



IMPERATIVES FOR QUALITY CANCER CARE:

ACCESS, ADVOCACY, ACTION,
AND ACCOUNTABILITY

*Adopted at the First National Congress on Cancer Survivorship
November 13, 1995*

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ACCESS, ADVOCACY, ACTION, AND ACCOUNTABILITY

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FROM THE TIME OF DISCOVERY AND FOR THE BALANCE OF LIFE, AN INDIVIDUAL
DIAGNOSED WITH CANCER IS A SURVIVOR.

NCCS Charter

The National Coalition for Cancer Survivorship (NCCS) has published *Imperatives for Quality Cancer Care* to put forth a Declaration of Principles and suggested guidelines for access, advocacy, action, and accountability in three specific domains: Quality Cancer Care, Physiologic Long-Term and Late Effects of Cancer Treatment, and Psychosocial Issues of Cancer Survivorship. Presented in this publication are the final versions of NCCS's position papers that initially were introduced as "working drafts" for the delegates to the First National Congress on Cancer Survivorship—an historic meeting hosted by NCCS and convened in Washington, DC, November 11-14, 1995.

With the publication of *Imperatives for Quality Cancer Care*, NCCS is marking nearly a decade of commitment to raising the issues explored in the position papers. At the first NCCS Assembly in 1986, the founders laid the groundwork for focusing on the psychosocial challenges and the physiologic long-term and late effects of cancer treatment faced by cancer survivors. In recent years, NCCS board members, community leaders, volunteers, and staff have contemplated other avenues for calling attention to these understudied areas, and on the more expansive topic of *defining quality cancer care*—a complex challenge that has come to the forefront in an era marked by cost-driven health care plans and health insurance reform initiatives.

Preparatory work on the position papers began by surveying nationally recognized individuals with expertise in the areas of quality cancer care, physiologic effects of cancer treatment, and psychosocial issues. Surveys were mailed to nearly 300 people in the summer of 1995. More than 50 percent of those surveyed responded, and they are listed as contributors to the position papers at the end of each section.

At the First National Congress, delegates participated in working groups around the three topics. In addition, during the Congress, a Leadership Forum was held for invited guests to further debate the parameters of quality cancer care. At a Speak Out, which was the final session of the Congress, issues raised during the working groups and in the Leadership Forum were further developed and discussed. Congress delegates voted to adopt the Declaration of Principles which is included as part of this document.

Coming together during NCCS's First National Congress on Cancer Survivorship as delegates from a diverse and sometimes divided community was a fairly new concept for many individuals involved in cancer research, prevention, control, and treatment. It is not, however, a new concept for cancer survivors in general or for NCCS members in particular. The 300

delegates to the Congress came from throughout the United States, including Alaska and Hawaii, all sharing a common interest in and commitment to cancer survivorship—defined by NCCS as “the experience of *living with, through, and beyond a diagnosis of cancer.*”

Collectively, the delegates to the Congress represented the many faces of cancer survivorship: cancer survivors and their community of caregivers including family members and friends, health care professionals, scientists, business and community leaders, policy experts, legislators, government officials, members of the clergy, and the media. Some came to the Congress as state delegates appointed by their Governors. Others came by NCCS invitation to ensure participation by a widely diverse and knowledgeable group. All who attended were there to make certain that people with cancer have a voice in establishing guiding principles for issues and policies that will affect the quality of their lives.

The impetus for exploring these particular themes in a forum such as the First National Congress on Cancer Survivorship and writing about them in the position papers, was inspired by the current leadership and staff of NCCS. Since moving NCCS's headquarters to Washington, DC, in 1992, NCCS has played a pivotal role in articulating concerns of cancer survivors in a variety of ways and to many diverse audiences. The following examples point to some of the ways in which NCCS has contributed to the debate on quality cancer care, physiologic long-term and late effects, and psychosocial issues of cancer survivorship.

- In response to requests from current and previous Directors of the National Cancer Institute (NCI), NCCS has provided written feedback on NCI's annual *Bypass Budget*—a budget estimate of NCI's current funding needs that, in effect, “bypasses” Congress and goes directly to the President. This mechanism for special appropriations was established by the National Cancer Act in 1971 and allows the Director of the NCI to base a funding request on the Institute's best estimate of where the most potent scientific opportunities are for making advances against cancer. In its comments, NCCS consistently has cited the need for more cancer research in the areas of psychosocial issues and physiologic long-term and late effects.
- Beginning in 1990, NCCS has committed staff time and resources to providing technical assistance—the provision of materials, advice, and counsel—to cancer support organizations by encouraging the formation and growth of community organizations linked in some fashion to NCCS. This effort has been designed to make survivorship services available to more people in their own communities and, where possible, to link existing resources to ensure a wider range of psychosocial and other supportive services. Referred to as the Cancer Community Organizing Project, this NCCS initiative will be expanded over the next several years and will include strategic collaboration with other national and locally-based groups to maximize effectiveness in advocating for quality cancer care.
- Annually, since 1991, NCCS has appeared before the Senate and House Committees on Appropriations for the National Institutes of Health to testify on behalf of specific requests for increased funding for survivorship research. Under its legislative mandate, the NCI must “conduct and support research, training, and health information dissemination” in such areas as the cause, diagnosis, and prevention of cancer, and the treatment and continued care of cancer patients and their families. Significantly, Congress amended the NCI's charge in 1988 to include “rehabilitation from cancer” as one of its legislative mandates (Health Omnibus Program Extension Act of 1988).

- Early in 1993, under the leadership of NCCS, the Cancer Leadership Council (CLC) was organized to develop a consensus statement on health care reform from the perspective of the cancer patient. With all of the health care reform proposals before Congress at that time and with increasing rhetoric about managed care organizations providing “patient centered,” “patient oriented,” and “patient focused” care, little attention was being given to the needs or input of people with cancer. NCCS organized the CLC with other cancer support and advocacy groups whose *primary* interest was to provide resources for information, services, and advocacy to meet the needs of people with cancer and their families.

In addition to NCCS, founding member organizations of the Cancer Leadership Council are: Cancer Care, Inc., Candlelighters Childhood Cancer Foundation, Susan G. Komen Breast Cancer Foundation, National Alliance of Breast Cancer Organizations, North American Brain Tumor Coalition, US-TOO International Prostate Cancer Organization, and Y-ME National Breast Cancer Organization. Building successfully on the momentum gained during the debate over health care reform, the CLC continues to discuss policy issues and to construct strategies that will improve access to quality cancer care for all Americans.

- In 1995, as a forerunner to the First National Congress, NCCS introduced a major publication, the *NCCS Town Hall Meeting Guide: Empowerment Through Advocacy*. Since its publication, interest in sponsoring NCCS Town Hall Meetings has been extraordinary. Nine Town Hall Meetings occurred in 1995, and ten more are slated through 1996. NCCS will continue to support this program to provide a forum in which communities can tackle the increasingly complex issues facing cancer survivors, their supporters and their caregivers.

