smoke exposure. Separating smokers from nonsmokers, filtering the air, and ventilating buildings cannot eliminate secondhand smoke exposure (HHS 2006). Policymakers in the public and private sectors have enacted policies to ban smoking from public places in order to reduce involuntary exposure to tobacco smoke. Studies show lower smoking prevalence and higher smoking cessation in worksites with smoke-free policies (Pierce and León 2008). Secondhand smoke exposure among U.S. nonsmokers has declined substantially. However, more than 126 million nonsmoking Americans, including both children and adults, are still exposed to secondhand smoke in their homes and workplaces (HHS 2006).

## **Healthy Eating May Prevent Cancer and Improve Survivorship**

Healthy eating may reduce cancer incidence and death, and may improve quality of life during and post treatment. Evidence-based recommendations call for high consumption of fruits, vegetables, whole grains, and lean proteins; limited intake of processed foods; and drinking alcohol only in moderation if at all. It is also important to balance food and beverage intake with the amount of physical activity in order to maintain a healthy weight (American Cancer Society 2006).

These healthy eating behaviors need to start in childhood and run throughout a person's lifespan for maximum benefit. In addition, we need to work as a community to improve systems to allow access and availability of these foods to all Americans.

Unfortunately, almost two-thirds of adult Americans are overweight—approximately half of whom are obese—and the numbers are growing (CDC 2006). Cancer death rates are as much as 50 percent higher in obese men and more than 60 percent higher among obese women compared with their healthy-weight counterparts (President's Cancer Panel 2007). Also concerning is

the rise in childhood obesity prevalence over the past few decades in the United States (IOM 2004). The effect of this obesity epidemic on health and health care are staggering, not just in relation to cancer, but also as it relates to other chronic diseases.

## **Being Physically Active May Reduce Cancer Risk and Improve Quality of Life**

Regular physical activity may reduce cancer risk and provide benefits for cancer survivors. For example, adults of all ages benefit from moderate-intensity physical activity, such as 30 minutes of brisk walking most days. Children should be physically active for 60 minutes a day, most days of the week. Physical activity does not need to be strenuous to be beneficial (HHS and USDA 2005).

Despite the knowledge that physical activity may reduce the risk of some cancers, 25 percent of all American adults engage in no leisure-time physical activity, and fewer than half of all adults engage in the recommended levels of moderate or vigorous physical activity. Most alarmingly, only 26 percent of males and 12 percent of females engage in moderate or strenuous activity at least five times per week by age 18 to 22 years (President's Cancer Panel 2007). Inactivity during childhood and adolescence increases the likelihood of being inactive as an adult. There is a need to develop effective community, worksite, and school-based physical activity opportunities, policies, and programs that easily incorporate an active lifestyle into day-to-day activities.

The benefits of physical activity contribute significantly to a cancer survivor's coping ability, rehabilitation, and long-term survivorship. Moreover, depending upon the type of cancer and the population, the protective effects increase when physical activity is more intense and of longer duration (President's Cancer Panel 2007).

## **Health-focused Policies Can Prevent Cancer and Improve Survivorship**

Our nation's desire for quick health fixes poses significant barriers to progress in cancer prevention and survivorship. Although it can take many years to yield benefits from healthy behaviors like not using tobacco, eating healthy foods, and being physically active, policies should continue to be enacted and consistent messages must be communicated that encourage the adoption of these healthy behaviors.

A growing number of local health departments as well as State, Tribe, Territory, and Pacific Islander Jurisdiction Comprehensive Cancer Control Coalitions have taken on the challenge of translating research about cancer prevention and early detection into action. Legislation that limits

exposure to secondhand smoke has been vigorously promoted and backed by health department authorities. Research on nicotine addiction has resulted in effective tobacco cessation strategies that include both pharmacological and behavioral interventions. Today, the evidence of obesity, caused in part by lack of physical activity as well as unhealthy eating, is prompting leaders across many sectors to speak out again.

## **Strategies for Action**

**GOAL 1:** Empower healthy lifestyles to prevent cancer.

- Provide resources to support innovative public and private partnerships in all settings to develop, implement, and evaluate community-based public health campaigns and media outreach to promote tobacco prevention and cessation, healthy eating, and physical activity.
- Ensure that health benefit programs include coverage for evidence-based tobacco prevention and cessation services, nutrition counseling, and physical activity promotion.
- Improve access to and affordability of evidence-based tobacco prevention and cessation programs, healthy foods and beverages, and safe areas for physical activity.
- Enact and enforce policies to:
  - Eliminate exposure to tobacco smoke.
  - Ensure that underage people cannot access tobacco products.
  - Increase the price of tobacco products.
  - Ensure that healthy food choices are provided in all settings.
  - Ensure that physical activity options are available in all settings.

