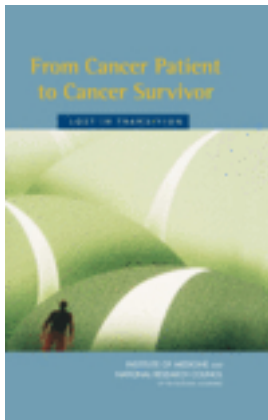


## Free Executive Summary



### From Cancer Patient to Cancer Survivor: Lost in Transition

Maria Hewitt, Sheldon Greenfield, and Ellen Stovall, Editors, Committee on Cancer Survivorship: Improving Care and Quality of Life, Institute of Medicine and National Research Council

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*With the risk of more than one in three getting cancer during a lifetime, each of us is likely to experience cancer, or know someone who has survived cancer. Although some cancer survivors recover with a renewed sense of life and purpose, what has often been ignored is the toll taken by cancer and its treatment—on health, functioning, sense of security, and well-being. Long lasting effects of treatment may be apparent shortly after its completion or arise years later. The transition from active treatment to post-treatment care is critical to long-term health.*

*This book defines the impact of cancer on survivors and their families, and advocates for better care and relationships with survivors. The book also identifies the needs of survivors and their families, and recommends strategies to improve their quality of life. The book also identifies the needs of survivors and their families, and recommends strategies to improve their quality of life. The book also identifies the needs of survivors and their families, and recommends strategies to improve their quality of life.*

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## Executive Summary

**W**ith a risk of more than one in three of getting cancer over a lifetime, each of us is likely to experience cancer, or know someone who has survived cancer. Although some cancer survivors recover with a renewed sense of life and purpose, what has often not been recognized is the toll taken by both cancer and its treatment—on health, functioning, sense of security, and well-being. Long-lasting effects of treatment may be apparent shortly after its completion or arise years later. Personal relationships change and adaptations to routines and work may be needed. Importantly, the survivor's health care is forever altered.

The transition from active treatment to post-treatment care is critical to long-term health. If care is not planned and coordinated, cancer survivors are left without knowledge of their heightened risks and a follow-up plan of action. However, such a plan is essential so that routine follow-up visits become opportunities to promote a healthy lifestyle, check for cancer recurrence, and manage lasting effects of the cancer experience. The nature of these lasting effects and their long-term implications for survivors and their families is the subject of this report. There are now 10 million Americans alive with a personal history of cancer, all of whom are considered cancer survivors. Widespread adoption of cancer screening, successes in treating cancers, and the aging of the population will contribute to an even larger cohort of cancer survivors in the near future.

A committee was established at the Institute of Medicine (IOM) of the National Academies to examine the range of medical and psychosocial issues faced by cancer survivors and to make recommendations to improve their health care and quality of life. In effect, the committee took up the

task identified by Fitzhugh Mullan, a physician and cancer survivor, who in 1985 said, “*The challenge in overcoming cancer is not only to find therapies that will prevent or arrest the disease quickly, but also to map the middle ground of survivorship and minimize its medical and social hazards*” (Mullan, 1985). **This report focuses on survivors of adult cancer during the phase of care that follows primary treatment.** The committee recognized the importance of addressing unmet needs of the large and growing number of cancer survivors during this phase of care. Previous IOM reports addressed the needs of childhood cancer survivors (IOM, 2003) and issues concerning care at the end of life (IOM, 1997, 2001b).

The committee reviewed the consequences of cancer and its treatment and concluded that they are substantial. Although the population of cancer survivors is heterogeneous, with some having few late effects of their cancer and its treatment, others suffer permanent and disabling symptoms that impair normal functioning. Psychological distress, sexual dysfunction, infertility, impaired organ function, cosmetic changes, and limitations in mobility, communication, and cognition are among the problems faced by some cancer survivors. The good news is that there is much that can be done to avoid, ameliorate, or arrest these late effects of cancer. To ensure the best possible outcomes for cancer survivors, the committee aims in this report to:

1. Raise awareness of the medical, functional, and psychosocial consequences of cancer and its treatment.
2. Define quality health care for cancer survivors and identify strategies to achieve it.
3. Improve the quality of life of cancer survivors through policies to ensure their access to psychosocial services, fair employment practices, and health insurance.

