

New Mexicans' Pivotal Role in the National Cancer Survivorship Movement



National Cancer Survivors Day Celebration on Civic Plaza,
Albuquerque New Mexico, November 20, 1987

Dedication:

This report is dedicated to the many New Mexicans who have created and supported local, statewide, and national survivorship programs, as well as to those survivors who have participated on national cancer-related panels and boards as contributors and consumer advisors. One such contributor is Jeanne Stover.

In 1991, Jeanne Stover, a New Mexican and a co-founder of the Albuquerque-based People Living Through Cancer, served as a consumer representative on a panel for the Agency for Health Care Policy and Research, US Department of Health and Human Services. She represented the National Coalition for Cancer Survivorship on the panel that developed a 257-page publication: Clinical Guidelines Number 9 for the Management of Cancer Pain.

Jeanne, a nurse and natural therapeutic specialist, lived in Sandia Park, New Mexico. She was a 23-year cancer survivor who had metastatic disease during the last nine years of her life, and she personally dealt with a great deal of pain. She died not long before the cancer pain guidelines were completed. Her fellow panel members dedicated the clinical guideline publication to her with a note of appreciation from panel members for the "insights and wisdom that Jeanne shared with us."

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In 1986, New Mexican cancer survivors played the key leadership role in the founding and early development of the national cancer survivorship movement. They helped shape, promote, and usher in this landmark social movement.

The Birth of New Mexico's Cancer Survivorship Activities

In 1983, five women⁽¹⁾ who had been diagnosed with cancer founded Living Through Cancer, later to be renamed People Living Through Cancer (PLTC), a cancer support organization in Albuquerque, New Mexico.

PLTC was created to build a supportive community of people who had personal and family experiences with cancer and, within that community, to establish support groups and other programs. All of the groups and programs were to be developed, administered, and facilitated by those with personal and family cancer experiences. It was the first grassroots cancer support organization in New Mexico, and one of the earliest established in the country.

The organization was well received in New Mexico and supported by an ever-increasing number of people dealing with personal or family cancer diagnoses, as well as oncologists and oncology nurses, counselors, and others in the cancer care community. Within a few years, PLTC had grown dramatically and had established itself as a reliable and responsible source of cancer support in the Albuquerque metropolitan area.

During its first 10 years alone the organization provided more than 7,500 cancer survivors and family members with hands-on assistance through peer-facilitated support groups and one-on-one support services. (S: PLTC 1993 Annual Report) By 1993, more than 2,500 people facing cancer had participated in PLTC's services, including more than 300 support group meetings. (S: 1997 PLTC Annual Report)

Across the Country, a Burgeoning Grassroots Movement

It did not occur to the founders and early members of PLTC that there might be similar organizations in other parts of the country. Their focus was on building the local organization and providing high-quality programs. Soon after establishing PLTC, however, they began to hear about other cancer support organizations that had developed independently across the country. Although no network linked these organizations, many had developed programs similar to what PLTC had developed in Albuquerque.

This included organizations like Cancer Lifeline in Seattle, Wash., Life After Cancer Pathways in Asheville, NC, Cancer Guidance Center in Pittsburgh, Penn., Cancer Share in Cincinnati, Ohio, Cancer Hotline in Plantation, Fla., and many more. Other organizations, like Commonweal in Bolinas, Calif. focused on a variety of approaches to addressing cancer, as described in Michael Lerner's book, *Choices in Healing: Integrating the Best of Conventional and Complementary Approaches to Cancer*.

The founding meeting of The National Coalition for Cancer Survivorship (1986), which is said to mark the formal beginning of the cancer survivorship movement, had not yet taken place when PLTC and other cancer support organizations developed independently across the country. In addition, the term "cancer survivor" and the concept of cancer survivorship had not yet been defined. Nevertheless, by the early and mid-1980s a grassroots cancer survivorship movement was already afoot.

Setting the Stage for the National Survivorship Movement & Its Agenda

In addition to grassroots activities among cancer survivors around the country, a number of other important influences helped set the stage for the cancer survivorship movement.

For several decades an influential and popular healthcare movement in the general population had encouraged Americans to become well-informed healthcare consumers and active participants in maintaining their health. This had a significant influence on the burgeoning cancer survivorship movement as an increasing number of those diagnosed with cancer were becoming more knowledgeable of and assertive about choices for their cancer care.