## GOAL 2: Apply What We Know About Cancer Screening and Early Detection to All People

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Recommended cancer screenings can detect some cancers at an earlier stage, before symptoms are evident, and when treatment is more effective. Screening refers to testing people who are asymptomatic for a particular disease (i.e., they have no symptoms that may indicate the presence of disease). Early detection of cancer can enhance the chances of achieving a cure, improve the quality of life, and prolong life for people diagnosed with cancer. Cancer screenings are underused and in many cases, not accessible or available.

New screening technologies with much greater sensitivity are becoming available to detect certain cancers. Research investments in screening technologies to detect cancers for which we do not have a screening procedure today could eventually have a significant impact on other forms of cancer.

### Cancer Screening Rates Are Too Low

Recommended cancer screening can save lives, reduce disability, and provide great value for invested dollars.

Yet despite the proven effectiveness of recommended screening and the availability of several different tests, overall rates of recommended cancer screening remain low in the United States and in other developed countries. Only 57 percent of age-eligible adults reported being up-to-date with recommended colorectal cancer screening (CDC 2006). In addition, only 60.8 percent of women for whom breast cancer screenings are recommended receive a mammogram (Smith et al. 2008). Thousands of lives would be saved if we increased the number of people who received the recommended cancer screenings (National Commission on Prevention Priorities 2007).

Unfortunately, people who do not have health insurance or who are underinsured generally have limited access to cancer prevention, recommended screenings, and early detection. This is particularly significant because many Americans are uninsured during some point in their lives.

One of the strongest predictors of whether a person will receive recommended screenings for cancer is whether his or her health care professional recommends it (Subramanian et al. 2004; Klabunde et al. 2005). Even

### Accessing Technology to Prevent Cancer

Prevention strategies are available to reduce cancer risk due to inherited susceptibility, but a shortage of board-certified genetic counselors has made access to reliable information challenging for patients and health care professionals.

Aetna, a health insurance company, offers access to confidential telephonic-based genetic cancer counseling to its members. The services are offered through Informed Medical Decisions (Informed), a national genetic counseling company staffed with board-certified genetic counselors with expertise in cancer genetic counseling. Aetna works to facilitate informed decision making through member education, increased access to genetic counselors, and involvement of the member's primary care physician.

Members receive information from Aetna about the availability of genetic cancer education and confidential, comprehensive counseling services through their Aetna benefit plan. Members can take a no-cost, web-based, pre-screening questionnaire to determine whether counseling would be valuable. They can use an online scheduler to make an appointment for a telephone consultation

with a genetic counselor, who works with participants to identify risk levels and assess the appropriateness of genetic testing. The counselor also assists the member's primary care physician in arranging for necessary genetic testing and post-testing services.

Aetna piloted this service with its own employees in 2006-2007 and found that only a small percentage of the employees understood their personal risk for cancer or the contribution of family history to that risk. Very few of the people who participated in the Aetna pilot program had been advised by a health care professional to consult with a trained genetic counselor. In fact, the majority reported that they were the first member of their family to speak with a genetic counselor.

After completing the genetic counseling services, the majority of participants reported a significant improvement in their understanding of their personal cancer risk and of the risk reduction strategies they can practice in their own lives. Sixty-six percent of participants reported that the telephonic aspect of the program was the determining factor in their decision to participate because of the convenience of the service.

when recommended cancer screening is accomplished, many people fail to receive timely follow-up, or sometimes any follow-up at all, for a screening with abnormal results. Implementation of reminder systems and other accountability tools by primary health care professionals and throughout the health care system can greatly increase the participation in recommended cancer screening and follow-up (*Ensuring Quality Care*, IOM 1999).

Similarly, effective delivery of information on recommended cancer screenings for all patients and cancer survivors will facilitate early detection, make earlier intervention possible, improve patient odds for positive outcomes, and enhance quality of life. Evidence suggests that multi-strategy interventions for recommended cancer screening and early detection are more effective than any one intervention alone. Many Americans tend to take action once they have heard a message multiple times. One challenge to offering screening services is ensuring that best practices and evidence-based cancer screening approaches are implemented across all populations.