The committee’s findings and recommendations that follow are directed to cancer patients and their advocates, health care providers and their leadership, health insurers and plans, employers, research sponsors, and the public and their elected representatives.

## RAISING AWARENESS OF CANCER SURVIVORSHIP

There are many ways to define cancer survivorship, but for the purpose of this report, it is a distinct phase of the cancer trajectory which has been relatively neglected in advocacy, education, clinical practice, and research. Quality cancer survivorship care involves the provision of four essential components of care within a delivery system that facilitates access to comprehensive and coordinated care (Box ES-1). Raising awareness of the medi-

**BOX ES-1**  
**Essential Components of Survivorship Care**

1. **Prevention** of recurrent and new cancers, and of other late effects;
2. **Surveillance** for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects;
3. **Intervention** for consequences of cancer and its treatment, for example: medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance, and disability; and
4. **Coordination** between specialists and primary care providers to ensure that all of the survivor's health needs are met.

cal and psychosocial needs that may follow cancer treatment will help both survivors and their health care providers to ensure that appropriate assessments are completed and available interventions employed. The constellation of cancer's long-term and late effects varies by cancer type, treatment modality, and individual characteristics, but there are common patterns of symptoms and conditions that must be recognized so that health and well-being can be improved.

**Recommendation 1: Health care providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care.**

Cancer patients and their advocates can call attention to their survivorship experiences and the need for change. The leadership of organizations representing physicians, nurses, and psychosocial care providers can collaborate to improve care. Third-party payors of health care and health plans can improve access to needed services through reimbursement policies and improvements in systems of care. Employers can ensure fair workplace policies and accommodations. Sponsors of research can improve the opportunities to increase what we know about survivorship and appropriate care. Congress and state legislatures can enact policies and ensure the support needed to improve survivorship care and quality of life.

**PROVIDING A CARE PLAN FOR SURVIVORSHIP**

The recognition of cancer survivorship as a distinct phase of the cancer trajectory is not enough. A strategy is needed for the ongoing clinical care of cancer survivors. There are many opportunities for improving the care of

cancer survivors—psychosocial distress can be assessed and support provided; cancer recurrences and second cancers may be caught early and treated; bothersome symptoms can be effectively managed; preventable conditions such as osteoporosis may be avoided; and potentially lethal late effects such as heart failure averted. Cancer survivors are often lost to systematic follow-up within our health care system and opportunities to effectively intervene are missed. Many people finish their primary treatment for cancer unaware of their heightened health risks and are ill-prepared to manage their future health care needs. Furthermore, recommended follow-up care is often not delivered and the psychosocial needs of cancer patients are often not addressed.

**Recommendation 2: Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This “Survivorship Care Plan” should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third-party payors of health care.**

Such a care plan would summarize critical information needed for the survivor’s long-term care:

- Cancer type, treatments received, and their potential consequences;
- Specific information about the timing and content of recommended follow-up;
- Recommendations regarding preventive practices and how to maintain health and well-being;
- Information on legal protections regarding employment and access to health insurance; and
- The availability of psychosocial services in the community.

These content areas, adapted from those recommended by the President’s Cancer Panel (2004), are elaborated on in Chapter 3.

The content of the Survivorship Care Plan could be reviewed with a patient during a formal discharge consultation. Appropriate reimbursement would need to be provided, given the complexity and importance of the consultation. The member of the oncology treating team who would be responsible for this visit could vary depending on the exact course of treatment. The responsibility could be assigned either to the oncology specialist coordinating care or to the provider responsible for the last component of treatment. Oncology nurses could play a key role. The survivorship plan may help patients share in the responsibility for their health care. It could prompt survivors to raise questions with doctors and help ensure appropriate follow-up care.

Survivorship care plans have been recommended by the President's Cancer Panel and by the IOM committee, however, the implementation of such plans has not yet been formally evaluated. Despite the lack of evidence to support the use of survivorship care plans, the committee concluded that some elements of care simply make sense—that is, they have strong face validity and can reasonably be assumed to improve care unless and until evidence accumulates to the contrary. Having an agreed-upon care plan that outlines goals of care falls into this “common sense” area. Health services research should be undertaken to assess the impact and costs associated with survivorship care plans, and to evaluate their acceptance by both cancer survivors and health care providers.