The mandate of the First National Congress on Cancer Survivorship was for a new generation of people with expertise in cancer—cancer survivors—to obtain input from leaders throughout the cancer community and to work collectively on strategic imperatives designed to improve access and to ensure quality in patient-oriented cancer research and cancer care to the year 2000. In light of this mandate, NCCS offers these position papers in the spirit of commitment to work with all individuals, organizations, and institutions who believe in the strength of collective wisdom and the ability of that strength to change policies and programs which govern access to quality cancer care.

Ellen L. Stovall
Executive Director
National Coalition for Cancer Survivorship



QUALITY CANCER CARE

Declaration of Principles

- Principle 1* People with cancer have the right to a system of universal health care. This access should not be precluded because of preexisting conditions, genetic or other risk factors, or employment status.
- Principle 2* Quality cancer care should be available in a health care system whose standards and guidelines are developed in consideration of treating the whole person with cancer. Health care plans must regard the cancer patient as an autonomous individual who has the right to be involved in decisions about his or her care.
- Principle 3* Standards of cancer care should be driven by the *quality* of care, not only by the *cost* of care, and should include participation in clinical trials and quality of life considerations.
- Principle 4* All people diagnosed with cancer should have access to and coverage for services provided by a multidisciplinary team of care providers across the full continuum of care. Health care plans should be held accountable for timely referral to appropriate specialists when symptoms of cancer or its recurrence may be present.
- Principle 5* People with cancer should be provided a range of benefits by all health care plans that includes primary and secondary prevention, early detection, initial treatment, supportive therapies to manage pain, nausea, fatigue and infections, long-term follow-up, psychosocial services, palliative care, hospice care, and bereavement counseling.

- Principle 6* People with histories of cancer have the right to continued medical follow-up with basic standards of care that include the specific needs of long-term survivors.
- Principle 7* Long-term survivors should have access to specialized follow-up clinics that focus on health promotion, disease prevention, rehabilitation, and identification of physiologic and psychosocial problems. Communication with the primary care physician must be maintained.
- Principle 8* Systematic long-term follow-up should generate data that contribute to improvements in cancer therapies and decreases in morbidity.
- Principle 9* The responsibility for appropriate long-term medical care must be shared by cancer survivors, their families, the oncology team, and primary care providers.
- Principle 10* The provision of psychosocial services must be safeguarded and promoted. Persons diagnosed with cancer should receive psychosocial assessments at critical junctures along the continuum of cancer care to determine availability of needed support and their ability to seek information and to advocate on their own behalf.
- Principle 11* Psychosocial research is integral to comprehensive cancer care and, as such, psychosocial outcome measures should be included in all future clinical trials. The importance of this research and its application and transfer to oncology care plans should be recognized and encouraged.
- Principle 12* Cancer survivors, health care providers and other key constituency groups must work together to increase public awareness; educate consumers, professionals, and public policy makers; develop guidelines and disseminate information; advocate for increased research funding; and articulate for and promote survivors' rights.
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QUALITY CANCER CARE

ACCESS

ADVOCACY

ACTION

ACCOUNTABILITY

INSURERS ARE BECOMING HEALTH PLANS AND PROVIDERS; PROVIDERS ARE BECOMING INSURERS; SUPPLIERS ARE BECOMING “DISEASE STATE MANAGERS;” HOSPITALS ARE GOING OUT OF BUSINESS; HEALTH CARE DELIVERY MECHANISMS ARE “MOVING” TO THE INTERNET; AND ANYONE IS IN THE BUSINESS OF WRITING CLINICAL PATHWAYS (A.K.A. PRACTICE GUIDELINES). THE RULES OF THE GAME ARE CHANGING FASTER THAN MANAGEMENT STRUCTURES AND INFORMATION SYSTEMS CAN SUPPORT, PAYERS CAN UNDERSTAND OR TRACK, AND REGULATORS AND LEGISLATORS CAN CONTROL. WALL STREET AND VENTURE CAPITALISTS ARE MAKING A KILLING. DEVELOPMENT OF CANCER CARE QUALITY GUIDELINES WILL OCCUR IN THIS VERY DIFFICULT “FREE-FOR-ALL” ENVIRONMENT.

Elan Rubinstein

BACKGROUND

In September 1995, the National Coalition for Cancer Survivorship (NCCS) surveyed health providers, government officials, professional and advocacy organizations, scientists, and others regarding a critical issue facing this nation's ten million cancer survivors: quality cancer care. The responses were illuminating as they portrayed a system in flux. The United States is moving away from a health care system where fee-for-service insurance plans predominate to one where market-based alternatives quickly are gaining favor among employers, consumers, and other purchasers of health care coverage. What this fundamental transition will mean for survivors and individuals with serious or life-threatening diseases and the people who care for them is an open question with important public policy implications.

This position paper summarizes the opinions of experts from a diversity of disciplines regarding the strengths and weaknesses of both fee-for-service and market-based approaches and the particular needs of cancer survivors. It incorporates input from invited participants at a Leadership Forum convened by NCCS during the First National Congress on Cancer Survivorship in Washington, DC, a working group on Quality Cancer Care comprised of Congress delegates, and a Speak Out where the working groups reported their findings to the assembled delegates.

FEE-FOR-SERVICE

STRENGTHS

Not surprisingly, the respondents cited choice—of providers, treatments, and institutions—as the overwhelming strength of fee-for-service plans. The experts agreed that the initial selection of, and resulting satisfaction with, a particular health care provider can be influenced by factors as distinct as convenience, cost, expertise, and personal compatibility. Freedom of choice was seen as offering both strictly medical advantages—for example, the ability to seek second opinions from specialists in cases of rare conditions—as well as psychological benefits, including the encouragement of strong doctor/patient relationships. As stated by one survivor:

In the traditional fee-for-service system, the patient/survivor has choice; from this stems the opportunity for control and confidence. If the opportunity is seized, the patient motivates the physician and the medical team to their best performances, and, through them, the delivery system to its best performance. With control, the patient can insist on explanations and alternatives. This leads to confidence. Lacking either control or confidence, the patient in this system still has the choice of finding a new physician.

In addition to choice, the availability of state of the art cancer treatment, including long-term followup by specialists, was regarded as another significant strong point of the fee-for-service approach. Although fee-for-service plans may not have paid directly for research treatments, generous reimbursement for ancillary costs often supported major clinical research programs. This led to a network of oncologists and specialized centers conducting clinical trials involving promising new therapies. As a result, the United States is a leader in innovative diagnostic, imaging, and therapeutic technology.

Fee-for-service also allows providers maximum flexibility in utilizing these advancements, as they can individualize treatment plans in order to care for patients as they deem best. Flexibility, discretion, and creativity were terms associated with fee-for-service. As one expert stated: “[T]he fee-for-service system has many faults but does result in physicians being advocates for therapy and for patients. Alternative managed care systems may make physicians the rationer[s] of health care rather than the advocate[s] of health care.”