By the mid-1980s a number of important changes related to cancer diagnosis and the consequences of cancer and cancer treatment were developing. These further set the stage for the cancer survivorship movement. They included:

- Improved treatment for cancer, resulting in longer, healthier lives for a growing number of those diagnosed.
- Heightened awareness that the success of cancer treatment had an unexpected downside for many in the growing population of long-term survivors. This included tumors and other serious health consequences of treatment.
- Recognition that cancer diagnoses carried significant social stigma, including shunning, legal issues such as cancer-based discrimination in hiring and in the workplace, and barriers to affordable health and life insurance.

With this new movement, then, came a broadened awareness of the consequences of cancer and cancer treatment, but it also encompassed the possibility of new opportunities for living after a cancer diagnosis. This led to a more optimistic philosophy and approach to life after diagnosis, empowerment of those diagnosed within the healthcare system, and strengthening of the social ties and mutual support among those diagnosed, their families, and close friends.

All of this required a new approach to life after a cancer diagnosis and new terminology to adequately describe the cancer experience.

The Seasons of Survival

New language — cancer survivor, survivorship, and the seasons of survival — was proposed by Fitzhugh Mullan, MD, a New Mexican cancer survivor and former Secretary of the New Mexico Department of Health and Environment, in his groundbreaking article “The Seasons of Survival.” It first appeared in the 7/25/85 issue of the *New England Journal of Medicine* (just two years after PLTC was established) and has been widely adopted both by cancer care consumers and the medical community. (See Appendix C for the complete text of “The Seasons of Survival”.)

This language of survivorship and the movement’s philosophy of survivorship helped to liberate those diagnosed from negative stereotypes and resulting emotional baggage associated with “cancer victim” (helpless) and “cancer patient” (passive), which had been the prevailing terms and identity of those diagnosed.

The Birth of the National Cancer Survivorship Movement

In October 1986, PLTC and Fitzhugh Mullan convened a three-day meeting in Albuquerque that became the founding meeting of the National Coalition for Cancer Survivorship (NCCS). This meeting has been called the birth of the cancer survivorship movement. It was held in Albuquerque, hosted by (then) Living Through Cancer and financially supported by St. Joseph Hospital in Albuquerque and St. Vincent Cancer Center in Santa Fe.

Participants at the founding meeting included cancer survivors who were leaders of grassroots support organizations across the country and other specialists with expertise in cutting-edge issues related to the growing cancer survivor population.⁽²⁾

After three days of discussion about a variety of survivorship issues, a founding charter for NCCS (see Appendix B) had been developed. And perhaps as important, the meeting had created new connections among leaders addressing a variety of survivorship issues, including cancer support, emerging health issues of long-term survivors, and employment, insurance, and other legal issues. These bonds would strengthen in the following years, and many others across the country would be drawn into the survivorship movement.

The NCCS founding meeting's participants were guests at one of PLTC's traditional community gatherings, a large potluck gathering held at the home of PLTC board member Mary Shoats. This experience with a thriving grassroots survivor organization was an appropriate send-off for a group that would go on to make significant improvements in the lives of cancer survivors and their loved ones across the country.

Before the founding meeting was adjourned, Fitzhugh Mullan was elected president of NCCS, and one of PLTC's founders, Catherine Logan, accepted the position of NCCS's executive director, and the NCCS national office was housed with PLTC in Albuquerque for its initial five years of development.

In 1990, NCCS opened a second office in Washington, DC. In 1991 it moved its headquarters to the nation's capital, where it has continued to advocate for cancer survivors and has become a leading voice for them in the political arena.

From its grass roots in New Mexico, the national cancer survivorship movement grew to successfully challenge the outdated concept that a cancer diagnosis is, for most, a death sentence, and for others, the end of productive, satisfying lives. It changed the language used to describe the cancer experience and empowered many cancer survivors to continue robust lives after diagnosis and to help one another through the cancer experience.

The movement has successfully focused attention on crucial issues such as the need to address late effects to cancer treatment and legal issues related to cancer-based discrimination. It also linked together grassroots cancer organizations from around the country that had already emerged in local communities.

In July 1996, 11 years after the NCCS founding meeting, the National Cancer Institute (NCI) established the NCI Office of Cancer Survivorship (OCS) to research and address the issues of the large and growing number of long-term cancer survivors and their unique and then poorly understood needs. It was an NCCS publication, "Imperatives for Quality Cancer Care" (1995), that was the impetus for NCI creating the OCS. In 1999, NCI chose as its director Julia Roland, PhD, who had been a member of the board of directors of NCCS and an expert in the field.

