

Executive Summary

The end of cancer treatment is not the end of the cancer experience. As nearly 200 American and European cancer survivors, caregivers, health care providers, advocates, researchers, and others detailed in testimony provided to the President's Cancer Panel between May 2003 and January 2004, the end of treatment marks the beginning of a new phase of life: living *beyond* cancer. For the nearly ten million Americans now living with a cancer history, life after cancer means finding a new balance—one that celebrates the triumph and relief of completing treatment, recognizes changes or losses the disease has wrought, and assimilates revised perspectives, newfound strengths, and lingering uncertainties. Typically, few signposts exist to guide these highly personal journeys into a familiar but forever changed world.

Life after cancer treatment may hold diverse and often unexpected challenges. These challenges may be influenced by numerous factors, including the survivor's age at the time of diagnosis, the type and severity of both the cancer and its treatment, the duration of an individual's survival, financial and geographic access to needed follow-up care, employment and educational issues, information needs, and cultural, spiritual, literacy, and language differences. The impact of many of these factors, and the issues that arise from them, is magnified among many survivors from minority and other underserved populations.

Issues Affecting Cancer Survivors Across the Life Span

Both the testimony and additional data gathered suggested that several issues affect cancer survivors and their families regardless of whether the survivor was diagnosed as a child, an adolescent or young adult, in adulthood, or in older age:

- Many survivors leave treatment with neither adequate documentation of the care they received nor a written description of recommended follow-up care and resources for obtaining



“...being a cancer survivor is at the forefront of my self awareness. It enters into the conversations that I have with myself about what I want to do, how I want to spend money, how I want to spend time, my energy, all of that. Being a cancer survivor has added another dimension to my identity. I am a cancer survivor.”

Mortimer Brown, 80, colorectal cancer survivor diagnosed age 75, Florida



“There is also an inefficient and sub-optimized patient data collection system and storage, where every doc holds on to their own records about the patient, and the patient holds on to nothing. And yet every doc has to keep in sync with all the other docs sharing the responsibility for the care of that patient.”

Richard Migliori, physician and administrator, United Health Resources, Minnesota



“...I found out that I could possibly do *in vitro* fertilization with a surrogate mother....Well, there is a \$10,000 payment that you have to plunk down right from the beginning...I am thinking, ‘I have a PPO [preferred provider organization]. There is going to be no problem.’...Well, I was denied because I was not married and I was already on a form of birth control—[a hysterectomy]....I look back and I think of so many things that I could have done to preserve my chance of biologically having a child of my own and I cry...no one told me these things.”

Tamika Felder, 28, cervical cancer survivor diagnosed age 25, Maryland



“...right now my health insurance is \$950 a month...it continues to go up every three months. So at the time in my life when I should be saving for retirement it is kind of hard to do when you are having to pay \$1,000 a month for health insurance.”

Gloria Jean Moore, 51, Hodgkin's lymphoma and breast cancer survivor diagnosed ages 27 and 50, Texas

that care. The lack of a national electronic health record system is an impediment to continuity and quality of care for cancer survivors.

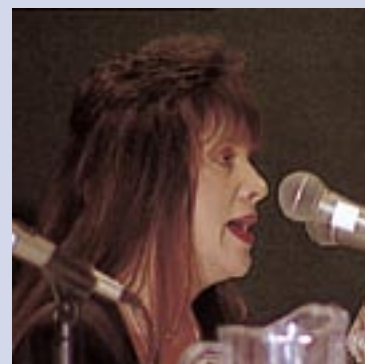
- Cancer survivors and their families need better information about existing laws and regulations that may protect their employment, insurance, and assets.
- Privacy provisions of the Health Insurance Portability and Accountability Act (HIPAA) are inhibiting needed research on survivor issues and blocking appropriate information sharing among providers and between providers and the patient's caregivers.
- Education about cancer, cancer treatment, and survivorship needs is inadequate. The general public, newly diagnosed patients and their caregivers, post-treatment survivors, and health care providers all have significant unmet information needs. Understanding of clinical trials also is limited among all of these groups.
- Many survivors, caregivers, and family members need, but are not receiving, psychosocial assistance and support, both during treatment and in the months and years that follow. Family caregivers increasingly are becoming medical care providers in the home, but are not receiving adequate training and ongoing support for this role.
- The risk of infertility associated with cancer treatment and opportunities for preserving reproductive capacity are not being conveyed fully to newly diagnosed cancer patients of reproductive age or to the parents of children diagnosed with cancer prior to selecting or initiating treatment. For many, access to available fertility preservation options is limited by cost.
- Existing insurance systems in the United States are a significant impediment to appropriate care for people with a cancer history. The link between employment and insurance particularly disadvantages cancer survivors, who risk losing both their employment and insurance during extensive treatment. Lower income, young adult, and near elderly survivors are particularly vulnerable to becoming uninsured. Coverage for psychosocial care and follow-up care is inadequate even under most comprehensive health plans or Medicare.