DRAWBACKS

As recognized in the foregoing statement, the fee-for-service approach does have significant faults. On a macro level, respondents pointed to financial incentives which can encourage over-utilization of services offering little or no improvement in either length or quality of life. The resulting inefficiencies have contributed to escalating health care costs that many regard as impossible to sustain in the future. Examples of situations where better use of our resources could be achieved included:

- Continuing aggressive care when support or palliative care would be more appropriate
- “Shopping” for third or fourth opinions
- Promoting expensive new care to patients before the efficacy of the particular procedure or treatment is clearly established through qualified clinical trials
- Allowing “me too” programs and services to proliferate in a manner that is not efficient or cost-effective given geographic location, population, or incidence
- Promoting clinical trials which are redundant or otherwise not designed to yield useful new data
- Practicing defensive medicine by using redundant or unnecessary treatments

A second fundamental problem of the current system is reflected in the more than 40 million Americans who do not have health insurance. With the fee-for-service system tied to employment, employees of small businesses, the unemployed, low-income individuals who do not qualify for Medicaid, undocumented workers, and other entire classes of people do not have ready access to the health care delivery system. Although respondents noted that most of these people can obtain health care, it is often fragmented and rendered at great expense. The result is cost-shifting, leading to higher costs, higher premiums, higher deductions, and higher co-payments for those who have insurance.

Once in the system, all participants—survivors, health care providers, and payers—face a labyrinth of codes, forms, bills, and other often duplicative records that exact huge administrative and psychological costs to process. Other weaknesses of the fee-for-service structure that directly impact survivors’ quality of care include: lack of coordinated services; failure to reimburse for preventive measures, supportive services, and long-term follow-up; and the absence of good quality control measures.

In addition, restrictive insurance practices—pre-existing condition clauses, life-time caps, and health-based eligibility standards—often act to deny people coverage when they need it the most. Cancer survivors in particular often experience difficulty in receiving state of the art care because many insurers refuse to cover the patient care costs associated with clinical trials and off-label or other “investigational” therapies.

Perhaps the crux of the problem with the fee-for-service system is that too many people do not have information about these limitations or do not comprehend their implications until it is too late. As one expert noted: “Beneficiaries may voluntarily choose reduced benefits in order to save monthly premium costs (goal: to maximize beneficiaries’ short term gain). However, it is important to note that employers generally establish the health insurance options, associated premiums and cafeteria-style variables among which employees may select, and that *beneficiaries may not be fully aware of the risk they run in voluntarily choosing less expensive health insurance*. Finally, it is critical to note that health insurance choices by healthy individuals may differ from choices made by those afflicted by serious disease, but one may not select a ‘better’ insurance plan once being diagnosed. Buying health insurance is like gambling in that respect.”

MARKET-BASED APPROACHES

OPPORTUNITIES AND POTENTIAL DRAWBACKS

At the time of this survey, respondents agreed that the fee-for-service system had fundamental flaws; market-based plans may well address many of these shortcomings, especially with regard to prevention and early detection. However, it also is apparent that some aspects of the transition to market-based health care are troubling to the surveyed experts. Most of these concerns focused on our ability to remain in the forefront of cancer research and care and to continue to encourage technological innovation if decisions are driven primarily by short-term financial considerations.

A hallmark of most market-based plans is the gatekeeping role played by primary care physicians who are responsible for coordinating individuals’ care and referring them to specialists. The surveyed experts were unanimous in stating that survivors *must* have continued timely access to specialists, and that they should not face high out-of-pocket expenses if they are forced to go outside of their plan to be treated by the needed specialist. Other important characteristics which the experts wanted to see in market-based plans were:

- Nondiscriminatory clauses based on preexisting conditions or genetic risk factors
- Guaranteed portability
- Expeditious and fair appeal mechanisms
- Inclusion of credentialed specialists in networks
- The ready availability of second opinions
- Coordinated care across the spectrum of survivorship

When specifically asked, most respondents felt that oncologists should be the primary manager of care for survivors with active malignancies and those in the early stages of remission. To support their position, they cited several factors:

- The complexities of treating cancer, a term which includes more than 100 different conditions
- Oncologists’ specific knowledge of long-term and late effects, rehabilitative services, and pain management and hospice
- Survivors’ increased risk for second malignancies and the importance of early detection and treatment

The respondents also acknowledged, however, that in many cases longer-term survivors can be followed successfully by a primary care physician, especially if (1) they have an annual evaluation by a specialist, (2) there was ongoing consultation between the primary care physician and the oncologist, and (3) there were adequate care guidelines for monitoring the physiologic long-term and late effects of cancer treatment. Education of primary care physicians, the development of guidelines, and more emphasis on extended follow-up were regarded as components that could improve survivors' quality of care under these circumstances.

In addition to continued access to specialists, respondents also were troubled about the commitment of market-based plans to support the cancer research system currently in place. They feared that we will be forced to seek increases in public funding for basic and clinical research at a time when neither the public nor Congress will support such expenditures. In fact, many felt that *all* health care plans, whether fee-for-service or market-based, should be required to cover clinical trials meeting specific standards.

Indeed, a refrain throughout the various opinions was that we cannot sacrifice long-term quality care for short-term cost savings. People lose confidence in systems that do not meet needs. Instead, there was widespread support for a more balanced approach that attempts to define cancer care which is both cost-effective and of optimum quality:

- Reasonable guidelines and clinical care pathways must be developed to standardize care and to help eliminate unnecessary, and often costly, services and procedures.
- Outcomes data need to be collected so that valid quality measurements are available to guide providers' treatment recommendations.
- Survivors must have access to information like practice patterns and outcomes data in a concise and easily understood form so that they are able to reach truly informed decisions.

MEASURING QUALITY CANCER CARE

SPECIAL CONSIDERATIONS

Although rudimentary attempts at assessing quality cancer care are underway, NCCS believes that several fundamental issues must be reflected in standards and guidelines if we are to design reliable measurements of care:

- Unlike many common diseases, "cancer" is many different diseases, some of which are not encountered frequently by any one provider.
- Cancer, particularly in the acute stage, often requires specialized care.
- Standards need to be developed that measure care across the spectrum of survivorship, from prevention and screening mechanisms through early diagnosis and treatment to long-term follow-up and palliative care.
- Variations in such important factors as geographic setting and socioeconomic status can dramatically impact the quality of available care.
- Cancer is unique because sometimes the best treatment available may only be found through a well-designed, patient-oriented clinical trial.
- Occasionally, state of the art cancer treatment offers only small benefits over established treatments, yet may be more costly.
- For cancer survivors, improvements in quality of life are significant end points that must be considered in addition to increased longevity.

SUGGESTED STRATEGIES TO ENSURE QUALITY CANCER CARE

INITIATIVES TO OVERCOME BARRIERS: DECEMBER 1995 – APRIL 1996

At the conclusion of the First National Congress on Cancer Survivorship, NCCS indicated it would go forward and discuss the issues raised in the working draft of this position paper with others in the community who might share our interest in reaching broad agreement on the definition of “quality cancer care.”