## Strategies for Action

**GOAL 2:** Apply what we know about cancer screening and early detection to all people.

- Improve health literacy about cancer screening and early detection by providing culturally competent information, health messages, and screening services.
- Ensure that all people receive all recommended cancer screenings.
  - Use innovative approaches to improve rates of recommended cancer screening.
  - Implement systems to prompt health care professionals to recommend cancer screening, facilitate referrals, and remind patients of the need for rescreening.
  - Develop outreach strategies and culturally competent messages to promote recommended cancer screening to all communities.
  - Improve awareness of cancer screening recommendations for high-risk individuals.
  - Improve access and affordability, including coverage in health benefit programs, for recommended cancer screenings.
- Ensure that cancer survivors are provided screening guidelines and are screened for recurrence of the primary cancer and new cancers.
- Focus research strategies on advancing existing screening and early detection technologies to improve sensitivity, increase availability, and reduce costs.

### Individual Inspiration, Community Improvement

My sister Joan walked on two years ago after battling cancer for several years. Our CHR [Community Health Representative] hounded her to get a mammogram. I think they needed one extra person to get the mammogram van to come out to Shoalwater Bay Tribe. Thank God they found out when they did. I think God gave her three extra years because she was a fighter and had a mission. When she was first diagnosed she called and reminded me to get my screening. Now I honor her by going every year for my mammogram and women's exam. I get my colon cancer screen now as well. I am a healthy person and I want to stay that way.

I'd like to see more education at the Tribal level, more awareness. We need more access to screening and follow up for all those in the community, both at the clinic and funds to send them for outside testing if needed. Everyone needs access to colonoscopy when they turn 50. We need to get more men screened, maybe a men's screening day. Skin cancer screening is needed as well. We need additional resources for home health care as well. A real exercise program and person to help out would be great. We have a strong community now, everyone looks out for each other, and we'd like to keep it strong.

— Lee Shipman, Shoalwater Bay Tribe

## GOAL 3: Ensure that All People Can Navigate Through the Health Care System

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Many Americans have experienced difficulties navigating the health care system for recommended cancer screening, diagnostic, treatment, and supportive services at some point (President's Cancer Panel 2001). Cancer patients and their families routinely report that difficulty in coping with the diagnosis of cancer is compounded by the complex and often confusing maze that comprises cancer care in the United States today—from treatment options to specialized care to clinical trials and financial consequences (Lance Armstrong Foundation 2006).

Patient navigation programs have been developed to provide assistance to patients, survivors, families, and caregivers about how to chart their way through the health care system and all along the cancer continuum—

### **Patient Navigation Programs Are Exploring Best Practices**

Cancer-focused organizations are developing, implementing, and evaluating best practices in patient navigation.

The National Cancer Institute's Patient Navigation Research Program (NCI PNRP) focuses on developing and testing interventions to promote cancer awareness and health literacy within communities and to help people manage cancer diagnoses and overcome common barriers to obtaining timely and appropriate cancer care and treatment. The primary participants for this research program are people experiencing cancer-related health disparities, including racial or ethnic minorities, people with lower socioeconomic status, and residents of rural areas. NCI PNRP captures valuable data for comprehensive evaluations of the effectiveness of its interventions in reducing cancer health disparities.

The American Cancer Society's Patient Navigator Program (ACS PNP) places trained ACS staff in strategically selected cancer treatment facilities that care for a large number of newly diagnosed and underserved cancer patients. ACS patient navigators ensure that the individual needs of cancer patients are addressed and that the treatment experience for patients and their caregivers includes attention to matters beyond clinical concerns. Nearly 100 ACS PNPs have been established across the country.

prevention, recommended screening, treatment, and survivorship. Effective navigation starts with outreach to the community to educate about prevention and early detection and to make people aware of all available health resources and services. It continues when a patient receives an abnormal cancer screening result or a cancer diagnosis. The patient navigator continues to support the cancer survivor and his or her caregivers, family, and friends through treatment and rehabilitation.

The first patient navigation programs combined community and culturally competent care-coordination with aspects of health literacy and disease management programs to reduce racial, ethnic, and poverty-driven disparities in care. Thus, although originally developed to reduce disparities in cancer care, patient navigation is now being replicated more widely across many populations and is receiving considerable support for demonstration projects and research to test its effectiveness.

Patient navigators come from a variety of backgrounds—trained laypeople and cancer survivors, social workers, nurses, and others—but they all share the ability to communicate credibly within the health care system and with patients and their families (NCI 2006). A patient navigator assists the patient through the cancer continuum, removing barriers to effective care through a variety of culturally competent and individualized interventions. This system of support increases the chances for survival and high quality of life (NCI 2005). Evaluation of patient navigation programs has shown them to be effective with minority and low-income people's experience with care and to reduce barriers to care (Steinberg et al. 2006).