In addition, testimony provided to the Panel highlighted important nuances of these cross-cutting issues, as well as additional issues, that are distinct to survivors diagnosed at different ages.

Survivors Diagnosed as Children

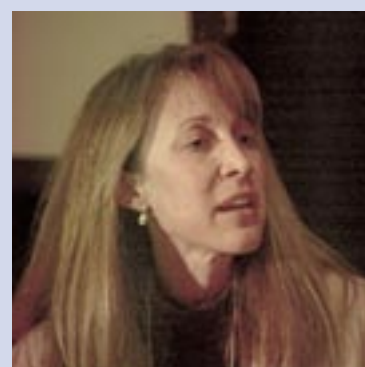
Speakers identified five issues of special importance to survivors diagnosed before age 15:

- Survivors of cancer diagnosed in childhood may need special assistance to re-enter the classroom setting successfully and may require accommodations to learning difficulties resulting from their disease or its treatment. Parents of these survivors may need help advocating for their children in the school system.
- Some survivors of childhood cancers have social development and psychosocial issues that require attention years after treatment ends. These issues may include depression, social problems due to missing typical childhood experiences, and difficulty integrating the cancer experience as a part of the individual's life.
- Many survivors of childhood cancers are not being transitioned appropriately from pediatric care to adult health care settings and receive inadequate assistance in coordinating their follow-up care. Issues include inadequate transfer of information between pediatric oncologists and primary care providers, particularly if the child received treatment away from home, and lack of understanding among primary care providers of the follow-up care needs of childhood cancer survivors.
- Caregivers and siblings of children with cancer have longer-term psychosocial needs that are not being met. Both parents and siblings are vulnerable to post-traumatic stress disorder. Support groups and services available during the treatment period are far less available post-treatment, particularly when the patient was treated away from home.
- Continued research is needed on the long-term effects of cancer treatment on survivors of pediatric cancers. Limited follow-up of pediatric patients, even those treated on clinical trials, is a major barrier to better understanding late treatment effects experienced by this population. Specialized late effects clinics may prove useful for addressing this issue, but require further development and evaluation.



“...the younger a child is when he receives radiation, the more damage he receives...[Adam] was unable to get his high school diploma because he didn't pass the math portion of the competency test. He took that test ten times from the 9th grade to the 12th grade. He missed it by five points. He passed the English portion, and he passed the computer portion...The diploma issue has been hard for him as far as finding a job...It is very frustrating as a parent to see your child struggling and to see him want to be productive and he is not being given an opportunity.”

Pam Cox, mother of Adam Cox, 20, brain tumor survivor diagnosed age 3, North Carolina



“It is clear from the last 20 years that these little incremental, piecemeal things, Federal and State legislation—we're not going to have major, effective, across-the-board health insurance reform until the public really demands it...”

Barbara Hoffman, attorney and advocate, New Jersey



“My concerns as a survivor have evolved the farther away I have gotten from treatment. . . . During my treatment and for several years after. . . my primary concern was recurrence and, although I haven’t had any, I would be lying if I say that I don’t think about it all the time. [Now] I worry about secondary cancers. . . and problems due to my splenectomy. . . I am in premature menopause because of the high doses of chemotherapy I received, so I worry about osteoporosis, sexuality, cardiac problems, and yes, even wrinkles. I take hormone therapy but so little is known about young menopausal women that I can’t help but be concerned.”