Between December, 1995, and April, 1996, NCCS leadership met with many experts in cancer research, cancer care, and health policy to discuss the position paper on quality cancer care. NCCS also has been invited to participate with oncology advisory boards and other cancer agencies which are exploring ways to deal with managed care organizations and private sector groups who are seeking to define quality care for their audiences. Over the last four months many groups used the working draft of the position paper as a point of information and discussion to examine ways their organizations and institutions could address the issues raised in the document.

In a direct response to the concerns articulated by NCCS, in December, 1995, Dr. Richard Klausner, the Director of the National Cancer Institute (NCI) appointed a working group to focus attention on the issues related to the psychological and biomedical consequences of a cancer diagnosis. The result has been Dr. Klausner’s public announcement in April, 1996, of the formation of a new *Office of Cancer Survivorship* within the NCI, located within the Division of Cancer Treatment, Diagnosis and Centers in the Clinical Investigations Branch, Cancer Therapy and Evaluation Program. The purpose of this new office is to explore the research issues and consequences of cancer survivorship. The office will interact with the entire spectrum of the NCI, including scientific disciplines ranging from those involved with genetics and clinical trials to behavioral research and quality of life. Survivorship issues for children and adults will be addressed, including long-term and late effects—the physiological and psychosocial aspects of cancer survival. The new office will take advantage of existing programs and develop new research initiatives.

Further development of the position paper on quality cancer care has taken place during the past several months, and overarching themes and issues have emerged. For example, in February, 1995, the Association of Community Cancer Centers (ACCC) sponsored a retreat entitled “Patient Advocacy Issues in a Changing Health Care Environment.” During this meeting and at the annual ACCC President’s Retreat immediately following, NCCS enumerated the criteria people with cancer should be looking for in health care plans. A version of these widely accepted criteria was published in the March/April, 1996, *Oncology Issues*. These criteria will be further refined as NCCS works with them in other settings, including the development of a “report card” for people with cancer. Briefly, these criteria are:

- The primacy of the doctor/patient relationship should be preserved.
- Health care plans should provide for appropriate and timely screening.
- Upon diagnosis of cancer, the patient should be referred immediately to a cancer care specialist.

- Cancer should be treated using a multidisciplinary approach.
- During active treatment, the gatekeeping function should be performed by an oncologist or other specialty physician.
- Children with cancer should be treated by pediatric oncology specialists.
- Where appropriate, and without additional financial burden, health care organizations should provide for treatment of people with cancer at specialized facilities.
- Health care plans should provide for enrollment of patients in clinical trials.
- Cancer patients in remission should be monitored periodically by cancer specialists—not only by primary care physicians—and have access to rehabilitative care when indicated.
- People with cancer should have access to a full range of supportive care services, including, but not limited to, psychosocial services, nutritional and vocational counseling, management of pain, nausea, fatigue, and other debilitating side effects of treatment.
- Systematic long-term follow-up care guidelines should be established for adult cancer survivors and incorporated into health care plans.
- People with cancer should receive referrals to hospice services in a variety of settings, including home health care.

NCCS has since used these criteria as a discussion document in several meetings about quality cancer care involving representatives from the American Cancer Society, the Cancer Leadership Council, the National Comprehensive Cancer Network, the Foundation for Accountability, the Alliance for Aging Research, and the American Society of Clinical Oncology. These opportunities for discussion among different groups over the last several months have enabled the cancer community to *begin using a common, patient-centered language* about quality cancer care.

STRATEGIC IMPERATIVES TO THE YEAR 2000

If the cancer community is to succeed in getting *its* definition of quality cancer care into the marketplace and into the reporting mechanisms of health care plans where people with cancer can directly benefit, it must ensure that strategies and a plan for implementing those strategies are in place.

While all of us have a stake in the outcome, it will be important that those who have the most to gain and the most to lose—people who have been diagnosed with cancer—assume some responsibility for ensuring that the messages in these position papers are delivered to the appropriate agencies, organizations, and the public at large. NCCS believes that, in the future, an educated and enlightened public will take the lead in mapping a course for an accountable health care system. As managed care evolves, *individuals will demand the most value for their health care dollar.*

One of the few remaining impediments to an educated public is a divided cancer community. Little else can stand in the way if the cancer community works *in concert*—united in its resolve to move forward in an expedient manner with the following initiatives:

- Develop a communications plan to educate the public about the need for a system of health care that will ensure quality cancer care for all people
- Work with all sectors of the cancer community to define quality cancer care and to develop a systematic methodology for having health care plans, accrediting agencies, and other constituency groups utilize that definition
- Develop a communications plan to educate the public about the need for patient-oriented cancer research
- Encourage the development of practice guidelines that will elevate the standard of cancer care; provide better choices for decision-making by patients; and look at quality of life (as well as survival) as a desired endpoint
- Develop standards of measurement (qualitative as well as quantitative) that are universal in their recognition of capturing the patient experience across the spectrum of cancer care and that are not specific to any particular setting or system of health care
- Convene meetings among health care providers, voluntary agencies, researchers, industry, and the federal government, to encourage more collaboration and avoid duplication of effort
- Educate and periodically update policy makers, opinion leaders, and the media about the importance of receiving quality cancer care
- Work with the cancer community to develop a legislative agenda that can be used by grassroots organizations and national associations to ensure that public policies are favorable to accessing quality cancer care
- Design a patient “report card” around the quality cancer care issues that is easy to understand and applicable to all populations

The National Coalition for Cancer Survivorship has grown in ten years into the largest network of independent organizations, institutions, and individuals working in the area of cancer support and advocacy. In the coming years, NCCS will continue to build on its growing reputation as a convener of cancer organizations and as an honest broker of good health policy information to ensure that people with cancer have access to quality cancer care.

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PHYSIOLOGIC LONG-TERM

ACCESS AND LATE EFFECTS

ADVOCACY OF CANCER TREATMENT

ACTION

ACCOUNTABILITY

CANCER SURVIVORS WHO HAVE A SOLID UNDERSTANDING OF LATE EFFECTS CAN AFFECT THEIR MEDICAL OUTCOMES BY DOING WHATEVER IS POSSIBLE TO DECREASE THEIR OVERALL RISK OF DEVELOPING LATE EFFECTS AND BY GETTING THE PROBLEMS DIAGNOSED EARLY WHEN LATE EFFECTS ARE MOST TREATABLE.

*Wendy Harpham
Physician and Cancer Survivor*

BACKGROUND

Scientific breakthroughs and medical advances have changed the course of cancer care in our country. While thoughts of automatic death after a cancer diagnosis can now be shifted to hopes of effective treatment and cure, recovering from cancer is not without its challenges. Advancements in technology have allowed us to increase the dosages and intensity of cancer therapy, yet minimal attention has been directed toward evaluating the potential negative results of these therapies.