### **Young People Need Access to More Resources through Patient Navigation**

Patient navigation should be expanded to other populations lacking resources to navigate the health care system, and should include the needs of children, adolescents, and young adults. These young people must navigate a complex health care system composed of multiple specialists and uncoordinated care and resources. They face quality-of-life and health literacy issues that are particularly challenging such as fertility concerns, peer relationships, and questions of how best to live a full life during and after their cancer experience.

The health care system is unfamiliar to this generally healthy population that previously has not needed to access these services. In many areas, the system is not yet

focused on the special needs of young adult cancer survivors and their care partners and offers limited appropriate or relevant resources (NCI and the Lance Armstrong Foundation 2006). A patient navigator can provide information and guidance regarding the treatment center, clinical trials, and supportive care services.

Patient navigation can greatly reduce the impact of cancer on the individual and the family or care system. It is a service that can be used to enhance the delivery of optimum care.

## Strategies for Action

**GOAL 3:** Ensure that all people can navigate through the health care system.

- Develop and evaluate innovative, culturally competent patient navigation tools and programs that address barriers for cancer survivors, caregivers, families, friends, and people at high risk for cancer.
- Increase adoption of patient navigation programs that address services across the cancer continuum of prevention through survivorship in all health care settings, including State, Tribe, Territory, and Pacific Island Jurisdictions Comprehensive Cancer Control Coalition plans.
- Ensure that all people diagnosed with cancer have access to culturally competent patient navigation services, and until patient navigators are available for all people who need them, identify tools and programs that can provide support in the interim.
- Explore policy approaches to incorporate patient navigation systems as a standard of care to benefit all people.

### Patient Navigation Removes Barriers to Care

This is the case report of Isaac B., a patient at the Ralph Lauren Center for Cancer Care and Prevention in Harlem, New York.

Isaac B., a 54-year-old African American man, came to the Center in response to an outreach effort to attract African American men for cancer screening. He was uninsured and unable to pay for a colonoscopy. Isaac B. was seen by a patient navigator who arranged for a colonoscopy free of charge. Isaac's colonoscopy was performed two weeks after his initial visit to the Center.

A large sessile mass in Isaac's colon was found and biopsied. It proved to be a non-invasive cancer.

The patient navigator then represented Isaac at the Medicaid office. The result was the rapid writing of a "Medicaid pending" letter. Based on this letter, the hospital allowed surgery to proceed.

His patient navigator also assisted Isaac B. in accessing necessary pre-surgery testing, completing forms, and keeping his medical appointments. A right hemicolectomy was performed on October 24, approximately one month after the colonoscopy.

In summary, a 54-year-old, poor, uninsured man who was asymptomatic underwent a colonoscopy with biopsy and colon resection in a one-month period of time. The pathologic findings strongly suggest that he is free of his colon cancer. The patient navigator was responsible for eliminating all barriers, including lack of medical insurance, and allowing this patient to undergo timely diagnosis and treatment.

## GOAL 4: Provide Survivorship Care Plans and Systems of Support for All Cancer Survivors

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Early detection of cancer and improved treatments are significant contributing factors to an ever-growing number of cancer survivors whose lives have been directly impacted by cancer and who are living healthier, longer, fuller lives with, through, and beyond cancer.

In 1971, there were only three million people living beyond cancer; today the population of survivors now approaches 12 million—approximately three percent of the U.S. population (NCI 2008). Approximately 66 percent of people diagnosed with cancer are expected to live at least five years after diagnosis. Life after cancer diagnoses poses many challenges for individuals, caregivers, families, and friends—all of whom have unique perspectives and needs. These challenges may be influenced by the person's age at time of diagnosis; type, severity, and duration of cancer and its treatment; financial concerns; access to support; geographic access to follow-up care; employment issues; cultural norms; spirituality; health literacy; and any language differences (President's Cancer Panel 2004). The main messages for all cancer survivors are:

- Discuss follow-up care with a health care professional and create a survivorship care plan.
- Eliminate tobacco use and exposure to second-hand smoke.
- Be active, eat healthy foods, and maintain a healthy weight.
- Follow recommendations to continue early detection and screening for secondary cancers and recurrences.
- Stay informed about health matters.
- Create an established, dependable support system.

Cancer survivors may face a myriad of physical, emotional, and cognitive short- and long-term side effects and/or late effects from treatment. For example, pediatric survivors may experience problems in skeletal and muscular growth, as well as in cognitive development. Two-thirds of childhood cancer survivors are likely to experience one late effect. An estimated one-fourth of childhood cancer survivors are likely to experience a late effect that is severe or life threatening (IOM 2008). Many pediatric clinical professionals are considering these issues when making treatment decisions, and they are being factored into survivorship care plans as well.