Karen Dyer, 24, rhabdomyosarcoma survivor diagnosed age 15, New York

Survivors Diagnosed as Adolescents or Young Adults

In addition to concerns common to survivors of all ages, people diagnosed between the ages of 15 and 29 have other distinct needs:

- Adolescent and young adult cancer survivors—sometimes called the “orphaned cohort”—are a vastly understudied population. Because they often relocate to attend college or obtain employment, follow-up on this population has been particularly difficult.
- Diagnosis and treatment during this crucial developmental period often results in a range of psychosocial issues, including problems with depression, limited social skills, difficulty planning for the future and establishing independence, and coping with neurocognitive problems resulting from cancer treatment. Body image and fertility issues may be a significant impediment to developing intimate relationships.
- Similar to childhood cancer survivors, adolescents and young adults treated in the pediatric setting are not being transitioned effectively to care in the adult setting.
- Adolescent and young adult cancer survivors, particularly those with disabilities requiring accommodation, may find themselves at a disadvantage when competing for jobs, and may be starting adulthood burdened by significant treatment-related debt. In addition, once terminated from their parents’ health insurance policies, they are highly likely to become uninsured and lose access to follow-up care.

Survivors Diagnosed as Adults

Survivors diagnosed between the ages of 30 and 59 face three additional issues that affect their care, livelihood, and quality of life:

- Limited recommendations exist to guide the follow-up care of people with adult-onset cancers due to a lack of research evidence on post-treatment needs of this population. Lack of recommendations limits insurance reimbursement for care recommended by survivors’ physicians and presents a barrier to follow-up care.
- Cancer occurring during the prime and middle years of adulthood may seriously disrupt the survivor’s ability to carry out family, social, and work-related responsibilities, which can damage self-esteem. In particular, many survivors of this age

are responsible for caring for children and aging parents at the same time they are battling their cancer or its after-effects. Recognition of and intervention for issues related to sexuality and intimacy is a largely unmet need.

- Many survivors diagnosed in adulthood face major income losses that endanger the security of their families, particularly if a spouse also must reduce work hours to care for the patient. These losses may be temporary or permanent. Adult survivors typically are unable to obtain or increase life or disability insurance, and may have difficulty securing mortgages or loans.

Survivors Diagnosed as Older Adults

Those diagnosed at age 60 or older comprise the majority of cancer survivors. In addition to issues relevant across the life span, five key issues were identified:

- Many survivors 60 and older still need and want to work. Job loss, forced retirement due to cancer, and resulting loss of health benefits prior to Medicare eligibility are of major concern. Out-of-pocket health care costs are a significant burden for those on fixed incomes.
- Many older people with cancer also have one or more other chronic medical conditions (comorbidities). Such illnesses continue to be a barrier to clinical trials participation by older survivors and to the best standard care for many who are treated in community settings. Comorbidities may mask signs of recurrence or late effects of cancer treatment, and suspicious symptoms may be attributed both by the survivor and medical personnel to age-related conditions.
- Because older survivors rarely have been included in research, little is known about late and long-term effects in this population. Providers may be unaware of cancer screening and other follow-up care needed by these survivors, and lack of Medicare reimbursement for preventive care has hampered efforts to gather information about them.
- Many older cancer survivors lack adequate social and caregiver support. Health care providers often assume that the patient has a support system; in fact, many—particularly older women—live alone far from family members or are cared for by an elderly spouse who may have illnesses, limited mobility, or short-term memory problems. For those who no longer drive, lack of transportation limits access to medical care or support services.



“I cannot lower my premium with [my] current insurance company because of my history of cancer and I cannot change to another insurance because of the same reason. I am not yet 65 years old and I am in the middle class, middle income household. And so I am not eligible for either Medicare or Medicaid. What can we do? Who do we turn to? I survived the cancer but I cannot pay for necessary treatment post-chemo. I feel like I am being punished for surviving cancer.”

Boonsee Yu, 57, colon cancer survivor diagnosed age 53, New York



“I am currently being treated as an outpatient. This has enabled me to continue working, a necessity for me because I am a single parent. I am also having to deal with other family issues—an aunt with Alzheimer’s and an 83-year-old mother. Many adult survivors are part of that “sandwich generation” caring for both their own children and helping their aging parents.”