Research priorities have focused primarily on methods of early detection and treatment of acute disease, but scant attention has been directed toward the study of long-term and late effects, two distinct entities. Long-term effects are described as chronic or lingering problems after the cessation of therapy, while late effects are delayed problems occurring months to years after treatment. Much of the beginning work in this area has been done with survivors of childhood cancers within pediatric survivors' clinics.

Models of systematic, long-term follow-up are found as frequently in pediatric oncology as they are infrequently in adult oncology. By the year 2000 there will be approximately 200,000 survivors of childhood cancer who will have access to 30 specialty survivor clinics nationwide. At the same time, millions of long-term survivors of adult cancers essentially have no specialized follow-up. Just as the number of long-term survivors with special needs increases, the current medical climate of managed care discourages the utilization of specialists, and provides few guidelines for long-term care by primary care physicians. However, numerous positive aspects of careful planning for long-term follow-up have been identified:

- enhancing services and extending research
- facilitating access to specialty providers
- providing solidarity for target populations
- ensuring highest possible quality of life

Long-term follow-up will not necessarily eliminate chronic or delayed effects of therapy, but it will enable survivors to take charge of their lives and make more informed decisions about issues affecting the quality of their lives. Awareness of risk can encourage changes in behavior that promote health (e.g., smoking cessation) and early detection (e.g., breast self-exam), thus optimizing the chances for long-term survival.

Experts in the management of physiologic long-term and late effects were sent surveys by the National Coalition for Cancer Survivorship (NCCS). The "experts" included both health care professionals and long-term cancer survivors, and their responses are summarized on the following pages. Of special note is the inability of most respondents to separate *physiologic* from *psychosocial* effects, a finding that emphasizes the need for holistic care.

PHYSIOLOGIC LONG-TERM AND LATE EFFECTS CHALLENGING CANCER SURVIVORS

SYSTEM-SPECIFIC

- Organ damage, failure, or premature aging due to chemotherapy, radiation therapy, biologic modifiers, surgery, or any combination of the above such as:
 - cardiomyopathy
 - renal insufficiency
 - bladder damage
 - carotid artery disease
 - cataracts
 - muscle atrophy
 - cognitive changes such as decreased memory function
- Compromised immune systems causing increased risk of infection (viral, bacterial or fungal) and possible increased risk of malignancy
- Damaged endocrine systems leading to thyroid dysfunction, hypothalamic-pituitary dysfunction, premature menopause, reproductive problems, or sexual disruption

RECURRENCE AND SECOND MALIGNANT NEOPLASMS

- Increased risk associated with primary malignancy (e.g., ovarian cancer after breast cancer)
- Increased risk associated with certain therapies (e.g., other cancers as a result of therapy)
- Increased risk of recurrent malignancy
- Risk of psychosocial problems related to risks of recurrence and second malignant neoplasms

RELATED PROBLEMS

- Functional changes (e.g., incontinence, immobility due to weakness or orthopedic problems, orthodontic problems, lymphedema, sleep disturbances, pain syndromes, fatigue, vaginal dryness)
- Cosmetic changes (e.g., amputations, ostomies, skin and hair changes)
- Chronic illness (e.g., osteoporosis, arthritis, scleroderma, hypertension)
- Psychosocial effects related to physiologic morbidity (e.g., anxiety, mood changes, depression, living with uncertainty, sexuality and relationship problems, insurability, employment issues, stigma)

LONG-TERM FOLLOW-UP SERVICES THAT SHOULD BE AVAILABLE TO ALL CANCER SURVIVORS

SURVIVOR CLINICS

- Access to long-term follow-up clinics that provide appropriate standards of care
- Follow-up care provided by a multidisciplinary team of health care specialists including oncologists, specialty physicians, oncology nurse specialists and nurse practitioners, social workers, psychologists, rehabilitation specialists, and school liaisons
- Development of guidelines/protocols for long-term follow-up that would be modeled throughout the health care system
- Availability of specialists for long-term follow-up relevant to medical history, age, risk factors, and presenting symptoms
- Emphasis on health promotion and wellness

SUPPORTIVE SERVICES

- Continued access to psychosocial support via individual or family counseling, support groups, information and referral services, and vocational counseling
- Increased attention to culturally-specific issues for the elderly, socioeconomically disadvantaged, and minority populations
- Reimbursement policies encouraging long-term follow-up

GENERAL CARE

- Education in areas of prevention (health maintenance behaviors) and control (screening, early detection, rehabilitation and treatment of late effects)
- Development and distribution of culturally-relevant educational materials regarding long-term and late effects and self-care
- Cooperation between oncologists, primary care physicians and other specialists for continued follow-up appropriate to the individual's cancer history
- Expansion of rehabilitation beyond conventional musculoskeletal dysfunction to include referrals for fatigue, chronic pain, weight changes, and decreased stamina

RESEARCH PRIORITIES ADDRESSING LONG-TERM FOLLOW-UP FOR THE NEXT DECADE

- Assess incidence and relative risks of the development of long-term or late complications in relation to the disease or treatment
- Maximize effectiveness of therapies while minimizing physiologic and psychosocial morbidity
- Develop standards of care for long-term survivors:
 - to provide broad based rehabilitation programs specifically designed to reduce the incidence and morbidity of physiologic late effects
 - to assure options for accessing appropriate providers
 - to include educational programs to increase the health care professional's awareness of long-term and potential late complications of treatment

- Determine the effect of cytotoxic agents, radiation therapy, or combinations of both on the incidence and type of second cancers and organ system failures
- Study the effects of primary prevention on the incidence and type of second malignant neoplasms and organ system failures
- Correlate psychosocial well-being with physical health
- Establish databases of long-term survivors:
 - for epidemiologic studies
 - for systematic long-term follow-up
 - for referral to support networks
- Include genetic counseling and education with assurance of privacy in all genetic-related screenings/clinics, especially in relation to:
 - genetic markers for inherited cancers and the accompanying psychosocial concerns
 - for childbearing decisions and the future of offspring
- Offer appropriate patient education that includes full disclosure of all potential long-term or late complications of treatment; warning signs of possible problems; symptom management strategies; wellness-promotion and self-help options
- Encourage the development of prospective, longitudinal outcome studies while encouraging survivor participation
- Develop parameters for physiologic functioning that is disease-specific and age-related
- Promote culturally-appropriate, wellness-focused research around behavioral modifications such as nutrition, exercise, stress management, smoking cessation, and sun protection
- Study health promotion behaviors in order to improve and strengthen damaged immune systems and prevent future malignancies and iatrogenic late effects
- Stimulate interest in research around prevention, early detection and treatment of long-term and late effects of therapy