### DEVELOPING CLINICAL PRACTICE GUIDELINES FOR SURVIVORSHIP CARE

The Survivorship Care Plan would inform clinicians involved in the subsequent care of cancer survivors about treatment exposures and signs and symptoms of late effects, and, in some cases, would provide concrete steps to be taken. To carry out this plan, an organized set of clinical practice guidelines based on the best available evidence is needed to help ensure appropriate follow-up care. Some guidelines are available for certain aspects of survivorship care, but most are incomplete. Such guidelines would provide specific information on how to manage the complex issues facing survivors of adult cancers. Assessment tools and screening instruments for common late effects are also needed to help identify cancer survivors who have, or who are at high risk for, late effects and who may need extra surveillance or interventions.

**Recommendation 3: Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public- and private-sector efforts.**

Cancer survivors represent a very large at-risk population and without evidence-based clinical practice guidelines, health care providers will vary widely in their practices, leading to inefficiencies in care delivery (see Chapters 3 and 4). More than 60 percent of cancer survivors are aged 65 and older, so the Centers for Medicare and Medicaid Services (CMS) the administrators of the Medicare program, have a stake in developing clinical practice guidelines. The Agency for Healthcare Research and Quality (AHRQ) maintains a National Guideline Clearinghouse and supports Evidence-Based Practice Centers that review relevant literature on clinical, behavioral, or-

ganizational, and financial topics to produce evidence reports and technology assessments (AHRQ, 2001). Such reviews can form the foundation of evidence-based guidelines. Professional organizations (e.g., those representing oncology, primary care, nursing) also have a role to play in developing interdisciplinary guidelines. The guideline development process is a costly one, and public and private support is needed to improve and expedite the development process. Evaluations are needed of the impact of guidelines in the context of survivorship care.

## DEFINING QUALITY HEALTH CARE FOR CANCER SURVIVORS

For certain types of cancer, some evidence-based measures of quality survivorship care exist. Survivors of breast cancer, for example, need to receive annual mammograms, survivors of prostate cancer need periodic testing with the prostate-specific antigen (PSA) test, and survivors of colon cancer require periodic colon examinations. Other measures could likely be developed with available evidence, for example, the need to monitor some individuals treated with certain chemotherapeutic agents for heart conditions and certain individuals treated by radiotherapy for thyroid conditions. In contrast to these disease-specific or treatment-specific measures, some evidence-based measures of quality apply broadly across all types of cancer. For example, routinely assessing cancer survivors for psychosocial distress is warranted because it often exists and effective interventions are available. Given the frequency of other common and treatable symptoms such as fatigue and sexual dysfunction, other measures of quality could likely be formulated with available evidence that would be broadly applicable to cancer survivors.

**Recommendation 4: Quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented by health systems to monitor and improve the care that all survivors receive.**

## OVERCOMING DELIVERY SYSTEM CHALLENGES

The problems that cancer survivors face in getting comprehensive and coordinated care are common to those faced by others with chronic health conditions. Because cancer is a complex disease and its management involves the expertise of many specialists, often practicing in different settings, cancer illustrates well the “quality chasm” that exists within the U.S. health care system and the need for health insurance reforms and innovations in health care delivery. The committee endorses the conclusions and recommendations in the IOM report *Crossing the Quality Chasm* (IOM,

2001a). That report provided the rationale and a strategic direction for redesigning the health care delivery system. It concluded that fundamental reform of health care is needed to ensure that all Americans receive care that is safe, effective, patient centered, timely, efficient, and equitable. Needed is a health care environment that fosters and rewards improvement by (1) creating an infrastructure to support evidence-based practice, (2) facilitating the use of information technology, (3) aligning payment incentives, and (4) preparing the workforce to better serve patients in a world of expanding knowledge and rapid change.

Barriers facing cancer survivors and their providers in achieving quality survivorship care include (1) a fragmented and poorly coordinated cancer care system; (2) the absence of a locus of responsibility for follow-up care; (3) poor mechanisms for communication; (4) a lack of guidance on the specific tests, examinations, and advice that make up survivorship care; (5) inadequate reimbursement from insurers for some aspects of care; and (6) limited experience on the best way to deliver care.