Debra Thaler-DeMers, 49, oncology nurse, Hodgkin’s lymphoma and breast cancer survivor diagnosed ages 25 and 45, California



“[For impotence] they have a vacuum pump and they have a prosthesis that you can insert surgically. There is a lot of different things....I was trying to do injections into the penis and I used to say to my wife, ‘Now, I am going to go in the bathroom and I am going to inject myself. If you get a headache you are in big trouble.’...Even though the mechanical part of it worked, the psychological, emotional part never worked.”

Emanuel Hamelburg, 63, prostate cancer survivor diagnosed ages 47 and 51, Massachusetts



“...all of the times that I went for the various examinations...I always was alone....I remember sitting one day waiting for the dye to go through my system and I am looking at everybody coming and going....Everybody had somebody and there I sat. I couldn’t help it. I wept. I had nobody but I managed to make it through.”

Grace Butler, 67, colorectal cancer survivor diagnosed age 63, Texas

- Intimacy and body image issues remain an important, though often unaddressed need among older cancer survivors.

The testimony received at these and previous Panel meetings provides a critical dimension to the growing body of knowledge about cancer and the needs of cancer survivors. These extraordinarily candid survivor accounts of life during and after treatment convey the qualitative experiences that place quantitative information in the very human context in which it must be evaluated. Likewise, the daily experiences of health professionals who provide care to people with cancer, their families, and their caregivers are rich reservoirs of front-line information on the poorly charted journey each diagnosed person must make to live with and beyond cancer. It is with this understanding and in this spirit that the Panel has developed this report and recommendations for legislators, policy makers, the scientific and medical communities, employers, insurers, advocates, and others whose actions can so greatly affect the quality of life of people with cancer and their loved ones.

Recommendations

Issues Affecting Survivors Across the Life Span

Treatment and Follow-up Care Information

- 1a. Upon discharge from cancer treatment, including treatment of recurrences, every patient should be given a record of all care received and important disease characteristics. This should include, at a minimum:
 - Diagnostic tests performed and results.
 - Tumor characteristics (e.g., site(s), stage and grade, hormonal status, marker information).
 - Dates of treatment initiation and completion.
 - Surgery, chemotherapy, radiotherapy, transplant, hormonal therapy, gene or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any), indicators of treatment response, and toxicities experienced during treatment.
 - Psychosocial, nutritional, and other supportive services provided.
 - Full contact information on treating institutions and key individual providers.
- 1b. Upon discharge from cancer treatment, every patient should receive a follow-up care plan incorporating available evidence-based standards of care. This should include, at a minimum:
 - A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which they should be performed.
 - Information on possible late and long-term effects of treatment and symptoms of such effects.
 - Information on possible signs of recurrence and second tumors.

- Information on the possible future need for psychosocial support.
 - Specific recommendations for healthy behaviors (e.g., diet, exercise, sunscreen use, virus protection, smoking cessation).
 - Referrals to specific follow-up care providers, support groups, and/or the patient's primary care provider.
 - A listing of cancer-related resources and information (Internet-based sources and telephone listings for major cancer support organizations).
- 1c. The Department of Health and Human Services (DHHS) should establish a consortium of public and private institutional and community health care providers and payors, patient advocates, and technology experts to develop a blueprint for functional, content, format, and technology standards for creating a nationwide electronic health records system.

Legal and Regulatory Protections

2. Procedures should be established within diverse patient care settings to better inform patients/survivors and their caregivers about available legal and regulatory protections and resources.

HIPAA Privacy and Insurance Portability Provisions

- 3a. The Institute of Medicine should be commissioned to evaluate the impact of HIPAA provisions and provide guidance to legislators on amendments needed to make this law better serve the interests of cancer survivors and others.

- 3b. HIPAA privacy provisions inhibiting the ability to track and collect data for research on cancer survivors should be re-evaluated.