Charting the Journey, A Cancer Survivor's Almanac

In 1996, NCCS published its first of three versions of *Charting the Journey, A Cancer Survivor's Almanac* (1996, 2000, and 2004). The first of the three versions was published by Consumer Reports Books. The books cover a comprehensive list of subjects related to cancer survivorship.

In each version, a chapter on peer support was written by one or more PLTC staff members known for their expertise in peer-facilitated support programs. The last two versions also include descriptions of model cancer support organizations, including New Mexico's People Living Through Cancer, which had become one of the best known cancer support organizations in the country.

The second version includes a chart outlining the differences between peer-led support groups and professionally-led support groups, and a document titled "Standards of Excellence for Peer Support Programs," which was developed by PLTC and reviewed by other cancer peer support organizations prior to being published.

Charting the Journey, a Cancer Survivor's Almanac is still available on Amazon.com.

Cancer Survivorship in Indian Country

While the national survivorship movement continued to grow and address national issues, PLTC moved forward in New Mexico to take on new programs. One of the most important developments was a program that emerged in a Native American pueblo in central New Mexico.

Mary Lovato, a cancer survivor from Santo Domingo Pueblo, joined the PLTC staff in 1993 as the director of a program called A Gathering of Cancer Support, which she had established at her pueblo. In 1986, she had gone through a bone marrow transplant for leukemia and felt strongly that Native American survivors could bond together and support each other in a positive way, one that would be mindful of their traditions and beliefs.

She also was determined to break the silence about cancer in the pueblo and confront the social stigma that she and her family had experienced, issues not unfamiliar to cancer survivors in other communities across the country. Lovato wanted

to start cancer support and education at her pueblo and asked PLTC to find funding for and help administer her program.

PLTC received a contract and assistance from the Indian Health Service (IHS) to support the Santo Domingo program, which eventually grew to serve additional pueblos in the state. By 1996, the program had expanded and was serving nine pueblos providing the following services: one-to-one support and consultation; peer support groups; a lending library; transportation to screening clinics and medical appointments; Keres/English translation; and presentations to community groups on prevention, detection, and survivorship. (S: PLTC Five-Year Strategic Plan, 1997-2001)

With IHS funding and the support of IHS and PLTC, Lovato's vision became a national program called Survivorship in Indian Country. The program served American Indian and Alaska Native communities across the country through a training program developed and initially administered by Lovato, PLTC Director of Support Services Gena Love, other PLTC staff members, and IHS staff. Training sessions were held at the IHS facility in Albuquerque and at Santo Domingo Pueblo.

The program has trained 175 people from tribes across the country. (S: Roberta Piasano, Indian Health Service)

New Mexican organizations & individuals that made the NCCS founding meeting possible

Planning Committee:

Edith Lenneberg
Catherine Logan
Fitzhugh Mullan

Sponsor: Living Through Cancer, Inc.

Financial Support:

St. Joseph Hospital, Albuquerque
St. Vincent Cancer Center, Santa Fe

Other PLTC Members/Volunteers:

Dianne Bushell
M. Barnett
Gena Hendrick (Love)
Graciela Olivarez
Audrey Wilson
Alice Hiat, LTC Member, ACS volunteer
Al Hiat, LTC Member

Cancer Survivorship Moves Forward in New Mexico

New Mexico continues to have a thriving survivorship community. In the years since the movement began, grassroots survivor support organizations have formed in communities across the state. Some of these groups have been established and sustained by cancer survivors who were active in the emergence of the survivorship movement in the 1980s and 1990s. Others have emerged under new leadership.

Services include support groups and one-on-one support, conferences for survivors and those who care about them, and resource libraries and directories. In addition, survivorship activities are conducted on a statewide level through the New Mexico Cancer Council.

The New Mexico Cancer Plan, which is developed and implemented by the Council, has included goals promoting quality of life for cancer survivors since 1996.