There are a growing number of follow-up care recommendations and services for cancer survivors of many different cancer types. Yet each survivor's experience is different. Many survivors face challenges when they are discharged from a cancer specialist's care and they can be confused as to whom to see for their follow-up care or daily health needs. Some survivors develop skin sensitivities, chronic fatigue, sleep disorders, graft vs. host disease, cognitive challenges, or other physical and emotional stresses during and post treatment. These issues may be short- or long-term and are often magnified among underserved and health-disparate populations. This can be a challenging time for many survivors as they work to create a "new normal" in their lives.

### Survivorship Care Plans Can Help Survivors Live Beyond Cancer

After Hurricane Katrina, there were a large number of displaced cancer patients who were in the middle of treatment and needed to continue treatment elsewhere. Both the cancer patients and their new medical teams were left without access to treatment plans or medical histories. This story and many others from survivor advocates have prompted the need to educate and provide treatment summaries to cancer survivors. Treatment summaries are electronic- or paper-based documentation of the treatment and care received, and include descriptive disease characteristics, recommended follow-up care, and available resources. Survivors should always carry with them or have access to their treatment summaries.

Many cancer survivors complete their primary treatment without being aware of additional health risks and without having a treatment summary and survivorship care plan to understand, balance, and manage their future health needs. As people live fully with survivorship issues for many years, access to appropriate care is essential and both the survivors and health care professionals must be informed and have suitable plans for that care. Survivorship care plans are key tools to the future health and wellness of cancer survivors. These plans should provide guidance about how to prevent recurrent or new cancers; monitor for cancer recurrence and other medical and psychosocial effects; intervene for any health consequences of the cancer or the treatments; and coordinate between the various health care professionals to address these needs (IOM 2006). Survivorship care plans should also include treatment summaries to ensure that each person has a documented history of the course of his or her treatment.

Templates are available and discussions are continuing as to how the survivorship care plans will be further developed and implemented in the health care system.

## **Comprehensive Cancer Control Plans Are Supporting Cancer Survivors**

State, Tribe, Territory, and Pacific Islander Jurisdictions are all actively working to support cancer survivors in their communities. Each of these regions has developed a comprehensive cancer control plan that includes goals and strategies to address the physical, emotional, and practical survivorship issues people face. Many public, private, and non-profit organizations have also made recommendations for improving health system performance in survivorship-related areas such as secondary cancer screenings, pain management, and other quality-of-life issues (President's Cancer Panel 2004). But much more can and must be done.

## **Cancer Survivorship Extends Beyond the Cancer Patient**

Unfortunately, almost every American has been touched by cancer, whether directly, or as a caregiver, family member, or friend. For most people diagnosed with cancer, a supportive family member or care-partner is part of the experience. Each caregiving relationship—whether husband and wife, partners, parent to child, adult child to parent, siblings, other family members, or friends—faces physical, emotional, and financial challenges. Although family and loved ones often provide substantial support to the cancer survivor, they often do so at great personal cost to their own health and well-being. These caregivers often miss their own regular health check-ups and screenings and may experience depression, anxiety, decreased health, difficulty sleeping, and an increased risk of premature death (Kurtz et al. 2004; Shultz and Beach 1999).

Evidence-based online, in-person, and phone-based education and support systems are available to provide care and support for caregivers, families, and friends. Survivorship includes ensuring that all people know about survivorship services and can utilize them.

## **Psychosocial Support Is Important for Cancer Survivorship**

Significant emotional and mental health problems, such as fear, depression, and anxiety disorders, are common in individuals, caregivers, families, and friends living through the cancer journey (IOM 2008). These problems can contribute to a person's ability to carry out commitments and can jeopardize adherence to ongoing clinical treatment and follow-up care. Fortunately, effective psy-

## **Survivorship Support Systems**

The words, "You have cancer," bring with them a host of issues that most Americans have never even imagined, much less have any experience navigating. The Lance Armstrong Foundation (LAF) provides free one-on-one support to help people understand what to expect from their cancer experience. The LAF's **LIVESTRONG SurvivorCare** provides cancer survivors with professional counseling and assistance with financial and legal matters, and connections to clinical trials. The LAF also offers cancer support information in English and Spanish, as well as printed and online materials specifically for minority and medically underserved populations including language-specific brochures for Hispanic-, Chinese-, Vietnamese-, and Arab-Americans. The LAF also addresses the unique needs of adolescent and young adult (AYA) cancer survivors through downloadable video podcasts discussing specific AYA concerns.