BARRIERS TO MANAGING AND RESEARCHING LONG-TERM AND LATE EFFECTS

- Inadequate funding for biomedical and behavioral research on long-term and late effects, management strategies, and rehabilitation measures
- Lack of reimbursement for experimental, epidemiologic, and long-term studies and follow-up
- Focus on disease, cure and longevity within the scientific and medical community at the expense of quality of life issues
- Inadequate information, lack of time and/or interest, and failure by professionals to evaluate surrounding long-term and late effects of cancer treatment
- Ineffectiveness of patients and families in articulating ongoing needs and/or their aversion to participate in studies that require a return to an oncology setting
- Changes in the health care delivery system to achieve cost containment by decreasing both utilization of services and referrals to specialists
- Lack of comprehensive databases that include recurrences, second malignancies, and other chronic or delayed treatment complications
- Increased fragmentation for funding sources and research interest among disease-specific cancer groups
- Slow pace of research and publication of study findings

- Lack of systematic follow-up by appropriately trained specialists (oncologists, nurse practitioners, physician's assistants) whose primary focus is long-term follow-up
- The difficulty and expense in carrying out long-term follow-up studies
- Insufficient understanding about the interrelationships between biomedical and psychosocial functioning and late effects
- Overworked personnel with less time and fewer resources

SUGGESTED STRATEGIES TO IMPROVE RESEARCH AND SERVICES SURROUNDING LONG-TERM AND LATE EFFECTS AFTER CANCER THERAPY

IMPROVE RESEARCH

- Develop collaborative relationships with physician, nursing, psychosocial, consumer and funding groups to study and support work in the area of long-term and late effects, including the development of practice guidelines
- Create guidelines and publications for long-term follow-up for managed care systems and third party payers in order to document cost-effectiveness
- Encourage Congress and NCI to dedicate funds for research on cancer survivorship, including both biomedical long-term and late effects and behavioral research
- Extend clinical trials evaluations to include long-term follow-up and quality of life measurements
- Educate private foundations about the need for funding for survivorship-related research
- Provide access to survivor groups who might participate in studies and offer suggestions and recommendations to researchers
- Incorporate long-term outcomes into design of clinical trials
- Stimulate interest in multidisciplinary and multicenter longitudinal research studies
- Collect and analyze prospective and retrospective data
- Incorporate and enhance data base

IMPROVE SERVICES

- Work with oncologists to broaden short-term "cure" focus to longer-term survivor focus
- Promote a massive public/professional educational effort to increase awareness of long-term survivorship issues, with a national, recognizable figure as spokesperson
- Improve tumor registries
- Develop a national computerized clearinghouse on survivorship issues available to health providers as well as to patients and families
- Play an active role in policy development through survivor participation and representation in the public policy arena
- Force legislative changes to ensure continuity of care and availability of insurance coverage for long-term follow-up, being aware of state-by-state differences
- Educate constituencies as to which models of health care delivery will be most beneficial to cancer survivors
- Educate primary care physicians about special needs of long-term survivors

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PSYCHOSOCIAL ISSUES

ACCESS OF CANCER SURVIVORSHIP

ADVOCACY

ACTION

ACCOUNTABILITY

THE BIAS AGAINST WHAT IS REFERRED TO AS “SOFT SCIENCE” IS NOT JUST INSTITUTIONAL—IT’S OUT THERE AMONG THE PATIENTS AND CONSUMERS AS WELL. HOW DO WE CHANGE THE PERCEPTION THAT PSYCHOSOCIAL SERVICES ARE NOT JUST FLUFF, BUT ARE AN INTEGRAL PART OF OUR TREATMENT?

*Comment made at the forum on
“Caring for the Whole Person”*

BACKGROUND

Clinicians have long recognized the importance of identifying and addressing psychosocial aspects of cancer. Professional groups such as the Pediatric Social Work Oncology Group, the Association of Oncology Social Work, the Oncology Nursing Society, the American Society for Psychiatric Oncology and AIDS, and other discipline groups have had a strong focus on comprehensively meeting the needs of persons with cancer. Service groups such as the American Cancer Society and Cancer Care, Inc. have offered support services for persons with cancer for half a century. Oncology research about psychosocial issues also has a long tradition. Beginning in the 1950s, landmark works by Bard and Sutherland and by Abrams and her colleagues formed the foundation for the field. Researchers such as Weisman and Worden, Kübler-Ross, and Holland further emphasized the importance of psychological and social factors in cancer care, and a recent meta-analysis by Meyer and Mark of 45 controlled outcomes studies demonstrated that psychosocial interventions are beneficial to cancer patients.

Today, we find ourselves in a changing health care arena, one where psychosocial care may be seen as an adjunct, “value added” rather than essential, and where the need for psychosocial research is considered questionable. In this current era of cost containment and minimal standards of care, the discoveries made by researchers to date may be disregarded, and the opportunity for advancing the field of psychosocial oncology may be greatly diminished.

To address these concerns, a survey of professionals well versed in the field of psychosocial oncology was conducted. They were asked to respond to questions about both psychosocial care and the need for future psychosocial oncology research. They also were asked to identify barriers to progress and strategies for removing these barriers. What follows are the summary points of the major survey areas.

MAJOR PSYCHOSOCIAL CHALLENGES FACING PERSONS WITH CANCER

ADAPTING TO THE PERSONAL CONSEQUENCES OF CANCER

- Incorporating the illness into one’s self concept, and maintaining a sense of autonomy and control
- Managing the physical aspects of the disease and treatment, and complying with treatment regimens
- Facing multiple cancer-related losses such as loss of body parts or bodily functions, loss of financial security, and relationship losses
- Adjusting to changes in appearance and activity level
- Finding appropriate coping strategies
- Maintaining or establishing intimacy and avoiding isolation
- Living with uncertainty and fear of recurrence or death
- Watching for long-term and late effects
- Maintaining a positive future outlook and the highest possible quality of life after a cancer diagnosis
- Dealing with issues of mortality and assuring a dignified death

ADJUSTING TO THE SOCIAL CONSEQUENCES OF CANCER

- Reconciling the “lived experience” of cancer with societal perception and expectations regarding persons with cancer
- Negotiating changes in interpersonal relationships, family roles and functions
- Recognizing that cancer still carries a stigma and dealing with discrimination based solely on a history of cancer
- Overcoming obstacles to financial stability, job security, and insurability

NAVIGATING THE HEALTH CARE SYSTEM

- Obtaining needed information about cancer and its treatment
- Dealing with inadequate insurance coverage and burdensome insurance processes and paperwork
- Finding needed support services including peer groups
- Addressing the inability to access comprehensive cancer care including rehabilitation, complementary therapies and spiritual care
- Adapting to a changing health care system where patients are being asked to manage more of their own care including continuity of care and long-term follow-up

**PSYCHOSOCIAL SERVICES THAT SHOULD
BE PROVIDED FOR EVERY PERSON
WITH CANCER MUST EMPHASIZE
CONTINUITY, COMPREHENSIVENESS, AND
A MULTIDISCIPLINARY APPROACH**