**Recommendation 5: The Centers for Medicare and Medicaid Services (CMS), National Cancer Institute (NCI), Agency for Healthcare Research and Quality (AHRQ), the Department of Veterans Affairs (VA), and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.**

Several promising models for delivering survivorship care are emerging, including:

1. A shared-care model in which specialists work collaboratively with primary care providers.
2. A nurse-led model in which nurses take responsibility for cancer-related follow-up care with oversight from physicians.
3. Specialized survivorship clinics in which multidisciplinary care is offered at one site.

There is limited evidence on which of these, or other delivery strategies, is feasible, cost-effective, or acceptable to survivors and clinicians (see Chapter 4). It is likely that different care models will be preferred and appropriate for different survivor groups and communities. Models for delivering survivorship care should address the fact that oncology specialists and primary care providers, facing an expanding population of cancer survivors, will become overburdened with follow-up care. The proposed demonstration programs could include assessments of methods to improve care with advanced information systems, such as electronic health records, virtual consultations, smart cards, and web-based approaches. CMS is the



primary payor of care for cancer survivors and should therefore have a strong interest in identifying cost-effective models of care.

### SURVIVORSHIP AS A PUBLIC HEALTH CONCERN

The Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation have developed a public health approach to survivorship care that may assist communities in identifying and addressing the survivorship needs of individuals, their families, and their health care providers (CDC, 2004; CDC and LAF, 2004). Among the public health capacities that could be addressed are:

- Population-based surveillance systems for survivorship care and quality of life;
- Areawide community-based resource guides for survivors and health care providers;
- Service needs assessments;
- A clearinghouse for health care provider education and training opportunities;
- Provision of primary and secondary prevention services (e.g., smoking cessation, cancer screening); and
- Program evaluation and identification of best practices.

Health departments have had a long tradition of managing cancer registries, offering health education, and providing community-based health promotion and disease prevention activities. Interventions for common chronic public health problems such as heart disease and diabetes could well be germane to cancer survivors and their families. These public health approaches are early in their development. Resources are needed to evaluate the effectiveness of community-based services and comprehensive cancer control plans in improving the care and quality of life of cancer survivors.

**Recommendation 6: Congress should support Centers for Disease Control and Prevention (CDC), other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care, and promoting the implementation, evaluation, and refinement of existing state cancer control plans.**

### IMPROVING HEALTH CARE PROFESSIONAL CAPACITY

Few oncology and primary care health professionals have formal education and training regarding cancer survivorship. With the growing ranks

of cancer survivors, it is likely that additional health personnel will be needed, particularly nurses with advanced oncology training. Online resources are increasingly available and appear to be an attractive means of reaching multiple provider audiences, but the effectiveness of this and other approaches needs to be assessed. Limited financial support has been available through public and private sectors for survivorship-related education and training.

**Recommendation 7: The National Cancer Institute (NCI), professional associations, and voluntary organizations should expand and coordinate their efforts to provide educational opportunities to health care providers to equip them to address the health care and quality of life issues facing cancer survivors.**

Efforts are needed to update undergraduate and graduate curricula for those in training and to provide continuing education for practicing providers of survivorship care. Continuing education is needed across many disciplines, but in order to ensure the provision of quality survivorship care, it is especially important to reach (1) medical oncologists, hematologists, urologists, surgeons, and radiation oncologists who initially treat cancer patients; (2) primary care physicians; (3) nurses; and (4) social workers and other providers of psychosocial services.

To augment the supply of nurses who could provide survivorship care, the committee recommends increasing the number of nursing schools that provide graduate training in oncology, providing incentives to nurses who seek certification in oncology, and supporting general efforts to ease the nursing shortage. To ensure access to psychosocial services, continuing education opportunities are needed for social workers and other mental health providers. In addition, efforts are needed to maintain social services in cancer programs. Detailed recommendations on professional education by health care specialty are outlined in Chapter 5.

## ADDRESSING EMPLOYMENT-RELATED CONCERNS

Most cancer patients who are working require some kind of accommodation to work throughout treatment, and some experience difficulties at work after treatment. Estimates of the impact of cancer on employment vary. The majority of cancer survivors who worked before their diagnosis return to work following their treatment. However, as many as one in five individuals who work at the time of diagnosis have cancer-related limitations in ability to work 1 to 5 years later. Half of those with limitations are unable to work at all.