Cancer-related Education and Information

- 4a. National public education efforts sponsored by coalitions of public and private cancer information and professional organizations and the media (e.g., film, television, print and broadcast news) should be undertaken to:
- Raise awareness of survivor experiences and capabilities, and of the continuing growth of the cancer survivor population. These efforts should seek to enhance understanding of the post-treatment experiences of cancer survivors of various ages and their loved ones and the need for lifelong follow-up care.
 - Provide accurate information and enhance community trust about participation in clinical trials and raise awareness of the importance of trials in developing new and better cancer treatments and other cancer-related interventions.
- 4b. Existing online resources, including those of the National Cancer Institute (NCI), that provide information on clinical trials and facilitate patient-trial matching should be improved to help patients more easily find trials for which they may be eligible and to simplify the enrollment process.
- 4c. A central online information resource on scientific evidence about late and long-term effects of cancer and its treatment should be developed and maintained by a consortium of interested constituencies (NCI, American Cancer Society, American Society of Clinical Oncology, and others). The NCI Physician Data Query database may provide a model for this effort.
- Using their existing networks, cancer awareness, education, and advocacy organizations should take a major role in helping

to collect and disseminate (e.g., through newsletters, lay educators, workshops, other outreach efforts) late effects information as it becomes available.

- Individual cancer survivors should be able to contribute to this database information about their own experiences with late effects.
- 4d. The potential role of specialized long-term follow-up clinics or departments within or operated by medical or cancer centers should be evaluated for their benefit as a central education resource for cancer survivors. Ideally, such programs should provide the most current information to survivors and their families about late and long-term effects of cancer and cancer treatment and on complementary and preventive strategies (e.g., nutrition, exercise, sunscreen use, virus protection, stress reduction) to promote wellness.
- 4e. Education about possible late effects of cancer treatment and survivorship needs should be part of the core curricula for health care providers in training, and a part of continuing education for primary care physicians, oncologists, and non-physician health care providers.

Psychosocial and Support Needs

- 5a. All survivors should be counseled about common psychosocial effects of cancer and cancer treatment and provided specific referrals to available support groups and services.
- 5b. A caregiver plan should be developed and reviewed with a survivor's caregiver(s) at the outset of cancer treatment. It should include, at a minimum:
- An assessment of the survivor's social and support systems.
 - A description of elements of patient care for which the caregiver will be responsible. Caregivers should be provided adequate

and, as needed, ongoing hands-on training to perform these tasks.

- Telephone contacts and written information related to caregiver tasks.
- Referral to caregiver support groups or organizations either in the caregiver's local area or to national and online support services.

5c. Providers should include psychosocial services routinely as a part of comprehensive cancer treatment and follow-up care and should be knowledgeable about local resources for such care for patients/survivors, caregivers, and family members. In particular:

- The transition from active treatment to social reintegration is crucial and should receive specific attention in survivors' care.
- Primary and other health care providers should monitor caregivers, children, and siblings of survivors for signs of psychological distress both during the survivor's treatment and in the post-treatment period.

Fertility

- 6a. All people of reproductive age who are diagnosed with cancer should be given complete culture- and literacy-sensitive information, both verbally and in writing, about options for preserving fertility and on possible effects of treatment on pregnancy or offspring before cancer therapy is selected or initiated.
- 6b. Parents of young children diagnosed with cancer must be given full culture- and literacy-sensitive information, both verbally and in writing, on the possible impact on fertility of treatment options prior to selecting and initiating treatment. If the patient is too young to understand this information at the time of treatment, parents should be urged to share this information with the survivor at the earliest possible time.

6c. Further research should be conducted to determine what fertility preservation options are possible for children and young adolescent cancer patients.

6d. Fertility preservation procedures and infertility treatment services should be covered by health insurance for cancer patients/survivors whose fertility will be or has been damaged by cancer treatment.

Health Insurance

- 7a. The Federal Government should revive efforts to implement comprehensive health care reform.
- 7b. Adequate reimbursement for prosthetics must be provided and it must be recognized that:
- Many prostheses must be replaced periodically.
 - Access to prostheses is an integral part of psychosocial care for cancer.
- 7c. Coverage should be provided routinely for psychosocial services for which there is evidence of benefit both during treatment and post-treatment as needed.
- 7d. Public and private insurers should provide reimbursement for risk assessments, surveillance, and other follow-up care for cancer survivors, including care provided by appropriately trained non-physician personnel.
- 7e. Existing follow-up care clinic models should be evaluated and compared to ascertain their impact on survivor outcomes and their cost effectiveness.