Endnotes:

1. Five women who founded PLTC:
Helane Abrams, Catherine Logan, Grace Muir,
Jeanne Stover, and Audrey Wilson
2. Participants at the NCCS founding meeting
Julie Becker, Cancer Share, Cincinnati OH
Harold Benjamin, The Wellness Community, Santa Monica CA
Peggie Carey, Life After Cancer Pathways, Inc., Asheville NC
Helen Crothers, ACS California Division, Oakland CA
Neil Fiore, author, Albany CA
Particia Ganz, UCLA Rehabilitation Project, Los Angeles CA
Barbara Hoffman, Cancer Patient's Employment Rights
Project, Philadelphia PA
Al Hiat, Albuquerque NM
Alice Hiat, ACS volunteer, Albuquerque NM
Jan Kinsler, Oncology Nursing Society, Pittsburgh PA
Pamela La Fayette, Cancer Lifeline, Seattle WA
Susan Leigh, University of Arizona Cancer Center, Tucson AZ
Michael Lerner, Commonweal, Bolinas CA
Catherine Logan, Living Through Cancer, Albuquerque NM
Shannon McGowan, Cancer Support Community,
Point Richmond CA
Shirley Miller, Cancer Hot Line, Plantation FL
Fitzhugh Mullan, Johns Hopkins University, Garrett Park MD
Yvonne Soghomonian, Candlelighters Childhood Cancer
Foundation, Washington DC
Wendy Traber, "Surviving", A patient newsletter, Stanford CA
Barbara Waligora-Serafin, Harrington Cancer Center,
Amarillo TX
Estelle Weissburg, Cancer Guidance Institute, Pittsburgh PA

Appendix A

Excerpts from news coverage in the early years of the national survivorship movement and its links to New Mexico.

1. January 28, 1986. "City must deal with cancer." *The Albuquerque Tribune* editorial. "Local cancer survivors have banded together to form a group, 'Living Through Cancer' . . . there is not now any national organization that serves exclusively the needs of cancer survivors. They say they're interested in developing a national federation with groups that share their concerns. This move is likely to bring Albuquerque a lot of good attention — a reputation as a progressive city that understands and cares about all of its citizens, cancer survivors included."

2. December 5, 1986. "Cancer survivors group picks Albuquerque as base." *The Albuquerque Tribune*. "Albuquerque today became the national headquarters of a group of cancer survivors. The National Coalition for Cancer Survivorship opened its doors at 323 Eighth St. S.W."

3. December 6, 1986. "Cancer survivor office open." *Santa Fe New Mexican*. "The National Coalition for Cancer Survivorship opened its national headquarters here Friday.

... The group will be a clearinghouse for information and activities related to cancer survivorship... will provide a voice for people concerned with issues affecting cancer survivors, and will advocate for the interests of survivors in areas such as employment rights and barriers faced in obtaining insurance."

4. March 8, 1987. "Life after Cancer . . ." *The Dallas Morning News*. "This community of survivors has traditionally been an invisible one. But that is changing — quickly . . . [Albuquerque] patients have formed a local support group, one of many that have been springing up around the country. Last year (they) helped found the National Coalition for Cancer Survivorship."

5. June 18, 1987. "Victims urge bill to outlaw cancer bias . . ." *The Philadelphia Enquirer*. "There is life after

cancer. It should be a full life of quality and equal opportunities, not one of narrow prejudice and stunted dreams," Barbara Hoffman told the House Education and Labor subcommittee on employment rights. Hoffman, a disability rights attorney with the National Coalition for Cancer Survivorship, said that there are five million cancer survivors in the United States and that at least 25% of them have experienced discrimination because of their medical history."

6. November 18, 1988. "Assembly on Cancer Survival Opens Today." *Albuquerque Journal*. "About 300

leaders in the cancer survivorship movement from across the country will gather in Albuquerque today for the second national assembly of the National Coalition for Cancer Survivorship. Grace Monaco, chairman of the Candlelighters Childhood Cancer Foundation of Washington D.C., will present the keynote address . . ."

7. November 6, 1989. "First you beat the cancer. Next you get employers and insurers to

believe it." *U.S. News & World Report*. This three-page article includes quotes from the executive director of LTC and features a half-page photo of Conjunto Classico, PLTC's ensemble with Deborah Ash (playing flute), Joel Wheeler (oboe), Adeline Wheeler (recorder), and Catherine Logan (cello).

8. Volume 9, #5, 1991. *Cancer Investigation*. A Special Section on Cancer Survivorship includes three articles. The first, titled "The Cancer Survivorship Movement," was written by Arizona cancer survivor and co-founder/board member of NCCS, Susan Leigh, RN, BSN, and New Mexican cancer survivor Catherine Logan, co-founder of PLTC and NCCS, the former Executive Director of PLTC, and at the time this article was written, Executive Director of NCCS.