All survivors are at risk of experiencing subtle, although not necessarily blatant, employment discrimination. Federal laws enacted in the 1990s

have offered cancer survivors some protections from discriminatory practices such as firing or denial of benefits because of cancer. Such laws have clarified the responsibilities of employers to accommodate workers returning to work with health-related limitations. The most important of these laws, the Americans with Disabilities Act (ADA), continues to be interpreted by the courts. Although protections cover disabled cancer survivors, some survivors have not been fully protected from job loss and access to accommodations for cancer-related work limitations. Successful resolutions on the part of cancer survivors who have filed formal complaints against employers suggest that not all employers have yet fully complied with the law.

**Recommendation 8: Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in ability to work.**

- Cancer providers, advocacy organizations, NCI, and other government agencies should continue to educate employers and the public about the successes achieved in cancer treatment, the improved prospects for survival, and the continuing productivity of most patients who are treated for cancer.
- Public and private sponsors of services to support cancer survivors and their families should finance programs offering education, counseling, support, legal advice, vocational rehabilitation, and referral for survivors who want to work.
- Providers who care for cancer survivors should become familiar with the employment rights that apply to survivors who want to work; make available information about employment rights and programs; and routinely ask patients who are cancer survivors if they have physical or mental health problems that are affecting their work
- Employers should implement programs to assist cancer survivors, for example, through short- and long-term disability insurance, return-to-work programs, accommodation of special needs, and employee assistance programs.
- Cancer survivors should tell their physicians when health problems are affecting them at work. Survivors should educate themselves about their employment rights and contact support organizations for assistance and referrals when needed.

### Improving Access to Adequate and Affordable Health Insurance

The health insurance issues facing cancer survivors bring into sharp focus the gaps and limitations of health insurance in the United States. All Americans are at risk of becoming a cancer survivor and finding themselves without access to adequate and affordable health insurance. Cancer survivors, like other Americans with serious, chronic health conditions, face significant barriers to coverage because of their health status. In particular, access to individual health insurance may be denied to residents in many states if they have a history of cancer. Cancer survivors may also face surcharged premiums for coverage because of their cancer history, depending on where they live and the type of coverage they seek. The improvements in the care of cancer survivors envisioned by the committee can not be achieved without health insurance that is accessible, adequate, and affordable.

Health insurance provides protection from the very high costs of cancer care. Most cancer survivors have health insurance through the federal Medicare programs because they are aged 65 and older. Nevertheless, 11 percent of adult cancer survivors under the age of 65 are uninsured and, for these individuals, the costs of cancer care can be financially devastating. These younger uninsured cancer survivors report access to care problems due to concerns about cost—51 percent report delays in obtaining medical care; 44 percent report not getting needed care; and 31 percent report not getting needed prescription medicine. The financial problems posed by cancer loom larger, because even those with health insurance can have trouble paying for prescription drugs and other types of care.

The IOM Committee on the Consequences of Uninsurance, in its 2004 report, *Insuring America's Health*, recommended that the President and Congress develop a strategy to achieve universal insurance coverage and to establish a firm and explicit schedule to reach this goal by 2010 (IOM, 2004).

**Recommendation 9:** Federal and state policy makers should act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and payors of health care should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.

Cancer survivors need continuous access to health insurance that covers their health care needs. Policy makers should act to ensure that cancer survivors and others with serious chronic health conditions can obtain

health insurance that is adequate and affordable. For example, policy makers could provide federal support to improve state high-risk pools—through premium subsidies, lower cost-sharing options (e.g., lowering copayments and deductibles), expanded coverage for prescription drugs, and elimination of preexisting condition exclusion periods. This could help such programs better serve the needs of people with serious and chronic health conditions. Federal programs that guarantee availability of coverage (e.g., those provided under the Consolidated Omnibus Budget Reconciliation Act [COBRA] and the Health Insurance Portability and Accountability Act [HIPAA]) could also be expanded to include premium subsidies. Because federal legislation generally covers only federal programs such as Medicare and Medicaid, many health insurance reforms must also be addressed at the state level.

Policy makers can also improve other existing programs aimed at improving health insurance coverage of cancer survivors. In 2000, Congress established a new eligibility category option in Medicaid for uninsured women with breast and cervical cancer. However, only women screened through CDC-funded programs are eligible for this Medicaid coverage, and CDC-funded programs today reach fewer than 15 percent of the program-eligible population. Policy makers could strengthen and build on this program, first by ensuring that more eligible women with breast and cervical cancer are reached by it, and second by expanding Medicaid eligibility to include other cancer patients and survivors who have no other coverage options.