In 2007, more than 7,300 individuals received support and information from **LIVESTRONG SurvivorCare**: 241,437 brochures were disseminated, 46,201 **LIVESTRONG Survivorship Notebooks** were ordered, and more than 415,000 individuals visited the cancer support section of [www.livestrong.org](http://www.livestrong.org).

In a survey of cancer survivors who have used LAF's services, 92 percent report that they would use the LAF's services in the future if they needed them, 91 percent would recommend the LAF's services to someone who was affected by cancer, and 90 percent think the LAF's services are helpful for people affected by cancer.

chosocial services are available to help relieve emotional distress for cancer survivors of all ages and stages, before, during, and after treatment. However, we must also have a system in place to identify people with psychosocial health needs and link them to the appropriate services as needed. Evidence-based practices for screening survivors and caregivers for psychosocial needs and referrals need to be instituted as a standard of care for survivors (President's Cancer Panel 2004).

## **Cancer Survivors May Need Support Regaining Financial Security**

In addition to managing physical and emotional needs, cancer survivors also need assistance in managing financial concerns throughout their treatment and

beyond their cancer experience. Cancer survivors diagnosed between the ages of 30 and 59 face additional financial and employment issues that affect their care, livelihood, and quality of life (President's Cancer Panel 2004). Travel and personal expenses, as well as increased co-pays for care and treatment, are some of the additional costs that cancer patients and their families must handle during a time of potential lost income for both the patient and the caregiver. Often, survivors and caregivers fear or cope with losing a job because their employers could have preconceived notions about the impact that cancer will have on their ability to work in the future.

Many cancer patients can continue to work throughout treatment, but may need certain accommodations or flexible schedules to help manage fatigue or illness from treatments as well as ensure follow-up care appointments (IOM 2006). With job changes, many survivors fear they will be unable to qualify for health insurance and may find it difficult or extremely costly to obtain life insurance, long-term care insurance, and disability insurance after a diagnosis (President's Cancer Panel 2001). Employers, health care professionals, and government agencies can work together to reduce discrimination due to a cancer diagnosis and provide support plans to help with continued employment.

The cost implications of a cancer treatment can result in lack of access to quality care, mounting debt, lost income resulting from work limitations, depleting retirement or other savings to cover treatment expenses, and the inability to build a retirement account or savings account for emergencies.

Trying to balance health and financial concerns at the same time is an overwhelming challenge. Cancer survivors and their families need available information about existing laws and regulations that may protect their employment, insurance, and assets. They need resources from advocates and organizations that could help support them through economic and employment challenges so they can focus on their care. There is tremendous need to improve all infrastructures—including legal, insurance, and financial—to ensure that cancer survivors and their caregivers and families are able to live fully and are protected in the future. Employers, lenders, and insurers (including health, life, and disability coverage professionals) must be informed of the longevity and renewed productivity most survivors can expect due to treatment advances and effective management of possible short- and long-term side effects.

### **Pain and Other Symptom Management, Palliative Care, and End-of-Life Care Are Available to Cancer Survivors**

Understanding and treating a patient's pain and other symptoms are critical aspects of good clinical practice.

Unfortunately under-treatment of pain is a serious problem in the United States, including chronic pain among cancer survivors. Cancer pain is a significant burden to improving the health and well-being of the person living with cancer and puts additional stress on caregivers and families. Other symptoms, such as fatigue and nausea, are similarly burdensome. This problem persists despite the widespread acceptance that effective palliative care, pain and symptom management, and hospice care, when appropriate, should all be integral and important aspects of quality medical care.

Effective pain and symptom management strategies should be developed between the cancer survivor and the health care professional to put the needs of the patient first. Many people living with cancer still suffer from unrelieved pain even though we have the tools—both pharmacologic and non-pharmacologic—to alleviate the pain and greatly reduce the patient's suffering. Underserved and health-disparate groups are also less likely to receive pain management and often are disproportionately affected by pain (IOM 2001; Payne et al. 2003).

Many factors contribute to untreated or undertreated pain, especially when the pain is chronic and severe and the use of pain medications is warranted. The most prevalent clinical issues relate to the knowledge and attitudes of health care professionals about the legitimate use of pain medications and to patient and family perceptions about pain management (Portenoy et al. 2006; Roth et al. 2007; McCracken et al. 2006). In addition, restrictive legislative and regulatory requirements, as well as concerns about scrutiny from health care licensing agencies when prescribing pain medications, have been recognized as significant impediments to pain relief (Gilson et al. 2007).