Appendix B

NCCS FOUNDING CHARTER

October 1986, Albuquerque NM

Preamble:

Cancer is an unwelcome intruder in life. Yet cancer is also an inescapable part of many lives. From the time of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor. Surviving is an enormously important, often difficult, always challenging human enterprise that involves the individual, the family, and the givers of care.

Mission Statement:

The mission of the National Coalition for Cancer Survivorship (NCCS) is to communicate that there can be a vibrant, productive life following the diagnosis of cancer; that millions of cancer survivors share a common, transforming experience that has impacted their lives with new challenges and enhanced potentials; and that these survivors, their families and supporters represent a burgeoning constituency and a powerful, positive force in society.

Objectives:

The objectives of NCCS are:

1. To serve as a clearinghouse for information, publications, and programs for the many organizations working on the issues of survivorship.
2. To provide a voice for the many common and recurring issues of those organizations reflecting the spirit, skills, and needs of the survivorship community.
3. To advocate the interests of cancer survivors, to secure their rights, and to combat prejudice.
4. To promote the study of the problems and potentials of survivorship.

Appendix C

The Seasons of Survival

Generous permission to reprint this article from *The New England Journal of Medicine* included a restriction on reformatting the article. It appears here as it was originally published in 1985.

The Seasons of Survival: Reflections of a Physician with Cancer.

New England of Medicine. Fitzhugh Mullan, MD, Health and Environment Department, State of New Mexico. Copyright © 1985 Massachusetts Medical Society. All rights reserved.

OCCASIONAL NOTES

Seasons of Survival: Reflections of a Physician with Cancer

WHEN I was given a diagnosis of cancer, my first thought was not, Will I die? but rather, How can I beat this? Like a youngster who flunks a big test, I immediately began to worry about what to do to pass the course. I was 32 years old at the time, a physician, a husband, a parent, and a son. I had been healthy, athletic, and free of pain, but with the diagnosis, I became formally sick. My mind and my hopes riveted

immediately on the goal of cure. *Cure*. The word itself became magic for me, a time when everything would be all right again, when the shadow in my life would be gone, when normal life would resume.

The tumor manifested itself as a mediastinal mass that I discovered on a chest x-ray film. During a subsequent closed mediastinal biopsy my innominate vein was inadvertently punctured, requiring an emergency thoracotomy and some heroic surgery to save my life. The tumor proved to be an anaplastic primary seminoma, and I underwent treatment with radiation and chemotherapy in the following months. After a toxic course, the tumor appeared to be arrested, and I regained strength and returned to work. A year later, intractable osteoradionecrosis of the sternum developed, necessitating a sternectomy followed by a multiple-stage plastic surgical repair of the chest. After that I recovered again and returned to work, a bit the worse for wear but, as it turned out, free of tumor.¹

It did not occur to me while I was acutely ill or for some time afterward that the simple concepts of sickness and cure were insufficient to describe what was happening to me. As with most cancer patients, the quality of my life during this period was severely compromised, and the possibility of death was always present. I was, in fact, surviving, struggling physically and mentally with the cancer, the therapy, and the large-scale disruption of my life. Survival, however, was not one condition but many. It was desperate days of nausea and depression. It was elation at the birth of a daughter in the midst of the treatment. It was the anxiety of waiting for my monthly chest film to be taken and lying awake nights feeling for lymph nodes. It was the joy of eating Chinese food for the first time after battling radiation burns of the esophagus for four months. These reflections and many others are a jumble of memories of a purgatory that was touched by sickness in all its aspects but was neither death nor cure. It was survival — an absolutely predictable but ill-defined condition that all cancer patients pass through as they struggle with their illness.

During these years I frequently wondered when I could safely declare victory. When could I say simply that I was cured? Actuarial and population-based figures give us survival estimates for various cancers, but those figures do not speak to the individual patient, whose experience is unique and not determined or described by aggregate data. Many patients are "cured" long before they pass the five-year mark, and others go well beyond the five-year point with overt or covert disease that removes them from the ranks of the "cured," no matter how well they feel. Survival is a much more useful concept, because it is a generic idea that applies to everyone diagnosed as having cancer, regardless of the course of the illness. Survival, in fact, begins at the point of diagnosis, because that is the time when patients are forced to confront their own mortality and begin to make adjustments that will be

part of their immediate and, to some extent, long-term future.