All health insurance in the United States, including Medicare, Medicaid, employer-sponsored group health plans, and individually purchased policies, should cover effective cancer survivorship care. National coverage standards should be promulgated and include interventions for which there is good evidence of effectiveness (e.g., certain post-treatment surveillance strategies, treatments for late effects, interventions for symptom management, rehabilitative services). Importantly, coverage standards should include the development of a post-treatment plan of survivorship care (see Recommendation 2). National coverage standards should evolve with the development of clinical guidelines and evidence-based research into the quality and effectiveness of care. Congress has already taken preliminary steps to assure adequacy of some cancer survivorship care. The Women's Health and Cancer Rights Act requires health insurance to cover reconstructive surgery, prostheses, and care for complications following mastectomy, including lymphedema. This model could be expanded to assure minimum federal standards for all cancer survivorship care under all health insurance.

### Making Investments in Research

Within the past decade, a focus for federally sponsored research has been organized within NCI's Office of Cancer Survivorship. Findings from this first era of dedicated research have informed much of this report. A greater investment in research is needed to learn more about late effects and their management. Cancer treatments are constantly evolving, and consequently, what is known about today's cancer survivors may not be relevant to future patients. Newer therapies hold the promise of limiting the late effects of cancer, but mechanisms to monitor long-term effects need to be put in place. Also needed are studies to determine how best to detect and treat cancer recurrence, new primary cancers, and other late effects. Providers responsible for follow-up need to know which tests to use, how often to use them, and the relative costs and benefits of alternative surveillance strategies. Investments are needed in the science on which clinical decisions must be based.

Among the challenges to conducting survivorship research are the difficulties and costs associated with long-term follow-up, the complexities of accruing sufficient sample sizes through multi-institutional research endeavors, and emerging problems associated with compliance with privacy provisions of the HIPAA. Survivorship research is funded at relatively modest levels within both public and private sectors, especially as contrasted to levels of support for treatment-related research.

**Recommendation 10: The National Cancer Institute (NCI), Centers for Disease Control and Prevention (CDC), Agency for Healthcare Research and Quality (AHRQ), Centers for Medicare and Medicaid Services (CMS), Department of Veterans Affairs (VA), private voluntary organizations such as the American Cancer Society (ACS), and private health insurers and plans should increase their support of survivorship research and expand mechanisms for its conduct. New research initiatives focused on cancer patient follow-up are urgently needed to guide effective survivorship care.**

Research is especially needed to improve understanding of:

- Mechanisms of late effects experienced by cancer survivors and interventions to alleviate symptoms and improve function;
- The prevalence and risk of late effects;
- The cost-effectiveness of alternative models of survivorship care and community-based psychosocial services; and
- Interventions to improve the quality of life of cancer survivors, their families, and caregivers.

To conduct research in these priority areas, large study populations are needed that represent the diversity of cancer survivors in terms of their type of cancer and treatment as well as their sociodemographic and health care characteristics. Existing research mechanisms need to be fully utilized and in some cases enhanced to provide better opportunities for cancer survivorship research. For example:

- More long-term follow-up studies should be conducted of individuals enrolled in clinical trials through the NCI-sponsored Cooperative Groups;
- Additional survivorship special studies should be conducted through population-based cancer registries;
- National household and health care surveys should be analyzed to capture information on survivorship;
- Opportunities should be sought to link data from cancer registries to administrative databases;
- The follow-up period of ongoing cancer health services research studies should be extended to yield more information on long-term survivorship; and
- Investigators should be encouraged to use existing primary care and health services research networks to conduct cancer survivorship research.

In addition to harnessing these existing mechanisms, the committee recommends that federal (e.g., CMS, AHRQ, NCI) and private (ACS, health plans) research sponsors support a large new research initiative on cancer patient follow-up. Answers to the following basic questions about survivorship care are needed:

- How frequently should patients be evaluated following their primary cancer therapy?
- What tests should be included in the follow-up regimen?
- Who should provide follow-up care?

A call for such research was made in IOM's *Ensuring Quality Cancer Care* report (1999), but it has not yet been conducted. In some cases large clinical trials will be needed to answer these questions. The committee concluded that improvements in cancer survivors' care and quality of life depend on a much expanded research effort.