**PERSONS WITH CANCER SHOULD HAVE ACCESS TO COMPREHENSIVE
CANCER CARE INCLUDING:**

- A primary medical provider and adequate insurance coverage for their care
- Rehabilitative services including physical, occupational, and vocational therapies
- Availability of a psychosocial program and case manager who provides assessment, education, support, and referral for services
- Screening for psychosocial risk and in-depth individual and family assessments conducted on a regular and continuous basis across the disease spectrum by qualified psychosocial specialists and, in conjunction with the medical plan, the development of a psychosocial treatment plan
- A choice of intervention modalities including individual, family, marital, peer, and pastoral counseling and access to complementary therapies
- Training in cancer related self-advocacy including information seeking, negotiation, communication, and problem solving skills

THE PATIENT AND THE FAMILY SHOULD BE SEEN AS THE UNIT OF CARE AND SHOULD RECEIVE:

- Culturally appropriate education about cancer, its treatment and side effects, and the necessary physical care responsibilities that need to be assumed by the patient and family
- Information about local, state, and national organizations that provide support, education and concrete services including how to access legal information and services for workplace, insurance and other cancer-related discrimination
- Special advocacy on behalf of children of cancer patients so that their needs are identified and addressed

THE MOST IMPORTANT AREAS FOR PSYCHOSOCIAL ONCOLOGY RESEARCH THAT SHOULD BE UNDERTAKEN IN THE NEXT DECADE

OUTCOMES RESEARCH

- Health related quality of life studies of outcomes of medical care should be linked with clinical trials
- Impact of psychosocial services on financial and health outcomes
- Differential effectiveness of different types of psychotherapeutic interventions in influencing survival and improving adjustment to cancer
- Psychosocial and behavioral links that may be predictive of cancer outcomes
- Psychosocial impact of involvement in clinical trials on quality of life
- Psychosocial impact of reduction of medical services and professional support
- Evaluation of outreach efforts to the underserved (what works and why)

EXPLORATORY STUDIES

- Impact and burden of cancer care on family caregivers
- The meaning of survivorship across cultures
- Examination of critical factors that contribute to or inhibit patient decision-making
- Psychosocial issues related to childbearing and impact of infertility secondary to cancer
- Long-term psychosocial sequelae of cancer survivorship
- Identification of resiliency factors of cancer survivors
- Ways that cancer changes spiritual/existential meaning for the individual

COMPARATIVE/INTERVENTION STUDIES

- Testing of case management models for effectiveness and appropriateness for populations served
- Effect of participation in a psychotherapy group versus a support or self-help group with comparison of facilitators from various professional disciplines and peer groups
- Identification and investigation of psychosocial and educational interventions that enhance patient satisfaction, quality of life, adherence to medical regimens, optimal coping, and high functioning
- Testing of life extension hypothesis of psychosocial intervention
- Evaluation of cancer-related self-advocacy training on quality of life

- Effect of cancer diagnosis on persons with history of psychiatric diagnosis
- Systematic comparison of in-home and residential hospice care to in-hospital care with regard to cost and family adjustment
- Clinical trials for reducing symptom distress

DEVELOPMENT OF PSYCHOSOCIAL ONCOLOGY TOOLS

- Need for reliable and valid assessment tools for understudied populations such as the poor and elderly
- Need for culturally and ethnically sensitive measures
- Need for standardization of quality of life measures

BARRIERS TO PSYCHOSOCIAL ONCOLOGY RESEARCH

GLOBAL BARRIERS

- Lack of perceived significance (or merit) of psychosocial research within the research community
- Lack of scientific rigor in many existing studies
- Lack of trained researchers in psychosocial oncology research
- Limited awareness of value of psychosocial interventions
- Needs of patients/survivors after treatment not considered important by medical community
- Inadequate training for cultural issues in research

NATIONAL BARRIERS

- Lack of cooperative efforts among researchers, especially across professional disciplines
- Lack of federal policy or mandate for psychosocial research
- Lack of national and private sector funding for psychosocial research

COMMUNITY BARRIERS

- Lack of collaborative research between academic centers and communities
- Lack of institutional support for research at hospitals and cancer centers
- Difficulty in recruiting subjects, especially minority subjects, for studies

SUGGESTED STRATEGIES TO IMPROVE RESEARCH AND SERVICES RELATED TO PSYCHOSOCIAL ISSUES

PSYCHOSOCIAL SERVICES

- Solicit input from cancer survivors and health care providers to define essential psychosocial and supportive services that should be routinely available to cancer patients and their families from diagnosis onward
- Speak against cutbacks in psychosocial oncology services at the local, state, and national levels
- Develop self-advocacy training programs for cancer patients and their family members
- Develop new service delivery models (such as oncology specific case management) to adjust to the changing health care delivery system
- Develop educational components about survivorship issues for incorporation into discipline specific professional training modules
- Target comprehensive cancer centers, clinical cancer programs, hospital administrators, insurers, and managed care plans for education about the importance of psychosocial services and research
- Encourage health care institutions and professional disciplines to move from competition to collaboration to avoid duplication of services and to promote co-sponsorship of activities
- Support the formation of freestanding psychosocial oncology agencies with the goal of providing full spectrum psychosocial services

PSYCHOSOCIAL RESEARCH

- Promote the parallel importance of psychosocial and biomedical research
- Explore funding for psychosocial research from new sources such as foundations and health care systems
- Advocate having psychosocial measures included in all future clinical trials
- Promote collaborative research between organizations, academic centers, professional organizations, and community-based groups
- Develop an interdisciplinary network of researchers to determine and prioritize a national psychosocial oncology research agenda
- Convene state-of-the-art consensus conference on psychosocial oncology research to delineate a minimum essential set of psychosocial services, demonstrate the benefit of these services, and justify their inclusion in reimbursable routine cancer care
- Design a media campaign to educate the public about the importance of psychosocial oncology research and its impact on quality of life and survival

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ABOUT NCCS

ACCESS

ADVOCACY

ACTION

ACCOUNTABILITY

OVER THE LAST DECADE, A STRONG INFRASTRUCTURE HAS EMERGED TO ADVOCATE FOR RESEARCH, HEALTH CARE, AND SOCIAL REFORM ON BEHALF OF CANCER SURVIVORS. THIS IS CLEARLY SEEN IN THE ESTABLISHMENT AND GROWTH OF THE NATIONAL COALITION FOR CANCER SURVIVORSHIP AND ITS INCREASINGLY SOPHISTICATED EFFORTS TO PUSH FOR CHANGES THAT IMPROVE THE OPPORTUNITY FOR CANCER PATIENTS TO SUCCESSFULLY REESTABLISH A NORMAL LIFE DURING AND AFTER THEIR DIAGNOSIS AND TREATMENT.

Measures of Progress Against Cancer
National Cancer Institute, 1993

The National Coalition for Cancer Survivorship (NCCS) was the vision of 25 individuals who, in 1986, met for three days in Albuquerque, New Mexico. Together they represented leadership and expertise in community-based cancer support programs, cancer research, cancer information services, and cancer advocacy. NCCS has spent the greater part of the last decade fulfilling the objectives of its founders—facilitating communication among people involved with cancer survivorship, promoting peer support, serving as an information clearinghouse, advocating for the interests of cancer survivors, and encouraging the study of cancer survivorship. Most importantly, NCCS has succeeded as an organization founded *of, by, and for cancer survivors*, and, through thoughtful and responsible advocacy, has assumed a leadership role in the survivorship movement and the cancer community.