Living on, as I have been fortunate to do, I have reflected on my experience and talked to many cancer patients about their experiences. Although the binary notion of cure versus noncure is understandably appealing to everyone concerned with cancer, most agree that it is not an accurate characterization of the experience. The vagaries, phases, and syndromes of survival are far more complex than that simple idea suggests. Moreover, the binary concept implies that there are two separate courses: one for those who are cured and one for those who are not. On the contrary, the events, therapies, and emotions that all patients go through are, to a point, similar. Patients with cancer, whether recently diagnosed and being treated or previously diagnosed and relatively stable, have more in common with one another than they do with people who have not experienced cancer. Although the circumstances and outcomes obviously vary enormously from person to person, I think that most patients go through some relatively predictable and potentially useful stages of survival. I do not suggest that these are formal stages in a strict clinical sense, but rather that there is a progression of events for most cancer patients that is definable in its general outline — the seasons of survival.

ACUTE SURVIVAL

The first season begins with the diagnosis of the illness. It is really the medical stage and is dominated by diagnostic and therapeutic efforts to stem the tide of illness. Fear and anxiety are important and constant elements of this phase, since all but the very young and the infirm have the ability to appreciate the gravity and life-altering potential of their diagnosis. People universally and reasonably fear cancer, and as a consequence, the mere fact of the diagnosis creates a state of mental ill-being that is sometimes more punishing than the biologic presence of the disease. Pain is also a common element of this stage, since both the illness and its treatment can cause considerable discomfort.

This is a time, too, when patients are called on to deal with their own mortality. Most of us assume that we are going to live for a long time into the future. The diagnosis of cancer immediately aborts that comfortable notion. We are forced to deal with the fact that we may be dead soon, that we may not see our grandchild born, or our daughter go to college, or next Christmas. Confronting one's own mortality is an immutable characteristic of the acute stage.

This season is defined and dominated by cancer treatment — medical, surgical, and radiologic. Simply coping with the effects of the therapies occupies all the adaptive energies of most patients. Family and community support of the sick person is an important buffer to the harsh realities being experienced. An often overlooked aspect of this phase is the needs of the patient's family. Backing for these "secondary pa-

tients" can take many forms but is often neglected in the rush of sympathy for the new patient.

EXTENDED SURVIVAL

When the patient goes into remission or has terminated the basic, rigorous course of treatment and enters a phase of watchful waiting, with periodic examinations and "consolidation" or intermittent therapy, the acute phase is over, and the season of extended survival has begun. Psychologically, this time is dominated by fear of recurrence — the punishing worry that the tumor, now in abeyance, will return to resume its perfidious work.

This is usually a period of physical limitations, since the tumor and treatment have exacted a corporal price. Diminished strength, fatigue, a reduced capacity for exercise, amputation of a body part, or hair loss occurred in the acute phase, but now they must be dealt with in the home, the community, and the work place. An altered body image and, perhaps, a different vocational role are intertwined with physical limitations to make reentry at home and at work a trying experience that calls for strength, patience, and a sense of humor.²

Unlike the acute phase, the elements of which are somewhat more uniform and predictable, the experiences of individuals in the extended period are as variable as their diseases, their adaptability, and their home and work situations. Responses range from isolation, devastation, and depression to minor disruption or anxiety.

Since this phase is not predominantly a medical one, doctors and nurses tend to have a diminishing role in providing support and counseling. The result is a void that leaves many cancer patients and their families fending awkwardly for themselves in the "healthy" world. A small but growing number of local groups and publications in various parts of the country address the needs of persons passing through this difficult phase. (The "I Can Cope Program" of the American Cancer Society is the most widely available program of this sort.) People who succeed in connecting with support services such as these tend to do it by word of mouth or through referrals from other patients. Treatment plans for patients in this postacute phase rarely address the psychosocial problems of reentering the active world. Systematic referrals by oncologists, primary care physicians, and nurses to support services for patients at this point in their recovery would do a tremendous amount to aid adjustment, relieve suffering, and stimulate the further development of these scarce resources.

PERMANENT SURVIVAL

The term "permanent survival" will not be found in the literature. It can be roughly equated with the phenomenon we usually call "cure." Permanent survival, however, has several dimensions beyond those of victory over the disease, including specifically a kinship and continuum with the previous seasons of survival.