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# From Cancer Patient to Cancer Survivor

LOST IN TRANSITION

Committee on Cancer Survivorship: Improving Care and Quality of Life  
National Cancer Policy Board

Maria Hewitt, Sheldon Greenfield, and Ellen Stovall, *Editors*

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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the NRC's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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## Preface

A rather startling statistic opened the eyes of many on our committee when they were invited to undertake a study for the Institute of Medicine (IOM) on cancer survivorship. The eye-opening statistic describes a burgeoning population of cancer survivors who live among us today and who are more than 10 million strong. Cancer survivors swell the ranks of the many places where we live, work, and play, yet, as our committee concluded, they remain largely understudied and lost to follow-up by our scientific research and health services delivery communities, respectively. Although the concept of survivorship is not new, we have determined there are times when trends in medical science, health services research, and public health awareness converge to forge a new realization. Such may be happening with respect to survivorship research and cancer care with the publication of this report.

These three trends forecast how we believe the findings and recommendations of this report can have an impact on our health care delivery system for the majority of cancer survivors who suffer the long-term and late effects of their diagnosis and treatment for cancer. First, for many, cancer has become a chronic condition as a new generation of cancer survivors is living longer following improved access to effective screening, diagnosis, and treatments. Second, strides have been made in the science of health services research with models of care emerging for individuals with chronic conditions needing complex care. Third, a persistent and energetic consumer movement has demanded patient-centered quality of care across the entire cancer trajectory.

These trends dovetail nicely with the extensive review of peer-reviewed



literature that was considered by the IOM Committee on Cancer Survivorship. The report by this committee builds on the large body of IOM's work to improve Americans' access to quality health care. By also reviewing reports that summarize the anecdotal and compelling stories of survivorship, we heard the voices of survivors who underwent a life-changing experience—learning that large numbers of them are dealing with a legacy of physical, psychological, social, vocational, spiritual, and economic consequences. Hearing about their experiences further opened our eyes to the unspoken and hidden disabilities that follow successful treatment for cancer.

The committee was composed of 17 members representing many disciplines with broad knowledge and expertise. Several committee members had a personal diagnosis of cancer, and others would be considered cancer survivors because they include the family, friends, and loved ones of individuals diagnosed with cancer.

Both of us have very personal reasons for wanting this report to find its voice with policy makers and all those who share responsibility for our health care financing and delivery systems. For one of us (Ellen Stovall), who is a 33-year survivor of two diagnoses of cancer, it represents a huge step in a dream come true for her and the founders of the National Coalition for Cancer Survivorship (NCCS): the recognition of cancer survivorship as a topic unto itself. Ellen currently leads NCCS, which began its efforts in the mid-1980s with few listening. For the other of us (Shelly Greenfield), it represents a rare victory, an endorsement of the recognition that the efforts of doctors alone, no matter how hard they are trying, are going to fall short if systemic issues such as care coordination, patient-centered care delivery, financing, informatics, and accountability for quality of care are not enjoined.

For all of us who have ever been diagnosed with cancer, for all of us who know someone with cancer, for all of us who have lost someone to cancer, for all of us who will be diagnosed with cancer in our lifetime, and the millions who will survive this diagnosis, we hope this report will forge a new era of cancer survivorship by raising awareness of the many concerns facing cancer survivors. Most importantly, we want to persuade the policy makers named in our recommendations of the imperative to assume the large tasks ahead and ultimately to improve the care and quality of life of individuals with a history of cancer.

On behalf of our committee, we want to extend our gratitude to the Institute of Medicine for giving us superb staff to guide our discussions and push us toward prioritizing what at times seemed to be an endless list of important issues on which to focus. With appreciation to all involved with this report, we are deeply indebted to Roger Herdman, Director, National Cancer Policy Board for his leadership. Maria Hewitt's organizational skills,

her vast background in cancer activities, her rare ability to handle highly opinionated experts from diverse fields, and her wide perspective blending both the professional and public aspects of this complex topic made this report happen. We also thank Elizabeth Brown for the flawless management of the project. The dedication of both the committee and staff to excellence in research has made this report a document that will guide critical work in health care for cancer survivors for many years to come.

Shelly Greenfield, *Chair*  
Ellen Stovall, *Vice Chair*



# From Cancer Patient to Cancer Survivor