Central to NCCS's mission has been generating a nationwide awareness of cancer survivorship. This has been accomplished through publications, education to eliminate the stigma of cancer, advocacy for insurance and employment rights for cancer survivors, and by networking and promoting the many organizations and institutions that strive to inform, serve, and empower persons with cancer in the communities where they live and work.

From the first NCCS Assembly in 1986 to the First National Congress on Cancer Survivorship in 1995, both cancer survivors and nationally known spokespersons have generously donated their time and expertise to the cancer survivorship movement. The result has been a strong, viable cadre of leaders across the country (and from other parts of the world) who write about, advocate for, speak up about, and inspire others to ensure the highest possible quality of life for persons living with cancer.

Illustrative of this success is the increasing responsibility that cancer survivors are taking to ensure that their views are heard when issues which will affect their care and the quality of their lives are being debated in public and private sectors. As informed and responsible advocates, cancer survivors must represent a collective voice in shaping health care policy and standards of quality cancer care.

On behalf of our country's ten million cancer survivors, and for the millions more who will be diagnosed with cancer, NCCS will continue to provide public policy leadership and to promote responsible advocacy among cancer organizations. We invite you to join with NCCS in this important effort.



THE LARGEST NETWORK OF INDIVIDUALS AND ORGANIZATIONS

SERVING PEOPLE WITH ALL TYPES OF CANCER.



ABOUT THE AUTHORS

ACCESS

ADVOCACY

ACTION

ACCOUNTABILITY

EXTREMITY DEEPENS RELATIONSHIPS, INTENSIFIES SOCIAL BONDING. SURVIVORS
DEPEND MORE ON OTHERS; IN FACT, SURVIVAL IS, AS WE HAVE NOTED, A COLLECTIVE
ACT. NO ONE SURVIVES WITHOUT HELP; MANY FIND GREAT JOY IN SERVICE TO OTHERS.

Natalie Davis Spingarn
*Hanging In There: Living Well
On Borrowed Time*

ELIZABETH J. CLARK, PHD, is Director of Diagnostic and Therapeutic Services at Albany Medical Center Hospital and an Associate Professor of Medicine in the Division of Medical Oncology at Albany Medical College. She holds a doctorate in medical sociology from the University of North Carolina and master's degrees in both medical social work and public health from the University of Pittsburgh. Dr. Clark has lectured and published extensively in the areas of social oncology, loss and grief, hope and burnout. For the past six years Dr. Clark has served on the Board of Directors of the National Coalition for Cancer Survivorship (NCCS), assuming the role of President in 1996. Her various activities with NCCS include Co-chair of the Public Policy Committee, Chair of the Research Committee, Co-chair of the First National Congress on Cancer Survivorship, and representing NCCS in discussions regarding end of life issues and in ethical considerations around genetic counseling. She is the author of the NCCS publication *You Have the Right to be Hopeful*.

ELLEN L. STOVALL, Executive Director of NCCS, is a 24-year survivor of two bouts with Hodgkin's disease. She has served on various advisory panels, working groups and committees of such organizations as the National Cancer Institute, the American Society of Clinical Oncology, the Association of Community Cancer Centers, the Southwest Oncology Group, and the United States Pharmacopeial Convention. Under her direction, the Cancer Leadership Council was founded in 1993 to develop positions on health policy matters of consequence to people with cancer. Ms. Stovall has given testimony before Senate and House Committees, the Food and Drug Administration, and other governmental bodies on issues such as cancer research funding, technology transfer, and FDA reform. Ms. Stovall represents NCCS on the Board of Trustees of the Foundation for Accountability (FACCT). In May 1996, she received the honor of being appointed by President Clinton to a six-year term on the National Cancer Advisory Board (NCAB).

SUSAN LEIGH, RN, BSN, is a founding member and the immediate Past President of NCCS. Drawing on her experience as an oncology nurse and a survivor of Hodgkin's disease, breast cancer and currently bladder cancer, she speaks and writes extensively on survivorship issues. Her primary focus is on long-term survival and late effects of treatment. Ms. Leigh initiated the formation of both the Nurse Survivors Focus Group and the Survivorship Special Interest Group within the Oncology Nursing Society, and recently shared the Upjohn Quality of Life Award and the Schering Excellence in Cancer Nursing Research Award at the 1995 Oncology Nursing Society Congress.

ALBERT L. SIU, MD, MSPH, is a Professor in the Department of Health Policy at the Mount Sinai School of Medicine in New York City. He also has secondary appointments in the Department of Medicine and the Department of Geriatrics and Adult Development at Mount Sinai. Previously, Dr. Siu was a Deputy Commissioner in the New York State Department of Health. He also has been a faculty member at the UCLA School of Medicine where he was jointly appointed at RAND. Dr. Siu is an internist and health services researcher whose work has focused on the interface between health policy and clinical medicine and geriatrics. He has served as an investigator in both academic and policy settings, and has lectured and published on issues relating to quality of care, aging, and health assessment. Dr. Siu has received honors from government, foundations, and academia. Since 1990, Dr. Siu has co-chaired NCCS's Public Policy Committee, and from 1992-1994, he was Vice President of the NCCS Board of Directors. Dr. Siu received his BA from the University of California at Berkeley, his MD from Yale University, and his MS in Public Health from UCLA.

DIANN K. AUSTIN, JD, is an attorney specializing in health care law and policy in Washington, DC. After graduating with a JD from the University of Virginia School of Law, Ms. Austin practiced at Loomis, Owen, Fellman & Howe, where she advised clients on a variety of food and drug issues. Thereafter, she joined the firm of Fox, Bennett & Turner and counseled pharmaceutical manufacturers, providers, patient interest groups and others on health policy issues including expanded access to promising therapies, health care reform, technology transfer programs, and the drug approval process. Most recently, she has served as a consultant to the National Coalition for Cancer Survivorship, and was responsible for authoring the *NCCS Town Hall Meeting Guide: Empowerment Through Advocacy* and coordinating the First National Congress on Cancer Survivorship.

JULIA H. ROWLAND, PHD, is Co-director of the Psycho-oncology Program and Director of Psycho-oncology Research at Georgetown University and its Lombardi Cancer Center in Washington, DC. With Jimmie Holland, MD, chief of psychiatry service at Memorial Sloan-Kettering Cancer Center in New York, she edited the first textbook on psycho-oncology, the *Handbook of Psycho-Oncology*. In addition to directing a comprehensive psychosocial research program at Georgetown, she is responsible for integrating research results into educational and support initiatives for cancer patients, their families and caregivers. Dr. Rowland has worked with NCCS on a variety of research initiatives, and she served as the Co-chair of the First National Congress on Cancer Survivorship.