The goal of palliative care is to prevent and relieve physical and emotional suffering and to ensure the best quality of life and care possible. Palliative care improves communication and decision-making between the patient and health care professionals and is appropriate for people of any age and at any point in an illness. It can be delivered along with curative treatments, post treatment, or as a means to make individuals more comfortable at the end of life. Palliative care services can assure comprehensive care by integrating the expertise from medicine, nursing, and social work, with additional support from chaplaincy, nutrition, rehabilitation, pharmacy, and other professional disciplines as needed (National Consensus Project for Quality Palliative Care 2008).

### **Hospice and End-of-Life Care Should Be Available**

Unfortunately, certain cancers will progress to terminal disease. It is within our ability to minimize the suffering that can be experienced during this stage of the disease.

Many Americans would choose to die at home rather than in a clinical setting (IOM 2001). Modern medicine has the ability to ease most pain, deliver supportive care, and provide excellent end-of-life care through palliative care, as well as hospice programs. Advanced care planning regarding end-of-life care options should be presented in a comprehensive, patient-centered care plan.

At the center of hospice and end-of-life care is the philosophy that each person has the right to die pain-free and with dignity, and that families will receive the necessary support to allow each person to do so. In many cases, hospice care is provided at home, yet care may also be provided at hospice centers, hospitals, nursing homes, and other long-term care facilities. More than 80 percent of Americans do not know about hospice care, even though they may have access to it through their insurance plan (O'Mahony et al. 2008). Hospice services are available to patients of any age, religion, race, or illness and

### **Research and Development of Cancer Treatments to Enhance Survivorship**

Few events cause people more fear and uncertainty than a cancer diagnosis. But today—because of a steady stream of new and improved medicines and treatments—cancer survivors and the health care professionals, caregivers, families, and friends who want the best for them can manage cancer, and even beat it. Survivors still need more and better treatments, and America's pharmaceutical research companies are responding.

Pharmaceutical researchers are now working on 750 medicines for cancer. Many are high-tech weapons to fight the disease, while some involve innovative research focused on using existing medicines in new ways.

These medicines in development—either in clinical trials or under Food and Drug Administration review—include medicines to treat specific types of cancer. In addition, companies are working on medicines to improve the quality of life for all cancer patients.

America's pharmaceutical research companies are working on many new approaches to fight cancer. The hundreds of new medicines to treat cancer now being developed by the pharmaceutical research industry demonstrate a lasting commitment to meeting patient needs, as well as hope for stemming the toll of cancer-related death and disability.

are covered under Medicare, Medicaid, and most private insurance plans.

### **Strategies for Action**

**GOAL 4:** Provide survivorship care plans and systems of support for all cancer survivors.

- Ensure that cancer survivors are given a treatment summary that includes all care received and important disease characteristics and a survivorship care plan focused on patient-centered, evidence-based standards of follow-up care.
- Engage cancer survivors and caregivers as active participants in their survivorship care plans.
- Ensure that survivors, their caregivers, families, and friends are empowered to access available resources, including information about:
  - Treatment summaries and survivorship care plans.
  - Psychosocial services.
  - Legal and regulatory protections and financial assistance programs.
  - Pain and palliative care services, and hospice and end-of-life care.
- Educate health care professionals and cancer survivors about long-term care needs of cancer survivors, including pain management and palliative care, and the value of survivorship care plans.
- Establish policies to balance appropriate regulatory barriers related to palliative care with the needs of the cancer survivor and caregiver to ensure pain management.

# Advancing the Call Nationwide

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With the significant burden of cancer in mind, the *National Call to Action on Cancer Prevention and Survivorship* was developed with insight from numerous public and private sector collaborators to identify and prioritize cancer prevention and survivorship public health efforts. The specific goals and proposed strategies listed in this *National Call to Action* are:

## **GOAL 1:** Empower healthy lifestyles to prevent cancer.

- Provide resources to support innovative public and private partnerships in all settings to develop, implement, and evaluate community-based public health campaigns and media outreach to promote tobacco prevention and cessation, healthy eating, and physical activity.
- Ensure that health benefit programs include coverage for evidence-based tobacco prevention and cessation services, nutrition counseling, and physical activity promotion.
- Improve access to and affordability of evidence-based tobacco prevention and cessation programs, healthy foods and beverages, and safe areas for physical activity.
- Enact and enforce policies to:
  - Eliminate exposure to tobacco smoke.
  - Ensure that underage people cannot access tobacco products.
  - Increase the price of tobacco products.
  - Ensure that healthy food choices are provided in all settings.
  - Ensure that physical activity options are available in all settings.