Issues of Cancer Survivors Diagnosed as Children

School Re-entry

- 8a. Qualified providers in the treatment setting should train and assist parents to assume their crucial roles in helping the child with

cancer return to school and becoming an educator and advocate with individual teachers and the school system.

- 8b. Pediatric cancer centers should offer and promote teacher training as a part of their community outreach efforts to help ensure that the needs of pediatric cancer survivors returning to the classroom are met. Internet-based training modules also should be considered to extend the geographic reach of these training efforts. If possible, continuing education units (CEUs) should be provided to participating teachers.
- 8c. NCI and the Department of Education should explore collaborative opportunities to improve the classroom re-entry and reintegration of young people with cancer or other chronic or catastrophic illnesses (e.g., remote learning, teacher training).

Transition to Adult Care

- 9a. Centers that care for both children and adults with cancer should consider establishing a department or service specifically geared to provide for the needs of older children, adolescents, and young adults with cancer and to assist in their transition to adult care.
- 9b. As part of the process of transitioning survivors of childhood cancers into the adult care setting, information about young adult support groups, Internet sites, and other sources of information and support specific to this age group should be provided to survivors and their families. (See also Recommendations 1a and 1b.)

Psychosocial and Support Needs

- 10. Cancer care providers should inform families of cancer patients about supportive services, including special camps for families and siblings. (See also Recommendations 5a and 5c.)

Issues of Cancer Survivors Diagnosed as Adolescents or Young Adults

Surveillance and Research

- 11a. A working group comprised of representatives from public agencies and private organizations with established surveillance databases should be convened to determine what additional data collection, infrastructure, and related funding would be required to better capture treatment and survival data on adolescent and young adult cancer survivors.
- 11b. NCI and other cancer research sponsoring agencies should increase the priority of and funding for research on the issues of cancer survivors diagnosed as adolescents or young adults. Studies of biologic differences in cancer type and host factors, and of late effects of cancer and cancer treatment in this population should be emphasized to improve the knowledge base and inform the design of treatment, prevention, and quality of life interventions designed to benefit this population.

Psychosocial and Support Needs

- 12a. Family members, primary care providers, cancer specialists, and others who are close to or provide medical care to adolescent and young adult survivors should be made aware that depression, anxiety, or other psychosocial issues may affect the survivor long after treatment ends and should be instructed on how to intervene should the survivor experience such difficulties. (See also Recommendations 1b and 5a.)
- 12b. Adolescent and young adult survivors should be taught self-advocacy skills that may be needed to secure accommodations for learning differences resulting from cancer or its treatment. Physicians and other providers should act as advocates for survivors when necessary.

Issues of Cancer Survivors Diagnosed as Adults

Follow-up Care Recommendations

13. The American Society of Clinical Oncology, the American College of Surgeons, the American College of Radiology, and other major cancer clinician and research organizations should develop more complete recommendations to guide the post-treatment care of survivors of adult-onset cancers. These recommendations should be published and posted on a website and updated regularly to ensure that survivors, patient educators, providers, and insurers have access to them.

Issues of Cancer Survivors Diagnosed as Older Adults

Insurance

14. The Institute of Medicine or other independent body should undertake a periodic assessment of the impact of Medicare legislative changes on older cancer patients' access to care and other follow-up services.

Surveillance and Research

15. Public and privately sponsored research and surveillance on survivorship issues among people diagnosed with cancer in older adulthood should be increased significantly to address the information void on the needs of this population that will comprise an increasing percentage of people with cancer over the next several decades. (See also Recommendation 3b.)

Psychosocial and Support Needs

16. Health care providers must ascertain the strength of an older survivor's social and caregiver support system. This should be assessed at diagnosis, during treatment, and at intervals after treatment is completed. Oncology nurses, nurse practitioners, other advanced practice nurses, physician assistants, social workers, patient navigators, or other non-physician personnel may be best able to make these assessments and arrange assistance and services for survivors who lack adequate support.
17. Health care providers should not assume that older cancer survivors and their partners are uninterested in sexuality and intimacy. Survivors should be asked directly if they have concerns or are experiencing problems in this area and should receive appropriate referrals to address such issues.