There is no moment of cure but rather an evolution from the phase of extended survival into a period when the activity of the disease or the likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested.

The patient in this phase is indeed a survivor. Whatever our wishes, the person who has come through a cancer experience is indelibly affected by it. The Humpty Dumpty idea of "as good as new" — a powerfully appealing notion for cancer patients — simply does not pertain. For better *and* for worse, physically and emotionally, the experience leaves an impression. No matter how long we live, cancer patients are survivors — at once wary and relieved, bashful and proud.

Problems with employment and insurance are common for persons who have been treated for cancer and are ready to resume a full life. Many people experience discrimination of various sorts as they seek employment and advancement.^{3,4} Health and life insurance are predictably troublesome issues, with many companies evincing reluctance to insure cancer patients or excluding coverage for anything remotely related to the disease. Not only do some people encounter prejudice as they seek work, but others who are able to resume their former jobs become "locked in," unable to advance or change their employment because of the vocational and insurance fallout from their former illness.

The long-term, secondary effects of cancer treatment on health represent another area in which permanent survivors are at risk. Secondary tumors have been reported in successfully treated cancer patients as a result of various oncolytic agents.⁵⁻⁸ The long-term noxious effects of radiation also appear to be an area of concern.⁹⁻¹¹ As such information is reported in the literature, it is important that permanent survivors and their physicians be kept informed. Primary care physicians, who provide most of the care for this group of cancer patients, are irregularly and unpredictably informed of these developments, and the patients themselves have no way to learn about them.

Reproductive health for young people who have been successfully treated is another rapidly changing area in which up-to-date information is not always available to general physicians or patients. The concerns here include the frustrations of sterility, the risks of mutagenicity, and guidance on matters of adoption. Advances in the treatment of acute lymphocytic leukemias in children, as well as Hodgkin's disease and germ-cell tumors, have greatly increased the number of young survivors.¹² For them the issues of health maintenance and particularly reproductive health are enormously important.

A STRATEGY FOR SURVIVORSHIP

The Herculean effort that the United States has put into cancer research and treatment over the past two decades has resulted in a substantial increase in survival. As recently as 1960, only 25 per cent of patients survived five years or more, whereas today the figure is

approaching 50 per cent.¹³ Despite this success on the treatment front, we have done very little in a concerted and well-planned fashion to investigate and address the problems of survivors. It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can. The current status of cancer treatment is a prime example of what Lewis Thomas calls "half-way technology" — technology that is far more effective than it used to be but that is gross and ineffective compared with what it will become.¹⁴ As we move from an earlier time when few cancers were treated successfully to the point when virtually all of them will be cured, we are passing through an uncharted middle ground, which in many aspects remains primitive. 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.

In this spirit, a thoughtful, coordinated national research enterprise in the area of cancer survival needs to be undertaken. Survivorship should be studied as a phenomenon in itself rather than as a byproduct or afterthought of basic research on cancer treatment. Organizations such as the National Cancer Institute and the American Cancer Society need to collaborate with interested groups and individuals in developing such a program. As a concept, survivorship has biomedical and psychosocial components. On the biomedical side, secondary tumors, the long-term effects of treatment, rehabilitation, reproductive health, and long-term health maintenance warrant systematic investigation. On the psychosocial side, such issues as community acceptance of cancer patients, insurance discrimination, barriers to employment, and education of youth about cancer need to be explored.

Cancer survivors themselves need to improve their communications. Currently, there is no ready source of information for people concerned with the issues of survival. An information network, even for such items as existing support groups or the status of laws concerning discrimination, does not exist. There is no publication written for a lay audience that provides periodic updates on the many long-term concerns of cancer patients. What is needed is a consumer network — really an alumni association — of cancer survivors, with meetings, newsletters, and periodicals. Individuals and groups concerned with cancer should focus on the development of such a network.

An appreciation of the seasons of survival will help both patients and health professionals develop better strategies for dealing with the difficult life event that cancer represents. The use of a staging system for the survival period will assist clinicians and those responsible for research policy to address the specific needs of patients and former patients at various points of their experience. Moreover, a sense of the progres-

sion of stages will help patients and their families cope with cancer and shepherd their energies in as useful a fashion as possible. This strategy promises to produce important improvements not only in the quantity of survivors but in the quality of survivorship in the future.

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FITZHUGH MULLAN, M.D.

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