## **GOAL 2:** Apply what we know about cancer screening and early detection to all people.

- Improve health literacy about cancer screening and early detection by providing culturally competent information, health messages, and screening services.
- Ensure that all people receive all recommended cancer screenings.
  - Use innovative approaches to improve rates of recommended cancer screening.
  - Implement systems to prompt health care professionals to recommend cancer screening, facilitate

referrals, and remind patients of the need for rescreening.

- Develop outreach strategies and culturally competent messages to promote recommended cancer screening to all communities.
- Improve awareness of cancer screening recommendations for high-risk individuals.
- Improve access and affordability, including coverage in health benefit programs, for recommended cancer screenings.
- Ensure that cancer survivors are provided screening guidelines and are screened for recurrence of the primary cancer and new cancers.
- Focus research strategies on advancing existing screening and early detection technologies to improve sensitivity, increase availability, and reduce costs.

## **GOAL 3:** Ensure that all people can navigate through the health care system.

- Develop and evaluate innovative, culturally competent patient navigation tools and programs that address barriers for cancer survivors, caregivers, families, friends, and people at high risk for cancer.
- Increase adoption of patient navigation programs that address services across the cancer continuum of prevention through survivorship in all health care settings, including State, Tribe, Territory, and Pacific Islander Jurisdiction Comprehensive Cancer Control Coalition Plans.
- Ensure that all people diagnosed with cancer have access to culturally competent patient navigation services, and until patient navigators are available for all people who need them, identify tools and programs that can provide support in the interim.
- Explore policy approaches to incorporate patient navigation systems as a standard of care to benefit all people.

## **GOAL 4:** Provide survivorship care plans and systems of support for all cancer survivors.

- Ensure that cancer survivors are given a treatment summary that includes all care received and important disease characteristics and a survivorship care

plan focused on patient-centered, evidence-based standards of follow-up care.

- Engage cancer survivors and caregivers as active participants in their survivorship care plans.
- Ensure that survivors, their caregivers, families, and friends are empowered to access available resources, including information about:
  - Treatment summaries and survivorship care plans.
  - Psychosocial services.
  - Legal and regulatory protections and financial assistance programs.
  - Pain and palliative care services, and hospice and end-of-life care.
- Educate health care professionals and cancer survivors about long-term care needs of cancer survivors, including pain management and palliative care, and the value of survivorship care plans.
- Establish policies to balance appropriate regulatory barriers related to palliative care with the needs of the cancer survivor and caregiver to ensure pain management.

## What Happens Tomorrow

Action needs to be taken by all Americans in all sectors of society to achieve these four goals and their proposed strategies. It is our hope that through collective action, we will eliminate cancer from the lives of millions of Americans and improve the survivorship experience for millions more.

We all have a role to play in advancing this *National Call to Action*. We can improve cancer prevention and survivorship by identifying and mitigating risk factors, such as tobacco use, diet, sun exposure, environmental exposure, and genetics; promoting the use of recommended cancer screenings and early detection; and utilizing a patient-centered approach in cancer survivorship as a matter of integrative health and appropriate clinical practice. National, state, and community leaders should work together to foster collaborations, enact policies, and support programs to achieve the goals of this *National Call to Action*.

By achieving these four goals, we as a nation will yield savings in both human and economic terms. Furthermore, we will have the added benefit of improving outcomes of other chronic diseases, such as diabetes and cardiovascular disease, that share some of the same risk factors and are influenced by similar gaps in our current health care system and our society.

This is not the first time that attention has been paid to cancer prevention and survivorship. However, it is the first time that an effort has been made to improve cancer prevention and survivorship by the former Surgeons General of the United States in collaboration with public and private partners. We believe that by unifying in a common front, with common messages, we can achieve optimal results. When resources are fully coordinated under visionary leadership and shared goals, we all benefit. It is our hope that this innovative and unprecedented *National Call to Action* will serve as a model for other public health challenges.

## Your Engagement in this *National Call to Action*

The *National Call to Action* is intended to inspire engagement among the American people across all sectors of society. We invite you to share the unique ways that you or your organization will achieve the goals and proposed strategies outlined in this *National Call to Action*. By doing so, you will help to write a chapter in the collective story of improving cancer prevention and survivorship for all Americans. To tell us what you are going to do now that you have read this *National Call to Action*, please visit [www.NCTAcancer.org/NCTAStory/](http://www.NCTAcancer.org/NCTAStory/) or write to:

Canyon Ranch Institute  
NCTA Story  
8600 E. Rockcliff Road  
Tucson, Arizona 85750

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